Ian Mitchell
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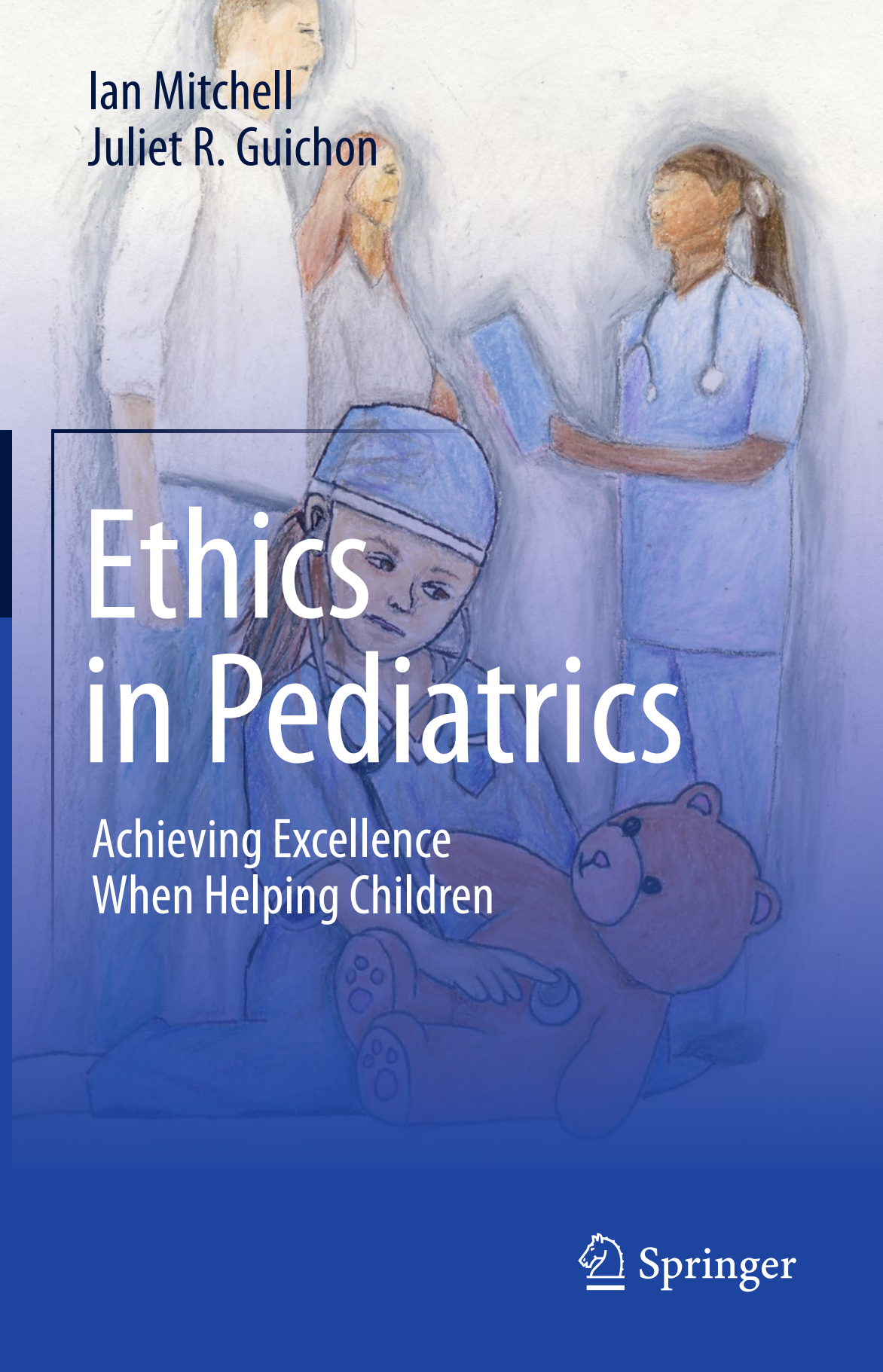

Ethics in Pediatrics

Achieving Excellence When Helping Children

Springer

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Ian Mitchell • Juliet R. Guichon

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ISBN 978-3-030-22616-9 ISBN 978-3-030-22617-6 (eBook)
https://doi.org/10.1007/978-3-030-22617-6

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The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

For all students and trainees over decades who have asked questions and challenged me to give meaningful answers.
Ian Mitchell

For Mary-Claire, and with love for Raymond-Laurent and Sophie-Charlotte.
Juliet R. Guichon

Preface

Pediatrics developed as a medical specialty in the late nineteenth century. In the latter part of the twentieth century and the first part of the twenty-first century, we have seen remarkable enhancement of child health around the world. Such advance has resulted mainly from a rise in economic well-being, in addition to improved hygiene, nutrition, and vaccination. These positive changes have been due also to improvements in pediatric care.

Such improvements include a wide range of new technologies and diagnostic tests and many new drugs including the latest biological agents. At the same time, pediatrics has changed considerably, as has all of medicine. The specialty has welcomed women, who are likely to be in the majority in the near future. In most places in North America and Europe, the specialty has become more welcoming of people who are gay, lesbian, bisexual, trans, queer, or other. The working arrangements of pediatricians have also changed, with the rise in subspecialists, and the general restriction in the time physicians, including pediatricians, will devote to their practice.

Despite the enormous changes, we continue to see trainee pediatricians who are committed to excellence in their care of children.

It is in that context that we developed this book. Two bioethicists with different, but complementary, backgrounds have written this work. The first, IM, is trained in pediatrics and has worked both in Europe and North America. He has been involved in ethics education and scholarship for about a quarter of a century and has a higher degree in Bioethics. The other author, JRG, has lived in four nations and has a background in law and legal scholarship. They have taught collaboratively and participate jointly in research projects and advocacy. They challenge one another and aim to ensure clarity in the ethical ideas articulated and advanced here.

The ethical practice of pediatrics is changing, just as pediatric practice constantly changes and as the pediatric work force changes. We understand pediatrics to be a triadic specialty, with the focus on the child, a general deference to the role of parents in decision-making (or the child, if sufficiently mature), and a definite role for the pediatrician. The process has been described as joint decision-making. We would emphasize that the deference to parental decision-making is never absolute.

Recently, one of us (IM) entered the hospital cafeteria and with tray in hand approached the seating area. As he passed two colleagues seated at a table, he saw that they were engaged in animated discussion and might even have been arguing with one another. He decided to nod politely and to move along to another table with different colleagues. As he went past the two colleagues, he heard one of them say to the other, "The problem with your group is that you allow issues of morals and ethics to get in the way of medical decision making." This is one instance when the colleague was not confronted at the time. It did not seem that a hospital cafeteria was the right place. Later, a meeting with the colleague was sought, and the view that issues of morals and ethics are involved in every action physicians take was advanced. That colleague was not convinced, but the interaction was an impetus to complete this book!

The content of the book is based on continuing contact with trainees and colleagues in pediatrics, the anxieties and concerns they express to us, and our own observations on pediatric practice. Such exchanges have informed personal choices of what is important to address, therefore, the content of this book. We have arranged the contents in five parts. Part I gives the background to pediatrics, including comments on boundary issues and how to obtain help when confronted with ethics issues. Part II addresses consent and confidentiality. We have called Part III "Everyday Issues," dealing with prenatal and pregnancy issues, child abuse, children with medical complexity, and advocacy. We also include in Part III a section "Misunderstandings and Disagreements" that offers help in a variety of perplexing situations. Part IV has topics that we regard as important, but do not fit neatly into other chapters, such as responding to errors, research, teenagers, and cost. Finally, Part V is our view of the topics that will be sources of anxiety and concern in the near future.

The book is not and cannot be comprehensive; it does offer information on most of the ethical problems that physicians in pediatrics, at any level of experience, will encounter.

We believe that this book is relevant to all who are involved in pediatrics, whatever their level of training or specific role. There is material for the beginner and also many sections that will provoke thought in those more experienced. We have addressed a myriad of ethical issues and have identified areas in which ethical concepts are evolving.

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Acknowledgments

The authors thank Springer Nature for agreeing to publish this work and for the support they have received from Floor Oosting, Executive Editor, Applied Ethics, Social Sciences and Humanities, and Christopher Wilby, Assistant Editor, Applied Ethics. Monica Ruff checked and collated references and abbreviations with meticulous care. Pediatric residents, Drs. Jody Platt, Simone Kortbeek, and Rubeeta Gill, gave invaluable help in developing the proposal, reviewing medical accuracy in our stories, and ensuring we were aware of the ethical concerns facing today's trainees. Dr. Kathryn Kenny helped us understand some of the nuances in reproduction and obstetrics. Dr. Julie Lauzon patiently explained some of the current complexities of genetics. Drs. Candice Bjornson and Kirsten Ebbert pointed out some issues to be included. Of course, despite the excellent help, errors might have crept in; if so, then the authors bear full responsibility. The cover illustration is by Jennifer Caldwell. Jennifer is a teenager who has a talent for art. She has had many contacts with Alberta Children's Hospital. Jennifer enjoys life and her art.

Ian Mitchell is grateful for the unwavering support of Anne, his late wife, throughout his career and the patience of his sons and daughters-in-law, David and Meredith, Neil, and Shonna. Inspiration comes from the "Mitchell cousins," Jordan, Ryan, Alexander, and Isabel.

Juliet Guichon thanks pediatricians for welcoming in their midst a scholar trained in law. She is grateful to her husband, Alain Verbeke, for his remarkable example and loving support, to her children, Raymond-Laurent, Mary-Claire, and Sophie-Charlotte, for their cheerful tolerance and the inspiration they offer daily, and to Editha Clemente for making many good things possible.

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Abbreviations

AAP	American Academy of Pediatrics
AAPHR	American Association of Physicians for Human Rights
ACMG	American College of Medical Genetics and Genomics
ADHD	Attention Deficit Hyperactivity Disorder
AE	Adverse Event
AIDS	Acquired Immunodeficiency Syndrome
AMA	American Medical Association
ART	Assisted Reproductive Technology
ASR	Acute Stress Response
BPD	Bronchopulmonary Dysplasia
CADTH	Canadian Agency for Drugs and Technologies in Health
CAM	Complementary and Alternative Medicine
CCC	Child-Centered Care
CCCs	Complex Chronic Conditions
CDC	Centers for Disease Control (United States)
CEC	Clinical Ethics Committee
CF	Cystic Fibrosis
CFSPID	CF Screen-Positive Inconclusive Diagnosis
CMC	Child with Medical Complexity
CMPA	Canadian Medical Protective Association
COI	Conflicts of Interests
CP	Cerebral Palsy
CPAP	Continuous Positive Airway Pressure
CPR	Cardiopulmonary Resuscitation
CSP	Child Standardized Patient
CT	Computed Tomography
DCDD	Donation after the Circulatory Determination of Death
DTC	Direct to Consumer
ECC	Early Childhood Caries
ED	Emergency Department
EEG	Electroencephalogram

ENT	Ears, Nose, Throat
ETS	Environmental Tobacco Smoke
FCC	Parents- and Family-Centered Care
FFM	Five-Factor Model
FGC	Female Genital Cutting
GDP	Gross Domestic Product
HATH	Heterosexual Attitudes Toward Homosexuality
HEEADSSS	Home, Education/Employment, Eating, peer group Activities, Drugs, Sexuality, Suicide/Depression, Safety
HIV	Human Immunodeficiency Virus
HPV	Human Papillomavirus
ICU	Intensive Care Unit
IM	Ian Mitchell
IOM	Institute of Medicine (United States)
IRB	Institutional Review Board
IV	Intravenous
IVF	In Vitro Fertilization
JRG	Juliet R. Guichon
LGBTQ+	Gay, Lesbian, Bisexual, Trans, Queer, or Questioning
LSMT	Life-Sustaining Medical Treatment
MAID	Medical Assistance in Dying
MCC	Medically Complex Child
MGA	Male Genital Alteration
MRI	Magnetic Resonance Imaging
MRP	Most Responsible Physician
NBS	Newborn Screening
NHMRC	National Health and Medical Research Council (Australia)
NHS	National Health Service (UK)
NICE	National Institute for Health and Care Excellence (UK)
NICU	Neonatal Intensive Care Unit
NIPT	Non-Invasive Prenatal Testing
NIS	Nationwide Inpatient Sample (USA)
NSPCC	National Society for the Protection of Children (UK)
OCAP	Ownership, Control, Access, and Possession
OECD	Organization for Economic Cooperation and Development
OSCE	Objective Structured Clinical Examination
PaCT	Palliative Care Team
PCC	Patient Centered Care
PDSA	Plan-Do-Study-Act
PGD	Preimplantation Genetic Diagnosis
PICU	Pediatric Intensive Care Unit
PKU	Phenylketonuria
PTSD	Post-Traumatic Stress Disorder
QALYS	Quality Adjusted Life Years
QI	Quality Improvement

RCPCH	Royal College of Paediatrics and Child Health (UK)
REB	Research Ethics Board
SDM	Shared Decision-Making
SIDS	Sudden Infant Death Syndrome
sJIA	systemic Juvenile Idiopathic Arthritis
SMA	Spinal Muscular Atrophy
SP	Standardized Patient
STD	Sexually Transmitted Disease
WGS	Whole-Genome Sequencing
WHO	World Health Organization
YCHW	Youth Community Health Worker

Part I
Background to Pediatrics

Chapter 1
What Is My Medical Specialty All About?

Key Points Concerning Pediatrics

- Pediatrics is a division of medicine related to the life and health of children
  - It concerns individuals from birth to adulthood, typically 18 years.
  - Pediatricians have additional training in the discipline after graduating in medicine and might have even more training related to a subdivision of pediatrics.
  - Pediatrics encompasses many activities from prevention, direct clinical care in many settings, research and education.
  - Pediatrics may take place in remote communities, large cities, academic medical centers, laboratories and even in international settings.
- Pediatrics aims to ensure that, when children become adults, they are as healthy as possible.
- Much of pediatrics is triadic – child patient, guardian and physician.
- Decisions focus on the best interest of the child patient.
- Pediatricians see children as whole persons, including understanding their environment (family-centred care).
- Pediatricians are compassionate and committed to working in a team-based setting, focusing on positive relationships.

1.1 Introduction

This chapter offers a background to pediatrics and describes features of the discipline, essential qualities of pediatricians, and a description of the pediatrician's role. The chapter will address the pediatrician's roles in the interaction with the child and various interactions with the parents, who are often the decision makers about medical care of their child. The topic of patient and family-centered care will be addressed in more detail later in the chapter. Other topics considered in this chapter include

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_1

developing an understanding of how parents might see us, and describing and commenting on similarities and differences in how pediatricians treat mothers, fathers and other guardians. The chapter's key points illustrate the broad nature of pediatrics and the wide variation in activities involved.

This chapter can be described as a "philosophy of pediatrics". This phrase is used with some trepidation because it might cause pediatricians, with their predominantly scientific training, to be anxious that we are moving into esoteric knowledge unfamiliar to them. On the contrary, this chapter merely considers what pediatrics is about. By "a philosophy of pediatrics" we adopt Pellegrino's understanding: a "critical reflection on the matter" of pediatrics; dealing with the ideas, and background presuppositions that are specific to pediatrics (Pellegrino 2001). This notion entails understanding that the clinical encounter in pediatrics is about the "good" of the patient where "good" means combining a devotion to healing of the child in a manner based on recognizing and respecting the "wholeness" of the child. In other words, a philosophy of pediatrics is not a daunting idea. Discussing the philosophy of pediatrics is just one way to describe the ideas that underlie pediatrics; these ideas will be described here in a friendly fashion.

We will also describe the many changes in society that have affected the practice of pediatrics. One example is that many new mothers are in their late 30s or early 40s and might already have established careers. For many mothers, care of the child is extremely important, but is an activity that they wish to balance with other activities. Many of these mothers with active careers are, themselves, pediatricians. Pediatrics now has a majority of women, and many individuals who no longer hide the fact that they are lesbian, gay, bi-sexual, trans, queer or other. In other words, changes in society affect the kind of person we interact with, and the kind of people we are.

1.2 Introductory Story: Emily

Emily always did well at school. Her friends and family noticed that she was always trying to help others and suggested that she apply to medical school when she completed her science degree.

In her teen years, Emily's very close friend, Louise, developed leukemia. Louise had a difficult time with chemotherapy, and later had a stem cell transplant. However, the end result was excellent, and Louise was also at university, studying music.

Emily visited Louise frequently when she was in hospital and spent time with her when they were both at home. Emily found staff including the pediatricians in the pediatric oncology unit to be friendly and helpful, and thought this field of medicine might be one in which she would like to participate.

Emily is now halfway through medical school and has had electives in pediatrics. In her electives, she has seen pediatricians working in hospital as generalists and as subspecialists and has also seen pediatricians working in a community practice. She is certain she wants to be a pediatrician but is uncertain whether she wants to be a generalist or specialist, and in what kind of settings she would like to work – whether in a hospital, a private office or a community clinic.

Emily meets her mentor in medical school, a pediatrician, someone well aware of her career ambitions. Emily asks, "What is pediatrics about anyway?"

1.3 Who Are Pediatricians? What Is Pediatrics?

1.3.1 Who Are Pediatricians?

A pediatrician is defined by the age of the patient for whom he or she cares. Yet the age limit of pediatricians' patients is not strictly determined. The pediatrician might be concerned with prenatal activities, including the family background and genetics. The definition of "child" as being humans aged 0–18 years, takes the upper age limit from a World Health Organization (WHO) (2013) statement on the rights of the child. The statement mentions that some countries might have an age limit that is lower. In the United States, the age limit is higher: the association of United States pediatricians, the American Academy of Pediatrics (AAP) (Hardin et al. 2017), indicates that pediatrics continues until the age of 21 years. In some jurisdictions, pediatricians provide primary care that is the first point of medical contact for a child patient. In others, pediatricians who provide clinical care, might do so almost entirely as consultants, that is, they receive patients only once they have been referred by other medical practitioners.

Pediatricians, whether trainees or people who have been in practice for years, tend to develop a personal narrative of themselves in relationship to pediatrics. Creating this narrative necessarily involves developing an understanding of the discipline. The description of pediatrics offered here is based on an exploration of the literature, some knowledge of the history of pediatrics; both are blended with personal experiences that have shaped the career of one of the authors. The personal experiences have occurred during many interactions with parents and children, with colleagues and with mentors (Mitchell 2015). New entrants to pediatrics will likely have similar experiences. Pediatrician's personalities are formed by contact with children experiencing illness and with their families; these encounters offer great opportunities for personal growth. To quote from Mitchell (2015) above, from children, "I've learned how to rise above adversity; from their parents, I've learned that silence can be better than speech."

1.3.2 What Is a Pediatrician and What Is Pediatrics About?

A different, but very closely related question is, "What is a pediatrician?" The American Academy of Pediatrics defines "a pediatrician" as "a physician who is concerned primarily with the health, welfare, and development of children and is uniquely qualified for these endeavors by virtue of interest and initial training." (Committee on Pediatric Workforce 2015). The article expects the pediatrician to have wide interests, and states, "Because the child's welfare is heavily dependent on the home and family, the pediatrician supports efforts to create a nurturing environment."

Aspiring pediatricians like Emily need some idea of the scope of pediatrics as they begin to develop their personal narratives as pediatricians. Emily also needs to know the scope of the discipline and the skills and experience practitioners need to face novel and challenging situations.

Emily has lots of other questions. Do pediatricians really enjoy what they do? Is their role challenging? Can she be the best possible pediatrician she might be? Emily particularly enjoys hiking and would like to have her own family one-day. Will there be time for other activities? Make no mistake, Emily, like almost every aspiring pediatrician, will not be satisfied with mediocrity or by just "getting by" in her chosen career. Nor will she want to neglect her own children or her enjoyment of life. She will want to be sure all are possible.

What will we say to Emily? You might see her question, "What is pediatrics about anyway*?"* as odd. Let's try to work out this out. A dictionary describes pediatrics as, "A branch of medicine dealing with the development, care, and diseases of children" (www.merriam-webster.com). The American Academy of Pediatrics offers more detail about pediatrics by defining it as:

> A specialty of medical science concerned with the physical, mental, and social health of children from birth to young adulthood. Pediatric care encompasses a broad spectrum of health services ranging from preventive health care to the diagnosis and treatment of acute and chronic diseases. (Committee on Pediatric Workforce 2015)

This description helps us quite a lot, but another way to answer the question, "What is pediatrics about?", is to examine its aims. An ethics think tank, the Hastings Center, explored the goals of all medical disciplines, including pediatrics (Allert et al. 1996). The resulting report concluded that the goals of medicine included prevention and health promotion, relief of pain and suffering, caring and curing, and when death was unavoidable, ensuring it was peaceful. (We will return to the notion of accepting that death occurs in children and the duties of ensuring that it is peaceful in Chap. 4 Consent, Chap. 8 Medical Complexity and Chap. 10 End of Life.)

Let's reframe these goals for pediatrics:

- The prevention of disease and injury from birth and throughout childhood.
- The promotion of normal development and achieving a healthy adulthood.
- The relief of pain and suffering caused by injury and illness.
- Helping siblings and parents as well as helping sick children.

- Caring for suffering children and curing them where possible.
- When death in childhood is unavoidable, ensuring that it is pain free and peaceful.

But how will Emily see things? Emily will have developed some opinions of her own, based on visiting her friend in hospital. She might also have some views developed from portrayal of healthcare in the media. Regarding pediatrics, news reports are frequently about a "miracle cure" or a very tragic death of a child. Pediatrics *per se* is rarely depicted in TV dramas, though children are often portrayed. Unfortunately, TV dramas tend to depict "high adrenaline" situations, often with the need for cardio-pulmonary resuscitation (CPR), unrealistically ignoring basic rules of medical practice. TV dramas also tend to place the physician at the center of every activity, disregarding the large number of team members essential to modern medicine. If you have ever watched these TV dramas, then you will know that romance is common, and intimate affairs frequent. As an aside, children are usually portrayed as just another patient and are depicted in the same setting as adults. Yet children should be seen by physicians and other healthcare team members in settings designed around their needs, whether in-patients in hospital, a specialized clinic, or a physician's office.

There will be more in this chapter about the role of parents, and the various relationships between pediatrician and parents; in the meantime, we will describe some other aspects of pediatrics.

1.4 Brief History of Pediatrics

Children have received healthcare from physicians from time immemorial and are mentioned in medical texts since the era of Hippocrates. Yet the role of a physician specializing in the care of children is a very recent development. Specialist doctors for children arose largely in the middle and late parts of the nineteenth century; pediatrics has developed further throughout the twentieth and into the twenty-first century.

Around the time pediatrics emerged (mid-to late nineteenth century), children's hospitals were being developed. Although there were buildings described as children's hospital just before this time, those institutions were usually for the general care of abandoned children rather than devoted to the care of ill and sick children. After 1850, it was becoming obvious that the diseases suffered by children were different from diseases suffered by adults and that treatment of children required a different approach. Even when children had the same condition seen in adults, the details were often very different.

At about the same time, the pathological basis of disease was being studied, leading to a reinterpretation of clinical medicine (and pediatrics). Moreover, physiology was developing as a field of study relevant to human disease. These three elements – children's hospitals, pathology, and physiology – were important to the initiation of pediatrics.

Changes in societal attitudes to children were of equal, or greater, importance. Physicians were paid by their patients or in the case of children by their patients' parents or guardians. Once society ceased to accept a high infant mortality as the norm and an inevitability, it followed that parents would be willing to pay for medical care of their children. Hence, pediatrics became possible. Please do not interpret this statement that payment of fees of children's physicians helped establish pediatrics as a discipline, as meaning that pediatricians are concerned solely about their income. But without a public being willing to pay, physicians cannot devote themselves to the care of children.

Physicians have become more and more specialized over the course of the twentieth century, almost always by body system, such as cardiology or by specific technical skills such as surgery and its branches. A specialty defined by the sex of the patients is gynecology. As a specialty defined by the age of its patients, pediatrics itself is part of the process of increasing specialization of medicine. The other age related-specialty, geriatrics, came along in the mid-twentieth century (Williamson 1979). Pediatrics is no different; there are now many specializations within the discipline, often called sub-specialists, or super-specialists if the area of concentration is very narrow. Many of the specializations parallel those found among physicians who care for adults, and include, for example, cardiologists, infectious disease specialists, endocrinologists and so on. A specialty of pediatrics that has no real counterpart in adult medicine is developmental pediatrics. As befits an age-related specialty such as pediatrics, two of the subspecialties are themselves age-related: neonatology, and adolescent medicine.

The reality of pediatrics is in one way duller than its portrayal in the media, but in another way, it is much more exciting. Pediatricians use their intellect and their physical skills and are usually emotionally involved in the care of their patients. Chapter 2 will deal with some of the limits of emotional involvement, and the need for boundaries between professionals, patients, and family members. Boundaries are important, but their existence does not mean that pediatricians are aloof from the suffering they see. Pediatricians are actively involved in the life of patients and are usually able to make a positive difference.

1.5 The Work of Pediatricians

One aspect of pediatrics involves the care of children who have suddenly become sick and require emergent treatment. The setting might be a hospital emergency department, a walk-in clinic, or a physician's office. Pediatricians will work with the families as they decide what interventions are required, whether surgical, drug therapy, or observation over time to see if the child will recover spontaneously. Television misrepresents how we handle acute life-threatening illnesses and injuries; on TV, actors use interventions much more readily than most pediatricians would. There is little time in a 30 or 45-min TV drama to wait to see how the child does. But waiting can be the best strategy.

Pediatricians are involved in many other vital activities that promote the well-being of children, far away from acute illness. The depth of this involvement will depend on the type of practice, whether primary or secondary (consultant) care. In some countries and sometimes in specific areas within countries, pediatricians will offer primary care to children. In other countries, pediatricians will act as a consultant for family physicians, nurse practitioners and midwifes, and will help to train other healthcare professionals in these activities and develop protocols to guide their colleagues. Primary care pediatrics includes supervising the growth and development of otherwise healthy children and identifying when these vary significantly from normal. Primary care pediatrics always includes encouraging parents to consent to vaccination of their children.

Increasingly, pediatricians are called to participate in the long-term care of children with chronic illnesses. There have been many successes in pediatrics over the last 100 years. Thanks to immunization, antibiotics and changing standards of housing and hygiene, many infectious diseases are now rare or have completely disappeared. Many other severe illnesses are no longer fatal. An example is cystic fibrosis. In the past, those affected all died in childhood, most of them before school age. The prognosis has gradually improved; it is now very rare for a person with cystic fibrosis to die in childhood. Today, the pediatrician's role is to provide supervision throughout childhood, developing a plan of management with the family, and intervening early in any acute illness to prevent deterioration, with its long-term consequences, and transitioning to adult care. The story of cystic fibrosis in moving from an illness that killed people in childhood to one with which adults now live, can be told over and over again regarding other ailments such as childhood cancers, cardiac disease, and many congenital anomalies. Most children who survive such illnesses or conditions look very healthy to the external observer, a tribute to the dedication of their families and to the skilled help offered by the pediatricians. Some of the children who survive previously fatal illnesses do so with continued ill health and these children involve a great deal of time of pediatricians. Their needs, and the specific ethical concerns, will be addressed in Chap. 8, Children with Medical Complexity.

Underlying all the various aspects of pediatrics – whether intervening in the care of an acute illness, providing supervision of well children, providing long-term care to children with chronic illness or advocating for improvements in the treatment of children – are a series of core beliefs that a child must be seen as an individual but at the same time understanding that children do best when in families.

1.6 How the Work of Pediatricians Changes with Societal Changes

The pediatrician's role is to help children with health concerns and to see the child in the context of the family, the community, and society as a whole. Families change. The 2-year-old who is a first child might present to a pediatrician for medical care. The same child might present again at the age of 15 with different concerns by

which time there might be two younger siblings and the parents might have divorced. That same child is now being seen by pediatricians in an entirely different context. Communities change. Families move away, new families move in, schools are built, shopping centres change, patterns of play change, recreational facilities can come and go. All such changes, and many others, too many to enumerate, will affect the family and the child. Finally, society is forever changing and many of these changes affect pediatrics. (And obviously pediatrics is changing, with new modalities of diagnosis, old interventions reevaluated, new drugs becoming available and so on.)

Some of these societal changes have been mentioned earlier, particularly as they affect the life of pediatricians. We will articulate them in more detail here, though we recognize some are already well known and well recognized. We will use information from official and other sources for Canada, the United States, and United Kingdom and note at the outset that the trends in these three countries are very similar.

The first examples of societal change are taken from Canada, and concern changes in family size, the number of one-person households and the number of single parents. The federal government agency, Statistics Canada (2012a), reported demographic information over a 50-year period from 1961 to 2011. The start of this period was near the end of the baby-boom period. During that period, people were marrying at a young age, and had relatively large families. By the end of the 1960s, childbearing was often delayed, family size was generally smaller and there was more variety in when women gave birth. During this period, the birth control pill came to market and was legalized, therefore women increasingly entered higher education and the workforce, and "no-fault" divorce was introduced. The change in the incidence of divorce is striking; in 1961 6.4% of parents were single and by 2011 the figure had risen to 16.3%. In 1961, there were 2.7 children per family, and by 2011 this number had fallen to 1.9. Households changed in 1961 dramatically. 9.3% of households contained one person, and by 2011 the number had risen to 17.6%. Larger households were becoming uncommon; those with five or more individuals in one household were 32.3% of the total in 1961 and 8.4% in 2011.

The changes in the United States were qualitatively similar, though the Census periods are slightly different (Hobbs and Stoops 2002). In 1900, the most common household contained seven or more people, with the numbers falling in the twentieth century. By the end of the twentieth century, the most common household number had only two people. In 1900, around half of the United States population lived in households of six or more. This changed dramatically, and by the year 2000 more than half lived in households with only one to three people. In 1950, households of married couples were 78% of the total, and by 2000, only one half consisted of married couples. As in Canada, the number of single-person households changed dramatically. In 1950 only 9.5% of households were one person, but by 2000, 26% of households were single person. The role of women in the household changed such that, in 1950, 21% of households were women. By the year 2000, 36% of United States households were women. There were also changes in the role of males. In the last part of the twentieth century, male family households with no wife present became much more likely to have children in the household.

In the United Kingdom, again the changes are qualitatively similar, though the number varies, and the time period studied is slightly different (Hicks and Allen 1999).

At the start of the twentieth century, the completed family size (mean) was 3.5, and by the end of the twentieth century was 1.7. Another study considered women born in England and Wales in 1964, comparing them with their mother's generation, women born in 1937 (Hughes 2010). 1964 was chosen because it was assumed that most of the women would have finished childbearing by the time of the study. Of the women born in 1937, 12% were childless but of those born in 1964 20% were childless. One in five of the women born in 1937 had a family of four or more, a number that had fallen to 1 in 10 by 1964.

The end result is that women were having not only fewer children but having the first child at a later time in their life. Consider data provided by Statistics Canada for the period 1991–2011, and which is probably qualitatively similar to data that might be collected in other Western countries ("Women and Health Chart 23" Statistics Canada 2012b). In 1991, the most common age to have a first child was 25–29 years, 37.1% of the total, and the next most common was 20–24 years, 27.1% of the total. It was uncommon to have children over 35, 4.5% were aged 35–39 years and 0.5% were aged over 40 years in 1991. In the 20 years that followed, changes occurred, all in the direction of later child bearing. In 2011, the most common age to have a child stayed at 25–29 years, 33.9%. However, the second most common was now not 20–24 years but 30–34 years at 27.7%. Those having the first child in the age range 20–24 years had fallen from 27.1% to 19.3% of the total. There were substantial increases in the numbers of women having their first child at ages over 35 years. In 2011, those aged 35–39 years were 10.1% of the total, and those aged over 40 years were 2.0% of the total.

Although the trend toward later child bearing is significant, it is important to note that the age of first childbearing can vary geographically within one nation. In a study commissioned by the New York Times (Quoctrung and Miller 2018) reported that first-time mothers in the United States are older in big cities and on the coasts, and younger in rural areas and in the Great Plains and the South. For example:

> In New York and San Francisco, their average age is 31 and 32. In Todd County, S.D., and Zapata County, Texas., it's half a generation earlier, at 20 and 21, according to the analysis, which was of all birth certificates in the United States since 1985 and nearly all for the five years prior.

The article noted that differences in maternal age and education can have a significant effect on life opportunities for the children.

The effect of increased maternal age is an overall increase in maternal and pediatric morbidity. Researchers explored attitudes to childbearing in a group of women, some who were not pregnant, some who were pregnant and some who were attending a fertility clinic (Cooke et al. 2012). In general, these women were not aware that being pregnant over the age of 35 leads to increased risks and did not believe that age alone would affect the outcome of the pregnancy. These women felt a lack

of control as to when to have a child. There were issues of relationships, finances, and fertility that they considered beyond their control.

A review of published work (Johnson and Tough 2017) noted the increase risk of infertility, complications of pregnancy, and adverse outcomes for the mother and baby because of delayed child-bearing. The authors also commented that many women did not know the success rates or risks of assisted reproductive technology (ART). Specifically, the women did not know that delaying childbearing and use of ART increased the risk of multiple births, preterm delivery, stillbirth and delivery by cesarean section.

The pronounced demographic changes have significant effects on health care services for children. Given the change in household size, parents are less likely to be familiar with children in general; the fact that there are fewer children means that there are fewer opportunities to help in the care of infants and young children, and hence less knowledge of parenting in general. If a child becomes sick, then there is less likelihood that there will be other adults in the household to provide support to the parents and to care for other children. The need for both parents to be at work presents an additional layer of problem if the child has either acute or chronic illness; workplace obligations and the need for family income might take precedence over a parent staying in hospital with the child. In terms of fathers, it seems that more men are assuming child-rearing roles.

Mothers today are more likely to have higher education and to be in the workforce. This fact might be helpful in terms of education and understanding the issues. On the other hand, high levels of education in one area do not entail competence in another; a highly qualified banker might have no knowledge of medicine. And high levels of education do not mean that highly educated parents will not be worried and anxious in ways that interfere both with their understanding of the problem and with the exercise of their decision-making abilities.

These mothers in their 30s might be interacting with pediatricians of their own age, or even younger, or pediatricians who are much older. Boysen et al. (2016) state that by 2020, there will be five generations in the workplace, but the majority will be millennials. These generations are: Traditionalists, born before 1946; Baby Boomers born 1946–1964; Generation X, the Gen Xers, born 1965–1980; the Millennial Generation, also referred to as Gen Y, Net Gen, the Google Generation, or Echo Boomers, born 1981–1996; and Generation 2020 born after 1997. Those born after 1997 constitute a generation that is still defining itself and already is revealing that it is heavily influenced by the internet and social media; referring to this generation, Boysen et al. (2016) stated that many members:

> merely tolerate their formal classroom experience until they can return home and go online. They have a sophisticated worldview when polled, with expectations of global learning opportunities, comprehensive personal medical data storage, and limitless opportunities for experiential learning and strong peer groups. Their mobile device will be their office, classroom, concierge, music player, video player, computer, and phone—all rolled into one. In 2020, this generation will be freshman medical students.

1.7 Who Chooses Pediatrics?

The road to a career in medicine is long, demanding high educational and other achievement in high school and college and also determination. Once a coveted place in medical school is obtained, then those chosen will turn their thoughts to a specialty, if they have not already decided that much earlier in life. The choice to be in a specific specialty is made by the medical student or physician himself or herself, constrained by opportunities. Obviously, there is not an unlimited supply of training slots in every specialty, including pediatrics. Nevertheless, most medical students eventually find themselves training in either their first choice of specialty or at least in the general area in which they wish to practice.

Once residency training is complete, physicians tend to be happy with their choice of specialty and look forward to practicing as pediatricians. Such satisfaction arises despite rapid changes in practice, in society overall, and with the challenges related to that long education (Frintner and Cull 2012). We might expect high levels of anxiety in these new graduates given that the work of a pediatrician involves humans at a very immature part of the lifecycle and who are almost always accompanied by worried family members. It is, therefore, reasonable to assume that if the trainees are satisfied that they have made the right choice, then there is probably a good fit between the personality and the specialty.

Some attempts have been made to identify the psychological frameworks involved in various specialties with only a few addressing pediatrics specifically. An editorial in the South African Medical Journal summarized some information available from various studies (Seggie 2012). Seggie reported from studies using the "Five-Factor Model (FFM) of personality, which posits that humans have five chief personality traits. Broadly, they are neuroticism (a tendency to hostility, negativity, anxiety and depression); extroversion or sociability (encompassing warmth, gregariousness and assertiveness); openness to experience (finding expression in intellectual curiosity, being excited about new techniques and technologies, having independent judgement, and needing variety); agreeableness (predicting a pleasant, empathetic and accommodating demeanor); and conscientiousness (careful behavior, dutifulness, self-discipline and an appreciation of strict rules and principles of practice). She compared results from specialists choosing internal medicine, surgery, obstetrics and gynecology, pediatrics, psychiatry, family medicine and anesthetics. Pediatrics scored higher on neuroticism and agreeableness than other specialists; less extroverted than surgeons, but more so than internal medicine specialists; less conscientious than specialist at obstetrics and gynecology and internal medicine. It seems as if pediatricians are both worried and agreeable. Being agreeable is not by itself an undesirable characteristic, but as we will discuss later in this chapter on "virtues", any human characteristic taken to an extreme becomes undesirable.

1.8 Gender and Pediatrics

This section is about people practicing pediatrics. In the past, pediatrics tended to be practiced by men. These men were presumed to be heterosexual; if they were not, they would be unlikely to disclose their sexual orientation because of social stigma. Change has come. Presumed heterosexual males are now in a minority in pediatrics. Women have entered the practice in large numbers partly because of the development of birth control. Further change has entailed the rejection of the idea that sexuality is binary. Hence, the nature of change for women and gay, lesbian, bi-sexual, transgendered, queer and other people in pediatrics is an important subject. Pediatrics is becoming more welcoming to everyone, making it more possible for people to present as who they are.

1.8.1 Gender: People Who Identify as Women

Throughout humankind's history, women have been associated with child care, and, superficially at least, women would seem to be a 'natural fit' for the profession of pediatrics because, of course, they give birth to children. The caring role that women have traditionally occupied is the foundation for a philosophical school of thought called the "Ethics of Care" to be discussed a little later in Sect. 1.10.2.7.

The history of medicine overall changed sometime in the early nineteenth century, with a move to formal education in a college or university and formal qualifications recognized by the state. The first woman recognized to graduate in medicine in the United States is Elizabeth Blackwell (1821–1910); after training in Europe, she returned to New York and became very involved in pediatric services. During the remainder of the nineteenth century, and into the twentieth century, many distinguished women contributed to pediatric care and advanced pediatrics. They included Dorothy Andersen, discoverer of cystic fibrosis, and the renowned pediatric cardiologist Helen Taussig, among many others who made original discoveries that enriched pediatrics (American Academy of Pediatrics 1983).

Yet, despite there being some highly distinguished women, pediatrics was a specialty dominated by men. Throughout the early part of the twentieth century in the United States, women were very unlikely to gain entrance to medical school, and hence, very unlikely to become pediatricians. The male dominated nature of pediatrics is probably a consequence of the famous Flexner report, which tried to improve standards by focusing on science content, and which led to the closure of many United States medical schools that specialized in training women, African-Americans, and poor Americans (Barkin et al. 2010). Only 2.9% of physicians in the United States were women in 1915, and even into the early 1970s, women were less than 5% of the medical workforce.

The introduction of the birth control pill in 1960 (Watkins 2011) and the resulting increased ability of women to control what labor they did and when (childbearing and rearing, or other), facilitated the entrance of women into almost all previously

male dominated professions. By 1980, 40% of United Kingdom medical school admissions were of women. By 1992, the same milestone was reached in the United States. By 2013, women constituted 55% of students who entered medical schools in the United Kingdom and 47% in the United States.

In 1990, academics argued that the practice of medicine could be changed to encourage more women to stay in the workforce and to advance their careers (Kappy and DeAngelis 1990). In 2005, the Federation of Pediatric Organizations noted that pediatricians support the care of children by the parents and argued that those pediatricians who are parents should be supported as they cared for their own children (Federation of Pediatric Organizations 2005).

The numbers of women continue to increase. Now in the United Kingdom, 61% of medical students are female (Allen 2005). The Royal College of Paediatrics and Child Health Workforce Census 2015 noted that more United Kingdom staff pediatricians are female than are male, and of trainees 74% are female. In the United States, an article about women in pediatrics by DeAngelis (2015) reported:

> Currently, 30% of all active physicians in the United States are women, but 58% of the 55,509 pediatricians and 50% of the 3844 internal medicine pediatricians are women. The only other specialty that comes close is obstetrics and gynecology, in which 47% of the 40 377 members are women. The trend continues: 72% of current pediatric residents and fellows are women, second only to the smaller field (in numbers, not stature) of obstetrics and gynecology at 81%.

There are many reasons to address issues of family balance in the lives of pediatricians during training and practice, including concerns regarding productivity, career advancement, and individual fulfillment. The most compelling reason derives from the central responsibility of our profession. The commitment of pediatrics to the health and well-being of children and youth should include commitment to the families of those who choose to pursue careers in pediatrics (Federation of Pediatric Organizations 2005). The Kappy and DeAngelis (1990) article offered practical suggestions including encouraging more flexibility and having childcare available. As Kappy and DeAngelis (1990) wrote, “The task is to change the rules, not help women adjust to them”. In this century, it is recognized that even though women constitute the majority of pediatricians, particularly younger pediatricians, they might be unrepresented in academic positions, subspecialty positions, and senior administrative positions. Women chairs of pediatric departments argue that there should be exposure to research, recognition that careers might be interrupted early, allowance made when women return to the workforce after child-bearing, and perhaps child rearing, appropriate mentorship, part-time work options and readily available childcare. (Women Chairs of the Association of Medical School Pediatric Department Chairs 2007). Academic institutions should ensure flexibility in tenure-track positions.

Most of this discussion pertains to pediatricians, and not to the specialty of pediatric surgery. A survey in 2004 noted that 10% of pediatric surgeons in the United States were women, and most seemed pleased with their career choice. Many of those with children, had deferred childbearing until the end of the training, and had used advanced reproductive technology options (Caniano et al. 2004).

To return to the opening of this section, and why this is called **gender and pediatrics** rather than **women in pediatrics,** we must review the comments made in a formal study of family physicians in Ontario, Canada (Williams 1999). Twenty years ago, Williams reported that woman physicians were less likely to be the breadwinner, more likely to be the main carer for children in the family, more interested in psychosocial medicine, more interested in supporting health system restructuring, and more likely to have interrupted careers. They were less likely to be involved in an academic center, and very underrepresented in some specialties such as surgery. The reality is that they had been socialized into behaving like most existing pediatricians in what was a male dominated profession. Nevertheless, the differences between male and female pediatricians were less than expected, and one third of the women physicians were the main breadwinners in the family, many of the male physicians were very involved in childcare and as interested in psychosocial medicine as the women. All branches of medicine, including pediatrics, will be affected by general societal trends.

1.8.2 People Who Identify as Gay, Lesbian, Bi-Sexual, Trans, Queer or Other

As noted, sexuality is not binary. The available literature about the experience of gay, lesbian, bi-sexual, trans, queer or other (LGBTQ+) trainees and physicians has developed principally since 1980s. This literature concerns the behaviours of health care professionals and patients. We will explore how people in the healthcare field treat LGBTQ+ trainees and physicians, and how LGBTQ+ trainees and physicians are received by their patients.

In the United States, a major development in reducing homophobia occurred in 1973 when the American Psychiatric Association removed homosexuality from the nomenclature of psychiatric disorders (Morgan and Nerison 1993). In assessing whether this change worked to improve the lives of (what we would now call) LGBTQ+ physicians, a 2001 literature review reported on three relevant themes: homophobia, homosexual issues in medical education and training, and discrimination (Burke and White 2001).

With respect to homophobia, the literature described an early survey in 1982 of San Diego physicians, which used a validated instrument called the "heterosexual attitudes toward homosexuality" (HATH) scale (Mathews et al. 1986). The authors of that study reported that 23% of respondents had homophobic attitudes. Such attitudes were accepted apparently casually in some quarters. A commentary published during the AIDS epidemic in 1984 in the Southern Medical Journal (Fletcher 1984) invited readers to "act as empirical scientists", and rhetorically asked,

> Can we not see the implications of homosexuality before us? If homosexuality, or just male homosexuality, is "OK", then why the high prevalence of associated complications, both in general and especially with respect to AIDS? Might not these "complications" be "consequences"? Might it be that our society's approval of homosexuality is an error and that the

> unsubtle words of wisdom of the Bible are frightfully correct? […] homosexuality is a pathological condition.

Homosexual issues in medical education and training were a significant concern according to the 2001 literature review. Such concerns focused on the amount of program time devoted to special health needs of the LGBTQ+ community, the extent to which there were support services for student members of the LGBTQ+ community and homophobic attitudes of program directors. A 1994 study of 291 family practice program directors and 67 homosexuals third- and fourth-year medical students reported that 71% said that their sexual orientation affected their specialty choice, interviewing for residence and the ranking of residents. Eight percent of program directors scored in the homophobic range on the HATH scale (Oriel et al. 1996).

The literature review authors, Burke and White (2001), describe discrimination as "homophobia in action". Such discrimination can include rating an LGBTQ+ trainee lower than a heterosexual trainee and refusing to refer a patient to a LGBTQ+ community physician. A 1994 survey (Schatz and O'Hanlan 1994) reported:

> 17% reported to have been denied referrals, 34% had experienced "verbal harassment or insult by their medical colleagues", and 66% felt that homosexual bisexual doctors would risk losing their practices if colleagues discovered their sexual orientation.

In Canada, a qualitative study published in 2000, reported that for trainees, safety of learning environments was of paramount importance. Authors, Risdon et al. (2000), stated that "safety" meant the ability of a trainee to take decisions about sexual identity disclosure, residency opportunities and career path, without punishment or disadvantage for being a LGBTQ+ doctor. Assessments of the actual level of safety (risk) was influenced by: identifiable supports, inclusive criteria and effective policy in censuring homophobia and discrimination.

Respondents to the Risdon et al. (2000) survey commented on the extra work that homophobia discrimination causes LGBTQ+ trainees, "We extend a lot of energy coping with homophobia that the institution throws at us – a ton of energy that we can turn instead toward making ourselves better doctors". They commented on discriminatory representations of gay people as patients: "Whenever a healthcare problem has a gay person, it has to do with AIDS or adolescent sexuality. There aren't any heart attack victim or diabetics who happen to be gay." They described challenges of finding a place to practice medicine, "I couldn't imagine setting up shop in a small town and being open about my orientation and having that accepted". But also commented that being marginalized, and therefore experiencing suffering, helped:

> Being gay has profoundly influenced the kind of physician I am. It has forced me to learn the skill of putting myself in outsider's shoes – whatever [whoever] that outsider is. It has forced me to see the linkages between all the forms of discrimination. (Risdon et al. 2000)

Given the advances in societal recognition of people with respect to sexual orientation, as represented in gay marriage laws that came into effect in Canada (2005); New Zealand (2013); England, Wales and Scotland (2014); the Republic of Ireland

and the United States (2015); and Australia (2017), one would think that homophobia and discrimination would diminish. Indeed, significant change has occurred.

Consider the experience of a pediatrician, Mark Schuster (2012) who looked back in on his experience as a 1980 trainee and how a homophobic advisor sought to sabotage his career:

> I met with my attending from my pediatrics rotation at [Boston] Children's [Hospital], who was also a member of the admissions committee for the pediatrics residency. He had decided that he should be my advisor. He told me that I was definitely going to get into Children's for residency, so I should take the opportunity to do adult rotations because I'd get plenty of pediatrics for the rest of my career. He told me who should write my recommendations, with him being at the top of his list.

After Dr. Schuster told the advisor of his sexual orientation, the advisor,

> looked stunned. He said nothing for a long time. Then he asked if I had told anyone else at the hospital. I said that I hadn't, and he told me not to tell anybody. […] he [later] informed me that he would not be writing me a recommendation. This time I was the one who was stunned. I hadn't seen it coming. It wasn't lost on me that without a letter from the attending of my only pediatric rotation, I wouldn't be able to become a pediatrician.

Reflecting, however, on this experience in the 1980s, Schuster (2012) commented on how much things had changed. He reported a then recent experience of being asked to find a spot for a spousal hire in a same-sex relationship. "I could not believe that in a mere two decades, we had gone from 'I've decided not to write you a recommendation' to 'Your job is to get this guy's [same-sex] partner a fellowship'."

Despite increasing acceptance of LGBTQ+ physicians, it would be incorrect to claim that the lives of all such physicians are easy. In 2010, the American Medical Association Journal of Ethics reported on challenges faced by rural physicians by offering a case study of a physician in a homophobic encounter with relatively little social support (Ng 2010). In the case, the gay physician is approached by a female patient to ensure that youth in the town are not exposed to gay people. She said, "I mean, if I ever found out that there was one of them here—especially a teacher or a coach—I don't know what I'd do." This case helpfully reveals the stresses that gay physicians face. Such anecdotal reports are affirmed by a study published by the National Health Service (NHS) in the United Kingdom in 2016, (The Association of LGBT Doctors and Dentists and the British Medical Association 2016) prompted the British Medical Association to write:

> One might think, in this day and age when gay marriage has been legalized in England, Scotland and Wales, that homophobia and discrimination against lesbians, gay men and bisexual people was a thing of the past. If only that were the case. The experiences related in this report show us that too many of our LGBT colleagues are still experiencing the NHS as a less than supportive place to work and be themselves.

According to the NHS, both its survey and two case studies indicate that experience of 'environmental' homophobia is very widespread, with many medical and other staff and service users still apparently finding homosexuality an acceptable subject for light-hearted banter and so on. While many gay medics say they don't

want to make a fuss about 'mild' homophobia, the case studies show it is often throw-away comments, rather than direct abuse, that actually have a lasting negative effect on their confidence about being gay in the medical world.

A case study of a trainee reported:

> Mark had been looking to specialize in pediatrics, but this all changed on a shift when a nurse snatched a child away from him and told him people like him need to be careful around children. "I had felt I had a good working relationship with everyone," he said. "I did not feel I needed to be anything but open." But after the nurse went on to say that the child had enough problems already, Mark was shocked to find that none of the colleagues present stepped in to defend him. "No-one said anything, everything went quiet and then everyone continued with what they were doing."
>
> But for Mark there was no way he could continue as before. "I was terrified; it made me think that there were some very frightening and ignorant views held by my colleagues."
>
> Mark did not report the incident. He did discuss what had happened with a consultant who assured him that his sexual orientation would have no ramifications on his career, but this did not stop him from feeling frightened that others shared the same beliefs as this nurse. (The Association of LGBT Doctors and Dentists and the British Medical Association 2016)

While change has occurred, clearly homophobia and discrimination can affect pediatric trainees. The Association of LGBT Doctors and Dentists and the British Medical Association (2016), have responded with specific proposals for action, including:

- Medical training to include diversity training, including information on where to go if you have a problem in relation to this issue;
- Mandatory education and training for doctors conducted by knowledgeable LGBTQ+ doctors;
- Mentoring of junior staff by more senior LGBTQ+ medical staff to help physicians come out or to step in if someone is being homophobic;
- Clear safe avenues for redress against homophobic or biphobic behavior; and
- Research and understanding of the complex issue of gender and chaperones (e.g. while male doctors have chaperones for intimate examinations of women, lesbian doctors may also need such protection).

1.8.3 Summary of Changes

Pediatrics has changed from a male dominated field where physicians presented as heterosexual, to become a diverse group of people who care for children. Clearly, when physicians are supported irrespective of their sex or their sexual orientation, and in their personal relationships, they are better able to focus on delivering the best quality medicine, the benefits of which accrue to the child patients.

1.9 Life At Work and the Rest of Life

It is likely that all pediatricians strive to achieve excellence in their professional lives and to do justice to the people in their personal lives. The challenge of finding what is now called "work-life balance" is thought to be significant but we think that the notion is not helpful. Schwingshackl (2014), a pediatric critical care physician, asks an interesting question, "Exactly how much life do we need to balance our work? Will we just wake up one day and feel "balanced?" Another author noted that a distinction between "work" and "life" implies that life occurs only away from work. The distinction between "work" and "life" has two unfortunate results: it devalues time at work and creates unrealistic expectations for our time off work. In reality, most people spend more time at work than they do with their partners, their families, in food preparation, conducting their hobbies or sleeping. In the discussion, Buddenberg-Fischer et al. (2008) is quoted, "A well-balanced integration (not separation) of professional and private life is an essential goal for the new generation of doctors". John Irving (1990) suggests that the aim should be, "Finding a way of life we love and having the courage to live it." Schwingshackl (2014) concludes his essay by stating that the time we spend with our patients is a part of life just as much as is the time we spend on a family vacation, fishing with friends or simply sitting in a bar sipping a drink. Each of us has better and worse days, but during most days, pediatricians will have made a difference in the life of at least one child. Such a way of life is a privilege.

1.10 Ethical Concepts and Pediatrics

1.10.1 Four Principles (Principlism)

Emily, like all current medical students, will be familiar with concepts of biomedical ethics and its role in helping to make complex decisions. Currently, the dominant medical ethics paradigm is principlism, a school of thought that developed in the 1970s. In "principlism", many different philosophical concepts are summarized as four principles: autonomy, beneficence, non-maleficence, and justice. These were first developed to advance understanding and to guide medical research. Now the same ideas are widely used in clinical medicine and pediatrics. These principles are useful in pediatrics. However, their application to pediatrics, with its triadic nature, is different from their application in adults, which is based on a dyadic relationship of patient and physician. The four principles complement, but do not replace, other aspects of philosophy that can be applied to medicine. In particular the principles were developed before modern concepts of feminist ethics were expounded.

The four principles, in their present form, are associated with the two philosophers Beauchamp and Childress (2013) and are described in detail in their book "Principles of Biomedical Ethics". We use the material in their book as a starting

point for our comments on the application of these principles to pediatrics. This book is an excellent source of detailed information on the philosophical concepts underlying the four principles, as it is in many other aspects of biomedical ethics.

In the preface to the Seventh Edition, Beauchamp and Childress (2013) note that the principles are usually listed in the order we give above, that is: autonomy, beneficence, non-maleficence, and justice. These authors stress that the principles are not in any order of preference. Nevertheless, we observe that autonomy generally is given preference. This fact is not surprising because the principles were conceived, and ideas developed at the same time as various "rights movements" were gaining traction throughout the Western world. Like almost all authors, we struggle when attempting to balance the value of each one of the four principles in relationship to the others in specific cases.

We caution against the assumption that the "Four Principles" are universally applicable in healthcare. Societies other than Western societies might use other bases for making health care decisions, particularly religious bases. Even if they accept the four principles, then interpretation of each principle might vary among cultures. One criticism, based on a case study in a Muslim culture showed that, for example nonmaleficence can be viewed very differently in different societies. A Western application of this principle might "be used to justify withholding or withdrawing futile or damaging treatments, whereas Islamic ethics applies this principle to forbid all actions that may harm life". Such thinking does not appear to distinguish between quantity and quality of life, and would regard withdrawal of treatment that leads to death as harmful. Commenting on the Islamic religious tradition, Westra et al. (2009) writes:

> Because of the unconditional valuation of human life, every additional day lived is of value; a treatment that prolongs life therefore cannot be harmful. The trust in an omnipotent God is a second reason why decisions to forgo life-prolonging treatments cannot be justified. Van Bommel: Muslims feel very strong that it is Allah who does the actual healing, the doctor being only the agent for the will of Allah. This consciousness is based on the Qur'anic verse: "*If Allah touch you with affliction, none can remove it but He*." (6:17)

This caution should also be heeded in that the interaction in Western societies with minority or immigrant groups who might have very different ideas of right or wrong, as compared to those who spent have spent their lives in a Western society. (Regarding the specific issue of end of life care, please see Chap. 10).

1.10.1.1 Autonomy

"Autonomy" derives from the Greek and means "self-rule". Autonomy might apply to patients in a variety of ways. Autonomy of a patient means, at minimum, that he or she may and can act in accordance with a self-chosen plan. To quote Beauchamp and Childress (2013), the two conditions essential for autonomy are *liberty* "independence from controlling inferences" and *agency* "capacity for intentional action". Autonomy in bioethics is presented generally as it applies to competent adults, with exceptions typically regarding those who are not competent adults. Such adults

include those who have had competence and have lost it because of disease or injury, those who never have had competence because of permanent neurological issues, and those who do not have competence but will develop it, that is, the vast majority of children. It is the last group, when interactions involve physicians, parents and children, in which simplistic views of autonomy will be, at the very least, unsatisfactory.

One way to apply autonomy to pediatrics is to assume that autonomy will be exercised on behalf of the child by the parents, who will be expected to act in the "best interests of the child". This standard might not be realistic, according to Walter and Ross (2014). They state that parents are "expected to make decisions based on the child's best interests, although in reality they only have to meet their child's basic interests." Meeting this low standard is all that is effectively required of parents because, as they say, "If their actions fall below a threshold of abuse and neglect, then the state may intervene". Even if we accept and aim for the best interest's standard, how do we define "best? Who defines "best"?

Walter and Ross (2014), cited above, ask us to consider autonomy slightly differently; not to assume without thought that the parents simply exercise autonomy on behalf of the child. They ask us to move from an individualistic view of autonomy to a relational view of autonomy. They point out that none of us can possibly have full control over every aspect of our life. All of us are "embedded" in society in many different ways, and the relationships we have are dynamic, and are constantly being re-constructed. In addition, taking a relationship view of autonomy allows us to include ways in which the developing autonomy of the adolescent can be recognized. (We will return to specific concerns about ways in which the autonomy of the adolescent can be handled, but in the meantime, we will continue exploring the relational approach to autonomy.)

To operationalize the theory of Walter and Ross (2014), consider that the patient we are dealing with and the families in which they are embedded are strongly interconnected. A relational view of autonomy allows us to balance the "best interests" of the child patient against the interests of the family. While basic needs must always be met, there is a need to balance the needs of other family members and the needs of family as a whole. This is how families function in general; a constant balancing of competing needs and wants. If one child in a family wants to participate in an activity which is very expensive, the parents might decide against the activity because the family as a whole might be threatened by lack of funding for general basic needs. Also, that child would need transportation by the single-family car to the out-of-school activities at the same time as the sibling needs transported to other activities. Clearly decisions need to be made on what is possible and how to benefit one child without significantly disadvantaging other children in the family.

Are we to assume that when a family member needs healthcare, that the needs of the other family members and of the family as a whole are subservient in all respects to the needs of one person? In the short term, and in life-threatening situations, the answer will be yes. Over the long-term, there will be paradoxical negative effects if the needs of other siblings in the family, the parents themselves, or family functioning overall are neglected. Using a relational lens to consider autonomy, the needs of

the child patient can be met, but always with recognition that needs must be balanced with other needs within the family. By contrast, if we delegate all decision-making for the child patient to the parents and ask them to use the "best interests" standard, there is little room to consider the needs of siblings, parents or family as a whole.

In other writings, Ross (2016) expands on some of these ideas. She notes that the law gives parents wide discretion in their decision-making, provided their actions are not abusive. The child has the right to have a fulfilling life but is not entitled to have every possible good in life. She uses the phrase "constrained parental autonomy" to describe this state of affairs.

As children move into and through adolescence, they gradually assume the rights and responsibilities of adult life. A similar trend occurs in how children relate to their health care professionals – they assume increasing amounts of responsibility in addressing their own health care issues. They might start to see a health care professional without a parent, or at home, they might assume the responsibility of taking their own medicines. When it comes to making health care decisions, the developing autonomy of the adolescent can pose problems. We believe such development causes fewer problems when pediatricians and ethicists use a relationship framework. By contrast, a parent might be given authority to make all decisions for the child, until some arbitrary moment occurs, and the child can make all decisions for herself. When a relational approach is used by pediatricians to guide their actions, the adolescent patient might still be given authority to make decisions, but the pediatrician will still recognize and will take into account that the patient is still embedded in a family.

Legal frameworks regarding adolescent decisional authority vary with the jurisdiction and are discussed to some extent in Chap. 4 on consent and in Chap. 14 on adolescence. In some specific situations, decisional authority is given to the adolescent, but such an award of authority is not based on decisional capacity, but rather on the concern that if the adolescent does not have freedom to choose then the adolescent will forgo important treatments. These situations include treatment for drug and alcohol abuse, treatment for sexually transmitted disease, counseling for contraception and the ability to authorize termination of a pregnancy.

1.10.1.2 Nonmaleficence

We will treat non-maleficence and beneficence as separate principles, though we do understand that they are often conflated, and certainly they are connected.

Nonmaleficence is avoiding harm in any patient encounter. The harm needs to be real, and not trivial. We inflict many harms every day; few rise to the level of a breach of the principle of nonmaleficence. For example, the surgeon cannot operate without causing, at least initially, some harm. We can disturb the playful toddler by having the parent hold him or her firmly while we examine the ears. A sick 2-year-old will feel pain as we insert an IV when he or she is in a life-threatening situation. In each of these situations, the harm is justified by the good that will follow.

Nevertheless, there are many situations when harm is caused by the action or inaction of physicians. These include instances of medical error, when we cause avoidable harm including missing a diagnosis, making an incorrect diagnosis, prescribing the wrong treatment, or prescribing the wrong dose of the right treatment. We have a duty to provide highly skilled compassionate care and breaches of that duty can amount to negligence.

We can cause harm in more complex ways. In our desire to avoid causing harm, we can overprotect children. For example, we might overprotect children by forbidding them to participate in sports. While some limitation on contact sports is likely to be reasonable, banning participation is not likely to be reasonable. Another form of overprotection is by forbidding any child from participation in research. If we banned children from participating in research, then we could not improve and evaluate current and new treatments. Of course, children do need appropriate protection during all aspects of research; the protection must be reasonable and such reasonable protection is described in Chap. 13. Likewise, and more seriously, we can cause harm by avoiding difficult decision-making. We might recognize that we are providing futile treatment, and perhaps causing discomfort for the child. Yet, sometimes, we avoid taking even the first steps towards withdrawing the intervention. When harm is being caused to the child, it is important for pediatricians to act. Some of the ways end of life decision making might be approached are described in Chap. 10.

A newly highlighted way of causing harm is overdiagnosis. To quote the authors, Coon et al. (2014), "Overdiagnosis occurs when a true abnormality is discovered, but detection of that abnormality does not benefit the patient". Such a diagnosis can arise when a test is done, the result identified is precisely the one that was sought but there is no benefit to the child from this true positive. Many examples are given in the paper; we cite two common conditions: gastroesophageal reflux and bronchiolitis. Gastroesophageal reflux is common in the first 6 months of life, and usually resolves by 1 year of life with or without interventions. However, the interventions may cause side effects. Despite this fact, investigations and the treatment for gastroesophageal reflux continue to increase. In terms of bronchiolitis, admissions have increased considerably during the period the pulse oximeter became available without any change in mortality. There is no evidence that oxygen therapy is beneficial for transient episodes of hypoxemia.

Doing nothing is hard even though doing nothing is not nothing – it is watchful waiting. Coon et al. (2014) speculate that pediatricians respond by doing something when watchful waiting would be better because they assume that parents always want an answer, and that parents think that if we do not do tests, we are less caring. In addition, watchful waiting can be perceived as ignoring parental anxiety. Trainees are more confident in doing things, and less confident in the face of uncertainty. Trainees are often taught via problem-based learning in which many diagnoses will be raised as possibilities, some unusual and all suggestions leading to some investigation or other. There might also be a fear of litigation.

Overdiagnosis is something that requires further study, and ought to be addressed in medical education; it is an ethical issue because of the harm it causes. If it is to be addressed, then we need to deal with the system incentives that lead to over investi-

gations, industry pressure to make a diagnosis, such as attention deficit hyperactivity disorder. Long term public educational campaigns can change the public's incorrect belief that tests are good and more are better.

1.10.1.3 Beneficence

Beneficence implies doing good. "Doing good" is the underlying ethos of pediatrics. Doing good encompasses being helpful, being merciful, being kind, being friendly and so on. Doing good is something we should aim for but is not necessarily obligatory. Doing good is a duty owed to patients, and it is also a duty we owe to those close to us, but not to everyone. The virtue of temperance suggests that even in doing good, temperance is valuable.

In the past, attempts to do good led pediatricians into morally questionable actions, specifically into paternalistic behaviors. Paternalism occurs when the pediatrician with the reality of superior training and knowledge goes on to assume an insight into the best interest of the patient and proceeds to take decisions. A paternalistic action subverts the autonomy of patients and subverts parental decision-making for their children. The belief that the pediatrician knew best, led to other morally questionable activities, such as deceptiveness, presenting misleading information and sometimes withholding information. On the other hand, the current view that doing good (beneficence) is always trumped by autonomy sometimes leads the pediatrician to believe she should confine herself to presenting information to the family and follow whatever they decide. We feel this view is extreme and even unprofessional. Pediatricians have trained for years to develop competence in their specific field of medical practice. When they present medical options to parents or patients, they are presuming that the parent or patient has the expertise to choose wisely. The fact is most parents and patients simply do not understand the nuances of the options that they are being given and need some advice as to what the better option is. Offering such advice is doing good; it is beneficent. Sometimes the need to "do good", supersedes slavish respect for autonomy.

An aspect of doing good that has demanded attention recently concerns the so-called bystander effect. We hastily add that this is a general societal issue, not one confined specifically to pediatrics. The bystander effect is the "phenomenon in which the greater the number of people present; the less likely people are to help a person in distress" (Cherry 2018). Some contributors to this phenomenon apparently assume that if many people are present, then "I do not need to respond because someone else will". Another apparently motivating factor for this behaviour is our common desire to behave in a socially conforming fashion: why jump out of a crowd when no one else is jumping out? Yet many people could stand by watching a situation where help is essential. Being aware of the tendency is one way to counteract the bystander effect. In the care of children, "bystanders" should not hesitate to call child protection services when they suspect children might be being abused.

Doing good is about doing the right thing. To return to the issue of overdiagnosis, doing good is not about doing more either because we are insecure, or because a

parent demands interventions or investigations that are not particularly helpful to the child (Ralston and Schroeder 2015). We see this is an important ethical issue, and consistent with the various campaigns to "choose wisely" (Moriates et al. 2013). Doing good, which can mean watchful waiting, is an important topic that should be featured at all levels of pediatric education.

1.10.1.4 Justice

We believe that children, who have an innate sense of fairness, readily understand the principles of justice. Children also have a sense of injustice and are prepared to protest when they identify unfairness. Those of us who are not children must struggle with various theories of justice and will usually conclude that no one theory of justice encompasses all the uses of justice in pediatric ethics. Topics considered under justice include the idea of fair opportunity, social justice, fair and unfair discrimination, recognizing and avoiding vulnerability, avoiding research exploitation, and answering questions such as is there a right to healthcare, and how do we set priorities? In the succeeding paragraphs, we will outline some ideas of justice, but recognize that our summary is limited. We recommend, as we have done earlier, that those who wish a deeper understanding should consult the book written by Beauchamp and Childress (2013).

A starting point in understanding justice is the phrase attributed to Aristotle: "equals must be treated equally, and unequals must be treated unequally". During the period of the Enlightenment, the notion of an individual's right to identify and to pursue his or her own idea of happiness took hold. A corollary of the notion that a citizen has a right is the idea that someone has a duty to protect that right. So, if we say that an individual has a right to healthcare, then it follows that someone, or something, has the duty to provide it. Yet, in a world of scarce resources, no one individual can have everything that he or she wants. In the nineteenth century, John Stuart Mill and Jeremy Bentham (Lebacqz 1986) articulated utilitarianism, which was further developed in the twentieth century to offer "the greatest happiness to the greatest number". These theories have given rise to, for example cost-benefit analysis, so prevalent in healthcare today. According to utilitarianism, individual rights should be supported by society, but they can be overridden by social utility. The goal is not individual satisfaction but the "greatest overall good". This method of thinking can seem harsh, but in dealing with justice as it applies to individuals, surely, we must also think about the common good. Utilitarianism is seen today is rather unsatisfactory, but its underlying concepts are useful in resource allocation.

The philosopher, John Rawls (1971), developed principles of justice focusing on the idea that justice is based on fair choices. He accepted the reality of inequalities, both social and economic. These inequalities could be just if they were compensating benefits for everyone and "in particular for the least advantaged members of society". Rawls posited the existence of a 'just savings principle" according to which the main duty owed to our successors is the saving of sufficient material capi-

tal to maintain just institutions over time. Rawls argued that social and economic inequalities should be arranged so that they are:

> to the greatest benefit of the least advantaged, consistent with the just savings principle, and attached to positions open to all under conditions of fair equality of opportunity.

In terms of bioethics, the most important message from Rawls, it seems to us, is the focus on the disadvantaged, and the need to fashion societal measures to lessen disadvantage of any kind.

Another school of thought, Communitarianism, bases its ideas on concepts of the general good rather than on individual rights. An emphasis on the community and on common good seems worthwhile in any discussion of the allocation of healthcare resources. We believe that the good of society, not individual rights, must be the basis of public policy.

More recently, Powers and Faden (2006) have developed theories of justice specifically focused on the needs of bioethics and health policy. Their focus is on egalitarian justice not simple social utility with the goal of reducing inequality in the world. They note that "a constellation of inequalities can systematically magnify and reinforce initial conditions of ill health, creating the perfect setting fact other dimensions of health". Justice must attend to health and social structures in mitigating "the interactive and cascading effects that lead to systemic injustice".

In succeeding chapters of this book, we use different aspects of each of these theories of justice to illustrate bioethical issues, particularly related to resource allocation.

1.10.1.5 Using the Four Principles in Assessing an Ethical Problem

This book aims to describe the ethical underpinnings of the highest standard of pediatric practice. We believe that ethics underlies all of pediatrics. Nevertheless, pediatricians or trainees might find themselves on ethics committees, and be asked to participate in clinical ethics consultations. Neither in this chapter, nor in the chapter on ethics committees will we deal in any detail about such consultations, but we describe here two ways in which these problems are approached, and indicate our preference for the second one, because it corresponds to the methods used in solving clinical problems in pediatric practice. Please note that ethics issue in research are handled by a different mechanism that is described in Chap. 13.

Jonsen et al. (2015) describe what is called the "Four Topic Approach". In common parlance, the word "topic" is often replaced by the word "box". The four topics are: *Medical indications, Patient preferences; Quality-of-life*; and *Contextual features*. Under each of these headings is a list of the ethical principles at play, and then a number of questions. Under *Medical Indications*, Jonsen et al. (2015) cite the principles of beneficence and nonmaleficence, and pose questions that address medical problems, diagnosis, goals of treatment, and how can harm be avoided. The section, *Patient Preferences* is about respect for patient autonomy. Here, the issue is whether the patient is mentally capable and competent and raises other questions

about the patient's understanding of what is happening. The heading *Quality-of-Life* addresses the principles of beneficence, nonmaleficence and respect for autonomy. The questions range from exploring the prospect of returning to normal life to the possibility of plans for palliative care. Finally, under *Contextual Features,* the principles are of loyalty and fairness, and the questions range from family issues to conflict of interest. Use of this technique certainly helps to paint a clear picture of what is happening in a complicated clinical situation. The four principles method offers a way in which the principles can be balanced. However, we agree with Ross (2016) (cited above) that this technique requires considerable modification for use in pediatric cases.

We suggest some modifications here but caution that, even with modification, the method is still not fully suitable for pediatrics. Without modification, the Four Topic Approach will inappropriately regard a child like any other patient who does not have competence and will assign parents a defined role similar to that of a surrogate decision-maker for an adult. To modify the Four Topic Approach for pediatrics, one essential change, therefore, is to recognize the triadic nature of pediatrics, and that there exist constraints on surrogate decision-makers for children that do not exist for surrogate decision-makers who make decisions for adults. As an example of such constraints on surrogate-decision making for children is the case of parents purporting to give consent to genetic testing of their child for an adult-onset condition. As Ross (2016) notes, many genetic laboratories will refuse to conduct such a test on a minor because to do so violates the child's liberty to make that non-reversible decision for him or herself. A second issues is related to *Patient Preference*; in pediatrics, *Patient Preference* can be devoid of content. A pediatric patient might not have developed a preference (for reasons of age or disability); nevertheless, it does not follow that the parent's preference should automatically be substituted. Thirdly, the typical way that the Four Topic Approach uses *Quality of Life* is not applicable in pediatrics. With adults, considerations for *Quality of Life* are attempts to determine how close the adult is to her/his baseline. Yet, when we deal with preterm infants, for example, there is no baseline, and estimating future quality of life is fraught with difficulty. In addition, there are some choices that we would not permit parents to make. For example, we would not allow parents to refuse to consent to blood transfusion for a child in a life-threatening situation only because the parents belong to the organization run by the Watchtower Society known as Jehovah's Witnesses which denies its adherents the freedom to access blood transfusion. One can see, therefore, that the Four Topic Approach was developed for adult patients. We recognize its popularity and would not criticize anyone who used it in pediatrics, with the qualifications we have identified.

An alternative way to approach ethical problems is described by the family physician/bioethicist Philip Hebert (2014). He calls his method, "A 'Good Enough' Ethics Decision Procedure". He argues that we should proceed through very familiar steps. Step one, recognizing that there is an important ethical problem, and then moving on to step two, defining the problem that is to be solved. Step three involves determining reasonable alternative course of action, and step four entails the detailed ethics work when each option is considered in relation to the fundamental four ethi-

cal principles. The principles, autonomy, beneficence, maleficence and justice, encompass a range of ethical concepts. The next step is to decide on a resolution, and then to consider the position very critically. Finally, it is time to act and "to do the right thing." (Hebert 2014).

More details of these two methods are provided in the books we have referenced. We believe that they are both suitable in dealing with clinical ethical problems involving children. We hope that the readers of this book will have a high level of sensitivity to ethics issues in their practice and will know when to request an ethics consultation.

1.10.2 Pediatric Character and Virtues

Having reviewed basic medical ethics principles and their application in the clinical situation, it is important to consider the character of the person applying the principles. In this section, we hint at some of the traits of pediatricians by describing their involvement in the life of the children whom they see and the need for some boundaries. In ethics, character matters. The virtues we each have are the essence of our character; hence, we will discuss some of the virtues needed in pediatrics. Before you read further, and to ensure Emily is not scared off by this section, please do not think the pediatrician is "goody two shoes" without blemish. A pediatrician is a person with virtues that she will develop over time in her career; she will have flaws in her personality, which she will acknowledge and also work to improve over time.

One such complementary aspect of philosophy is "Virtue ethics". This is a branch of philosophy gaining prominence in medicine, and pediatrics. We affirm that principlism is useful in identifying and analyzing difficult clinical problems. Virtue ethics is valuable, too, in that it shifts the spotlight to the person identifying and analyzing the difficult clinical problems. Virtue ethics stresses that the character and personality of the pediatrician is very important. Virtue ethics belongs to the earliest period of Ancient Greek philosophy, "Classical" virtues" (Van Hooft 2014). The idea that character is important remains true and thinking in this area continues to develop. In considering the virtues, a pediatrician might draw from more than one school of thought, especially feminist virtues. However, there is considerable overlap among ways of thinking about virtue; different schools complement (rather than oppose) one another.

The field of virtue ethics in medical practice was, for many years led by one person, Edmund Pellegrino (2001). His work, now receiving wider attention, is based on classical virtues. Perhaps the first exponent of the classical virtues was Aristotle in the *Nichomachean Ethics* (Welldon 1867). He stated that the principal virtues are temperance, wisdom, fortitude, and justice. We identify these virtues as important for pediatrics. Aristotle identified other virtues, but we have not included them as relevant to modern-day pediatrics.

Pediatrics has been enriched also by an understanding of virtues of empathy, caring, and relationships that have been identified and lauded by feminist ethics. The virtues we describe contribute to concepts of "professionalism". After addressing virtue ethics as enhanced by feminist ethics, we will return to concepts of professionalism within pediatrics.

1.10.2.1 Temperance

Temperance does not mean avoiding alcoholic drinks or the occasional glass of beer; it means leading a life in moderation. Temperance sets the scene for all the other virtues. We might conceive of the virtues of courage and bravery as a temperate midpoint of a spectrum. At one extreme of the spectrum is cowardice and at the other extreme is foolhardiness. Both extremes indicate the absence of the virtue of temperance. It is easy to understand that avoiding an issue to make life easy for oneself is tantamount to cowardice and is not virtuous. Placing oneself in a position in which harm will almost certainly occur might be extreme courage, but in reality, it is foolhardiness. Doing something very rash that brings danger to yourself or others is not virtuous. Such inclinations should be modified by temperance!

1.10.2.2 Wisdom

Wisdom is very important to every pediatrician. Sometimes, people think that wisdom is an attribute only of the old. There is little doubt that those who have made many mistakes, something we call "experience", might seem wise. Yet the relevant form of wisdom can be characteristic of pediatricians of any age. This wisdom is called "phronesis" and means "practical wisdom". Some people demonstrate practical wisdom quite young; some have difficulty ever grasping the concept. For most people, the concept is easy to grasp; with work and attention to concepts, behavior and results of action, young pediatricians can develop skills in practical wisdom. These skills are probably more important than the skills for, as an example, lumbar puncture, but such skills might never have been taught. They might be modelled by mentors. Practical wisdom is used every day: knowing when to intervene, knowing when to speak up, when to listen. Some days, the practice of pediatrics seems to consist entirely of fretful toddlers, surly teenagers, angry parents and infuriating colleagues. Practical wisdom might help us understand that the fretful toddler might be missing her nap, the surly teenager might be suffering from sleep deprivation, the parents might have many stressors outside of pediatrics that is affecting their behavior or they might be unwell themselves, and our colleagues might be struggling with some outside concern such as an ailing parent or a troubled marriage. Practical wisdom will help us in deciding when to act and when to be still and silent.

1.10.2.3 Fortitude (Bravery)

Fortitude was mentioned earlier; this is an important attribute and an important component of advocacy. An example of a brave pediatrician is Henry Kempe who with his colleagues published a paper titled, "The Battered Child Syndrome" (Kempe et al. 1962) which encouraged the medical community to identify and to recognize child abuse. He and his physician wife, Ruth, focused on child abuse in a major piece of advocacy in the 1960s. Their bravery in speaking out led to substantial changes in pediatric practice, to the introduction of legislation making child abuse illegal, to revolutionary changes in child welfare systems and to the development of child death review committees. The culture of Kempe's time was that we should not interfere with how parents look after their children. (Spousal abuse was also seen as something that should stay in the family; outsiders shouldn't "meddle".) Even when children were admitted to hospital with bruises, and it was suspected that the parents were the perpetrators, pediatricians of the day felt it was inappropriate interfere in something that was a family matter. Such an attitude would never be countenanced now thanks to the bravery of the Kempe's and their colleagues.

In our day, opportunities for bravery also exist. Almost all pediatricians are wisely in strong support of immunization. Those pediatricians who dare to comment positively in a public forum (i.e. on line) about the benefits of immunization and the dangers of being unimmunized, are often criticized very soundly by those antagonistic toward immunization; such criticism might be expressed in a very personal fashion. It takes bravery to speak out when such attacks are likely to result. Such bravery is rewarded by improvement in child health.

1.10.2.4 Justice

Justice, or fairness, indicates that we must practise pediatrics without any discrimination. That is often easier said than done. Indeed, a few studies have shown that physicians relate more closely to people who are "like us" than to people who are unlike us (Dovidio and Fiske 2012). The patients we deal with, by and large, have had negative effects from "life's lotteries". We aim to achieve some degree of fair opportunity for these children and their families. Such effort entails not just offering the best possible pediatric care we can, but also making some effort to mitigate the social disadvantages of many of our patients. A full discussion of the implication of justice for pediatrics is beyond the scope of this book. However, at the very least, when we care, communicate or make decisions about patients, we must avoid discriminating on the basis of race, ethnicity, gender and social status. We recognize that this is difficult, but achievable.

Moreover, we must move beyond a minimal concept of justice, that is avoidance of discrimination, and move to help those families who have been discriminated against. There are numerous examples based on the determinants of health particularly in the area of chronic disease, mental health, educational outcomes and expo-

sure to toxins (Oberg et al. 2016). We encourage pediatricians of all level of seniority to take an interest in ways of ameliorating those disadvantages in their area. Methods of doing so will be explored further in the section on advocacy.

1.10.2.5 Compassion

This inclusion of compassion marks an extension in our description of virtue ethics, beyond the classical virtues. Patients and families, pediatricians themselves, and professional bodies all regard compassion as an essential characteristic of all physicians. Compassion is described as "sympathetic consciousness of others' distress together with a desire to alleviate it" (Compassion 2018). Compassion in the physician certainly improves relationships with families, and it seems that physicians feel better when they act compassionately (Fernando and Consedine 2017). Compassion is seen as an essential component of professionalism in pediatrics and is described as "the ability to understand children's and family members' reactions to pain, discomfort, and anxiety from their point of view, not that of the physician" (Fallat et al. 2007). The particular section is described as "Compassion/empathy" conflating these concepts. We will discuss compassion and empathy in turn.

The literature on compassion describes barriers to its presence and to its failure, when the pediatrician experiences compassion fatigue (Fernando and Consedine 2017). Understanding the existence of barriers to medical compassion in pediatrics is important to knowing how to encourage compassion. Such barriers are surprising because pediatricians are known to value "interpersonal contact" and "working with people". Some people fear that trainees and junior pediatricians are less compassionate than those senior to them. Pediatricians are embedded in a complex system with other medical staff, patients and family, clinical realities and institutional constraints. Junior pediatricians must deal with struggles such as distressed and angry parents, complex clinical situations without clear resolution, and child abuse. Experience can offer some help in the development of compassion (or perhaps the reestablishment of compassion) but experience alone without a nurturing environment within institutions and with colleagues is inadequate to foster compassion. Compassion is something that we must encourage and support in our colleagues. To this end, Fallat and colleagues consider that it is essential for pediatricians to develop understanding by dealing not just with the practical realities of illness but also the emotional and spiritual aspects, and the effects of illness on children and families (Fallat et al. 2007). Not to be forgotten are the effects of all these factors on the trainee pediatrician him or herself and recognizing that self-help is important in the development of compassion.

Compassion, like all virtues, can also be associated with specific problems. These problems are described in the American Academy of Pediatrics statement (Fallat et al. 2007). For example, in a discussion of "boundaries in patient care", the document states that "Compassionate and empathetic care for the child historically has been balanced with the need to remain objective and avoid becoming overinvolved." There is no doubt that as trust develops within an evolving relationship,

there will be changes in boundaries. These include such seemingly innocent activities such as exchanging gifts between patients and pediatricians, and other more egregious activities that violate boundaries (a subject addressed in more detail in Chap. 2). Care in avoiding boundary violations should not be at the expense of diminished compassion.

1.10.2.6 Empathy

To return to empathy, this characteristic is defined as "The ability to understand and share the feelings of another". In pediatrics, the practice of expressing empathy is the attempt to describe what the pediatrician understands about the feelings of the patient and family, and to communicate that concern to the family. Physicians who exhibit empathy demonstrate concern for others and are motivated to help. Their emotions tend to be similar to those emotions experienced by another individual, such as a patient. Empathetic individuals might blur the line between the self and others. Empathy is characterized by understanding another's experience, communicating that understanding to the other person, and offering help.

Given the nature of pediatric work, of dealing with stressed families dealing with severe illness in the child, the development of empathy is challenging (Gleichgerrcht and Decety 2013). One undoubted challenge is the nature of the work which might well lead to anxiety in the pediatricians, and if the anxiety is uncontrolled, can decrease the ability to help families. In the past, "detached concern" was often encouraged in physicians and seen in contrast to empathy. It was thought that an attitude of detached concern facilitated better, more objective, decision-making by the physician. This idea found some validity in the fact that a very close involvement, such as the type of involvement we have with our own children or those of close friends, might lead to poor decisions. Yet, there is no evidence that "detached concern" really did lead to better decisions. We have no idea if it had a positive or negative effect on the physicians. Given the association of loss of empathy and burn out, we suspect that the deliberate avoidance of empathy probably had negative effects on the satisfaction of those physicians in their interactions with families.

We wish to support the development of empathy, and to discourage any return to a sense of distance between the pediatrician and the family. The pediatricians who develop empathy are likely to avoid burn out and to have a positive experience of pediatric practice.

A consequence of not providing encouragement and support for the development of both compassion and empathy is the development of "compassion fatigue", which is closely akin to "burnout", sometimes described as emotional exhaustion. (Kase et al. 2018) describes compassion fatigue as "secondary traumatic stress experienced by providers through repeated exposure to their patients' suffering." The same authors describe burnout as "occupational distress because of uncontrollable workplace factors that manifest as career dissatisfaction and the sentiment of being overworked".

Burnout has immediate consequences for patient care. Mahan (2017) note some of the consequences are an increase in errors and patient dissatisfaction. Burnout also has direct consequences for practitioners and trainees including high levels of job dissatisfaction, failed relationships, and mental health and substance use issues. Burnout impacts others; those affected have additional destructive behaviours and poor staff relationships. Pediatric trainees might be particularly affected, given their traits of compassion and perfection. When mental and physical stress is extreme, pediatricians might tend towards burnout. Training often pays less attention to the personal, social factors and teamwork skills necessary in pediatrics; it pays more attention to direct clinical abilities. Hence, a high priority is to encourage and foster resilience in oneself and to develop skills related to social interaction and teamwork. As Mahan (2017), cited above, says, modelling should be offered by "physicians who retain the joy, passion, and purpose of the calling that is pediatrics".

The obverse to compassion fatigue and burnout is compassion satisfaction (Kase et al. 2018). Compassion satisfaction is emotional fulfillment derived from caring for patients; this is clearly something to be encouraged and can occur with appropriate self-care. One aspect of the self-care that can encourage compassion satisfaction is talking about distressing issues with those who might understand. In the case of pediatricians, an understanding person might best be a colleague. However, support might also come from partners, friends, family members and spiritual advisors. In seeking support, pediatricians must be attentive to protecting the patient's confidentiality.

1.10.2.7 Pediatric Character and Ethics of Care

Caring is related to the "virtues". Philosophers disagree about how to classify care. Obviously, care should be fundamental to any activity within healthcare (the word "care" is pervasive). It is probably unimaginable to be a helper professional and not be caring. Benner emphasizes that care is about being attuned to others; it is about the relational aspects of how we lead our lives (Benner 1997).

The virtue of caring is central to the work of feminist philosophers who have chosen to look at virtue in a new way. This new way is very relevant to pediatrics and came to prominence in the 1980s with Carol Gilligan's important work which identified and challenged a male understanding of virtues (Gilligan 1982). Some of the features of care ethics listed by one author (Carse 1991) are:

1. Partiality – focusing on the individual;
2. Antiprinciplism – reasoning from particulars rather than from universal principles;
3. Emotionalism – emotions matter in moral decision making, as opposed to an insistence on all moral decisions being solely rule-guided; and
4. Relationships matter – looking at the relationship between individuals as the basic unit of analysis, relevant to each individual strictly.

Care ethics is relevant to the work of the pediatrician in emphasizing the importance of the relationships we develop, whether with children and families or with colleagues. Care ethics holds that it is not wrong to be concerned about an individual, and that emotions matter and should not be discarded. An ethics of care should be seen, in our view, as an extension of the virtues required of a pediatrician.

The support for collegiality contained within an ethics of care is consistent with the pediatrician's desire to work within a team to help children and families. As in other personal characteristics, there are limits to collegiality. Maintaining a collegial atmosphere is an important, but not the first concern. When a colleague or team member significantly breaches standards of care, and that physician's action leads to harm to a child, collegiality should not be the focus but rather protecting children. Collegiality is not a workplace value that permits ignoring harm to children; a desire to focus first on collegiality would wrongly privilege the interests of adults over those of a child.

1.11 Professionalism and Pediatrics

Medicine has been recognized as a profession since ancient times. Although pediatricians were latecomers to the rank of physicians, they now share in this recognition. Professionalism received little attention until recently; with the upsurge of new technology, major changes in the organization of medicine, and the erosion of trust the practice of professional behaviour has become a focus of medical organizations, including those devoted to pediatrics. Thistlethwaite and Spencer (2016) describes the characteristics; they state that a profession:

- Is driven by a sense of vocational calling, implying service to others.
- Has a distinctive knowledge base, which is kept up-to-date.
- Sets its own standards and controls access through examination.
- Has a special relationship with those whom it serves.
- Is guided by particular ethical principles.
- Is self-regulating and accountable.

Pediatric organizations have adapted these general principles specifically for pediatrics, and we use descriptions from two, the American Academy of Pediatrics and the Royal College of Physicians and Surgeons of Canada. In describing professionalism in pediatrics, the United States says that a pediatrician is someone:

> "Who can give advice without being patronizing, who is concerned about how an illness and its consequences (financial, emotional, psychological) will affect the family, and who strives to help the child and/or parent understand a disease process and its natural history (compassion/empathy). This doctor is thorough and technically skillful and continually incorporates new knowledge into his or her practice (self-improvement)." (Fallat et al. 2007)

The Royal College of Physicians and Surgeons of Canada (2018) has developed the Can MEDS concepts of the role of physicians and describe them as:

- Medical Expert (the integrating role)
- Communicator
- Collaborator
- Leader
- Health Advocate
- Professional.

In these documents the professional is defined for pediatricians as individuals who "***are*** committed to the health and well-being of individuals and society through ethical practice, profession-led regulation, and high personal standards of behavior." The detailed requirements are:

- A commitment to their patients, profession, and society through ethical practice
- A working knowledge of medical ethics, and recognize and appropriately respond to ethical issues encountered in practice
- Recognize the principles and limits of patient confidentiality as defined by professional practice standards and the law
- Identify, declare and manage conflicts of interest including appropriate relationships with industry
- Demonstrate tolerance for ambiguity and uncertainty and the possibility of error in decision-making
- A commitment to their patients, profession and society through participation in profession-led regulation.

The requirements of the Royal College of Pediatrics and Child Health (2018) in the UK are similar and admirably state that the College's aim is to train a "great pediatrician". Many of the issues raised under "professionalism" are addressed in later sections. (For example, conflict of interest is considered under "Boundaries".)

1.11.1 Physician Autonomy

Physician autonomy is related to the professional role of the pediatrician and to the understanding of professional self-regulation. The phrase itself, "Physician autonomy" is widely used but with little clarity as to its underlying meaning. By this phrase, we mean the societal protection of the physician's ability to take those steps that advance the interests of the patient. This form of autonomy arises in the context of, and because of, the patient-physician relationship. This autonomy is not the "possession" of the profession or of individual physicians. The existence of physician autonomy acknowledges the high standing of the medical profession in the community at large, related to, among other things, level of education, skill level, ability to apply scientific concepts in a practical way, and finally, and most importantly, a commitment to the welfare of the patient. When we move from the concept

of professional autonomy to the liberty of individual physicians to take action, we must be careful to remember: "the ethical justification for physician autonomy requires that they exercise liberty to promote their patient's best interests not their own interests" (Emanuel and Pearson 2012).

Physician autonomy does not include freedom to act without restraint. Constraints have always existed in how far physicians may go in the treatment of individual patients. In the past, pediatricians were constrained most often by the availability of resources, and specifically, the ability of patients and families to pay for treatment. In most Western countries, resource constraints are not currently an issue. Paradoxically, despite the availability of funding for individual patient care, physicians might feel that their autonomy is being limited in what they can do for patients. Limitation on physician autonomy is occurring because of the creation of ever-larger healthcare organizations, whether managed by governmental or private institutions, each with their own set of rules. These rules can affect physicians' liberty to act freely as individuals, in many different ways including remuneration, hours of work, and control of non-physician healthcare professionals. Although this loss of personal liberty can be real, it should not be confused with loss of physician autonomy. As citizens, physicians have the same level of liberty in their personal life, and of course the same restraints, as others. That personal liberty allows negotiation of, for example, remuneration for medical work. The autonomy granted physicians to assume the special responsibility that they have toward their patients and to act in the interests of their patients, requires physicians to restrain themselves from using the societal privileges to advance their own interests. For example, imagine a physician calling a telephone operator to say, "I'm a physician. This is an emergency. Please break into the conversation that people are having on this telephone number" when there is no medical reason to interfere with the conversation, but the physician simply wants to talk to one of the people who is tied up speaking with someone else. Clearly, physicians have societal privileges that must be reserved for medical purposes.

However, the current practice of medicine might involve some loss of societal protection of such physician decision-making autonomy in the interest of patient care. To quote Emanuel cited above, "To many, physician autonomy means that physicians should have complete freedom to provide treatments for patients according to their best judgment." But they should not have such unfettered freedom, because it leads to very wide variation in practice. In turn, this variation might increase the risk of error because of the complexity imposed on the many healthcare workers who share the care of patients (Reinertsen 2003). The development of consensus statements and guidelines, with a full assessment of the best current science improves patient care even if individual physician freedom is restricted. The restriction is far from absolute. Generally, the various consensus statements and guidelines allow variation in individual cases. When physicians choose not to follow consensus statements closely, the physicians should be willing to justify their action.

We support the general concept of "physician autonomy" as something that enhances high-quality patient care while accepting that some restraints placed on

the practice can be appropriate. We do support the availability of data on the outcome of various interventions, and data on practice variation as it affects patient care. We do not see these as limits on physician autonomy. We see them as enhancing physician autonomy, by providing information to improve the quality of patient care decisions.

Professional behavior is vital to a pediatrician and yet is difficult always to capture in words. The American Academy of Pediatrics has done so elegantly in defining a good pediatrician: "To other physicians, a 'good pediatrician' is a colleague to whom they would entrust the care of their own child."

1.12 Parents and Family-Centered Care (FCC)

Since about 1950 and increasingly in the twenty-first century, western society has affirmed the central role of families, especially parents, in the life of children. Pediatrics was perhaps slow to recognize how important parents and families are in the life of all children, in particular in the life of children with chronic illness. Pediatricians might be involved with children during one episode of illness or be involved over many years with an individual child, but this involvement is not nearly as significant as the role parents play throughout the child's life.

Current pediatricians and current pediatric trainees expect parents or another family member to be with the child in hospital. The daily practice of pediatricians and pediatric trainees includes discussing the details of the child's condition with parents and collaborating on defined solutions.

It was not always so. Many pediatricians would be surprised at how recent such collaborative practices are. Consider a true story from the 1930s involving the separation of the hospitalized child from the family:

> Juliet was a patient on many different occasions in the late 1930s. Her longest admission was two and a half years, during which she saw her father only once. because he had to travel 230 km from the home village to visit. She did not see her mother or a sibling at any time in the admission. When she entered hospital, she was fluent in French. When she returned home, she was fluent in English and could barely remember French. Religion played an important role in the life of the family. Juliet came from a Roman Catholic family but learned all the Protestant hymns from the Sunday hymn sing. (Coppes-Zantinga and Mitchell 1997)

Even in the 1950s, physicians thought that the presence of parents when the child was in hospital would delay recovery. From the 1950s to the present day in the United States, United Kingdom and Canada, a number of movements changed that situation culminating in what is now called, "Family Centered Care". An early phase in this transition was "enhanced visiting by parents" of children in hospital. This change (small, as we might now consider it) was the result in the United Kingdom of an official report that argued for less separation of family members:

> Admission to hospital appears to be potentially more detrimental than any other common form of separation because it so often involves an element of fear. […] Hence, the desir-

> ability of frequent visiting by parents; for when a child is confused, afraid and perhaps in pain it is especially difficult for a stranger to offer him the sort of reassurance and comfort that makes him feel secure. Thus, parents should not be denied access to their children in hospital in the mistaken belief that reassurance to a frightened child can be sufficiently afforded by a succession of nurses, however sympathetic they may be … (Platt 1959)

Now the mantra we use is that "parents are not visitors"; in other words, parents are an essential component of the care provided. In the United States, the changes that occurred in the medical and hospital care of children were part of a general movement toward empowering consumers, leading to greater decision-making authority for patients (and by extension child patients) in interactions with physicians. These beginnings led, over time, to Family Centered Care, as it is now conceived.

Johnson describes Family Centered Care as:

> "an approach to healthcare based on mutually beneficial partnerships among patients, families, and healthcare professionals" (Johnson 2000). Family-centered care (FCC) has been described as a partnership approach to health care decision-making. "As a philosophy of care, FCC, and the related term patient-centered care (PCC), have been recognized by multiple medical societies, health care systems, state and federal legislative bodies, the Institute of Medicine, and Healthy People 2020 as integral to patient health, satisfaction, and health care quality." (Kuo et al. 2012)

In pediatrics, there is a fundamentally strong recognition that the families are the constant in the life of the child. Healthcare professionals, of any discipline, or government, come and go, or play specific roles for a specific length of time, but in the end, the family will still be there. If the child is in hospital, then the family is still the most important thing. Even in complex chronic illness, the child will spend more time in home than he or she ever will in a hospital or in clinics (with rare exceptions).

In the early stages of this new orientation, family centered care was trivialized by arranging for parents to room in, but without ensuring the parent became a full collaborator. So, it is important to state the fundamental features of family centered care which are:

- Recognizing the family as a constant in the child's life;
- Facilitating parent-professional collaboration at all levels of health care;
- Honoring the racial, ethnic, cultural, and socio-economic diversity of families;
- Recognizing family strengths and individuality and respecting different methods of coping;
- Sharing complete and unbiased information with relevant (our emphasis) family members on a continuous basis;
- Encouraging and facilitating family-to-family support and networking;
- Responding to child and family developmental needs as part of healthcare practices;
- Adopting policies and practices that provide families with emotional and financial support; and

- Designing health care that is flexible, culturally competent, and responsive to family needs.
- (Shields et al. 2006)

It is a sad commentary on the development of pediatrics that the first point (the family as a constant in the child's life) even needed to be stated. Obviously, this is true. Yet, we have specific concerns about some of the items, in so far as they can be misleading and potentially damaging. Of course, health information and advice that is shared should be complete and unbiased but might require a recommendation from the physician. The sharing with families, in our view, can be problematical. We deal with this in more detail in the chapter on confidentiality. It is not clear that the patient wants every detail of their personal or medical life shared with every other member. Moreover, some people who have a role as a family member, might be too remote to have full access to the medical information of a patient (for example, the father's girlfriend, though 'family' might not receive all the information given to the father). In a study carried out by one of us (Wadman et al. 2014), at least one respondent demonstrated confusion in understanding the concept of adolescent confidentiality. This professional responded, "as we believe in family centered care, we have to tell the parent everything that is going on in the adolescent's life". Our concern for judicious limits on sharing information does not in any way diminish our support for the general aims of family centered care.

This partnering with parents can offer significant benefit to the child. Unlike the case with traditional pediatric practice (where a health care professional planned around a child's illness, developed a treatment plan and expected the family to follow instructions) families are more likely to follow a plan if they have been involved in developing it (Ahmann 1998).

Whether family centered care actually benefits children has been studied. A Cochrane review reported some limited evidence of benefit of FCC in terms of children's clinical care, parental satisfaction, and costs (Shields et al. 2012). Of course, a substantial change in organization such as FCC has always been difficult to study. Indeed, it is now impossible to study because FCC has become the norm in all institution. On the other hand, the Cochrane review found no evidence of any harms. The reviewers noted also that there was high-quality qualitative research. They encouraged more such qualitative research, with diverse participant groups, in many different clinical settings, given the impossibility of more rigorous studies. Such research can be used in the development of larger, more definitive studies.

There are other components of FCC such as taking a family history. It is a truism that when a child is admitted, the whole family is affected. In fact, we start with the traditional "taking a family history" – an essential part of pediatric practice, and the key, often, to making a specific diagnosis. Taking a different type of family history is also important. This entails asking how the siblings and half-siblings are, and how they are responding to this admission to hospital. Such a history is an extremely important part of developing a relationship with a family. It is more than a polite nicety, more than inconsequential conversation.

FCC is well intentioned, a warm and fuzzy idea, even a noble aspiration. On the other hand, there might be problems with FCC. One study of parents' impressions (MacKean et al. 2005) reported that parents interviewed stated that they were expected to "do" caring things for the child and lamented a "devolution of responsibility" to the parents. In other words, parents did not think that they were being asked 'to collaborate' by doing what parents might do, but rather they were delegated nursing tasks by the nurses. "Collaboration" was interpreted by professionals as parents doing some tasks that a professional might do. By contrast, parents interpreted "collaboration" as joint planning of what needs to be done, and who does what tasks. The fact that one word is understood in in different ways, and in different degrees, by health care professionals and parents also occurs with the word, "autonomy". Here, parents "want more [autonomy] in that they want truly informed choice, and they want less in that they do not want to make all of the decisions by themselves." In other words, the parents did not want more autonomy, if such autonomy was, as it seemed to them, to be at the expense of relationships and working together. They wanted help from a trusted professional in understanding the implications of the various choices they might make. The parents were keen to work together with all the staff, rather than being assigned segments of their child's care. They wanted to share fully in all aspects of decision-making. These might be "small" decisions such as when to change diapers, or major decisions such as a need to change treatment, start a different antibiotic as an example. In essence, parents are worried and want respect, which is a central aspect of FCC.

Some of these concerns about a variation in understanding the content of FCC are mentioned in the Cochrane review cited earlier. Some healthcare professionals do not fully understand the underlying concepts of FCC, and some might be judgmental. The consequence might be that such healthcare providers put up barriers between themselves and the parents.

FCC arose because of changes in society; yet society continues to change. Some changes have not been sufficiently recognized in how pediatric hospitals are run. The original ideal of FCC was developed at a time when at least the mothers of young children tended to be in the home and not in the workforce. There are now more single parents than there were in the twentieth century, and, as mentioned above under societal changes, it is now the norm in two parent families for both parents to be in the workforce. In addition, health care is changing, with new technologies and innovative health care delivery processes. Opening the hospital doors so that parents may be with the child all the time for every hospital admission, does not mean that every parent can be present all the time on every admission. Parents might have obligations to other children, other family members and to their employers; sometimes, parents feel that they are being judged negatively if not they are not constantly in the hospital. Even if the parent is not visiting at any given moment, they remain the constant in the life of the child.

Despite FCC's strong statement of the essential role of parents and families, children are at the center of any pediatric activity. In FCC, the child is "inherently a part of a whole seen family"; hence FCC requires us to refocus our attention on the child (Shields 2017). In pediatrics, the child patient has traditionally been the cen-

tral focus of our attention. In our laudable attempts to ensure families are seen as key, care must be taken not to diminish the interests of the child. Shields advances the idea of Child Centered Care (CCC), where the child is "an individual whose needs are paramount". This statement does not in any way remove the key role for parents in pediatric health care. But it can be helpful in certain circumstances. Consider the very difficult example of a child whose life is ending and who is being kept alive by assisted ventilation and intravenous fluids and nutrition. Pediatricians will often delay withdrawing ineffective, invasive and burdensome treatment because the 'parents are not ready'. Yet when doctors take such a decision to delay withdrawal, whose interests should predominate? Family Centered Care can confuse the issue and Child Centered Care can help refocus physician attention on what the child needs. It is likely that there will be continuing discussion on the integration of FCC concepts and CCC concepts.

In all this discussion of FCC and CCC, there are important messages for pediatricians (Committee on Hospital Care and Institute for Patient- and Family-centered Care 2012). Our summary of what we see as most important regarding the orientation of pediatric practice follows:

- Pediatricians must develop "true collaborative relationships with patients and families… into all aspects of professional practice".
- "Pediatricians should unequivocally convey respect for families' unique insights into and understanding of their child's behavior and needs, should actively seek out their observations, and should appropriately incorporate family preferences into the care plan."
- "Pediatricians should share information with and promote the active participation of all children, including children with disabilities, if capable, in the management and direction of their own health care.
- The adolescent's and young adult's capacity for independent decision-making and right to privacy should be respected."
- "Pediatricians should create a variety of ways for children and families to serve as advisors for and leaders of office, clinic, hospital, institutional, and community organizations involved with pediatric health care."
- Pediatricians should remember that the child is at the center. What is best for the child might be hard for parents to endure. When a focus on adult interests threaten to overtake decision-making for a child, pediatricians should gently redirect everyone's focus to the child.

1.13 Using Patients to Train Pediatricians

In practicing their profession, pediatricians aim to be as skilled and knowledgeable as possible. To achieve such goals, they must attend seminars and read medical journal articles and books, but they must also engage in quiet, thoughtful reflection on their actual interactions with patients and their families. We agree that "to study

the phenomenon of disease without books is to sail an uncharted sea, while to study books without patients is not to go to sea at all." (Osler 2017). Medical and continuing medical education has embraced modern educational techniques including the use of simulated medical encounters with lifelike manikins, and the use of actors who pretend to be patients, Standardized Patients (SPs). There are limits to the use of SPs, and sometimes child patients are the only possible way to teach some specific points, and to assess whether the educational program has been successful.

There are, however, ethical concerns about using child-patients as teaching tools for physicians and prospective physicians. Khoo and et al. (2017), offer an actual case study to highlight such ethical concerns. (We have modified abridged the story.)

> The 6-year-old child with hemoglobin E/β thalassemia, lives on a farm in Indonesia with parents who were poor. The patient had very characteristic physical findings. Medical educators asked the family for permission for the child to participate as an CSP (Child Standardized Patient) in an exam (Objective Structured Clinical Examination – OSCE). The medical educators wanted the child to participate in 5 to 6 hours per day of continuous contact with potential examinees, on two consecutive days. The medical educators offered the parents a small amount of money if they permitted the child to participate.

Khoo et al. (2017) present a number of different assessments of the ethics of such a situation. They highlight the conflict of interest in the medical educators. As physicians, they have a duty to care for this vulnerable child; as medical educators, they are seeking to offer trainees a productive educational experience. They put the parents in a conflict of interest; the parents have a duty to care for the child, but the medical educators have offered them money to subordinate care of the child to their need for money. Moreover, the child is "doing work", possibly breaking employment law related to minors. None of the commentators on the story, all physicians, thought that there should be a national ban. Yet the request, as made, seems unreasonably burdensome, and extremely uncomfortable. It is unclear how the child patient could dissent. One of the points made is that the boy's distinctive features may already have led to teasing by his peers. The child seems already to carry an undue burden, that the physicians would inadvertently exacerbate for their purposes, and not in the interests of the child.

This was an extreme case, probably deliberately described as such, to highlight the discussion, the issues and problems. To suggest that child patients with distinctive features of a condition should never be used in pediatric examination would seem extreme and would disadvantage future patients. On the other hand, given that the child does not benefit and might be harmed by being used as a teaching tool, there must be many safeguards.

The literature has paid much more attention to otherwise healthy children acting as CSPs (Gamble et al. 2016) and (Tsai 2004). Some recommendations have been made that we support and paraphrase here:

- Limiting the number of examinations an individual child is involved in to perhaps less than five per session (the authors suggested ten, we disagree)
- Schedule the child for, at the most, a half day;
- Try to find two or three children with some commonalities who can substitute for one another;

- Do not use inpatients, a group already exposed to learners;
- Obtain informed consent from a parent or guardian, and assent from the child patient;
- In the case of younger children, a parent should stay with the child and should be encouraged to intervene if the child becomes distressed;
- Offer the child some reward valuable to the child such as the opportunity to play or, for example, to visit an ambulance or a fire station;
- if there is any concern about the child's comfort, do not schedule that child as a CSP.

1.14 Conclusion

Pediatrics is a relatively new medical specialty that focuses on the care of children and has a strong interest in child health generally. The practice of pediatrics is changing rapidly, with advances in technology and changes in healthcare organization, that require adaptation by pediatricians. Aspiring physicians are encouraged to develop and amplify specific useful virtues: temperance, wisdom, fortitude, justice, compassion and empathy. One role of pediatrics described in Mitchell (2015), cited above is:

> the role of companionship with the patient cannot be understated. Susan Sontag (Sontag 1978) speaks about illness as being "the night side of life". She claims that everyone is born holding "dual citizenship, in the Kingdom of the Well and in the Kingdom of the Sick". Sontag refers to adults, but her words are also applicable to children. I have spent my career as a companion of those who were born into the Kingdom of the Sick and remained there throughout childhood. This is a very humbling and rewarding companionship. And "companionship" is the correct descriptor of the role of pediatricians. (Mitchell 2015)

Pediatrics has changed remarkably in past 70 years. Those training in pediatrics are now very likely to be female and to place a priority on interacting with families. Yet, the interaction remains triadic, child patient – family members – physician, with the pediatrician focusing on promoting the interests of the child.

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Chapter 2
What Are the Boundaries Between My Role, Children and Parents, and Others Involved in Pediatrics?

Key Points Concerning Boundaries in Pediatrics

- Boundaries affecting the triadic relationship (child patient, guardian and physician) are important.
- The limits of permissible relationships should be defined, in the context of a relationship that aims to be collegial and supportive.
- Boundaries can be breached in a number of ways.
  - Some breaches are egregious, such as sexual relationships with any parties in a professional relationship or with children at any time.

    Such relationships are related to the power imbalance.
    If with a child, then they are illegal.
    If with the child's parent or guardian, then they are unethical and can be illegal.
- Pediatricians might have activities that are related to pediatrics but not direct patient care.
  - These include carrying out research, giving advice to commercial entities or owning companies providing health care or a health care product.
  - These activities might also lead to boundary breaches.
  - The activities should be public, but disclosure by itself is insufficient to ensure there are no boundary breaches.
- Care is required in boundaries between colleagues.
- Pediatricians are entitled to personal, religious and political opinions but expression of, or acting upon, these opinions might cross boundaries when these opinions affect patient care decisions.

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_2

2.1 Boundaries: Definition and Scope of the Problem

In Chap. 1 we described some features of the specialty of pediatrics and some of the characteristics of pediatricians. This chapter is complementary to the previous chapter and describes ways in which the pediatrician can 'connect' with children and families, but also understand when they are breaching a boundary that ought to exist between a patient and family, and professionals. We will discuss the moral justification for establishing and maintaining this boundary and will advance further the understanding pediatricians have of their specific, but varied, roles. One reason for establishing boundaries is the power imbalance between the pediatrician, the child patient and the families. The focus of the pediatrician should be the interests of the child, and whenever the focus moves, even if only slightly, in the interests of the pediatrician then a boundary has been crossed. Another reason for establishing boundaries is the perceived need for pediatricians to be objective, and the concern that if they are over-involved then they will lose their objectivity, and decision-making will be poor. Issues that arise in establishing boundaries in the context of patient care can vary from sexual behavior between the pediatrician and the patient, or members of the patient's family, to treating family members and children of friends and accepting gifts from families of patients. Some boundaries are absolute, and any sexual contact with the patient, or the parent or sibling of the patient, is an undoubted violation. In this context, care should be taken with language, and making personal comments on clothing, attractiveness, and so on.

Pediatricians have warm and friendly relationships, and fear of intimacy should not lead to coolness or indifference. Handshakes and socially approved touching are okay. It would also be appropriate to hold the hand, briefly, of a parent whose child is dying or has died recently. Having said all of that, pediatricians should be aware that there are many personal and religious beliefs related to touching that can make touching improper.

Sometimes boundaries may be breached, but thoughtfully, and might not be ethical violations. The troublesome issue of small gifts can be one of these breaches that might be acceptable in some specific situations, (please see Sect. 2.4 for more discussion on this topic).

The use of social media is increasing rapidly, though the analysis of the ethical issues remains very incomplete. For a physician to be on a common form of social media, such as Facebook, jointly with the family of the patient might be a boundary breach but, in some situations, we may consciously accept it.

2.2 Boundaries and Power Imbalance

Sometimes the power imbalance occurs unconsciously as we meet families. Consider this physician-patient interaction described in a blog:

> I don't mind if a doctor uses my first name, if I can use his. But a doctor who says, "Hi, Liz, I'm Dr. Smith" is just being rude. He's trying to assert himself as an authority figure who should be obeyed, not as my collaborator in health.
>
> I also have a title, a PhD that took me longer to earn than his MD took him. I almost never use my title, not even with my students. But when I get the "Hi Liz, I'm Dr. Smith" routine (and I don't go by Liz!), I give the icy stare and say, "Hi Joey, I'm Dr. Jones." That usually makes the point. (Parker-Pope 2014)

The issue is not whether first names should be used, the issue is that one party in the relationship uses a title and the other party is addressed by a diminutive. The use of first names as opposed to a title (Mr. or Ms.) followed by a last name is evolving rapidly in society. While accepting this societal change in etiquette, we see little harm in addressing the families of our patients as Ms. or Mr. "Lastname" and asking them how they would like to be addressed. We want to have a warm relationship with the patient and families we see, but do not want to start the relationship by causing offence, no matter how minor. Janvier and Lantos list some simple rules of etiquette useful in the NICU (Janvier and Lantos 2014). We will quote them in detail in 4.6, and recommend reviewing the Janvier and Lantos paper, because their comments have general applicability in pediatrics.

2.3 General Issues About Relationships with Patients and Families

Pediatricians often see children and families over many years, and close relationships typically develop. This is a reality, and of course we encourage compassionate and empathetic care for the child patient and the family. While boundary violations might be a risk as relationships become closer over time; developing attitudes of being cold and distant does not prevent these. The risk of boundary violations becomes more likely over time and is related to closeness of relationships as a consequence of proximity. Peter and Liaschenko (2004) used the phrase "perils of proximity" in terms of nurses, but it is relevant to physicians, including pediatricians, too. Such proximity has physical, narrative and moral components. Physical proximity is self-explanatory, narrative is understanding the patient and family story and moral proximity is recognizing that we need to act on behalf of that child. These authors note that proximity is, and should be, a positive force, but that sometimes proximity can be problematic. Some of the problems relate to witnessing suffering of course, and some of the problems are those we cannot resolve or can resolve only with extreme difficulty.

2.3.1 Sharing Our Personal Lives with Families

Jeremy (Dr. Garcia, but he always used his first name) was a very popular pediatric resident. He was knowledgeable and friendly and had very good relationships with parents, with other residents, and with staff pediatricians. He had come a little late to medicine but was determined to succeed in his chosen area of community general pediatrics. Both he and his wife Elizabeth had been schoolteachers, and they had three children about whom Jeremy spoke frequently and lovingly whenever he had the opportunity.

Jeremy was with a senior physician in clinic. They were seeing four-year-old Aurora brought by her mother. Aurora had had a stormy start to life and had continuing multiple complex severe health care problems. She had several surgical procedures some of them followed by significant postoperative problems including admissions to the pediatric intensive care unit. She had recently had a full sleep study that confirmed a suspicion of obstructive sleep apnea. She was being seen to develop a plan, which would likely include referral to an ENT surgeon for tonsillectomy and adenoidectomy. The senior pediatrician had discussed with the mother the pros and cons of the need for the procedure, but the mother was clearly extremely anxious, and understandably apprehensive at the thought of another surgical procedure.

Jeremy was very concerned and decided to take part in the conversation. He thought his main role was to reassure the mother, and to that end he told her about his recent experience with his six-year-old daughter Amy, his middle child. She also had developed obstructive sleep apnea, had had tonsillectomy and adenoidectomy uneventfully, recovered quickly and had benefited enormously from the procedure. Amy had been healthy before the procedure and returned to full health after the procedure. Aurora's mother was noncommittal when she heard Jeremy's comments. The mother decided to think through the various questions she had and agreed to meet with the senior physician later or would discuss the proposed surgery by telephone.

The mother herself was thoughtful and considerate, and recognized the network of relationship she had with many different professionals in the hospital and with community agencies. She welcomed the involvement of trainees, including pediatric residents, but was always watchful when they were around Aurora. This mother had the ability to speak up when things were not quite right in terms of Aurora's care but was very careful to do this ***without*** *antagonizing the staff. She did not want to be labeled "a difficult mother".*

In this case, Jeremy's mentioning of his own children was very unhelpful. The apprehension at the thought of a surgical procedure of the mother of a child with complex health problems who had already had surgical complications is unlikely to decrease when hearing about an otherwise healthy child having the same procedure. The context really does matter, the surgery is the same, the condition of the children is vastly different.

This story raises the issue of how much our private, personal life, belongs in our professional, pediatric life. Specific events in our personal life might immediately affect our professional behavior. These events might be very positive, such as the birth of a child, or being able to buy one's first house. These events might, on the other hand, be negative such as a divorce or separation or a death of a close

friend or relative. Many professionals, including pediatricians, try to carry on, despite adverse personal circumstances and draw sharp boundaries around our personal and professional lives. Other pediatricians, particular regarding happy events, see no reason for these boundaries, think them harmful, and, like Jeremy, use a specific experience in their own family to help in their discussions with the family of patients.

Society is now very open, and it can be difficult to maintain separate personal and professional lives. With the advent of social media, it is probably impossible. Use of, for example, Facebook is ubiquitous in all circles, including professional circles. Parents might access their Facebook account and there learn for the first time that they have a new grandchild. Information that used to be communicated only privately is now communicated publicly. Times have changed.

Hence, placing a boundary between our professional and personal life is more difficult now than it has ever been in the past. Even Jeremy might grant the need for some boundary no matter how loose. Others will see the need to describe where the boundaries should be between a professional and a patient or family. Families might also need there to be boundaries between them and the professional caring for their child.

Our personal lives and circumstances obviously influence our professional behaviors and understandings. These influences can have long-term effects, and sometimes personal or family experience of illness will lead to a career in pediatrics. From these personal experiences we will have some understanding of the behaviours of pediatricians that can be helpful to families, and behavioural traits that can set up barriers. Our personal circumstances determine "who we are", and it is not likely we can totally separate our personal life from our professional behavior.

Janvier (2016) very strongly advances a contrary view. She tells the story of the father of an infant in the NICU who started a conversation with her, as the baby's neonatologist, about tattoos. The story unfolds as she learns about the father's feelings, the fact that a previous child had died in the NICU and finishes with long-term contact with the family via Facebook. She relates the story as an antidote to the "professional" movement that she believes has sterilized patient family relationships. She mentions resident discomfort with such activities as sending condolences cards to bereaved parents. We disagree with her assessment of professionalism as banning such supportive and caring activities. We see the current focus on professionalism as a re-affirmation of our commitment to patients, and a partial reaction to barriers of aloofness we had created in the past. We are sorry if residents feel uncomfortable with sending cards to parents after a long hospital stay or express condolences when a baby dies. This is not boundary crossing but professional behaviour. We see these actions, and other actions of reaching out to families, as in the best tradition of professionalism. Sometimes such actions might involve breaches of accepted boundaries, without being violations, but we hope the "professionalism" of the residents will lead to their thoughtful behavior. In terms of connecting with families with social media, such as Facebook, we can see occasions when this might be appropriate. Again, we hope any pediatric trainee who befriends a family online does it cautiously, and after careful consideration.

2.4 Exchange of Gifts

It certainly seems churlish, perhaps even rude, to refuse a small gift given after a patient encounter. The most common gifts are alcohol and chocolates. Money, even in small amounts, should always be refused. In a consideration of the ethics of gift giving in the medical context, Spence (2005) writes that we should ask two questions: "(1) Should any gift be accepted? and (2) Should this gift be accepted?" It is certainly easier to say no to the first, because the second does not then need to be considered! Any acceptance of any gift, no matter how small, risks some compromise with ideas of justice. Will we now treat some families more favourably than others? Will one child become our "favourite" patient? Our advice is to be consistent, to refuse the gift and to develop a gracious speech expressing thanks for the thought and explaining why the gift is refused. Such a speech might be: "I am grateful that you wish to recognize what I did for your child with a gift. However, I was doing my job, and will do so again when your child and many other children need me. Unfortunately, others sometimes misunderstand generous gifts such as yours. Therefore, I do not accept personal gifts from families or patients but encourage you to recognize what I did by making a small donation to…. "(Mention a relevant charity)". If we decide to accept, then we should keep a record of the gift, and we can **never** accept gifts in advance of our treatment.

We note that these rules to maintain boundaries do not seem to apply to our institutions that have no difficulty in accepting multimillion-dollar donations from "grateful families"!

2.5 Relationships with Colleagues

Jeremy sought the advice of a senior pediatrician, cautiously and obliquely. He told his senior about a situation in a previous rotation where the staff pediatrician developed a plan of care for a child with a complex seizure disorder. Jeremy had read quite a bit about the child's specific underlying condition and thought that the plan was not really appropriate. He had attempted to approach the staff physician by asking for educational help for himself, as a junior trainee; Jeremy inquired how the plan fitted with available guidelines. The staff physician was quite abrupt, and indicated that she was senior and experienced, and that Jeremy should follow her plan for the child. Jeremy was concerned for the child's health, and was also concerned for himself, specifically in terms of the staff pediatrician's assessment. Jeremy's formal end-of-rotation evaluation was "satisfactory", but he suspected informal conversations might be less positive.

Jeremy asked how the senior pediatrician might have handled the situation, and what help might be available.

In the case Jeremy is worried about, the child is described as having a "complex" seizure disorder; the reality of caring for children with common and straightforward disorders is that there might be legitimate disagreements on management. These variations in approach to management are magnified in complex conditions. The

issue here is not that the staff pediatrician opted for some variation of standard guidelines, the issue is that the staff pediatrician chose not to answer a legitimate question from a trainee. Jeremy's approach is very reasonable in asking for an explanation. He is, after all, learning. His attempts to understand why there might be variations from the guidelines he has studied are an important part of his development as a pediatrician. Regarding the way his inquiry was addressed, Jeremy has several options, but in our view none of them include ignoring the episode. The two major options are to speak to the resident representative in the program, ask for her advice, and perhaps ask her to take the concern anonymously to the director of pediatric training. An alternative is for Jeremy himself to go to the director of pediatric training and to ask for help. For most trainees, the second option is very difficult, and we would suggest the first as more reasonable. Jeremy might also want to advocate for a change in the assessment process, so that trainees assess individual staff physicians in terms of the approach to education and educational abilities. These assessments should be passed on to the individual pediatrician and to the program director at fairly long intervals, perhaps 6 months or so, to reduce the possibility of identifying the author of the comments. Some courage, a virtue we identified in Chap. 1, is required as this problem is being addressed; the courage should not become foolhardiness.

2.6 Disagreements

Another situation in which trainees in pediatrics are usually at a loss on how to proceed is when two staff pediatricians, or two groups of staff pediatricians, disagree markedly on management of a patient. This situation is not unusual! Charitably, we will assume that both groups are acting out of concern for the well-being of the child, and neither is acting from the dictates of their own strong egos.

This is not a situation for which a trainee holds any responsibility. It is not a situation where any action is required of the trainee. It is a situation where the trainee should avoid becoming allied with one or another group.

In terms of the immediate management, it is the clear responsibility of the most responsible physician to decide how to move ahead. She might decide to choose the course of action suggested by one or other of the consultant pediatricians or might decide on a different course of action. She should meet with the individual pediatricians, or groups of pediatricians, and develop some understanding of the rationale for the suggestions they make. She should ensure that they give references she can access and read and might ask them to comment on the suggestions made by the other group. She should also ensure that consultants communicate with the most responsible physician, and that the family does not become embroiled in this medical disagreement. If the latter happens, then resolution can be very difficult, and the most responsible physician will know that she will need to spend many hours with the family.

It is also possible that the disagreement is part of long-standing differences between groups, and that one or another physician is known to be "difficult" and disruptive. (While disruptive behaviour is traditionally associated with physicians, Rosenstein and O'Daniel (2005) claim that nurses behave destructively almost as frequently as physicians.) If the disagreement is part of a pattern of disruptive behaviour, then this is something that must be addressed by the hospital administration. Examples of disruptive behaviour included verbal outbursts, threats and such behaviours as refusing to perform assigned tasks or having a generally uncooperative attitude. There is no doubt that disruptive behaviour is stressful, increases negative feelings and can lead to increase in errors and patient care. From an ethical point of view, given the adverse consequences of this behaviour on both patient care and outcomes, and staff morale, the behaviour must be addressed by administration. We hope this would be addressed by education that would include all levels of staff, and all disciplines. Developments of attitudes of mutual respect are very important and are the underpinnings of teamwork.

The question of whether we can separate our personal or professional life pervades this section and is mentioned in other sections. One further difficult situation is when the pediatrician becomes a parent, and the child needs medical care. If the treating physician is a colleague, then the treating physician must respectfully focus on the child, and make decisions on diagnosis and treatment their affairs, not the physician parents'. In other words, the treating physician must be the doctor and the parents must be the parents. If the assessing or treating physician is a trainee, then the issue becomes more complex. The physician parent(s) should be respected as parents, but of course they might well be senior colleagues of the trainee at the same time. There is clearly the possibility of intimidation in such a situation. Our advice is simple; keep the focus on the child. One or other parents might be particularly forceful and seem to want a particular course of action. Here, we would recommend an empathetic response to what is a manifestation of parental anxiety, taking care not to patronize the worried parent who has extensive medical training and experience.

2.7 Should We Treat Our Own Children?

Dr. Anita Lopez is a community general pediatrician. She practices in a town of around 100,000 people and is in a partnership with two other pediatricians. She and her husband Frank have three children aged 3, 7 and 10 years. The seven-year-old, Clara, has had recurrent urinary infections from the age of two years. When she develops discomfort on urination, Dr. Lopez starts an antibiotic, and at the same time, obtains a urine culture.

On one occasion, a multi-resistant organism was grown, and as per protocol the local microbiological laboratory phoned the office with an alert. Dr. Lopez was away when the phone call came in, and the office staff directed the alert to a partner, Dr. Moore, who asked to see Clara's file. She was surprised to find that Clara did not have a file in the office. Dr.

Moore filed an appropriate prescription to a local pharmacy and let Dr. Lopez know what she had done. She also asked if she could meet Dr. Lopez the following day in the office.

Dr. Moore is concerned that Dr. Lopez is treating her own child, something she knows should not happen, unless in an emergency. Dr. Moore also notes that no records have been kept about Clara's symptoms, tests, diagnoses and treatment. This boundary, of not treating those close to us, is important. It is not clear that an adequate history has been taken or that appropriate investigations have been conducted. It is possible that Clara has had substandard care. We are pleased that Dr. Moore has the courage to deal with this, rather than taking the easy route of sweeping Dr. Lopez's misbehaviour under the carpet. Dr. Moore has placed the interests of the child above her desire to have cordial relations with her business partner, demonstrating that she is a professional pediatrician.

2.8 Is Seeing a Patient Without a Referral an Issue of Etiquette or Morals?

Leigh Harris is pregnant with her first child. On a prenatal ultrasound some cysts are seen in the fetus' right kidney. It was explained to Leigh that the differential diagnosis was wide, and that full assessment would need to wait until the baby was born. Leigh found the rest of the pregnancy very difficult and was often quite anxious about the findings on the ultrasound. Her sister was an operating room nurse in another city and spoke to her quite frequently by telephone. Shortly after birth, another ultrasound confirmed cysts in the right kidney; the left kidney was normal. The likely diagnosis was unilateral multicystic dysplastic kidney (Aslam and Watson 2006). Leigh and her child, Patricia, met with a pediatric nephrologist and urological surgeon. Both reassured her that that the long-term prognosis was good, and that in the short term she would be followed by the nephrologist, with ultrasounds over the first 2 to 3 years of life. Leigh remained very anxious.

She continued to speak to her sister, and her sister spoke to a urology surgeon with whom she worked. That surgeon indicated that this kidney should be removed, and that he would be willing to see Leigh and her child, with a plan for nephrectomy. This information was passed on to Leigh who was very happy that "something was being done for Patricia". The surgeon in the other city carried out the nephrectomy about two months after this conversation.

There are many findings detected during pregnancy by various investigations, including ultrasound, whose implications for the future child's health is uncertain. Many of the ethical implications of the various tests are discussed in detail in Chap. 6 on prenatal care. It is entirely understandable that the uncertainty will lead to anxiety, no matter how much support is provided to Leigh. It is entirely understandable that Leigh's sister should respond to the anxiety and might want to help. It is entirely understandable that the sister would turn to someone she knows for an authoritative opinion. It is beside the point that the opinion given by the surgeon is wrong – as outlined in the paper cited by Aslam and Watson (2006). There are various outcomes, including spontaneous regression, and specific indications for surgery, if complications arise.

Even if the surgeon had been right that nephrectomy is indicated, he was wrong to see Carla based on the sister's communication. We are assuming that the surgeon is able to access all of the medical opinions and results of investigations already conducted. Nevertheless, a formal referral would clarify who is the most responsible physician leading Carla's care, and what the role of a referral might be. The major reason that the referral is arranged is Leigh's extreme anxiety. It is easy to criticize the first team; it would seem not to have provided appropriate support. On the other hand, of the various sources of authority in Leigh's life, her sister with a background in pediatric nursing will be much stronger than any outsider. The strategy adopted by the first team is well described as "watchful waiting". Such a strategy is more likely to be effective when time is taken in explanation, and a planning effort is made to include the parent as a member of the team.

2.9 Boundaries in Research

Dr. Rhoda Walker is a pediatric neurologist with an extensive practice of children with difficult-to-control epilepsy. She is approached by a large pharmaceutical company that has a new drug, with a novel form of action. The company plans to conduct a phase 3 clinical trial (see Chap. 14 Research) and would like Dr. Walker to contribute 6 to 10 patients. There will be 700 patients in the study overall, a careful sample size calculation having been done. Dr. Walker signed a contract with the company, which will pay her for the work she does, and which will supply the drug. The study is approved by the local regulatory authority (various names of this authority are used in different countries) and she begins to recruit patients from her practice.

There is an inherent conflict of interest in Dr. Walker's actions. She has two very distinct roles. One of these roles is as a physician, with the primary responsibility to the patient before her. The other role is as a researcher with a commitment to the uncertainty of science. She already has a clinical relationship with the family members whom she will approach to participate in the research. That clinical relationship, by itself, makes it likely that the families will agree to the study. There are many safeguards to protect the children in the study if they become research subjects. Despite such safeguards, there are many examples of egregious misconduct, some of which are described in the Chap. 14. Dr. Walker might be considered on both sides of the boundary at once! While it may seem unsatisfactory, the major safeguard for the safety of the children is Dr. Walker's integrity. If that is lacking, then it is unlikely that any degree of oversight will protect the children. Dr. Walker must understand and appreciate that her first duty is to the child as the child's physician. Should any other role she occupies conflict with her role as physician, then Dr. Walker must act as the child's physician to protect the child's medical and related interests.

2.10 Conscientious Objections

Yvonne is aged 15 years and has a boyfriend, aged 16. Yvonne lives in a small town with one hospital that has religious affiliations. On one recent occasion when Yvonne was having intercourse with her boyfriend, the condom burst. Yvonne went with her boyfriend to the nearest emergency department for advice. Dr. Dubois who saw her, advised that they would need to wait to see whether she might become pregnant. As the young couple left the hospital, the nurse in the emergency department intercepted them. She told them that the "morning after pill", emergency contraception, should be taken as soon as possible, and that it was available at only one of the three local pharmacies. She gave Yvonne the name and address of this pharmacy.

There are a number of ethical issues within this brief vignette. Does an institution have the right to limit the lawful healthcare treatments it offers? Does the physician have the right to give restricted and misleading healthcare advice, on the grounds that to do otherwise would infringe on his conscience rights? Did the nurse overstep the boundary of her professional relationship with the physician in her employment status with the institution? Do pharmacies have the right to restrict the medications they are willing to offer?

To deal with the first and last of these questions: Yes, an institution has a limited right to restrict the treatment it offers, and yes pharmacies have a limited right to restrict the medications they carry. There are many legitimate reasons why an institution might restrict the treatment it offers. For example, it might have decided not to equip an operating room to conduct neurosurgical procedures, and therefore neurosurgical services are not available at that institution. Such a decision would be taken both for financial reasons, and because of issues of patient safety. Similarly, pharmacies might decide how much space to allocate for storage, and what preparations they will carry. For example, many pharmacies do not carry opiates and indicate by way of public notice that opiates will be available only by advance request. There might be business reasons why pharmacies would not carry emergency contraception. It is more problematical, both for the institution, and for pharmacies, to limit services that do not require special equipment or storage requirements. Our personal view is that restrictions allegedly based on concern for allocation of storage space have little ethical foundation, but we recognize that that would not be a general view.

Business decisions are different from whether individual healthcare providers have a right to refuse to provide lawful health care based on a negative conscience objection. Conscience rights are both negative and positive (Wicclair 2009), though most attention is placed on negative conscience rights. A negative right allows individual providers, on the basis of their personal beliefs, to refuse to provide, or even to participate in, a specific treatment. While healthcare providers might refuse to be involved in any treatment, typically the refusal concerns female reproductive issues, as in the vignette involving Yvonne. Positive rights receive much less attention in the medical literature and in the mass media. Positive rights are a conscience-based obligation to provide a service. For example, a gynecologist in the hospital in which Yvonne presented might think that tubal ligation is a procedure that is indicated for

one of her patients. The institution might have decided that such sterilizing procedures will not be allowed. Here, both the gynecologist and the patient have had their rights to engage in lawful healthcare affected. The impact on the patient will almost certainly mean travelling to another town and consulting another gynecologist. The impact will be greater the further apart the towns are and the poorer the patient is.

We think that both the positive right of the patient to access lawful healthcare and the positive right of the physician to provide indicated lawful treatment are important rights, and the argument supporting one will also support the other. We do not accept the argument that there is an asymmetry between positive and negative rights, such that negative rights are more important to be recognized. Negative rights do not trump positive rights in the delivery of lawful healthcare.

The integrity of an individual pediatrician is of great importance and is related to his or her self-respect. This integrity must be protected. We recognize the strong relationship between individual conscience and individual integrity, but do not believe that this relationship, by itself, justifies a negative conscientious objection. The objection should not be self-serving and should be a persistent part of the pediatrician's belief system. The objection should be based on principles, not on an objection to the individual patient. Currently, no one would support a conscientious objection not to provide care to a patient of colour, or to someone whose sexual orientation is not heterosexual. (Before disregarding these examples as being unrealistic, please recall that they were common objections until fairly recently, particularly the issue of sexual orientation.) It is important to remember that "Some refusals constitute an imposition of the physician's moral beliefs on the patient." (Committee on Bioethics 2009).

How might the physician in this emergency department, Dr. Dubois, have acted? First, he should act with both sympathy and respect. Second, if Dr. Dubois' integrity requires him to avoid being involved in advice about emergency contraception, then the same integrity should insist on honesty. In other words, Dr. Dubois should tell Yvonne that there is a medical response to her current problem that he does not wish to discuss because of his personal attitudes and beliefs. From Yvonne's perspective, this would be only a partial response, given that there is only one hospital in the small town. If Dr. Dubois regards participation in any part of advice on emergency contraception as contrary to his personal beliefs, then this fact should be made known to Yvonne before the consultation so that she can understand and appreciate that the physician will give incomplete medical advice, and there should be a physician on call to provide the lawful healthcare which Dr. Dubois refuses to provide. Dr. Dubois should refer Yvonne to this physician.

It is important to note that Dr. Dubois' refusal to prescribe emergency contraception is not part of what it means for a physician to be professional. The exercise of conscience is not equivalent to being a professional, on the contrary it is wrong to confuse professional and personal commitments. The American Academy of Pediatrics (AAP) statement (Committee on Bioethics 2009) cited above notes that a refusal to prescribe antibiotics for viral respiration infection, for example, is based on good medical evidence. Conscientious objections in general, are not based on medical knowledge, but are based on a variety of beliefs, commonly

either political or religious. While they might be important to the individual physician such as Dr. Dubois, they do not constitute medical care.

2.11 Conclusion

Pediatricians aim to be professionals who are warm and friendly toward both children and parents. This friendliness, a very positive feature, brings with it the risk that the relationship will become too close, making objective decision making difficult. Hence the existence of important rules about the boundaries between pediatricians, on the one hand, and the child patient and guardians, on the other. Such rules are required because of the power imbalance between the pediatricians and those whom they serve. Some breaches of the boundaries are clear violations, such as sexual activity, sexual contact and grooming for sexual contact between the pediatrician and the child patient, or the family members of the patient. Many other breaches of boundaries might be regarded as minor transgression rather than violations, but the individuals involved should take all breaches very seriously. Some breaches become more likely as relationships develop over time, so attention to boundaries is a persistent feature of pediatric practice, no matter how long the pediatrician has been seeing a particular child or family.

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Chapter 3
How Can I Receive Help with Ethics Issues?

Key Points Concerning Ethics Consultations

- An ethics consultation is a meeting to focus on a particular clinical ethics problem.
- The consultation might be conducted by the whole committee, a subgroup of committees or by an individual ethicist.
- Ethics consultations were developed to respond to clinician and family concerns and are generally advisory.
- Those providing ethics consultations require training.
- Ethics consultation services require funding.
- Pediatrics poses many specific ethical issues.
  - The most pervasive issues in pediatric consultations are:

    Special role of parents;
    Limits on parents' decisional ability; and
    Evolving competence of adolescents.
- Residents facing ethical problems may seek help from ethics committees, colleagues, faculty mentors, professional organizations and lawyers knowledgeable in medico-legal issues.

3.1 Background

Healthcare professionals have many formal and informal ways of receiving help with complex ethics issues. Informal mechanisms are probably used many times every day and have an important place in healthcare. These can be as simple as "hallway conversations" with a peer or mentor or more formally by speaking to a professional representative or an administrator. However, almost every healthcare institution now has some form of clinical ethics service. The details vary, but typi-

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_3

cally there is an "ethics committee" supported by a professional ethicist. Such a service can offer advice and assistance that might be immediately helpful in dealing with challenging aspects of a healthcare situation. Unlike "hallway conversations" and the like, consultations by an ethics service will be structured and documented. They can be a very valuable resource for healthcare professionals at every level from the very earliest training stage to those who are very experienced. There have been many changes in the formats of ethics services since they were first conceived in the 1960s including that all healthcare professionals now have formal training in ethics.

3.2 Introductory Story

Riley was born at 23 weeks' gestation and required intubation and assisted ventilation at birth. He was the first child of parents in their late 30s, who had had three earlier pregnancies each ending with miscarriage early in the second trimester. Riley had a number of complications including intraventricular hemorrhage grade 4, necrotizing enterocolitis requiring surgery and several episodes of sepsis when he was given intravenous antibiotics. His mother was at the bedside every day, and on the weekend that both parents spent time in the NICU. Numerous attempts were made to wean ventilation, always unsuccessfully. The parents were forceful in their commitment to Riley, and whenever attempts were made to discuss withdrawal of assisted ventilation, they became angry and distressed. After considerable discussion with various neonatologist, neurologists, unit nurses and social workers, it was agreed to transfer Riley to the pediatric intensive care unit (PICU) for a tracheostomy. Some staff members in the PICU were uncomfortable with the decision to perform the tracheostomy and pressed for further attempts to wean Riley to noninvasive ventilation. The weaning attempts were unsuccessful. The tracheostomy was done, and Riley is now aged six months. His ventilatory and oxygen requirements remain high and there is deterioration whenever attempts are made to reduce pressures or inspired oxygen concentration.

Dr. Chloe Lewis is a second-year pediatric resident on the rotation in the PICU. She notes that the staff physicians and nurses vary in their attitude to the treatment of Riley with the majority making negative comments about the fact that he is still being treated actively. However, two of the intensivists feel that it is important to continue active treatment, given the parents' commitment to Riley. Attempts to discuss the prognosis with the parents have generally ended in acrimony.

Dr. Lewis recognizes the complex ethical situation and asks the attending physician in the PICU if there are resources to deal with the ethics of the situation and perhaps mediate among the various parties involved in Riley's care.

3.3 Why Were Clinical Ethics Committees Founded?

Concern about ethics situations in medicine and the production of a vast literature, both technical and in lay media, arose in conjunction with medical developments and changing societal attitudes toward medicine in general and to physicians spe-

cifically. An early technical development was the advent of renal dialysis, which meant patients with renal failure could survive. When a reliable indwelling shunt was developed, dialysis could be used indefinitely. This technical development created a problem for its Seattle-based inventor Scribner: there were more patients with renal failure than could be treated with dialysis. Who would choose which patients would receive dialysis and therefore survive, and which patients would not receive dialysis and therefore die? The hospital developed a committee to help Scribner with this life-and-death resource allocation problem.

The story of Scribner and the committee to allocate the scarce resource of dialysis has been frequently told. This account is taken from the book by Pence (2015). At the time, inpatient dialysis cost $20,000/year, and many insurance companies refused to pay for it. At first, the hospital dialyzed patients without charge, but then administrators told Scribner that it could not continue doing this. Scribner realized that dialysis could be conducted outside hospitals; it began in 1963 but could deal with only 17 patients. To choose, Scribner formed an admission and policy committee to take the burden of decision off the physicians. Included in the committee were a minister, a lawyer, a 'housewife', a labour leader, a state government official, a banker, and a surgeon. They had advisors who were physicians familiar with dialysis; applicants were initially screened for medical unsuitability. The first criteria developed were that those who were permitted dialysis were required to be under the age of 45, to be able to afford dialysis, and to live in the state of Washington. These criteria were insufficient to limit the numbers and so more criteria were developed related to the candidate's employment, children, education, motivation, achievements, and promise of helping others. They later added more criteria such as the candidate's ability to tolerate anxiety and whether he or she was able to manage medical care independently.

In his attempts to lobby for more resources for renal failure, Scribner took a patient to an Atlantic City newspaper convention. Scribner told assembled journalists about the problem of inadequate resources for dialysis and related how the committee had been developed. This committee caught the attention of the reporters. Newsweek gave the committee the title, the "God Committee", a term which stuck.

The effort of a physician to bring this matter to national attention resulted in US national funding for renal failure and analysis. Scribner received much adverse publicity because of the "God Committee". He always clearly stated that the idea of the committee came from the hospital not from him, that he didn't like the committee, and that when they refused one of his patients, he tried to circumvent the decision! Scribner was an advocate for the individual patient and at the macro level for all patients with renal failure. Advocacy is discussed in detail in 3.7.

Current ethics committees can trace their origins, at least in part, to attempts in the US in the 1960s to deal with resource allocation. Such committees became commonplace only in the 1980s. Aulisio (2016) notes that by the late 1980s there were such committees in over 60% of US hospitals, and by the late 1990s in over 90% of hospitals. In the 1970s, however, a number of well publicized cases occurred in which families and physicians disagreed about withdrawing treatment. There were political disagreements in the US on issues such as termination of pregnancy and

whether all infants, no matter how handicapped, should be treated so that they survived. In other parts of the world, ethics committees came much later. Medical organizations pressed for development of interdisciplinary ethics committees as preferable to government interference in medical decisions (Strain 1983).

Aulisio summarizes what creates need for ethics committees: "technological developments, value laden questions, clashes between values in a pluralistic context, and relative time pressures for decision-making". He believes the need for these committees will continue unabated. According to researchers, Slowther and Hope (2000), US clinical ethics committees typically perform at least one and often more of the following functions:

1. individual case consultations in response to requests from clinicians or occasionally from patients or their families;
2. providing ethical input into hospital policies and developing guidelines; and
3. education of health professionals within the institution.

They note that case consultation is more likely to be carried out by individual ethicists or increasingly by small multidisciplinary teams, which can include ethics committee members as part of the team.

Ethics committees developed in other countries much later than in the US. Storch and Griener (1992) conducted a survey about ethics committees in Canadian hospitals in 1990. They noted that there had been 26 ethics committees in Canadian hospitals in 1985. By 1989 the number had risen to 70. The committees varied in composition, with between 5 and 25 members. Physicians, nurses, administration and clergy were constant members, other members varied. Most committees gave advice, offered a consultation service, and some participated in policy development and in education. The researchers interviewed a number of physicians, with some saying the hospital is a better place with the committee, and that they had a good experience when they had used the committee. Other physicians were unsure of the place of the committees; they stated that the physician's role is to take decisions, and that, if physicians have problems, then they would consult colleagues. Many nurses consulted were unaware of the existence of a committee, but once they knew it existed, then they welcomed its presence. A smaller number of a variety of allied healthcare professionals were interviewed; they had the same response as the nurses. Generally, the participants thought that ethics committees could assist, particularly with interdisciplinary communication.

Gaudine et al. (2010) reviewed the situation in Canada in 2008. There were 126 hospital ethics committees by that time. Ethics committees remained mainly advisory but were much more likely to be involved with education, counselling and support rather than with discussions on policy. The paper noted the time-consuming nature of this committee work and the lack of evidence of benefits in terms of outcome.

There is no comprehensive report about the early development of such committees in the UK, which developed much later than in the US and Canada. Meslin

et al. (1996) reported on three UK committees that they had developed and referred to three other UK committees known to them. The committees were based in hospitals with different functions; typically, the ethics committees' main function was to engage in ethics education. The researchers explained the committees' function, which was different from the research ethics committees that had already been set up. At least in the early stages, medical staff were not very supportive of the committees and did not understand the role that such committees might play.

Discussion continued through the 1990s regarding whether there should be ethics committees in the UK, and what their role might be. Gillon (1997) noted that there was considerable dissatisfaction with how difficult ethical problems were addressed. For example, unit psychosocial meetings might be used to resolve ethical problems, but these discussions were ad hoc, unstructured and often with insufficient time to address complex issues. There was dissatisfaction with other informal ways of dealing with ethics problems and the increase in the number of ethical problems inevitably led to the development of formal ethics committees to help achieve resolution. In 2000, Slowther and Hope argued that if UK ethics committees were to develop effectively, then they should communicate closely with each other "to share experience and to establish the basis for systematic evaluation and research" (Slowther and Hope 2000).

The UK now has a formal ethics committee network ("Clinical Ethics Network" www.ukcen.net). A report in 2011 surveyed all 82 members of the network (Slowther et al. 2011). At that time, ethics consultations were increasing (about a third of the respondents reported spending 50% of their time on them). Committee members provided most consultations; only one committee had an ethicist. The committees attempted to evaluate the committees' effectiveness by satisfaction surveys. The network website reveals that there are now a very large number of hospital and healthcare organizations as members. The website does not provide an overview of the activities of individual ethics committee though it is likely that consultations are increasing.

There are occasional reports in the medical literature on the development of clinical ethics consultation services in other countries. For example, a survey was reported about European ethics support services in 2007 (Hurst et al. 2007). That article noted that ethical difficulties were increasing in clinical practice; there was a need for ethics support services and that the provisions vary considerably from country to country. Another commentary states that, "In Australia, by 2000, it has been claimed that there were roughly 120 CECs [Clinical Ethics Committees] in operation" (Gold et al. 2011).

We suspect that such services are being developed in many different countries. They are mandated only in the US, Belgium and Norway (Cottle et al. 2017). Perhaps some of them will have the funding that seems lacking in the reports from the more established countries with ethics consultation services.

3.4 When Were Pediatric Ethics Committees Developed?

Meyers and Lantos (2014) state that a pediatrician proposed the first hospital ethics committee. The American Academy of Pediatrics (AAP) helped press for the initiation of clinical ethics consultation. A report published in the 2001 makes clear that ethics committees were by then established in pediatric units throughout the United States with still considerable variation in how they operated and how they were funded (Committee on Bioethics 2001).

In 1992, approximately 10 years after the AAP requested clinical ethics services to help pediatricians face ethical problems, the Great Ormond Street Children's Hospital in London formed a Working Party to provide a forum for the discussion of evolving ethical issues. They surveyed staff and found that ethical dilemmas were frequent, and the way they were resolved was unsatisfactory and "not conducive to interdisciplinary cooperation". The working party formed a Clinical Ethics Forum whose main function was to allow discussion of clinical ethical problems. At that stage, there was no discussion of clinical ethics consultation (Committee on Bioethics 2001).

A report published in 2011 (Gold et al. 2011) described the formation of an ethics consultation service in Melbourne, Australia, starting in 2002. The initial reason for forming such a committee was a specific clinical event, relating to a late-term abortion, which gathered a great deal of publicity. A clinical ethics committee in the Royal Children's Hospital began in 2005.

These vignettes from Canada, the US, the UK and Australia do not aim to be comprehensive. We suspect that children's hospitals and pediatric units in most countries face the same ethical problems and similar conflicts arising from the handling of the problem. It is likely that the continued development of committees follows the trend set by the US in forming clinical ethics committees. However, there are great variations in attitudes to ethics consultations, to ethics committees, to the availability of trained ethicists and to local acceptance or non-acceptance of advice from a person or group outside the health care professions. Hence, any service must be tailored to the local needs.

Some problems persist. There is still no formal certification for ethics consultants and reimbursement for ethics consultative services is rare. It is unclear whether ethics consultations improve patient care. Myres and Lantos (2014) argue that assessing "the quality and effectiveness of ethics committees and consultants" is an urgent task.

3.5 What Are the Main Issues Addressed by Pediatric Ethics Committees and How Do They Function?

The Melbourne report (Gold et al. 2011) stated that clinical consultations occurred principally because of specific requests; some of the concerns were:

- For experimental treatment (from parents and clinicians);
- Parental refusal of recommended treatment for child;
- Refusal of, or resistance to, treatment by patients themselves;
- Parents wanting treatment to continue for children with life-limiting conditions, when clinical staff believe that the treatment is not in the child's best interests;
- Requests from adolescents for predictive genetic testing; and
- Parental decisions that their child not be told the truth about their diagnosis, prognosis or other aspects of their hospital stay.

The group in Melbourne recognized that traditional ways of dealing with ethically troubling cases – to review them after-the-fact – was less than helpful. They wanted to find a way to deal with ethically challenging situations as they were occurring (Gold et al. 2011).

Cottle et al. (2017) surveyed eight pediatric hospitals in Australia and New Zealand; seven had access to a clinical ethics service. The one without a clinical ethics service addressed ethical problems by soliciting a second opinion from another clinician. They found wide variation in how case consultation was conducted, whether or not patients and families were involved, and whether or not the consultations were documented in the patient's health record. However, they did note that a multidisciplinary approach was increasingly used in consultation and the clinical ethics service was independent of other departments. As has been noted several times in this chapter, clinical ethics committees tended to lack formal funding. This group made specific recommendations as follows:

- Clinical ethics services should have terms of reference with details on how they approach consultations.
- The clinical ethics consultation should be documented, in a standardized form.
- Sustainable funding should be provided to increase opportunities for education and research. (Cottle et al. 2017)

Gaucher et al. (2013) examined the general mode of functioning of ethics committees in four countries. All available documents from each of these countries were obtained. Systematic content analysis examined such issues as guideline development, the specific role of clinical ethics committee (CEC), how they carried out consultations, and if there were education requirements for committee members. In essence, the researchers concluded that CECs function differently in each of these four countries, partly related to cultural differences, contexts and how CECs developed. In summary:

American CECs, established within a strongly litigious context are perceived to play strong decision-making roles, whereas British CECs, encouraged by clinicians, endorse a more supportive model. Canadian guidelines focus on the role of the ethicist, while the French model is interested in a theoretical interdisciplinary approach. (Gaucher et al. 2013)

3.6 Are the Committees Successful?

There are many ways to approach the question whether clinical ethics committees are successful. Do CECs make disagreements less likely? Earlier, we quoted Myers and Lantos that the effectiveness of committees should be assessed urgently. Some specific questions arise: Do they improve outcomes? Do they contribute to shortening lengths of stay? Are those who participate satisfied? This last question might not be focused on the most important outcome; yet there should be satisfaction because one function of ethics committees is to provide a forum to permit all parties to be heard.

Most of the outcome literature we could identify came from adult institutions. Nevertheless, we will quote some of this literature here because the conclusions might have some relevance to pediatric committees. In terms of satisfaction, one early study produced mixed results (Yen and Schneiderman 1999). Forty ethics consultations were reviewed. Physicians and social workers involved in 23 were interviewed. Ninety percent were satisfied. The situation with families was different in terms of recruitment and satisfaction. Only four were interviewed and two were dissatisfied.

A literature review of ethics consultations in adult ICUs produced positive findings (Au et al. 2018). Of 325 articles read, 16 met inclusion criteria. Generally, the use of committees was seen as positive with a subset of surrogates and providers (113/431) being dissatisfied. Clinical ethics consultations were likely to lead to consensus on a clinical decision and were also associated with a significantly reduced length of stay. Despite this positive finding, the authors list process measures in the role of ethics committees in good end of life care that might be more relevant than data on length of stay. The help that might be provided by ethics committees should include increased communication, participation in dispute resolution, support for moral distress, and building resilience within the healthcare team. These should be measured as outcomes along with documentation of the family's journey, timeliness of specific conversations, and referrals. Such measures could be supplemented by continuous quality improvement using standard questionnaires to obtain information and feedback on what is working well and what might need to be improved.

Jansen et al. (2018) reviewed their clinical pediatric ethics service in Brisbane, Australia. This service was staffed by a part-time physician with training in ethics, a pediatric trainee and an administrator. There were several other staff members who contributed to the pool of people who were willing to do consultations. They used a "facilitative model"; in other words, they listened carefully to the various parties in an ongoing ethics issue and gave advice which was non-binding. They aimed to be:

- Multidisciplinary,
- Deliberative,
- Have published terms of reference and standard operating procedures,
- Have quality improvement as a basic element,
- Be accessible and well resourced,
- In addition to case consultation, provide education and policy work.

They thought that they fell short of their own ambitions in not having complete terms of reference and regarded the resources as inadequate. The issue of resources is mentioned in almost every paper on clinical ethics services. Over the 2-year time of this review, there were 24 consultations, involving 17 different specialist services. They sought the opinion of those who had used such a service and had a 36% response. Most felt that the consult helped in reducing their own moral distress. The main sources of "moral tensions" were:

- Appropriateness of experimental therapy,
- Difference in perception of child's best interest between parents and treating team
- Difference in perception of child's best interests between treating teams,
- Establishing extent to which adolescence autonomy should be respected,
- Challenges of respecting parental autonomy in protecting child from potentially unethical research group.

Carter et al. (2018) asked an interesting question: Why Are There So Few Ethics Consults in Children's Hospitals? They reviewed the literature and confirmed that it was true that there were few pediatric ethics consultations. They also noted that in their hospital, there were fewer than one ethics consult per month. They noted that there were many venues for ethics discussion and these other venues may provide adequate resources to help clinicians facing complex ethics issues. The venues were:

- Ethics committee meetings,
- Nursing Ethics Forum,
- Ethics Brown Bag workshops,
- PICU ethics rounds,
- Grand Rounds,
- NICU Comprehensive Care Rounds,
- Palliative Care Team (PaCT) case conferences,
- Multidisciplinary consults in Fetal Health Center,
- Ethics consultations.

Ethics committees developed at a time when there was little general understanding of how to approach such problems, little or no education in ethics in any healthcare profession, including medicine. Clinical ethics committees first evolved in the US, and as noted above, partly because the US is a litigious society, but perhaps also because the US was one of the first Western countries to identify the rapidly changing relationships between physicians and families and the impact of rapidly developing technology, and it had a relatively young population that valued innovation and engaged in early adoption of ideas. Whatever the reason, such committees have since developed in other countries. They help clinicians and families with problems (ethics consultations), comment on policies produced by their institution, have a strong educational component, and some pursue their own research on clinical ethics problems. The committees have developed many ways of working and typically see themselves as being under-resourced.

While now all healthcare professionals have extensive ethics training as undergraduates and also in continuing professional education, fewer have the higher level of ethics education arguably necessary to act as a resource to others. The literature suggests that many committees function with individuals who have non-ethics roles within the hospital, rather than having a dedicated trained ethicist. A paper published in 2010 reported that the training of those leading ethics services at children's hospital varied. The most common training was on the job (24, 73%); next most common was attendance at intensive bioethics mini-course (13, 40%); only 5 (12%) had completed an ethics fellowship (Kesselheim et al. 2010). We suspect that, over time, almost all institutions will have trained ethicists with at least a Master's level education if not a PhD in bioethics. Some institutions have trained ethicists as part of clinical teams, the "embedded ethicist" model (Bruce et al. 2014). We support leadership of ethics services having appropriate training and believe that institutions which ignore the pool of interested clinicians to work with this ethicist will lose a valuable resource.

3.7 Comment on Riley

Riley's situation is likely familiar to almost everyone in pediatrics. A preterm infant is born; skillful care is given with great optimism. Then complications arise and the initial optimism diminishes. Over time, it becomes increasingly difficult to initiate discussions with the family over limitations of treatment and discord develops among the various staff members involved. Procedures such as a tracheostomy with life lengthening possibilities but without addressing the underlying neurological or respiratory problems are performed. In the meantime, while his life continues, Riley experiences a life with little or no pleasure and probably filled with pain and discomfort. The last might be ameliorated with medication but their use will make it even less likely that he has any enjoyment in life.

Sometimes a sense of hopelessness descends on all the team members. They complete their tasks mechanically, accept the discordance in the unit, and start to avoid discussion on Riley's future. Here, an outsider can be very helpful. This outsider might be an individual ethics consultant, a subset of an ethics committee, or the whole committee, though the last is probably the least desirable. If the outsider can persuade Riley's parents to attend a meeting or at least to speak with these parents, then the staff might begin to hear some of the parents's concerns and anxieties. It is important to keep in mind that not only do parents typically have great love and concern for their child, but also have a societally approved role: parent. Committee members proposing that because treatment is futile it should cease, must be sensitive to all implications for parents of such a decision. The consultant or committee should also meet with the staff, because the discord usually covers up a great deal of moral distress. The ethics committee will have a role of listing possible decisions, and perhaps advising about which decision to take, but not a role of taking decisions.

The most we can hope for is that there is meaningful discussion between Riley's parents and the staff, and that the different staff members can also listen to one another. At the very least, we may be able to reduce some of the tension in the unit, work on improving relationships, and revisit the discussions on Riley's future in a few weeks.

It is possible that a different model of ethics involvement, that is the "embedded ethicist", mentioned above, might have been helpful in preventing the tension that developed over time. However, it is fairly early in the evaluation of such a service, and only time will tell if this is a very successful innovation.

We hope that Dr. Chloe Lewis can participate in some of the discussions because the more junior members of the healthcare team often bear the brunt of much of the moral distress in situations where there is so much conflict.

Dr. Lewis, and perhaps some of her fellow residents, should consider asking if they might become members of the ethics committee. Such membership will improve the residents' understanding of the complexity of situations involving many staff members as well as the family with many different opinions. The committee may find a way to understand the role of the resident and to listen to the perspective of someone with a great deal of education but who is relatively new to healthcare.

3.8 What Is the Future of Ethics Committees?

Predicting the future can prove an embarrassing enterprise. Nevertheless, we do not believe that healthcare will become less complex, nor that there will be fewer technological innovations. Hence, it is very clear to us that there will continue to be difficult situations in healthcare that require understanding, and perhaps some form of mediation to achieve resolution. It is also very clear that the power of social media to influence direct contact between healthcare professionals and families will increase rather than lessen. There will continue to be a need to understand evolving ethics issues and to have a way of understanding and mediating complex conflicts.

Consequently, we believe that clinical ethics committees will continue to exist and like every aspect of healthcare will continue to evolve and change. The role of the trained ethicist will probably become more prominent and this increase in the role of the ethicist needs to be balanced with the need to ensure that healthcare professionals are engaged in the understanding and resolution of ethics problems and conflicts.

The need for ethics education should continue. Whether such education is provided by the ethicist, by members of the committee, or by some other means is probably not relevant.

Ethics committee should continue to be allowed and encouraged to review policy documents. In addition, if in the course of an individual consultation, a problem is seen with institutional policy, the committee chair should approach senior adminis-

tration and request change in the policy and should have the right to contribute to deliberations about the change.

Finally, ethics services should be recognized as a legitimate service that requires adequate sustainable funding.

3.9 What Other Resources Are Available to Pediatric Trainees Facing Ethical Challenges?

For all the reasons listed in the previous paragraph, there will continue to be major ethical challenges in the practice of pediatrics. Education in ethics should continue, perhaps with the use of simulation to familiarize trainees with real-life situations. One Canadian study (Lieberman and Hilliard 2006) reported that residents thought they were well trained in ethics, but whether this would be generally true in all countries at different times is less clear. Ethics education, like other parts of medical training, must continue to evolve as the challenges change.

Yet, ethics committees are certainly one way in which help can be given, but as was noted in a paper by Myers and Lantos (2014), formal consults might not be common. The implication then is that pediatric staff, including trainees, seek many different ways of receiving help in dealing with complex ethics situation.

The first method of seeking help is through informal networking with colleagues whether peers or more senior, or in other healthcare disciplines. The fact that pediatrics is now practiced in a multidisciplinary fashion means that it is possible to receive multiple inputs into any given situation. Then, focused rounds on ethics would be helpful, as would specific time allocated in general health care education to discuss ethics situations, whether in an institution-wide format, or in specific units. In the Myers and Lantos (2014) paper cited above, PICU ethics rounds were listed. We would encourage such rounds, but we caution that many children with complex medical situation will be in different parts of pediatric institutions at different times. Dealing with the ethics issues, including staff moral distress, in one specific unit is likely to help staff in that unit. However, helping staff in one unit will not necessarily help staff in other units. Excellent communication between staff in different units is essential.

There are many other ways of obtaining help in worrying ethics situations (Watson 2005). Healthcare providers might approach their professional associations, whether for a particular group, such as that for trainees, for their region, or nationally. In countries where there are dedicated legal defence organizations, physicians might seek help from such organizations as the Canadian Medical Protective Association or the UK Medical Defence Union. Various ethics “think tanks”, such as the Hastings Centre or the Nuffield Centre in the UK produce working papers of relevance to practising clinicians. Those clinicians who have a strong interest in ethics should join one of the many professional organizations such as the International

Association of Bioethics, the American Society for Bioethics and Humanities, the Canadian Bioethics Society, Institute of Medical Ethics and so on.

3.10 Conclusion

The development of ethics consultations was a response to the increasing complexity of medical practice, the changing relationship among patients, families and physicians, and the increasingly successful use of technology in medical practice. (The last has revolutionized outcomes, but sometimes increased problems by misuse). These ethical consultations have taken different forms in different countries; the "clinical ethics committee" originated in the US and can now be found in most countries. There are other forms of ethics consultations, including consultation with a trained ethicist. These formal ways of obtaining ethics consultation have not replaced informal consultation with peer groups or senior colleagues. Pediatrics is committed to team-based functioning; hence, pediatricians have the ability to obtain many different views from different professionals and different specialists in any given profession on a specific topic.

The need for ethics consultation will continue into the foreseeable future.

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Part II
The Basics

Chapter 4
How Do I Know from Whom I Need Permission and When I Have It?

Key Points Concerning Consent

- Consent is a prerequisite for any action or procedure, no matter how minor, carried out by a healthcare professional on a patient. Even touching the patient requires consent.
  - Consent is based on respect for persons and their inherent dignity.
- To consent to a procedure or therapy, the person must have capacity which entails:
  1. competence, that is the ability to make reasoned decisions;
  2. voluntariness, that is the freedom to consent or refuse to consent without fear of reprisal from anyone; and
  3. full information regarding the risks and benefits of accepting or refusing the proposed medical treatment.
- Consent is a process, though institutional regulations and legal precedent may require physical evidence of consent and so, by requiring a signature on a consent form, make consent a moment in time.
- Children should be involved in all decision-making processes, in a manner consistent with their developmental age, and emotional and cognitive level. In pediatric practice, "consent" is, by default, given by parents or legal guardians, but the respect underlying consent is respect for the inherent dignity of the child.
  - Parents or guardians have less latitude and ability to consent or to withhold consent for the child-patient than they do on their own behalf. They must base their decisions always on the best interests of the child.

    Hence, "parental permission" is language that is more apt than "consent".

    In some situations, the parents' inability or unwillingness to agree to necessary medical treatment will trigger a process by which the state consents on behalf of the child.

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_4

- Adolescents in specific situations may give consent on their own behalf without their parents or guardians knowing about the decision.
- In emergencies, physicians are morally bound to act to save life without seeking formal permission if the physical condition of the child does not permit the physician to seek permission.

4.1 Introductory Story: Dr. Wilson and Consent

Dr. Wilson had just started pediatric training and was doing a rotation in the emergency department. Nicholas was 22 days old and was being seen because he had seemed lethargic, had repeatedly turned away from the breast after about 1 minute over the previous 8 hours and had developed a fever of 38.5 °C. Dr. Wilson had assessed Nicholas together with the staff physician, Dr. Singh, and after discussion away from the bedside; the physicians decided that Nicholas should have blood work including blood culture, and a lumbar puncture. Dr. Singh asked Dr. Wilson to seek permission from Nicholas's mother for the lumbar puncture.

Dr. Wilson was familiar with the reason for the lumbar puncture, how it would be performed, the benefits of conducting it and the possible complications. Dr. Wilson's medical assessment, based on her training and reading, was that the lumbar puncture is essential; the situation is in keeping with neonatal sepsis including meningitis. She regards the need for appropriate antibiotics to be urgent.

What ethical factors are involved when Dr. Wilson approaches the mother to ask for permission to conduct the procedure? What advice would you give Dr. Wilson on how best to seek permission for lumbar puncture of Nicholas?

Consent is as important in pediatrics as it is in any other branch of medicine. The difference in pediatrics is that a surrogate usually gives consent. In other words what we call "consent" is usually given by a parent or guardian; such consent gives permission for medical treatment to occur on the body of another person. (We will usually use the word "parent" and recognize that, in most situations, a guardian who is not a parent has the same authority over the child's treatment as the parent). This chapter uses the word "consent" because this is conventional usage, but it is more accurate to speak of "parental permission" for a proposed procedure or treatment of a child rather than consent. Using the term, "permission" emphasizes that truly the process of consent is part of respect for the child, but given the developmental immaturity of most children, we see the parents as the most appropriate decision-makers. When the child is not able to give legally binding consent, but can understand part of the process, we must seek the child's assent as well as the parent's formal authorization. The American Academy of Pediatrics defines "assent" as "agreement with proposed interventions" and is described in detail later (Katz et al. 2016).

Pediatricians do not take orders from parents but rather they care for children. Please note that the now common pediatric practice of automatically deferring to the wishes of the parents when obtaining permission for treat-

ments or procedures on children (or accepting refusal of recommendations) is not principled. It is an action of physician convenience, not one that meets ethical standards. Parents do not have absolute rights to make whatever decision they wish for their child. Surrogate decision-makers, including parents deciding for children, do not have the same unfettered decision-making power that they have when making decision about themselves. Parents, or any decision-maker, must decide on the basis of the "best interests" of the child. Ross has coined the phrase "constrained autonomy" to indicate that when giving permission to treat their child, parents have less discretion than when giving permission for their own treatment (Ross 1998).

In this chapter, we will discuss in detail the issue of parental permission and other ethical issues arising from Nicholas's need for a lumbar puncture. We will offer guidance on situations when there is refusal of conventional treatment for any reason, and not limited to religious or cultural disagreement. We will discuss a myriad of minor issues that arise – so-called "micro ethics", including how to accommodate wishes of the children themselves. The chapter will also discuss when the child must be heard alone and offer strategies to ensure that this occurs. Hearing from a child alone is usually taken to be about adolescents, but sometimes younger children want to be heard and it might be the case that their wishes can be heard only in the absence of their parents.

4.2 Dr. Wilson Seeks Parental Permission: Operationalizing Consent

Dr. Wilson and her preceptor have already accepted the medical realities that meningitis is likely, and that the lumbar puncture is in the best interests of Nicholas. Lumbar puncture will give confirmation of the diagnosis, and if Nicholas does have meningitis, the specific organism and its antibiotic sensitivities will be known. Dr. Wilson understood that because lumbar puncture is an invasive procedure, specific consent for lumbar puncture is required. Whether this specific consent must be evidenced in writing on a standardized form is determined by local, institutional practice and rules. As a side issue, whenever medical staff start working in a new facility, they should clarify which procedures require oral permission from parents, in which case they will make a note in the chart about the discussion, and which procedures require written consent. All procedures involving general anesthesia, or carried out in an operating room, require written consent unless the emergency is so urgent that there is no time to seek consent. In summary, all procedures require the informed consent of the parent or guardian; in some cases, such consent will be informally given and received.

When seeking consent for a lumbar puncture on Nicholas, consent must be explicit. In other situations, consent might be implicit or presumed. For example, by bringing Nicholas to the emergency room, and allowing him to be seen by healthcare staff, the staff may reasonably presume that a physical examination does not

require explicit consent. Nevertheless, they will talk to the mother, and the child, as they proceed through stages of the examination. In the hospital in this example, it was accepted that lumbar puncture was a procedure in which an explanation and verbal consent from the guardian, with a confirmatory note in the chart, would be sufficient to document that the parents agreed, on behalf of Nicholas, to the painful test that would be done to Nicholas to obtain a definitive diagnosis.

Because Dr. Wilson had watched another preceptor in a different rotation discuss lumbar puncture, Dr. Wilson thought that she was well enough informed on the details, including risks and benefits, to proceed to discuss the procedure with the mother. Dr. Wilson also thought that she understood the ethical requirements for informed consent. Dr. Wilson understood that receiving permission for the procedure was an important part of Nicholas's medical care, that the setting was important, her communication should be clear and respectful, and that she should follow all ethical and legal standards.

What are the ethical issues involved in consent? In general:

- The individual giving consent should be competent, aware and capable of receiving, reflecting upon and making decisions about information;
- The physician or healthcare professional should have provided full information of benefits and of all serious risks and of common minor risks;
- The patient or guardian should understand the information, and the physician should accept the responsibility for ensuring that information is understood; and
- The consent should be voluntary, without any form of coercion.

Leading writers on medical ethics agree with the issues described above. They organize them in a different way. Beauchamp and Childress (2013) describe three parts to the process:

1. Threshold elements;
2. Informational elements; and
3. Consent elements.

The "**threshold elements"** are really the two preconditions of competence and voluntariness. These preconditions concern the status of the patient as being cognitively and developmentally capable of making such decisions and of not being under any type of threat. The **information elements** are equally important. They are featured in medical ethics writing because physicians must participate in ensuring that the patient has the requisite type and amount of information. Physicians must disclose all the relevant information along with a recommended plan and must verify that there is an understanding of these. Finally, the **consent elements** include the decision-maker's choice to accept or to reject the plan, and the physician's confirmation in writing that the decision-maker has authorized or rejected the medical procedure. Given that we seek permission from the parent before going ahead with the procedure, it follows that we will not always receive permission. If the parent refuses to consent, then further discussion is required with members of the pediatric team, and perhaps others, considering the ethical dimension of the refusal.

The healthcare professional seeking permission would, in general, assume competence of the parent or guardian. Only if there were indications in the interaction with the guardian of lack of competence would a physician request formal assessment of parental competence; such a course of action is rare. In the first instance, the clinician should offer the parent every opportunity to give consent for the child, including providing support, perhaps from family members or the social workers in the institution. The fact that the parent did not agree with the physician's recommendation is not, by itself, a reason to question the competence of the parents. If the physician thinks that the parent lacks competence, then we recommend that the physician seek legal advice regarding the next steps.

We also suggest very strongly that assumptions about competence to consent – whether parents who are themselves minors, teenagers who might otherwise be mature minors, or adults – should not be based on superficial factors. For example, many individuals with trisomy 21 have intelligence in the range in which they can be assumed to have competence to make medical decisions. If an individual with a condition associated with lower levels of intelligence appears to lack competence, then we should not assume that relatives such as parents automatically have the authority to consent or refuse to consent. This is also a situation in which legal advice should be sought. The same reasoning that applies to individuals with trisomy 21, or similar conditions regarding their ability to make decisions above the age of majority, will also apply to their ability to make decisions while a minor. Such individuals might well be assessed as a "mature minor" and be able to make their own decisions.

Another situation that can lead to confusion in assessing parental capacity is misreading cultural clues. In Western society we put great store on speaking directly, and on eye to eye contact. When we speak to parents who do not look at us directly and whose appearance is impassive, we may erroneously assume that that parent does not understand what we are saying. It is more likely that the parent is being respectful by not staring at us, and by listening intently without interrupting.

4.3 Young Parents

Even though a parent is a minor, we should assume that she is nevertheless able to give consent for a surgical intervention on her child – unless there is overwhelming evidence that she may lack capacity (competence, voluntariness or adequate information). In some jurisdictions, such a parent is described as "emancipated", a term that has different definitions in different legal jurisdictions. Typically, this phrase is used for minors who are parents, on active military duty, or can support themselves financially and emotionally (Greydanus and Patel 1991). From an ethical point of view, by far the most respectful thing that can be done is to defer to the parent when decisions are required for the child, even if the parent is a minor. As in some of the other complex situations involving consent, the physician might want legal advice, particularly if the intervention requested is major, and has a possibility of a poor outcome.

4.4 Information to Be Provided

How and what information should be provided raises more questions. In terms of how information is presented, the professional has a responsibility to explain the situation to families, outline pros and cons of specific treatments, using language appropriate for the parents, not the technical language of the medical "insider". In terms of what information should be provided, many healthcare professionals think that conveying full information is an impossible assignment. They have concerns that the imbalance of knowledge between them and the family is so great, that the notion of "informed consent" is a sham. We disagree and believe that it is possible to receive fully informed consent in almost all situations. Healthcare professionals have an armamentarium of detailed information from their background knowledge of physiology, biochemistry, and pharmacology. Some may suppose that this information is the standard of understanding required for parental consent to be valid. Yet full information to such a standard is clearly not possible, and not necessary.

Decision-makers for children need information that is understandable and meaningful to them. They must be informed to a standard that meets the requirement of respect for persons. The standard is not what the physician thinks the family should know; the standard is what the family wants to know, and also what the family needs to know. Physicians must assume the responsibility and have the skills to ensure that there is ample opportunity for the family to ask questions, and that she or he uses language that families can understand. It is also part of the responsibility of the physician to ensure that there is an understanding of what is to be done, the common complications, and whether there is a possibility of disastrous complications, however rare. The consent process would not be complete without the guardian knowing the likely outcome if the procedure is not performed. While it is important to ensure there is no coercion, that fact does not mean there should not be persuasion. At the very least, it is essential that the family understand the recommendation that the physician is making and why the physician thinks it is important. The family should not be given information in a vacuum, and then be expected to make a decision without guidance.

4.4.1 Historical Background

The ethical issues involved in consent were described in the twentieth century in a process that began after the Second World War. Until the 1940s, patients, physicians and society in general, including legal authorities, accepted that the physician should decide what should be done for a patient, and would inform the patient of that decision. Changes in attitudes to consent began when the Allied powers of Great Britain, France, the Soviet Union, and the United States sought to hold accountable German physicians who had conducted experiments on prisoners in Nazi concentration camps.

The Nuremberg Trials of 22 physicians that took place in 1945 and 1946, focused on research undertaken by doctors under the Nazi regime, not on clinical care. Nevertheless, the outcome came to influence the ethics of clinical care. The judges formulated ten principles that should be followed in medical research; these principles became known as the "Nuremberg Code". The Code initiated a process that led to the re-evaluation of the relationship between physicians and patients. The first of the Nuremberg principles concerned informed consent, as described below:

> "The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject, there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment. The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs or engages in the experiment. It is a personal duty and responsibility which may not be delegated to another with impunity" (Shuster 1997).

The story of changes in attitudes to consent, initiated by the Nuremberg Trials and Code, has many different strands. These strands relate to changes in society, with an increasing focus on human rights, and the use of litigation to establish legal precedents on what informed consent means and what it does not mean. While accepting that legal processes have driven many of the changes in attitudes to informed consent, it is important to realize that a patient's or parent's signature on a form does not, by itself, mean informed consent, nor does a reluctant "Yes, I suppose it is OK." from a patient or parent necessarily meet all the ethical requirements.

As the process of obtaining consent unfolds, there are obviously many important background facts about the family and its situation that we may not fully understand, but that are relevant. One piece of background detail that is obvious that whoever is giving the consent will be extremely anxious and worried; these are states of mind that demand respect. There is an important inequality of information as between the physician and the parent. Returning to the example of Dr. Wilson seeking consent for lumbar puncture, she will be familiar with what a lumbar puncture entails and how it is done; this procedure will have been part of her studies for a year or two or more. On the other hand, the parent may never have heard of lumbar puncture, and will likely never have been asked to consent to lumbar puncture before. If the parent has heard of lumbar puncture, then the parent might know only of horror stories from acquaintances or friends. It is likely that Dr. Wilson will also be anxious partly because she is relatively inexperienced, but also because she is worried about Nicholas. Dr. Wilson knows how important the lumbar puncture is in determining the best course of action to help him. However, this desire to help coupled with the parental anxiety does not mean that Dr. Wilson can avoid giving full information. She must resist the temptation to withhold a full description of

complications fearing that the mother will not consent to the procedure. The temptation to withhold information exists, and it is based on Dr. Wilson's anxiety to do good and to ensure that Nicholas gets excellent care. Nevertheless, the duty to provide full information remains.

There are unknowns. Perhaps the person we are asking to give consent for this procedure has had a lumbar puncture himself or herself and found it unpleasant. Or a relative or a friend may have had a lumbar puncture and passed on unpleasant details. Such background information may lead the guardian to decline permission. If the mother declines to give permission, the first step would be to identify her reasoning, if at all possible. If the reason is past experiences that are only partly relevant to the current need, then the parent should be encouraged to focus on the current needs of Nicholas. Recall that the standard for consent for a child is not what the parent would want for themselves, but what is in the best interests of child. In this case, what is best for Nicholas is what the parent must choose.

4.5 Best Interests

We have used the phrase "best interests" earlier in this chapter. Almost certainly anyone involved in pediatrics has heard the phrase already, and most will have used it at some time or another. It is in common currency when decisions must be made on behalf of a child. The best interest standard is one of the ways surrogate decision-makers, such as parents, may make decisions for others.

But what does "best interests" mean? The concept serves both as direction and guidance to parents and other decision-makers for children. Insofar as "best interests" is direction, the concept serves to limit parental decision-making to that which aids the child. While concerns for parental grief or anxiety are important, they do not have priority. What is good for the child is the first concern when making medical decisions for the child. It is important to understand that "best interests" is a vital concept and is useful to physicians caring for children when parents stray by focusing on what is best for themselves; physicians can and must guide parents back to considering what is best for the child.

Insofar as the term "best interests" is guidance, a range of authors in medical ethics has considered its definition. Medical ethicists Beauchamp and Childress, in their book, "Principles of Medical Ethics", state that best interests are about maximizing benefits and minimizing harm (Beauchamp and Childress 2013). Beauchamp and Childress advanced other standards for decision-making in the patient's best interests which are the "substituted judgment standard", and "pure autonomy standards". But these are not necessarily relevant to children. The substituted judgement standard is the decision-making standard by which the decision-maker decides as the patient himself or herself would decide if capable (and not the decision that the substituted decision-maker would make if he or she had been the patient). The pure autonomy standard gives authority to choices articulated when the patient was competent. These decision-making standards are not applicable to children because

such standards require understanding of the patients "life values"; children might not have had a chance to determine their life values. The same authors note that the concept of "best interests" is also about chance of survival, long and short-term outcomes, and long-term quality-of-life. Another medical ethicist describes "best interests" as "the option that maximizes the person's overall good and minimizes the person's overall risks of harm." (Kopelman 2013).

But the exact meaning of "best interests" is difficult to pin down. Maximizing a patient's overall good is usually a shared goal; there is no doubt that both parents and pediatrician almost always are sincerely concerned about the child and have a general desire to do good for the child (as stated, parents must be directed back to that goal should they stray when making medical decisions for the child). But identifying how to operationalize that goal is challenging. Some claim that the concept of "best interests" is often confusing rather than helpful in guiding decision-making because of its lack of precise definition. Medical ethicist, Veatch (1995), notes that conflicts can arise when healthcare professionals focus exclusively on health issues and family members are focusing on other interests and goals. The concept might unhelpfully suggest that there is one option (after all this is the meaning of "best") when in reality there could be many good options.

Other authors stress that the shared goal of achieving the "best interests of the child" means that the physician must assume some role in deciding whether a parental decision for a child actually advances the child's best interests. These authors stress that pediatricians should accept the responsibility of assessing the choices parents make to decide whether some choices should be resisted (Rhodes and Holzman 2014). By what standard, however, should physicians assess whether parents have decided in the child's best interests? We believe that the standard should be "Not unreasonable". In other words, parental choices for their child's medical care that are not unreasonable should be accepted by physicians. But if the parents refuse treatment that is likely to be highly beneficial, then that unreasonable choice must be rejected by physicians.

The "not unreasonable standard" of judging whether a decision is in the "best interests of the child", means that decision-makers need not make an ideal choice, but also that physicians should not accept any choice. Physicians should not permit refusal to consent to an intervention with significant benefit, but if an intervention has significant risks and a low benefit, then parental refusal to consent seems an appropriate course of action. Medical associations and pediatric organizations throughout the world assume parental authority as the default position in decision-making, Using the "not unreasonable standard", also allows parents, legitimately, to take into account interests other than the narrow interests of the child patient. These other interests might include their other children, and family values. Notwithstanding that statement, when parents are choosing medical care for their child, the interests of that child ought to come first. In other words, we agree with the validity of other interests, but note that they should not be the dominant factors in making decisions about children.

When there is disagreement among the pediatricians and other healthcare staff and parents on a course of action, resolution can almost always be achieved. Such

resolution can occur in a number of ways, including compromise on the part of all parties. Additional supports for the families can be helpful, such as social work and pastoral care, whether by the help of an institution's spiritual advisor or the parent's personal pastor. Throughout the process of attempting to resolve disagreement, it is important that strong efforts be made to maintain good relationships among parties. The clinical situation must be carefully assessed to reveal when decisions are urgent, or when there can be more time for attempts at resolution. Institutional ethics committees can be an important bridge and can help all parties to the dispute understand the values that have led them to their current position.

Very rarely, some form of legal intervention will be required, and such intervention is most often the requirement to contact child welfare agencies.

4.5.1 Seeking Consent to Treatment or Treatment Withdrawal When Parents and Physicians Absolutely Disagree

When there is an absolute impasse in decision-making about a pediatric situation, all parties become extremely distressed. The parents might feel very strongly that they have a "right" to make decisions about the child, and that the hospital and medical staff should follow their lead. When parents are making decisions about their own medical care, they are in a dyadic relationship with the physician. The child-physician relationship is complicated, and is triadic, at least regarding decision making. All physicians, indeed, all health care professionals, accept some responsibility for the well-being of the child, while acknowledging the overwhelming influence of the parents. In a situation when agreement has not been reached, and all resources have been explored, the pediatrician is justified in seeking external help.

The development of child protection services, and formal child-abuse legislation is a feature of the second half of the twentieth century. Some semblance of protection for children originated in ancient times, but the intensity arose in the twentieth Century for several reasons. The principal reasons were the recognition that parents did not own children, parents should not have total control of their children, and we, as a society, have an interest in seeing that all children are well treated. In the early stages of child protection legislation, the focus was on such "obvious" items as starvation, severe neglect, and severe physical injury. It did not take long for the recognition to come that allowing a child to suffer harm because medical treatment is not provided is a form of neglect. The wider application of child protection laws will be discussed in Chap. 7; in this section, we will limit the discussion to parental refusal to consent to recommended medical treatment of a child.

Involving child protection services is a major course of action. Healthcare professionals find the process unpleasant because reporting that a child needs intervention tends to mark a change in the physician-parent relationship from ideally collaborative to adversarial. Moreover, the process takes the physician into the

unfamiliar world of legal investigation and adjudication, in which the physician is not in control. Here, the physician might need direction because the physician might stray to focus on his or her interests rather than those of the child. Despite the hardships that the process might create for the physician, the process must be undertaken when doing so is required by law because of society's desire, instantiated in law, to achieve the best interests of the child.

In the discussion above on the concept of best interest, we suggested that the "not-unreasonable standard" be used to judge whether a parent's decision is in the child's best interests. But the standard to involve child protection services must arguably be higher.

Child protection law typically requires doctors to report that a child needs the intervention of the state when the parents (or legal guardian) are unable or unwilling to provide necessary medical treatment. Usually the courts accept physician consensus as to what treatment is "necessary", understanding "necessary" to mean significant in preserving the life of the child. For example, "necessary medical care" means at least, treatment of sepsis (R. v. France 2017), (B.(R.) v. Children's Aid Society of Metropolitan Toronto 1995) and of significant blood loss (A.C. v. Manitoba 2009). This relatively minimal understanding of "necessary medical treatment" is consistent with state deference to parents prior to interfering with parental care of children. Consistent with the belief that parents have the primary responsibility for caring for children, and for decisions concerning their well-being, there is a high threshold for state interference. Such a threshold has been justified in this way: "Coercive state interference with parental prerogatives, for the good of the state and the good of the child, is justified when there is 'clear and convincing evidence' that parents' actions or decisions represent likely and serious harm to the child" (Deville and Kopelman 2007). Consistent with that justification, Diekema (2004) emphasizes the value of giving wide latitude to parents in making decisions. Too early, too frequent, or too broadly construed criteria for intervention might lead to harm to family members and disturb family functioning. Therefore, Diekema advances the concept of the "harm principle" as the justification for intervention. He lists eight conditions that should be fulfilled to justify intervention. These are:

1. Existence of "significant risk of serious preventable harm";
2. That harm be imminent, requiring immediate action to prevent it;
3. Treatment plan rejected by the parents is of proven efficacy;
4. Interference with the parental decision and provision of the treatment to which they object is necessary in order to prevent serious harm from coming to the child in question". This means that if there are acceptable alternatives, then they must be pursued;
5. Interference with the parental decision offers net benefit to the child;
6. The extent of state intervention and the treatment allowed under the authority of the state represents the least intrusive alternative that will reduce harm to the child and minimize the impact on parental authority;
7. The decision to seek state intervention is not influenced by morally irrelevant considerations (i.e. the religious nature of the decision). The example cited is

that of children of Jehovah's Witnesses parents where the child requires a life-saving blood transfusion. The transfusion is almost always ordered, not because of the religious aspect of the parents' life, but only because the child's life is at risk;

8. The decision to seek state intervention passes the test of publicity: the anticipated outcome of state intervention is what reasonable parents would agree is appropriate for all children. (Diekema 2004)

4.6 Aiding Parental Decision-Making

To return to the case of Nicholas and lumbar puncture, Dr. Wilson will be seeking consent from Nicholas's mother in an interesting societal era. The movement towards full informed consent arose partly because of the rise of human rights movements, paralleled by a distrust of authority. With the current rise of social media, Nicholas's mother will be exposed to an enormous amount of information and opinion. It is clear that amidst the now easily accessible "information", there are many lies and urban legends which characterize the "post-truth" era. "Post truth" is a new adjective "relating to or denoting circumstances in which objective facts are less influential in shaping public opinion than appeals to emotion and personal belief" (Flood 2016). ''Post-truth" became such a dominant phrase that the Oxford English Dictionary declared it to be its 2016 international word of the year. Lee McIntyre (2018) describes post-truth phenomenon as including obfuscation of facts, abandonment of evidential standards and outright lying to shape political opinion. Dealing with false and misleading information is another important task physicians have when providing decision-makers the information they need to come to a decision about proposed medical treatment.

Despite the challenges of offering scientific evidence in a post-truth era, Dr. Wilson has available to her some new developments in ethics, and a greater understanding of cognition and decision-making. One of the new developments called, "nudges" is an activity described as "gently helping people to make better choices". This approach is viewed at the governmental level "as a new and better method to change people's behavior in order to improve their health and wellbeing" (Vallgarda 2012). Some of these ideas can be adapted to the communication of information that is required to make individual medical decisions.

The idea of nudges arose from the fact that individuals do not always make decisions that are in their interest. This fact led to attempts to understand why this should be, and what might be done to help. For example, individuals might not have access to complete information, and even when they do, they might not pay full attention it; they might take what they see as "the path of least resistance"; their personal cognitive abilities might be limited; or they might be strongly influenced by emotional factors. Authors speculated that nudges might be a way to help them make more positive choices. It is not surprising nudges have been attacked as too paternalistic, and a way of limiting autonomy.

Levy (2017) advances a different approach. He argues that nudges may be an acceptable form of paternalism and asserts that nudges may facilitate good decision-making. He uses the phrase "nudges to reason", on the grounds that the nudges may help reasoning. In other words, far from limiting autonomy, nudging aids autonomy by providing information about what people in positions of responsibility recommend. Nudging does not force but recommends a choice.

It is well known that too strong a presentation of arguments in favour of a particular action may increase resistance, the so-called "backfire effect". When individuals hold beliefs that are not supported by evidence, and are given currently accurate evidence, the belief in the original information may be decreased. Paradoxically, the effect on behaviour may be quite the reverse. In the context of debunking scientific myths, this backfire effect may arise because of defects in the way we remember knowledge (Peter and Koch 2016). One way of avoiding backfire could be to present positive information first. For example, "a lumbar puncture on Nicholas is safe, and will give information essential to his best treatment". Reinforcement of this message should follow with a more detailed description of what the procedure involves. Certainly, information on side effects and potential complications must be included, but this information needs to be placed in context by Dr. Wilson so that the risks can better be weighed against the benefits. Clearly, if Dr. Wilson did not believe that the risks are not as great as the benefits then she would not propose lumbar puncture. It is her duty to convey where the risk-benefit balance lies.

To avoid assuming this important duty of recommending lumbar puncture and simply to give the "medical facts" is insufficient. It is important that Dr. Wilson explain why she believes the benefits outweigh the risks and to convey clearly to the mother her medical opinion of the best course of action. To quote a distinguished physician and author (and please ignore the once acceptable use of solely male pronouns):

> "The physician should recommend a specific course of action. He must take responsibility, not shift it onto the shoulders of the patient. The patient may then refuse the recommendation, which is perfectly acceptable, but the physician who would not use his training and experience to recommend the specific action to a patient […] does not warrant the somewhat tarnished but still distinguished title of doctor." (Ingelfinger 1980)

The transmission of factual information is probably the easiest part of the encounter. Dr. Wilson will find it more difficult to find and to take the necessary time to listen and to respond to the mother's questions. We have information from many studies that physicians interrupt parents and tend to speak much more than they listen.

During discussion on what the future holds for a child, when parents must make one decision or another, a very common question is "What would you do doctor?" Sometimes the question is even more specific, "What would you do if this were your child, Doctor"? Physicians respond to this question in many different ways, and most trainees will struggle to decide what an appropriate response is. Truthfully, there is not and cannot be a standard response to this question. We believe it would be coercive and disrespectful to both the child and the parent for the physician to

respond directly by answering the question that has been asked without exploring nuances. On the other hand, we also see it as disrespectful to refuse to answer a question which is a very reasonable one from the parent's perspective. It lacks compassion to say, even though it is true, that "This is your child not mine, and what might be reasonable options for someone in my situation might not be reasonable options for someone in your situation". Such a response fails also to provide any support to the parent and may shutdown further questions and responses.

Edmonds et al. (2015) suggests that physicians might not want to answer the question because they respect the autonomy of the patient's decision-maker and also, they might be anxious that if they were to answer the question, then they might increase their legal liability should complications arise. In response to such concerns, Edmonds makes a very important statement:

> Being asked the question, "What would you do?" represents a pivotal moment in the doctor-patient relationship. The question gives physicians an opportunity to join with patients in a meaningful way to build trust, which is essential in delivering patient-centered care. (Edmonds et al. 2015)

Recognizing the importance of the question, let us consider how to respond. First, the question itself is quite ambiguous (Baylis and Downie 2001). Does this apparently simple question mask more complex underlying questions? The question may simply be a request for more information so that the mother can clarify her own understanding of what is to be done. The mother may also know that later in the day she will be a "messenger" and explain the conversation, and subsequent events to the child's father, grandparents, relatives and friends. She will want to be reassured by the physician that she understands the facts that make the recommended lumbar puncture the best decision for Nicholas. She might also want reassurance that the decision to perform a lumbar puncture is the correct one. It is reasonable to give reassurance about both points, and to note that many caring parents have made the same decision to consent to lumbar puncture for their child when recommended. The mother's question may simply be an underlying request for empathy and evidence that the mother perceives herself as being in a difficult position. Perhaps the mother does not want to take the responsibility for the decision and would be happy if the physician would take responsibility for her. Montello and Lantos (2002) suggests we often place too much emphasis on parental autonomy.

For this situation, Edmunds et al. provide a helpful mnemonic device: ANSWER. This device provides a process to follow when faced with the question, "What would you do, Doctor?" The mnemonic is:

A Active listening;
N Needs assessment;
S Self-awareness/reflection;
W Whose perspective?
E Elicit values;
R Respond.

As indicated earlier, perhaps the most difficult part for physicians to follow is "A", active listening. Giving the mother time to formulate her thoughts and questions, and to tolerate moments of silence, is essential. The second part "needs assessment" means determining what lies behind this deceptively simple question. Exploring the next three questions about identifying what the physician's underlying beliefs and perceptions are, determining from whose perspective the responses should be made, and determining the underlying values of the mother, the extended family and indeed the physician, will set the scene for a thoughtful, empathetic response.

One aspect of obtaining and informed voluntary consent before performing a procedure has not yet been discussed. Things do not always go as planned and hoped. Should there be a complication or some untoward event, having followed a good process of discussion with patients and family prior to obtaining consent, might give some protection to physicians against potential legal action.

Dr. Wilson knows that there are many challenges in having sensitive discussions with families in an emergency department, which is typically a very busy and noisy environment. She will try to meet with the mother in a quiet area. If that is not possible, then she will at least ask another member of staff to look after her pager while she is speaking with the mother and will try to arrange things so that she is in an area without phones. Dr. Wilson will ensure that she is sitting, and not standing to increase the mother's sense of safety and well-being. She will try to make sure the mother is comfortable and, as far as possible, not distracted. Dr. Wilson will ensure that there is adequate time for the mother to ask questions, and answers them thoughtfully, carefully and honestly.

There are aspects of obtaining informed consent from a parent that, superficially at least, appear challenging. What does it mean in an era when family centred care is prominent, to ask permission for a procedure from one person? Should we assume that the parent we speak to has had full discussions with the other parent, assuming co-guardianship, or is this putting an undue burden on the physician who is seeking consent? The current focus on "joint decision-making" means that the physician and the parent become almost co-decision-makers. What does that mean in the context of requiring verbal or written permission from one person, typically a parent, to do something to another person, the child-patient?

4.7 Communication and How Communication of Information Is Received

Communication matters! It is important that trainees in pediatrics develop their own style of communication. Yet there are some general questions that should be asked and principles that should be followed in obtaining an ethically valid consent.

Trainees should remember that deciding whether a decision is straightforward and easy, or complex and difficult, is related to the perceptions of the decision-maker,

not the physician. Families might see some decisions as complex and difficult that physicians might see as straightforward. Examples might be use of antibiotics in bacterial infection, or administration of vaccination. The physician might think it very obvious that the child has a bacterial infection that would respond to antibiotics, or, in the other instance, that vaccination will benefit the child by preventing disease. On the other hand, physicians might see some decisions as nearly impossible for families, but the families could see the same decisions as straightforward. Examples might be placement of a tracheostomy in a child with a neuromuscular disease to facilitate invasive ventilation. Physicians might see this as a very difficult decision for parents to take. However, the parents might already have decided early in the course of treatment that they wanted to continue legitimate possibilities for their child. Once the issue of tracheostomy is raised, and a request made for a specific decision the parents might well see the placement of a tracheostomy is something in keeping with that goal, and something to which they will give their consent.

Biases in medical decision-making exist in both physicians and patients and parents. Following is a review of such studies of both physicians and parents. Authors, Blumenthal-Barby and Krieger (2015), reviewed relevant papers published from 1980 to 2013 and, using rigorous criteria identified 213 studies. They included information on the type of bias, population studied, decision type, real and hypothetical studies, study methods and conclusions. Most of the studies dealt with hypothetical scenarios, nevertheless the review contains a great deal of essential information for those wanting to excel in communication. What follows will be guidance on how "decisional shortcuts" might lead to systematic errors in judgment.

Three principles of rational decision-making are:

- **dominance**, decision-makers should choose the outcome that may provide a better outcome, and is never worse than any of the other alternatives;
- **invariance,** decision-makers should consider the same information in the same way no matter how it is presented;
- **sunk cost**, decision-makers should look at future considerations, and not at previous behaviors.

Effective communication will help parents follow the first principle, of choosing the alternative with the better outcome. The second principle of "invariance" is important; reception of information is strongly affected by how it is presented. The last of these principles, the sunk cost effect may present the most difficulties. The sunk cost effect is described as the "tendency to continue an endeavor once an investment in money, effort, or time has been made". When a child has been in a pediatric intensive care unit for, say, 8 weeks, there is a natural disinclination on the part of both providers and family members to consider discontinuation of an intervention when so much has already been done in the interests of keeping the child alive. Nevertheless, the appropriateness and implications of continuing interventions, starting new interventions, or discontinuing interventions should be part of the daily discourse, and parents should be involved in that discourse. Despite the emotional difficulties, the focus should always be on the future, on what life would look like if we were to continue, modify or stop an intervention.

The sunk cost effect is magnified in the minds of both physicians and parents by the "default bias", or "status quo bias". This is the human tendency to see the many disadvantages of changing the status quo much more readily than identifying any possible advantages of any change. As Kahneman stated, "Losses loom larger than gains" (Kahneman and Tversky 1984).

Before embarking on a meeting with parents to discuss a course of action, and to obtain consent, careful consideration should be given to the order in which the relevant information should be presented. There is little doubt that "information presented at the beginning or end of a series is remembered and chosen more often than information presented in the middle of the series" (Loewenstein and Prelec 2000).

Probably trainees will think carefully about how they will open a discussion with the family, and just as probably will give little or no thought as to how they will close the discussion. While no amount of planning or forethought can possibly deal with every contingency that will arise in a discussion with families, the beginning and end of the discussion can be planned in detail.

In the discussion concerning consent, honesty matters. Given that most medical graduates have scientific training, most physicians know that absolute certainty is elusive. To quote Edwards (2003), "Offering too much apparent certainty may be to misinform." However, family members and patients are likely to have some understanding of this fact, but high levels of numeracy or of health literacy cannot be assumed in discussions with families. Nor can it be assumed that physicians necessarily have appropriate understanding. Gigerenzer and Edwards (2003) quoted a story of a group of physicians who were given information on the results of screening for colorectal cancer. The information included the prevalence of cancer, the sensitivity of the test and the false positive rate. From the information given, the correct answer as to the probability that someone who tests positive actually has cancer was 5%. The answers given by these physicians vary from 1% to 99%. In other words, physicians can make mistakes. Before sitting down with families, we should ensure we understand the statistical information before we take on the task of explaining it to families. The review by Gigerenzer and Edwards is a very useful resource to all physicians; it provides information on how to give "Simple representations of risk can help professionals and patients move from innumeracy to insight and make consultations more time efficient" (Gigerenzer and Edwards 2003).

We should present the information as accurately as possible, in ways that can be understood by the decision-maker(s). A useful resource is a paper by Paling (2003) suggests using verbal descriptions and numbers and using absolute numbers, rather than relative risks or percentage improvements. For example, instead of using instead of using 1/25 or 1/500 in describing risks, use 40 cases in 1000 and 2 cases in 1000. This format is much easier for patients and families to understand. When describing odds, he recommends using a consistent dominator, and stating the odds from both a positive and negative respect. For example, we might state that the chances of being cured of a particular condition are 97/100. Many of us would choose this way of describing the outcome of treatment of a child rather than the other way of expressing it, which is also true, that the risk of dying is 3 out of 100. Both ways of expressing information should be used in the same conversation.

When presenting information regarding a specific treatment intervention, it is very important to describe the outcome if the intervention is not used. It is important to recall both that doing nothing is a choice; and that all choices come with risks and benefits that must be assessed by the decision-maker.

When there is uncertainty about the reliability of the information, whether it is credible, or whether there is enough detail, we use the term "ambiguity aversion". This specific aversion is shared by patients, family members and physicians. Physicians attitudes about communicating and managing scientific uncertainty differ by perceived ambiguity aversion of their patients (Portnoy et al. 2011). When ambiguity is perceived by decision-makers, interventions are likely to be rejected. Hence, when the information we have to convey is ambiguous, a situation more common than we would like, care must be taken to be clear and to use everyday language. Our explanation should not be followed by: ''Did you understand?'' We should ask the decision maker to tell us what he or she seems to have heard. Only by asking this question can we be sure that we have been clear.

As noted above, uncertainty and ambiguity are ubiquitous in medical practice. None of us should present questionable information to families, and, a physician who does so is likely to be corrected quickly by a colleague. Similarly, none of us should present vague information as if it is clear-cut. Yet in our desire to be as accurate as possible, we might inadvertently convey ambiguity that is not present. In medical research, findings that exceed the statistical probability of 95% are accepted. Within the bounds of integrity and honesty, if we reach the same standard of certainty about a projected intervention in clinical practice, then we should present the information with the high degree of certainty it deserves. As Paling (2003) instructs us, "Make sure the patient's informed consent is based on information – not just data."

Consider the paper by Blumenthal-Barby and Krieger (2015) as an important resource for many more details on cognitive. These authors do not agree that biases are necessarily bad and produce less than optimal decisions. They point out that the "biases" may lead to more efficient decision-making. They make a plea for future studies based on actual decision-making in a variety of situations, rather than theoretical vignettes. They may consider ways of presenting information, such as "frequencies or percentages, benefits prior to risks or vice versa, losses or gains''. Future studies should look at different ways of presenting information in different situations, because it is likely that there is no ideal way to present information that works for all situations.

4.8 Assent

Assent is obtaining the child's agreement to an intervention. It is a method of providing the child with a voice in the decision-making process. Assent is interactive and continuous, is respectful of the child and is a foundational step in the process to transition to adult life. Assent differs from the consent given by parents, usually

seen as the decision-makers, in that assent can be ignored. But encouraging then ignoring assent are such contradictory activities that going ahead over the child's objections should be rare and done only for major reasons. Ignoring assent is a message to the child that their agreement to a course of action is not important. If the intervention is so important that it will go ahead even if the child dissents, then physicians should not engage in the pretense of asking for the child's "assent". In such a situation, the importance of why something is being done, and what might be expected should be explained to the child in developmentally appropriate language.

In dealing with assent, a developmental approach fits with what should be fundamental behaviour of pediatricians. The information given to the child will vary with age (AAP Committee on Bioethics 2016). At a minimum, assent should:

- Help the patient achieve a developmentally appropriate awareness of the nature of his or her condition;
- Tell the patient what he or she can expect to feel in the process of undergoing tests and treatments;
- Make a clinical assessment of the patient's understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy);
- Solicit an expression of the patient's willingness to accept the proposed care.

Assent is not an option that individual physicians can choose or avoid; it is an essential part of pediatric care.

"Inclusion of children in medical decision making, to the extent of their ability and interest in doing so, should be the default position, ensuring that children are routinely given a voice." (Aleksandra and Goldkind 2018).

Other authors agree on the importance of assent in stating, "We believe that engaging in an ongoing assent conversation with each patient about the physical, psychological and existential effects of their treatment is necessary" (Koshy and Sisti 2015).

As noted earlier, sometimes assent is not appropriate. In such situations, physician should give an explanation to the child because treatment will proceed whether the child agrees or not. Nevertheless, it should be clearly understood that the process of seeking the assent of a child "is not a binary distinction, but rather a fluid and continual process." (Aleksandra and Goldkind 2018). In other words, there should be continual reassessment of the situation, and a physician should ensure a positive relationship with the child, respect the child's developmental status and cognitive abilities, and have knowledge of the child's understanding of the situation and their preferences. The physician should also minimize coercion, ensure the family is included and, as appropriate, obtain outside help such as a social worker.

Despite our assertion that assent is important, it may still be a misunderstood concept among individual providers. One study demonstrated that pediatric subspecialists working at an academic tertiary care pediatric hospital had limited understanding of the concept of assent for medical treatment and were largely unaware of recommendations from the American Academy of Pediatrics related to assent. Only 35% of clinicians surveyed knew that assent included the element of obtaining the

child's agreement to a proposed treatment plan or intervention and only 26% were aware of the 1995 AAP Policy Statement on Assent (Lee et al. 2006). The conclusion of this study worries us because we believe strongly that direct communication with the child-patient and obtaining his or her agreement to a course of action wherever feasible is an ethical imperative. Strategies to involve children in decisions about their own care, and assessing when assent should be obtained, are a basic part of pediatric education.

4.9 Shared Decision Making: Legal Guardians (Usually Parents) and Physicians Deciding in Consort

The concept of shared decision-making (SDM) by patients and physicians started in adult medical practice more than 20 years ago and is being advocated for use in pediatrics. SDM has been described as activity that "aims to engage patients and clinicians in a partnership to make medical decisions that are supported by the best available evidence and aligned with patient's values, preferences, and treatment goals." (Wyatt et al. 2015). It is now suggested that SDM be used in pediatrics, but it is not clear that the differences between adult and pediatric medicine have been carefully considered. Specifically, pediatric medicine is, as noted, a triadic relationship, child, parent and physician, whereas adult medicine is a dyadic relationship. How do we incorporate the child's values and preferences along with the parents' when we make decisions? Also, it is not clear how shared decision-making differs from family centered care, and it is likely that there are many elements in common between the two.

SDM does not differ significantly from the process of seeking consent for medical treatment of a child already discussed in this chapter. One description of informed consent is "a conversation between physician and patient about a proposed treatment, alternative treatments, nontreatment, and the risks and benefits of each of these options. Informed consent does not happen when a form is signed; it occurs when patient and physician discuss a problem and choose an intervention together, a process that may take place in one sitting or over the course of several encounters" (Whitney et al. 2004). SDM occurs when there is a full exchange of ideas between physicians and patients, and full collaboration in that the decision. There can be SDM only when real choice exists.

Another concern about SDM and pediatrics is whether SDM enhances the child's ability to participate. One study concludes that the benefits of SDM accrue mainly to decision-makers, and not to the child (Birchley 2014). Having said that, in many of the situations described by Birchley, the child was in the pediatric intensive care unit, usually very young, and even if not young, unconscious. While the SDM may not have achieved its aim that everyone's values be included in the discussions, if it allows decision-makers to be more comfortable with the decision made, then there might be some benefit in the process.

Wyatt et al. (2015) cited above is trenchant in his comments: "The research enterprise to promote SDM has left children behind". He concludes, "SDM interventions improve parent knowledge and decisional conflict. Further studies are needed to advance the science and practice of SDM in pediatrics." Yet other authors are more enthusiastic and see great promise in SDM (Bauchner 2001). However, even those who are enthusiastic concede that SDM is more applicable in ambulatory care, and management of chronic disease where there is frequent uncertainty rather than when a specific individual decision needs to be made. A plan is made for adults, and if adapted for pediatric practice would read:

- Develop a partnership with the patient and parents
- Review the patient and parent's preference for information
- Review the patient and parent's preference for role in decision making
- Ascertain and respond to patient and parent's ideas, concerns, and expectations
- Identify choices and evaluate evidence from research
- Present evidence
- Make or negotiate a decision
- Agree on an action plan.

You may see these as existing principles underlying good pediatric practice!

4.10 When Consent Is Not Needed: Emergencies

Jennifer presents to the emergency department at the age of nine days. She was a second child of unrelated parents; the first child is three years old and is healthy. The pregnancy with Jennifer went well, delivery was normal and uneventful in a local hospital, and mother and baby went home after 24 hours. Jennifer passed meconium and seemed to breast-feed well on a few occasions in the hospital. After she was at home there were no more bowel movements, she was progressively disinterested in feeding, and her abdomen became distended. The parents were orthodox Jehovah's Witnesses who adhere to the dictates of an organization that forbids blood transfusion and requires shunning of those who agree to blood transfusion. The parents were concerned that if they took Jennifer to hospital, then she might receive a blood transfusion. The parents eventually decided to take Jennifer to hospital because they were concerned that she might die. Intravenous fluids were started, a surgeon and anesthesiologist saw her, a presumptive diagnosis of bowel obstruction made, probably with peritonitis, and she was taken immediately to the operating room. In the operating room, the diagnosis was confirmed, but her blood pressure started to fall. The parents had had a conversation about transfusion and use of blood products with the parents before surgery; the physicians promised not to use blood products unless the situation was life-threatening. When the blood-pressure started to fall, albumin was indicated. The anesthesiologist was unwilling to administer this without consent. She called the emergency contact for child welfare, who contacted a judge, who give permission by phone for the albumin to be given. Sadly, despite the combined efforts of the anesthesiologist and surgeon, the child died in the operating room.

The parents made several unfortunate choices, especially in delaying seeking medical attention. Their anxiety arose because the parents feared that an interven-

tion to which they objected might be used (administration of blood products). Even if the intervention is contrary to the parent's religious beliefs, it is obviously not contrary to the infant's religious beliefs because she had not had an opportunity to develop any such beliefs. The duty of the parents as surrogate decisions makers is to make decisions in the child's best interests. The medical team had a number of choices and focused on intervening quickly as the best chance of saving the child's life. Perhaps the team might have approached child welfare before surgery so that they would feel more comfortable in using best of medical interventions as they attempted to save the child's life, without interference by the parents. Generally, legal authorities support initiating lifesaving treatments in children even if parents do not give consent. By starting surgery with the partial consent of the parents (they indicated opposition to the use of blood products), the medical team created a problem for themselves. Once the child clearly needed blood products, given how close the child was to death, the medical team should have transfused the child without waiting for legal processes. The issue here is not that the parents might have certain religious beliefs. The issue here is that the child is near death and there is a moral duty on the part of the medical team, and also on all citizens, to do everything they can to save the child's life.

This might seem an extreme example, and it is. Nevertheless, in an emergency we are expected to act. Requesting legal authority to give a blood product to a child who is moribund is not, in our view, any different than seeing someone choking on food and asking for permission to do the Heimlich maneuver! There are many medical situations when urgent action is required to save life or limb; action is required, formal permission is not. However, this statement does not mean that physicians may always proceed without consent. Action without permission must be taken only in a genuine emergency, but not if there is time for full discussion with the family, including the child, if possible.

The fact that physicians must act in an emergency situation without waiting for permission has been codified by The American Academy of Pediatrics (Committee on Pediatric Emergency Medicine and Committee on Bioethics 2011) which describes the emergency/doctrine of implied consent as follows:

> "[the] rule is based on the assumption that reasonable persons would consent to emergency care if able to do so and that if the legal guardian knew the severity of the emergency, he or she would consent to medical treatment for the child. Under the emergency exception rule, a medical professional may presume consent and proceed with appropriate treatment and transport if the following four conditions are met:

1. The child is suffering from an emergent condition that places his or her life or health in danger.
2. The child's legal guardian is unavailable or unable to provide consent for treatment or transport.
3. Treatment or transport cannot be safely delayed until consent can be obtained.
4. The professional administers only treatment for emergent conditions that pose an immediate threat to the child."

4.11 What Do I Do When a Minor Comes Without a Parent to the Emergency Department

Raymond is a 12-year-old boy. He visited his grandparents on their farm, a 2-hour drive from his parents' home in a nearby city. While helping his grandfather repair a fence, Raymond cut his arm. His parents are at a resort two hours flying distance from their home city. Raymond is in pain and is bleeding. His grandparents wrap his arm with plasters from an emergency medical kit. Before leaving for the emergency department in a small town nearby, they call Raymond's parents who do not answer. They leave a message. At the emergency department, the grandparents give Raymond's details to the clerk. (At this stage, depending on the country, the jurisdiction, and the variations and legislations, there will be discussions on payment for healthcare services. While we recognize the importance of these discussions, we will leave them to one side and focus for the moment on his treatment.) The triage nurse assesses the wound and concluded that it is urgent, so a physician sees Raymond in a few minutes. The physician decides that the wound requires suturing and is concerned about damage to deeper structures. He decides that this repair should be done in an operating room. He identifies a need for consent from the parents, and using the same phone numbers the grandparents gave, made an attempt to contact the parents. He was able only to leave a message.

This case is obviously different from the one the surgeons faced with Jennifer. It does have features in common: there might be a need for urgent surgery. What is different is that the parents are absent. We don't know their views, and therefore we don't know if they object to any surgical intervention. On the other hand, it is more than likely that they would want their son to have the best treatment, and to have it done in the timeliest fashion. Having made the assessment that the repairs should be conducted under general anesthesia, the next assessment is that of urgency. Is this repair required in the next few minutes, the next hour, or can it wait? Some guidance is given in another American statement (Fanaroff 2017).

Even though the initial examinations by the triage nurse and the emergency department physician were done without formal consent, they were well justified. They both had a duty to determine that treatment was required, and how urgent it might be. Absent a written authorization from the parents allowing the grandparents to give permission for surgical procedures, the treating team is in a quandary. The attempt to contact the parents is obviously the first step, but having failed to succeed in a reasonable time, the medical team has further decisions to make. Should they accept authorization from the grandparents, or they should seek authorization from child protection services? Also, should they administer a tetanus vaccination, as per standard of practice, without knowing the parent's attitude to immunization?

In the case of Raymond, consent must be sought from the parent or parents because we are assuming that they are the legal guardian of the child. If, however, one or both grandparents have been declared the guardian (for example, by court order or agreement), then he or she may consent to treatment. If the legal guardian is not on the scene and cannot be contacted, then we suggest seeking urgent legal help (hospital counsel or if physician has medical malpractice insurance, counsel

with that company). But if that legal help is not immediately available, then such advisors to the physician must involve child protection services to receive consent to treat Raymond.

There are other situations regarding consent to treatment of a child when consent is sought from someone other than the parents acting as guardian. Such situations arise when someone other than parents bring a minor to see a physician and when a physician might want to see a minor without the parents.

A child might have a minor illness or injury while at home under the care of a nanny, a child minder or a relative such as a grandparent. The temporary caregiver might, without giving the subject much thought, bring the child for medical attention. Whoever then sees the child for medical assessment has no real authority to proceed. Attempts should be made to contact the parent, and a brief medical assessment should be conducted to determine urgency. Urgent care should never be delayed before formal permission is sought. Care that is not strictly urgent should not be labeled "urgent" to avoid administrative issues. Contact with a parent or guardian should be made, and for treatment of a child's minor illness or injury parental permission given by phone would be satisfactory in most jurisdictions.

The situation is slightly different when a minor aged somewhere between 12 and 16 years comes with a parent to see a physician. Time alone with the physician is a step towards the independence that may not be achieved for a few years. Nevertheless, it is important for adolescents to be seen by the physician without the parent, and part of standard pediatric practice. The complex relationship between physicians, parents, adolescents and society, and whether another adult should be in the room, will be dealt with in much more detail in the chapter devoted to adolescents.

4.12 The Practicalities of Seeking Consent: Case Examples

Here we follow trainees through several different rotations in their pediatric training. We will review situations occurring before the delivery of a child, within the NICU and PICU, including inter-unit and inter-hospital transfers, experiences in ambulatory care, oncology and hematology in discussions with adolescents. The ethical issues arising in other issues in adolescents, such as reproductive issues, will be dealt with in the Chap. 14 "Adolescence". The discussion in that chapter will include approaches to consent in developmentally challenged teenagers.

Pregnant Woman's Case, Part One: Preterm Labor

Dr. Singh is on her Neonatal Intensive Care Unit (NICU) rotation. She has been notified that a woman is in preterm labor, with the obstetrician estimating gestational age at 23 weeks. Dr. Singh is asked to meet with the laboring woman to provide information on possible immediate and long-term outcomes with preterm delivery. She is also tasked with having a discussion surrounding resuscitation care; whether the pregnant woman wishes full resuscitative care at birth or whether she would alter goals of care depending on her infant's status at birth. Dr. Singh has previously been present with a staff neonatologist in a similar situation, though the infant was slightly more premature at 22 weeks gestation. She had also attended a teaching session where local and national data on the outcomes for

preterm delivery were presented, as was a review of the relevant literature. Furthermore, she had also attended a session on ethics, when the discussion focused on the rights of the parent to make all decisions about a child soon to be born, and how the child once born might have her/his own rights. What are the ethical factors in this situation? How should Dr. Singh approach this mother and what should the focus of the conversation be? Is Dr. Singh too junior for this conversation? If so, how does she gain experience?

We use conventional terminology. Twenty-three weeks means the period from 23 weeks and 0 days from the start of the last menstrual period to 23 weeks and 6 days. Extreme prematurity means those born at 22 weeks and zero days to 25 weeks and 6 days from the start of the last menstrual period. Precision is required as the prognosis varies considerably by each week of completed pregnancy, affected by other factors such as sex, week of birth, whether singleton or not, and whether given antenatal steroids (Lemyre et al. 2017). We will also assume that Dr. Singh is working in a referral centre that is able to offer Level I care to the infant. If not, the issue of immediate transfer to such a unit, or transfer after birth needs to be included in the discussion.

The first thing to be said is that this discussion involves high level communication and counselling skills in a highly emotionally charged atmosphere, and even staff neonatologists and obstetricians should have additional training (Boss et al. 2013). So, the trainee is now in the position, not an unusual one, when she must indicate to the staff physician that she is uncomfortable in leading this interview. Undoubtedly, she will be uncomfortable telling the staff physician that she is uncomfortable! Nevertheless, she should look upon this as an educational opportunity, both in how to discuss what is and is not appropriate for a learner to do, and how she can advance her learning. She should request the staff physician to lead the consultation, and she (Dr. Singh) would like to attend to observe the discussion, with the permission of the expectant mother. As noted in the Canadian statement, "Clinical learners may benefit from observing these prenatal counseling sessions" (Lemyre et al. 2017). This is not the end of it, and Dr. Singh should discuss education in this topic with the staff physician, her fellow trainees, and the program director. Use of simulation may be very helpful in such training.

Once the discussion begins, and we hope led by a well-trained staff pediatrician, many different ideas need to be conveyed simply and clearly. Earlier in this chapter we outlined the undoubted truth that consent is a process, not a moment in time. It could not be truer in this situation. Pregnancy is a time of hope, of looking forward to a joyous event. That is the reality of the pregnant woman, and a state of mind that must be constantly in the forefront of those counselling her. One additional reality is that in most jurisdictions, but not all, the fetus is not regarded as a person in the sense that the fetus does not have rights and responsibilities, of an infant once delivered. However, it is reasonable to assume at this stage in the pregnancy, there is an intention on the part of the pregnant woman that she will deliver a child whom she was planning to care for. Hence the focus of the discussion will be the life, including quality of life, and survival of the fetus once delivered. This focus at this moment is not in any way contradictory to the notion that pregnant woman who do not wish to deliver a child should, in very different circumstances, have the option of termination.

The overarching goal of the physician participating in the discussion is to be:

- Aware of the family's understanding of the situation;
- Aware of the family's beliefs about pregnancy delivery and childcare;
- Aware of the family's understanding of the benefits and limits of neonatal intensive care;
- Deliver information on the likely outcomes in different scenarios, in ways the family can understand.

This list quite deliberately places the family's understanding and priorities before medical/scientific information is conveyed. Frequently, physicians placed in this situation say their role solely as one of informing the family of risks and benefits so that the family can make a decision in the interests of the yet-to-be-born child. Of course, the discussion is this, but given the many uncertainties and disagreements in the scientific and ethics literature about interventions in preterm infants, any decision must be specific to the family with which we are dealing. We cannot deliver information in a "boilerplate" manner. In those infants classified as "extremely premature", one extreme of the medical/scientific/ethics opinion would be that survival without handicap is unlikely, and hence any decision should be the parents alone. The parents therefore have a specific need for information about likely outcomes. Another extreme view of the "extremely premature" infant, is that once delivered, this child now has all the rights of any other child and should be offered interventions even if the parent objects. We do not hold either of these positions but do believe the parents input and decisions are extremely important, given that they will spend the life with the child, if he or she survives with handicap, and will live for life with grief if he or she dies.

One specific case that raised grave concerns with pediatricians, and indeed with parents, occurred in Texas (Paris et al. 2005). A woman presented in preterm labor, at an estimated gestation of 23 weeks, and an estimated birth weight of 690 g. Attempts were made to delay the labor but were discontinued when the mother developed a life-threatening infection. At that stage, delivery was induced, and there were discussions with the pregnant woman, a neonatologist, and an obstetrician and gynecologist. It was thought that the child was unlikely to survive, and if the child did survive a high likelihood of severe impairment. The woman, obstetrician and neonatologist agreed not to resuscitate the infant when it was born. Then notification was sent to the neonatal unit that a neonatologist should not attend this delivery. An administrator became aware of this instruction and asked that a neonatologist attended the birth. The woman eventually delivered a baby at 23 weeks and 1 day, actual birth weight 615 g. The neonatal fellow who attended decided to resuscitate. The case came to light when the mother sued the hospital, the child then being aged 7 years. The child was described as someone who "could not walk, talk, feed herself, or sit up on her own. [She] was legally blind, suffered from mental retardation, cerebral palsy, seizures, and spastic quadriparesis in her limbs. She could not be toilet-trained and required a shunt in her brain to drain fluids that accumulate there and needed care twenty-four hours a day. The evidence further demonstrated that her circumstances will not change." A jury found in favor of the parents, but the

Texas Supreme Court overturned this decision, to the great consternation of all commentators, including Paris et al. (2005) cited above.

This decision overturned conventional practice, that when the medical prognosis is very uncertain, as it is in preterm infants, genuine parental decision-making will be supported unless it varies considerably from the medical advice they have been given. The court rejected advice that the American Academy of Pediatrics and the (British) Royal College of Paediatricians and Child Health supported; they recommended "counseling parents on the survival and outcome prospects of strikingly premature deliveries and involving them in decisions for their infants" (Paris et al. 2005).

This case allows some rethinking of how we should approach the situation, and Paris et al. have suggested a framework for decision-making, and when we overrule parents. They group situations into four classes:

- **Mandatory**, in this situation parents ask to withdraw or withhold support that will almost certainly benefit the child. An example might be a child requiring what the professionals see as temporary assisted ventilation with an eventual good prognosis, and parents demanding a guarantee that the child will be "normal". Here treatment should continue.
- **Optional**, when the risks are high and the benefits uncertain or low. Here the parent's decision to accept or reject ventilator support should be followed.
- **Investigational,** you want to try a new intervention in a child with a very poor prognosis. Formal parental permission is required, akin to that required in a research proposal
- **Unreasonable,** when parents want full support for an extremely severe preterm infant, say 20 weeks gestation, with in addition, a severe congenital anomaly. Here the parents should be overruled (Paris et al. 2005).

The information in the medical literature about extreme prematurity does not seem encouraging, with a low likelihood of survival, and of those who survive a very high likelihood of moderate or severe handicap. Having said that, those parents whose preterm child has survived with major handicap, continue to support aggressive resuscitation for other infants. Despite continued health problems, and continued frequent contact with the healthcare system, most parents are satisfied with the family's quality of life (Cummings and Committee on Fetus and Newborn 2015). Much of the information on survival and quality of life is institutional specific, and whoever is leading the discussion must be aware of the outcomes locally. This discussion should also be honest, if the outcomes at their institution are significantly worse than the regional or national norm.

Even factoring in as many relevant pieces of data as possible, there will remain a major degree of prognostic uncertainty. The discussion, on the side of the healthcare practitioner, will focus on two broad options, early NICU care, and palliative care from the moment of delivery. These broad choices contained within them many details and may demand change depending on the infant's progress. If NICU is chosen, then it should be clear to the family that this as an intervention that should be continually reassessed. It is possible that the infant's progress is so poor the

recommendation will be made to discontinue this intervention. If palliative care is chosen, then the details need to be discussed with the family, and whatever plan is developed it needs to include a response to an infant that is born apparently vigorous, though extremely preterm.

David's Case, Part Two: Born Alive but Premature

The neonate was born alive, resuscitated and initially treated with Continuous Positive Airway Pressure (CPAP) by facemask. At four hours of age, he was intubated and placed on assisted ventilation. Three weeks later, the infant is still dependent on invasive ventilatory support. Since then, he has been found to have three intra-ventricular bleeds on ultrasound, and an MRI revealed cystic white matter abnormalities. The mother has conveyed her anxiety about her child David and wants to know what else needs to be done to enable him to breathe on his own and to recover fully. The bedside nurse is concerned that the mother does not fully understand the true nature of David's prognosis with a likelihood of long-term survival with poor neurological function or death despite all treatment. The nurse opens discussion with the mother regarding her expectations for David. The conversation becomes heated just as Dr. Singh comes by. Should Dr. Singh join this conversation? How far should she go, given that the conversation that started with the nurse, however inadvertent, and that it might end with a formal discussion with the attending staff about withdrawing assisted ventilation?

Dr. Singh has a number of choices here, some of which are ethically sound, and some are ethically questionable. One of the ethically questionable choices is simply to walk on. Another ethically questionable choice is to intervene in the conversation and enter into a discussion with the mother on the substance of continuing intensive care for David. Our preferred ethical choice is for Dr. Singh to sit with the nurse and the mother and ask for more information about the disagreement. We hope that Dr. Singh will finish up with some understanding of the mother's understanding of the meaning of the clinical findings in terms of survival and likelihood of severe handicap, and her position about continuing with assisted ventilation. What Dr. Singh is likely to hear is a mixture of information gathered from direct conversation with the NICU staff, overhearing conversations with the NICU staff, information on social media, information from her family and friends and the mother's own underlying beliefs about life, death and the nature of motherhood. The mother will likely be in an emotional turmoil. Dr. Singh, like many physicians, will not truly understand the value of listening. Dr. Singh should listen to the mother, with minimum interventions. She should answer direct factual questions, but not volunteer information without being asked. Dr. Singh should also offer to arrange a formal meeting with attending staff to discuss developing plans for David. Dr. Singh should encourage the mother to focus her thoughts on David's best interests.

David's Case, Part Three: "Do Everything"

A meeting takes place with the attending staff. After listening to the staff, David's mother insists on continuing assisted ventilation and full life-prolonging support. Dr. Singh is uncomfortable with the mother's decision and seeks out a faculty mentor to discuss her concerns.

The discomfort that Dr. Singh has with the mother's decision is not unusual, and is generally based on some combination of concern that the child will experience pain and discomfort because of the interventions, concern for the child's "dignity", concern for the mother who may have unrealistic expectations, concern felt by her-

self and all the staff of all disciplines every time new complication occurs, an additional intervention is required, and concern that the child will die in any case, perhaps relating to recognition of the expensive nature of NICU care.

To deal first with a concern not raised in the previous paragraph, that is, is it breaching confidentiality for Dr. Singh to seek out a mentor? We see this as a very "technical", breach of specific confidentiality, but the mentor will need some context to offer help to Dr. Singh, and we think that this breach is appropriate. Ultimately, it can be argued that it is in the interest of David, because a discussion between a more experienced physician and Dr. Singh might lead to improved care for David. Dr. Singh and the mentors should confine themselves to Dr. Singh's feelings, how she is coping with them, and steps that she can take. Neither of them should deal specifically with changes that could be made in David's care. This discussion would be going too far in terms of confidentiality and overreaching the norm regarding patient management. We would also support Dr. Singh in seeking help in other ways, such as peer supporters mentioned earlier in this chapter, or formally via a professional organization.

To return to the specific concerns, and to deal with the last one first, the concern that scarce resources are being "wasted. We do not believe for one minute that Dr. Singh would either think about or state the problem with such crude and direct language, but indeed that is the meaning. Resource allocation will be dealt with in a separate chapter, but typically it is not something that should factor into an immediate clinical decision by the bedside. Resource allocation decisions are better dealt with at different levels, perhaps by developing institutional policies. Indeed, if the concern is raised with the mother, by health authorities, or by insurance companies that there is concern about the expenditure, then the first response might be to develop a "Go Fund Me Page"!

Concern about the child's comfort and pain is important, and it should be noted that little attention was paid to the pain of children in general, and specifically preterm infants, until the last decade (Franck et al. 2004). This is something parents worry about and clinicians have problems assessing. There are a number of assessment tools, using some combination of behavioural observations such as facial grimacing, limb movement, and physiological measurements such as heart rate, blood pressure and oxygen saturation, but it is not clear how accurate any of them are. In a formal assessment of a tool to measure the severity of pain in combination with a measure of brain activity, it was found that a positive brain response to discomfort could occur in the absence of any change in facial expression. (Slater et al. 2008). Despite the foregoing statement, we strongly support continued efforts to assess and minimize pain and discomfort in any child receiving intensive care, or indeed a child in discomfort in any medical situation.

The concept of "dignity "is commonly discussed in clinical settings, but we have not identified a satisfactory definition of what "dignity" means. The protection of human dignity forms the basis of many international human rights treaties even though the term is not defined and seems to elude categorical definition for legal purposes (Henteleff et al. 2011). Nevertheless, "dignity" means being worthy of honour or respect. Humans are each worthy of honour or respect no matter their age or capacity. This is a fundamental principle of liberal democracy.

We regard Dr. Singh's anxiety about dignity, even if she cannot define it, as evidence that she sees David as a complete human, worthy of respect and concern. Dr. Singh should arrange for further meetings between the attending neonatologist, the nursing staff and some support person such as a social worker to provide a mother with information on her current status.

David's Case: Part Four: Deciding on Tracheostomy

At term, David is still dependent on assisted mechanical ventilation. Dr Powell is the current attending neonatologist and initiates discussion with the mother about placing a tracheostomy tube to improve David's comfort. During a discussion with an ENT surgeon, David's mother has many questions. Following that meeting, the mother still has questions. The resident in the NICU is now Dr. Joshua Martinez; he is aware that his fellow residents have had a number of discussions with the mother. What is Dr Martinez' role? Should he simply indicate that he is inexperienced, and will expect someone else to continue the discussion, or should he at least try to identify the mother's concerns? If he does listen to the concerns, then how will he respond, and does he have any role in the discussion about seeking informed consent from David's mother?

Wait! We seem to have missed a step here. Placing a tracheostomy is an invasive procedure, and, correctly, the ENT surgeon seeks formal written consent. The fact that a parent consents to tracheostomy does not mean it is in the child's best interest. Placing a tracheostomy has many more implications beyond the immediate surgery. It is generally undertaken when there is consensus among the medical staff, the nursing staff and allied health, that this is medical treatment that will be beneficial to the child and for which they seek parental permission. As with the earlier discussion on the various approaches to extreme prematurity, there is no doubt that some clinicians will say that, even if the medical consensus is that the tracheostomy is not appropriate, they must offer tracheostomy and the parents should be left to decide whether or not to proceed. This attitude presupposes that, at parental request, procedures might be done on children even if professionals are unanimous that the procedure is not indicated.

It is important to examine this situation. We have shifted here from the language of asking parental permission for beneficial pediatric medical treatment to 'offering tracheostomy' to the parents. The shift in language raises the issue as to whose interests this "offering" serves. If an 'offering' to the parent harms the child by being invasive medical treatment without benefit to the child, then why is the pediatrician even making the proposal? Is the pediatrician attempting to help the parents feel better or less bad about the serious and life-ending nature of the child's illness or condition? Is the pediatrician trying to avoid a difficult conversation? Such uncomfortable questions must be asked when a pediatrician proposes medical treatment that is not beneficial to the child because a pediatrician's duty is to place first the needs of the child, despite understandable compassion for parents and for herself.

The pediatrician's ethical imperative is to make the child's interest central. We agree with those clinicians who think that tracheostomy has such profound long-term implications that the request for consent should be preceded by discussions within the treatment team, perhaps including such people as a unit social worker, and ethicist in the hospital ethics committee, before proceeding further. This is a

serious decision, the results of which are complex and far reaching. The whole decision-making approach to consider is discussed in Chap. 8 "Children with Medical Complexity".

Dr. Martinez should explain his position, as someone in training, albeit the training in neonatology as a subspecialty has been preceded by years of training in medicine generally, and in pediatrics specifically. He needs to discuss with the staff physicians the need for continuity, as the neonatologist who came before Dr. Powell were not supportive of tracheostomy. If there are unit meetings to discuss the future care of the child, he should speak up and not be inhibited because he is a junior member of the team.

David's Case: Part Five: Leaving Familiar Territory

The parents have decided to consent to the placement by physicians of a tracheostomy tube, a decision supported by the attending neonatologist and ENT surgeon, but with lukewarm or no support from other staff members because they believe that this measure merely delays David's death and prolongs his suffering. As per local policy, David will be transferred from the NICU to the surgical PICU prior to surgery. Despite some disagreements with the staff, and occasional mishaps in treatment, the mother has grown close to several staff members and expresses concern about the quality of care, David will have in the new PICU environment. The staff physician has discussed transfer with the mother. She goes to Dr. Martinez, with her concerns. How should he now proceed?

Dr. Martinez is now in the situation of discussing with a parent the inevitable consequences of a decision with which he is not in full agreement. Indeed, he is aware that there is strong feeling in the unit about this decision. His feelings are those of moral distress, something first described in nurses, but also present in other medical staff. This emotion occurs when an "individual knows what is ethically appropriate but is unable to carry out that action or carries out what is believed to be the wrong due to an institutional constraint" (Jameton 1984). Moral distress has unfortunate effects on the residents and on patient care. It is not burn out or compassion fatigue, described earlier, but has many features in common with them, and may lead to these feelings.

Moral distress is a human experience, and many of the steps suggested earlier regarding burnout and compassion fatigue are also appropriate with moral distress. Absent formal programs that provide support and foster resilience, talking with colleagues or senior staff members will be helpful. In this NICU, something that will be helpful to all staff are regular rounds to discuss patient management. These rounds can be a potent force in improving communication and care, but only if staff members of many disciplines and many levels of seniority are able to speak freely.

Meaghan's Case

Dr Evelyn Goudreau is a resident on rotation in Pediatric Oncology. Meaghan is aged 11 years and has acute lymphatic leukemia. She has had all the usual diagnostic procedures, and standard chemotherapy has been initiated following consent from her parents. Meaghan is now in her third week of chemotherapy and has extreme nausea. She wants to stop the treatment and says that she doesn't care what her parents think. The nurse passes this conversation on to Dr. Goudreau. Should Dr. Goudreau accept this refusal of treatment from Meaghan? If so, then why? Although Meaghan is a minor, may Dr. Goudreau refuse to accept Meaghan's point of view and if so, then is such refusal disrespectful to Meaghan?

Dr. Goudreau's first step is to spend time with Meaghan to get to know all her concerns. Dr. Goudreau also must ensure all reasonable steps have been taken to find ways to control the vomiting. Such steps will likely involve conversations with pediatric specialists such as gastroenterologists and with a pharmacist. Respect for Meaghan will involve acknowledging and validating her concerns without necessarily agreeing with her actions.

While we hope Meaghan has been kept informed about her illness and its treatment, this may not always happen. Some professionals assume that if a minor does not have the ability to consent or refuse, they do not need to aim for the child's full participation, by always explaining what is happening, and why. Her parents may also have been protective and therefore limited Meaghan's knowledge. If this is the case, then skillful counseling by a social worker can help the parents understand why Meaghan must know as much as possible. So, Meaghan needs to know, in ways appropriate for an 11-year-old, that her therapy is likely to be successful and that without treatment she will die. The social worker can provide support and help the parents find ways to explain things to Meaghan.

Time spent in discussing Meaghan's diagnosis, prognosis and treatment with the parents is time well spent. These talks should include medical, nursing and social work staff. However, there is some urgency in ensuring that treatment continues, but usually these situations can be resolved. Developing and maintaining good relationships is essential.

When the parents, despite full explanation, decide to allow Meaghan to discontinue therapy, we must act. Such as situation arose in 2014 when we responded: "Paediatricians will go to great lengths to work with families and to achieve consensus before accessing child protection services. When a child, Indigenous or non-Indigenous, is in a life-threatening situation and all attempts to implement cooperative and effective treatment have failed, a paediatrician's primary duty is to the health and welfare of the child; paediatricians have a legal and ethical duty to report their concerns to the local child protection authority. This vital responsibility should not be taken lightly, and a paediatrician should strive to give every child the best chance at good health and a long life." (Mitchell et al. 2015). The reference to "indigenous" refers to a specific situation in Canada, involving two girls, aged 11 who were Indigenous and had leukemia. In both cases, child protection was involved but initially refused to act, and the court agreed with child protection's decision. The end result was that one of the children died off therapy after an initial positive response to treatment. This case will be discussed further in Chap. 7 "Child Abuse and Neglect". The important point is that not giving lifesaving treatment is neglect. In Sect. 4.5.1, "Seeking Consent to Treatment or Treatment Withdrawal When Parents and Physicians Absolutely Disagree", we discuss the practical application of "best interests" and the "harm principle" in deciding when to involve child protection services. We accept that calling child protection when a family disagrees with our recommendation is an unpleasant step in the minds of pediatricians (and reality). We hope our readers accept there are occasions when it is their duty to do so.

As an aside, even although the cases cited in our article were about the death of one child, and the suffering of another, the necessity of child protection was opposed

by many. In a local newspaper, we commented about the need to ensure that the children were treated, something opposed in some online comments (Guichon et al. 2014).

Courtney's Case: 11-year-old Needs Blood Transfusion

Dr Joshua Burke is a second-year pediatric resident, in his rotation in hematology. Courtney is an 11-year-old girl who presented with pallor and is noted to be anemic. Her hemoglobin is 4 g/dl. The emergency department doctor recommends that she have a blood transfusion while investigations continue to identify the underlying cause of her anemia. Her parents tell Dr. Burke that they are among those Jehovah's Witnesses who adhere to a blood ban. They refuse permission for the transfusion. Dr. Burke wants to talk to Courtney before he discusses the situation further with the staff hematologist. Is it appropriate to speak with Courtney alone, and what would be the weight of Courtney's views on the transfusion?

The short answer is that Dr. Burke should speak to Courtney and ascertain her understanding of her medical situation, and also to let **her** talk about her religious beliefs. We emphasized "her" for a reason. We are among those who believe in the freedom of religious belief. The religious freedom to be protected is that of the person for whom medical treatment is proposed. When it comes to children, some may describe the patients as "Jehovah's' Witnesses children", as in this case, or in other cases as Jewish children, Catholic children, and so on. We know many sincere and compassionate religious people who use this language. Despite our respect for their beliefs, these minors are actually citizens of a country, whose parents follow a certain set of beliefs. Dawkins, the British scientist reports a controversy about banning pork in schools and argues that it is nonsensical to talk about the "beliefs" of children (Dawkins 2015).

> "Their" beliefs? The "beliefs" of four-year-old children? Did it not occur to this spokesperson that children who are too young to realize the importance of "their" beliefs might also be too young to *possess* those same beliefs in the first place? How can the "beliefs" of a four-year-old child be "important" to her if she doesn't even know what her beliefs are?

There is no doubt that a religious upbringing as a child affects attitude to religion as an adult. The Pew Research Center (2016) in the United States says:

> Those adults who say religion was very important to their family while growing up and whose parents frequently discussed religion are more likely than others to continue to identify with their parents' religion as adults.

But these studies also show divergence.

> Indeed, the survey makes clear that many Americans – even among those raised in a single religion – ultimately adopt a religious identity that is completely different than the faith of their parents.

To return to Courtney, we are sure Dr. Burke will report the conversation to the attending physician. We are now dealing with a situation where both the minor patient and her parents oppose life-saving treatment. Agreement is possible, with explanation and discussion. In a series of cases we reported (Guichon and Mitchell 2006), we said that "In striving to find agreement on medical treatment, physicians, patients and Jehovah's Witness family members seek and, in fact, often achieve

mutual understanding and cooperation". Further attempts should be made to ensure Courtney is acting on the basis of accurate medical information. We should also explore the possibility of coercion, something that might occur by shunning, whether actual or threatened. However, if agreement is still not reached, then there is no alternative other than to seek urgent child protection intervention. We do not believe this step is interference in religious freedom; indeed "In this context, a court order authorizing medical treatment can, therefore, be seen as enhancing patient freedom." (Guichon and Mitchell 2006). It is important to remember that "sensitivity toward the issue of religious freedom can obscure the fundamental question for medical practitioners when seeking a patient's consent: 'Is the patient in a position to give or refuse consent to proposed medical treatment?' It is important to help children live so that, one day, they are sufficiently mature to decide whether they wish to adopt their parents' religious beliefs, other religious beliefs, or no religious beliefs.

4.13 The Practicalities of Seeking Consent in Suspected Case of Neglect, Abuse or Self-Harm: Case Examples

Trainees and new pediatricians tell us that the need to seek consent in cases of abuse or neglect commonly raises fears, and that they do not wish to deal with these situations. They do, of course, deal with them conscientiously, but need help and support. Some preliminary information will be offered here on initial approaches to families and children when abuse, neglect or self-harm is suspected. In addition, we will indicate when we should not involve child protection, even when parents ignore medical advice. Involvement of pediatricians with child protection services will be dealt with in much more detail later in Chap. 7 Child "Abuse and Neglect".

Dr. Ryan Suen is a pediatric resident in his third year completing a rotation in the Allergy Clinic. He sees a seven-year-old girl, Ashley, with her parents as a new referral, and identifies that Ashley almost certainly has asthma. He tells the family, "I think Ashley has asthma." He tells Ashley and her parents that standard treatment would involve inhaled corticosteroids. They express some discomfort with this proposed treatment and have heard that corticosteroids may affect Ashley's growth. Should Dr. Suen insist on Ashley actually being treated with inhaled corticosteroids? Is there any way he can require that Ashley receive this treatment?

Dr. Suen will already have spent at least 30 min, perhaps 60 reviewing Ashley's history, examining her, and explaining the results of investigations to her parents. We hope seven-year-old Ashley has been included in the discussion. Hence, there is already a relationship. It is by building on this relationship that Ashley's parents will come to understand her need for this treatment. Dr. Suen should focus on Ashley's problems, the prognosis, and how well she is likely to feel when taking effective treatment. At this stage, enquiry should be made on sources of knowledge, such as social media, relatives, friends neighbors and so on. Listen, but do not comment on peer review, relative risks and so on at this stage. Then the anxieties regarding

growth can be addressed, with a plan for monitoring. The scientific information should be presented accurately at this stage.

If Dr. Suen truly believes the diagnosis is asthma, accepting that 100% certainty in most aspects of pediatrics is elusive, why does he not say so? By using the common phrase "I think." when describing his conclusion, he may feel he is being scientifically precise. And so he is. But he is also sowing seeds of doubt in the parents' minds. Most parents will hear the straightforward statement "your child has asthma" as a springboard to action.

The parents might still be adamant about refusing to use inhaled corticosteroids. If the child has life-threatening asthma, real but uncommon, then additional help is needed, from more senior physicians and from clinic social workers, with close follow up needed with some sort of safety net. The parents must also be taught about the early signs of danger, and when to seek emergency help. We hope when Ashley and her parents are next seen, the relationship is preserved, and discussion continues on the best therapy. Child protection might need to become involved, but in this situation (unlike a child with severe anemia who needs a life-saving transfusion) such action will be rare.

In the more common situation when the asthma needs to be addressed, but the child's life is not in danger, at least not in the foreseeable future, the focus should be on preserving good relationships. Heavy handed action or overly forceful language may alienate the parents and ultimately delay their acceptance of the best treatment.

Dr Amber Gill is in a community outreach clinic and sees Daniel who is 14 years of age. Daniel presents with the complaint of anxiety but while she is taking the teen's history, Dr. Gill discovers that Daniel is using street drugs. Daniel indicates that he may be interested in being involved in treatment to reduce his substance use. Should Dr. Gill move ahead and arrange treatment? Should she identify who Daniel's parents are? Daniel discloses who his drug dealers are – should Dr Gill disclose this information to the police?

This case overlaps with the discussion of similar situations in the Chap. 14 on the adolescent. Some of the ethical issues are the degree to which the underlying commitment to confidentiality is kept, how Dr. Gill maintains trust between Daniel and herself, and whether it is possible to move ahead without parental or child welfare involvement.

Daniel's "best interest" are best served by enrolment in a program to help with the reduction in his (presumed) dependence on street drugs. It is possible, indeed likely, that his voluntary involvement is central to success. Dr. Gill has assessed that he is a mature minor and makes the referral on that basis. If Daniel agrees to enrolment, then there seems little reason to involve child welfare. Dr. Gill would need to explain to Daniel why she believes he is at such high risk of harm that she is willing to breach her confidentiality to pass information to child welfare. Almost certainly, trust would be lost.

Concerns about notifying parents are similar and different to concerns regarding notifying child welfare. They are similar in that an automatic involvement of the parents by the physician will lead to a loss of trust by the child patient and almost certainly a loss of cooperation. It is different in that parental support can be a positive force. Dr. Gill should encourage parent involvement, but not insist.

There is no legal obligation, as far as we know, regarding notifying police about drug use. Such notification cannot occur without also identifying Daniel to the police. The considerations above remain relevant; maintaining Daniel's confidentiality is an inherent and important part of the trusting relationship between him and his physicians. Daniel can report to police if he likes, but he should be aware of the risks.

4.14 Conclusion

Consent of one kind or another is required for every medical intervention. In the triadic pediatric relationship, permission for physicians to proceed is often given by parents/guardians. The basis for parents authorizing an intervention is the best interests of the child. The respect underlying the need for consent "belongs" to the child. In many circumstances, the child may consent on his or her own authority, the so-called mature minor. When there is disagreement between physicians and children/families regarding the best course of action, a decision must made on the gravity of the situation and whether the proposed intervention is life-saving. If so, then consent might need to be sought in court, via child protection authorities.

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Chapter 5
What Goes in the Chart and Who Can See It?

Key Points Concerning Confidentiality

- Confidentiality is the requirement to maintain the privacy of personal health information
- Confidentiality is a key ethical value in relationships among health care practitioners and patients
  - It is based on respect for the patient, particularly the patient's dignity
- Parents and other guardians must have access to all health care information for their child in infancy and early childhood (with some exceptions)
  - The child also must have access in an age-appropriate manner
- As the child matures, he or she must begin to control who has access to the health care information and should be able to do so (subject to local laws)
- Health care team members should have access to confidential information only on an "as needed" basis
- Breaches of confidentiality are an ever-present possibility and risk.
  - They are often inadvertent or due to misunderstanding of the ethics involved
- Some breaches may be permitted
- A few "breaches" are obligatory

5.1 Introductory Story

Kenneth was six years old and had experienced seizures since the age of nine months. The seizures were only partially controlled on his current medication regimen and he recently had a prolonged seizure at home necessitating a 911 call. His parents brought him to the emergency department; he was briefly in the pediatric intensive care unit and was now settling into an inpatient unit. The physicians caring for him were concerned that Kenneth might not be on the right anticonvulsant regimen, or that the dose might need to be altered,

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_5

or that the parents were not fully adherent to the recommendations. The physicians also wanted to request extended genetic tests, because the routine tests previously conducted did not show any specific abnormality. The parents, too, were worried about Kenneth; their worries included whether the physicians had the right diagnosis and whether further anti-convulsants as a response to this prolonged seizure might lead to drug side effects. Moreover, the parents felt some guilt that they had been late in giving Kenneth one of his regular medications and were anxious because the father had been told he might lose his job if he again stayed away from work to be with his son in hospital. The mother devoted care to Kenneth and to his older sibling Regina; income from her part-time work was insufficient for the family. Both parents were concerned that Regina, aged eight, might not be doing well at school because Regina worried a great deal about Kenneth and had trouble sleeping. The maternal grandmother was in a hospice in another city 600 km away.

This is not an unusual story and is helpful to elucidate important points in this chapter on confidentiality. We already know that many individuals have been involved in Kenneth's care in a very short time period, and most of them will not have met Kenneth before this admission. Three separate teams of individuals - physicians and the trainees, nursing staff and student nurses, technologists and students, a number of allied health individuals and clerical staff have had access to Kenneth's health records. In the course of his medical care, Kenneth and his family will have interacted with one, or several, primary care physicians, and a variety of specialists including genetic specialists. We will explain why confidentiality is important, why sharing of information is important to excellent healthcare and will focus on the duties and obligations of physicians. We stress that the physician is only one member of the healthcare team and will also mention the duties and obligations of those many other healthcare professionals who are involved with the family.

In the situation described above, the health care team will have access to Kenneth's health care information, of course; because a family history will have been taken several times since Kenneth first came to the emergency department, the team will also know private matters about people associated with Kenneth. They will know details about the health of both parents, Kenneth's sister Regina, and perhaps the grandmother. They might also be aware that Regina is having problems at school and will also know that genetic testing has been undertaken in the past, and that further testing is planned.

The principles of confidentiality apply to all the information about Kenneth. In addition, the other individuals mentioned also have their own personal need for confidentiality. Should details about the family's financial worries, Regina's school performance, or the grandmother's illness be factors, of which the whole healthcare team should be aware? If we identify genetic factors, do we have an obligation to make sure that the parents' siblings and the children are aware of the results, and are offered testing?

We must affirm to the family our commitment to confidentiality. However, we must tell them clearly that information in Kenneth's health record about all these issues will be available to many different individuals involved, even remotely and/or transiently, in Kenneth's care. In terms of specific personal information, it would be best if full information were available to only a few key individuals. This limitation

of access should not be regarded as elitism, but rather as a practical expression of respect for the patient, part of the underlying justification for confidentiality. Nevertheless, it has proven difficult, even in an era of electronic records, to protect non-health information of family members in a manner that does not disrupt the child's care.

The issue of information about genetic factors is different from most other aspects of health information, in that genetic information can be directly relevant to the health of other family members. Traditionally, the parents, or the child herself if old enough, have been entitled to keep genetic information of family relevance secret. It is not too big a stretch to say that there is a duty to pass this information on when it is relevant to health. On the other hand, the use of the word "duty" implies action on the part of someone, and in the past the actor with the duty is assumed to be only a family member. Ideas are evolving, and are not yet settled, but it is at least arguable that the healthcare professional in possession of genetic information has a duty to convey the information to other family members at risk. For the present, healthcare professionals are advised to encourage family members to convey information, and to coach them on how to transmit the information in a sensitive fashion.

5.2 Overview

It is important to recognize that, in pediatrics, the right to confidentiality concerning the child's health belongs to the child patient, though in the early years of life the parents exercise control of confidentiality. As the child matures, she has a moral right to control who has access to her health information. In the jurisdiction in which the authors work, this moral right to control access to health information is also a legal right. However, confidentiality is not an absolute right in pediatrics, or indeed in any branch of medicine. Therefore, this chapter addresses many of the nuances, and those occasions when confidential information must be passed to another person or to an external agency.

Confidentiality is so central to medicine that a commitment to maintain confidentiality is part of the medical oath which originated in ancient Greece. There, medical practice was conducted in homes or in the public square. If in the home, then the physician would see and hear many things not relevant to the consultation, and therefore should not speak about them. At the very least, if he did, then he would have been unlikely to be consulted by that household again! In terms of medical information, the male head of the household, or the guardian, was entitled to information on women, slaves and children. The head of the household was entitled also to make medical decisions about everyone in the household. Some modern codes of ethics extend the confidentiality of individual patients even after death (American Medical Association 2008). Respecting the ancient origins of their profession, when medical students graduate, they usually affirm their commitment to patients and to the profession. This affirmation is traditionally called the "Hippocratic

Oath", but it is more likely that some modern version is used (Markel 2004). The oath contains reference to confidentiality:

> What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account must be spread abroad, I will keep to myself, holding such things shameful to be spoken about. (Hippocrates)

(The male pronouns, "he" and "him", reflect the fact that the vast majority of physicians in ancient Greece were males, though not exclusively so.)

This oath might seem like a strong, perhaps absolute, commitment not to disclose the content of communication. It was correct in the times in which it was written. Today, however, there are circumstances in which the law requires that confidentiality be breached. (The fact that the oath does not accord with current standards might be another reason to jettison the Hippocratic Oath!)

Contemporary medical practice makes the protection of confidentiality more difficult than it was in Ancient Greece. Indeed, even before the age of electronic information had really begun, a physician raised concerns about maintaining medical confidentiality in a 1982 paper pointedly entitled, "Confidentiality in Medicine – A Decrepit Concept" (Siegler 1982). Seigler argued that confidentiality could no longer be protected because of the sheer number of healthcare professionals, including trainees, who are immediately involved in the care of a patient, and the large number of individuals behind the scenes who also provide services relevant to the patient's care. He counted 75 individuals involved in helping Dr. Siegler care for a particular patient. The obvious implication is that some of these individuals will disclose confidential information in public places usually without thinking through what is happening. In the story about Kenneth that begins this chapter, we can estimate that many more than 75 individuals will help care for this child.

5.3 Justification for Protection of Confidentiality

The importance of protecting patient confidentiality is evident in medical codes of ethics. For example, the Canadian Medical Association (2018) states:

> Privacy and confidentiality are cornerstones of the Canadian health care system. Together they play a key role in the physician–patient relationship by establishing trust and contributing to the integrity of the medical profession.

We protect confidentiality for two important reasons. First, we share the societal value of protecting the vulnerability and inherent dignity of the patient; by keeping the patient's health matters confidential, we respect this value. Second, we recognize and respect the unspoken agreement made by the patient and physician: the patient discloses personal and private information only because the patient needs health care; the healthcare provider receives that information understanding that the information is specially entrusted to the physician only for the benefit of the patient. For example, a patient might disclose to a doctor that he or she has pain in the genital area; from this information, the doctor might diagnose and treat a sexually transmitted disease.

In certain cultures, a young person could be at risk if the symptoms and diagnosis were known widely. So, the sharing of the disclosure of the pain creates risk for the patient. Hence the agreement the patient makes with the doctor is "I will make myself vulnerable only if you will help me." For a physician to reveal the information to someone whose goal is not to help the patient is to break the agreement and arguably to bring medical practitioners into disrepute.

In her consideration of the term "confidentiality", philosopher Sissela Bok states: "confidentiality refers to the boundaries surrounding shared secrets and to the process of guarding these boundaries" (Bok 1989). She offers straightforward justifications for confidentiality:

- Respect for the individual patient to whom the information belongs;
- Having personal secrets is quite legitimate, and avoiding repeating them, is part of a respectful relationship, especially if the relationship is intimate such as that between a healthcare professional and a patient; and
- Unless confidentiality is assured, patients might fail to request help. (Bok 1989)

Concern that private medical information about the child be shared only with the appropriate person or persons is a concern that applies to all aspects of health information. Some clinicians might regard certain parts of health information as "sensitive". Although the concept of "sensitive information" is useful, the definition of what information is sensitive regarding a particular patient should be determined by the patient and the family, not by the clinician. This idealistic control of the health record by patients and families is almost certainly impossible in the current era of teamwork and electronic health records. Perhaps a new generation of clinicians will work closely with IT specialists to give children and their families more control over which aspects of their health information will be shared.

What physicians, whether a medical student, a medical graduate in training, or a staff physician, should do regarding the protection of confidential information communicated to them is clear. The information we gather about the patients who come to us for treatment is precious information that belongs to the child; this secret information must be kept confidential. What follows in the rest of the chapter is a description of the many nuances involved. None of the nuances in any way contradict **the basic principle that abiding by the pledge of confidentiality is both the basis of a strong relationship between physicians and patients, and a necessary condition for professional behavior.** Patient confidentiality matters and, almost always, must be protected.

5.4 Inadvertent Breaches

An "inadvertent breach" of confidential information occurs when those breaching the confidentiality overlook the fact that others, who have no right to the information, are within earshot of a conversation among healthcare professionals. Such breaches of confidential information can take place anywhere; hospital elevators are

perhaps the most common places for wrongful disclosures of patient information. In a study in Toronto Canada, medical students observed and overheard conversations in elevators when healthcare professionals and members of the public were both present (Vigod et al. 2003). The students noted breaches of confidentiality in 10% of the conversations that began with an inquiry about a patient's health. Moreover, the initial question often gave rise to a longer conversation with more breaches of confidentiality. It was rare for any other individuals, whether healthcare professionals or members of the public, in the elevator to comment on the breach or to try to stop it, with the exception of the occasional medical student. (We might speculate that the medical students spoke up to protect patient confidentiality because they are midway between being members of the public and fully-fledged physicians; their sensitivity to many topics becomes blunted with greater exposure to medical practice). To return to the elevator study results, sometimes the hospital personnel tried to disguise the patient's name with initials or referred only to the diagnosis, at other times the patient's name was openly declared. Using a diagnosis to describe a patient both depersonalizes the patient and fails to protect the patient's confidentiality. When the diagnosis is rare, the patient is much more likely to be known. Even in the largest pediatric facilities, there will usually be only one or two patients with a specific rare disorder, making the individual patient easily identifiable to other healthcare providers and family members. Moreover, healthcare professionals can be particularly curious about those who have rare disorders; this curiosity can lead to inadvertent breaches of confidentiality. Although conversations about patients in elevators are notorious, they can take place also in the corridor, in the cafeteria, on the stairs or in a locker room.

In 2018, it is much more difficult to preserve confidentiality than in the past. We live in a more open and less hierarchical society with characteristics that lead to confidentiality breaches: electronic health records and large databases, electronic communication and social media, genetics and family members interested in the DNA of their kin, more complex medical care and more individual providers, and team care of a patient. There is no doubt that patient confidentiality is becoming more complicated. Some of this complexity reflects the fact that almost every jurisdiction has laws regulating maintenance of privacy of health information.

5.5 Carelessness

Carelessness in handling information is common, particularly when a healthcare professional has a conversation by telephone and parts of the conversation can be overheard. Other instances of carelessness arise when healthcare providers leave computers unguarded and folders open, and improperly destroy health records such as by discarding hardcopy documents in an open garbage can. Documents might be sent to those who are not entitled to receive them; this is an example of poor administrative practice, poor or inadequate infrastructure and the absence of policies on the best way to handle information. (Rarely breaches of confidentiality are deliberate and malicious; such intentional breaches are so clearly wrong that we will not deal with them in detail.)

Breaches of confidentiality due to carelessness might occur when insufficient thought is given to administrative issues. For example, if a teen is seen in a family planning clinic, assured of confidentiality, and notice of the next appointment is sent to her home with the return address of the clinic on the front, then the teen has lost confidentiality. Something as trivial as the selection of an envelope with an address window big enough for the sender's name to be visible can also be a source of breach of confidentiality.

5.6 Protecting Confidentiality

Clearly it is important to avoid breaching the patient's confidentiality. But pediatrics presents at least two particular challenges to protecting confidentiality appropriately. First, it can be difficult to identify who may access information because to do so entails assessing the age and maturity of the patient – a difficult task. Second, one must keep confidential the aspects of the child's healthcare chart that concern **others** such as a psychological assessment of one or both parents.

5.7 Family Centered Care and Confidentiality

Family centered care (discussed in Chap. 1 "What is Pediatrics About" and Chap. 2 "Boundary Issues") is now fully accepted as fundamentally important to pediatrics. The American Academy of Pediatrics (2003) describes its importance in this way:

> Family-centered care in pediatrics is based on the understanding that the family is the child's primary source of strength and support and that the child's and family's perspectives and information are important in clinical decision making.

Put simply, parents and families are the constant in the life of the child; we healthcare professionals have only brief, time-limited, involvement with the patients we see. Even when we follow an individual child over many years, our contacts are limited. The family provides everyday care and support of children. We will provide occasional, highly specialized care and treatments. Therefore, we must partner with the family to care for the child.

Nevertheless, the partnership essence of family-centered care can raise concerns about patient confidentiality, giving rise to problems, and more importantly, some necessary actions by pediatricians. Family-centered care does not automatically imply that every piece of information about members of the family, including the child patient, may be shared with every other member of the family. Confidentiality is so important in developing a trusting relationship that careful thought should always be given to how it applies in an individual situation. Family-centered care should not be used as an excuse to avoid considering confidentiality, or to justify

breaching it. The child patient and individual family members all have an expectation of at least a degree of protection of their personal secrets.

Conversely, recognition of possible problems with confidentiality within an ideal of family-centered care should not be used as an excuse to avoid this model of healthcare.

Despite a philosophy of family-centered care, the child retains full individual rights. In Canada, the Supreme Court stated:

> The rights enumerated in the Charter [of Rights and Freedoms] are individual rights to which children are clearly entitled in their relationships with the state and all persons - regardless of their status as strangers, friends, relatives, guardians or parents. (B.(R.) v. Children's Aid Society of Metropolitan Toronto 1995)

The aspirations of the American Academy of Pediatrics statement on family-centered care are that, "In every health care encounter, pediatricians should share information with children and families in ways that are useful and affirming" (American Academy of Pediatrics et al. 2003). It is tempting to read and focus within this carefully worded statement on the importance of the concept of "sharing". For the purpose of this chapter, the focus should be on the desire to make information "useful and affirming". Given the many forms which families might take, the complexities of relationships within them, the varying sensitivity of information that physicians have about a child, and the evolving nature of childhood itself, an early discussion in a healthcare encounter on the meaning of "family-centered care" as it applies to that specific encounter, is vital. The parents, and the child, depending on age, should define what they mean by "family". This should be done privately to avoid generating tension within families. Most families will want to include close relatives such as grandparents and aunts and uncles, but not all. Families themselves will decide the limits of who should have access to health information.

When reaching an agreement on what confidentiality means for a specific family, collaboration is as important as it is in all aspects of pediatric practice. Pediatricians should indicate to families the limits of confidentiality and should seek feedback on family functioning regarding information relating to the child. This effort is becoming ever more important as detailed reports, sometimes about psychological, social or immigration status, often contain sensitive information about specific family members that they would like to keep private. Accidental breaches of confidentiality, when trying to achieve family centered care, are extremely common. In other words, a healthcare professional might begin a discussion about the child's status with what the professional regard as a family member, without establishing how that family functions and how individual family members, including the child patient themselves, might handle health care information. For example, a child who is an inpatient might be in the company of an adult when visited by a healthcare professional. The healthcare professional might be a medical consultant, or technologist who does not know the family. The adult might be a neighbour who was sitting with the child while the parents have a break. The neighbour might innocently ask about the child's condition, and the healthcare professional, without establishing who the

adult is, might launch into an over-detailed conversation. Always establish the identity of the adults and the nature of their relationship with the child they are accompany to the clinic or hospital. If healthcare professionals find themselves in the situation where a new and unrelated adult is with the child, and the professionals have no prior knowledge of the parents' attitude to this particular adult, any comments should be confined to bland statements such as, "Mark is doing well".

5.8 Networking

Dr. Jones was examining Elma in his clinic, and noted she had an unusual birthmark that would require treatment. Dr. Jones also noted that Elma and her parents had travelled from a small town for this appointment. Dr. Jones remembered another child, Hannah, who was three or four years older than Elma, and also from the same small town. Dr. Jones asked Elma's mother if she knew Hannah and her family saying that Hannah's family could help Elma's family understand what was ahead in terms of treatment.

Oh my! Dr. Jones began with the best of intentions to facilitate peer support in two patients with whom he was involved. Now that society has open communications, physicians can fall easily into the trap of reducing social barriers among people. Indeed, what Dr. Jones is doing is consistent with another aspiration of the American Academy of Pediatrics that:

> Pediatricians should encourage and facilitate family-to-family support and networking, particularly with families of similar cultural and linguistic backgrounds of families who have children with the same type of medical condition. (American Academy of Pediatrics et al. 2003)

Yet, whatever the underlying relationship, if any, between the two families, Dr. Jones has no right to tell one family about the other because to do so violates the confidentiality of the families. Dr. Jones might have asked Elma's parents if they wanted to meet another family with a similar history, without making any suggestion that the other family lived near their home. While most families want to meet families who have experience with the same condition, not all do. If Elma's family replied that they would be happy to meet another family, then Dr. Jones could have contacted Hannah's family to ask if they would be willing to help. If Dr. Jones calls Hannah's family, then she must handle this conversation very carefully because of the power imbalance between Dr. Jones and Hannah's family; Hannah's family might agree not because they truly wish to but just to please the child's physician.

There is no doubt that encouraging family-to-family support and succeeding in this aspiration can be very helpful to families and can provide support in ways that healthcare professionals cannot. The cautions regarding protecting confidentiality here are obvious: physicians should ensure that all parties agree to share information, and they should also ensure that what they regard as "similar cultural and linguistic backgrounds" are actually accepted as similar by the individuals within these groups.

5.9 Confidentiality Is About More Than Written Records

Written, or electronic text records contain important confidential information, but do not constitute the full extent of health information concerning a child. The very fact that a child is in hospital or a clinic is health information and therefore confidential. From time to time, healthcare professionals with the best of intentions will take a family contemplating an invasive procedure, such as placement of a gastrostomy or tracheostomy tube, to see the device in place on another child without the full (or any) permission of the second child or his/her guardian. Taking a stranger, without permission, to see an individual child is most certainly a breach of confidentiality. Moreover, such a visit turns the child into an object on display and leads to loss of respect for that child's dignity and individuality.

5.10 Teams and Confidentiality

A team approach to pediatric healthcare is an integral part of how we help patients and their families achieve a diagnosis and develop a treatment plan. That we work in teams is a fact and is complementary to family-centered care. The teams can be as small as the physician and the nurse, and as large as several different physicians from different specialties, the trainees, nurses, many allied health professionals such as psychology, physiotherapy and occupational therapy, social workers, but also healthcare aids, orderlies, porters, cleaners and administrative staff. Teams work effectively only when there is both leadership and sharing of information. The pediatrician is often the person in the position of leadership, but not always. While in that role, the pediatrician is responsible for ensuring effective communication of health information. The responsibility for maintaining confidentiality is shared. All members of the team must understand why they need information about a particular child and her family and why that information should not be shared outside the team. Whoever is the leader must ensure that all team members understand and respect the child's right to confidentiality and that there are effective administrative arrangements to prevent confidentiality breaches.

Modern technologies, such as email or videoconferencing, are widely used in team discussions. There are benefits and risks with all these modalities. The child benefits from a wider range of expertise and opinions that can be brought in to discuss the child's condition, without the bedside being corroded by strangers. Email allows the direct care provider of the child to seek help from a peer who might live in another city, another country or even another continent. Again, this communication might allow the child's caregivers access to the opinions of the leading expert in the child's condition. On the other hand, the risk of using identifiable information is high, and care should be taken when describing the child to use only those details that are essential in terms of obtaining advice and how to look after the child. There

are specific risks with emails, for example they might be inadvertently forwarded or accessed by individuals not involved in the child's care. Whoever is in a leadership role must ensure that all team members understand the benefits and limitations of each mode of communication in respecting patient confidentiality.

Some very important members of healthcare teams are not, strictly speaking, professionals. These include healthcare aides and student volunteers present in hospitals and community centers; aides are particularly important when the child is receiving home care. The healthcare aides have specific skills, usually in a narrow area, and typically have more direct contact with sick children and their families than any members of the traditional, regulated, professions. They cannot do the job well without information about the patient; we must include them in healthcare communications. These aides are not governed by a professional regulatory body that polices breaches of confidentiality. To ensure that aides comply with the obligations to respect confidentiality, employers will typically require these aides to sign a "confidentiality agreement". Such an agreement is enforceable under contract law; breach of the agreement could entail loss of employment.

Conversely, families might confide in healthcare aides and ask them not to relay the information to the professionals involved. Also, healthcare aides, particularly those in the home might be privy to important information, such as abusive or neglectful behavior towards the child. The duty to disclose such information is addressed later in this chapter and in Chap. 7.

It is important that companies who employ healthcare aides have open discussion on these issues and establish support mechanisms to help the aides decide what information must be passed on to the wider team.

Student volunteers are in a different position from most aides. For one thing, they are young. If they are not properly trained and supervised and yet train successors, bad practice can be taught. We have heard of an undergraduate university student volunteer at a children's hospital telling a first-time volunteer, "And when I'm bored, I read the charts of the mental health patients. You can access them like this." Pediatricians are responsible for helping to protect the confidentiality of children in the hospital.

5.11 Children Grow and Develop

We have stressed that confidentiality is a very important part of the compact between the healthcare provider and the patient. And so it is; respecting confidentiality is fundamental to the trusting relationship healthcare providers foster with their patients and their families. In the case of pediatrics, this compact might be between the healthcare provider and the patient, but often the patient is so young that the compact is between the healthcare provider and the parent of the patient. It is important to remember that the confidentiality belongs to, and is protected in the best interests of, the child patient while authority over the maintenance of confidentiality

is held by the parent or guardian. Given that children mature, at some stage most child patients will have the intellectual maturity and the moral right to exercise control over the confidentiality of their own health information. For most individuals this right will become absolute at the legal age of majority. The age is usually 18 years, but may be less in some jurisdictions, or may extend up to the age of 21.

Some pediatric patients have persistent intellectual deficits. In some patients, the intellectual deficits are so severe that the patients will never develop the maturity to exercise full control over who has access to their health information. Even when in an adult age range (usually >18 years), such patients will need a legal guardian to take medical decisions for them.

Many young people who have not reached the age of legal majority, have the intellectual capacity to determine who should have access to their information, including whether the parent or guardian may access the health information. Giving control over health information to someone who is, in legal terms, a minor is justified on a number of grounds. The two principal grounds are that of respect for the adolescent patient who has sufficient maturity, and the reality that healthcare professionals will not receive important information from the minor unless the professional can assure the minor that the information will be kept confidential. The latter ground applies very strongly to information about sexual activity and substance use. The whole topic of teenagers and confidentiality in general, and as it relates to consent, is addressed extensively in the chapter on adolescence.

Who controls the confidentiality of health information is of concern to all children. If a parent or guardian is the one authorizing medical or surgical treatment, then that person needs full access to the child's health information to make an informed decision on behalf of the child. This fact does not imply that the parent or guardian has access to information about the child to the exclusion of the child. Far from it. Children also need access to their own confidential health information, but in a way that is comprehensible to a person of their age and development. The latter statement might seem too obvious even to be stated. However, recognition of the need to involve children in their own care, and to assure them of confidentiality, relevant to their age, developmental status, and the medical, familial and social context is an important development in pediatrics.

5.12 Is Confidentiality a Valid Concept After Death?

The question whether confidentiality protection persists after death might be surprising because the answer might seem obvious. Unfortunately, there is no agreement as to what the obvious answer might be! Because no harm to an individual can occur after death, some argue that therefore there should be no assurance of confidentiality after death. Others argue the polar opposite. Confidentiality should be maintained after death for two reasons: to respect the agreement with the child before he or she died, and to prevent damage to reputation after death.

Even though the issue of confidentiality after death is not settled, there is at least one situation in which parents should have access to the child's health record. In the case of children who die in the intensive care unit, parents benefit from meeting with the intensive care physician, seeking information and emotional support, activity recommended by pediatric organizations, and formally studied (Meert et al. 2007). Nevertheless, even allowing for the benefits of such meetings, care is still required. Are there comments that the child has requested be kept confidential, even after death? Are there reports on one or other of the parents that they would not like the partner to see?

Some of the same principles that apply during life also apply after death. Various authorities have the right to see the chart, including those responsible for infectious disease and the coroners or medical examiners. If other bodies wish to review the chart, such as child welfare or the police, then they should seek a legal order. It is difficult to imagine any circumstances under which a chart should be released to someone other than the parents or guardians, or one of the authorities mentioned above.

We believe maintaining confidential after death maintains respect for the child.

5.13 Should We Keep Information from Children?

How much, and at what time, children should be told about their own healthcare condition has been debated and studied, mainly in children with cancer.

The general principle is that children should be told about their own healthcare. Children vary a great deal in how much they wish to know, and they vary of course by age and understanding. In communicating with children, physicians must identify what the child wants, and proceed at a pace that is comfortable for the child. That pace will vary enormously. For example, many children with chronic disease have not only a long experience of illness but also of interacting with many healthcare practitioners; such children might want information early. On the other hand, children who only recently had major encounters with the healthcare system might want to wait until they are more comfortable with their new situation and with the health care providers they meet before receiving more information. Nevertheless, the trainee pediatrician should cultivate the skills of talking to children, and including them in conversations, in a fashion that is appropriate to their age and development. Over time, and usually fairly swiftly, the ability to speak with children in an age appropriate way will become second nature to the aspiring pediatrician. Some children will seem as if they are not listening, when in fact they are. The healthcare practitioner must avoid teasing a child who wants to listen carefully and ask questions later and must avoid talking over the child as if she were not there. Children can be more aware than adults realize.

In her book, "I AM I AM I AM: Seventeen Brushes with Death", autobiographer, Maggie O'Farrell (2017), describes her experience as a pediatric patient when her neurological symptoms are investigated:

> Because I am only eight, and not spoken to by doctors – beyond them asking me, do you feel that? Can you do this? Are you able to follow the path of this torch? – I must develop new methods of interpretation. I am aware that there is a great deal being said outside in the corridor, along phone lines, behind closed doors, in the scribbled notes at the foot of my bed. I become instead a listener, a witness. I glance from the faces of my parents, standing on one side of the bed, to those of the doctors, standing on the other. I learn to be alert to nuance, to inflexions of prose, to minute alterations in facial expressions, to the setting together of teeth, the gripping of fists, to my parents effortful, watery smiles. A search for meaning in the gaps between words, between questions, and the hesitations before the doctors' answers, in the way they all look down at me before moving towards the door and talking outside the window. (O'Farrell 2017)

In the past, children were often not told about their condition, especially if the child was near the end of life; sometimes children were not even told the specific diagnosis (Bluebond-Langner 1980). The justification given for not telling children the truth was the view that withholding information protected the child. Sisk et al. describe the evolution of ideas on this topic in detail (Sisk et al. 2016). Perhaps, however, the decision to avoid speaking directly to the child was less altruistic and more about protecting physician and parents from conversations they might find painful and had no idea how to begin. In other words, when a child has a poor prognosis, the adults involved might lack the skills or indeed the courage to communicate the truth in a skillful, compassionate, and age-appropriate manner. Whatever the reason for failing to tell children the truth, adults were essentially lying to children to keep them from knowing the truth. Moreover, their lies were almost always ineffective. Children were usually already aware of their condition, and often that they would probably die in the near future.

The children maintained the façade that they did not know, to protect the adults; such effort used up much of their energy. The children were often afraid to ask the adults around what was happening. This fear inevitably led to an environment that was far from open. The evidence accumulated from 1960 to the present day is that being open with the child is helpful and allows the child to be an "active agent" in his or her own healthcare. And contrary to the view that knowing the truth would destroy hope, in reality hope remains. Even when death is imminent, children find ways to identify areas of hope.

Notwithstanding this evolution from secrecy to openness about a devastating diagnosis, it is well worth noting that families often vary in their attitude as to how much their child should be told. When families adamantly insist the child not be told, it is important to explore gently why that might be. Such insistence might be consistent with the child's wishes, but perhaps not always. When there is a sense that the child might want to know more, and the parents wish the child to know less, the healthcare practitioner needs to explore the underlying reasons for the discrepancy. It is possible that the parents are unsure about how they might convey what they see as unpleasant information to the child; such a problem might be resolved

by a member of the healthcare team "coaching" the parent. Whatever the reason, the physician must keep in mind that the child is the patient and the child's needs are primary.

5.14 Interacting with Immigrant Families and with Minority Cultures Within Western Society

Being aware that there might be special nuances in working with some cultures does not mean that the initial approach to children and families should be any different from a physician's approach to families in the mainstream culture. We should approach families with openness and should always make clear that we want to listen to what they have to say and will try to accommodate requests in terms of communication.

Rosenberg and colleagues describe the hypothetical case of a 15-year-old girl. She has "advanced liver cancer", despite treatment in her home country, and was brought "to the United States for additional treatment". Her uncle was described as the family decision-maker, and he requested that she not be given any details about her diagnosis and prognosis (Rosenberg et al. 2017). The case of this near adult patient has implications for how we deal with teenagers and offers an example that will be useful when dealing with younger children. Regarding the general point of communicating sad news to families, the authors make a number of general points.

The first major point is that truth telling is part of the culture of Western society because nondisclosure rarely, if ever, serves the interests of the child or the family. Deliberately withholding the truth, even if the reason for this is kindness, might have unintended unpleasant negative consequences. For example, patients and families might ask for toxic therapy, travel a long distance for unproven therapy or avoid symptom-relieving therapies included those within palliative care. The fact that the patient is aged 15 years raises specific issues: teenagers usually want to know what is happening to their health and want to participate in any treatment decisions. Despite this general statement, some teenagers do want information filtered via a trusted adult. It is also generally true that dealing with disturbing and difficult truths is very distressing to patients and family, and as the authors of this paper say, it takes time for "understanding to take fruit". Discussions need to be held frequently, as the family's awareness evolves over time. Some of the concepts about telling the patient about his/her own illness apply to younger children, and when it does, language appropriate for the child's age and developmental status must be used.

Healthcare staff who are approached by an adult to withhold information from a teenage patient are likely to feel a degree of tension between, on the one hand, a commitment and desire to honour the culture of the patient and family, and the milieu in which they live, and, on the other, their strong professional commitment to the ethical values of respect for autonomy and truth telling.

Nevertheless, openness to the family's perspective allows continued dialogue and the building of collaboration. In other words, it would be wrong to act precipitously to tell the patient a devastating diagnosis given the family's opposition to that course of action. This **initial** course of action could permanently impair the physician-family-child patient relationship. Although Rosenberg and colleagues tell the story of someone who comes from the Middle East, they note that within the Middle East, personal preferences might vary considerably within families, and from country to country. In addition, they indicate a trend towards truthful disclosure, even in communities previously opposed to such disclosure.

Rosenberg's story raises two other concerns of general relevance. The first is the issue of "cultural relativism": do we really think that the ethics we follow are universal values? Such an attitude will be perceived as arrogant and insensitive. Nevertheless, some values, such as respect for the dignity of each individual, should not be ignored. In addition, we should not ignore our own personal values. The principle of justice suggests that persons from different cultural, religious, and ethnic groups must be treated fairly, but – importantly – does not require that specific cultural practices must always be tolerated equally. Macklin (1998) makes the point that while intolerance is reprehensible, we must avoid "over-tolerance". The fact that a healthcare provider recognizes that some practices are not to be tolerated, does not, in itself, mean that the provider is intolerant.

A second point that arises from Rosenberg's example is perhaps a misunderstanding about what autonomy is about and what it is not about. Macklin tells us that the modern concept of autonomy was developed at a time when paternalism was pervasive. She notes that autonomy is not about "unfettered belief in individualism". It is about asserting that the right to make decisions belongs to patients, and the role of the physician is to describe the available options as fully as possible and to guide patients to make decisions in their best interests.

5.15 Confidentiality and Genetics

The phrase "genetic exceptionalism" (Chadwick 2016) has been coined to indicate that confidentiality requires particularly careful handling of genetic information. While we are not sure that genetic information is completely different from other health information, it is important to bear in mind:

- Blood relatives share genetic information contained in DNA and hence predisposition to particular diseases.
- Information about genes might be predictive at any time in a person's life; in other words, a test done in childhood might predict a disorder that does not manifest until middle age or later.
- Genetic testing might reveal information that could lead to uncomfortable discussions such as parental consanguinity (see Sect. 5.14 for extreme consequences), and non-paternity.

Recall Kenneth's story that appeared at the beginning of this chapter. He experienced seizures and was brought by his parents to the emergency department. The physician considered ordering extended genetic testing because of the phenotype of intractable seizures, with negative results on conventional genetic testing. Extended testing will include some form of genome-wide screening (Hammond et al. 2018).

Before the testing, Kenneth's physicians would have spent a great deal of time on the consent process (see Chap. 4) and would have explained that the results might very well help to make a specific diagnosis, which could be helpful in prognosis, and perhaps also in treatment. If a meaningful genetic variation is identified, then the fact that the variation might be present in one or other parents, Kenneth's sister, and other close relatives would be discussed, along with the ethical concern about whether these relatives should be told.

There are other possible outcomes of extended genetic testing. Genome wide screening might disclose genetic variations that cannot readily be interpreted, or perhaps no variations might be detected. If the latter were the outcome, then the medical team would not have advanced in trying to determine the underlying diagnosis. There is always the possibility that the extended genetic testing might disclose a genetic variation that is not relevant to Kenneth's health, but might well be relevant to his relatives. An example might be identification of one of the genes concerned with breast cancer.

The value of such genetic testing is confirmed by Hamdan et al. (2017) in a study in which whole genome sequencing (WGS) was performed on 197 individuals with difficult to control epilepsy and their unaffected parents. Taken together with the identification of known pathogenic variants (53) and new candidate genes (10), 32% of these individuals had an underlying genetic variation associated with their condition.

Of course, the hope is that with the identification of a specific genetic variation will come information on prognosis and treatment. Even if a specific diagnosis does not provide guidance for treatment, parents find value and comfort in having as much information about the child's condition as possible. At the very least, extended genetic testing can guide their reading, online or elsewhere. Such testing can help parents also in developing online support groups of children with specific variations; the support groups, in turn, can often provide information on phenotype to the parents.

5.16 Should Children Know Their Origins?

Adoption is not a new social practice. In the ancient world, the adoptee, who might be an adult, would have inheritance rights. The way western society responded to adoption since the mid-nineteenth century parallels how society responded to children. The phrase "put up" for adoption implied that the children were a burden to the "altruistic" parents who adopted them. Ideas that the needs of the children should be prioritized came only in the latter half of the twentieth century. As a corollary, it

followed that adoptive parents should be assessed in detail to ensure they have the abilities to care for the child successfully. As part of prioritizing the needs of the child, it has been accepted over the same time period that adopted children should be told about their origins,

> Taking a child from one set of parents and placing him/her with another set, who pretend that the child is born to them, disrupts a basic biological process. The need to be connected to one's biological and historical past is an integral part of one's identity formation. The sealed record in adoption blocks this process (Sorosky et al. 1989).

In adoption, the need for the child to have continued contact with his/her biological parents and the needs of the child to have access to all aspects of family history are accepted. Parents are vetted and given support regarding many aspects of adoption, including how and when to disclose to the child his/her relationship with the parents who reared them. In Canada, all provinces and territories permit adoptees to know their origins, either as of right or with the agreement of the birth parent (Guichon 2012).

5.17 Should Children Conceived by Assisted Reproductive Technologies (ART) Know Their Origins?

12-year-old Naomi's Story

> I was born using the help of sperm insemination.… But, because the donor is anonymous, this means that it is very likely that I will never know who my biological father is.
>
> The amount of information that I know about my sperm donor is very limited. I've always been looking for answers that aren't available to me.
>
> The curiosity is always there, as to who my sperm donor is. As I walked down the street, I could be walking past him. I could have a dozen half siblings that I don't even know about. And, I will probably never know, because of the fact that a sperm donor's identity is kept confidential. (Williams 2012)

This section is about assisted human reproduction, so let's first deal with an overview of what this is about, and a few definitions. ART is the creation of new human life other than by sexual intercourse. The first form of ART was the non-sexual insertion of sperm into the uterus, so-called artificial insemination (AI). In AI, the egg comes from the mother's ovary, conception occurs within the woman's body and gestation is in the mother's uterus; she experiences labour, delivery and lactation; and she usually provides nurture throughout childhood. In this early form of ART there is the possibility of three "parents", or just two! There are just two parents when the sperm comes from the mother's lifetime partner who is unable to inseminate sexually, and in this case the biological father might also be the social father who provides a lifetime of nurture. There could be three parents where, on the other hand, the sperm might come from a male who is not in relationship with the mother, in which case, this male is not likely to have a nurturing role in the life of

the child. The mother's partner might be the male social parent. Some form of artificial insertion of sperm into the uterus has been documented since the nineteenth century but it increased in frequency in the second half of the twentieth century. We could not find information on how frequent this modality of conception is today.

In vitro fertilization (IVF) was first performed successfully in 1977. In this situation, eggs are extracted from the body of women, and these eggs are placed in a petri dish into which sperm is introduced to achieve fertilization. The resulting embryo is then inserted into the uterus.

IVF is now used extensively in the developed world. In a report on ART using data from Australia and New Zealand, Canada, Continental Europe, the United Kingdom (U.K.), Japan, Latin America, and the United States (U.S.) in the time period, 2004–2013, there were "7,079,145 total ART cycles utilizing both fresh and previously cryopreserved embryos from autologous oocytes that resulted in 1,454,724 live births." (Kushnir et al. 2017). A report from the United States of America suggests that the pediatric outcomes are not as good for children of IVF than for children conceived naturally (Sunderam et al. 2018), there were 182,111 ART procedures in 2015. There were 59,334 live births, 1.7% all US births. 25.5% of ART births were low birth weight, compared with a rate of 8.1% overall. Of all multiple births, 17.0% were due to ART. Being of low birth weight and being one of a multiple birth, brings specific comorbidities, mainly related to prematurity, a need for neonatal intensive care, and a possibility of developmental difficulties in the years ahead.

With IVF, the number of possible "parents" increases considerably. The woman who carries the child during pregnancy through to delivery might or might not be the source of the eggs and might or might not be a person who provides the nurturing role of mother for the life of the child. When one woman carries the child during pregnancy but does not intend to rear the child after delivery, she's referred to as the "surrogate mother" – a term that tends to diminish the bodily role she plays. The sperm used in IVF might come from the male who will provide lifetime nurturing for the child, or from another man altogether.

Hence IVF (and AI) in reality, not just potentially, might separate the biological origin of the child from those who will rear the child. This complex situation, in different legal jurisdictions, may be governed by regulations, a formal reproductive authority, the criminal code, legal precedent, or by none of these.

ART gives rise to at least two ethical issues concerning the resulting child: secrecy and anonymity. A child of ART might not know his or her method of conception. For example, a child reared by two parents, male and female, but conceived by the sperm of another man, might not know that: (1) AI was the mode of conception and (2) His or her social father is not also the genetic father. Secrecy is intertwined with anonymity in this case. A child cannot begin to search for his or her biologically related father, if he or she wrongly believes the father is living in the same house. A child conceived by AI who is reared by the mother and her female partner, does not have to contend with secrecy even if anonymity of the sperm provider, the genetic father, remains an issue.

Has Naomi been wronged by the anonymity of her genetic father? We believe she has been. (Guichon 2012) The practice of denying children of assisted human reproduction information about their progenitors is a practice that aims to address the desires and perceived needs of adults at the expense of the needs of the child. It is wrong to deny children basic genetic information about themselves and to cause them avoidable "identity harms". We agree with Bok (1999) who argues that we must "respect children enough to be honest with them" both about the mode of their conception and the identity of their progenitors. In other words, there should be neither secrecy nor anonymity. Lying about such fundamental issues as the unusual means of conception and parentage are unnecessary and would not be tolerated in a society that put the interests of children first.

Secrecy and anonymity inhibit a child's identity formation. Identity formation is the universal, vital and continuous task of human development in which we ask, "Who am I?" and "How am I like or different from others in terms of appearance, personality, traits and talent?"

Secrecy about the mode of conception is harmful to children's well-being because it can end in discovery. Discovery that a person or the people whom a child thought were genetic parents are not, can cause painful deconstruction and reconstruction of identity. Consequently, when ART is used to achieve a conception, the child should ideally never remember a time when he or she did not know about the mode of conception and the identity of his or her progenitors.

Anonymity of one or both progenitors is also harmful to well-being because it inhibits identity formation. Individuals form identities best when they can:

1. See genetic resemblance in others;
2. Hear people engage in resemblance talk; and
3. Understand where they fit in past and future generations.

Anonymity deprives children born of ART of these benefits that accrue to almost all other children (Benward 2012).

Consider for example, the arrival of a child in ordinary circumstances. The birth of a new baby is an exciting time in the life, not just of the parents, but also of the extended family, friends, acquaintances and neighbors. Speculation tends to be rife – who does the baby look like? Does the new baby have Granny's nose, Aunt Elizabeth's eyes, and so on? The child will take up these observations him or herself with growth and development, as the child engages in identity formation.

A three-generation family history is the easiest way to obtain genetic information, to make a genetic diagnosis, and deciding on optimum treatment. This family history, even in an era of whole genome sequencing, is still the easiest and swiftest way to obtain genetic information. Because of the possibility that ART was used, physicians should, in a routine pediatric history, ask about conception, and about family history. When the clinician identifies that the child has been conceived by some form of ART, then the parents should be asked, "How much does the child know?" When parents reply that they have not disclosed the mode of conception (secrecy), then they should be encouraged to do so, but will need help in knowing

how to do this. If the parents tell us that the child knows the mode of conception but not the identity of the progenitor, then at least there is no secrecy but rather openness in the family. But there is still anonymity and so the problems for the child in engaging in identity formation are not solved. The donor-conceived speak of how the pain of the missing genetic information about a progenitor is magnified when they themselves have children.

Despite this pain and knowledge of this pain, it seems that families commonly deceive their ART children. In a meta-analysis of 19 articles published 1996–2015, 2814 parental responses are listed. Twenty-three percent had already told the child and 44% planned to tell the child, 13% were uncertain and 29% planned not to tell the child about the conception (Tallandini et al. 2016). There were drawbacks with the studies available for analysis: there were few studies of children >10 years, and no studies were longitudinal. The greatest drawback is that all parents volunteered for the studies, leaving open the very high possibility that those who decided not to volunteer are, in some way, fundamentally different from those parents who did volunteer. In other words, the number of parents with ART children who intend to engage in secrecy or anonymity, or both might be significantly higher than the studies suggest. The meta-analysis concluded that: parents tend to underestimate medical risks to offspring; they give children's rights insufficient consideration and ART parents needed greater psychological support over time.

Some of the confusion over the relevance to the offspring of knowing about ART possibly relates to early consultations. The prospective parents, or at the very least the intended mother, is regarded as the "patient" by the fertility specialist. This specialist is unlikely to recognize a responsibility to others involved, such as egg donors, sperm donors and 'surrogate' mothers. Even less will the fertility specialist recognize a responsibility to someone not yet conceived. Yet it hardly needs stating that the very purpose of infertility treatment, including ART, is to create a child. The interests of the child to be created must be placed first because that person is most affected and for the longest time. Placing the interests of the intended child first can best be achieved by introducing the need for the child to be told the truth very early in the process and offering long term psychological support to the adults.

Parents might disclose to a physician that their child resulted from one form or another of ART, but then tell the physician that they do not want the child to know. While the physician should not go ahead and tell the child the truth immediately, she should initiate discussion with the parents. Why did they not want the child to know? In whose interests were they taking the decision? Did they intend to tell the child in the future? Did they want help in how to disclose the information? Have they considered the possibility of unplanned disclosure by others, such as family friends or close relatives? Have they considered that the child might already suspect that one of the parents is not a progenitor? (In such a case, the child might wrongly assume that one parent had a sexual relationship with a third party (Corday 2012). Have they considered that the child, when an adult, might need to consent to diagnostic genetic testing on the parent's grandchild, which testing might reveal clues about biologic parenthood?

These questions might encourage the parents to reconsider their commitment to deception. If so, then the physician has a duty to help in lifting the secrecy and addressing the anonymity of the progenitor. To facilitate such disclosure, the physician should probably enlist the help of a psychologist or social worker. If the parents are still determined not to tell the child about the mode of conception and the identity of the progenitor, then the physician should explain the disadvantages of this course of action. "Disadvantage" is actually a weak word to describe the likely outcomes of continued secrecy. In fact, what can occur are potential disasters. This life of secrecy, and having to watch disclosures, is at the very least uncomfortable. More than that, there might be inadvertent disclosure by a relative or friend who is aware of the means of conception and does not know that the parents wish to be deceptive. The child, who might of course be an adult and should be referred to as the "offspring", might be extremely resentful that deception has played such a large part in much of their life. Parents might be encouraged to consider that the offspring might have a long relationship with the people who raised her but that the relationship can be seriously jeopardized by their lying to the offspring on a matter central to that person's being and identify.

A unilateral disclosure by the physician to the child is not appropriate. However, the physician should tell the parents that she is not willing to lie to the child and if a direct question is asked, then the physician will answer it truthfully. Of course, parents might then decide to take their child to a different physician. But the child may access his or her medical record at maturity and will see that the physician recorded the truth there.

5.18 When We May Release Information About a Patient

Serena is 12 and has had severe asthma since the age of 3 years. She has been prescribed standard therapy and continues to have symptoms that limit her enjoyment of life and lead to frequent school absences. She seems to be compliant with her therapy and there are no obvious environmental triggers. Her asthma specialist has recommended omalizumab. This is a biological agent effective in severe allergic asthma. The cost might be in the range of $10,000–$30,000 per year, depending on dose given, the dose schedule (every 2 weeks or every 4 weeks) and whether the payer has arranged a special price with the manufacturers. Serena lives in Canada, a country in which drugs are not usually part of publicly funded health care. The pharmaceutical company has appointed a liaison person to help the family apply to their insurance company for coverage. The parents are asked to sign a form allowing this third party to act on their behalf. When the parents applied for insurance, they agreed that the insurance company could access the health records of any family member to ensure a drug cost was legitimate.

We have emphasized throughout this chapter the ethical relevance of confidentiality. We have also made it clear in the opening section, and in the subsequent text, that confidential information might need to be shared. Identifiable confidential informa-

tion should be shared when it is essential for the child's health care. We assume that confidential health information is kept safe, and that any access is carefully regulated.

In terms of the insurance company, their access to Serena's health record is reasonable, and they have written permission from her parents. This access to confidential information is justified because it aims to provide the child with needed treatment. The insurance company will have internal controls to protect confidential information. The permission requested by the pharmaceutical company for information about other family member's health is more problematic; its stated purpose is to help the parents, an argument of convenience. The pharmaceutical company's stated purpose might actually be the only purpose. On the other hand, the real purpose might be to allow the pharmaceutical company access to confidential information that it would otherwise not have. If the latter is the company's motive, then we have no way of knowing how this information will be used. The liaison person will have detailed knowledge of the requirements of many different insurance companies and can save the parents time by ensuring documentation is presented in a favourable manner. On the other hand, the liaison person has a major obligation to her employer, the pharmaceutical company, and is not obviously a member of the health care team. Serena's information may be shared with other sections of the company without the parent's knowledge. The parents might agree to disclosure of Serena's confidential health information because they want to ensure Serena receives the best treatment, but Serena's immediate health care team must ensure that the parents are aware of the risk to confidentiality if they sign the form.

Serena's situation is very specific and is becoming more common with an increase in use of expensive therapies whose indications are very specific. Other examples of sharing confidential information have been given earlier, but the most common occurrence of sharing of confidential information is with the extended health care team. While we believe that information given to many team members should be limited to an accepted essential minimum, in an era of electronic health records, this is not always possible. In practical terms, parents, and the child patient, should be aware that a very large team of individuals will have access to confidential health information, and that such sharing is essential to give the child excellent healthcare.

Health information might also need to be shared to help teachers educate the child-patient and to facilitate treatment. Consider, for example, the case of a child with scoliosis who needs to wear a brace to reduce curvature of the spine. There is a risk that the child will be bullied in the classroom or on the playground and so might become unwilling to comply with this treatment. Here, the teacher is an essential ally to prevent bullying and thus to help the healthcare team. To assist, the teacher will require usually specific information; written consent to disclosure from the parent and perhaps also from the child should be obtained. The pediatric professional should discuss with the parent the extent of information required by the teacher, and how that information should be transmitted. In other cases, involving, for example, administration of drugs at school, medical reports might be required to support the supply of equipment or unusual drugs.

Those who pay for the equipment or drugs, insurance companies or governments, will want to know that the cost of the drug or equipment is justified, and is in keeping with the terms of the insurance policy. In these situations, the parent will

usually have given permission to the funder of the equipment of all the drugs to have access to full medical information. The physician should ask to see that authorization for disclosure before the report is sent.

Depending on the legal jurisdiction, and the system for paying for healthcare, where private insurance is involved, the healthcare funder is usually entitled, by means of pre-existing written permission from the parent, to access the child's confidential health record. In publicly funded healthcare systems, such as Canada and United Kingdom, the funding authority is the government, and unlikely to access a specific health record unless to deal with a complaint.

On the other hand, such authorities are likely to use "big data", anonymized, to improve the system.

In a different vein, healthcare professionals should ensure that they are providing good care to all patients by participating in quality assurance or audit activities. Here, confidential information is required, but it often can be anonymized, and reviewed in summary form. Typically, patients might not be told about every healthcare audit ordered, but introductory pamphlets to private physician offices, in healthcare clinics or hospitals, should indicate to families that these activities are conducted, why they are conducted, why they are important and how their confidential health information is protected.

5.19 When We Must Release Information

The previous section dealt with the situation for which there might be an element, albeit small, of choice about whether to provide information about a child's health or how much to provide. This section deals with the situation when there is an obligation on the pediatrician to release confidential child health information. The situations envisaged below arise because of the common desire to advance the interests of the child.

> *Charles was seen in a pediatrician's office at the age of four months when he was still slightly under his birthweight. A full history was taken, and apart from evidence of loose skin folds, and the fact that Charles was rather lethargic, there were no specific findings. The pediatrician immediately admitted Charles to hospital, and he was given standard amounts of infant formula in hospital. At the same time, a number of investigations were conducted to exclude common causes of failure to thrive. By the time Charles had been in hospital for 10 days, he had gained 250 g (more than twice the expected rate) and it was known that the investigations were negative. He was no longer lethargic, was bright and attentive, and the nurses noted no problems with feeding, no vomiting, and normal urine and stool output. Presumptively, Charles was greatly underweight because he had been underfed at home. The pediatrician wondered if he should breach confidentiality to tell someone outside the circle of care that Charles is likely to be at risk of harm if sent home.*

There are many more relevant details that the reader of the story might want to know. These include the socioeconomic status of the family, whether the mother had tried breast-feeding, and had been unsuccessful, whether they had adequate income to buy infant formula, and so on. But the pediatrician should understand that if the

mother had tried breast-feeding and had not recognized that her supply of milk was inadequate and that her baby was not growing normally, there might be risks in sending the child without supervision back to the same environment.

The suspicion by anyone, including a physician, that a child has been a victim of some form of abuse or neglect should lead to action to protect the child. The development of recognition of the fact that children might be hurt or neglected by those close to them is grounded in respect for the child, and the ethical imperative to act in the best interest of the child. The more general topic of child abuse and neglect, and their great importance in pediatric practice, merits their own chapter in this book, Chap. 7. Abuse and neglect of children are not new, but their formal recognition and the development of a process to help children who have been abused or neglected did not occur until the mid-twentieth century.

This chapter addresses confidentiality of a child's health information. Hence it focuses here on the role of confidentiality in child-abuse and child-neglect, and when confidentiality must be breached in the interest of the child. While the word "breach of confidentiality" is used, in practical terms a report is made to a designated authority. The specific requirements for reporting will vary from one legal jurisdiction to another, but the ethical requirements do not vary. The ethical requirement that the child should be protected, in turn mandates that the appropriate authorities must be informed. These authorities will usually be one form or another of child protection services, and again the names of these entities will vary from jurisdiction to jurisdiction, with "child protection services" and "child welfare services" being the most common. The language used in statutes in various jurisdictions is consistent in imposing an obligation on the physician to breach confidentiality when the child is at risk (Asnes and Leventhal 2010).

We will use the legislation in the jurisdiction in which the authors work as an example, recognizing that the underlying requirements will be similar across jurisdictions, even if the language varies a little one from another. Our governing statute is entitled the Child, Youth and Family Enhancement Act, RSA 2000, C-12 (2017). This statute applies to all adults in the Province of Alberta; it emphasizes that while our society entrusts special responsibilities to parents in the care of children, in the end, each of us shares some obligation to all children. This is more than fine words about a general obligation. As individuals, we each have a specific moral duty to help a particular child we have reason to believe is in need of protection.

The statute states that when people suspect that a child is in need of intervention, then they have a legal obligation to report this fact to the director of child welfare; failing to do so is not an option. The statute states, "Any person who has reasonable and probable grounds to believe that a child is in need of intervention shall forthwith report the matter to a director." "Intervention" means a service provided by provincial child welfare authorities that include assessing a child's welfare, aiding the parents or guardians to care better for a child and, in extreme circumstances, removing the child from parents or guardians who are unable or unwilling to care for the child. A person must report when he or she has "reasonable and probable grounds" to believe that a child needs help from the state; the person reporting need not be certain that the child needs an intervention. Indeed, the person reporting is usually

not qualified to make this determination. But those who are qualified to determine whether a child needs help and the specific help required, rely on people who have a reasonable belief to tell them, so that these qualified people can decide whether intervention is appropriate (and possibly life-saving). People who have reasonable and probable grounds to believe that a child needs an intervention but who fail to report this fact to a director of child welfare are guilty, in Alberta, of an offence and liable to a fine of not more than $2000 and in default of payment to imprisonment for a term of not more than 6 months. In other words, the state takes seriously the duty of strangers to help care for children when children are in need of intervention by child welfare authorities. No healthcare provider may claim that the information is confidential and so must not be shared. On the contrary, the state relies on people who have that information to share it with the proper state authority when there are reasonable and probable grounds to believe that the child needs an intervention (Child, Youth and Family Enhancement Act 2017).

This law, and similar laws in other jurisdictions, imposes a direct duty on each of us, as individual citizens, to act when we know of harm occurring to a specific child. Thinking that "someone else will do something" is not a moral response and failing to act certainly is against the law.

In Charles' case, any adult who knows that Charles is failing to thrive, probably because of lack of adequate nutrition, must notify child welfare authorities that Charles needs their intervention. This duty applies no matter the status of the person who has the knowledge. Clinicians leading the care of the Charles should tell team members that they will notify child welfare so other team members know that that obligation has been fulfilled and can defend themselves from a claim that they failed to fulfill their statutory obligation to notify.

People often hesitate to notify child welfare because they wrongly believe that the child will be removed from the home. It is important to note: (1) Such action is not the preferred option for child welfare; and (2) whether such action is taken is not the responsibility of the person who has the duty to notify and is ultimately taken by the courts. In other words, people who have knowledge that a child is in need of state help must notify the child welfare authorities so that the system that is focused on what children need (as opposed to what adults might want), can function properly.

Once notified, the child welfare authorities will carry out a full investigation and will assess the risk to Charles in detail. In general, they will make great attempts to keep the baby at home, with his parents, but at least in the early stages there might be some compulsory supervision until the authorities are sure things are going well. The child welfare authorities might identify other issues, such as substance use by the parents, in which case the long-term care of Charles is more problematic and will be decided by courts rather than by medical services. The principle point to understand is that child welfare authorities do not have a mandate to punish parents; their goal is to help children.

Riya is 14 and goes with a school friend but not with an adult to a local center where abortions are provided. A nurse took a brief history and noted that Riya was part of a large extended family, with many relatives living in a three to four block area. These relatives included a number of cousins; three of the cousins were teenage girls and two were teenage

boys. The physician confirms pregnancy and estimates gestation at nine weeks. Riya disclosed that the pregnancy was a result of a rape by one of her cousins and requested that the physician not disclose this to anyone, including her parents or the police. Riya has taken steps to ensure that the cousin will not be able to attack her again, and she has warned her female cousins of the risk.

Riya's story raises many ethical issues beyond the specific one of confidentiality in relationship to child welfare reporting. These issues will be explored in great detail in the chapter on adolescent health and adolescent sexual activity. Healthcare providers will wish to avoid escalating a difficult family situation. But even if all of the caveats given by Riya in terms of self-protection are true, and even if there might be unpleasant consequences within the family to her if action is taken against the cousin perpetrator, the physician is not in a position to investigate or to find ways to protect her. We hope that child welfare will take great care in how they address the situation, and in the complex family situation. The family may even blame Riya, something Riya might suspect will happen, but in the end the needs of all the young people take priority over the desires of adults to "save face". Riya and her cousins, and perhaps others not known to the family, must be protected from physical and mental harm and criminal behaviour. Almost all child protection legislation would require that such information gained by a physician must be reported to child welfare authorities, who are likely to involve the police.

Despite the legal requirement to report the alleged sexual assault of a minor to child welfare authorities, Riya still has the ability to make her own healthcare decisions as a mature minor. The physician should provide Riya information about her options and then follow a request for termination of pregnancy. (In some legal jurisdictions, there might be mandatory reporting to parents of requests by minors for terminations of pregnancy. If the physician practices in such an area, then the physician should both notify child welfare and consider whether obeying such a law is in keeping with the duties of a physician to a patient. He/she may need to seek independent legal advice for him or herself.) While notification to police is not a duty of the physician, child welfare might report the situation to the police. The time sequence of conducting the abortion and notifying authorities should be considered. Before performing the termination, the physician should inquire of the local prosecutorial authority as to how products of conception should be collected and preserved such that they can provide evidence about the identity of the perpetrator (Crawford-Jakubiak et al. 2017).

Another area when confidential health information about a child must be released to authorities is in the case of some specific infections. Infectious diseases have been scourges of child health from time immemorial. Even before the discovery of bacteria and viruses, humans were aware that infections could appear in epidemics, and one way to avoid becoming infected was to stay away from those already infected. Cities would isolate those infected, by sending them away from the city, or quarantining them in institutions until they were free of infections (or died). One of the great triumphs of twentieth century medicine was the reduction in childhood mortality by controlling infectious diseases. Control was achieved by high standards of hygiene, quarantine, general improvement in nutrition and living standards, immunization, and, to a lesser degree, antibiotics.

However, infectious diseases still exist. At one stage in the twentieth century, it seemed as if we should no longer concern ourselves with infection. This apparent conquering of infection was premature. Many pathogens changed in virulence and multiple antibiotic resistance became an issue. However, the reduction in the incidence of common infectious disease led to a lack of familiarity with them and was one reason for low adherence to recommendations for immunization. The advent of acquired immune deficiency disease (AIDS) due to HIV infection was one reminder of the dangers of hitherto unrecognized pathogens. Another such case was the more recent appearance of the Zika virus.

Awareness that an individual has a specific infectious disease allows a number of actions to be taken. Diarrhea might affect a child whose parent is in an occupation that might put others at risk, such as handling food, caring for children, or working in healthcare. The child herself will be at risk to other children if she were to attend daycare. When a child has infectious diarrhea, a physician will give advice on reducing contact with others who might be vulnerable until the illness is resolved. In addition, public health will attempt to trace the source of the infection. If many children have infectious diarrhea, then the source might well be a fast food restaurant. Public health should be notified so that it may conduct a restaurant inspection.

An important infectious disease issue that is becoming more prevalent is that childhood infectious diseases that we thought had almost disappeared, such as measles or pertussis, are now being seen in populations whose parents have chosen not to vaccinate their children. In these cases, restrictions on the movement of unvaccinated children, such as not attending school or daycare while infectious, are appropriate and might well be required by law. These restrictions would apply to the contacts of the index case. Moreover, public health might use vaccine-preventable infections to publicize a continued need for parents to agree to vaccination of their children. Some governments mandate that children be vaccinated before they may attend school. Information on vaccination status is shared between public health and education authorities.

When sexually-transmitted disease (STD) is identified in a teenager, the infection is usually reportable to the public health authorities. But caution is required. It is important to establish from the teen whether he or she consented to sexual activity. If the STD is one that is required to be notified to public health, then the physician should do so. In every day medical practice, the laboratory that identifies the organism will have notified public health on an automatic basis before the physician evening knows.

Another area where physicians are obliged to breach confidentiality of a child's health information is when a subpoena is received. The subpoena might concern a number of different situations. The physician might have cared for a child who had been injured by the parents, or had been involved in a vehicle injury, and the prosecutor might want full information of the extent of the injury and illness. The parents might be in the process of divorcing and call a physician to the proceedings to give information on the child's condition. The physician might be called simply as a "witness to fact", in which case he or she will describe what they saw in the child. In giving evidence in this situation, physicians should confine themselves to what they saw and heard and should not go beyond their expertise. (A good rule to follow in all aspects of pediatric practice!!)

Sometimes the physician is called as an "expert witness", when he or she might need to give an opinion. Acting as an expert witness can be seen as a duty, but when a pediatrician is acting in this role, then he or she must remember that the role is to help the court make decisions, not to be an advocate. The "expert" might give advice to lawyers outside the court, might prepare formal reports that they should be prepared to defend, in criminal prosecutions, or in a civil lawsuit. The precise requirements to be an "expert" will vary from jurisdiction to jurisdiction, but at the very least, the person should be qualified and skilled in the topic at hand, will have appropriate training and education, and in general will have relevant experience. If the pediatrician is acting as an expert, then he or she will generally be given access to the child's health records, or at least to part of those records. Permission to access health records will have been given by the parent, the child if old enough, or by a court. Nevertheless, all of these records should be handled very carefully and should not be discussed outside the relationship of the pediatrician acting as an expert and the lawyer who requested the report. Detailed guidance is given in a publication of the American Academy of Pediatrics (Narang et al. 2017). While this is most relevant to the situation in USA, it has guidance that will be of general help to anyone who is to act as an expert witness.

The story of a British pediatrician giving evidence in a murder charge is worth retelling, because it shows how easily even experienced pediatricians might wander outside their expertise, and the human cost that might be born because of an injustice (Shaikh 2007). Sally Clark had two children who died suddenly and unexpectedly, with no clear cause of death in either child. The children might have fit the profile of sudden infant death syndrome (SIDS). This is not a diagnosis that can ever be made with certainty; it is a diagnosis of exclusion. The Crown prosecutor decided to charge her with murder of the children because she had been alone with them, and the prosecutor believed that having two children dying of SIDS was extremely unlikely. One of the prosecution witnesses was Sir Roy Meadow, a distinguished pediatrician. He was a specialist in kidney disease and rose to prominence when he described several cases where mothers had harmed their children. In some of these cases, the mother's actions had led to the death of the child. In his evidence in the Sally Clark case, Meadow claimed that the chances of two children dying of SIDS in one family was "1 in 73 million". Clark was convicted, jailed, after prolonged legal proceedings the convictions were overturned, and she was freed. It remains unclear why the children died. It is very clear that Meadow had no experience of statistics, and his claim of 1 in 73 million was nonsensical (Watkins 2000). He was subsequently censored by the British medical regulator.

5.20 Physician-Initiated Breaches of Confidentiality

The breaches of the obligation to protect the confidentiality of a child's health information listed above are mainly breaches mandated by the law. As stated, when the physician breaches confidentiality, such as by notifying a child welfare official of

suspected child abuse or notifying a public health authority about an infectious disease, or by responding to a subpoena, she is complying with and respecting a legal requirement. In the first two cases, the issue of notification relates to protection of the child, or third parties' other children in the family who might be targets of abuse or neglect, and people who might be affected by an infectious disease. There are different situations when a breach of confidentiality might be appropriate, in terms of protecting third parties, but the ethical issues are more complex, and some people argue that no such breach should ever occur. Even when it is appropriate, it is conceded that such breaches should be rare, such as when a physician is aware that the third person is at risk (Bozzo 2018).

The possibility of harm to third parties is highlighted in a US lawsuit, called the Tarasoff case. In this case, a therapist became aware during counseling of a young man that Tatiana Tarasoff's life was at risk. The counselor involved notified campus security in the University of California, but campus security took no action to protect Tatiana Tarasoff. Ms. Tarasoff was subsequently killed by the young man. Her parents successfully sued the University of California. Herbert (2002) describes the convoluted legal processes in his article that concludes that the Court of Appeal created a new legal responsibility: the "duty to warn".

In pediatric practice, the issue of protecting child health confidentiality might arise when dealing with troubled adolescents, often involved in dispute between parents. Any breach of confidentiality should occur only when the risk is real, and it is directed towards an identifiable person or persons. When in distress, many of the people we see will indulge in "venting" against others, which by itself does not lead to any requirement to warn. What we should conclude from the Tarasoff case, and the subsequent ethical discussions, is that there is a "duty to warn" when we receive information from a patient or family member that clearly puts a third person at risk. This duty to warn should be assumed and acted upon after careful (though not unduly delayed) thought and consideration and should be a rare event.

5.21 Confidentiality, Social Media and Technology

5.21.1 Definition and Effects of Social Media

The various forms of social media are a fact of modern life, and widely embraced. They are defined as "digital media and technologies that enable users to exchange information and to create media content individually or in community with others" (Denecke et al. 2015). They include Facebook, various blogs, Twitter, YouTube, MySpace, PatientsLikeMe, Wikipedia and so on. Facebook seems currently to be the most popular with a reported 2.2 billion people using this modality every month (Statista 2018). Facebook earns money from advertising to its users and is said to be worth more than US$500 billion. The same company is under criticism for its role in the United States presidential election of 2016 by misusing the power of its

advertising and for permitting the misuse for political purposes of the data it holds on Facebook users (Chadwick 2018; Dwoskin et al. 2018).

Presumably there is some boundary between revenue generation and protection of privacy, but it is unclear to these authors that protection of privacy and confidentiality is a priority of the companies profiting from social media. Most users are aware of some of the other drawbacks in social media, but not of the full extent. For example, information on social media can be used to facilitate identity theft and also to stalk and harass individuals. These introductory remarks are meant to illustrate the wider implications of social media. This section focuses on issues of confidentiality as they apply to social media use in healthcare and offers information for our patients who are described as "digital natives", individuals who have not known a time without social media.

Authors on this topic have taken varied points of view. Chretien and Kind (2013) write:

> It is an exciting time to practice medicine during our digital "coming of age." Social media, the freely available Web-based platforms that facilitate information sharing of user-generated content, such as social networking sites, media-sharing sites, blogs, microblogs, and wikis, have transformed the way we communicate as a society. Through community building, message amplification, rapid dissemination, and engagement, social media has changed our interactions with others and, by direct consequence, our relationships. For health care, this represents a veritable social revolution.

The details in the article are more nuanced than this quote suggests, and include cautions, but they do note the many benefits from widespread use of social media. On the other hand, Denecke et al. (2015), cited above, spent a great deal of time pointing out problems in social media, without in any way gainsaying the many advantages.

The benefits of social media to the healthcare practitioner are numerous. Social media make it possible to interact with a much wider circle of colleagues to help in complex problems and, at the same time, to make information more tailored to specific audiences and more accessible. Through social media, pediatricians can access support for their patients and families. An internet search by diagnosis will identify on-line parent groups. In any situation, but especially with rare disorders, these groups offer support to parents with a focus on children with a specific disorder. Pediatricians might find peer support for themselves when facing common situations, such as combining being a parent with providing medical care for the children of others. Physicians might also be able to find specialists with skills in specific rare diseases. Of course, great care must be taken to avoid use of identifying information. Social media can also be used for public health surveillance, and to influence health policy.

Pediatric patients who use social media are unlikely to engage in evaluation as to whether social media is beneficial or harmful because social media are part of their life, and always have been. Social media is the means by which young people connect with others, explore ideas, develop an identity, address problems, and receive feedback. Families might not understand all the ways in which young people use social media but see great benefit in such use. They see this means of communica-

tion at the very least as a way of gaining information and of forming supportive networks of parents facing similar problems. Many of them see other uses, such as developing political activity to achieve access to specific treatments or interventions.

The concerns about social media and healthcare are many, and at the forefront concern for the lack of quality control of the information available, and the lack of reliability. It can be difficult for families to apply information found online to the health situation of their child. There is frequently information overload, and sometimes information on social media deters families from taking their child to a health professional. It is becoming increasingly clear that there is very little privacy online, no matter how many precautions are used, and which "privacy settings" are used. Families might well be unaware of this lack of confidentiality and privacy, a fact that requires discussion.

5.21.2 Disclosure of Child's Health Information by Parents Online

Parents routinely breach a child's right to privacy of his or her medical information online. Parents can write stories that are vivid and lively, often illustrated, and of course such stories do not respect the child's privacy because the information is available for everyone to see. There is immediate availability in real time of personal accounts of the parents' experience. Publication of a patient's experience of illness is not new, but in the past, there were delay (days, months or years) before the information became available. Times have changed.

There are many social media forums that convey the same information, examples being Listservs, chat rooms, message boards and Web 2.0. One author has said dogmatically that, "Staff should generally not read online discussions about their patients without the patients' permission." (McKlindon et al. 2016). This seems an extreme position because it is not eavesdropping to read a public account of illness.

Consider, for example, this posting on a social media website by a mother who shares a picture of her child and discloses the child's age, the child's US state of residence and the child's health information (PatientsLikeMe 2018):

> Godsmiraclebaby She's 13 and lives in GA, United States, Living with epilepsy since 2007. Latest activity Jun 8, 2014.
>
> My daughter Tamyra is 5 years old born March 8, 2005. She was diagnosed with hydrocephalus (fluid on the brain) before birth. She was diagnosed with cleft palate at birth. She has been so many things, but God is always faithful to us. She has had 4 brain surgeries or shunt reevaluations. Because of the shunt she later started having uncontrollable seizures which doctors concluded to be epilepsy. My daughter is still battling like many others. But she is such a blessing and an inspiration to me and hopefully many other people.

This information shared with the world can identify the child and breaches the confidentiality of the child's health information.

Another mother posted on Facebook a picture of her child actually dying later commenting, "I shared it because even though it's a painful moment, it's a beautiful moment in our eyes" (Zwarensteyn 2018).

Parents use means other than existing social media platforms to share information about their children. Increasingly, they are using blogs to convey their experience of healthcare and to tell the world about their child.

Blogs are unsolicited, interactive and published in real time. Individuals start blogging and continue to blog for reasons that are unique to their circumstances. Illness blogs are the online version of personal journals, but with the interesting, but thus far unexamined, dimension of interactivity with family members, friends and strangers who respond to entries in real time (Heilferty 2011).

Pediatricians must accept that they might be featured in blogs posted by parents, family friends, or even by patients themselves. It is important that we react and use positively the blogs by our patients, well-known patients, or family members who openly discuss their medical journey.

Although, there is little we can do to stop parents' revealing their child's medical information, we must help the parents understand that while it is one thing for a parent to disclose their own health information, it is another for parents to do so about their child. The health information a parent has about his or her child, is held only in trust by the parent. It belongs to the child and so parents should not share it unless they can sincerely agree that at the age of majority, the child would be glad to see that information on line. Social media's invention and use also give rise to the question as to how to respect the dignity of the dying child.

5.21.3 Disclosure by Pre-teens and Teens of Their Own Health Information on Social Media

In addition to parents, many children, and especially pre-teens and teens, give online accounts of their experience of illness. Again, it is not possible for us to stop this. The best we can do is to give information to our patients that the release by them of this information on websites means that the information can be viewed by the whole world and cannot be erased. We must encourage these minors to imagine how they will feel as they mature about having their information available to others, for example, to possible dating partners and to reflect on the notion of themselves as adults.

5.21.4 Use of Social Media to Gain Advantage

McKlindon et al. (2016) quoted above, described a hypothetical situation whereby a family used social media to draw attention to the plight of their child, and to press for access an uncommon form of treatment. The hypothetical situation was derived from a number of real situations: a 10-year-old boy experienced cancer, was discharged

home, then readmitted 1 year later with a relapse. The parents launched an online petition to allow the boy access to a novel biological agent which had not had formal government approval. The institution and physicians learned about this petition only when the media arrived at the hospital and requested interviews. The physicians agreed to use the agent on a compassionate basis, if the company would make it available. The authors than tell us the end of the story and move to a discussion of the ethical issues that arise. They point out that:

> In many ways, the ethical challenges raised by social media are similar to those that health care professionals have always encountered. Clinicians have long worked to protect patient privacy, maintain appropriate therapeutic boundaries, help patients and families make difficult decisions, and treat all patients fairly. (McKilindon et al. 2016)

They also note that, "What has changed is the speed with which complex issues can be publicized and the fervor that can result."

The main ethical challenges regarding the use of social media to obtain unusual medical treatment for a child identified privacy, maintaining boundaries, and fairness. In terms of privacy, the parents might decide not to protect the child's privacy, but the institution and the staff must continue to protect the child's privacy because, as we have discussed, it is their professional obligation to do so. The fact of unbalanced protection of the child's privacy can lead to problems in communicating with families, and in communicating with the media. When a pediatrician is caught in this situation, he or she should seek help from public relations staff on how best to frame responses. In these situations, the parents often forget that the protection privacy of confidential health information is required to respect what belongs to the child, and that this breach of privacy will live online forever. In addition, parents might breach the privacy of other children in this situation by discussing how these other children have been treated. This asymmetry in privacy protection, where parents can readily breach it, and we healthcare providers may never breach it, might be unfair. Nevertheless, no matter the provocation, we must maintain vigilance to protect privacy. Consider, as an example, the appropriate response of a Canadian hospital administrator concerning two children whose parents would not consent to necessary treatment. "Dr. Fitzgerald, the hospital president, said he could not comment on either girl's condition, citing patient confidentiality." (Grant 2014).

Social media's use to gain an advantage for one's child invites physicians to blur the boundaries between themselves, and their patients and families. This is a temptation that physicians must resist. The widespread use of the word, "friend" in social media has bred confusion. The word is used very loosely to describe someone with whom we are in communication by social media. In terms of maintaining boundaries, we do intend to be friendly with the families, but we are not truly their "friend", and we should avoid using this terminology. Having said that, the specific word is so widely misused that it is unlikely that anyone of us can change this use of the English language. All of us should be aware that the boundaries that exist when we see families face-to-face, exist also when we see them online.

The use of social media to seek an unusual intervention, usually expensive, and usually not generally available raises the issue of fairness. Social media is not available to all parents who would like to use it to mobilize the public and the media is

not available to everyone, and if the specific biologic agent is appropriate for the child subject to the campaign, then we should ensure that other children in the same situation also have access to the same treatment.

5.21.5 Social Media in Physicians' Day-to-Day Work

To return to every day practice, many pediatricians use social media to communicate with families with items such as appointment times, requirements for appointments, and communicating results of tests. We recommend that the ordinary rules applying to confidentiality and privacy be respected, and that these actions are appropriate, but as with everything else, action needs to be taken carefully.

5.22 Pediatricians' Personal Use of Social Media

Pediatricians are individuals, with a personal life. This statement of the obvious is still necessary, because pediatricians, like all physicians, have a special place in society. This fact means that they need to work carefully to preserve the boundary between the personal and professional life, and to think carefully regarding disclosure of personal information to patients and families about themselves. This is so important a concern that the American Medical Association (AMA) offers advice to physicians on social networking (American Medical Association 2015). The AMA recommends that private and professional parts of a physician's life should be kept separate, and physicians should use the highest levels of privacy settings to safeguard their personal information. Having said that, physicians should realize that privacy settings are not absolute. Physicians are not the only group to learn that once information is on the Internet, it is probably available permanently.

5.23 Are Physicians Entitled to Privacy Regarding Their Own Lives?

We have outlined in this chapter the importance of the healthcare professional protecting the confidentiality of the family for which they are providing care. Healthcare professionals acquire a great deal of very personal, intimate information about children and families in the course of their everyday work. However, the interaction between the healthcare professional and the child and family is not impersonal; it is a human, and emotional, interaction. The feelings of the healthcare professional in this interaction matter; there is an increasing insistence on empathy on the part of the healthcare professional. The healthcare professional is seen as a human being with feelings, not as an unemotional, dispassionate participant in a consultation.

This revision of relationships within a healthcare consultation raises further issues regarding how the healthcare practitioner should behave. Specifically, how much information about the practitioner including details of his or her personal life and health history should the practitioner share with the patient?

Healthcare practitioners are quite entitled to decide to go public with information about their personal health care history, but are patients entitled to full information about the physician? One illustrative case occurred with a surgeon with Tourette syndrome, a neurological disorder characterized by tics, involuntary touching, and involuntary vocalization, among other features (Hallett 2015). The surgeon concerned became a spokesperson for Tourette's syndrome, and many news articles have been written about him and his affliction. The famous writer and neurologist, Dr. Oliver Sacks (1962) even wrote a *A Surgeon's Life* based on his life. In this case, given the obvious nature of the tics and involuntary movements in the consulting room, the surgeon felt it essential to reassure patients by telling them about his condition. He emphasized that the tics had never appeared in the operating room. He worked in a small community where his reputation mattered, and his reputation was positive in terms of his skills (Yu and Ganesh 2014). This is an example of a genetic condition that cannot be avoided, and healthcare professionals might be as likely as any other individual to have such conditions.

This case might be seen as exceptional and as requiring disclosure, but should physicians with healthcare problems disclose them to patients? Healthcare professionals might also be attracted to a field which is concerned with the condition which affects them, in other words they have the condition before they become healthcare practitioners. There is no doubt that the concept of the "wounded healer" is popular in the lay press, and such practitioners might be willing to inform patients and families of the conditions, in the belief that it might improve empathy. Healthcare professionals have an increased incidence of alcoholism and substance abuse. If they have conditions that might affect their performance, then should patients and families be made aware? Healthcare professionals have an increased exposure to some conditions, specifically infections, and this fact has led to a great deal of discussion in the literature as to how much patients should know about healthcare professionals who have chronic infection.

Anxiety about the possible transmission of infectious disease arose specifically with the rise of AIDS in the 1980s (Jonsen et al. 1986). Yet, individuals with HIV infection now have a much better prognosis than their counterparts did in the 1980s because of the availability of effective anti-retroviral therapy. While in the past, there was considerable pressure on all healthcare practitioners to disclose whether they had HIV infection, this pressure has subsided considerably. Currently, we would suggest that physicians or other healthcare practitioners with chronic infection should notify their institution and their regulatory bodies. The vast majority of patients are not at risk from these physicians. Those patients who are at some risk are those on whom the procedure is being performed, where there is a risk of the surgeon's skin being pierced by a scalpel or a needle and the possibility that the surgeon's blood might infect the patient.

We would not suggest that those physicians who are at risk for specific infections because of their behavior, such as having multiple sexual partners, disclose this fact to patients. However, we suggest strongly that these physicians have a duty to be tested for such conditions as HIV and hepatitis B, and that they seek medical advice regarding the best approach to their infection, if the tests are positive. They should also inform the regulatory body and their institution and seek further advice on whether their practice should be modified, and whether there should be any monitoring (Johnston 2018).

In the larger context of whether healthcare practitioners should discuss their own health to patients, it should be remembered that these healthcare practitioners are themselves patients and are themselves entitled to confidentiality. This obvious fact reminds us that healthcare practitioners, and specifically physicians might choose not to have a regular physician, especially a colleague, fearing that otherwise their confidentiality might be compromised. We would remind all physicians that the duty of confidentiality applies to all patients whom we see and that includes colleagues.

The discussion so far has been in the context of the putative risk of physician illness to patients. In other contexts, is self-disclosure of physicians' lifestyle and medical history of benefit to medical practice? Allen and Arroll (2015) explored this subject by interviewing a number of family physicians. The authors noted that there is dispute as to whether disclosure by physicians of personal facts enhances physician-patient relationship, is detrimental, or indeed becomes an issue of violation of conventional boundaries. The 16 family physicians who were interviewed did self-disclose on the basis that they believed such disclosure created empathy. However, there was considerable variation about the specifics of self-disclosure, with comfort around disclosing family hobbies and experiences of physical illness. Experience with mental health and adverse relationship issues were less commonly shared. The participants in the study, whom, it must be remembered were volunteers, reported only positive outcomes from their self-disclosures. Given the positive publicity with which narratives from "wounded healers", are usually received, it seems likely that patients welcome such self-disclosures, though this does not seem to have been formally studied.

5.24 Confidentiality and Education of Health Care Professionals

Jessica was in her second year as a pediatric resident and had completed a rotation in general pediatrics two weeks previously. She was in the elevator when Michael, also a second-year resident, but currently doing the rotation that Jessica had just completed, entered along with several other people. Jessica had been very involved with a two-year-old child with complex congenital heart disease who had been scheduled for surgery just as the rotation ended. Jessica had thought a lot about this baby since she moved on to the next rotation. She asked Michael if the operation had gone well.

5.24.1 Confidentiality and Education Overview

On the face of it, Jessica was asking Michael to breach confidentiality in public. Of course, her concern for the baby is admirable (and it is very common for pediatricians and pediatric trainees to care a great deal for the children under their care). Moreover, we might believe, as a trainee, that she is "entitled" to this information but should have asked Michael in a private area. Perhaps she should have just accessed the chart by herself. She also might have emailed Michael, or being aware that the parents were in Facebook, might have accessed their posting about the baby. Despite these qualifications, confidentiality is as important in pediatrics as in any other part of medicine and Jessica was clearly seeking to breach the child's confidentiality.

We might assume that the issue with this breach of confidentiality by Jessica was a brief moment of carelessness, or a transient indiscretion. The story of Jessica who acts from concern for the well-being of the child, and to further her own educational experience, is a story of a well-intentioned pediatric trainee who has erred in asking for information to which she is not entitled. Her admirable motives do not justify this attempted breach of the confidentiality of the health information of a child.

There are circumstances, however, in which the trainee might have been entitled to know the outcome of the surgery. The word "entitlement" is used, to imply more than simply satisfying curiosity. If Jessica had requested information from Michael in an area where she could not have been overheard, that request would have been justified. There are pedagogical reasons to seek such information; trainees on specific rotations can need to know the outcome of interventions and investigations that they might have initiated. This information is clearly educational but is also important that the trainee knows what happens to patients. Such information is invaluable when trainees meets patients in similar situations later in their professional career. Without placing specific time limits, it is important to recognize that the pedagogical benefit to the trainee does not give the trainee permission to access information about a patient indefinitely. This pedagogical need does give permission to access the patient's electronic health record, at least in the short term.

5.24.2 Bedside Teaching and Confidentiality

We opened this section with the story of a trainee taking the initiative to further her education. Another form of education, direct interaction with the child and family, led by an experienced preceptor, is a very valuable way for medical trainees to learn. This so-called "bedside teaching" was advocated strongly by renowned McGill, University of Pennsylvania, Johns Hopkins and Oxford professor of medicine,

William Osler, in the early twentieth century. Such teaching is still relevant. Bedside teaching helps pediatric trainees become knowledgeable and skilled and can model the observed interaction between the experienced pediatrician and the child and family. Such bedside teaching is in decline, perhaps because of time pressure on all concerned, and because of a common assumption that use of modern technology and simulation will be a more effective educational modality. Often "rounds" may be a meeting in a room to review the current status of patients. Wherever the discussion of the child actually takes place, at the bedside or in a conference room, such situations are teaching opportunities. If the discussion takes place at the bedside, the action of a preceptor in appropriately handling sensitive and confidential information can be a model to be emulated by the trainee.

A further question about teaching on rounds is whether the parents should be present in the 'classroom'. Should the parents attend these discussions of the child patient? Wang-Cheng et al. (1989) state that "Patient and family presence has been viewed as an impediment to bedside teaching, despite the fact that the majority of patients viewed bedside case presentations as positive." A number of studies have confirmed that, generally speaking, parents prefer to be present (Davidson 2013). For example, the parents' preference to be present has been confirmed in randomized studies in both pediatric intensive care (Landry et al. 2007) and in ambulatory settings (Baker et al. 2007).

For those preceptors who lead bedside rounds, and for those trainees who participate, a stepwise approach will ensure that such teaching is conducted in a manner consistent with ethics norms. In most cases, the presence of the family is an affirmation of their importance. As Davidson (2013) said, "parents are not considered visitors in pediatric ICU". First, families should be asked if they wish to be present during rounds, and their wishes should be respected. The focus on bedside rounds should be on the current status of the child patient, results of recent investigations and immediate plans. If there is a need to discuss more sensitive issues, such as problems with family dynamics, or obviously emotional issues such as whether continuing intervention is justified on a number of grounds, then these discussions should take place in a separate private area at a time when there is support for the family. Second, any privacy concerns should be identified, and a risk reduction strategy agreed upon between the healthcare professionals and the family. This strategy might be something as simple as asking a family in an adjacent bed to step aside briefly when a specific patient is being discussed. Communication that takes part in rounds should be recognized as only one part of overall communication with the family. However, the communication that takes place in bedside rounds must be communication not only among doctors but also between doctors and parents, and it is this aspect that parents' value. Parents have the opportunity to offer observations on the child that staff might not have identified, and to ask for clarification when specific ideas have been discussed. Typically, this parental contribution does not prolong the time taken for rounds (Baker et al. 2007).

Parents can sometimes help physicians learn how to manage awkward matters. As Patel et al. have written,

> "Similarly, we grappled with parent involvement on ward rounds. We wanted to support their active participation but worried about confidentiality. Staff could not agree, but parents gave us a workable solution. The majority told us that they did not mind other families being present, had no interest in eavesdropping and understood if they were asked to step out. They favoured a flexible, pragmatic policy and trusted staff to manage this" (Patel et al. 2017).

The child will be present in the bed. Many will be infants or toddlers and indifferent to the presence of the group of physicians. But older children might be sensitive to becoming an object of discussion. It is important to stress that one of the first actions of the preceptor who is leading bedside rounds is to give some consideration to the feelings of the child patient and to answer questions that the child raises. If the child is upset or embarrassed before, during or after the rounds, even if the parent feels better informed, then something has gone wrong. While, in general, we support the involvement of families in teaching, we are disappointed that we cannot find information in the literature on how best to handle the child patient. The literature focuses on the parent, almost entirely.

5.25 Conclusion

Protecting the confidentiality of health information is one of the most fundamental obligations of healthcare practitioners towards patients and their families. In many instances, a child's health information seems to be something that parents "control", at least until we deem that the child patient is mature. However, confidentiality is part of the respect we owe all child-patients; any access to the information is entrusted to their parents only so that they can act in the child's best interests.

Confidentiality is not absolute. There are occasions when confidentiality must be breached in the interests of the child. These include issues of child abuse and when helping the child comply with treatment while in school. There are other occasions when confidentiality must be breached to help others, specifically the notification of infectious disease. There are still other occasions when confidentiality might need to be breached because of a legal order. Sometimes we breach confidentiality to protect others when we become aware that there is a high likelihood that one of our patients might harm a third party.

Some of the ideas we have about confidentiality are evolving. In this context, we cite the fact that genetic information about the child can have implications for other family members. At present we maintain personal confidentiality regarding genetic information, but it is likely that this attitude will change in the next few years.

Please remember, the basic principle is that a physician's duty to respect patient confidentiality is both the basis of a strong relationship between physicians and patients, and a necessary condition for professional behaviour.

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Part III
Everyday Issues

Chapter 6
What Happened Before Birth and How Is This Relevant to the Child Now?

Key Points Concerning Conception, Pregnancy and Early Neonatal Care

- Preconception genetic testing and screening can contribute to child health.
- Pregnancy testing is:
  - Optional;
  - Can provide useful information about the health of the fetus; and
  - Can provide useful information about the child after birth.
- Reproductive freedom is an international norm.
  - Pregnant woman of any age generally has autonomy to make decisions about her life and the pregnancy.
- Maternal life style (e.g. diet, drugs and nicotine) is relevant to fetal outcome
  - However, changes to benefit the fetus must be encouraged not coerced.
- Termination of the pregnancy is part of reproductive freedom, but legislation or threat of shunning or violence might limit availability.
- Mode of conception is relevant to pediatric care:
  - Advanced reproductive technology (ART) is any manipulation of conception and gestation outside sexual intercourse that results in a pregnancy in the same body;
  - May occur because of subfertility (including effects of childhood diseases), woman is single, or same sex partnership).
  - Outcomes for the resultant pregnancy are generally favourable.

    Slight increase in neonatal morbidity.
  - The resulting children are entitled to know their genetic origins.
- Premature delivery might or might not lead to a live child.

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_6

  - Major advances in neonatal care make survival possible after 23 weeks' gestation; and
  - Collaborative decision-making in premature labour (mother, neonatologist, obstetrician is important).

- Neonatal screening:
  - Allows early diagnosis and treatment of serious health problems;
  - Might identify conditions for which there is no treatment; and
  - Might identify findings with no implication for the child's health.

6.1 Overview of Topic

This chapter addresses the ethics of managing pediatric-related events before conception, during the process of conception, during pregnancy and in the immediate aftermath of delivery. These topics are very important to the work of pediatricians, even if not every child is adversely affected by events prior to their infancy.

Today, medical science and healthcare systems can offer women tests and procedures related to pregnancy and childbirth. Such tests and procedures were developed to promote a woman's autonomy in making decisions for herself and to improve outcomes for desired pregnancies. These two goals (promoting a woman's autonomy and improving the outcome of desired pregnancies) can sometimes be at odds, where for example, a woman has a desired pregnancy and a test reveals that the fetus has a condition that will lead to a child with medical complexity. On the one hand, she might want to advance her autonomy by deciding to terminate the pregnancy, and on the other, a decision to terminate the pregnancy means that there will not be health outcomes for a child. Women do most of the reproductive labour in bringing a fetus from conception to the stage at which a resulting child can fend for itself in the world. Consequently, it is an international norm that women should have liberty and power to decide when and how they wish to expend their reproductive labour.

In relation to this norm, pediatricians sit in two positions. For example, with a first pregnancy and delivery, pediatricians are typically 'downstream' from decision-making and medical treatment of the woman. Whatever happened, (for example, a decision not to terminate a known Tay Sachs pregnancy, a refusal to have a cesarean section when so advised, or birth anoxia), pediatricians must deal as best we can with the child and the family before us. Whatever personal and medical decisions that were made before conception or during pregnancy, including during labour and delivery, those decisions were made in the past. Pediatricians must handle discussion of these past opportunities or events very carefully as they work to deliver care to the child.

Regarding a subsequent pregnancy, however, pediatricians might be asked for information and advice. Here, the decision making is not past but in process. Such conversations must also be engaged in with great care though there is perhaps more opportunity for the pediatrician to address prospective suffering. Genetic testing is

a rapidly advancing field, and it is our responsibility to ensure access to the best advice when parents are planning another pregnancy on the assumption that the woman is better positioned to make decisions about allocating her reproductive labor when she has reliable information.

This chapter aims to address how the pediatrician and pediatric trainee can best help ensure that the women are supported in decision-making and that outcomes of their reproductive labor are good.

6.2 Introductory Story

Arianna was excited when her sister Nora became pregnant. The two sisters had been very close during childhood and remained in almost daily contact. Arianna looked forward to becoming pregnant eventually but wanted to wait a few years. There was great family excitement when Nora's child Kaylee was born at term. Kaylee had some difficulty in finishing her feeds, but a lactation consultant helped Nora in the initiation of breast-feeding. When the problem persisted, the lactation consultant suggested that Nora should take Kelly to see a physician. The pediatrician who saw Kaylee noted generalized poor muscle tone and referred her urgently to see a pediatric neurologist. A diagnosis of spinal muscular atrophy I (SMA I) was made.

Nora and her husband had extensive meetings, discussions, and counseling with medical and support staff, and also joined a Facebook group for children with SMA. During this period Kaylee deteriorated, and required intermittent non-invasive ventilatory support.

Nora and her husband were introduced to the local pediatric palliative care team and opted for comfort measures. They were given support to care for their daughter at home. Kaylee died at four months of age.

Arianna had been present at a number of the discussions and learnt that SMA was an autosomal recessive disease. She and her husband sought genetic counseling to determine whether they were carriers before she would even consider becoming pregnant.

6.3 Preconception Genetic Testing and Screening

Preconception genetic testing is conducted on the parents' blood (or saliva). Unlike testing during pregnancy, preconception testing is seen as non-invasive and low risk. The results will indicate the probability of a child of these particular parents having or not having a condition. The parents have a number of decisions to make once the probabilities are calculated, and assuming they understand the concepts of risks that are explained to them by genetic counselors. They might decide not to have their own genetic child, or might decide to initiate a pregnancy, request early pregnancy testing, and at that time consider termination or continuing the pregnancy. They may also decide to use some form of ART, and implant only those embryos that do not have the condition.

We appreciate that we run the risk of being misunderstood by referring to "the parents" and "they" when the legal decision maker is the pregnant woman. Our hope is that prospective parents who are at risk, or who think they might be a risk, for a genetic disease, will discuss this matter carefully with one another, and listen to the counselors. In general, it is helpful in any medical consultation for two people to attend. When the discussion in the consultation is reviewed later, two minds can compare perceptions of what was said and can share ideas. They can consider the future of themselves as a couple, and perhaps as a family if they decide to go ahead and attempt a pregnancy. When it comes to issues such as testing during the pregnancy, or considering termination, again, in an ideal world, decisions should be taken jointly. However, there should be no doubt that the woman is the final decision maker.

The challenge for pediatricians in those meeting with couples is that it is very difficult to have insight into the underlying relationship. If the wife does most of the talking and asking questions, then we might happily assume that she also takes the decisions. The reality might be different. Once at home, the husband or partner might dictate actions to be taken. Conversely, if the male partner does most of the talking during the consultation, then we might be concerned that this behaviour implies that he is taking all of the decisions. It is likely that we are right in that assumption, but we can never be sure. Our advice is to take the greatest care in how we request permission, and from whom, in all such sensitive consultations. We should make it very clear from the outset that the decision-maker, when it comes to testing during pregnancy or considering termination, is most assuredly is the woman.

The preceding paragraph deals mainly with heterosexual couples. In same-sex couples, with present technology, genetic material can come from only one partner. Again, the person who gestates a pregnancy is the decision-maker regarding pregnancy-related matters including prenatal testing.

To return to Kaylee's story, she has SMA, a severe neuromuscular disease with degeneration of motor neurons in the spinal cord. The condition entails progressive proximal muscle weakness and paralysis. Kaylee could well be described as a "classical" case of SMA. Nora and her husband chose palliative care for Kaylee. The availability of pediatric palliative care has led to a vast improvement in end-of-life care for children and, therefore, for their parents. At the same time, the response of parents to information that the child has SMA is changing; there are currently a number of options actively to treat children like Kaylee including expensive medicines. The ethical issues involved in extremely expensive experimental medicine for rare disorders is discussed in Chap. 9 "Advocacy" and Chap. 15 "Resource Allocation". SMA is described in one publication as "the second most common fatal autosomal recessive disorder after cystic fibrosis, with an estimated prevalence of 1 in 10,000 live births and a carrier frequency of 1/40–1/60" (D'Amico et al. 2011).

As an aside, this last sentence – and its claim regarding the prognosis of children with CF – by itself raises many issues relevant to modern pediatrics. With the rapid development of new therapies, diseases that were once considered fatal might no longer be fatal. Certainly not so long ago, in the 1960s and 1970s, cystic fibrosis was fatal. However, today, cystic fibrosis is rarely fatal in childhood. Perhaps SMA will cease to be a fatal illness soon.

Arianna has a very specific question that she would like answered before she considers pregnancy. Testing is possible on Arianna and her husband and will tell them with a high degree of probability whether one or both are carriers for the SMA gene. Conducting this test in this situation is justified because it is respectful of Arianna's autonomy, and can help prevent the conception of an infant with SMA, something she might consider a harm. However, some physicians suggest that the whole population should be tested to detect SMA gene preconception (or early in pregnancy), not after individual request as in Arianna's case. This proposal raises different ethical issues and if done must follow genetic counseling to include a description of SMA, including the variation in severity, and also an understanding that molecular testing does have limitations. The testing should be voluntary.

Pre-conception testing on a population basis, is available for a number of disorders in addition to SMA. This form of testing started with Tay-Sachs disease. Tay-Sachs is another autosomal recessive disorder in which infants lose the ability to roll over by 6 months of age, then seizures develop, and death commonly occurs in early childhood. It is seen in Ashkenazi Jews, some French Canadians from Southeastern Québec, and Cajuns of southern Louisiana. Enzyme tests were used before molecular testing was available, and it has been estimated that, using both tests, more than 1.4 million people have been tested since 1970 to determine whether they carry the gene for Tay-Sachs disease (Kaback 2000).

In the case of Tay-Sachs Disease, testing was conducted on both married couples and high school students (Mitchell et al. 1996). In married couples, if carrier status is confirmed in both partners, then the decisions outlined earlier in this section must be considered by the partners. Should pregnancy be avoided? Should pregnancy be attempted, and fetal diagnosis performed? If fetal diagnosis is positive, then should the pregnancy be terminated or carried to term, recognizing that there will be a neonatal death? ART was not an option when this testing started. In some areas, high school students were tested, presumably to influence choice of partner (Edelson 1997). The stated goals of one high school (Mitchell et al. 1996) testing programs are to:

- Communicate relevant information to the communities at high risk […];
- Identify carriers by reliable screening tests;
- Inform the carriers confidentially about their test results; and
- Facilitate making informed decisions about reproductive options later in life and to obtain prenatal diagnosis, if desired.

Kaback (2000) suggested some pre-conditions before we embark on population-based pre-conception, or early pregnancy, genetic testing of prospective parents. These are:

- Availability of an accurate test, allowing for molecular polymorphism;
- Voluntary nature of program;
- Effective education;
- Valid consent;
- Availability of counseling;
- Attention to privacy and confidentiality.

The American College of Human Genetics is concerned with the whole issue of preconception or early pregnancy testing in an era with the possibility of speedy whole genome sequencing and micro array hybridization analysis (Grody et al. 2013). Early whole population preconception screening until recently was confined to single gene recessive disorders, such as cystic fibrosis, spinal muscular atrophy, and some conditions relevant for specific populations. The College believes that for whole population carrier screening, we should have clear criteria. In addition, any laboratory performing the tests should be fully compliant with all standards, including quality control. The considerations advanced by the College are:

There must be definite clinical association between limitations and the severity of the disorder;

Disorders included should be sufficiently significant to affect reproductive decision-making. There are specific problems in disorders with variable expression, incomplete penetrance, or with a male phenotype, and these should all be explained;

If adult onset disorders are included, then there should be a specific consent for such testing;

For every disorder included, the gene's mutation and mutation frequencies should be known so that if there is any residual risk in a negative test, then the risk can be calculated.

These recommendations are made in an attempt to be respectful to future parents and their offspring, and to avoid doing harm. However, test results, once conveyed to prospective parents are presumably a prelude to moral decision-making by the partners about what action they should take. Should the partners go ahead with natural conception and continue the pregnancy to term? Should they avoid natural conception and use some technique of ART? Should they conceive and request early pregnancy diagnosis, with possible risks to fetal survival whether or not the fetus has the targeted disorder? If the diagnosis is confirmed, then should they request a termination or carry the affected fetus to term?

The focus of ethicists has been on the newer modalities of testing, and specifically on both the benefits and the problems raised by extended genetic testing. The benefits are access to the results of, we hope, accurate predictive tests. Some predict problems if testing becomes easier in that termination in some conditions will become "routine". In this regard, most anxiety concerns trisomy 21. Extended testing might disclose conditions that are minor or that are only manifest in adult life. In both situations, parents will be faced with difficult decisions.

It is important to remember that there are other forms of preconception counseling and treatment, well within the ambit of conventional, standard medical practice (Beckmann et al. 2014). These include reviewing diet, particularly folate intake, immunization such as against influenza and hepatitis B, assessing optimal weight gain, managing hypertension, and screening for gestational diabetes. Attention to these factors improves maternal and neonatal outcomes.

Given the rapid changes occurring in genetic testing, new benefits, and new problems, will surface!

6.4 Pregnancy or Prenatal Testing

Layla Gutierez is aged 30 and is pregnant for the first time. This is a wanted pregnancy, which she intends to carry to term. Her sister is an operating room nurse in a pediatric facility in another town, and is also excited about the pregnancy, and maintains frequent contact with Layla. She encourages Layla to undertake all the routine pregnancy tests.

Pregnancy testing is now commonplace in the developed world.

Some tests related to genetic conditions are similar to those listed in the previous section on preconception testing. More tests are available during pregnancy than prior to conception, and the menu of tests is rapidly evolving. Prenatal ultrasound can be helpful in the first trimester in estimating gestational age, number of fetuses and in screening for some congenital abnormalities. Obstetricians regard this first trimester "dating ultrasound" as important in managing routine care and especially managing a pregnancy when it continues past the 40-week period and identifying a multiple pregnancy. In Canada and the UK, the value of an early ultrasound is stressed. The Society of Gynecologists and Obstetricians of Canada (2018) suggest this might be done 11–14 weeks gestation and in the UK the National Institute for Health and Care Excellence (2017) suggests 10–13 weeks. The American College of Obstetricians and Gynecologists (2017) puts less stress on this ultrasound but suggests that it ought to occur in the "the first trimester".

By contrast, all three organizations strongly advise an ultrasound at 18–20 weeks gestation to give detail of fetal anatomy and position of the placenta. Some fetal anomalies which can be identified on ultrasound can dictate where the delivery should occur. For example, a cardiac anomaly can mean that the woman should deliver where there are specialized neonatal cardiac services. Other tests that women are advised to have during pregnancy have specific indications such as a known genetic risk to the fetus (as discussed in the section above), or maternal illness such as diabetes mellitus.

The tests advised, ultrasounds as described above, are clearly important in planning the best possible care for the pregnancy and in identifying fetal anomalies. That is, they are about beneficence. It has become commonplace to describe the tests as "standard", implying that the woman should not be asked to consent before the test proceeds. All tests, even those aimed at detecting major problems with the pregnancy such as placenta previa, or anomalies in a fetus, should be conducted on a voluntary basis. It is appropriate to describe offering the tests as standard, but the test should take place only after information about the risks and benefits is given and consent received from the pregnant woman. This takes time but can be helpful because it is likely that many pregnant women will be unaware, for example, that with some fetal anomalies, if the woman intends to continue the pregnancy, delivery can safely take place only in a small number of hospitals.

The temptation for physicians to offer Non-Invasive Prenatal Testing (NIPT) and for women to accept this early, reliable and safe test is easily understandable. This is a non-invasive blood test that measures the amount of cell-free fetal DNA circulating in maternal serum. Consequently, the test has become "routinized" which is

the process of an innovation becoming standard. “Routinization” might affect reproductive autonomy. Kater-Kuipers et al. (2018) have pointed out that the routinization of NIPT might affect informed choice, freedom to choose, and might have an impact on people with disabilities. With respect to informed choice, choosing an NIPT seems so obvious, that the near certainty of results leaves less time to deliberate, and might increase terminations because of the pressure to perform the tests as early in the pregnancy as possible. Regarding the woman’s freedom to choose, there might be societal pressure on the woman to have the test, which pressure might manifest itself as simply innocent questioning from friends about results. There are general concerns about prenatal screening identifying disorders such as trisomy 21, leading to pressure to terminate. In turn, this testing and the decisions taken by women with positive results to terminate the pregnancy might lead to discrimination against those children and adults with trisomy 21.

Consequently, we believe counseling is required before these “simple” tests are conducted. Is reproductive autonomy respected with NIPT? The casual booking of the test by a receptionist (quiet ‘railroading’) without the physician discussing the test with the pregnant woman is a denial of reproductive autonomy. We will know that reproductive autonomy is respected when it is easy for women to decline the tests, and it is easy for them to decline pregnancy termination. This last statement does not mean that the availability of the tests is wrong or that gaining knowledge that might lead to termination is wrong. It does mean that both the testing and the determination about how to respond to test results should occur only after thoughtful consideration. Clearly it is up to the woman to decide about testing and about termination.

Verweij et al. (2013) used questionnaires to explore the possible effect of NIPT on the behaviour of pregnant women. The results seem to suggest that there would be an uptake in NIPT testing compared with current options especially in those women who would terminate a pregnancy if the test were positive. Their opinion was that some women avoided testing because of the possibility harm to the fetus via of miscarriage. However, these women thought that counseling was inadequate; it focused on the test, not the outcome. If we are able to make a definitive diagnosis of trisomy 21 early in pregnancy, then there is more time for detailed counseling about what the diagnosis means, and what the life of the child would be like, and what the life of the family would be like. These authors supported NIPT as a way of improving reproductive autonomy. The topic of whether or not to test for trisomy 21, and whether or not to terminate if the fetus is shown to have this condition is widely discussed. For a range of views on this issue see the article by Fogle (2017) in a popular magazine.

Most pregnant women want reassurance that the child is normal and are very willing to undergo ultrasound at the suggested times, because the test does not seem very invasive. It does not entail drawing blood, or amniotic fluid or biopsying the chorionic villus though the probe can be used transvaginally. However, the results of ultrasound testing can be disconcerting and uncertain. Disconcerting results disclose a major anomaly that is unlikely to be associated with survival of the fetus once it is born. In this case, the woman in discussion with her partner might opt to

continue the pregnancy, without resuscitation once the baby is born, and with palliative care. They might also choose to terminate the pregnancy once a diagnosis is confirmed, though as we have emphasized the ultimate decision maker is the woman. Yet the results might be uncertain, but still disconcerting. There might be findings that may resolve. The current form of ultrasound discloses a degree of detail not seen in the past. Sometimes the precise diagnosis and the prognosis is not certain even though there are undoubted abnormalities. An example is a choroid plexus cyst. These brain cysts often resolve. The woman is told that there is cyst in the fetal brain, but no need to worry!

In the latter situation, when a prognosis, and sometimes an accurate diagnosis, is uncertain, considerable patient support and counseling is required. In Sect. 2.6 of Chap. 2, we told the story of a pregnant woman's ultrasound that revealed that the fetus had renal cysts. In that chapter, we focused on the boundary issues that arose. Now, we focus on the issue of uncertainty. Uncertainty is a pervasive reality in medical practice. Some physicians are uncomfortable with the fact that there are many situations in which we do not have sufficient information or knowledge to make a diagnosis; such discomfort can lead to overuse of diagnostic tests and sometimes errors. In other physicians, uncertainty can lead to overconfidence (Hatch 2017).

Patients and their family members are often ignorant of the reality and frequency of uncertainty. We do not help them when we make dogmatic statements. A woman has the ethical and legal authority to take decisions that affect her body. We hope she will discuss all of the issues with her intimate partner. Many women also seek advice from other family members such as a mother or a sister. The woman will often be relaying medical information to others; we must be careful to be truthful. Making overconfident assertions is not being truthful. We encourage our readers to follow the advice of Hatch (2017):

> In practice, the admission of uncertainty forms the starting point for a more open conversation between patient and clinician. By being more direct about our limitations, we are likely to foster greater trust and hopefully greater confidence in our joint efforts to manage the patient's condition. We ignore those benefits at our peril.

6.5 Reproductive Freedom

In most centers, when a fetal anomaly is suspected, a maternal-fetal medicine specialist will be involved. That specialist will confirm (or not) the previous findings and consult appropriately and refer to, or more likely involve, an appropriate pediatric specialist (i.e. cardiology or general surgery); sometimes genetics is involved in these discussions).

What happens once the patient receives the devastating news that her test results reveal a fetal abnormality? The question is usually binary – to continue with the pregnancy or to terminate it. People can and do disagree as to what constitutes a fetal 'abnormality' and how severe it should be to justify termination. How should

trisomy 21 be described to pregnant women? What about other trisomies? While pediatricians are not usually involved in pregnancy termination, it is an issue that affects, and is of concern to, pediatricians. Moreover, obstetric colleagues or pregnant women might approach pediatricians for information on care required for conditions identified in pregnancy.

Of course, when the pregnant person is a child or teen, then pediatricians are fully involved. Information concerning termination of pregnancy when requested by pediatric patients is offered in Chap. 14 Adolescence.

Termination of pregnancy occurs because of reproductive freedom. Reproductive freedom is about making personal choices about reproduction. If the concept is accepted, then it follows that state law and regulation should facilitate reproductive freedom, or at least not impede its exercise. It also follows that women should be able to make their own decision whether to continue a pregnancy. Dugald Baird (1965), at a time before effective contraception was available used slightly different language, to convey the same idea. He referred to United States President Franklin D. Roosevelt's four freedoms:

The first is freedom of speech and expression.
The second is freedom of every person to worship God in his own way.
The third is freedom from want.
The fourth is freedom from fear.

Baird (1965) suggested adding a fifth freedom, "the freedom from the tyranny of excessive fertility". Here, he was referring to readily available tubal ligation and abortion.

The right of a woman to terminate a pregnancy is contentious. The fact is, a man can reproduce only through the body of a woman. Men who have succeeded in achieving a pregnancy in a woman's body are on the way to having offspring. For them, there is little disadvantage to the pregnancy continuing. Consequently, certain organizations dominated by men (Markwell and Brown 2001) stipulate that the woman has no right to interrupt a pregnancy taking place in her body, even if the pregnancy was the result of rape or incest, and no matter the consequences to her own health.

For the women, however, a pregnancy is vastly different from the situation for a man. From the very first days of the pregnancy, her life starts to change, including interrupted sleep and bodily changes, which accelerate as time goes by. Complications such as preeclampsia can threaten her life, and the process of labour and delivery are typically arduous and painful, even in the best cases. Once the child is born, the woman will typically devote round-the-clock care and then years of her life to keeping the child alive, helping it to become socially acceptable and training it to support itself, irrespective of whether the father stays to assist. A woman willing to undertake this years' long enterprise, upon which the human species depends, is to be applauded and supported, though not everyone shares this view. Some people regard a pregnant woman as holding a human being inside her; many people argue that a woman who is pregnant must be required to remain pregnant, and to labour, and to deliver the resulting child.

Because of the fundamentally disparate roles that men and women play with respect to bringing a human being to life, there will remain strong discussion in the mainstream media and social media about reproductive liberty; political action and public demonstrations will continue. Yet change does occur and seems to occur more rapidly as social media advances. For example, Ireland was a country that forbade abortion. A pregnant woman, Dr. Savita Halappanavar, died in October 2012 (Health Information and Quality Authority 2013). She was in the process of miscarrying, and the physicians were clear that the fetus would not survive. Yet heart sounds were heard, and the physicians would not bring her miscarriage to an end. (O'Connor 2017). After being repeatedly refused an abortion, Dr. Halappanavar was required to wait until the heartbeat stopped, which occurred after 7 days. Then, the uterine contents were removed but she died of septicemia the following day.

The general public outrage that followed led to calls for a nation-wide referendum on the then existing Irish abortion law known as the "Eighth Amendment" which read:

> The State acknowledges the right to life of the unborn and, with due regard to the equal right to life of the mother, guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate that right. (Specia 2018)

The Irish government's proposal, should the referendum succeed, was to remove the equation of a woman's life with that of a fetus and to make abortion lawful up to 12 weeks. Beyond 12 weeks of pregnancy, termination would still be possible – up to 24 weeks – if two doctors determined that a woman's life was threatened by the pregnancy or that there was serious risk to her health.

On May 25, 2018, 66.4% of Irish voters voted to repeal the impugned law ("Abortion Referendum" www.irishtimes.com). As the Irish Times editorial board commented, the voters' decision was effectively about women's autonomy:

> A hundred years after one generation of Irish women won their battle for the right to vote, another generation has used the ballot box to deliver a thunderbolt that will echo for years to come.
>
> The emphatic decision of the Irish people to remove the Eighth Amendment from the Constitution is perhaps the most remarkable referendum result since Independence. No single moment better captures the quiet but rapid revolution in social attitudes that has taken place in less than 40 years – one that has turned a closed, conservative Catholic country into one of Europe's most liberal, outward-looking states. ("The Irish Times View on the referendum: This belongs to the women of Ireland" www.irishtimes.com)

Availability of abortion varies considerably from country to country (Berer 2017) and (Guttmacher Institute 2017), even though international organizations have made it clear that the fetus has no legal rights that can override the woman's right to make her own health care decisions (Baylis et al. 2008). For example, the United Nations Convention on the Elimination of All Forms of Discrimination against Women in Article 16, 1(e) states that women should have:

> The same rights [as men] to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights. (United Nations General Assembly 1979)

We realize that medical students, physicians, and indeed all health care practitioners are likely to show the same range of opinions regarding pregnancy termination as other citizens; some will be strongly in favour and others strongly opposed. This section has attempted to offer, as background, an overview of why the issues is so contentious, the range of constraints on pregnant women, and to focus on our duties and responsibilities as physicians. We have accepted the principle of reproductive freedom; in Chap. 14, when we consider stories regarding choosing abortion, we use actual cases involving minors.

6.5.1 Can We Forcibly Protect a Fetus?

If reproductive freedom is protected, then it follows that the woman may make her own healthcare decisions throughout pregnancy. Some would agree with a right to termination but would then insist that if the woman decides to continue her pregnancy, then her behavior should be focused entirely on the well-being of the fetus, and action should be taken to protect that fetus. People who make this argument tend to regard the pregnant woman as being in conflict with the fetus. In fact, the concept of "maternal-fetal conflict" appears in the title of chapters in ethics books and in scholarly bioethics articles. The concept seems to us an odd idea. The Canadian Royal Commission on New Reproductive Technologies in Canada (1993) eschewed the concept, writing:

> From the woman's perspective, … considering the interests of her fetus separately from her own has the potential to create adversary situations with negative consequences for her autonomy and bodily integrity, for her relationship with her partner, and for her relationship with her physician. Judicial intervention is bound to precipitate crisis and conflict, instead of preventing them through support and care. It also ignores the basic components of women's fundamental human rights – the right to bodily integrity, and the right to equality, privacy, and dignity.

Nevertheless, people do ask, "When a woman engages in behavior that harms the fetus what, if anything, should the state, do?" This question was considered in a 1997 case that came before the Supreme Court of Canada (*Winnipeg Child and Family Services (Northwest Area)* v. *G.(D.F.)* 1997). The state had attempted to restrict the liberty of a pregnant First Nations woman, known as "DFG" in an effort to care for her fetus. The issue was whether the state acted lawfully in so doing. The case headnote reads:

> In August 1996, the respondent was five months pregnant with her fourth child. She was addicted to glue sniffing, which may damage the nervous system of the developing fetus. As a result of her addiction, two of her previous children were born permanently disabled and are permanent wards of the state. [The government applied to a lower court] which ordered that she be placed in the custody of the Director of Child and Family Services and detained in a health center for treatment until the birth of her child.

But the pregnant woman had not intended to harm her fetus. According to the judge (who would later become Canada's Chief Justice and) who wrote the decision for the court majority,

> at an earlier stage of her pregnancy, she had voluntarily sought treatment but had been turned away due to lack of facilities. [Later,] when asked to take treatment she agreed and only later refused because she had fallen into a state of intoxication.

The majority of judges rejected arguments that the Court could use tort law to make the pregnant woman responsible for the costs of healthcare for the harm caused, or its jurisdiction to care for children (parents patria) to interfere with a woman's decision-making during pregnancy. The majority recognized that the woman was not a villain and that her story was merely the "all too common story of people struggling to do their best in the face of inadequate facilities and the ravages of addiction."

The judges doubted that tort law could deter such behaviour and quoted with approval from an article by Hanigsberg (1991) who wrote:

> "Women do not abuse drugs out of a lack of care for their fetuses. Drug abusing pregnant women, like other drug abusers, are addicts. People do not want to be drug addicts. In addition, a product of addiction is the inability to control in-take of the substance being abused.
>
> Treating pregnant substance abusers as fetal abusers ignores the range of conditions that contribute to problems like drug addiction and lack of nutrition, such as limited quality prenatal care, lack of food for impoverished women, and lack of treatment for substance abusers." (Hanigsberg 1991 p. 53)

The judges stated that attempts to use tort law to govern the behaviour of pregnant women would inevitably backfire because, first, it might

> drive the problems underground. Pregnant women suffering from alcohol or substance abuse addictions may not seek prenatal care for fear that their problems would be detected, and they would be confined involuntarily and/or ordered to undergo mandatory treatment. As a result, there is a real possibility that those women most in need of proper prenatal care may be the ones who will go without and a judicial intervention designed to improve the health of the fetus and the mother may actually put both at serious health risk.

Using tort law would have a second negative effect because it

> might persuade women who would otherwise choose to continue their pregnancies to undergo an abortion. Women under the control of a substance addiction may be unable to face the prospect of being without their addicting substance and may find terminating the pregnancy a preferable alternative. In the end, orders made to protect a fetus' health could ultimately result in its destruction.

The judges also ruled that the Court could not use its residual authority to step in to make orders in the best interests of children when needed, because there was no child, and the residual authority does not extend to a fetus:

> The law as it stands is clear: the courts do not have […] wardship jurisdiction over unborn children. This is the law in the European Community, Great Britain and Canada.

In other words, the Supreme Court of Canada decided that the courts had no power to order the detention of a pregnant woman for the purpose of preventing harm to her fetus.

This case (*Winnipeg Child and Family Services (Northwest Area)* v. *G.(D.F.)* 1997) and the judges' comments illustrate the great difficulty in helping women to have healthy pregnancies when they use substances and are addicted to doing so. We agree that coercion will not be effective and might be harmful. Moreover, it is important for healthcare providers to offer a 'place of safety' – to be encouraging and supportive in helping a pregnant woman care for the fetus. (Of course, if the child is born alive and needs protection, then the pediatrician must act in ways detailed in Sect. 7.4 of Chap. 7, but such action would not interfere with the bodily integrity of the woman.)

Beyond the case described, there are a variety of situations, in which physicians would want to help a pregnant woman change her behaviour for the sake of her fetus. For example, physicians might be concerned about alcohol and nicotine consumption, both of which are lawful substances, and which harm the fetus. In terms of alcohol, the physician's approach should be exactly the same as with an illegal substance, to provide support. However, the support provided should be extensive, might involve non-healthcare organization such as Alcoholics Anonymous, and should be offered after attempting to engage the woman's partner, if any. Regarding smoking cessation, a similar approach should be offered. A physician might also be concerned about a woman's weight during pregnancy, whether it is extremely underweight, or overweight. The ethical approach to the pregnant woman must be to support her. That support will start with an explanation on how the woman's substance use, diet and bodily habitus might affect the fetus and should move on to ask the woman how best she thinks she could be helped. We are not disingenuously ignoring the difficulties of offering effective help in such situations but believe firmly that coercive measures are unlikely to be effective and worse, might lead women to avoid any healthcare, which will make it even more difficult for physicians to help the woman have a good pregnancy outcome.

Nevertheless, these behaviours can be significantly harmful to the fetus and do focus physicians' attention on wanting them to cease. Is there anything beyond spoken encouragement and referral to supportive organizations that might be effective in changing a pregnant woman's harmful behavior?

This question was considered by researchers who investigated incentives offered to encourage smoking cessation. Tappin et al. (2010) described the range of services available to help pregnant women cease smoking, and the various outcomes in one country, Scotland. Their survey principally used routinely collected data. Approximately a quarter of the women reported being a current smoker at the first antenatal visit (13,266 smokers of 52,370 women attended). The researchers used non-judgmental language but were aware of evidence that there might be underreporting of smoking behavior. Clinical assessment and the various routine blood and urine tests listed in Sect. 6.4 above were supplemented by measurement of carbon monoxide to assess whether the woman had recently smoked. The test became "routine", with a brief explanation and an opportunity to decline. The clinic

services included smoking cessation support and, for a smaller number who asked for help, home-based support. Yet both types of support had low rates of success. With the first method, 3.5% had ceased smoking after 4 weeks and in the home-based program 4.3% had ceased after 4 weeks. Referral and attendance at both programs were low. With clinic support, 370 set a quit date and 409 did the same with home support. The authors suggested a more aggressive approach: routine identification of smokers with carbon monoxide breath testing and an automatic referral to cessation services, with an opt out provision.

A second study of the effectiveness of smoking cessation measures accepted that lifestyle behaviours that compromise health in the pregnancy and perinatal period cluster in more disadvantaged communities. There is more smoking among women in manual occupations as opposed to professional and managerial positions. Accepting that monetary incentives might be more valuable to people of low income than of high income, Hoddinott et al. (2014) reviewed public attitudes to incentives. The researchers had a long definition of incentives that included:

> financial (positive or negative) and nonfinancial tangible incentives or rewards. This includes free or reduced cost items that have a monetary value or an exchange value, like refreshments, baby products or services like childcare or ironing.

The definition of "incentive" excludes intangible incentives such as supportive, motivational or persuasive relationships with professionals or peers. The authors stated that "Incentives might be delivered directly or indirectly at local, regional or national level by organizations." The incentives studied were:

1. Shopping vouchers for women who prove that they have stopped smoking during pregnancy.
2. Shopping vouchers for a woman for 2 months after the birth of her baby if she proves that she is still not smoking.
3. Shopping vouchers for a woman for 2 months after the birth of her baby if she never lets anyone smoke in her home.
4. Shopping vouchers for women who prove that they are breast feeding for the first 6 months after birth.
5. A breast pump costing around £40 provided for free by the health service.
6. Additional funding for local health services if they reach targets for the number of women who prove that they have stopped smoking during pregnancy.
7. Additional funding for local health services if they reach targets for the number of women who prove that they are breast-feeding.

Hoddinott et al. (2014) reported that study participants varied in their support from 35–46% depending on the incentive offered and the segment of those surveyed who responded. That is, these study participants did not seem to support financial incentives to encourage pregnant women to adopt a healthy lifestyle. Yet those participants who had previously tried to stop smoking had a different view. 85% supported vouchers of £40 (US$51.76). These incentives were provided in a country (UK) that has publicly funded health care because poor pregnancy outcomes (e.g. low birthweight babies) cause not only human suffering but also considerable cost

to the healthcare system. So, finding non-coercive ways to reduce harmful behaviour in pregnancy affects everyone – even in the United States where there is likely to be public provision of some pregnancy health care for the poor.

Such incentives to encourage healthy behavior might indicate to the recipients that they are worthy of help and might be a first step in connecting recipients with appropriate care. We recognize that some people will object to the state providing such incentives. Some people might say that providing funding to those who smoke to encourage them to discontinue smoking is unfair to those who are non-smokers. This argument does not take into account the savings of funds not spent on the mother and the child if smoking ceases. Some will argue that the incentive "rewards" some kinds of abuse, and that such money is then unavailable for other services, so-called "opportunity cost". This argument incorrectly regards incentive as a reward when it is an inducement to change harmful behavior; the cost of not taking the action is likely larger than the benefit of redirecting the sums. Some might say that the use of incentives smacks of state overreach and interference with autonomy, but the woman retains the right to 'take it or leave it'. If we look at the issue through the lens of consequentialism (the moral theory that judges an action by its consequences), incentives are likely to improve the outcome of the baby born and thus ultimately reduce health and social service costs. Incentives are part of a supportive approach to substance abuse during pregnancy and stand in contrast to confining a woman by coercion to ensure she is not exposed to noxious substances.

In the case of the Ms. DFG (Winnipeg Child and Family Services (Northwest Area) v. G.(D.F.) 1997) who was addicted to glue sniffing in her fourth pregnancy in the 1990s, later news reports reported outcomes. In 2010 she spoke to the media explaining that her mother had died in the 1980s when she was young; she had been moved from a rural community to the city where her father was not attentive. She fell into substance use and prostitution, and during the litigation she voluntarily entered addictions treatment. Although she had been advised to abort the fetus, she did not. In 2015, her son had grown up to be, as she said, "an intelligent young man who is in great health without any deficits". He has fetal alcohol syndrome; and when he graduated from high school, he told a journalist, "I'm proud of it. Proud I proved them wrong […] I'm not a vegetable. (" Ms. G, Winnipeg woman in 90s fetus rights case, watches son graduate." www.cbc.ca).

6.6 Advanced Reproductive Technology (ART)

ART is any manipulation of conception and gestation outside sexual intercourse that results in a pregnancy in the same body. A description of the various forms of ART was given in Sect. 5.17 of Chap. 5. That section focused on confidentiality of sensitive information noting that confidentiality is not the same as secrecy, and that the offspring of ART should be able to know their genetic origins. In this section, we focus on two specific situations involving ART that are of particular significance to

pediatricians. These are its role in patients with malignancy, and secondly there might be immediate and long-term healthcare problems with the offspring, especially prematurity.

Madelyn's Story

Madelyn Blythe was a healthy teenager. She had progressed normally through puberty, and at the age of 14 had regular menstrual cycles. She found some lumps in her neck. They were painless, and she mentioned them casually to her mother 2 or 3 days later. Her family physician thought this might be the result of infection and prescribed an antibiotic. Four days after the antibiotics started, she told her mother she felt weak. Madelyn was reassessed by the family physician, who noted the swellings had increased in size and Madelyn was very pale.

A pediatric oncologist saw her urgently and suggested this might be lymphoma. The oncologist reviewed with Madelyn and her parents the various tests needed to confirm the diagnosis, and the treatment options. Madelyn's mother had already spent a great deal of time on the internet and asked if Madelyn's eggs could be frozen, so that they would be available to Madelyn when she was an adult so that she could have a child.

The question is reasonable (Saito et al. 2005). Whether the procedure can occur will depend on the urgency of starting treatment. It might be possible to harvest and to freeze her ova if time, and Madelyn's condition, permit. In teenage males with malignancy, semen can be frozen. Semen has been frozen, and then thawed for use in ART for many decades; the techniques have been refined, and there is a high likelihood of success (Walters et al. 2009). Freezing, thawing and successfully creating a pregnancy with ova is a much newer technique. Techniques are improving (Saumet et al. 2018) and (Arav and Natan 2013), and it seems that this is something that should be offered (Martinez et al. 2014). In prepubertal females, it may be possible to resect part of the ovary, freeze that, in the hope that it could be grafted back into the abdomen after the malignancy had resolved, and some time had elapsed after chemotherapy had been stopped (Robertson 2005). The chances that this will be done successfully are unknown. The uncertainty of success needs to be conveyed to the child and family.

This is clearly a very sensitive topic. The degree of urgency with which treatment must be started is very important. If chemotherapy must be given very soon, then it will be very difficult to obtain semen or to extract eggs or ovarian tissue. Providing full information about future fertility is a major challenge when it must be done in the midst of communicating a diagnosis of malignancy in a child, and the need to explain treatment in great detail.

There are methodological problems in establishing the precise short and long-term risks of pregnancies created after ART. Accurate information on the neonatal and pediatric outcome must come from large scale comprehensive registries of pregnancies created by ART. However, in ART, the mode of conception is often concealed, as discussed in Chap. 5 on confidentiality. Follow-up information that is based on incomplete numbers of infants will always be suspect.

Regarding neonatal outcomes after ART, there are known immediate complications. The degree of prematurity is much higher, mainly due to the high rate of multiple pregnancies, as mentioned in the next section on prematurity. These infants will then have all the complications of prematurity, including a higher neonatal mortality, chronic lung disease, neurological damage, and developmental delay.

Longer-term problems have included congenital anomalies (Hwang et al. 2018), but in a comprehensive review of published reports Shankaran (2014) did not identify such an increase. He noted that most studies did not allow for the confounders of infertility and increased maternal age, both indications for ART, and independent predictors of congenital anomalies. We hope that the era of secrecy in ART will come to an end soon so that we will have access to accurate information on long-term outcomes of ART on the children these procedures create. Until that day arrives, information on long-term outcomes for children should be regarded cautiously.

6.7 Fetal Surgery

Directly intervening in the care of the fetus might have started with intrauterine transfusion for rhesus iso-immunization in the 1950s. Now surgery is possible in the fetus for a number of conditions, including spina bifida and diaphragmatic hernia. Once we consider surgery for the fetus, and declared the fetus to be a patient, we face a number of ethical issues. We do not believe that stating the fetus to be a patient has somehow allowed the fetus to gain independent moral status. The fetus is still totally dependent on the mother. Respect for the mother's autonomy takes priority.

In modern surgery, unmanaged interventions are major problems; surgery on the fetus is no exception. Interventions go from being speculative to standard care with little in the way of formal evaluation. We believe that this is never ethical, and especially in the case of fetal surgery with risk to both the survival of the fetus and the health of the mother. Such an intervention must be formally evaluated in clinical trials. In these clinical trials, informed consent will clearly be extremely important. We suggest that the consent process should be nondirective. We agree with Chervenak and McCullough (2009) that we should avoid the terms mother, father, or baby, and instead use more neutral terms pregnant woman, potential father, and fetus. In any research in this area there must be adequate time to reflect.

We do accept that fetal surgery has the potential to improve the outcome of a number of conditions that can be identified during pregnancy. We do not accept that "pioneering" surgery should be conducted without formal evaluation. After all this is not 'standard of care' medical practice but research. We believe that knowledge of the availability of fetal surgery, even if not evaluated, can be coercive for women. Not only is informed consent important in clinical trials, it is extremely important in discussing novel surgical interventions.

6.8 Should Children Be Conceived by ART to Benefit Another Child?

In Sect. 5.17 of Chap. 5 we asked, "Should Children Conceived by Assisted Reproductive Technologies (ART) Know Their Origins?" Now we ask whether one child should be created specifically to help another. The medical issue is the use of preimplantation genetic diagnosis (PGD) and IVF in this situation; the ethical question is whether such use is right or wrong. Here IVF is used to test embryos for single gene disorders and human leukocyte antigen (HLA)-type. The umbilical blood or bone marrow of the new child will be used to save the life of a sibling who is gravely ill. This so-called savior sibling was first reported in the case of Fanconi anemia (Verlinsky et al. 2001).

This ethical issue has caught the popular imagination, especially when the book, "My Sister's Keeper" by Jodi Picoult (2004) was used as the basis for a movie.

Zierhut et al. (2013) surveyed parents of children with Fanconi anemia. There was a total of 123 responses of which 119 were be used in the analysis. These parents indicated that the most important factors in PGD decision making were the health of the child patient and his or her emotional responses and moral judgments. Only 70% of parents were aware of the option of PGD and only 35% were offered this option. We have no information on why professionals might or might not suggest PGD to parents.

The questions that arise are:

1. Are parents who opt for PGD "good" parents who do the best for their (existing) child?
2. Are parents who opt for PGD "bad" parents who value one child over another?

In a philosophical analysis, Strong et al. (2014) review various understandings of childhood and families. They reject older understandings of children as property of the parents. Nevertheless, they do not oppose creation of "saviour siblings". They make the general point that "the notion that one is making a decision about an individual neutrally or without any consideration of other people in the family is neither ethically coherent nor empirically supportable." One might argue that the concern and parental distress about the plight of the sick child makes ethical parental decision-making impossible. This argument ignores the reality that family functioning occurs within complex, interrelated relationships. As Strong et al. note, "parents balance multiple motivations and interests all the time". We see the creation of a saviour sibling as an ethically acceptable intervention. We suspect that, despite the circumstances of the child's creation, the child will receive the unconditional love of his or her parents.

Consistently with our recommendations in Sect. 5.17 of Chap. 5, we think the saviour siblings must be made aware of the circumstances of their conception.

6.9 Prematurity

Hailey was born at 24 weeks gestation and was the first child of Nora and Gabriel. During labour, there had been extensive discussion about the action to be taken after birth. Should full resuscitation be followed by NICU admission? Nora and Gabriel strongly supported all interventions. As it turned out, Hailey cried briefly at birth, though she was weak. The healthcare team started Hailey on non-invasive ventilation for the first week of life, and then used CPAP, followed by supplementary oxygen. By 32 weeks gestation, she did not require any supplementary oxygen. She pursued an uneventful course as far as nutrition is concerned, with a brief period of IV nutrition but progressing to pumped breast milk by tube, and by stages to suckling from the breast. She was discharged home at 38 weeks to be followed up by her family physician and pediatrician.

Pediatricians will follow premature infants such as Hailey closely. She has done well, but still may have issues with growth and development. The healthy outcome illustrates just how much neonatal care has changed. There have been remarkable changes in the outcomes of preterm infants in the last 70 years (Philip 2005). In 1960, a 1 kg baby had a 95% likelihood of dying. In the year 2000, a 1 kg baby had a 95% chance of surviving. The results will probably be even better in 2025.

These survival rates have changed because of many medical advances, including the miniaturization of blood analysis, the availability of intravenous nutrition, attention to thermal regulation, the use of assisted ventilation and constant positive airway pressure. As an aside, the first incubator was used in 1835, but a deeper understanding of the need for thermal regulation and the need for an incubator in which the infant was clearly visible had to wait for modern physiology, and for modern plastics. Errors have been constant companions of neonatologists (Ramachandrappa and Jain 2008) but error has led to insight and to improvement in practice. There have been other changes such as the development of the specialty of neonatology (the word was first used in 1960), and more recently the close involvement of parents in the care of the preterm infant. As mentioned in Chap. 1, neonatology like all aspects of pediatrics, continues to be affected by technological developments and societal changes. For example, currently there is an increase in pregnancies with multiples, and 40% of the multiples are due to ART. There is a resultant increase in prematurity.

When a woman presents in premature labour, pediatricians are frequently asked to go to the obstetrics unit to speak to her, as likely happened in Hailey's case. Typically, the conversation will address immediate issues such as the likelihood of an NICU stay, the kind of interventions used in NICU, and the long-term outcomes of prematurity for the child. The more preterm the infant is, the more difficult the conversation will be. Most institutions have policies about when infants are too preterm for resuscitation to be attempted. Deliveries in the range 23–24 weeks are very contentious, and many physicians have strong feelings for and against aggressive treatment of this age of gestation.

Before addressing the nature of the recommendations, it is important to pause to consider the situation of the woman whom the pediatrician addresses when beginning to inform her about the effects on the fetus of the impending premature birth. She might never have had a child before and might not regard herself as the mother

of the child you are speaking about because the idea of 'her child' is still a concept. She probably does not want to be in labour and might be shocked that she is in the hospital so soon. The pregnant woman is likely trying to process the information the pediatrician is giving her while coming to terms with the fact that one of the most important events in her life is happening much sooner than she expected and in a manner beyond her control. From the pregnant woman's perspective, the presence of a pediatrician by her bed, speaking about a baby is evidence that the unwanted situation is real. Depending upon her stage of acceptance of what is happening, the pregnant woman might have difficulty taking in and reflecting upon the complicated information being offered by the pediatrician.

Nevertheless, the pediatrician must attempt to give recommendations to the pregnant woman. Professional recommendations, based on published data on survival and quality of life, are that resuscitation not be attempted before 22 weeks' gestation (Cummings and Committee on Fetus and Newborn 2015). One of the scientific issues that affects the ethics of communicating with the pregnant woman and her family is that changes in approaches might lead to survival of even smaller children. Ahmad et al. (2017) describe an infant born slightly under the 22-week cut off whose mother pleaded for resuscitation. The infant is reported as having an "unimpaired 2-year outcome".

The pregnant woman and her family will count on the pediatrician to answer this important question, "How do premature babies do?". Neonatal outcomes of preterm infants vary greatly within and between countries. There are substantial concerns that this variation is related to local decisions about which groups of infants to treat actively. Janvier et al. (2017) cite data on infants born at 22–26 weeks' gestation in France in 2011. There was extreme variation in proactive antenatal care, from 22% to 61%. Twenty-eight percent of 24-week infants survived; none before that gestation. These authors cite evidence from another country (England) that 78% of the variation between hospitals studied is due to variation in delivery room practice. Janvier et al. (2017) call for an end to the "prevailing pessimistic philosophy regarding extreme prematurity". They call for active antenatal care such as ensuring preterm infants are delivered in a hospital with an NICU and ensuring that pregnant women are given steroids before delivery.

Whoever leads the consultation with the pregnant woman will recognize its importance. The major problem in communicating in this situation is that if the communication is too brutal, then the pregnant woman will be even more upset, and if too optimistic, then she is misled. We hope that the neonatologist navigates this difficult consultation thoughtfully and kindly. In a study of how pregnant women perceived this consultation, Gaucher et al. (2018) asked 341 women who had had an antenatal consultation to complete a survey. Two hundred twenty-six (72%) completed the survey. Most (83%) were reassured by the consultation. It is concerning that so many (23%), even if a minority, were worried. The groups most likely to be worried were those whose labour came at the earliest stage of gestation, and women with higher education. Longer consultations with full information and a trusting, expert, team were most likely to lead to reassurance. The advice to neonatologists was: "to strive to establish a trusting relationship with mothers, in which realistic and clear, but optimistic, information is offered." (Gaucher et al. 2018).

Janvier et al. (2017) called for careful discernment of the wishes of the pregnant woman and, once born, of the parents of the child. Typically, if the potential father is available and supporting the woman, then he should be involved in the discussion. In another study of NICU staff attitudes, Janvier and colleagues showed wide variation in recommendations between providers of identical clinical situations. They concluded, "Practitioners should take care to avoid basing treatment recommendations on their own perspectives if they are not well aligned with those of the parents". The ethical challenge, of course, is that parents are not well informed about how exactly their lives will change when a child is born extremely prematurely.

The issue of variation in care of preterm infants is pervasive, even with guidelines. A Dutch group (Verweij et al. 2013) studied the attitudes of obstetricians and neonatologist as to whether existing guidelines regarding active care of preterm infants were followed. The conclusion was:

> There was a wide variety in individually preferred treatment decisions, especially when aspects were not covered in the Dutch guideline on perinatal practice in extreme prematurity. Furthermore, obstetricians and neonatologists did not always agree.

Once in the NICU, the trainee pediatrician will be a member of the team involved in the care of the infant and will participate in communicating with the pregnant woman and her family. If the trainee is involved with communicating with a woman who is 22–26 weeks pregnant, then he or she needs to try to paint a realistic picture of the possible health of her baby should she give birth. The picture should not necessarily be gloomy, but should not focus on the very rare "perfect" survivor seen as the "miracle" in the popular press. Staff members are likely to be enthusiastic, and optimistic as they provide support to the pregnant woman and her family. We understand the enthusiasm and optimism of staff who have chosen to work with preterm infants, but that enthusiasm must be tempered with the reality that the staff will not be providing lifelong care for the child. Most neonatologists would like to discharge a baby who has a healthy life in a family who can live a life not entirely consumed by care of that child, rather than to discharge an infant who is alive but with extensive care needs. If pregnant woman and her family ask trainees for further information, then as far as possible, the trainee should review the evidence-based literature first. Trainees are unlikely to be taking the lead on these discussions and should request to join meetings between prospective parents and experienced neonatologists.

To ensure that pregnant women can receive realistic information about outcomes for her fetus, units should regularly review their own outcomes of preterm infants in terms of survival and quality of life and compare them to those of other units. There should be a common policy on the approach to premature labour and an agreed communication strategy. All unit policies must have wide involvement in the development of the approach and strategy. All staff members' care for the infants; not just physicians. The input of neonatal nurses, who spend many hours with the infant (and parents), is particularly vital. This collaboration with staff must also occur when decisions for individual infants are being considered. It might seem obvious that obstetricians and midwives must be full collaborators in care of individual

patients and in developing policies. Given the conclusion of the Dutch study (Verweij et al. 2013) cited above, perhaps physicians' apparent inability to follow guidelines also needs to be stated clearly.

Trainees should keep in mind that some preterm infants will be in research studies. Some studies will be collecting medical and social data. Others might be evaluating an intervention. Randomization and obtaining informed consent are particularly problematic in this situation. We will deal with this issue in more detail in Chap. 13 Research. A trainee who is interested in the research should ask to read the protocol. Properly conducted research is important. Neonatology remains a rapidly developing area of pediatrics, and sometimes interventions are introduced in the care of patients, without a solid evidence base, and without being part of a research protocol. If trainees see such a change occurring, then they might seek further advice from a colleague, a mentor, the professional organization or ethicist or ethics committee. While of course marshalling the available information and seeking advice before speaking, a trainee might need to know that it is important to raise questions. Often it is the newest person on a team who asks the important question.

6.10 Delivery Recommendations

In term pregnancy, women might accept or disregard medical advice about the mode of delivery. For example, a woman might be advised based on a test that she needs to have a caesarian section to avoid health problems for the resulting child. Or she might be in active labour and be advised that the fetus is in distress and needs to be delivered immediately by caesarian section. The understandable focus on the well-being of the fetus might leave the woman feeling "invisible" or merely a "fetal container" (De Vries 2017). Again, pediatricians must work with the parent as they care for the child, whatever the outcome of the decision the pregnant woman took.

6.11 Newborn Screening

Pediatricians, including trainees, will be informed of the results of newborn screening, which they will discuss with parents. If the test is positive, then the pediatrician will need to have information about the disease or condition and to know how to proceed to manage the situation. Also, new mothers might ask them to explain the test. What is newborn screening? In describing the history of newborn screening, we refer to conditions discussed at the beginning of this chapter regarding preconception and early pregnancy testing. However, newborn screening is different from such testing because newborn screening concerns a baby, not a fetus, and it has a much longer history than testing before or during pregnancy.

Newborn screening began with testing for phenylketonuria (PKU). This is an inherited metabolic disease with severe neurological consequences, called "mental retardation" at the time. In the 1950s, it was known that the consequences of PKU could be lessened if a phenylalanine-free diet was given. However, because of delays in clinical diagnosis, the baby often suffered permanent damage before the diet could be started. Obviously, very early diagnosis was needed. Dr. Robert Guthrie became involved in the problem because one of his children was mentally disabled and his niece was affected with PKU (Zhu 2017). He had been a cancer researcher but switched to this new field. He developed a urine test for PKU, the "Guthrie test". The outcome of widespread use of this test was that children could be placed on the special diet very early in life, with a vastly improved outcome. Later, a test was developed in which a spot of blood taken from the newborn was sufficient for testing. Tests for other conditions started with hypothyroidism, and it soon became possible to test for many other disorders. With modern technology, particularly molecular techniques, screening can be conducted for a very large number of disorders. As the numbers of tests increase, the ethical questions have also increased, and the underlying principles guiding testing have experienced considerable modification from those developed in the first few years of screening (Clague and Thomas 2002). These principles are detailed below.

6.11.1 Chase's Newborn Screen

Eleanor and Jason Kelly were pleased to be expecting their first child. They had been together for a number of years and had been trying to conceive for one year. They knew from the ultrasound that the child was small, and decided to call him "Chase". There were no complications during the pregnancy, the labour was straightforward, and Chase was born after a normal delivery, birth weight was 3.2 KG. He established on breast-feeding easily. He had a drop of blood collected after birth; the nurse explained to the parents that this was a screening test for several important conditions.

Less than two weeks after his birth, Eleanor's family physician called her to ask her to come in for a visit with Chase. There, the physician told Eleanor that Chase had screened positive for cystic fibrosis (CF). The physician explained a little bit about screening tests, and a little bit about CF. The physician had already contacted the local CF Centre to ensure her knowledge was current. She explained that the screening test is not a diagnostic test, and that Chase would need a sweat test to confirm, or to rule out CF. The physicians also told Eleanor that the local CF clinic would contact her to arrange testing.

For Eleanor and Jason, this was a time of extreme anxiety. Fortunately, the sweat test was completed within a week, and the results showed that Chase did not have cystic fibrosis. However, the screening test revealed that he is a carrier. Hence, at least one of his parents must be a carrier of CF. Genetic testing of the parents was recommended before another pregnancy. These test results have implications for relatives of Eleanor and Jason.

6.11.2 Comments on Neonatal Screening

Is neonatal testing a good thing? At first blush, without reflection and conditioned by the experience with PKU, it seems obvious that neonatal screening must be good. Newborn screening triggers timely treatment and advice to parents and is a highly cost-effective strategy to identify genetic disorder and to provide early treatment to the child. In the decade after the establishment of testing for PKU and hypothyroidism, it became obvious that tests for other conditions would be developed, and so some principles were established regarding what tests should occur for all babies. These principles included:

- The test is accurate, with few false positives and no false negatives;
- The disease targeted is a significant public health problem;
- There is an effective treatment for the disease; and
- A cost benefit analysis is favorable.

Over time, as more conditions are added, these initial principles seem to be inadequate. The public health benefits of newborn screening (NBS) programs are well established. These programs initiate timely treatment and advice to parents and are a highly cost-effective strategy for early identification of genetic disorders. An expanded set of principles was developed using a Delphi technique and published by Dobrow et al. (2018) under four headings: Epidemiology (1–3 below), Test Characteristics (4,5) Post Screen Options (6) and Program Principles (7–12). The decision about which tests should be conducted are never taken by individual pediatricians, though their opinions might be taken into account in decision-making. Trainees should review these principles; they might find them helpful in their career when they are called upon to advise on testing or advocate for testing. These principles are:

1. Epidemiology of the disease or condition
   The epidemiology of the disease or condition should be adequately understood, and the disease or condition should be an important health problem (e.g., high or increasing incidence or prevalence, or causes substantial morbidity or mortality).
2. Natural history of disease or condition
   The natural history of the disease or condition should be adequately understood, the disease or condition is well-defined, and there should be a detectable preclinical phase.
3. Target population for screening
   The target population for screening should be clearly defined (e.g., with an appropriate target age range), identifiable and able to be reached.
4. Screening test performance characteristics
   Screening test performance should be appropriate for the purpose, with all key components specific to the test (rather than the screening program) being

accurate (e.g., in terms of sensitivity, specificity and positive predictive value) and reliable or reproducible. The test should be acceptable to the target population and it should be possible to perform or administer it safely, affordably and efficiently.

5. Interpretation of screening test results

   Screening test results should be clearly interpretable and determinate (e.g., with known distribution of test values and well-defined and agreed cut-off points) to allow identification of the screening participants who should (and should not) be offered diagnostic testing and other post screening care.

6. Post screening test options

   There should be an agreed on course of action for screening participants with positive screening test results that involves diagnostic testing, treatment or intervention, and follow-up care that will modify the natural history and clinical pathway for the disease or condition; that is available, accessible and acceptable to those affected; and that results in improved outcomes (e.g., increased functioning or quality of life, decreased cause-specific mortality). The burden of testing on all participants should be understood and acceptable, and the effect of false-positive and false-negative tests should be minimal.

7. Screening program infrastructure

   There should be adequate existing infrastructure (e.g., financial resources, health human resources, information technology, facilities, equipment and test technology), or a clear plan to develop adequate infrastructure, that is appropriate to the setting to allow for timely access to all components of the screening program.

8. Screening program coordination and integration

   All components of the screening program should be coordinated and, where possible, integrated with the broader health care system (including a formal system to inform, counsel, refer and manage the treatment of screening participants) to optimize care continuity and ensure no screening participant is neglected.

9. Screening program acceptability and ethics

   All components of the screening program should be clinically, socially, and ethically acceptable to screening participants, health professionals and society, and there should be effective methods for providing screening participants with informed choice, promoting their autonomy, and protecting their rights.

10. Screening program benefits and harms

    The expected range and magnitude of benefits (e.g., increased functioning or quality of life, decreased cause-specific mortality) and harms (e.g., overdiagnosis and overtreatment) for screening participants and society should be clearly defined and acceptable and supported by existing high-quality scientific evidence (or addressed by ongoing studies) that indicates that the overall benefit of the screening program outweighs its potential harms.

11. Economic evaluation of screening program

    An economic evaluation (e.g., cost-effectiveness analysis, cost-benefit analysis and cost-utility analysis) of the screening program, using a health system

or societal perspective, should be conducted (or a clear plan to conduct an economic evaluation) to assess the full costs and effects of implementing, operating and sustaining the screening program while clearly considering the opportunity costs and effect of allocating resources to other potential non-screening alternatives (e.g., primary prevention, improved treatments and other clinical services) for managing the disease or condition.

12. Screening program quality and performance management

    The screening program should have clear goals or objectives that are explicitly linked to program planning, monitoring, evaluating and reporting activities, with dedicated information systems and funding, to ensure ongoing quality control and achievement of performance targets (Dobrow et al. 2018).

The conditions screened in any given area will be recommended by pediatricians. However, approval will be by administrators who will consider a number of factors including disease incidence, cost and accuracy of test, availability of treatment, ethnic composition of population, politics and ethics. The most common tests to be included are:

- Phenylketonuria
- Congenital Hypothyroidism
- Cystic fibrosis
- Galactosaemia
- Congenital adrenal hyperplasia
- Aminoacidemias,
- Hemoglobinopathies
- Biotinidase deficiency
- Duchenne muscular dystrophy.

6.11.3 Ethical Concerns with Neonatal Screening

As we review the story about baby Chase being discovered to be a CF carrier, many of the ethical concerns arise. An obvious feature of this story is the anxiety caused by our "positive" screening test, when the diagnosis is not confirmed later. In Chase's case, the period of anxiety for his parents was short, but in many other situations, the wait is much longer. Any organized system of screening must establish mechanisms to help with the anxiety of the parents, while they await definitive results.

It is important to note that Chase's parents were probably unprepared for the news that the screening test, something they had probably forgotten about, indicated that more tests were needed. The screening test itself was performed after the briefest of explanations. In some jurisdictions, this screening test is mandatory, but in most jurisdictions, it requires some form of consent, usually opt out after a brief explanation as happened here. The principle underpinning mandatory testing is that an affected child, if missed because screening was not done, would suffer great

harm. It would be unfortunate if a test were not done because we are unable to inform parents about what are now routine newborn tests, and a child suffered the consequences of late diagnosis of any of the diseases that routine newborn screening can identify.

On the other hand, it is unlikely that full informed consent in the traditional sense (see Chap. 4) will ever be possible. The information is complex, includes disease information on all of those screened, and the various outcomes. Such a process would be time-consuming, and it is unclear who would interact with the parents to deliver this information. The screening test would usually be conducted by the healthcare employee whose training is in blood testing in the units, not in communicating complex information. However there needs to be a mechanism so that the patients who wish more information are able to obtain it. Providing the required information might be achieved simply by referring parents to an informative website.

In Chase's case, it was established that he did not have CF, but that he was a carrier. Typically, genetic laboratories will refuse a request for a test for carrier status in minors, but here we have the information by default. It is unclear whether this information will affect parental response to the child.

In newborn screening, including for cystic fibrosis, the answer obtained by so-called "definitive" testing might in fact not be definitive. Is the benefit, on a population basis, of an early diagnosis in those who develop CF, or any disease, worth the anxiety and expense of those left with inconclusive information? Those responsible for caring for children with CF will say yes, and presumably health authorities that organize and pay for testing agree. We agree that the testing is worthwhile (one of us, IM, cares for CF patients) because of the improved health of infants diagnosed by screening. We accept, however, that the ethics of mandatory newborn screening for CF are not straight forward. The success in identifying and starting early treatment to infants with CF must be balanced against anxiety caused to parents of children with ambiguous results, many of whom will require long term follow up. In a study of 511 infants assessed in an English center (Edmondson et al. 2018) because of a positive screening test, 95 had a normal sweat test, apparently excluding CF. Seventy-nine were thought to be normal, and on completing follow up questionnaires, 51/79 did not develop CF. Five were found to have CF, after further genetic testing. Eleven of the children were described as CF screen positive inconclusive diagnosis (CFSPID). In other words, it was not clear whether they had CF or not. These children require long-term follow up that creates anxiety for parents.

From the study by Edmondson et al. (2018), another issue arises, that of deciding how much time and money will be spent on screening and diagnosis. CF might be one disease, but there are many alleles, perhaps more than 2000. Only a few common ones are included in the screening test. In the study, two patients with normal sweat test were identified as having CF after extended genetic testing. How many tests are enough? How do we decide on a budget? If more is spent, then will the funding for such tests be taken from other programs? We will discuss these issues in Chap. 15 "Resource Allocation".

Once the screening test has been done, whether the results are negative or positive, the various issues will have been resolved within a few weeks of birth. It is likely that the blood will be stored long term, because the storage is not expensive. The blood tested can be used for quality assurance of the process. To stay with the example of CF but accepting the conclusions might apply to other disorders, the test can be rerun much later using more alleles to consider the cost of identification of cases. When exploring the possibility of new tests, the tests conducted on children in the past can be used in developing the new tests. In the sad situation when a child dies shortly after birth, but after the test has been done, the results might be helpful if there is an underlying genetic cause of the death. In this case, results should be passed to the physician who cared for the child before death. If there are implications for future pregnancies, then parents must be told, but with care and sensitivity. None of these uses of the stored blood raise much in the way of controversy. Much more controversial will be the use of the specimens for research or for later identification of a criminal ("Guthrie Cards" www.abc.net.au). If identifiable data arises, then who will give consent? We suggest that research on the specimens must be limited to anonymized specimens.

In exploring the issue of newborn screening, and reviewing the principles, it is clear that the issue of benefit to children and society has been in the forefront of decision-making. Will the results of this test benefit an individual child? Will the results of this test improve the health of society, and perhaps justify its use? Tests have been suggested for other conditions, yet the specific benefits are less clear. An example might be Duchenne muscular dystrophy. This condition causes considerable disability in childhood, and usually death sometime in the 1920s. All patients with this disease require a great deal of treatment and support; there are no available curative treatments. One argument for screening for disorders with no current curative treatment is that diagnosis might be made earlier, reducing anxiety for families and starting supportive care sooner. A second argument with newborn screening is that it provides clear knowledge of who has a disorder, which knowledge will be helpful when specific treatments are discovered. We are not convinced by the second argument but do see the benefits of the first argument: early diagnosis can prevent the common scenario of multiple physician consultations, marked parental anxiety, and a later diagnosis without screening. We expect the present generation of trainees to be asked to provide information to administrators as more tests are proposed.

In summary, newborn screening started with PKU and was accompanied by enormous enthusiasm and promise. Newborn screening still has the potential to achieve early diagnosis and treatment of serious health problems. It can identify conditions for which there is not yet a curative approach. Finally, screening might yield findings with no implication for the child's health.

6.12 Conclusion

This section addressed issues arising before conception, various modes of conception, investigations during pregnancy, and management of the infant after birth. Modern technology has given prospective and new parents a new range of choices to make for the fetus and infant. The issue of informed consent pervades this whole chapter, yet communication takes place in these situations always with a sense of urgency. This chapter also addressed the issue of reproductive freedom, an issue about which we accept fully there are many different views. We have tried to encapsulate what a good physician will do when helping pregnant women without the physician forcing his or her personal views on the patient.

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Chapter 7
I Think Someone Has or Is Deliberating Harming This Child. I Think There Is Neglect of the Child. Help!

Key Points Concerning Child Abuse and Neglect

- Child abuse and neglect concerns the actions (or failure to take action) of a parent/guardian/caregiver that results in serious harm or a risk of imminent harm.
  - Includes neglect, physical abuse, sexual abuse, and emotional and psychological abuse.
  - Can involve fabrication or induction of illness
  - Occurs in all societies and all levels of society
- All citizens have an obligation to report harm or imminent harm to a child to designated authorities.
  - Pediatricians have a specific moral (and sometimes legal) responsibility to report given their specialized and intimate knowledge.
  - This reporting is not a breach of confidentiality
- Investigations are conducted by child protection authorities.
  - Pediatricians have an obligation to cooperate with child protection services in the investigation and to give evidence in court if asked.
  - A wide range of interventions are possible, including apprehending the child.
- Action taken is based on the best interest of the child and evidence is assessed on the balance of probability.
- Sometimes there will be doubt as to whether actions are child abuse/neglect or not.
  - If a pediatrician is in doubt, a report must be made to allow investigation to resolve the doubt.
  - The pediatrician is not in charge and has a duty to authorities to alert them so that they can take charge.
- Many trainees and pediatricians find this area of practice intellectually and emotionally difficult.

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_7

7.1 Introduction, Significance and History of Recognition of Child Abuse

Child abuse and neglect have long been recognized to occur. The novels of Charles Dickens created a depressing picture of the plight of some children in Victorian England who did not receive adequate care from their parents. However, until modern times, many in society regarded child abuse and neglect as a problem within families, and not necessarily something that demanded the intrusion of other citizens, or the state, to protect the child. Child abuse, the intentional infliction of harm, was recognized as part of a spectrum of harming children, but its recognition did not lead to protective action. By the 1960s, child abuse and neglect were recognized as societal problems; children often needed intervention and help from outside the family. More recently, specific forms of abuse have been recognized. These include physical abuse, psychological abuse, sexual abuse, female genital cutting and medical abuse. Child abuse and neglect in any and all of its forms have definite long-term deleterious effects on the children affected and can be a cause of death. Recognizing, treating and reporting child abuse is an essential part of pediatric training (Shabde 2006).

Child abuse and neglect are major child health problems. Despite the discomfort felt by many in pediatrics in dealing with these problems, healthcare providers must address child abuse and neglect. This is an important part of caring for children. In the USA in 2014, 1580 children are thought to have died of abuse and neglect ("Child Abuse Statistics" www.childhelp.org). Of the deaths, more than 70% were 2 years of age or younger, and 80% of the child abuse fatalities involved at least one parent as a perpetrator. Despite these many reported deaths, there might be under reporting by 50%. The same 2014 US study stated that there were 6.6 million referrals of children to child protection agencies. Other countries present statistics slightly differently, but all paint a very uncomfortable picture. In the UK, 58,000 children were identified as being in need of protection from abuse in 2017 (NSPCC 2017). In a Canadian study from 2014 (Hango 2014), some characteristics of childhood physical abuse are listed. It is clear from that study that the probability is that different forms of abuse frequently occur together. For example, 70% of children who had experienced childhood physical abuse had frequently witnessed parental violence. Of those who were sexually abused, almost half had also experienced childhood physical abuse. The same study confirmed the long-term consequences. Those abused as children had "lower levels of social integration, trust, and physical and mental health" as young adults. Of those who had experienced very severe physical abuse, 31% had a psychological or health condition that limited their daily activities some of the time.

Much of the modern focus on child protection comes from the work of Kempe, who in his pioneering article coined the term, "The Battered Child Syndrome" (Kempe et al. 1962), that caught the attention of the public and politicians. Kempe's work was conducted in the United States and had a world-wide impact on the practice of pediatrics and social work, and on legislation. This work was mentioned in

Sect. 1.10.2.3 as an example of bravery on the part of Kempe. In correspondence, Kempe describes his experience as a professor of pediatrics.

> Day after day, while making rounds at the University of Colorado Medical School whose Department of Pediatrics I headed since 1956, I was shown children with diagnoses by residents and by consultants and attending physicians which simply were examples of either ignorance or denial. I thought very much the latter. I was shown children who had thrived for seven months and then developed 'spontaneous subdural hematoma.' . . . 'Multiple bruises of unknown etiology' in whom all tests were normal, who had no bleeding disorders and who did not bruise on the ward even when they fell. 'Osteogenesis imperfecta tarda' in kids who had normal bones by x-ray except that they showed on whole body x-ray many healing fractures which could be dated. 'Impetigo' in kids with skin lesions which were clearly cigarette burns. 'Accidental burns of buttocks' in symmetrical form which could only occur from dunking a child who had soiled into a bucket of hot water to punish soiling. In these cases, and many others, we did often learn from one or both parents, in time and with patient and kindly approaches, that these were all inflicted accidents or injuries. (Heins 1984)

Kempe also pointed out physician reluctance to become involved.

> … underreporting by physicians still results from failure to diagnose abuse or ignorance about its seriousness. Some physicians resist reporting because of its potential effect on their relationship with the family or their practice. Many also are reluctant to become involved in legal or social bureaucracy. Physicians, as well as the public, are influenced by what Kempe called the "three almost sacred sayings" of our culture. "Spare the rod and spoil the child" highlights our traditional sanction of corporal punishment. "Be it ever so humble, there's no place like home" reminds us of the importance of parents to their children —even flawed parents. "A man's home is his castle" reinforces our sensitivity to the private rights of others, including their right to rear their children without intervention. (Heins 1984)

In his writings, teachings, and talks to politicians, Kempe advocated reporting laws. He also understood the need to change. This applied to the name "Battered Child Syndrome" and the overall reality (Heifer and Kempe 1976).

> The term 'battered child' has been dropped. When coined fifteen years ago, its purpose was to gain the attention of both physicians and the public. We feel now that enough progress has been made to move on to a more inclusive phrase – child abuse and neglect. The problem is clearly not just one of physical battering. Save for the children who are killed or endure permanent brain damage (and these remain a prime concern), the most devastating aspect of abuse and neglect is the permanent adverse effects on the developmental process and the child's emotional well-being. (Heifer and Kempe 1976)

7.2 What Is Child Abuse?

Current definitions of child abuse tend to be broad, emphasising a wide range of concerns for children including neglect, emotional and psychological abuse, physical abuse, sexual abuse, female genital cutting and medical abuse. Abuse may be due to directly harming the child (commission) or not doing something for the child (neglect or omission).

7.2.1 Neglect

Neglect is a subset of child abuse. The World Health Organisation (WHO) (Krug et al. 2002) defines neglect (including emotional neglect) as:

> The failure of a parent to provide for the development of the child – where the parent is in a position to do so – in one or more of the following areas: health, education, emotional development, nutrition, shelter and safe living conditions. Neglect is distinguished from circumstances of poverty in that neglect can occur only in cases where reasonable resources are available to the family or caregiver.

In the UK, "Neglect is the persistent failure to meet a child's basic physical and/or psychological needs, likely to result in the serious impairment of the child's health or development" (UK Department of Education 2011).

Neglect can include a number of items, such as not providing enough food for the child, leading to failure to thrive, or providing the wrong food leading to severe obesity. Other forms of neglect include having poor hygiene in the home leading to infection of cuts, providing inadequate supervision resulting in children being exposed to poisons or to injuries. Physicians must exercise an element of judgement in these items, but none of these symptoms should ever be ignored. Some forms of neglect are "culpable" in the sense that the parents have the means to provide better care for their children but do not offer such care. Clearly parents who have insufficient means and give their children everything they can are not neglecting their children in a 'culpable' sense. While each identified problem needs to be evaluated individually, good record-keeping will ensure that patterns of harm are identified. Neglect can occur also in interaction with health care practitioners, such as non-adherence to medical recommendations jeopardizing the child's health or delay in seeking medical, mental or dental help that may sometimes be so severe as to amount to child abuse.

7.2.2 Emotional Abuse

Child abuse also includes emotional abuse which is "unresponsiveness to a child's basic emotional needs."

> The failure of a caregiver to provide an appropriate and supportive environment and includes acts that have an adverse effect on the emotional health and development of a child. Such acts include restricting a child's movements, denigration, ridicule, threats and intimidation, discrimination, rejection and other non-physical forms of hostile treatment. (Krug et al. 2002)

Emotional abuse is a general term that encompasses psychological abuse, mental cruelty and psychological abuse. The terms seemed to be used interchangeably. In all of them, psychological maltreatment is the core of this form of child abuse. In the Brassard et al. (1987) study some examples of emotional abuse include inducing

fear by holding a knife to a child's foot, creating insecurity such as by leaving young children with unknown carers, tormenting in a vindictive fashion, and threatening to destroy a child's favorite toy or pet. One parent put an adolescent girl on public potato weighing scales to degrade and shame her. In other cases, verbal abuse and derogatory name-calling was used. Some children were told persistently that they were not wanted, and many children were not given any emotional warmth or praise. Some families isolated children by not allowing them to play with friends even during school vacations.

7.2.3 Sexual Abuse

Child sexual abuse occurs when a child is engaged in a sexual situation. Some cases of sexual abuse involve physical contact between the victim and the perpetrator, with or without oral, anal, or vaginal penetration. In other cases, there is no touching, but the child is made to watch sexual acts or pornography (Fortin and Jenny 2012). The division of sexual abuse into touching or non-touching categories is useful but it should not be concluded that non-touching categories should not be taken seriously. They should be, and even if there is no physical injury, there can be lasting psychological and emotional damage.

A new problem of sexual abuse is that of making and downloading sexual images of children on the Internet. Anyone who views these such images is himself or herself participating in the abuse of a child.

7.2.4 Physical Abuse

Physical abuse is the use of force that harms the child's health, threatens the child's survival, and impairs the child's development or dignity. The physical force may involve punching, or kicking the child, but it may also involve the use of an object such as a belt or a stick. Children may be burnt with splashes of hot water or may be held in hot water, or burnt with a cigarette, or even with an iron. Children are sometimes tied up for long periods. Severely shaking a baby and leading to bleeding inside the brain is also a form of physical abuse.

The general approach to a child with bruises, bites, fractures or indeed any injury, should follow the standard format for any medical interaction with the child. The physician should take a history, examine the child, and order appropriate tests. Some decision needs to be made as to the plausibility of the explanation given by the parents about the origin of the injury. There are many pitfalls in differential diagnosis that are described in standard pediatric texts. An article by Dubowitz and Bennett (2007) is a useful source of information on making a diagnosis that abuse is the cause of an injury, and conversely that injuries are likely due to disease.

7.2.5 *Female Genital Cutting*

"Cutting" of the female genitalia involves removing part or all of the female external genitalia. It is described in a number of ways, such as female genital cutting (FGC), female genital alteration, female genital surgery, female circumcision, and female genital mutilation. We will use the first, as it is neither value laden nor judgmental and avoids possibly stigmatizing the mother who might have undergone this practice. The use of "circumcision" implies that it is appropriate to make an analogy with male circumcision, a claim denied by most, but not all, commentators. One commentator (Kluge 1993) sees commonalities in cutting males and females and argues that if one is banned, so should the other be banned. FGC has immediate and long-term complications, and no obvious physical benefits. Some argue that FGC has social benefits in some societies, where women who have not had FGC might be shunned. It is seen as a human rights abuse (Cook et al. 2002). It is illegal in many countries. (Center for Reproductive Rights 2008).

Despite international condemnation, FGC continues. Arora and Jacobs (2016) note that, in Egypt, the percentage of women who had any procedure that altered external genitalia fell minimally from 77.8% in 2006, to only 71.6% in 2011. These authors advocate that medical personnel perform what they call Category 1 and 2 Procedures on the female genitalia. These are procedures that involve minimal cutting, without complications, whether in respect of sexual activity or reproduction. Their arguments are based on cultural sensitivity and gender equality. They do equate male circumcision to FGC. The approach which Arora and Jacobs call culturally sensitive and is an attempt at harm reduction, has been strongly opposed:

> FGM represents a form of discrimination against women and girls and is a violation of the rights of children. The practice also violates a person's rights to health, security and physical integrity, the right to be free from torture and cruel, inhuman or degrading treatment, as well as the right to life when the procedure results in death. (Askew et al. 2016)

We will also discuss this topic in Chap. 11 in the context of cultural differences. We give FGC as an example of a practice that should not be tolerated in any culture.

7.2.6 *Medical Child Abuse*

In his original publication, Kempe wrote, "Parent or parent-substitute may also have assaulted the child by administering an overdose of a drug or by exposing the child to natural gas or other toxic substances." (Kempe et al. 1962) The idea that parents would deliberately harm their own children still seems unbelievable to most of us. The sophisticated harm of child abuse caused by fabricating or inducing illness as described by Kempe, seems outlandish and perhaps outrageous. Just as the catchy phrase "Battered Child Syndrome" brought child abuse in general to public attention, the term, "Munchausen syndrome by proxy" brought fabrication of, or inducing, symptoms to public attention (Meadow 1977).

Like "Battered Child Syndrome", "Munchausen syndrome by proxy" is a phrase that has almost disappeared from medical papers. However, both titles live on in the popular imagination. For the latter, the term, "Medical Child Abuse" is used. This form of child abuse is also called "Child Abuse in a Medical Setting" (Stirling and Committee on Child Abuse and Neglect 2007). Whatever the name, "the central issue of importance is that a caregiver causes injury to a child that involves unnecessary and harmful or potentially harmful medical care." There needs to be recognition of the possibility, then an assessment of probability, and then involvement of child protection. If physicians are concerned about collaborating with an external agency dealing with child abuse in general, then they will be more concerned in this situation. We described earlier in this chapter Kempe's conclusion that sometimes physicians were reluctant to make a "diagnosis" of child abuse because this diagnosis might affect their relationship with the family, and because they hesitated to become involved with legal and social authorities. There may also be hesitation at the possibility of giving evidence in court. In medical child abuse, these concerns are likely magnified, because such cases tend to be extremely time-consuming and complicated. There is a further risk in this situation specifically of public vilification by parent organizations (Mothers Against Munchausen by Proxy Allegations 2018). Nevertheless, the safety of the child makes formal reporting to child welfare authorities essential. As discussed, there is almost always a legal obligation to do so.

Stirling and Committee on Child Abuse and Neglect (2007) state that physicians must ask three questions:

1. Are the history, signs, and symptoms of disease credible?
2. Is the child receiving unnecessary and harmful or potentially harmful medical care?
3. If so, who is instigating the evaluations and treatment?

They note that it is not child abuse when overly compulsive and incompetent physicians offer excessive and unnecessary medical care. They note also that some parents are overanxious and consult physicians when their child has minimal symptoms. Here education of the parent is key for both physicians and parents. But if the parent fabricates or induces symptoms and the physician continues with investigation and treatment, parents and physician both bear responsibility for the harm that comes to the child. The correct medical approach is no different from any other case of child abuse; the child's safety is paramount. Hence physicians must involve child protection, and the medical and social authorities must collaborate to help the child in what is a very complex situation.

7.3 Evolving and Controversial Issues

In the introductory part of this section, we noted that society has evolved in its attitude toward the harming of children by the caregivers, and that the notion that society should intervene has evolved dramatically in the last 50 years. There remain

some aspects of parental behaviour (or other caregivers such as teachers) that might be considered child abuse in some situations and by some individuals, and not in other situations or by other individuals. Such controversial areas include the role of physical punishment in children, the use of unusual diets and avoidance of immunization.

7.3.1 Physical Punishment

Physical punishment of children can be a contentious issue among some people and in some societies. Such punishment is rarely described as abuse; it is more likely to be called "spanking". The noun "spanking" is defined as "an act of slapping, especially on the buttocks as a punishment for children". "You deserve a good spanking" (Urban dictionary). A Google search will yield many references to media articles both for and against spanking of children. Spanking seems to be very common, occurring in up to 80% of families (O'Callaghan 2018). It is also described as something that should be abolished, because it has long term consequences, and is likely ineffective in any case in changing behavior (Hamblin 2017).

One distinguished medical editor, Catherine D. DeAngelis MD encapsulated the issue:

> Years ago, I taught classes on child abuse to police officers. I started each new class by asking how many had ever spanked a child; almost all hands were raised. I then asked how many had ever beaten a child; no hand was ever raised. I then asked them to explain the difference, and the fun began. (Editor's note in Fargason et al. 1996)

Fargason et al. (1996) surveyed pediatricians involved in child abuse about their attitude to spanking. Surprisingly, 39% thought spanking was sometimes appropriate. However, the majority did not. When spanking was observed during a clinic visit, all thought there should be some response. On the question of teaching residents on how to handle such situations, only 29% of educators had taught this. The teaching included provision of reading materials (35%), lectures (60%), and interactive teaching sessions (55%). One respondent used videotape scenarios and interactive role-play sessions. All believed that residents witnessing spanking in clinics should intervene, but none had protocols on dealing with the situation.

In a different study, Gershoff et al. (2016) examined attitudes about spanking among staff throughout medical settings. Of the 3313 included in the study, about half were staff who provide direct care to patients (e.g. physicians and nurses) and half held non-direct care positions (e.g. lab technicians). The great majority acknowledged that spanking could lead to injury, but less than half thought that spanking is harmful to children. To be clear, the authors of this text believe that physical punishment of a child is never appropriate, and that we should work to abolish it.

7.3.2 Diet in Childhood

Good nutrition and subsequent growth are very important for the overall health of every child. Parents may, with the best of intention, impose unhealthy feeding regimes on their child. Pugliese et al. (1987) reported on seven children with failure to thrive. The parents had a variety of concerns that their children might become obese, develop atherosclerosis, become junk food dependent or develop eating habits that the parents believed were unhealthy. The diets imposed on the children were those recommended for adults at risk for cardiovascular disease. The children had inadequate weight gain and linear growth. The parents were offered full explanations of the medical situation, provided support, and all children showed catch-up growth. This is an example of parents who mean to do the right thing by their child but who do not know that what they are doing is inappropriate. Such parental behavior is perhaps not uncommon and is not charted. On the other hand, if the parents refused to accept advice, and continued with diets that are unsuitable for children, then the best interests of the child will be met only by involving child protection services.

Some diets popular in society, such as vegan diets, may lead to problems in children if full attention is not paid to the child's specific nutritional needs. Children might remain healthy on these diets, but care must be taken that they have sufficient calories and protein, and that they have supplements of items such as calcium, vitamin B-12, vitamin D, and trace minerals (Amit et al. 2010). In other words, healthcare professionals have a role in advising parents on the essential elements of a healthy diet in childhood. Again, referral to child protective agencies should be considered for the small number of parents who adopt specific diets without heeding dietetic or medical advice on ensuring good growth and avoidance of deficiencies.

7.3.3 Immunizations

Childhood vaccination has been one of the greatest medical advances of all time in reducing childhood mortality and morbidity. The words, "vaccination" and "immunization" are subtly different. "Vaccination" was first used to describe the prevention of smallpox, but is now used for any inoculum to stimulate antibody formation. "Immunization" implies that the process has been successful, and antibodies have been generated. In everyday usage, the words are used interchangeably.

Current evidence is that the recommended routine childhood vaccinations are safe. Despite such evidence, many parents do not have their children immunized. Is this failure to follow medical advice tantamount to neglect? One difficulty in conflating failure to have a child vaccinated and child neglect, is that the risk of infection is very distant in time from the opportunity for vaccination. If there is an epidemic of a specific infectious disease, and vaccination is advised as a control measure, then in this specific situation failure to vaccinate might be reportable to

child protection authorities (Kirkey 2017). We emphasize that this is a very exceptional and unusual situation. In general, concerns about vaccination should be addressed by providing support and information to parents (Levi 2007).

7.4 Duty of Physicians Regarding Child Abuse

The ethical issues considered here include the necessity of breaching the child's medical confidentiality to aid the child, the need to collaborate with non-health care professionals, the necessity for intrusive probing into personal issues without being judgemental and why we need to focus on the best interest of the child, and not the wishes of parents. There might be rare occasions when deception is required. Finally, as in other branches of pediatrics, attention should be paid to prevention of child abuse, and here physicians may have a duty of advocacy.

Even as we make judgments as to whether child abuse in one of its forms might be occurring, it is important to be non-judgmental, to try to understand why child abuse has happened and to deal supportively with parents whose neglect or actual abuse has harmed a child. The abuse might be occurring by a non-parent family member, family friend or other person. Recognize that the aim of any intervention is to work with families, not to punish them. Recognize also that abuse can occur in affluent, well-educated families, though physicians are sometimes reluctant to believe this. The ways we help the child should be the same, whether we are dealing with an affluent or a poor family, whether the parents are well educated or not. The children are equally vulnerable.

Almost all pediatric facilities have a dedicated team to help pediatricians identify child abuse and neglect, to give advice on communicating with the family and to identify when formal notification to child protection services is essential. Nevertheless, issues about child abuse and neglect cannot be considered the sole province of such a team. All pediatricians must, at a minimum, be able to recognise when abuse is possible, and how to get skilled help. This is particularly so as these issues are pervasive in pediatrics. Even when care is transferred to the dedicated child abuse team, pediatric trainees should make a strong effort to stay in touch as events unfold. Observation of how the events unfold is important in the education and the maturation of the trainee.

In the key Part II on Consent and Confidentiality, the ways in which child protection affects decisions are listed. In Consent (Chap. 4) we give examples of when treatment refusal becomes neglect and child protection must be involved. In Chap. 5 on Confidentiality we emphasize that, when a child is being abused or neglected, protecting the child has a higher priority than maintaining confidentiality. In the chapter on Consent, we gave some reasons why many pediatricians and pediatric trainees dislike child protection work. We said there: "Healthcare professionals find the process unpleasant because reporting that a child needs intervention tends to mark a change in the physician-parent relationship from ideally collaborative to adversarial. Moreover, the process takes the physician into the unfamiliar world of

legal investigation and adjudication, in which the physician is not in control". Other concerns are very understandable and include concerns about missing a treatable disorder. Often the pediatrician has an understanding of why abuse/neglect occurred and knows there was not a deliberate attempt to harm the child. There will be stress and there can be concerns about complaints. Having said all that, the greatest concern is that the physician has no control over child protection services. Another major concern is doubt about the benefits of a child protection investigation. Physicians often and incorrectly believe that if they refer the case to child protection services, then the child will automatically be separated from the family. That outcome certainly can occur, but only where there is strong evidence that the child's safety requires this action. In almost all jurisdictions child protection legislation now puts a high priority on keeping families together and providing support and supervision when a family is in trouble.

It is now accepted that when a pediatrician sees a child whose injuries are not in keeping with the history, that further investigation is by child protection services. Formal notification must be made. This does not mean that medical investigations should not continue. It does mean that the pediatrician is ethically obliged to collaborate with child protection in the investigation. Often, the child will remain with the family while the investigation is underway. When the suspicion arises, the family should be told directly of the concerns. There will be many responses including anger, and, although very unusual, attempted physical harm to the hospital staff. When planning how to tell families, the pediatrician should ensure first that he/she is not alone; and second that the family is not between the pediatrician and the door. When there are grounds to believe that physical harm to staff and/or absconding with the child is likely, other strategies are needed. These include deception. Perhaps the family can be told "we are waiting for the results of the tests", while child protection and hospital security is notified. We believe this is justified. We will not call this a "white lie"; it is deception. This is only justified when there are real concerns about safety. It cannot and must not be the norm.

In any discussion with the family, as mentioned earlier, physician questions and responses must be non-judgemental. We do not know the pressures, tensions and problems the family are facing. It is likely that they already feel very guilty about the abuse. Also, a supportive approach is much more likely to lead to honest answers. Such an approach also sets the stage for an open relationship with other physicians and staff members as long-term care and support is provided.

7.5 How Abuse Might Present

7.5.1 Why Is Aurora Not Gaining Weight?

Dr. Rodriguez saw Aurora, age 2 months for a routine examination. Aurora was the first child of unrelated parents. Her weight was plotted on a growth chart. At birth she was at the mean, and now she was at the 10th centile. Dr. Rodriguez reviewed how Aurora was being

fed. She had been breast-fed for the first week of life, but subsequently was fed by formula. The amount of formula given seemed inadequate for her age and weight. On physical examination Aurora seemed otherwise healthy, apart from a mild diaper rash. Her clothes seemed rather dirty. In keeping with the failure to gain weight, she had the reduced muscle mass. Drs. Rodriguez gave Aurora's parents advice on how much formula to give and arranged to see Aurora in a week's time.

When Aurora was seen seven days later, she had gained only 30 grams, much less than expected (perhaps 100–200 g might be reasonable, depending on intake). Dr. Rodriguez arranged for her admission to the pediatric unit for further investigations. On admission to hospital, a decision was made to observe her, offer regular feeding, but defer investigations until it was seen how she would progress. She was fed both by the mother and the nurses, and the nurses noted that Aurora was always hungry. The nurses also noted that the mother seemed to lack confidence around Aurora and did not seem to realize when the child was hungry. After four days in hospital, Aurora seemed more active than before, and had gained 180 grams.

The hospital social worker met with the family and was concerned that neither of the parents had had any experience in caring for an infant in the past, and that there was little family support. There also seemed to be financial problems in the home.

Dr. Rodriguez has a primary duty to the child. His first duty is to review the history, the examination and order any appropriate tests. Is there a medical explanation for why the child has not thrived? It seems unlikely that this will be so as she gained weight on a standard diet without any medical intervention, nevertheless Dr. Rodriguez needs to take reasonable steps to ensure that he is not missing some other obvious diagnosis, but he should not delay action by pursuing some very rare and unlikely medical possibility. He should inform the parents about his concerns and proceed to make contact with child protection services. Thereafter, he needs to cooperate with the investigation.

The reporting seems an obvious step and is one way in which support can be provided to the family so that they can give appropriate care to the child. Yet it is true that some physicians are reluctant to call child welfare in such situations. Gunn et al. (2005) explored by means of a questionnaire pediatricians' experience of child abuse, and reasons why they would not report the situation to child protection authorities. They had information from 195 respondents (56% response rate), and almost all (98%) had made a report to child protection services at least once in their career. Almost half (49%) had made a formal deposition, and 41% had been in court to give evidence. Of note, 13% had been threatened with a lawsuit by parents, and 3% had been sued. 28% had considered referral to child welfare services but didn't. The reasons they gave were varied, from immediate consequences to the child, family and themselves. Some had previous experience of child welfare services and did not believe that the child always received help. In terms of the impact on the family, and the impact on themselves, they had concerns related to a fear of alienating the family, and perhaps precipitating a family crisis. Some of the pediatricians had a fear of being wrong and were uncertain in their diagnosis. Some hesitated to report when faced with angry parents, and some felt that child abuse or neglect was unlikely as the family was "nice".

While accepting the validity of some of these concerns, Aurora's needs require the protection that can come only from formal child welfare services. She is entitled to have enough food to eat to develop normally.

7.5.2 A Day in Emergency

Dr. Nguyen is a second-year resident in pediatrics doing a rotation in emergency. She sees Crystal, aged 6 weeks, bought in by her parents because of onset of persistent crying when her diaper was being changed. The parents seemed concerned and wanted the best care for their daughter. The parents said Crystal had rolled over in the crib and caught her leg in the slats. Dr. Nguyen sees swelling in the right thigh, and X-ray confirms a fractured femur. Dr. Nguyen informs the staff physician. What else should she do?

If you have even superficially scanned the preceding section, you will know that child protection must be informed urgently. This is a serious injury; it is nearly impossible for a child of this age to have an accidental fracture of a major limb bone. Of course, Dr. Nguyen and her staff physician will together explore the possibility of alternative diagnoses such as osteogenesis imperfecta. The immediate issue is the protection of Crystal, and this need is best served via child protection authorities. Crystal may have siblings; the parents might be caring for other children. All these issues can be explored by a full child welfare investigation.

7.5.2.1 A Surprise in the Clinic Room

Dr. Nguyen is now in an ambulatory clinic seeing a child of a different family. She is assigned the task of taking a history from the mother about the progress of 8-month-old Anita, who was born at 32 weeks' gestation. Anita's 4-year-old brother is in the room and is very active. The mother is having trouble concentrating on giving an account of Anita's health because of her son's behavior. At one stage, the mother became very agitated at her son's rumbustiousness and slapped him. He quietened immediately. The mother resumed talking about Anita.

Dr. Nguyen is taken aback at the mother's action, and her apparently being unaware that she has hit her child.

She is not sure about her next action.

So, what should Dr. Nguyen do? Professional organizations are clear, perhaps not in their unequivocal condemnation but at least in their discomfort with spanking. The American Academy of Pediatrics recommends that parents be encouraged and assisted in the development of methods other than spanking for managing undesired behaviour (Committee on Psychosocial Aspects of Child and Family Health 1998).

A Canadian document from a number of organizations is more forthright that spanking is not effective, is harmful, and should be banned by legislation (Durrant et al. 2004). The document argues that children should receive the same protection from assault as adults.

It seems that Dr. Nguyen must act in some way, but this situation might the rare case when reporting to child protection should not be automatic. But such action should be considered. Dr. Nguyen must respond immediately, by, at the least, asking why the mother acted as she did. The episode should be documented in her notes and discussed with her physician preceptor and by clinic staff. A nurse might have witnessed a similar episode when the family was waiting to be seen. In such a case, a referral to child protection is warranted.

7.5.3 Sonja Has Problems at School

Anita Lopez is an elementary school teacher, teaching Grade 6. She enjoys teaching and takes an interest in all of the children. Sonja is 11 years old and had been doing well in her classroom work until recently. Ms. Lopez noted that Sonja recently did not complete assignments, something new for this child. Sonja also seemed less willing to volunteer answers in the classroom. Ms. Lopez spoke to Sonja in a supportive fashion about the late assignments. A week or so after she had first asked the questions, Sonja told Ms. Lopez that her mother often turned out the light when she was trying to do her assignment in the evening, making it impossible for her to do the homework.

This situation is emotional abuse. One of the differences from the other stories in this chapter is that the person who identifies the issue, Ms. Lopez, is clearly not a healthcare professional. We have pointed out that a pediatrician ushered in the modern era of recognition of child abuse, and development of child protection services. Nevertheless healthcare professionals make only a minority of referrals to child protection services. Hence, this situation is not unusual.

Ms. Lopez will go through a similar thought process to that of healthcare practitioners facing a child who is being harmed by behaviour of the main caregiver. She will know what resources are available in her school in terms of counselling, and support to Sonja. She will likely seek advice from a senior colleague. One of the differences between this situation and that in a healthcare encounter is that Ms. Lopez will have frequent and direct contact with Sonja, and very infrequent contact, if any, with the parents. While it might be appropriate to notify child welfare, absent other evidence of abuse, it is possible that support might be provided in the school, and a meeting sought with the mother before further action is taken.

7.5.4 Charley's Story

Charley's stepfather joined her family when she was 2 years old. Sexual abuse started when she was 4 years. At age 10 years she took an overdose. She was treated and subsequently saw a psychiatrist. No one asked why she had taken the overdose. At age 14, the abuse resulted in pregnancy. Her stepfather paid for an abortion. No one asked who the father was. Charley ran away at age 17 years. Some years later, with support, she went to the police. Her stepfather was charged and sentenced to jail. (NSPCC 2018)

This is clearly sexual abuse that was continued over many years. It is outrageous that none of the clues when she took an overdose, or when she heard became pregnant at the age of 14 were explored and the sexual abuse uncovered sooner. The ethical issue that we derive from Charley's story is that early diagnosis of any form of child abuse is important, and part of the role to be played in preventing persistence of the abuse. It **is** ethical to explore the underlying cause for any medical situation; it is **not** an invasion of privacy to find out why a 10-year-old took an overdose, or a 14-year-old became pregnant. It **is** ethical to see a child by herself to allow exploration of sensitive topics.

7.5.4.1 Can Cultural Practices Be Abuse?

Dr. Torres is a third-year resident in pediatrics and is on a rotation in the renal clinic. She sees Rachel, a seven-year-old child referred because of recent onset discomfort with urination and known to have had three urinary infections in eight months. The family immigrated to North America nine years ago and has excellent English. Dr. Torres reviews the symptoms and takes a general history. She is told the family have recently returned from a visit to grandparents in the Middle East. Rachel seems generally well, and well nourished. On examining the pubic area, Dr. Torres notes inflammation. On examining the genital area, there is evidence of injury. The family say that Rachel had 'cutting' while with her grandparents, a custom in their family.

How should Dr. Torres proceed?

Please see the earlier Sect. 7.2.5 in this chapter for more details about female genetical cutting. At the very least, Dr. Torres should endeavour to conceal any feelings of revulsion by controlling her body language and speech. Being non-judgemental is essential, but easier to say than to do. She should proceed with medical recommendations, including antibiotics. She needs to think carefully whether surgical reconstruction needs to be explored, but likely will defer that option at least in the short term. There are number of choices. Taking a child abroad for female genital cutting is a criminal offence in some countries. Where FGC is illegal, Dr. Torres may report this information to the police. She may involve child protection, but it is not clear that Rachel is at risk of further physical harm by cutting: the FGC has occurred! Rachel's sisters and cousins might be at risk of FGC. Whatever Dr. Torres does, she should keep the family informed and ensure that they have support.

7.5.5 Caught in the Crossfire

Dr. Jackson is a third-year pediatric resident on an in-patient rotation.

He was told at handover about Erica a seven-year-old child admitted with abdominal pain, and who was found to have proteinuria of 10 g/1.73 m^2 per day. There was no peripheral edema. Serum concentrations of total proteins, lipids, and creatinine and immunological investigations were normal. Kidney biopsies were negative, and she was discharged home.

Several weeks later, Erica was admitted for intestinal hemorrhage with significant anemia. Endoscopy of the esophagus, stomach, colon, and small bowel (via laparotomy) were normal.

Some staff had become concerned at the discrepancy between objective findings and the results of invasive and non-invasive test. Those particular staff members wanted to approach child protection and to obtain an order to observe the child when his mother was not present.

Other staff members thought that this mother was devoted to her child, and some of them considered the 'accusation' of potential abuse as merely the result of physician embarrassment that they could not identify the underlying diagnosis. Feelings were strong on both sides, and Dr. Jackson felt himself being pulled in to the controversy.

What is he to do?

Conflict over cases of medical child abuse, if this is what is happening, is common. Dr. Jackson should avoid the conflict, obviously, but should not avoid the patient. He should review the whole chart, including nursing notes. He noted that electrophoresis of urine proteins revealed an albumin fraction of 99.4%. This is unusual, and he managed to get a urine on an occasion the mom had left the unit. That specimen was free of protein. This story, without the conflict, is (very) loosely based on a real case (Ulinski et al. 2004). In the case reported, the mother who was a nurse, admitted that she added human albumin to the urine samples.

Important social details must always be part of rounds, even if time permits only a brief outline. In this specific case, communication between professionals might permit early identification of "at risk" situations. The greatest ethical issue is the need for wholehearted collaboration between agencies, focusing on the child's safety. The medical and other healthcare staff need to debrief regarding the antagonisms that developed during this case and find ways of working together again!

7.6 Conflict Over Treatment (Parental Unwillingness to Consent to Necessary Medical Treatment)

This book addresses parental refusal of necessary medical treatment in Chap. 4. While some details were given in that section, some discussion is included here because, at least in part, failure to provide necessary medical treatment is denying the necessities of life to a child. In the section on Consent we also discuss that when parents refuse permission for a life-saving intervention, physicians might be obligated to report this situation to child protection services. We emphasized then, and re-emphasize now, that this is an exceptional course of action. But reporting might be required and can be life-saving. It is important to highlight that the duty to report usually arises when a person has reasonable grounds to believe that a child needs help. Whether the state will actually interfere with parental duties occurs usually based on a higher evidentiary standard. We quoted Diekema:

> Coercive state interference with parental prerogatives, for the good of the state and the good of the child, is justified when there is clear and convincing evidence that parents' actions or decisions represent likely and serious harm to the child. (Diekema 2004)

We also listed some conditions, and for convenience we repeat them here:

1. Existence of "significant risk of serious preventable harm";
2. That harm be imminent, requiring immediate action to prevent it;
3. Treatment plan rejected by the parents is of proven efficacy;
4. Interference with the parental decision and provision of the treatment to which they object is necessary in order to prevent serious harm from coming to the child in question. This means that if there are acceptable alternatives, then they must be pursued;
5. Interference with the parental decision offers net benefit to the child;
6. The extent of state intervention and the treatment allowed under the authority of the state represents the least intrusive alternative that will reduce harm to the child and minimize the impact on parental authority;
7. The decision to seek state intervention is not influenced by morally irrelevant considerations (i.e., the religious nature of the decision). The example cited is that of children of Jehovah's Witnesses parents where the child requires a life-saving blood transfusion. The transfusion is almost always ordered, not because of the religious aspect of the refusal, but only because the child's life is at risk;
8. The decision to seek state intervention passes the test of publicity: the anticipated outcome of state intervention is what reasonable parents would agree is appropriate for all children.

7.7 Reporting Child Abuse: Benefits and Responsibility

Charley's story of sexual abuse by her stepfather is told in 7.5.4 above. There were times when she had medical assessment but none of the professionals explored possible underlying problems. One of these occasions was when she took an overdose, and had immediate medical care followed by psychiatric care. Surprisingly, no one asked Charley why she had taken an overdose. The other opportunity to help Charley arose when she requested an abortion when she was 14 years; the physicians carried out the procedure without determining whether Charley had consented to sexual intercourse and the relationship between Charley and the father of the fetus. (It was the stepfather).

The important opportunity that all physicians, including pediatricians, have to detect child abuse must be recognized; taking action can make all the difference to a child. The website of a UK organization, the National Society for the Protection of Children (NSPCC) tells many stories including one about how pediatricians did not seize the opportunities presented. One professional told us about being sexual abused as a child saying, "I waited for the doctor to ask, but he never did." In Charley's case, had the opportunities to identify her abuse been seized, her life course might have been altered (NSPCC 2018).

The clinical features that seem to identify child abuse can actually be misread. Sometimes, what appears to be child abuse is something else. Are physicians responsible for the harm they inflict in reporting child abuse when such abuse has not occurred? When physicians report their suspicion, the parents might suffer harm

emotionally and psychiatrically, and their reputations might suffer. Is such harm to parents actionable at law? In the United Kingdom, the Supreme Court considered three cases in which pediatricians had informed child protection services that a child appeared to be suffering from abuse at the hands of the parents. Extensive medical, psychiatric and social reviews concluded in each case that the children concerned had medical conditions that explained their symptoms. The parents' claims for damages for the suffering that arose from being suspected of child abuse, were not accepted. The court concluded "no duty of care can be owed by the doctor or the social worker to the parent" (JD (FC) v. East Berkshire Community Health NHS Trust and others and two other actions (FC) 2005). In other words, the child's interests are paramount; the professional's duty of care was solely to the child and not to the parents.

The situation appears to the be the same in the United States where litigation against physicians for reporting the possibility of child abuse was dismissed. The court denied the claim by a mother that the doctors acted improperly:

> Everything the plaintiffs claim the doctor defendants did occurred within the hospital and the scope of their duties as doctors. They observed KB on admission and ascertained immediately that she presented what they diagnosed as classic indicia of Shaken Baby Syndrome. They then conducted follow-up tests and examinations that, in their professional view, confirmed that initial assessment.

In dismissing the case, the judge noted that there was no evidence of any case in the United States finding physicians having violated parents' constitutional rights by reporting suspected child abuse.

> Most importantly, plaintiffs have failed to cite a single on-point case from any court at any level that withholds qualified immunity from a medical professional sued under § 1983 after making a mandatory report of suspected child abuse. There is no case, much less a clearly established legal doctrine, that would have put these defendants on notice that they were violating the plaintiff's constitutional rights, even if the § 2151.421 report was (as it was not) ill-founded, mistaken, reckless, or conscious shocking. (Blythe v. Schlievert 2017)

Most United States have statutory protection for "good faith" reporting of suspected child abuse (Child Welfare Information Gateway 2016).

Physicians may be civilly liable for NOT reporting child abuse to government authorities and thus required to pay for the lifelong injuries the child suffered that could have been prevented had the physician reported the abuse. For example, in the United States a Pennsylvania judge noted that child abuse law does not expressly prohibit suits for malpractice against physicians who fail to report child abuse and emphasized that physicians have a duty of reasonable care to their patients because of the physician-patient relationship. In other words, reporting suspected child abuse is the standard of care that a physician owes the child (K.H. v. Kumar 2015).

7.8 Conclusion

Child abuse and neglect can present in many ways, and often give rise to major health problems, sometimes death, in the children involved, and their family members. Child protection officials and agencies have the authority to investigate. Pediatricians have a legal and moral obligation to report their suspicions to child protection authorities. Such suspicions might be ill founded but it is important that the investigation take place to determine whether they are ill founded; "it is better to be safe than sorry". Physicians have a continuing moral obligation to collaborate with social agencies, always placing at the forefront the best interest of the child.

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Chapter 8
What Are my Roles in the Many Issues that Arise with Children Who Are Described as Being Medically Complex? How Do I Help in the Long-Term Care of These Fragile Children, Whether in Hospital, At Home, At School or in Long Term Residential Care?

Key Points Concerning Medical Complexity

- Children with medical complexity are a new population that have:
  - Multisystem conditions
  - Dependence on technology
  - Long stays in hospital
  - The possibility of never going home
- Consent process for life-prolonging procedures should:
  - Detail benefits and risks of procedure
  - Outline impact on life of the child and family
  - Include the option of not going ahead with the procedure (understanding that death of child is possible)
- Children with medical complexity who go home still require advanced medical care.
  - Most of the care at home is provided by parents and extended family (informal caregivers)
  - Parents have responsibilities at home that, in hospital, are the responsibility of professionals
- Care needs are usually lifelong.
- Many of these children are at high risk of dying during childhood.
- These children and their families present novel ethical problems:
  - Professional/family boundaries need to be defined
  - Continuity of care must be maintained
  - Advocacy at many levels is required of health care professionals
  - Collaboration with community agencies is essential
- Care must be provided to the whole family, not just to the vulnerable child patient.

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_8

8.1 Introduction

A new population of children now spends a great deal of time in hospital, and requires complex care throughout their life, often in the family home, which may need special adaptations. This population exists because of medical advances in the fields of obstetrics, neonatology and pediatric intensive care. These children usually have multi-system disease, and many are dependent on medical technology to live. The ethical issues raised by this population are novel, and are very important to be understood by pediatricians, almost all of whom will have contact with such children at one time or another. These children will likely take much of the time of those currently training in pediatrics.

8.2 Charlotte's Story

Charlotte was a second child. Her parents, Monica and James, looked forward very much to taking her home after delivery and joining their son, Malcolm. Things went well for the first 2 to 3 weeks, but Monica noted that Charlotte was taking longer and longer to finish feeding from her breast. Sometimes Monica thought Charlotte would slip through her hands. After speaking to a community health nurse, the parents visited the family physician who found nothing specifically wrong with Charlotte. However, the feeding problem persisted, and Charlotte started making a funny noise when she was breathing in. This time the family physician made an urgent referral to a pediatrician who noted poor muscle tone.

Charlotte was admitted to the nearest pediatric unit, but because of respiratory distress, she was transferred urgently to a specialized pediatric facility. Specialists in neurology and respirology were consulted, and a battery of investigations ordered. Meanwhile, Charlotte had trouble maintaining respiration and was intubated. The results did not lead to a definitive diagnosis, but there was suspicion that Charlotte might have a mitochondrial myopathy. The tentative diagnosis was explained to the parents, along with the likelihood that Charlotte would need assisted ventilation for the rest of her life. The parents agreed to placement of a tracheostomy tube and because of continued feeding problems, a gastrostomy tube was also placed.

Four weeks later, Charlotte was transferred out of the intensive care unit to a special inpatient unit for children who are dependent on a ventilator. The health care team started to plan her long-term care at home. Unfortunately, Charlotte required transfer back to the intensive care unit after she acquired a viral infection. She was then transferred out of the intensive care unit again, two weeks later on the unit for children dependent on ventilators.

Charlotte is on seven drugs at present, including vitamins prescribed at the mother's insistence after she heard about them from a social media discussion group led by parents whose children have the same disorder as Charlotte.

Nurses and respiratory therapists frequently suction Charlotte's tracheostomy tube to keep secretions clear, constantly monitor her oxygen saturation, and regularly draw blood for CO_2 monitoring. She has chest physiotherapy and also physiotherapy to improve her limb movements.

Charlotte's parents are friendly and make it clear that they are looking forward to having Charlotte at home. They also make it clear that they are well informed about her disorder and always expect the best treatment.

8.3 Children with Medical Complexity, Incidence and Explanation for Rise

Charlotte is among those children described as "medically complex, or medically fragile, children including those with intense medical needs that result from multisystem disease states, technological dependence, or complex medical regimens". Such children have also been referred to as having "complex chronic conditions (CCCs)" (Burns et al. 2010). We define the child with medical complexity as one who depends upon medical technology and requires care by two or more subspecialists. We will use the acronym "CMC" as an adjective to refer to the Child with Medical Complexity, as opposed to Medically Complex Child (MCC). Both are used, but the first focuses on the child and not on the medical components of the child's life.

Another description of children considered CMC can come from information about specific institutions. Davies and her co-authors (2014) considered children who were in hospital for 6 months or longer in a pediatric institution in Edmonton, Canada. Among the children studied, 64 were in hospital for 180 days or more between the 2007 and 2012. The hospital concerned in this report had 137 beds, and these 64 patients accounted for 7% of the annual inpatient bed use. The mean length of stay for all patients was 6.1 days, but by contrast the mean length of stay of the 64 children who had been in hospital for months was 326 days. Children who were technologically dependent were included in this study.

Davies et al. (2014) reported that the most common diagnoses were a need for long-term assisted ventilation (52%), waiting for an organ transplantation (39%) and using ventricular assist devices (11%). The mortality in these children was high (26%), but even that might be an under estimate given that some of the survivors might have died after discharge from hospital. The majority of those who did go home, required extensive support with only 5% of the children needing few or no health support needs in the community. The other children needed a variety of supports, including nutritional support, nursing care, a variety of therapeutic interventions, and early intervention programs. The most extreme need for support at home was one child with around-the-clock supervision by two caregivers. Clearly, these children have complicated health needs that we consider in this section.

This section will also touch on topics considered elsewhere in this book because they are prominent in the situation of medically complex children; these include physician compassion fatigue (Chap. 1) and addressing parents who challenge many aspects of their child's medical care (Chap. 11). We will also revisit the subject of consent (Chap. 4) in the context of when one procedure can profoundly affect the trajectory of the life of the affected child and the whole family.

8.3.1 Rising Incidence

Most pediatricians agree that there are more children like Charlotte, children who are medically complex than ever before. Burns et al. (2010) used the Nationwide (United States) Inpatient Sample (NIS) and examined "trends in hospitalization rates for medically complex children over a 15-year period from 1991 to 2005". For their review, they adopted two definitions to define medical complexity.

> The first consisted of children with diagnoses in more than one chronic-condition category, defined by organ system, without requiring the presence of any single specific condition. The second consisted of children with a single specific diagnosis, cerebral palsy (CP) or bronchopulmonary dysplasia (BPD), and the presence of a diagnosis in one of the chronic-condition categories.

The data confirmed their suspicions; the date revealed more hospitalizations of children with the general label of medical complexity. The increases in hospitalization rates in children with multiple diagnoses were contrasted with the stable hospitalization rates of children with a single diagnosis. In other words, the relative medical complexity of hospitalized children has increased. The change in rates was impressive in children with diagnoses in more than one CMC category. In 1991–1993, this group of children had a hospitalization rate of 83.7 per 100,000. By 2003–2005, the rate was 166 per 100,000 (Burns et al. 2010).

Although the researchers confirmed that there has been a two-fold increase in a short time of hospitalized children with complex health needs, their study was unsatisfactory in that the methodology did not enable them to include infants of the highest need, that is those with technological dependence. So, an infant such as Charlotte might or might not have been included in the study. Also, their method would have included one infant many times because one of the characteristics of the medically complex infant is frequent re-admission to hospital. These caveats notwithstanding, the overall conclusion is clear, the general assumption of an increase in numbers of children with medical complexity is correct.

8.3.2 Reasons for Rising Incidence

Why has there been a rapid increase in the number of children with medical complexity? Burns et al. (2010) speculated that the possibility of home treatment might be a factor in the increase and considered various other explanations such as the increased survival and decreased mortality of preterm infants and infants with congenital anomalies.

Burns and his colleagues (2010) considered one institution at one moment in time. Another way to explore what is happening is to consider the changes over time in a single institution. Namachivayam et al. (2010) sought to identify some of the reasons for the increase in children with medical complexity by reviewing their data over a 30-year period in Melbourne, Australia. The authors accepted that, over the

period of the study, there have been many improvements in intensive care including a better understanding of critical care illnesses in general, centralization of pediatric intensive care units, advances in pediatric cardiac surgery, improved peri-operative care, and new treatment modalities. Hence, some critically ill children who might have died in the past now survive. Yet, the authors also thought that there had been a change in practice with intensive care now being offered and delivered to some children with complex chronic diseases, whereas in the past, such children would not have been admitted to intensive care.

There is speculation in an article by Davies et al. (2014) that there has been a reduction in pediatric intensive care unit mortality at the expense of an increase in survivors with moderate to severe disability.

Namachivayam et al. (2010) reviewed their data to consider the same question raised by Davies et al. (2014) viz.: Are children being kept alive who would not have been in the past, and then living with significant disability? They reviewed a database that had existed in the institution throughout the 30 years of the study and compared 3 years: 1982, 1995, and 2005–2006. The database held information on pre-admission health status and long-term outcome; a standard "risk of mortality index" was available for all years of the study. The review revealed a clear drop in mortality over the three decades: it was 11% in 1982 and fell to 4.8% in 2005–2006. As an explanation for this change, the researchers posited that intensive care might now be offered to children to whom it would not have been offered in the past. Yet this hypothesis did not seem to be supported by the data they presented, at least in children over 1 month of age, because the proportion of children with pre-existing moderate or severe disability hardly changed: from 12% in 1982 to 14.6% in 2005–2006, an insignificant increase. By contrast, however, there was a sharp change in the health status of survivors. In 1982, 8.4% had moderate or severe disability at follow-up in 1982; but in 2005–2006 this figure had risen to 17.9%. In other words, it seems likely that the children who would have been allowed to die in 1982 and 1995, "were kept alive in 2005–2006 but survived with disabilities".

The researchers concluded by writing, "This trend has important implications for our patients and their families, and for the community as a whole." (Namachivayam et al. 2010). This statement about keeping children alive now who were not kept alive in the past can be seen as a major understatement! It is important to appreciate what this means: decisions made at the bedside in the midst of acute illness to offer the child medical care which, in the past, would not have been offered, has meant that we have a growing population now of very sick children, many of whom will not survive to adulthood, and some of whom will never leave hospital to experience life at home. What has happened is nothing short of revolutionary. Pediatric institutions, the profession of pediatrics, the community support of parents, and the funders of health care have all been significantly affected, and all four struggle to cope with this major change.

How should pediatricians respond to children with medical complexity? Pediatricians will have many interrelated concerns that arise over the long term, irrespective of whether the child remains in a hospital, in a long-term care institution, or in the home. These concerns include defining and maintaining professional/

family boundaries, ensuring continuity of care, and collaborating with community agencies in the provision of support whether financial, equipment, or personnel. We will address these issues as they arise when the child is in hospital, when transitioning to home care and when the child is at home.

8.4 Caring for Children with Medical Complexity in Hospital

The child's stay in hospital is only one part of the very long story of a child with medical complexity. The stay may be very long – months or even years. By contrast, in most children's hospitals the average length of stay is in the range 2–4 days. Children are admitted, treated, and discharged home in an instant. We know these many families with short stays very intimately but for a very brief period of time. On the other hand, the children with medical complexity are with us for a very long time and our knowledge of them and their family situations is generally extensive. Some of the children with medical complexity never go home because they die or because there is no suitable alternative to a hospital facility. When they do go home, they are more than likely to be readmitted with acute episodes of deterioration. For many of them, readmission is something like visiting their second home and meeting old friends, no matter how unhappy they might be about the admission.

During the hospital stay, particularly the initial stay, many major decisions are taken that have a huge impact on the child and family's life. It is during this stay that decisions are made to use intravenous nutrition, to feed via gastrostomy tube, to start dialysis, and to insert a tracheostomy tube. These interventions can be done singly or in any combination. The initial hospital stay itself and all decisions made at that time set the scene for the rest of the child's life. Whenever it is agreed to discuss any intervention with parents, the consequences of not acting should be part of the discussion whether with the team or subsequently with parents.

8.4.1 Introduction to Caring for Children with Medical Complexity in Hospital

Caring for children with medical complexity in hospital involves much more than practicing conventional pediatrics. Trainee pediatricians who become involved in the care of these children will, inevitably, become involved in what appear to be non-medical issues. In reality, all the issues are relevant. Pediatrics does involve dealing with parents, as well as dealing with the medical problems of children. There might be parental anxieties and concerns that can affect the care of the patient before them. These issues are amplified in children with medical complexity. The child patient's care can be addressed satisfactorily only if there is an excellent relationship with the parents, and if we identify resources that can offer help to

parents regarding issues such as dealing with siblings. In addition, at all stages, there are frequent episodes of deterioration that might need to be managed by the pediatrician, but again by cooperating with the family.

The medical condition of these children gives rise to many issues for which there might be no clear-cut solution. Different pediatricians can have different views on the best way to treat a new complication; the parents are knowledgeable and might have another view. Such difference of opinion can create conflict. Trainees should avoid "taking sides"; they should learn how to navigate the situation. However, trainees are entitled to have an opinion on what should be done based on their experience with the particular child, with other children with similar problems, and with their understanding of the literature. Despite having an opinion, trainees are not the ones allowed to make the final decision. A decision might be taken with which they disagree. Trainees should learn how to disagree respectfully with decision makers while keeping the focus on the child.

Developing an understanding of the roots of conflict is an important ability that trainees should try to acquire. Resolving conflict is not the direct responsibility of the trainee. Nevertheless, developing an understanding of techniques of how to approach conflict resolution are skills that will become valuable. Many organizations offer short workshops on this topic. While it might seem an unusual way to use valuable learning time, skills in dealing, or more importantly avoiding, conflict will bring lifelong benefits.

8.4.2 Approach to Decision Making

Children are not born labeled as "medical complex". In some, it might be obvious at birth that we are probably moving in the direction of medical complexity because of, for example, a genetic condition. In others, such as preterm infants, complications might arise that change the life of a child whose only problem is prematurity to a child with medical complexity. Many other children with one condition, such as congenital heart disease, then have complications during the treatment or surgery that change the trajectory of their life and mean that the child has medical complexity.

Since the process of becoming a child with medical complexity is one that evolves as the child's condition evolves, there is usually no precise moment or date when the label can be applied. Whether or not the label is applied, these children have an eventful medical life. They will be having surgeries, usually by more than one surgical specialist, will have complications of treatments, will be exposed to nosocomial infection with resultant deterioration and lastly, but perhaps most importantly, are often subject to medical error or iatrogenic illness.

During the course of that initial stay in hospital, there are moments when major decisions must be taken. These are decisions that alter dramatically the trajectory of the child's life, and indeed the family's life. If the child has complex cardiac disease, then will we start using a ventricular assist device? If the child has a nutritional problem then will we start using long-term intravenous nutrition, or request permis-

sion to place a gastrostomy tube? If the child has persistent airway obstruction, then will we place a tracheostomy tube to bypass obstruction? If the child has persistent problems in maintaining ventilation, then will we commit the child to long-term assisted ventilation?

Just as there is no magical moment when a child is declared to be medically complex, so there is no magical moment in the life of children when one of the above decisions must be made. The reality is that different healthcare professionals will reach the conclusion that a major intervention is needed at different times. We have called this the "period of contemplation". During this period, some staff members think it is obvious that an intervention is required, some think it will never be required, or might not be required for some time. They will lobby one another. The period of contemplation affects all staff members, not just physicians and can be particularly stressful for bedside nurses who have to spend a long time with families. During this period of contemplation, the parents might hear some of the discussion and might ask questions of different people at different times, such as nurses or respiratory or other therapists, or pediatric trainees. These individuals will try to answer the parent's questions but they themselves will be confused as to which course of action is to be recommended. Of course, given the familiarity of parents with the World Wide Web, they might in their reading come across children similar to theirs who has one of the interventions mentioned above and might initiate the discussion.

The movement from the period of contemplation to clarity should be short. Once the idea is raised that a child might need ventricular assist device, for example a tracheostomy, there should be an urgent meeting of the main medical specialists. At this stage, only a small group should be assembled. The point of this meeting is to give general directions not to make detailed decisions. The fewer the number involved, the easier it is to have the meeting in a short timeframe. Those present must include the most responsible physician, the systems specialists most involved, and if there is already a long-term pediatrician, then that person also. A social worker who knows the family and perhaps someone from the nursing services helps such a meeting. That group should come to one of three decisions. The first decision is that the procedure is indicated. The second decision is that more information is needed, and more consultations are required before a decision can be made. The third decision is that the procedure is not indicated at this time. Which of these decisions is taken should be made known to all relevant staff members who now have some guidance on how to proceed when speaking to the parents.

Regarding the first decision, there must be a meeting with the family to discuss the procedures proposed in general terms. If the family agrees with the decision, then there are two processes about informed consent that should proceed in parallel. One process is the familiar process of obtaining permission for a surgical procedure and is the responsibility of the surgeon. These processes are well laid out in Chap. 4. The family needs to know what the surgeon will do, what the outcome will be, and the possible complications. The second process of informed consent for the particular procedure is different; it involves ensuring that the parents have a clear understanding of what life for the child and the family will be like with the new

intervention. That second process is probably longer, might involve the help of social workers, might involve the help of staff involved in long-term care, might involve the help of parents who care for a child with that particular intervention. In other words, the decision to do a procedure on the child can be so significant as to entail a lifestyle change for the entire family.

In terms of the second decision – that more information is needed before a decision can be made –, the family should be told by the most responsible physician about the discussion, and that there will be more consultants coming to see the child.

If the third decision is taken – that the procedure is not indicated -, there is no real reason to tell families what we are not going to do. However, if the family is aware that the procedure has been discussed, then they must of course be told about what the decision was and why it was taken. Likewise, if the family initiated the discussion then they must also be told why this procedure did not seem appropriate at that time. This discussion should be conducted in such a way that time is not an issue, and the family understand the various courses of action that will follow from the decision taken.

8.4.3 Coordination of Multiple Specialists

It is not just in the context of major decisions that coordination is essential; coordination is a daily task of the most responsible physician, the bedside nurse, and the pediatric trainee. Many different medical specialists are needed to achieve optimum results. The wellbeing of the child depends on successful multiple collaborations. Again, the medical life of children with medical complexity is complex.

Some of the coordination required is obvious. For example, if a complex diagnostic procedure is to be conducted under sedation, then the physician should check to ensure that another procedure could not be combined under this sedation. Similarly, if a surgical procedure is required, and another procedure by a different surgeon might be required later, perhaps a second one can be brought forward and both conducted at the same time. These combinations of investigations and procedures are important and useful but must always be conducted with a view to safety. Sometimes it will be unsafe to do more than one procedure at a time; if so, then that decision should be made in a team basis among the various people involved such as different surgeons, anesthesiologists, and the most responsible physician.

Another form of collaboration, even when the child is in hospital, is dealing with community agencies. This collaboration might well involve the physician completing documents or sending individualized letters to ensure services and benefits are obtained. There is no sharp boundary between the sort of collaboration and advocacy that is expected of the pediatrician involved in the care of any child. Much of the collaborative and advocacy work involves releasing confidential details of the child's medical condition; such breach of the patient's confidentiality should always occur only with the permission of the parents/guardians (see Chap. 5 "Confidentiality").

8.4.4 Must Recognize and Support Unusual Parental Role, Such as "Extraordinary" Mother

Professionals can find well-informed patients or parents challenging. Most pediatricians have become familiar with many children with medical complexity such as Charlotte. The parents themselves become very well informed and are often connected via social media with parents facing similar problems with their children all over the world. The mother, particularly, will often be described as "extraordinary" in her diligent exercise of maternal care. But sometimes staff will consider her "difficult" because she is knowledgeable and has an idea that more might be done for her child. The staff member's expression of opinion might be venting on the part of the staff, and if this is so, then no immediate action is required. If the staff member's expression of opinion about the mother seems to be affecting staff – family relationships, then action must be taken. The trainee might express concern to the staff physician, and she in turn has a number of ways to address the staff member voicing such a negative opinion. One way is when the child is discussed on rounds to ask a general question about the parent-staff relationship. There is unlikely to be a direct answer, but the staff physician might make the obvious statement that problems are common, and one solution is to try to put ourselves in the other person's shoes. This comment might defuse the situation, but if there is escalating disagreement between staff and families, then there is a duty to inform management of the problem and to cooperate with administration to restore good relationships.

Physicians might have specific problems in the developing relationship with parents of a child with medical complexity. There are several possible explanations including rapid changes in medical knowledge and practice, parents who are extremely knowledgeable, and, perhaps most of all, a relationship that is intense and continues for a long time.

Physicians might also be challenged to obtain the relevant medical knowledge that, of course, is changing rapidly in all aspects of medicine. Because medical complexity is a field that has only recently been recognized, medical knowledge is increasing much more rapidly than in longer established areas of pediatrics. It can be difficult for an individual pediatrician to keep up with all of the relevant advances in the care of a child with medical complexity, given that the advances will occur in many different body systems. The parents almost always are checking for information on the Internet and are commonly in touch with other families. They become very well informed. This interaction of very well-informed parents with physicians who are trying to acquire knowledge rapidly does not change the power imbalance between physicians and families. What does change, however, is that the physician can no longer be regarded as the main source of information.

The fact that children with medical complexity present many new problems and have many periods of deterioration leads to many family-physician interactions when treatment must be explained, and permission sought. These many interactions make it inevitable that relationships with families become intense. The physician comes to know the families very well and sometimes will tailor explanations

according to how the family functions and has responded to good or bad news in the past. On the other hand, this frequent contact means that the families know the physicians very well. They will have some idea about how we responded to questions in the past. The parents will raise questions in ways that, in their previous experience, has worked and has been acceptable to us. They might also choose to ask questions of one physician rather than another.

The title "extraordinary" applied to these mothers refers to the strong and unwavering commitment to the child along with a willingness to challenge any authority figure or any authoritative body that seems not to be acting in ways that promote the child's interests and health.

8.4.5 Must Trust the Parents But Be Attentive

It is always important in pediatrics to begin by trusting the parents and this becomes especially important when the child is being cared for long-term at home. However, just as we do not believe parents should have absolute trust in health care professionals, we recognize a few parents might harm their child with medical complexity (see Chap. 7 "Child Abuse"). Fortunately, the norm is that most parents are devoted to their child and have a view of the child that is unique; the parents' view should always be sought by the pediatrician and attended to. The parents' view supplements the view of the professional caregivers. Even when the child is in hospital, the parents constantly surround the child. The caregivers have shifts and varying standards about the significance of observations of the child. Their interpretations of whether something might be significant or not significant has developed with their experience of many children. The parents only have one child as a patient, and if he or she sees a change in the child's condition, a full assessment by a staff member is needed. If the person doing the assessment finds there is no change, then that finding should be communicated clearly to the family, but never in a disparaging fashion.

The family should be encouraged to speak up, and even if an initial assessment has been negative, the family should be encouraged to speak up again if the child shows further change in their eyes.

8.4.6 Must Care for the Whole Family

Whether the child is at home or in hospital, it is the responsibility of the pediatrician to consider the whole family. The parents are likely to have many anxieties to add to the anxieties they have about the child patient and might have responsibilities that prove difficult to juggle. While it is not the responsibility of the pediatrician to solve these many problems, it is a responsibility to be aware that some of them exist. Attention to problems within the family while the child is in hospital will make problems at home less likely.

In this regard, the pediatrician should be ready to involve colleagues to help the parents with her own anxieties and worries, and to be able to help siblings. Again, it is not the role of the pediatrician to deal directly with these, but of the many allied health professionals available, the social worker often proves the most important at helping in these complex issues. Sometimes, social workers are consulted to help with funding issues, something that is of course very important, but we would hope that the social worker will be persuaded, and would have time, to move beyond this role to help in family relationships.

8.4.7 Need for Vigilance Regarding Boundaries

The maintenance of boundaries (discussed in more detail in Chap. 2) is an issue that is relevant whether, the child is in hospital, or in their home, or in some kind of long-term facility. Caring for a child with complex medical needs requires a lot of everyone. To deliver such care, people need to work together. In the process, relationships develop among pediatricians and the families and patients. Empathy is a vital part of this relationship. The empathy we show and the good will that parents show us must be handled carefully so the relationship between caregiver and parents does not develop negative qualities or problems.

Specifically, it is important to create and to maintain boundaries between pediatricians and families. The professional must be constantly vigilant about boundaries, but not at the expense of the empathetic relationship. When parents of children with medical complexity become more familiar to us than other parents, then there is a risk that professional care of the child might be compromised. We are not considering here egregious violations of boundaries, such as developing sexual or romantic relationships. We are addressing the possibility that friendly relationships between the professional and the family might lead to them becoming friends. By this, we mean there might be meetings other than professional ones, perhaps over coffee or lunch, or some other social activity. At one level, this seems a natural extension of the friendly relationship, but such social friendship is likely to complicate the professional relationship. In addition to complicating the professional relationship, the fact that the professional becomes the social friend of the family might naturally lead to gift exchange. Again, exchanging gifts at say holiday seasons or birthdays and so on are natural behaviours, and are usually innocent. Yet on another level, the gifts can be misperceived as a request for special treatment.

8.4.8 Help Manage Response to Invasion of Privacy

When the child is in hospital the parent, however privately he or she would like to be, abruptly become public personages. They park in a public parkade, walk the corridors and rise in the elevators and over time will be recognized by many staff

members. They will be depersonalized; no longer “Samantha”, but now “the mother of Elliot”. When they enter the ward, the staff will know they are there. If they change a diaper on the child, this routine maternal practice will be observed. Their intimate feelings will be observed. If they are excited when things are going well, then the staff will be pleased with them. If they are sad when things are not going well, that too will be observed.

This then is the reality of being with a child who is in hospital for a very long time. This is the reality of being the parent of a child who presents medical problems and is involved with many medical services. We have no easy solutions but do suggest that staff recognition of the problem is the first stage in helping parents. Thereafter, we must continue to be respectful and when parents want privacy then to make sure they have it.

8.4.9 Help Prevent and Manage Conflict

We referred earlier in this chapter to the study by Davies et al. (2014). These authors commented that the care provided in hospital to these children involved much more than straightforward pediatric medical issues, (if the medical issues of children with multisystem disease can ever be called ‘straightforward’). Psychiatric services were needed in 39%, and Child and Family Services were involved in 30% because of concerns about parenting. There was also concern about care of these children at home. 26% were placed in long-term care or some form of out-of-home care after the hospitalization.

The involvement of psychiatric services, child and family services, and the need to find care outside the hospital but away from the parents suggest that physicians have concerns that probably rise to the level of conflict. CMC will develop complications, develop side effect of treatments, and suffer from errors, all events that are far too common. These things are all compounded by lapses in communication. There are multiple handovers of care that are usually handled very carefully with good communication between staff members, but not always.

The first priority is care of the child, and if there are concerns about parenting ability, then it is important to assess the family’s caring abilities. However, even when there are no concerns about parenting, we must be alert to the early signs of conflict to take the necessary steps to ensure it is a rare event and to take steps to recognize when it occurs and to deal with it supportively. Conflict arises within families, between staff members and families, and between staff members.

Much of the material elsewhere in this chapter contains ideas that would help reduce any conflict that might arise, whether it is family member-family member, family member-staff, or staff-staff. It is unlikely that conflict can ever be completely abolished. There is a need to maintain good relationships between members of the care team, and with the family. There is a need to develop friendly relationships that recognize the boundaries between professionals and healthcare professionals. There is also a need to provide support to families. On the other hand, the first duty of the

professional is to the child, and though we have stated earlier that pediatricians should support the whole family, this statement in no way diminishes that first duty. When we do disagree with families about what we think is the best course of action for the child, we must do so respectfully; in our discussions, we must always return to have a focus on the child and the child's future.

8.4.10 Maintenance of Professional Duty to Child

Earlier in this chapter we addressed many of the decisions that must be made for CMC and a process that might be helpful. Implicit, and indeed explicit, is that decisions taken are for the child's benefit, and that the major decision-maker is the parent or guardian. If the patient under consideration is an infant, then the physician will regard the parent or guardian as the decision-maker without much thought. When children are older, their view should be sought and should be one consideration in planning and making decisions.

As time goes on, parents will become more confident and more knowledgeable. They are likely to make many requests, some of which are fairly straightforward. They might want a simple change in routine. While this can sometimes be difficult in an institutional framework, a request for change of routine is not in itself a difficulty. The parents might have read about a better but different antibiotic, another anticonvulsant, or any other alternative to the drugs the child is having. They might request this new medication be used. Physicians' approach to such a request should be first of all to listen, secondly to gather scientific information, then to discuss further action with the parent. The parental suggestion might turn out to be appropriate, in which case the new treatment should be used. Alternatively, it might be that the existing treatment should perhaps be given for another few days before the switch is considered. With good relationships, and good communications, these issues are likely to be resolved readily.

Parents might also make requests for an entirely different way to treat their child. The parent might have read of an approach available only in one institution in the world and can ask whether the child can be transferred. These requests can be more difficult, but again there should be a process of listening, gathering information, and then joint decision-making.

Common in all of these requests is that the parent is making the decision for the child and the pediatrician is responding. The fact that the parents take the initiative is not surprising, but when the pediatrician responds, he or she should always have in the forefront of his/her mind that duties are owed to the child not to the parents. In practice this can be difficult advice to follow, but difficult or not, it is the guiding principle. Acting in accordance with this basic principle will sometimes mean that disagreements form between the pediatricians and the family, but usually, if on the background of a good relationship, and attempts are made to sincerely listen, the difficulties can be overcome.

The first duty of the pediatrician is to the child.

8.5 Values That Mean Home Care Should Be Encouraged for CMC Children and Youth

Children with medical complexity spend a very long time in hospital. The aspiration is that they can be cared for at home. Home is not an easy option for parents in terms of the emotions involved or the time commitment needed by the parents. It is not easy in terms of the cost to the parents. Some costs incurred relate to making alterations to the home, having increased utility bills because lighting and heating are used more than they would be in another household, and incurring more travel costs as parents take the child to and from hospital. Home is easy in that it is the natural place for a child to spend the bulk of his or her life. Home is difficult for parents with CMC because they must bear costs – financially, physically and emotionally – that most parents don't bear.

Such extensive home care needs require the government, in government funded health care systems, to agree that home care is important. Yet, though governments claim to value home healthcare for children, supports vary. A Canadian research group (Peter et al. 2007) considered the homecare policy in Canada and arrived at a conclusion applicable to most Western countries. The researchers examined all government documents related to home care of children in detail. They found:

> Four over-arching themes were identified in the abstracted data. These themes represent the most predominant concepts of values that underlie homecare policy for children and youth. They include (1) home and community care as ideal, (2) the importance of independence and self-care of citizens, (3) family as primary care provider, and (4) citizenship as entitlement to rights and justice". (Peter et al. 2007)

8.5.1 Home and Community Care Are Ideal

The first value that "Home and community care [are] ideal" represents much more than a shift in the site of care because the home is not simply another place to deliver complex medical care that might be less costly for the healthcare system. In the early stages of development of long-term services for technologically dependent children, the bioethicists Arras and Dubler (1994) wrote about "bringing the hospital home", but of course the hospital does not come to the home. His claim is very far from the truth. Once the child is home, even if the equipment is the same, everything changes, Home is "an environment of life", a place where we carry out many activities, maintain our closest relationships, and fulfill key social roles. Medical care in the home ought to be seen in this light.

Arras (1994) also wrote about the "technological tether", an uncannily realistic description. The child cannot move without the equipment, and the equipment limits choices parents might make. As examples, a neighbour can no longer be a babysitter without training in the child's specialized care or if the parents relocate to another house, even if in the same area, they first need to assess its suitability for

specialized equipment and probably make renovations. Even though equipment and skills must be brought to the home and the child is tethered in these ways to the home, the home is still the home. It is a different home from what it was before. But it is still a home. Whereas, medical care delivery is the very purpose of a hospital, medical care delivery in the home is ancillary to life.

8.5.2 Independence and Self-Care of Citizens Is Relevant

The second principle articulated by Peter et al. (2007) is that "The importance of independence and self-care of citizens is relevant." Well-being is best achieved with attention to "Individual autonomy, dignity, and freedom of choice". Children's future independence is important. Parents want their children, even if they have complex medical conditions, to grow up to be healthy, confident, accomplished individuals who have realized their potential and are prepared to contribute to society in an independent, productive fashion."

8.5.3 Family as Primary Care Provider

Peter et al.'s (2007) third principle, "Family as primary care provider" offers a double-edged sword. Governments might well expect families and relatives to provide high-level medical care to a child in the home without any monetary compensation. Families often have extra expenses for equipment, even if there is notional funding from various authorities, common utilities costs such as for heat and electricity might be higher. As mentioned, there must be heat and light at night for the caregivers, and cooking, or at least for re-heating food. The long-term costs are disproportionately borne by women, such as in lower pensions and lower savings because they typically must leave the paid workforce. The financial burden on families will be discussed below in Sect. 14.2

8.5.4 Citizenship as Entitlement to Rights and Justice

Peter et al.'s (2007) fourth principle, "Citizenship as entitlement to rights and justice" is regarded differently in different countries. Most Western democracies regard access to healthcare as a fundamental right. However, even in a country such as Canada which prides itself on universal healthcare, home care is not a right. It is often provided by provincial and territorial authorities, but there is great variation from one to another. Where funding is provided, it is often disjointed with many different ministries contributing each in a different way. Sometimes jurisdictions

fight about who has the responsibility to provide home care for a child with each saying the other is the responsible party (Lavallee 2005).

8.5.5 Preparing Parents for Transition to Home

The idea that the child might be going home is exciting, but it is also daunting. The parents will have been learning the details of the child's care, and how they ought to deliver it. They need to find a source of funding for the specialized caregivers. The source might be existing insurance, private or via employers. Even in areas with government-funded health care, funding might come from more than one agency. They probably will have done at least some modification to their home but for the move home to be successful much more needs to be done.

8.6 Ensuring Continuity

Ensuring continuity of care is part of a larger commitment to physician advocacy on behalf of Charlotte, and children like her. As stated, from the first contact with Charlotte, and increasingly as time passes, the physician must provide care to the whole family, not just to Charlotte, the vulnerable child patient.

8.6.1 Definition of Continuity

Given the importance of continuity to the families, and the importance of continuity in reducing errors and in ensuring the highest standard of care, we need to understand a little bit more about continuity. There are three components to continuity described in the literature: relationship continuity, informational continuity and management continuity (Guthrie et al. 2008). The last is most valued by families, and the least supported by the organizational changes in the practice of medicine.

8.6.2 Parents Value Continuity Which Benefits Child

Families also value continuity of care. In fact, provision of continuity is probably the most valuable attribute of the caregivers. Children with medical complexity have survived because of the skills and training of the professional caregivers, and also because of the availability of technology that can be used at home. We recognize fully the rapid changes in the technology in use as time progresses.

Paradoxically, while the technology is vital to the child's survival, the non-technological aspects of care is also valuable to the family. By non-technological aspects we mean the caring shown by the physician as the relationship evolves. With the relationship with their physician comes a degree of continuity for families.

Yet, times are also changing not just to permit the existence of CMC but also for the organization of medical practice. Specifically, it is unlikely now that one single physician can provide all the care or indeed would be willing to provide all the care to any patient, never mind a child whose care is as complex as Charlotte's. We can no longer expect continuity to be embodied in one person, even if that was ever a reality. Continuity remains important but we must find other ways. We will attempt to describe them in the next sections.

8.6.3 Relational Continuity

One of the many reasons that families preferred a strong relationship over time with a specific person is that a single relationship is both efficient and effective in their complex life. It is efficient in that they do not need to spend time at every encounter explaining every nuance of the details of past care, current status and future plans. A single relationship is effective because the family is much more likely to be involved in decision-making, and as noted earlier the relational continuity is based on the trust that develops over time. Relationship continuity has, in the past, entailed the knowledge of what the families prefer, and their specific individual circumstances accumulated in the mind of the trusted physician, but rarely formerly recorded. Such relational continuity is strongly based on trust.

We affirm here that the relationship between physicians and families continues to be extremely important and should be. Yet, "relational continuity" does not today mean that a particular physician should be available for 24 h every day throughout the year to attend to Charlotte's medical needs. That is not possible, is an outdated concept, and is extremely unhealthy for both Charlotte and her family, and for the pediatrician. For the family, a dependence is likely to develop and might challenge boundaries. Also, even if the physician wants this role, it is impossible. A physician has family commitments including holidays and outings, and unexpected illnesses affecting the physician or her family that call the physician away from tending to Charlotte. The pediatrician might be on maternity leave! What happens when Charlotte needs help during these periods when the ONE physician is unavailable and help is available only from a physician unfamiliar to Charlotte and her family, and unfamiliar with the details of Charlotte's life? Nevertheless, relationship continuity is very important. It must be achieved without damaging the physical or mental health of the professionals.

Relational continuity is now likely to be achieved by a small group of pediatricians rather than one individual. The notes taken by the physicians about the patient must be impeccable. The physicians must make it be obvious to the family that all

the physicians in the group care very much about Charlotte, all are very knowledgeable, and all talk to one another about changes and developments in Charlotte's care.

Explaining how we can achieve relational continuity in the current age requires consideration of the other two forms of continuity: informational and management continuity.

8.6.4 Informational Continuity

Informational continuity is about formally recorded information. In the past, this informational continuity was usually, like relationship continuity, achieved by the physicians with whom the family already had a relationship; he or she had the information. Now physicians must be careful to record a great deal more information in the written records than mere basic medical information because more than one healthcare provider is caring for the child. These written records, that is informational continuity, are vital to achieving relationship continuity as it is understood today.

8.6.5 Management Continuity

Management continuity is also important and concerns the development of shared management plans, perhaps standardized care protocols with explicit statements as to who has responsibility for which part of follow-up and for overall coordination. Effective management continuity provides a sense of predictability and security in the minds of the families for the future effective care of the child. Effective management continuity also implies an investment into record systems appropriate for care of a child with medical complexity. It must be possible for members of different health care professions to access one another's notes. If Charlotte shows deterioration, then whoever is responsible for an emergent assessment must have immediate access to her full health record.

8.7 Gathering Resources

8.7.1 Home Care Staff/Equipment

Children with medical complexity being cared for at home require (obviously) staff trained in the care of this child regarding his or her specific needs and specialized equipment. Many of the staff and equipment issues that arise are related to funding. Funding sources might be the government, depending on overall health care

organization, perhaps a special program for home care, insurance provided via parents' employment, or purchased privately. Another important issue is whether the organization that is responsible for hospital care is the same organization that is responsible for home care. In most jurisdictions, these will be separate. Even if there is some overarching healthcare system dealing with both hospital and home care, at an individual decision-making level the management is likely to be quite different.

Determining how much money to spend, whether it is provided by a government organization, a volunteer organization, or insurance company, is important. Whoever pays will want "value for money", which might be code for "at the lowest possible cost". One way to reduce cost is to attempt to arrange for someone else to pay the bills! Hence, when the child is in hospital, the hospital authorities might want the child home. This will not necessarily save money, though it could, but it will mean that the hospital is no longer paying the bill. Another way to save money is for the organization responsible for home care to have contracts with companies that provide staff, and contracts with equipment suppliers for specific models of equipment that are supplied at a discount.

What this means for individual families is a great deal of phoning, writing and attending meetings, with many different people, sometimes in the same organization, more usually in different organizations. One thing the staff in the hospital responsible for discharge can do is to create a list of supplies that is regarded as essential for the child at home and indicate which items on the list are funded through various governmental, private or insurance programs. In addition to equipment, the necessary supplies that are required on a regular basis must also be funded. For example, if a suction machine is supplied, then some catheters will be required on a regular basis. Funding for the supplies must be included in the overall budget. In addition, there is a need for some redundancy in the supplied equipment. Such provision of extra supplies or equipment would be very important in rural areas, but it remains important in the cities. If the child is dependent on a ventilator for respiration, or a pump for nutrition, there might need to be a backup in the home if there is a malfunction. There must be arrangements for equipment that will function with back up batteries when power outages occur. Also, utility organizations need to know there is a vulnerable child in a specific address.

The role of the pediatrician in all of this is to work with local organizations to ensure the focus remains on the needs of the child and the family. There should be a coordinator, usually a nurse, available to help the family with much of the legwork in arranging for funding and for supplies. It is essential that the supplies are available before the child goes home and to ensure that the equipment works well for this particular child.

In addition to all of this preparation, many homes will require modification for the child. The modifications might be ramps, wider doors, extra shelves and so on. The home must be inspected by someone knowledgeable about the needs of CMC at home.

8.7.2 Ready to Provide Care at Home?

The parents or guardians will provide direct care for the child at home and will provide leadership to others. By the time the child gees home, parents must be competent in all the technical tasks that will be required at home and should be emotionally ready.

8.7.3 Ensuring Parents Are Competent

The parents must be aware of the expectations regarding knowledge and skills required and must be helped to achieve the standards. A written curriculum should be available, and the teacher(s) should be able to keep track of what is being taught and the skills the parents have mastered. The dialogue between those teaching and the parents should be open, and when skills are not achieved, then the parents must be aware that they still have learning to do. Teaching should be available to other close family members, such as grandparents, aunts and uncles of the child and so on, all of whom might be important in providing some respite for the parents and guardians.

This is no different from any other educational venture; repetition and practice are key to success. Those caring for the child of the bedside should be well aware of the parents' progress as they work their way through the curriculum. In hospital, staff at the bedside should allow the parents to complete tasks. They should gradually increase the responsibility carried by the parents while the child is still in hospital, a place where there are many supports immediately available.

A difficult problem is posed when the parent is single with no nearby relatives. It can be very challenging for two guardians to look after a child with medical complexity. For this burden to be carried by a parent alone is not only challenging, but also very risky. Aside from the lack of support, and we recognize this is not a little aside, parents and other caregivers do get sick. Who is then to care the child? We see no easy standard, "cut-and-paste" solution. There must be a full assessment of the various risks and benefits, in an open discussion, before the child can go home. It might be possible under some circumstances for a single parent to be able to provide care safely, but the circumstances are likely to be unusual.

8.8 Ethically Pushing Reluctant Parents to Take Child Home

Caring for the child with medical complexity at home will be daunting for every parent. In the previous paragraph, we emphasized the importance of teaching, assessment, and practice. We also emphasized the need for continuing assessment, and for repetition. The family must be helped and encouraged to perform tasks for their child so that they can master the task.

Nevertheless, some parents might be so overwhelmed that even when they have mastered the skills required, and even when funding is in place, they might be reluctant to take the child home. In such cases, we suggest that a full social work assessment follow. We need to identify the barriers perceived by the parents to help them troubleshoot and to find solutions to enable the child to go home. Do the parents live in a remote area? Do they have major responsibilities for other children? Have they been exposed to medical mishaps that make them fearful of something similar happening in the home? Is the response of ambulance services rapid or delayed? We could go on, but it is sufficient to say that there are many reasons why the parent might be reluctant to care for the child at home.

Having said all of that, we need to help find solutions, and need to, gently but persistently, encourage the parents to take the child home. It would not be ethically acceptable to keep the child in hospital long-term when the parents are skilled, and we have provided solutions to all reasonable problems.

If the reluctance persists, we may need to consider a voluntary placement in a medical foster home to allow the child to be in a non-institutional environment. This last "solution" should be the last resort, but in terms of benefits to the child, moving out of hospital is high on the list.

8.9 Ethically Restraining Parents Whose Child Isn't Ready for Home or Have a Child Ready for Home, But Parents Aren't

Most parents find caring for a child with medical complexity at home daunting. Still they are willing to acquire skills to allow them to care for their child.

However, there might be a few parents who visit infrequently and are slow to participate in education. Some members of this small subset of parents might want to take the child home sooner than the child's medical condition would permit, or sooner than their skill acquisition would permit. In an even smaller subset, it might be appropriate to consider whether the child would, in fact, be safe at home. This very small group of parents provide many challenges to hospital staff. When trying to find solution to this problem, it is important, as always, to keep the needs of the child and the safety of the child in the forefront. Earlier in this particular section, we mentioned the importance of an agreed curriculum and agreed standards of achievement. The parents must be reminded of these, and it must be emphasized to them that these are not bureaucratic requirements; these are ways to reduce the risk to their child when their child is at home.

Here, parental desires and professional assessment are not congruent. As happens in other such circumstances, with patience and explanation, the differences in expectations can be resolved. However, if there seems to be a risk to the child, then child protection services should be consulted. We emphasize, as in other sections in this book, that while child protection services are an important resource, it is an important resource that should be used rarely and when necessary.

8.10 Challenges of Caring for CMC at Home for Pediatricians

Now that children with medical complexity are going home, trainee pediatricians, and staff pediatricians, must learn the new skills of helping families whose child at home is dependent on technology and whose condition is life threatening. Collaboration with a multitude of agencies should occur. Children at home might deteriorate episodically; their parents will need advice on managing deterioration and the child will sometimes require re-admission. However, the pediatrician must develop a trust in the skills of the parents so that admission is not the automatic response to any worsening of the child's medical condition. Other children with medical complexity will have a less eventful life, might show improvement and eventually no longer need the technology to survive.

Consider again the case of Charlotte:

Charlotte has a myopathy and has a tracheostomy and is on a ventilator. She is now cared for at home, in a small town. She still needs frequent suctioning of the tracheostomy tube to keep secretions clear, but now has minimal electronic monitoring. Her parents and an aide do chest physiotherapy daily and also follow instructions from the physiotherapist on movements to improve the range of motion of her limbs.

The parents are in touch with international social media groups that help keep them well informed on her disorder.

Charlotte is followed by a number of clinics in a pediatric referral centre. She sees Dr. Ward, a general community pediatrician, in a nearby town from time to time. She can call Dr. Ward or her partners for advice when needed.

Dr. Ward informs herself about Charlotte's condition to offer the best pediatric care she can. What else will Dr. Ward need to do and to be vigilant for?

In this evolving relationship between the professional and the family, the family members have taken on some professional roles. When Charlotte was in hospital, a nurse or respiratory therapist decided when her tracheostomy needed suctioning and might have decided to do it more frequently than is in the care plan because of changes in the quality or quantity of secretions. The nurse or the respiratory therapist, in consultation with perhaps a trainee pediatrician, decided whether secretions should be sent for culture, and antibiotics considered. They decided when to inform the staff pediatrician of the change in Charlotte's condition. The nurse or respiratory therapist decided when to call for help, even if the mother was at the bedside.

Now Charlotte is being cared for at home. Now the mother or another family member decides when suction is to be done, and how often. If there is any deterioration in Charlotte's care, then the parent or a close family member decides whether to seek further advice. They decide when to wrap up Charlotte and take her to emergency or to call 911 because they perceive a crisis. If the tracheostomy becomes dislodged or blocked, then the caregivers in the home must recognize that there is an emergency, and its nature, and must act quickly to replace the tracheostomy tube in the correct position, without blockage. On a daily basis, the family members are taking the everyday micro decisions essential for safe care of Charlotte. Day by day, they are becoming more skillful at assessing Charlotte and deciding about care; they

are steadily gaining confidence. Of course, in the early stages they will need a great deal of support, but the end result, sooner or later, is almost always an increase in confidence level. This confidence is based on the performance of specific tasks and is appropriate.

Such confidence, however, might become problematic. That specific confidence might, however, move to a different level of confidence should the parents see little difference between their level of skill and that of the pediatricians. If that were to happen, then parents might act in a way that harms Charlotte. For example, in intercurrent illness the parents might interpret early signs of deterioration as of little significance and delay seeking help. They might see deterioration and increase the amount of oxygen given masking signs of further deterioration. Fortunately, confidence at the extreme level, what we have just described is rare. Less fortunately, lesser degrees of confidence are inevitable.

8.11 Issues at Home

Some issues identified in hospital are magnified when the child is in the home, others are less prominent. Conflicts between staff members are just as likely to occur at home. Nevertheless, when conflict does occur, it is in the confines of a very limited environment and must be addressed very quickly. By "dealing with the conflict", we mean providing support and also recognizing that sometimes changes in staffing must be made. Some of the major issues we discussed earlier occurring in hospital are the reaching of major decisions about accepting the interventions to make long term dependence on technology a reality. In the home, decisions will principally be "micro" decisions. Such decisions might be about whether to seek help, whether to carry out an intervention in the child at some particular time, and so on. Yet, there is a time when major decisions are needed in a child at home: when death is approaching. There might have been intellectual recognition by the parents that the child would not live to be an adult, but often everything changes when the reality must be confronted. We address this subject in more detail later in the chapter (see Chap. 16) below.

Support for parents carrying out an extraordinary role must continue when the child is at home. Some challenges for the pediatrician are the reality that these parents are extraordinarily well informed, often about very rare conditions. The parents also have skills in managing advanced equipment that most pediatricians would not be able to do.

We emphasized earlier the importance and need for support, and with a child at home, such pediatricians' support continues. If anything, such support is much more important. When parents tell us of observations they make about the child, we need to believe and act on them. If concerns are expressed, then again, we must listen and respond.

The pediatrician needs to provide care for the whole family. This of course is relevant at all stages, but now that the child patient is at home the challenges are immediately visible and occur minute by minute throughout the day and night. For

example, if the child patient is a preschool child, and there is a baby in a home then that baby must be fed and changed and played with. If there are older children in the home, then they will need food prepared, will need to be taken to school, and from time to time, one or other of the parents might need to meet with teachers and indeed to take that child to the doctor or dentist.

If the pediatrician who is providing the support, displays the empathy mentioned in the previous chapter, many problems will be overcome successfully!

8.11.1 Must Visit the Child at Home and Rules for So Doing

In a prophetic paper, Goldberg et al. (1994) noted that hospital and office-based care of sick children is a recent phenomenon, and that the survival of children with complex chronic conditions is even more recent. Paradoxically, as an increasing proportion of children at home require complex care, physicians were becoming much less likely to participate in their medical assessments because the children are at home. Let us add that wholehearted physician participation in the care of a child at home with complex medical needs, is much more than "a house call". However, an occasional assessment in the home can give valuable information.

Despite the reduction in assessing children in the home, physicians still have the responsibility to initiate, to supervise, and to decide whether home care is no longer required.

8.11.2 Principles to Follow When for Caring for Child at Home

Goldberg et al.'s (1994) paper was published decades ago. He laid down principles to guide pediatricians. They seem to us still relevant today, not just to pediatricians, but to all involved. The principles are:

1. Understand and utilize community resource in home care;
2. Know available home care techniques;
3. Apply home care principles guidelines and protocols. These are medical, psychosocial and environmental, technical, organizational and financial. There is a need to understand "supplemental services" – such as occupational therapy, speech therapy, physical therapy, speech therapy and nutrition;
4. Play an active and major role as a home team member;
5. Integrate home, ambulatory, and hospital care for patients;
6. Evaluate the adequacy of family and informal care resources;
7. Evaluate home care for continuous quality improvement; and
8. Demonstrate the value of home care to the child and family. (Goldberg et al. 1994)

Perhaps item (4) "play an active and major role as a home team member" is the most challenging. We mentioned that at a time of increasing delivery of health care at home, physician "house calls" (to use a traditional term) have declined dramatically. There are many reasons including inadequate reimbursement for home visit by physicians, efficient use of resources in office visits and a change in pediatric culture that views home visits as a quaint anachronism. The pediatrician acts as a team member by communicating with those who are actually in the home. Given the increased number of children with medical complexity and the significant cost savings of children being at home rather than in hospital, it seems appropriate that physicians would be compensated appropriately for visiting the child at home. In other words, it is perhaps time for another culture change, a return to making home visits acceptable and to recognize their desirability from a patient care perspective. This change would require negotiation on reimbursement and a recognition that the visit would not be in the format of a physician visiting the home alone. In other words, some team visits to the home might include the physician. Pipe dream or way forward?

8.11.3 Need for Vigilance Regarding Boundaries

Boundaries issues can arise with other healthcare professionals, such as nurses in the home and homecare aides. The issues will be like those occurring with pediatricians in being based on confusion over relationships and skill. But they will be different in that the healthcare team is now split geographically such that the other healthcare professionals are likely to be in the home, whereas the pediatrician is likely to see the family in her office or the hospital. Respect for differing roles remains important.

8.11.4 Help Manage Response to Invasion of Privacy

When the child goes home, he or she goes into a private space. Because of the need for help, the parent must tolerate a certain amount of intrusion into that private space. A study of the experience of nine parents who had technologically dependent children raises the issue of boundaries issues between families and healthcare providers in the home (Coffman 1995). The study found that having a nurse or any professional healthcare professional, including aides, in the home has a "double edged impact". On the one hand, such a person is a blessing in sharing the care tasks including caring and playing with siblings, and in the general tasks of looking after running a household. On the other hand, the presence of the healthcare provider entails a marked infringement on family privacy. The study mentions such issues as nurses taking food from the refrigerator for their own meals or snacks, and a nurse complaining that the outdoor sprinkler put some water spots on her car. The parents might feel that the infringement of their privacy is difficult to bear, and yet, if they

pay too much attention to these trivial matters, then the professional caregivers might become distant, making the development of a positive empathetic relationship problematic.

8.11.5 Supervision of Homecare Professional

As mentioned above, the parents are gaining confidence in their abilities of assessment and knowing when to intervene. The professional caregivers must trust that the family caregivers are getting things right. The one who gives instruction to the professional caregiver is a family member, not, as in hospital, another professional of slightly higher rank. Of course, the caregivers in the home might be paid by the family, via an insurance policy or by some government healthcare agency. They will, therefore, have professional supervisors. Having a professional supervisor does not make the supervisory relationship in the home any easier because the professional supervisor is some distance away; the family member who is "supervising" is only too visible.

8.11.6 Relational Boundaries

On a more substantial level, parents might have warmer relationships and more detailed conversation with one professional caregiver rather than another. They might pass on confidences that go beyond the professional. Conversations can move to personal confidence. For example, the mother might confide that there are marital problems. The nurse will probably keep track of these conversations in her notes about things happening during her shift and will pass on a summary of that conversation to the next professional caregiver involved with the child. The mother might become very hurt; she might have believed that this information, confided to the nurse in the expectation of privacy, would not be shared with anyone else.

8.11.7 Maintenance of Professional Duty to Child

The professional caregivers, like any citizens, also have an independent responsibility to the child, as well as the responsibility via the parent. If the professional caregiver has the impression that the child is suffering from neglect, or is being abused in some way, then he or she has an obligation to notify child protection services. When this legal duty is necessary to discharge, the responsible behaviour of the healthcare professional in reporting that the child is need of state intervention can cause overwhelming difficulties with continuing relationships, given the closeness between parents and care provider that can develop in the home.

The responsibility to identify that a child needs intervention by child protection services, and to make the initial notification is an individual, legal responsibility of the healthcare professional, as it is for all citizens. However, without detracting from the individual responsibility, in such a complex social and medical situation, it is important first to convene a meeting to review all that is known about the situation, unless there is a situation of extreme urgency. There might be other ways of dealing with the perceived problem such as increasing the support provided to the parent. However, if such a group agrees with notification of child protection services, then the fact that the referral has followed a discussion of informed professionals will prove important.

8.12 Pediatricians Must Advocate for Clinical Services

The advocacy required for children with medical complexity is mainly clinical. Such advocacy entails finding ways to address the major clinical problems, perhaps by ensuring that specialists request early review when specific problems become more severe (Hubinette et al. 2014). The advocacy will also involve what is called "para-clinical", that is ensuring the child and family have access to a wide range of supports, such as respite care, developmental stimulation, counselling, and so on.

A different level of advocacy concerns the efforts of individual physicians and others to address challenges at a population level. For example, a pediatrician might join other citizens in becoming involved with the local cystic fibrosis society. Such activities are important. The organizations are often local and national organizations. Some advocacy activities will be addressed in more detail in Chap. 9.

8.13 Need for Collaboration

The need for the pediatrician to be a collaborator was emphasized earlier in this chapter, and that particular need continues. The need for collaboration is with community agencies might be the most important form of collaboration that families need from the pediatrician. That need might be as simple as a phone call or email message to affirm a family's need, or a detailed report, or even a plea to make procedures more "user-friendly".

The pediatrician must also encourage collaboration with other physicians and health services. The families might have appointments with multiple specialists at a university center. We hope that within the center there are mechanisms in place to encourage collaboration and to combine visit so that family's time away from home is minimized. If such arrangements do not exist, then it is the duty and responsibility of the pediatrician to contact specialist services to ensure they coordinate appointments with colleagues.

8.14 Burdens of CMC

8.14.1 Financial Cost to System

To gain insight into the financial aspect of this revolutionary change in pediatric practice, a study was conducted in Ontario, Canada (Cohen et al. 2012). Using several databases and preserving anonymity, the study considered health care costs incurred from 2005 to 2007 that were related to neonates and children up to the age of 16 years. The researchers examined only direct costs, and showed that the children with complex, chronic medical needs were only 0.67% of the child population. However, this small group accounted for 33% of direct child health costs. Clearly the health care needs of CMC pose a significant financial burden on healthcare funders.

This issue of cost to the system, as far as we can tell, applies to all western countries. We suspect there might be differences in initial willingness to initiate and to discontinue therapies once started. These differences might be related to cultural attitudes among countries, institutions, or health care professionals. Within-country differences might be as great as differences among countries. However, we have not found any comprehensive comparative review of attitudes to cost of CMC.

8.14.2 Financial Cost to Family

In coming to their conclusions about costs, Cohen et al. (2012) did not capture costs borne by families. Such direct and indirect costs are important to consider because they concern the life these children have at home, a life which is markedly different from that of most other children. Anderson et al. (2007) reviewed the literature published between 1989 and 2005, on personal costs borne by families caring for a child with disabilities. The authors developed a comprehensive economic conceptual model and concluded that "the burden incurred by these families can be substantial, especially among families who care for a child with a severe disability." However, variation in the methodology of the studies included in the review made specific conclusions difficult.

Gerber et al. (2001) tried to quantify the financial burdens of parents of children with congenital cardiac disease. They included direct non-medical and indirect costs. They defined, "direct non-medical costs" to be all those costs (e.g. transportation) not directly related to medical services. Indirect costs included lost productivity measured in lost income from wages. Fifty-four families responded to a questionnaire that was sent to 198 (response of 27.7%). "Depending on severity, total direct non-medical and indirect costs in the first year of life ranged between an average of 1654 Euro in children with no or mild (remaining) cardiac defects and an average 2881 Euro in children with clinically significant findings". By the sixth year

of life, costs varied: 562 Euro if no or mild cardiac defects up to 5213 Euro with potentially life-threatening cardiac disease. Hence, a considerable financial burden can be added to the huge, emotional burden borne by families.

8.14.3 Caregiving Burden of Family

Siden and Steele (2015) also explored the experience of families facing chronic life limiting illnesses while caring for their child at home, including financial burdens but going beyond them. They begin their article with the story of a seven-year-old girl with a mitochondrial and peripheral myopathy and severe neurological impairment. She has seizures several times a month, has a gastrostomy tube, has chronic cough and is frequently hospitalized for aspiration pneumonia. She has a modified wheelchair, and has contractures, hip dysplasia and scoliosis. The authors offer this girl's story to humanize their study of 358 families (258 were enrolled). Among the children studied, there was a high symptom burden, sleep problems, feeding problems respiratory difficulty, seizures, and problems with alertness and interaction. The study was conducted over three and a half years and during that time 54 (19.6%) died. Some additional reports were family challenges, slightly more than one half changed their occupation or job status, and annual income was below that of Canadian median. There were problems in meeting needs better than "adequate" level. There was difficulty meeting the additional costs associated with an ill child. Time spent caring for the child was approaching 100 h per week for many families, and over 100 for some (whereas a work week is 40 h). Hence, respite was very important. Parents experienced anxiety and depression, though some reported positive life changes and high degrees of spirituality.

8.14.4 Maternal Employment and Health

Most families rely on two incomes. The need for one parent, more often the mother, to stop or limit paid work to provide direct care to the family can cause hardship, especially as financial needs will now be higher.

This issue, how the impact of having a child with a chronic condition at home affects employment and maternal mental health, was investigated by Thyen et al. (1999). The authors studied the 6-month post discharge status of 70 mothers of children assisted by technology (study group) and compared them with the 6-month post discharge status of 58 mothers of children (matched for age and gender) hospitalized for acute illnesses (a comparison group). The study was conducted in 1993; we can assume that if the same study were to be done now, then the children would be even more complex and the impact on the family even greater. "One third of mothers in the study group reported that they quit employment to take care of a child at home with only 37.1% remaining employed outside the home, compared

with 69.0% of comparison group mothers." Single mothers were 15 times more likely to quit employment than those in two-parent families.

More recent studies reach similar conclusions. Kuo et al. (2011) used data from the 2005–2006 (US) National Survey of Children with Special Health Care Needs to examine caregiver challenges. Of 324,323 children with special health care needs, 3.2% met the definition of complexity, that is medical technology dependence and care by two or more subspecialists. The caregiver challenges were family-reported care burden (including hours providing care coordination and home care), medical care use (on the basis of health care encounters in the previous 12 months), and unmet needs, whether medical or non-medical.

The parents spent 2–6 h per week coordinating care and 11–20 h on direct care. Financial problems were common, present in more than half (56.8%), and a family member stopped working because of the child's health in 54.1%. Almost half the parents (48.8%) had at least one unmet medical need. Access to non-medical services were reported as difficult to access in 33.1%.

In sum, caring for a medically complex child can cause families to be significantly burdened financially, to bear a large caregiving burden, to limit a mother's employment and to restrict other family members opportunities for self-care.

8.14.5 Overall Effects on the Family

The effect of having a child with medical complexity at home on the family is a theme pervading this chapter. There have been a number of studies on these effects. One is particularly pertinent because it focuses specifically on the moral issues that arise. The study was conducted in Québec Canada, based on a home ventilation program (Carnevale et al. 2006). Of the 39 children in the program, 15 met criteria for recruitment, 11 agreed to participate in the study, and of two children in hospital considering discharge, one agreed to be in the study. Of the four at home who were not included, three had major psychosocial issues, and one agreed to be in the study then withdrew. So, this report is about 12 families. It was published in 2006, and thus reflects issues in the early 2000s.

The starting point was the child, but the study focus was the whole family. Demographic information was collected, followed by structured interviews, first of the family as a whole, then of individual members, when the parents allowed this. The main themes arising from the interviews were:

- Confronting parental responsibility
  - This theme covered a number of issues, including the sensation of being overwhelmed when first looking after the child at home, being "stuck" at home, the injustices, the fact that many costs were borne by the family, the energy required to get through the day, a sensation of guilt that they were not quite able to do enough for the child, and for siblings if they had any, the sensation of isolation, and that this was hard on the parents as a couple.

- Seeking normality
  - The parents were unsure of what "normal" was but set out to establish routines that would meet family needs as well as needs of the child patient, the aim to have stability, and the attempt to ensure that the home looked normal, despite the medical equipment.
- Conflicting social values
  - There was a feeling that the life of the child was devalued, and there is difficulty in having relationships with other families in their kinship or neighbourhood. Some healthcare practitioners were uncaring in their remarks, and sometimes there was concern that staff might not be as skilled as possible. There was an issue also of the social responsibility of society to provide resources.
- Living in isolation
  - There was a sensation of loneliness, which is made worse if the child had a rare disease. There is difficulty in getting respite, and sometimes extended family were not very supportive and regarded the family of the child with the complex condition as having a "crazy" life.
- Voice of the child, patient and sibling,
  - There was concern about "silencing" of the child, and concern that the child patient had not been included enough in decision-making. Some of the child patients considered that they might be a burden to the family, but others were puzzled by such a concept, as they had only known one type of life. The remarks of the siblings will be addressed in the next section.
- Moral order of their lives
  - The families reflected on the fact that this was not the life they had chosen, there was a certain degree of fatalism, but a determination to get on with life and do the best for the child.

It is not clear what the results would be if such a study were to be repeated today. Our suspicion is that there would be very little difference, apart from the issue of "loneliness" of those who have a child with a rare condition because social media exists and is widely used. While there will be debate on the benefits and disadvantages of our extensive reliance on social media, there is little doubt that social media has brought parents of children with rare disorders together. It no longer matters where in the world the child lives, the parents can at least have online companions.

In terms of conclusions, there are two comments from Carnevale et al. (2006) worth quoting:

> Although these parents seem courageous to the investigators, parents resisted such characterization. They typically believed that they had no choice, that they were doing what they had to do.
>
> The extraordinary complexity of these parents' responsibilities corresponds with the wide range of invisible activities associated with parenting chronically ill children.

8.14.6 The Life of Siblings

In the study by Carnevale et al. (2006) cited above, some comments by the siblings interviewed were interesting. It should be borne in mind that some of the parents who participated in the study would not allow siblings to speak by themselves, and some of the siblings were reluctant to speak.

These children who did participate spoke about the limitations in their life because so much attention was focused on their sibling patient. Sometimes they expressed resentment at the extra attention to the sibling and told the parents that they were not loved as much as the child who was the patient. The parents acknowledged that when the child with complexity developed complications and became sicker, sibling care came second. The siblings also felt they lived an isolated life and did not have a sibling with whom they could have a normal relationship.

In another study, the mothers offered perspective on the siblings of technologically dependent children (Toly et al. 2017). The authors of the study noted that 75% of such children have another well sibling at home. They managed to interview 60 mothers and identified three main themes: the well sibling adjustment, upside issues, and downside issues. The well sibling adjustment was that there is less time with the well sibling than with the child who was technologically dependent, some isolation, and several limitations on their life. However, the upsides were that the sibling could develop altruistic traits, more maturity, and advocacy skills for the sick sibling. The downside was that the siblings were very likely to have anxiety and worry, be stressed, and exhibit aggressive behaviour.

In a meta-analysis of the issue of siblings in a family with a child with chronic illness, 12 articles were identified (Deavin et al. 2018). There were two overarching themes: changing relationships and managing changes. The changing relationships focused on changing relationships within the family, but also the sibling of the children with chronic illness looked at how their relationship with themselves changed. The second theme about managing changes dealt with coping and acceptance, getting support from friends, peers and support groups, and dealing with negative reactions from others. These authors concluded, "The findings are used to outline how changes in family relationships often result in reduced communication and a suppression of healthy siblings' needs. Siblings develop strategies to help them cope with and accept their circumstances, including finding new prosocial ways of meeting their needs in the form of skills and roles they develop." (Deavin et al. 2018).

The literature on siblings of children with medical complexity is limited. We review here two studies on specific conditions. One is about siblings of children with cancer and the other about siblings of children with congenital heart disease.

The experience of siblings of children with cancer, is described in a systematic review (Yang et al. 2016). The authors reviewed published papers; they found nine categories of concerns and four major themes. Despite the sadness of the situation and many of the problems related to having a sibling with a life-threatening illness, the overall conclusion of the various studies was positive, and often the sibling of the affected child became more mature during the experience.

The first major theme was disintegration of life. With the admission of a sibling with cancer, the parents' attention was focused on the sick child. The sibling had a life of chaos and disorder both at school and at home, and often had a very vague understanding of what was happening. Parents sometimes, in an attempt to be protective, did not tell the sibling enough of what was happening. The siblings develop some specific mental issues including abnormal worrying and anxiety, and the fear of cancer. Academic difficulties were common.

Another theme was marginalization of the sibling in the family with her parents single-minded focus on the child with cancer and undoubted neglect of other siblings. There was a loss of intimacy with the sibling with cancer and insecurity within family relationships.

Another theme was self-transcendence. Despite the chaos in family life, the siblings remained optimistic, joyful, and positive about the family. As time passed a caring relationship developed between the sibling and the child patient. The well sibling became more mature than perhaps the chronological age would indicate.

A final theme was maintenance of family integrity and family normality. As the author wrote:

> Siblings did their utmost to stay by their parents' side, to accompany their sick brother or sister, and to cautiously guard him/her and their parents from physical or emotional affliction. Most importantly, their attitude helped the entire family feel that they are united and that they should stay at each other's side. (Yang et al. 2016)

The second study was quite different; it considered the role of grandparents of children with complex congenital heart disease, and how they might help with siblings of the patient (Ravindran and Rempel 2011). The main findings were that these grandparents were "stepping in as needed" and "safeguarding relationships". They adopted, at least in the short term, a parental role with toddler and preschool siblings by helping with the other routines and also through involvement with recreational and play times.

This second study report points a certain one specific direction to use a resource, grandparents if possible; they might be able to help. A more general conclusion is that the siblings of children with medical complexity have their own problems, and it was a duty of any pediatrician involved with the patient with CMC to ensure that attention is also paid to siblings. Parents should be encouraged to consider the needs of the siblings, and to seek professional help if psychological problems seem to be emerging.

8.15 System Responses to CMC

8.15.1 Introduction

The survival of many children within the rubric of medical complexity is a new phenomenon. As stated, these children are heavy users of medical technology, have long initial stays in hospital and, in the long-term, are being cared for at home,

though a minority of CMC children live in hospital until they die. We have already suggested many ways in which pediatricians must adapt to offer the maximum help to the children and their families. Such a major change in medical practice with such a large impact on resources also means that systemic changes are required in how we organize healthcare.

A superficial view is that, in principle, nothing much has changed because, after all, home is where children are cared for whether sick or well. But with CMC children being cared for at home, their very survival depends on medical technology, with their parents and many caregivers, conducting many interventions that, until recently, were conducted only by healthcare professionals whether in hospital or by specialized home care.

8.15.2 System Has Changed to Accommodate the CMC Situation

The system is changing for many reasons, one of which is to accommodate the needs of these families. For example, development of the new generalist pediatricians called "hospitalists" is partly because of this new reality (but of course there were other reasons for hospitalists developing, including among other things the overall complexity of medical care and lifestyle changes in the lives of pediatricians). The American Academy of Pediatrics has developed the concept of the "medical home" as one way to promote continuity of care. The reality is that we are still learning how best to help children like Charlotte and their families, and that the traditional ethical framework is by itself inadequate. The ethical concepts that have been developed will be described, but it should be recognized that the ethical issues that arise will vary with time and with the specific situation including the site of care. Ethical realities when the child is in hospital are not the same as those when the child is at home.

8.15.3 Systems Are Just Learning How to Address CMC

While the paper by Peter et al. (2007) relates to the situation in Canada, it is likely that the situation they describe is similar in most Western countries. Healthcare organizations, whether governmental or otherwise, are in a catch-up phase regarding the extended care of children with medical complexity. There will likely be many different interventions that are tried out in different jurisdictions, while we identify which are most successful and which are likely to lead to harm rather than to help.

8.15.4 Focus on Continuity

In response to the rise in CMC children, institutions have responded with as mentioned, "pediatric hospitalists". They have responded also by focusing on continuity by developing appropriate information systems. Of course, information systems by themselves will not ensure the continuity is provided, but poor information systems can be a barrier to any form of continuity.

8.15.5 Medical Home

One development mentioned earlier is that of the "medical home", and we will provide more information here. Medical home is a concept. It describes an organization in which care is delivered by a physician who is well-trained to facilitate and manage all aspects of care. A medical home should be "accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective." (Medical Home Initiatives for Children with Special Needs Project Advisory Committee and American Academy of Pediatrics 2002). This is an ideal, and something to strive for. It is the antithesis of uncoordinated care delivered by multiple subspecialists. The reality of children with medical complexity is that many subspecialists are involved in the care; a primary care physician should have the role of coordinating the many recommendations that are made, and that primary care physician is called "the medical home".

8.16 End of Life Issues

As this section stresses, there are now a large number of children with medical complexity, who, in the past, would have died very shortly after birth. It is not surprising then that some of these children, like Charlotte, will live into adult life and still require complex care. Others might show surprising improvement and need minimal medical care as adults. A few might die before becoming adults. There is a whole section on "End of Life Care" in Chap. 10 but there are some specific features about end of life care in this group of children addressed here.

8.16.1 Mohammed's Story

Mohammed Jafari was born at 24 weeks gestation and required immediate resuscitation. He was placed on a ventilator, and some seizure activity was noted at about four days of age. He remained on the ventilator until he was five months of age, and after a number of attempts was weaned successfully. However, he moved very little, and occasional seizures

continued, and his feedings were by gastrostomy tube. He had a great deal of oral pharyngeal secretions and required frequent suctioning. He was dependent on oxygen by day and by night.

There were many discussions with the family on how best to look after Mohammed, and it was agreed that the parents would take him home with support. He had overnight caregivers who looked after the suctioning and ensured that the nasal prongs delivering oxygen were always in position. In the first 12 months at home he was re-admitted to hospital, twice. On both occasions, Mohammed required a considerable, temporary, increase in the supplemental oxygen, and on one occasion was given non-invasive ventilation for about four days. However, after each admission he was able to go home, although not to his baseline. The parents noticed that his movements were less, and the spasticity increased with time.

When Mohammed was three years old, he had a further deterioration at home and was brought to hospital. Non-invasive ventilation was started and there were further discussions with the parents and extended family who been helping in the care of Mohammed and were well aware of his fragility. The family agreed that further aggressive intervention was not appropriate should he have another episode of deterioration. After about a week, Mohammed was able to manage without non-invasive ventilation, but his supplementary oxygen was much higher than it had been before. He was visibly weaker. The family took him home once more, but with a plan to look after him at home if he had another episode of deterioration.

Mohammed and his family had considerable support from a pediatric palliative care service. Four months later he suddenly deteriorated and died over the course of four hours.

8.16.2 Comments on Mohammed's Life and Death

We have made it clear in earlier sections of this chapter that many children with medical complexity do not live long enough to see adult life. Some die in hospital, having never been able to transition home, even for a short period. The parents care for many others lovingly at home for varied periods of time. The course of events with Mohammed is not unusual. Of course, there are things we wish we knew, that we do not know. Was there a discussion in the early weeks of life about withdrawing ventilation? If that had happened, he might have died then. Did such discussions take place much later once the course of his life with its many limitations was established? The family was fortunate to have funding to pay for overnight caregivers and extensive family support. The question is whether the family was fortunate to have a four-year experience of a child whose death was inevitable at some time in childhood. Would a life limited to a few hours or even days of have been better for the child? For the parents?

What makes the death of this child with medical complexity different from other childhood deaths? In one way, all childhood deaths are tragic; this one as much as any other. However, it is likely the family were very well aware of the ultimate outcome, even though the timing of course would never be known. The family and the system had invested enormous amounts of time and energy into caring for him. The fact that he lived as long as he did is a tribute to the care offered by all the healthcare professionals and the family.

When death is approaching, some parents (like Mohammed's) may wish to restart invasive ventilation. Such a request should be listened to with respect, while

gently pointing out to the family that ventilation might delay the death but it will not prevent it. We suggest very strongly that the word "futility" not be used. The professionals may use the word "futility" to refer to the treatment; the family might understand "futility" as a description of Mohammed's life. If a major continuing disagreement on the goals of care develops, then this is an example of a situation where a referral to an ethics committee is warranted.

In the situation described here, there was family support and also support from pediatric palliative care. Other families might have much less support. The role of the pediatrician will vary depending on how much support and what kind of support is available.

There are other people to be considered in this situation. There were overnight caregivers. Were they the same three or four people over the few years of Mohammed's life? They might well have been, and while clearly, they are not ever the people to take decisions, someone should spend time listening to their thoughts on Mohammed and they should be provided support after the death.

8.17 Transitioning the CMC Child to Adult Care

Charlotte Grows up

Charlotte is now 14 years of age and Dr. Ward discusses with Charlotte and her parents the issue of transition to adult services. Charlotte and her parents were quite taken aback and asked, "Is this not too soon?" Dr. Ward indicated that though the actual transition would not take place for some years, the family needs to start taking some steps now.

8.17.1 Children with Medical Complexity Must Transition

This chapter has described a new reality, that many children survive beyond the neonatal period with conditions that were previously fatal. This is the result of advances in medical care, available technology that can be used in the home, and changes in societal attitudes. Children who survive to adult life will need continuing care throughout their adulthood. The medical component of that care will bear some similarities to care they have already received, but there will be many and major differences.

8.17.2 Many Adults Exist Who Were CMC

The increased number of patients with medical complexity occurs not only in pediatrics (Cohen and Patel 2014). Throughout modern medicine, there is an increase in patients with medical complexity. In Canada, the healthcare system is transforming

in many aspects to meet the many adults with complex health conditions. The article makes the point that at the other end of the lifecycle "a small but growing population of children has equally important, complex health needs that warrant our focus and attention". The article draws attention to many of the points made earlier in this chapter on the frequency of hospital readmissions, the high incidence of medical contacts, inadequate care coordination, and adverse mental health outcomes for caregivers. The researchers note the high social and financial costs and many unmet needs. While many individual programs exist to deal with this new phenomenon, there is very little data on their effectiveness.

8.17.3 Transitioning to Adult Care Is Not a New Problem

Arranging for the care of children with chronic illnesses into adult life is not new. Specifically, major advances in medical and surgical care have meant that there are now many young adults with what was seen as childhood disorders. Examples might be cystic fibrosis, diabetes mellitus type I, chronic renal failure and those with congenital heart disease. What has happened to individual children, or groups of children with a specific condition, has varied with time. In the early stages, once it was realized that those who had chronic childhood diseases were surviving into adult life, pediatricians continued to care for them.

This practice was sustainable, at least to some degree, where the numbers were small and there was no supervening medical crisis. But the situation would become difficult for pediatric units when one of these young adults, for example, became pregnant or required sophisticated surgery of a type not usually done in pediatric units. The next stage was to move to encouraging joint clinics with pediatric and adult specialist. These were successful up to a point and certainly facilitated the training of adult specialists but were ultimately doomed to fail as the numbers grew and the medical comorbidities became more adult like.

Hence, the next stage was the development of "destinations". These destinations would be clinics staffed with specialists knowledgeable about the medical condition who would be willing to work with their pediatric counterparts. In fact, these specific adult clinics, whether for cystic fibrosis, adults with congenital heart disease, or another specific chronic illness have worked well, to some extent.

While developments in transitioning to adult care was occurring, pediatrics was increasing its understanding of adolescence and developing specific services for adolescents. These services acknowledged that adolescents were no longer children, were not quite adults, had specific social and psychological needs, and that meeting those needs was important in helping adolescents become functioning adults. If such services are important for adolescents in general, they are obviously much more important for adolescents with major chronic complex illnesses.

8.17.4 Transition Requires Both Destination and Process

Therefore, there is now recognition that there must be a process of transition as well as a destination for young adults with chronic childhood disorders. Just as a destination by itself was insufficient, so is transition by itself insufficient. Reiss and Gibson (2002) state that "health care transition is a journey that does not have a clear destination." This process of transition was described by the American Society for Adolescent Medicine as: "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems." (Viner 1999).

8.17.5 Consensus Statement on Transition

Other organizations have also addressed the issues of transition. A statement issued jointly by the American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine (2002) states that:

> Children grow up within complex living arrangements, communities, and cultures and receive medical care within an equally complex, interlocking set of relationships that includes social services, education, vocational training, and recreation.

This group also states:

> The goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. It is patient centered, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination.

The Center for Health Care Transition Improvement (2018) has outlined principles to help transition be successful; these steps are recommended to be followed by both pediatric and adult centers. The pediatric centers must have:

1. Transition Policy
2. Transitioning Youth Registry
3. Transition Preparation
4. Planning
5. Transfer of Care
6. Transfer Completion

Simultaneously adult centers receiving young adults for continuing medical must have:

1. Young Adult Privacy and Consent Policy Young Adult Registry
2. Transition Preparation
3. Transition Planning
4. Transition and Transfer of Care Transition Completion

Despite the existence of these principles, difficulties remain on both sides. Often adult providers are wary of and feel unprepared for accepting such patients.

In one institution, these principles were followed in an innovative fashion (Wu et al. 2018). A youth who had transitioned was appointed as a youth community health worker (YCHW) into a team of physicians, a nurse practitioner, a nurse coordinator, and social workers. This person worked with transitioning youths to help in goal setting. More such innovative ideas are needed; the numbers of CMC requiring care as adults will continue to increase.

8.17.6 Despite Good Will, Many Transition Barriers Exist

While accepting the sincerity and energy of those who plan appropriate, caring and compassionate services for young adults with complex chronic illness, it is important not to minimize the barriers. Viner (1999) notes that "Adolescents sit poorly between the family centered, developmentally focused, paediatric paradigm (which frequently ignores their growing independence and increasingly adult behaviour) and the adult medical culture, which acknowledges patient autonomy, reproduction, and employment issues but neglects growth, development, and family concerns." In other words, successful care of young adults with chronic complex illness will require development of new services and new skills for physicians and many other healthcare professionals who are used to dealing with a different range of chronic illness. Those in pediatrics should not feel smug about our family-centered, socially-oriented care. Pediatric care must change as well.

8.18 Conclusion

This chapter about children with medical complexity is probably very complex to read. We outlined the size of this new development and many of the reasons why it happened. We pointed out that these children have long stays in hospital with some dying in hospital, and others still require complex medical care when at home. We dealt with many of the ethical issues arising in the hospital and in the home. Given that this is a new phenomenon, suggestions are still evolving. One area where a great deal of action is taken is the transition of children with medical complexity from pediatric care to adult services. Children with medical complexity will occupy a great deal of the time of pediatricians (and of ethicists!) for many years to come.

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Chapter 9
What Can I Do to Advocate for this Child, and for Children Like Him or Her?

Key Points Concerning Advocacy

- Pediatricians engage in advocacy when they use "their expertise and influence to advance the health and well-being of individual patients, communities, and populations." (Frank and Danoff 2007)
  - The scope of advocacy varies from helping individual children and families access essential resources, to improving services in health care facilities, to national and international endeavours to improve child health.
- Advocacy is about speaking for others to achieve ends they cannot achieve on their own.
- Advocacy is a key activity in pediatrics.
  - Some advocacy activities are an essential part of the practice of every pediatrician.
  - Some activities will be conducted by only a few, but they require support from colleagues.
- Advocacy requires specific skills that can be learnt.
  - Many resources are available.

9.1 Descriptions and Scope of Advocacy

Advocacy is defined as "the act or process of supporting a cause or proposal" (Advocacy 2018). Other definitions offer other insights into the nature of health advocacy. Waterston (2002) lists several definitions of advocacy, such as "Influencing those who have power on behalf of those who do not"; "Pleading, interceding or speaking for another" and "Promoting the rights of oneself or others". A more expansive definition of advocacy is "the application of information and resources

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_9

(including finances, effort and votes) to effect systemic changes that shape the way people in a community live." (Christoffel 2000).

We regard each of the definitions to be helpful and thought-provoking in creating a picture of the entire range of advocacy activities. In the context of healthcare advocacy, the range includes working with medical organizations and not-for-profit groups to influence elected officials as they make policy decisions regarding the health and healthcare of children.

We emphasized in "Key Points" that advocacy is a responsibility of all pediatricians, whether in training or staff physicians. We recognize that many pediatricians might have limited time to devote to this activity or might be unwilling to allocate time for advocacy. This chapter reviews the various ways in which the pediatrician can act as an advocate for individual children, individual families, communities, for children with specific disorders and children, and child health, generally. How much time to give to particular child or to a particular cause will always be a personal decision. Nevertheless, we encourage all pediatricians to incorporate advocacy into their daily work.

In doing so, we note that advocacy has been a defining quality of pediatrics from the beginning. Such advocacy was for individual patients, for the health of children in individual countries and worldwide, and for the very existence of the specialty. Indeed, considerable advocacy work was required to establish that children should have specialists skilled and trained in their specific needs. Much of the advocacy work in pediatrics and child health has been the combined effort of healthcare professionals, parents, and other interested citizens including politicians. Specialized facilities for sick children did not arise by chance. They were developed because of vigorous advocacy for the concept that children had special needs when sick. Advocacy continued in the mid-twentieth century for recognition that children in hospital needed their parents; by the end of the twentieth century parents were welcomed in all healthcare facilities. Pediatric advocacy addressed many general issues too, such as reduction in injuries by, for example, car seats and sport helmets; advocating for development of and funding for immunization; advocating for good hygiene; reducing exposure to tobacco; and advocating for appropriate nutrition especially breast-feeding.

Many of these more general topics that have a major impact on child health require continuing advocacy and often further development. For example, the achievement of institutional welcoming of parents as essential to the hospitalized child's well-being was only a first step; this successful advocacy is now extended to family centered care and might extend further. Advocacy to reduce children's exposure to the second-hand effects of tobacco, and to the possibility of addiction are activities that must continue in developed countries, and even more so in developing countries. Similarly, while there are many advocacy groups around the world to ensure that supports are available for women to breast-feed infants, activities still occur which undermine this important public health initiative. For example, a 2018 World Health Organization resolution that "called on governments to 'protect, promote and support breast-feeding'" and on "policymakers to restrict the promotion of food products that many experts say can have deleterious effects on young chil-

dren" was passed. Yet the resolution had faced strong opposition, apparently from infant food manufacturers determined to sell their products throughout the world, without restraint (Jacobs 2018). Constant vigilance to protect and promote child health is advocacy!

Deciding whether a specific activity can reasonably be described as falling within the rubric of advocacy might often be an individual decision. Although Bergman (2005) writes: "It has become fashionable in pediatric circles to describe as advocacy virtually any warm and squishy activity thought to be well intentioned", we disagree. We regard health advocacy for children as an important, defined series of activities that aim to effect positive change for a child or population of children.

With that background, let us consider some current developments in advocacy. First, advocacy has been formally recognized as being part of the necessary training of a physician. For example, in Canada, the CanMEDS initiative, developed by the Royal College of Physicians and Surgeons of Canada (2018), describes a series of interrelated qualities and skills a competent physician should have. These include medical expert, communicator, collaborator, leader, health advocate, scholar, and professional. The definition used in the first "key point" is taken from that initiative, and some components required of a health advocate are useful in developing an understanding of the scope of advocacy. The CanMEDS initiative is included in the training requirements for pediatrics. Pediatricians acting as health advocates "responsibly use their expertise and influence to advance child health and well-being of individual patients, families, communities, and populations."

The ethical rationale for physicians acting in an advocacy role is the belief that physicians are "accountable to society", and in this regard, they have a duty to work to improve the health and well-being of their patients, and also of their local communities, and the broader population. In the course of medical practice, physicians develop a unique perspective on health. More specifically, they hear patients' accounts of their experience both with illness and with the healthcare system. They are companions to young people born into the "Kingdom of the Sick" (Sontag 1978). The experiences they have are matched with medical knowledge, and training in the social determinants of health. In other words, pediatricians are able to speak on behalf of others and to help mobilize resources to effect change. The role of advocate aims not just to lessen the impact of illness on patients; it also seeks to prevent disease and to promote and to protect health.

9.2 Levels of Advocacy

In practical terms, physicians work with patients and families helping them access appropriate resources, helping them navigate the healthcare system, and promoting health equity. Regarding larger issues, physicians work within complex systems that can be difficult for patients and their families to understand. These systems are typically better understood by physicians; consequently, physicians are in a better position to advocate within these systems. There is a great need for collaboration, and

for those physicians who engage in advocacy to work closely with their colleagues in all healthcare disciplines, healthcare administrators, community agencies, and the policymakers. Some say that collaboration with teams is becoming more prominent, and regard advocacy as undergoing transition, "moving from relying on individual physician-advocates to expecting advocacy from the profession at large." (Nerlinger et al. 2018). Certainly, the examples of advocacy efforts to limit tobacco exposure and to encourage breast-feeding demonstrate that advocates must collaborate and often need to be persistent over years and even decades to succeed.

We have already indicated that advocacy can range from helping individual patients (something that many will consider simply as "being a good physician"), to activities that might change the whole of society. Waterston and Haroon (2008) classify advocacy as relating to:

- Clinical encounters with families
- Situations in the local community
- Children's health within society as a whole (child public health).

Other authors have offered classifications of advocacy that are very similar to those listed above. For example, Hubinette et al. (2014) explored physicians' understanding of health advocacy, based on their specific experiences. They identified three ways of understanding health advocacy:

1. Clinical: Health advocacy as support of individual patients in addressing health care needs related to the immediate clinical problem within the health care system,
2. Paraclinical: Health advocacy as support of individual patients in addressing needs that the physician preceptors viewed as peripheral yet parallel to both the health care system and the immediate clinical problem,
3. Supra-clinical: Health advocacy as population-based activities aimed at practice and system-level changes that address the social determinants of health.

The Canadian Paediatric Society (2018) uses slightly different language and makes similar points that advocacy can have different targets, and certainly occurs at different levels. The levels listed by this organization are:

- Case advocacy (for individual children/youth),
- Systems advocacy (for practice changes that affect many children/youth)
- Policy advocacy (for changing legislation, regulation).

In essence, these various classifications of advocacy reveal that there are different, but equally relevant ways, to view this topic. We suggest and use a common classification that is easy to understand:

1. Micro-level (Case advocacy)
2. Meso-level (System advocacy)
3. Macro (Policy advocacy)

Of these, 1 and 3 are the easiest to understand.

9.2.1 Micro-level Advocacy

Micro-level, case advocacy, is the everyday physician practice to help families. This might entail writing letters, meeting with local hospital administrators, and so on. It is about helping individuals.

9.2.2 Meso-level Advocacy

Meso-level or system advocacy entails, for example, considering budget allocations in cities, provinces and states. Decisions are made to allocate money to items such as education, social service, and healthcare. Pediatricians have an interest all these fields because they are all are relevant to children; and we hope the pediatricians would not reflexively support spending on healthcare if it means a reduction in spending on education and social services. The connection between social circumstances and health is emphasized by Modi (2018): "That there are strong, consistent associations between poverty, deprivation and poor health is undeniable." Meso-level activities involve working with individual institutions such as hospitals and geographically based local health agencies. Again, meso-level activities can affect facilities for children, and availability of funding for, for example, specialized allied health services such as physiotherapy or occupational therapy devoted to the care of children. At this level, pediatricians are able to marry their knowledge of pediatrics and determinants of health and needs of patients, with their knowledge of the local healthcare system and the decision-makers within that system. It is here, at the meso-level, where pediatricians might have the greatest opportunity to impact child health and the well-being of individual patients in a given geographic area.

Consider for example the enormous effect of a pediatrician, Dr. Mona Hannah-Attisha, who led the advocacy for child health in the geographic region of Flint, Michigan. Of Flint's 100,000 residents, approximately 40% are affected by poverty. The city had financial problems. To save money, city officials decided to switch the source of city water on April 25, 2014 from Lake Huron to the less costly Flint River (Weiss 2017). Immediately, the public complained about the colour, taste and smell of the water. Indeed, abnormally high levels of E. coli, trihalomethanes, lead, and copper were identified in the city's water supply. The population was advised to boil the water. Six months later, General Motors refused to use Flint River water because the chloride was too corrosive of its metal parts. Despite GM's announcement, Flint officials continued to assert that the water was safe and added more chlorine to the water supply (Pearce 2016).

At a barbeque, Dr. Hannah-Attisha met a high school friend who had become a water expert. The friend told her, "It's missing something called corrosion control.… Without that corrosion control, there is going to be lead." (Hanna-Attisha 2018). In other words, the corrosive water affected the city's old water pipes so that they would continue to release lead into the drinking water. That lead is harmful is well known. Throughout the process of becoming physicians – from medical school, through pediatric training and on to continuing medical education - the toxicity of lead is emphasized. There are no obvious early warning signs of the effects of lead on all tissues, with major effects on the brain, bones and blood. Children who are exposed to lead will show poor growth, developmental delay due to permanent brain damage, renal damage and anemia.

Dr. Hannah-Attisha knew that the hospital where she worked was concerned about lead toxicity. Lead levels of children were checked at 1 and 2 years of age. By examining lead levels detected in children before and after the water supply switch, she commenced a research project. The research revealed a huge increase in lead levels in children after the city changed its water source. Her research was published first on line (Fonger 2015) in September 2015 and then in a peer reviewed journal (Hanna-Attisha et al. 2016) in February 2016. In September 2015, she wrote,

> It's our professional obligation to care for the children of Flint (and to tell parents) if we know something. […] Lead poisoning is irreversible. This is not what our community needs. You have to err on the side of caution (and) educate the public.

The politicians labeled her as an "unfortunate researcher" and accused her of causing hysteria. They said her figures were inconsistent with the state findings. Within a very short time, the politicians admitted that she was correct, and the city returned to sourcing its water from Lake Huron. But this political retreat did not solve the problem because the city's pipe system had been permanently damaged by exposure to the corrosive Flint River water, and there were now many children with neurological damage because of exposure to lead. Dr. Hannah-Attisha not only spoke up about her research results, she formed a group called the Pediatric Public Health Initiative (Michigan State University 2018), a group of physicians and members of the public who work to implement change and to provide service for the children. Dr. Hanna-Attisha received many awards for her work and has published a book describing the episode (Hanna-Attisha 2018). Her work continues.

Few of us are likely to achieve what Dr. Hanna-Attisha achieved in her advocacy work, yet her work is an inspiration. Trainee pediatricians should note four things: First a person raised a concern with her and Dr. Hanna-Attisha thought not just that something should be done but that **she** should do something. Second, she did her homework, (in this case, by conducting a peer reviewed study). Third, she was prepared to go public, even if that meant facing abuse. Finally, she continued to work on solutions after achieving her first objective, restoring uncontaminated water. She recognized the long-term implications of her findings. We believe that she did all these things because of her steadfast focus on child health.

This example of meso-level advocacy demonstrates that, as with all other advocacy activities, there is a great need for partnership with patient and family and community organizations and with a range of healthcare professionals.

9.2.3 Macro-level Advocacy

Macro, policy advocacy, is fairly easy to understand. It entails working at a governmental level, and, for example finding ways of dealing with epidemics and addressing special underserved populations at a national level. At this level, considerable resources are required for advocacy, and individuals work usually in association with national organizations such as the American Academy of Pediatrics, the Canadian Paediatric Society, the Royal College of Paediatrics and Child Health, and other similar groups. Indeed, these national organizations might well partner with other organizations, such as nursing, obstetric, and public health groups, where the interests of children are at the intersection of activities of different professional groups. To be effective, macro-level advocacy can require partnership at a national level with parent organizations, whether disease specific, or at a more general level.

Macro level advocacy involves working at levels where decisions are made for great numbers of people and entails political activities. Making change at the macro level, over a large part or the entirety of a country, or even at an international level is worthwhile. It is unlikely that any trainee pediatrician can achieve change at that level by herself or himself, but that should not stop any pediatrician from joining efforts. Trainee pediatricians might make an observation at the patient level that suggests higher-level advocacy is needed. Examples of advocacy at this level are important and include attempts at tobacco control. Pediatricians are particularly keen to limit access of young people to tobacco. Tobacco companies are anxious to "recruit" teenagers to the rank of those addicted to tobacco.

Other areas of activity at a national or international level include removing barriers to breast-feeding and dealing with international companies that promote bottle feeding in the developed world and the use of flame retardants in children's pajamas, the so-called "toxic pajamas" (American Academy of Pediatrics 2013).

Another recent example of macro-level advocacy is the effort of the American Academy of Pediatric Association in protesting the United States Federal Government's decision to separate children from parents who entered the United States without authorization. As the AAP stated, "Separating children from their parents contradicts everything we stand for as pediatricians – protecting and promoting children's health" (Miller 2018).

Levels of advocacy can work in concert to achieve improvement in child health such as when micro and meso efforts to help individual children achieve systemic change. One such example is advocacy to access extremely expensive drugs for small populations of children, an example that will become increasingly prominent. This area of advocacy starts with the individual and moves very quickly to a governmental level, and perhaps an international level as it deals with the price charged for drugs. We regard this is as a very important area and discuss it further in the Chap. 15 "Resource Allocation".

Because pediatricians' time is precious and limited, it is important that pediatricians allocate it wisely. What merits a pediatrician's non-clinic time and how can it be used most effectively? Creativity researcher, Jacob Getzels (1975), recognized that is important not just to seek the right solution but to find the right problem.

As he wrote, the quality of the solution attained is a function of the quality of the question asked. Emotional investment in an issue can focus the mind to discover the right problem. Consequently, it is important to remember that the most difficult aspect of advocacy can lie in finding an issue about which one is passionate and taking the first steps to address the issue (Satcher et al. 2005).

9.3 Common Objections to Advocacy

Including advocacy as an element of medical professionalism is relatively new. We noted earlier in this chapter that micro-level advocacy is not controversial. Many physicians would say this is an essential extension of interacting with patients and will be reluctant to call it advocacy. Meso-level advocacy might be slightly more controversial, but again it is not new; for example, physicians actively encourage change within their institutions. Pediatricians would expect that they and their colleagues would seek to ensure that the parents could be with the child throughout the 24 h while the child was in hospital, and that neonatal units encouraged and fostered breast feeding. Yet when we come to more general activities of advocacy that occur at the meso or macro level, we begin to meet physician resistance to engage in such advocacy. Nevertheless, the advocacy component of CanMEDS encourages involvement of pediatricians "to advance child health" in community and population settings. Is it because these activities are inherently political, time-consuming, and involve collaboration with many people who are not healthcare professionals that they can be viewed by pediatricians negatively? Is it because the decision-making process might include factors that are unfamiliar to physicians such as constituent preference and elected officials' concern for re-election?

Waterston (2002) agrees that there is not universal acceptance of advocacy as a core skill and expands a little on the objections of some physicians to meso- and macro-level advocacy work. He asked the question, "Why is advocacy sometimes viewed negatively?" Some of the responses suggest that physicians should not move out of their core activity and "intrude on the patch of other disciplines". Some respondents observed that advocacy can be political, and, for that reason, commented that this is something the physician should avoid. Some respondents stated that physicians engaging in advocacy might lose objectivity. The final two objections are even more interesting: Advocacy is time-consuming (true) and lacks an evidence base (misleading). The claim that advocacy lacks an evidence base is odd. There is no reason to advocate unless there exists evidence that the solution advocated for is better than the status quo. Obviously, a physician's advocacy efforts should be based on the best available evidence. Any physician who uses his or her medical degree to advocate for change in policy or practice that is not evidence-based (such as to oppose vaccination or fluoridation) should be criticized on that basis. Although there is less evidence on the specific advocacy techniques to be used, clearly the underlying evidence for the proposed change should be strongly based on relevant, peer-reviewed evidence.

A different objection to physician advocacy is raised by Huddle (2011). He believes that advocacy for improvements in healthcare, including environmental changes that would enhance child health, are a civic virtue not a professional virtue. Hence, physicians might participate in such activities but as citizens not as medical professionals. He thinks that the time devoted to advocacy detracts from time available to practice medicine. He also thinks that if academic centers devote time to advocacy, then they are detracting from the key roles of teaching and education.

We understand these arguments; at least we think we do. Nevertheless, we reject them. Physicians have combined a busy medical practice, teaching, and advocacy without sacrificing their duties to their patients or their students. Moreover, physicians have a high social standing in society, a much greater income than most citizens, and while they have invested their own money in that education, citizens have contributed to that education, too. Citizens pay taxes and give donations that fund universities and medical schools, and are willing, as patients, to allow trainees to interact with them.

Advocacy at a societal level is part of the social contract physicians have with society and is part of their professional duty. This concept will not be universally accepted immediately. A study of internal medicine residents' beliefs, perceptions, and expectations of medical professionalism reported recurrent primary themes of knowledge and technical skulls, patient relationships and character virtues (Wagner et al. 2007). Other themes identified were "medicine as a unique profession, personal congruence and the importance of peer relationships". Themes related to social justice elements were not found in the focus groups. If trainees are to accept advocacy as an essential role, then it must be emphasized during training that it is not an option. Advocacy work is essential.

Waterston and Haroon (2008) addressed in a general way the comments they had heard from trainee pediatricians, many of whom were opposed to being involved in advocacy. The trainees asked the question, "Why should pediatricians bother with advocacy?" Some concerns raised related to knowledge, which is identifying what advocacy is and how to be an advocate. Other trainees lacked understanding of how healthcare systems work and thought that advocacy might really be someone else's job. Some trainees stated that no one seemed to care if advocacy was done or not, and that if the activity was political, then they might get into trouble. The clincher, "I don't have time" finally; the implication being that direct clinical care must always take priority. It would be fair to say that advocacy activities, beyond helping individual children and families, are not for every pediatrician. In our view, it would be just as fair to say that every pediatrician should find ways to support their colleagues who participate in these activities.

Arguably, however, the future is in health advocacy. Research suggests that residents involved early in advocacy projects during their training might be more likely to pursue such initiatives in the future. We accept that successful advocacy is a learned skill, but we agree with Paulson (2001), "Anyone who can learn the Krebs cycle can learn to be a child advocate".

In a paper that was both a plea and a description of what needs to be done, Gosselin-Papadopoulos and Pang (2016) pointed out that health advocacy educa-

tion is now a necessity. They argued that there is a need for a solid "national advocacy curriculum that exposes paediatric residents to social determinants of health and fosters skills to effectively develop and evaluate interventions that improve health outcomes". Residents should acquire the skills to work with policy makers and to speak up about concerns such as child poverty, food insecurity, childhood obesity, and injury prevention. The future of child health depends on the effective education of trainees on what to advocate about and how to conduct advocacy successfully.

What follows are case stories of advocacy activities at each of these different levels.

9.4 Micro or Case Level Advocacy: Why Advocacy Matters to Individual Children (Micro or Case Advocacy)

Noah is 3 years and Sophia is 5 years old. The siblings have asthma and attend a community clinic. You know that they have multiple allergies and that they have been prescribed standard anti-asthma treatment. Social services have paid for the medicine. You also know that Noah and Sophia's father is in jail. Their mother, Emma, depends on social security and they live in a public housing apartment which is noisy causing sleep disturbances in the children. One of their neighbours participated in the crime the husband committed and has also been jailed. You discuss various approaches to asthma particularly avoidance of allergens. Emma believes that many of the allergens that cause Noah and Sophia trouble are related to previous occupants of the apartment. She asks you to help them in seeking a move to a single-family home.

Children by their very nature are vulnerable. Every additional adverse factor adds to the vulnerability. We see in this short story a whole conglomeration of the various social determinants of health, and family and societal factors that affect child health. Pediatrics cannot be practised without considering the environment in which the child lives, in addition to the medical facts. Pediatricians will routinely consider nutrition, education, psychological and emotional factors, and growth and development, however briefly, in all consultations.

This particular situation arises from the clinical encounter but is also specific to the local community. There are aspects here that might move beyond the local community. The case raises issues related to incarceration, such as when this is an appropriate penalty. Are there other penalties that might be used for some breaches of law to enable a man to continue to provide for his children? How do we deal the situation when the main financial support of a family is unable to earn any income? How do we break cycles of disadvantage? How do we help children such as Noah and Sophia achieve their whole potential? We recognize these are important questions, and address them later in the chapter, confining most of our remarks at this point to the specific situation at hand.

To address the questions asked, to help Noah and Sophia, there seems to be a duty on the part of the physician to support the request. As mentioned earlier, many of our readers will not regard such a response as advocacy, or even a particular ethi-

cal issue, simply that of being a good physician. We have sympathy with this view but would frame providing support for a housing change on health grounds in terms of "duty", something a professional should do. The physician involved might want to do "due diligence", and, with the mother's permission, contact the social worker involved with the family. The social worker might have more information on the family that is relevant to the report to be written and might well have carried out home visits and will be better informed on the home environment than the physician would be.

It is also relevant that this advocacy comes at the request of the mother. Parents are generally the best advocates for the child, but there are many situations where they are unable to advocate effectively by themselves. The dyad of pediatrician/parent is a very powerful force for successful advocacy. This particular advocacy effort might involve as little as a structured letter to the housing agency or social services authority, perhaps supported by a telephone call. It would be important to have the consent of the mother before revealing any medical information about the child, but obtaining such consent should be straightforward, given that the request for help has come from the mother.

Advocating for some change that will help the patients we see is the most common form of pediatric advocacy. It is likely that all pediatricians have helped families in this way many times. Nevertheless, there are some simple points to bear in mind when advocating for patients:

- Make sure your evidence is accurate.
- Be prepared to defend what you say.
- Start at lowest level of decision-making.
- Contact the decision-maker personally if possible.
- Use email discriminately:
  - One topic
  - Subject line
  - Think about whether to use cc and reply all
- Send by email or post.
- Draft clearly/succinctly.
- Have someone review.
- Be courteous.
- Be clear in request.
- Follow-up.

What happens next will vary considerably, but, if the correspondent refuses the request, then consider an appeal process. It is generally a mistake to aim for the "top" administrator; it is best to go up the administrative ladder in stages creating an evidentiary record. If there is no success, further strategies are more problematic and difficult, but must be used on some occasions. We do not encourage rudeness, a tantrum or forcefulness. We do understand why they might be used even in situations of extreme frustration but they are unlikely to help the child or children.

9.5 Meso-level Advocacy: When One Family's Story Leads to Change for Many Families

Observant pediatricians, whether in training or staff, will see opportunities to advocate for improvements in the care of individual patients. Discerning pediatricians, whether in training or staff will see opportunities to improve the care of many patients. This is one such story:

9.5.1 Alex's Story

Alex Cantrill was a 3 1/2-year-old boy. His seizures had started when he was three months of age and had proven difficult to control. He was admitted to hospital at that time and was in hospital for four months before going home. There, he also required a gastrostomy tube for feeding. He had been readmitted to hospital five times since going home at 4 months of age.

Dr. Caden Bonsall was a resident who saw Alex on his most recent admission. Alex had a prolonged seizure at home. His mother Chelsea had experience in dealing with seizures, and most of the time was able to manage them at home. Occasionally such management was difficult in which case she brought Alex into emergency. On this occasion, the seizure was eventually controlled in the emergency department, but it took over an hour. He was admitted to the inpatient ward for at least overnight observation with a plan to obtain a neurological consult to see if his therapy should be adjusted.

Dr. Bonsall did his best to obtain a history from Chelsea Cantrill but by the time Alex (with her mother) had been admitted to an inpatient unit, Chelsea was irritated. She pointed out that Alex was well known to the hospital, his history was well documented, and why did she have to answer all these questions again? Every time she had to go over the birth history, the early experience with seizures, diverse investigations that had been conducted and list his current therapy. Wasn't there a better way?

Dr. Bonsall worried that if he didn't do a full history, he might miss something important, but did sympathize with the point Alex mother was making.

Dr. Bonsall then spoke to his fellow residents, all of whom had had a similar experience with irritated parents of children with chronic, complex disorders. Dr. Bonsall sought advice from a senior hospital pediatrician and was encouraged to gather data as a first step. Dr. Bonsall established the number of children whose initial stay had been greater than two months and how often they had had subsequent admissions. He found that this was, at least numerically, a substantial problem. He presented his data and received support from the pediatricians and emergency physicians who attended to continue. He asked if there was any willingness to change hospital procedure and was able to form a small task force with some residents and some staff physicians. A parent (who was already overstretched) was asked to join the group. This task force – residents, staff physician and the parent generous with her time – met several times and produced a recommendation that they presented to the medical management of the hospital to simplify the documentation required when chronic patients were readmitted, whether these children had disease confined to one system or were Children with Medical Complexity.

9.5.2 Comments on Alex's Story

This is an example of meso-level advocacy. In this case, Dr. Bonsall led the creation of change within an institution. Dr. Bonsall responded to a legitimate complaint from a parent. He recognized that the method of collecting histories from children well-known to the hospital was something that could be changed, but first he checked with his fellow residents to ensure that they were seeing what he was seeing. His next series of actions were to gather allies at his own level and at more senior levels, from different professions, remembering to include at least one parent in his group. From his group he was able to consider the problem, develop a solution, and then take it to management. This change is simple and obvious, but the stage after implementation is sometimes the most difficult. Once the solution is implemented, then there must be two related plans. The first plan is to ensure that everyone knows about the agreed-upon change, the second is to monitor that the change is actually taking place. There are many worthwhile initiatives, and many fail because of poor implementation. Others fail because enthusiasm tends to decline over time. Enthusiasm and persistence sometimes to the point of "dogged determination" are two important characteristics needed in advocacy.

9.6 Meso Level Advocacy: A Second Case

9.6.1 Dr. Gomez and Hudson

Dr. Aria Gomez saw a child Hudson, a 2 1/2-year-old sent in by his dentist because of facial swelling. The swelling was painful and red. Hudson looked sick, and the likely diagnosis was facial cellulitis with a possible dental abscess. She was unsure of what the next step would be and spoke to the staff emergency physician on duty, Dr. Ivan Kolisnyk. Dr. Kolisnyk agreed with the diagnosis, and outlined a course of action, including starting intravenous antibiotics, with consultation with the infectious disease service and consulting the specialist dentists in the hospital. He thought that the child would probably eventually need surgery to remove the infected tooth. Dr. Kolisnyk was new to the town and commented that he had seen four children like Hudson in the last several months. In his previous position, in another city, facial cellulitis associated with dental abscesses in children were rare. He related this change to the fact that fluoride levels were not adjusted in the community drinking water in the city where he now worked but had been in his previous city.

Dr. Gomez spoke to some of the other residents, who retailed similar stories. The infectious disease residents confirmed that they were now used to seeing children with dental abscesses requiring intravenous antibiotics, and quite often dental procedures under general anesthetic. Dr. Gomez contacted one of her medical school classmates who was a resident in public health and asked if she would work with her to persuade the local authority to adjust fluoride concentration in city water. Dr. Gomez recognized that she would need to involve several other people, and that this effort would inevitably be political. She also recognized that the work would be time consuming, and that she might not be immediately successful.

9.6.2 Comments on Dr. Gomez and Hudson Story

This is still meso-level, bordering on macro level advocacy. It will reach the macro-level if a national organization is persuaded to advocate for fluoridation in many municipalities. Not all pediatricians will regard a child's dental health as something of interest to them. They should! Dental decay is the most common chronic disease of childhood (US Department of Health and Human Services et al. 2000) and (Clark and Slayton 2014). According to the American Academy of Pediatric Dentistry (2018):

> Tooth decay has become epidemic among our youngest children. a rapid form of tooth decay, known as early childhood caries (ECC), is the most common disease faced by young children – and it's on the rise. Research shows that ECC can cause lasting harm to a child's oral and general health, and social and intellectual development. Children from low-income and minority families are particularly vulnerable to ECC. […] What is most frustrating for our organization is that most tooth decay is preventable.

Community water fluoridation is a major public health benefit that can reduce dental decay by 26–44% in children and adolescents (NHMRC 2017). It is the single most important method of preventing dental decay in populations, and must, of course, be accompanied by good diet, regular brushing and flossing, and regular dental care. Poor dental health affects much more than the teeth.

Hudson, the child in the story above, has systemic illness, abscess formation, and there are many recognized complications of dental abscesses. The complications include intracranial infection, sinus infection, pulmonary infection and so on. There are many other issues with poor dental health, including constant pain, an inability to chew food; these issues foster a vicious circle that starts with a diet of soft, sweet food. Poor dental health means that the child is unlikely to smile, and this trait will affect how adults respond when they meet him or her. Chronic sepsis will affect mood and concentration, and hence affect learning. Poor dentition affects life opportunities such as obtaining employment and finding a life partner.

But to deal with this city-wide issue is much more complicated than the stories we have told in the past. This is an issue of meso advocacy, and it involves dealing with an issue of public health and with politicians. Dr. Gomez has already realized that the task of achieving community water fluoridation in her city will take time and will be time-consuming. She needs allies, and public health is the obvious first ally. However, public health physicians, who are specialists in prevention, and we hope also specialist in advocacy for prevention, are often helped by retelling the stories of children whom they see. Dr. Gomez also realizes that the range of skills needed is fairly wide and must include individuals with skills in dealing with the media and with politicians.

We wish her well. If she succeeds then she will have helped hundreds, perhaps thousands of children and their families.

9.7 Macro Advocacy: Tobacco Control

Reduction in the use of tobacco in adults results in immediate benefits to children. The effects of tobacco on child health are well known (DiFranza et al. 2004). Prenatal exposure is associated with low birth weight, ear infections in infancy, SIDS, behavioral and neurocognitive effects. Postnatal effects of environmental tobacco smoke (ETS), also called second hand smoking, include middle ear disease, cough, diseases of adenoids and tonsils. In the case of both asthma and bronchiolitis, ETS increases frequency and severity. Adult smokers, and adults exposed to ETS have, among other problems, severe chronic lung disease, lung cancer, and cardiovascular disease. It is no surprise that reducing tobacco use is a current important public health activity. More importantly as pediatricians, we want to prevent individuals from starting the use of tobacco. The tobacco companies target teenagers who are at an age vulnerable to risk taking behaviour. Once these young people start smoking, they become the adult consumers of the future. At one level, we have achieved success in these efforts, smoking rates are low and smoking in public in North America is unusual. At many other levels, tobacco consumption remains a problem.

Current medical students and training pediatricians watching movies made in the 50s, 60s and 70s are often surprised at how common and pervasive smoking was, and how it was acceptable at all levels of society. One general trend in movies of the 1980s and later is "major characters who smoke tend to be of lower socioeconomic class and villains" (Glantz and Polansky 2006). This is not invariable and two of the young stars in the 1997 movie *Titanic* both smoke. The same students and trainees see much less public smoking, realize there is less smoking overall in Western society, and might be tempted to conclude that this is no longer a major public health problem. In 2007, the Lancet stated that "For the first time ever, the world's leading agent of death is a man-made substance – tobacco." (Frieden and Bloomberg 2007).

The same young people of today might wonder how such a harmful and addictive substance became embedded in our society. The information that follows is taken from a paper about tobacco use in Canada, but the information relates to the western world in general (Collishaw 2009). The tobacco plant is indigenous to South America, and became established in North America, where it was used as part of religious ceremonies. The invading settlers of the sixteenth century took the product to Europe. By the late nineteenth century tobacco smoking was established as the "polite thing to do", at least for men in Western Europe and North America. By the late nineteenth century, and into the twentieth century, there were various attempts to reduce tobacco consumption, but were unsuccessful. The evidence that it caused ill health was available by 1938, but this evidence did not change the behaviour of individuals or of public health authorities. More powerful evidence was published in 1950 (Doll and Hill 1950); again, little political action followed.

Two reports appeared in roughly the same timeframe, one from the UK in 1962 (Royal College of Physicians of London and Committee on Smoking and Atmospheric Pollution 1962) and one from the United States in 1964 (United States Public Health Service 1964). Both presented to the public the scientific proof of the connection between tobacco consumption and ill health. These reports also had little effect on public health authorities, and perhaps a modest effect on public opinion.

From the time these reports were published until the present, activities on smoking followed two main and opposing tracks. The tobacco industry strategy was always to create doubt and to insist that there was not 100% certainty that tobacco caused disease. The public health strategies were designed to reduce tobacco use but were ineffective and poorly funded. Later, public health strategies relied on legislation and became progressively more effective.

The public health campaign against tobacco involved individual activists, political activity by non-governmental organizations, and activities of various degrees of effectiveness by all levels of government. At every stage, the tobacco companies blocked the campaigns and activities by spending large amounts of money on lobbying and disinformation.

The public health campaign against tobacco is typical of many public health campaigns in that constant vigilance is required. The struggle is not over, the companies are still active in various activities, such as encouraging the sale of flavoured tobacco, investing in e-cigarette (vaping) companies (LaVito 2018) and developing new products such as gadgets that heat, but do not burn tobacco (Valinsky 2019). These efforts seem designed to appeal to youth and to encourage their addication to nicotine - a necessary activity for companies whose products kill their customers. Some companies are apparently active in preventing teens taking up smoking but on close inspection "industry programs neglected the health effects of tobacco use and subtly promoted smoking" (Landman et al. 2002). Tobacco companies are encouraging tobacco consumption in developing countries.

Issues of macro-advocacy are complex, involve all levels of government, including international relationships, well-funded non-governmental organizations committed to strong public health activities and outspoken individuals. Still, there remains constant opposition to public health activities by tobacco companies, sometimes overt, but often covert.

How might the trainee become involved in issues of macro advocacy? One way is to join one of the active NGOs, another way is to encourage professional organization such as medical associations or pediatric associations to remain active in reducing access to tobacco and nicotine-based products. Successful macro advocacy efforts can be achieved only by widespread competition. At a local level, it is important to recall that nicotine addiction is an addiction. Saying to parents "You shouldn't smoke around your child." isn't enough and isn't even helpful. Trainees can support provision of pharmaceutical products to help reduce nicotine addiction.

9.8 Requirements of Advocacy

Once we move beyond helping individual patients, and sometimes when doing just that, there are realities to be appreciated. Advocacy can be difficult. As Hunter (2015) notes that "Health systems are complex, messy, hard to comprehend and harder to change". Therefore, there is an inevitable political component to policy change. There are ethical tensions and balances that need to be struck between public and private interests, personal and collective responsibility, and rights of community and personal freedoms.

Moral courage is an essential virtue for the pediatric advocate (Martinez et al. 2016). This is especially true when we "use" media to deal with entrenched interests. As Martinez et al. write:

> When we move our efforts upstream, beyond individual treatment to prevention initiatives that address environmental factors, we often find ourselves at odds with powerful institutions in both the public and private sectors. Therefore, gaining community support is essential and using the media is a crucial strategy in this endeavor.

Change to promote child health is possible and is usually achieved when people work together with a fixed focus on helping children.

9.9 Conclusion

Advocacy is an essential component of pediatric activities. All pediatricians are familiar with helping individual parents and children in this regard. This "case advocacy", can be supplemented by advocacy to change systems, to develop new unhelpful policies, and to make substantial changes that will help children nationally or internationally. Advocacy requires training in the necessary skills to be effective, collaboration with other physicians and non-physicians and groups, and moral courage. Some pediatricians regard advocacy as beyond them and consider the skills impossible to learn. We disagree with both of these conclusions. Pediatricians are intelligent, committed individuals with high emotional intelligence, who learn on the job. We encourage all pediatricians to act as advocates for children and for child health.

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Chapter 10
When and How Do I Stop Certain Treatments, Accepting That Death Is Near?

Key Points Concerning End of Life Care

- Death in childhood has become dramatically less common in the past 100 years
- Death in childhood has a lifelong effect on parents and all family members
- Death is most common in the first month of life
- Today, >6 million childhood deaths occur per year
- Death rates are much higher in the developing world than in Western countries
  - In developing countries, causes of death in those <5 years in 2013 were infections 51.8% (3.257 million) and neonatal issues in 44% (2.761 million)
- In USA, (results are typical for other western countries):
  - Most deaths occur in the first year of life due to pregnancy related events or genetic causes
  - Deaths aged 1–4 years: the most common causes of death are accidents (unintentional injuries), congenital malformations, deformations and chromosomal abnormalities, and assault (homicide).
  - Deaths aged 5–14 years, the most common causes of death are again accidents (unintentional injuries), but then follows cancer and intentional self-harm (suicide) (CDC 2015)
- Many current childhood deaths would have occurred in the neonatal period until recently
- Many deaths now occur after withdrawal of an intervention
- The need for end of life decisions is often a source of conflict but pediatricians can help by choosing words carefully and being available before, during and after the death
- Pediatric palliative care is a new and welcome intervention

All pediatric trainees will have contact with children who are dying. Some understanding of the underlying principles, underlying problems, and various approaches are essential. To help advance such understanding in this section, we tell some

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_10

stories to illustrate some important points in helping children and families at the end of life.

10.1 Child Death Is No Longer Common

Today, many of us have no personal experience of a child dying. We tend to hear of such cases in conversations with friends and acquaintances or from the media. Media stories can be sensational. Examples in one week are of a woman who comforted a dying child at a crash scene, "I blinked and a young boy got hit by a car" (Burns and Spink 2018); of a boy with cancer and a poor prognosis who sought racing stickers to cover his casket (Associated Press 2018); and of a politician whose child had died in the neonatal period of a congenital anomaly (Wood 2018). The most sensational stories seem to be those reporting that a child has been murdered by a parent; for example, the story of a father who appears to have shaken his son so hard that the 6-month old baby boy died ("Kayden Walker" www.bbc.com). Given that one such story is broadcast widely, we might come to believe that homicide is a common cause of childhood death.

Each of the stories is sad in its own way, but the broad picture of childhood death painted in the media is far from reality. In the Western world, death in childhood is no longer the expected event that it was in the early part of the twentieth century. For example, between 1881 and 1890 in Scotland, one in five deaths were to infants under the age of 1 year, and one ten were to infants under 3 months (Reid and Garett 2012). By contrast in 2014 in Scotland, 1 in 233 deaths was to a child 4 and under (National Records of Scotland 2014). In Canada in 2016, one in 131 deaths was to a person under age 4 and under. There were 3120 deaths in children aged less than 19 years and 267,213 deaths in total (Statistics Canada 2018). The details of the childhood deaths are as follows:

- Most pediatric deaths (1741, 55.8%) were under 1 year.
  - Of these 1021 (58.6%) were due to perinatal events, 404 (23.2%) due to congenital malformations and chromosomal abnormalities.
- 287 (9.2% of total) were aged 1–4 years.
  - Causes in this age group were: accidents 68 (23.7%), congenital malformations and chromosomal abnormalities 53 (18.4%) and malignant neoplasm 47 (28.8%).
- 163 (5.2%) were aged 5–9 years,
  - 47 (28.8%) were due to malignant neoplasm, 34 (20.8%) due to accidents.
- 242 (7.8%) died aged 10–14 years,
  - 47 (19.4%) due to suicide, 46 (19.0%) due to malignant neoplasm, 44 (18.1%) due to accidents.

- 687 (22%) were aged 15–19,
  - 232 (34%) were due to unintentional injuries, 185 (27%) were due to suicide.

In both the neonatal period and later, most deaths occur in hospital and most follow withdrawing or withholding a life-prolonging intervention. These causes of death in western countries contrast sharply with the situation in developing countries where there is a continuing high incidence of death due to infection.

10.2 Children and Families Need to Know

It is important to state that not all patients and families know that the child is dying because they are not always told. Dr. Rebecca MacDonell-Yilmaz (2015) describes her experience as a medical student when, in the autumn, she met a 15-year-old girl with metastatic cancer. Although an X-ray revealed new, multiple lung metastases, the girl and her mother were cheerful and were planning to shop for a prom dress for the spring dance. At a unit meeting one of the nurses asked, "Isn't it time to have the difficult discussion?" The chaplain had a discussion with the family, but it is unclear what was said. Later, the mother was in the hallway asking why palliative care was being discussed. She said that her daughter is a fighter and the physician had not previously mentioned stopping active treatment. The child died before Christmas. The question for an observer is, "How could the parents be planning for the girl's spring prom when her healthcare providers suspected that the teen would likely be dead before Christmas?" Why didn't the physician tell the family?

Communication can break down near the end of life. In this case, when the nurse asked about telling the family the poor prognosis, there were murmurs of agreement but no volunteers. A nurse practitioner said, "The attending doesn't like those conversations, […] He avoids them until the very end." The nurse practitioner apparently did not like them, either. As MacDonell-Yilmaz (2015) writes, "Nurses fiddled with stethoscopes. Residents glanced at their watches."

Thus, through a combination of avoidance and misunderstanding, pediatricians can fail to equip patients and their families with information and options that might affect the way the patients choose to live and to die, or their parents make those decisions for them. As MacDonell-Yilmaz (2015) writes, she has seen how physicians "suitably sugarcoated, danced around, or outright avoided these topics". Of course, some families cannot conceive of any outcome other than a cure. Some of the strategies used by physicians to stay away from meaningful discussion are to focus on curative treatments even when they have become very unlikely to work, to avoid discussing palliative care until time is short and to allow their own insecurities to affect their interaction with patients and families. This is a hard situation for physicians. But it is ever so much worse for families, and physicians can help by offering the gift of the truth.

Decision-makers, almost always the parents, should understand all options. However, they can achieve understanding only with our help. Communication must be honest, open and continuing. Conversations should be conducted in such a way as to help parents and children develop a clear understanding of what is happening. We understand that some parents might find it impossible to conceive of any action that will not lead to complete cure. Nevertheless, physicians must give the evidence of the diagnostic tests and our best clinical judgment.

As we have said, such communication is difficult. Breaking dreadful news to parents is perhaps the hardest part of the pediatrician's job. Nevertheless, it must be done. Trainee pediatricians should watch it be done. They must have an opportunity to observe skilled practitioners interact with families and children and have time to reflect on what they are experiencing. Before they break such news to families themselves, trainees can practice by interacting in simulation scenarios. It is critical that trainees develop the skills needed to helping parents and children as a child approaches death, during the dying process, and afterwards.

Of course, trainees are affected by such situations themselves. In Sect. 10.20 below, we discuss such effects and methods of minimizing trainee suffering.

10.3 Choices Are Rarely Wrong

When parents (and children if mature enough) are making their choices about end of life care or continuing interventions clear to us, in general we would not consider any choice to be really wrong. We might find many choices uncomfortable, but if decisions are based on full information that is understood, in general we will support families. However, the phrase "in general" is very important. If choices are very far removed from reality, or if they will cause the child extra pain or discomfort, then we would help the parents find another approach.

If we disagree with the parent's choice, then the first consideration should be the child. If the choice causes or prolongs suffering, then we need, in the first instance, to work with the parents. We can ensure that there are supports for the parents such as family members and hospital staff including social workers. We must continue to be supportive, and communicate clearly. We can use the technique of "nudging" described in Chap. 4 "Consent". We can use other resources such as ethics committees to help. The families might become confrontational, but we must not be. We can legitimately refuse to escalate interventions when we believe the end is near and the child is suffering. However, unilateral action by healthcare teams to withdraw a life-prolonging intervention should not be done. Disagreement with a parent's choice that is so extreme that we feel we must act to oppose the choice is very rare; involving legal remedies must be a last resort because there are usually better ways to address the conflict and the legal system, which is adversarial by nature, locking people into opposing positions that prevents collegial and common focus on the child's best interests.

Sometimes parental choices might seem odd to the doctors involved. The choices made by Gabriel's parents in this story certainly did, but they caused no discomfort to the child.

10.4 Gabriel's Story

Amy Kuebelbeck was pregnant with her second child. An ultrasound at 25 weeks disclosed hypoplastic left heart syndrome. There was a meeting with the obstetrician and a cardiologist, and the possibilities for treating the child after birth were reviewed. The possibility of termination was also discussed. Amy and her husband asked if they could have time to think about these options and arranged to meet the cardiologist and obstetrician again in 48 hours. During that time, the prospective parents had many discussions. They felt they did not want any of the surgical options for their son. But neither did they want to terminate the pregnancy. They wanted to hold him after birth, even if he was going to die.

At the next meeting, they conveyed that opinion to both the obstetrician and the cardiologist. Both professionals were surprised because they had not met a parent who wanted to continue the pregnancy but did not want active surgical interventions. The professionals agreed to help with the request. Amy and her husband assumed that they might have a week or so during which they could hold their son.

Gabriel Kuebelbeck Neuzil was born alive but lived only two- and one-half hours.

10.5 Comment on the Choice to Labor and to Deliver Knowing a Child Will Die

This story is true, well documented (Kuebelbeck 2003), and probably helped to change the thinking of many practitioners of obstetrics, cardiology, neonatal pediatrics and indeed ethics. Prior to this case, many physicians assumed that, given the choice of caring for a child who would need multiple cardiac operations when many of the operations would only palliate the symptoms, some parents would choose to consent to the surgeries. Other parents would choose to terminate the pregnancy, perhaps thinking that the fetus, once born, would have a very painful and uncomfortable life. Yet, the parents here took an unexpected, third option. They wanted to see and to hold Gabriel, however briefly and when he was still alive, and thus the pregnancy continued until spontaneous, natural labour started. The parents had hoped that they might be able to spend a few days with their baby, but in fact they had only 2 h. From this episode, and the brief life of the child, the concept of perinatal hospice, not in itself new, grew and developed. The language used by the woman was "hospice in the womb" (Collier 2011).

Amy Kuebelbeck created a website, "Perinatal Hospice and Palliative Care" www.perinatalhospice.org, with helpful information for interested parents, including a list of hospitals that supported the concept. Ms. Kuebelbeck co-authored another book (Kuebelbeck and Davis 2011) that told the stories of 120 women who had a pregnancy with a fetal anomaly and an expectation of neonatal death, or stillbirth. Many of these women were helped, but others had obstacles placed in their way by physicians who did not understand continuing a pregnancy when the sad end was inevitable. "Physicians are trained to do something", says Kuebelbeck. "Termination feels like doing something. They may think that's the best way of helping." (Collier 2011).

The action of physicians when faced with this new situation was discussed in a peer-reviewed article (Hoeldtke and Calhoun 2001). Until the advent of advances in prenatal ultrasound, infants with hypoplastic left heart presented with sudden collapse in the first week of life. Now "the suddenness of a surprise death was replaced by the suddenness of a surprise diagnosis". In the US, legal abortion had become widely available at about the same time as these accurate prenatal diagnoses became available. Hence, the recommended course of action by physicians when a so-called lethal anomaly was detected during pregnancy came to be termination of pregnancy.

The pregnant women interviewed saw things differently, and the intensity of their grief after termination was similar to that of mothers whose child had died as a neonate. But these mothers (and fathers) were without the comfort of holding their infant while it was still alive. We hope all women given a diagnosis of a lethal anomaly in the fetus will be given full support for all choices, including palliative care in the neonatal period.

10.6 Riley Redux

In Chap. 1, Sect. 1.3.2, we told the story of the premature infant, Riley. There was conflict and Riley's situation was discussed in a formal ethics consultation. We remind you of the story and continue it here:

> *Riley was born at 23 weeks' gestation and required intubation and assisted ventilation at the time of birth. He was the first child of parents in their late 30s, who had had three earlier pregnancies each ending with miscarriage early in the second trimester. Riley had a number of complications including intraventricular hemorrhage grade 4, necrotizing enterocolitis requiring surgery and several episodes of sepsis when he was given intravenous antibiotics. His mother was at the bedside every day, and at the weekend, both parents spent time in the NICU. Numerous attempts were made to wean Riley from ventilation, always unsuccessfully.*
>
> *The neonatal staff asked for a formal meeting with both parents and asked the unit social worker also to attend. At that meeting, the staff reviewed the very poor progress, that Riley was very unlikely to survive, and that they would like the parents to consider withdrawal of the ventilation. The staff also mentioned that there was a palliative care team, that attention will be paid at all times to Riley's comfort, and the support was available for the family.*

10.7 Comments on Riley

We hope that when Riley was born and admitted to the NICU, that the very first thing that happened was that the staff established a positive relationship, initially with the mother, then with the mother and the father. Issues of relationships are

extremely important in any sensitive issue. Then, we hope that the staff would have been very honest at all stages with the parents, and at the same time displaying compassion. This combination of skill in communication and compassion are essential companions in working with families. The many issues that would have arisen in Riley's short life would be about particular interventions that might be used, if and when they might be stopped, and when the support of a palliative care team would be offered.

The discussion here is about withdrawing an intervention. In most discussions among ethicists, the issues of withdrawing and withholding an intervention are seen as moral equivalents. They might be. Yet for physicians, and healthcare professionals in general, withholding in some ways is an easier option than starting an intervention then discussing stopping it with parents. If something is not done, then the issue of undoing does not need to be addressed. The parents, however, might see the issue quite differently. They might be comforted that a great deal of effort and skill was used in Riley's care. Having seen that skill and compassion, the parents might be more willing to consider withdrawal of the intervention if there is no longer a reasonable chance of Riley's survival. The challenge for the physician is to recognize the need for attending to the suffering of the parents while not taking steps that might harm, or prolong the dying of, the child.

Communication is key. If the trainee is involved, then we hope that she or he continues in the same way as the staff pediatrician and the other staff, by communicating honestly and openly with the family. The trainee will not be the one interacting directly with the family when decisions must be made about withdrawing an intervention. However, the trainee should gently repeat information that the parents might not have fully heard or understood before. The trainee should ensure that he or she is included in important meetings and observe the sequence of events very carefully.

If the parents agree to withdraw the ventilation, then they will receive a great deal of support from a palliative care team. If Riley dies, then there should be a meeting after the death to review his care. This meeting should include all staff and is for quality assurance and to identify areas where care might be improved. We believe this meeting should focus on issues of communication as well as medical issues.

An issue that is always relevant is the impact of the infant or child's death on the staff, including the trainees in pediatrics. In a story told by Crowe (2017), a child who has many similarities to Riley affects a pediatric fellow in the PICU. After the child dies, the PICU fellow "feels a sense of emptiness and is unwilling to engage with other patients and their families." Crowe describes this as "disenfranchised grief". When a child dies, we recognize fully the intense grief of the parents and arrange support for the families. But when a child dies, the staff who have provided care will also have a sense of grief. This grief is important to acknowledge, and also requires support and recognition. It will be discussed in greater detail below in Sect. 10.20.

10.8 Palliative Care

Palliative care has been a recent development in medicine overall, and an even more recent development within pediatrics. The World Health Organization (WHO) (2018) describes palliative care as:

> an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual. Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death.

Palliative care in adults was once synonymous with the period when end-of-life was near. That was not and is not the case in pediatrics. Palliative care in pediatrics is certainly about children in whom death might occur before they become adults. This medical specialty also aims to help children living with chronic life-threatening illnesses. At one stage in adult palliative care, there was a sharp barrier between palliative care, and treatment aiming to cure the patient. All curative treatments must be discontinued before palliative care could begin. Again, that sharp boundary was never present in pediatrics, and palliative care can be initiated even as treatment intended to cure continues. Palliative care continues for the life of the child, and carries on after death with bereavement support for the family.

Earlier in this section on End of Life, we addressed causes of death. Modes of death are also important. In the time before death, there might be periods of acute decompensation, with some recovery, and acceptance of a new life. There might be acute decompensation with full recovery, or acute decompensation with death. Some children have a slow decline. In the case of Riley, death might occur as a result of a thoughtful decision to withdraw life-prolonging aspects of his treatment.

Riley would experience palliative care from a whole team of which the pediatrician is one member. The team's focus is on symptom management to improve the child's and the whole family's quality of life. Pain might be the most prominent symptom to be relieved. Other symptoms include nausea and vomiting, constipation, anxiety, dyspnea, excessive secretions, and feeding issues.

Palliative care teams focus very strongly on communication with both the family and with the child. When issues of death and dying are discussed with children, whether the child patient or siblings, then the person who is speaking to the child must be aware of children's developmental understanding of death.

10.9 Metaphors and Miracles

Throughout Riley's stay in hospital, metaphors will undoubtedly be used. The metaphors are many, and most are quite unconscious. If he is prescribed antibiotics, then he might be said to be "covered with antibiotics", as if these drugs were another

duvet. Another commonly used metaphor in medicine generally, and in intensive care units particularly, are the military metaphors of fighting. Riley might have had periods of acute decompensation, then showed a degree of recovery though not to his baseline. Some of his professional caregivers, or perhaps his parents, will express the satisfied statement that this degree of recovery occurred because he is a "fighter". We do not disagree with the use of metaphors; they are embedded in our everyday language. A study that reviewed metaphors (Tate and Pearlman 2016), presented evidence that metaphors might improve communication. (If the reader is interested in a short but amusing vignette on metaphors, we suggest they consult the paper by Hodgkin (1985).)

Most parents understand that metaphors are, well, metaphors. From time to time, some parents will regard the military metaphor as a literal statement. Then, problems can arise. If having a child in intensive care means that we are at war, then who is the war against, and who or what will be the winner? Taking metaphors seriously changes the whole tenor of the dialogue. There is an easy transposition by which the enemy ceases to be the disease and becomes instead the physicians because they are suggesting some form of limitation of treatment. The parents might then see the battle as one to overcome the physicians and to ensure that their child continues with whatever intervention was being used. We are not sure how to handle this overuse of metaphor. We suggest that when we see metaphors dominating the discussion, rather than just being an illustration of the situation, that we at the very least stop using this language ourselves.

Another word that is grossly overused about children in Riley's situation is that there will be "miracle", or that survival to this point means that there has been a "miracle ". While perhaps not a metaphor, the term "miracle" might have similar consequences in its overuse. Again, we accept the reality that the word "miracle" is used to suggest that something extraordinary has occurred. We understand this use; however, we regard the word "miracle" to mean something apart from reality. The existence of a miracle implies some supernatural intervention. Yet the interventions that occur daily in intensive care units and that result in "miracles" are in fact the application of medical knowledge and modern technology with incredible skill and dedication by the healthcare staff. We follow the lead of the philosopher David Hume (2016) when writing about miracles. He said miracles, if they occurred, would be a "violation of the natural order".

As with military metaphors, the word "miracles" will continue to be used extensively. When "miracle" is no longer a word to describe some amazing phenomenon of modern care and compassion, but a word that is used to delay the limitation of treatment intervention while we wait for a supernatural event, it can be difficult to engage parents in meaningful discussions. In speaking with parents about limiting treatment, or even simply discussing a prognosis, it is easy to understand why parents would want a miracle for their child. Who wouldn't? Perhaps we can be careful in our use of the word "miracle: and if we cannot avoid using it, then at least use it in strictly limited situations.

10.10 Costs

Cost is an important issue in end of life care, even if it is rarely mentioned. Our chapter on resource allocation (Chap. 15) tends to focus on costs at a population level; costs are not usually addressed at an individual level. We do not intend to suggest in any way that the treatment of any particular child should be limited because of cost. However, it would be naïve not to understand that extensive care of children at the end of life in the intensive care unit contributes greatly to healthcare costs. Whatever the system of healthcare, there will not be unlimited resources. Money spent on one child might mean that another child does not receive a useful intervention. Refocusing our efforts toward comfort care at the end of life and away from multiple interventions of doubtful value to the child might simultaneously improve care for the individual child and allow reallocation of resources towards helpful interventions for other children.

There are many studies of how much is spent on adult patients near the end of life, but few in children. One study of resource use in children at end of life by Widger et al. (2017) reviewed demographics, location, cause of death and health care use and costs in Ontario, Canada of children aged 1 month to 19 years. The study was conducted over the 3 years, 2010–2013; of the 1620 children included, 41.6% died of a chronic disease. Over the last year of life, the median cost was CDN $18,450 yet the mean cost CDN $78,052. In other words, some deaths are extraordinarily expensive. For children with chronic illness or perinatal or congenital illnesses, cost nearly tripled over the last 4 months of life. Two thirds of the costs were in acute care settings, with almost 90% of children with a congenital illness, and 80% with a chronic illness dying in acute care. Of major note, only one third of children received home care in the last year of life.

This was a study of health care data that does not provide details of what happened and why. However, it does suggest that care at the end of life might have been preoccupied with interventions rather than the child's comfort and the parents' solace. Would a focus on comfort care be less costly? We will never know, but if so, then such a conclusion does not deny any one individual child any specific item of treatment. It moves us towards providing more appropriate and compassionate care. Such a positive result in terms of the child's comfort might occur with a reduction in societal spending.

10.11 Brain Death and Organ Donation

In the past, death seemed simpler to determine. As far as we can tell, human societies have recognized death and had ceremonies to honour the dead. The ancient Homeric poems, the Iliad and the Odyssey written perhaps in 7000 BCE described in great details burial rituals and the afterlife (Department of Greek and Roman Art 2018). In more recent (!) times, "Roughly 5,300 years ago, a group of ancient sheep

herders in East Africa began an extraordinary effort to care for their dead." (Weintraub 2018). These sheep-herders dug deeply to bedrock to create graves for men, women and children. Their dead were often interred with personal ornaments the ceremonies depended on the fact of death, generally determined by the cessation of all activities, particularly the cessation of cardiac activity. Merriam-Webster's dictionary defines "death" as "a permanent cessation of all vital functions". (Death 2018)

In the 1960s, two contemporaneous developments in medicine occurred to change the lives of some patients. The first was the increasing ability of intensive care equipment and skills to keep people alive for extended periods, even if they have little or no neurological activity. The other trend was the development of the ability to transplant organs. Given that intensive care can support almost every organ in the body, except the brain, there was speculation that organs (at the time, kidneys) could be removed from individuals who were dependent on ICU care and transplanted into a patient with kidney failure. The questions were, how was this to be done, and was it legal and ethical?

A group of individuals published a foundational paper in 1968 to describe something they called "brain death", and outlined criteria justifying that this is death. The primary purpose of this group was "to define irreversible coma as a new criterion for death". They defined the characteristics of a permanently non-functioning brain. They believed that this situation that could be determined clinically, and that the diagnostic criteria should be repeated more than once. The specific criteria have varied with time and might vary from one country to another. In addition, some intensivists support conducting ancillary tests such as electroencephalogram (EEG), angiography, and others see them as unnecessary. We accept that "brain death" is a valid construct, and that the patients who are brain-dead are dead. We advise pediatric trainees who are involved with brain-dead patients in the ICU to consult current literature on the best means of establishing whether a patient has experienced brain death.

One concern regarding the criterion of "brain death" and using organs for transplantation is that the criterion is more about the potential recipient than about the comatose patient. It is true that if we had not developed the ability to transplant organs, and thus the need for available functioning organs, then the detailed literature on brain death would not exist. These patients would have been in the ICU, would be recognized as having an irreversible condition, and discussions with the family would focus on the irreversibility, and the wisdom of withdrawing ventilation and allowing the heart to stop. However, many people believed that burying or cremating functioning organs would not be as wise as moving the organs to a person whose life might thereby be saved. Such movement might also bring some comfort to the deceased person's family.

The concept of brain death has been accepted as valid in children even though some have raised arguments that the developing brain might overcome brain death. With the exception of preterm infants, brain death can be diagnosed in all children from term newborns and infants to children and adolescents; it is "a clinical diagnosis based on the absence of neurologic function with a known irreversible cause of

coma." (Nakagawa et al. 2012). The various qualifications are described in the paper by Nakagawa et al., including ensuring that that any reversible conditions have been addressed, the child is not inadvertently sedated, that more than one physician is involved in the examination, and that detailed examination should be done more than once, by different clinicians. If all criteria are met and the conclusion has been reached each time that the brain is dead, then the child can be declared "brain-dead".

It has always been surprising to one of the authors (IM) that parents, when faced with their child in the pediatric intensive care unit, with respiration supported by ventilator, but of normal temperature, and a good colour, are almost always willing to accept the diagnosis of brain death. True, there will be some parents and some groups who refuse to accept the very concept and will refuse to allow ventilation to be withdrawn. We need to understand their reasoning, before we can help. One explanation might be that they had been misinformed before they met the physician. Jones et al. (2018) reviewed Google web sites and YouTube videos giving information about brain death. Inaccuracies were frequent and sometimes coupled with negative comments about physicians. Coma, persistent vegetative states, brain death and death, were not distinguished. In any discussion about brain death with families, physicians should always ask about what family members know already, and how they received the information.

Parents with a child in the ICU usually are already aware of the possibility of organ donation. They might be comforted by the phrase: "something good can come from something bad". Nevertheless, this is a situation where there must be great attention paid to the details of communication, and to the provision of support for the family. Prior to a definitive diagnosis of brain death, the family should be told that brain death is being considered, that there are very strict criteria, and no action will be taken until these criteria have been identified more than once and by more than one physician. The families might want to meet with a transplant coordinator who can describe the process of determining whether the child has experienced brain death and will have experience in discussing organ donation with families.

There are potential conflicts of interest in the whole process of donation after brain death. Some physicians might assume that because one patient is destined to die, whether organs are removed for donation, and that another could be saved, then we should move quickly. There will be temptations to take shortcuts. One principle underlying organ donation after brain death is that the donation should not cause or hasten death. It is important to ensure that more than one physician is involved in assessing that the patient meets brain death criteria. The absolute rule should always be followed that any physician caring for a potential recipient should never be involved in caring for the potential donor. A safeguard has arisen accidentally in that hospitalized patients are usually looked after by more than one team (multidisciplinary), meaning many people are involved, and relationships between disciplines and within disciplines are less hierarchical. These developments make it increasingly difficult to hide unethical behaviour. However, such hiding is not impossible, and so there must be constant vigilance. The benefit to someone in end-stage renal failure of rapid transplantation should not trump the care of someone, even someone with suspected brain death, to caring and skillful consideration.

In discussing the situation with the family, a compassionate physician might inadvertently use language that is very confusing. If the patient is brain-dead, then the patient should be spoken of as dead. If a physician, in discussion with the family, says something like your child is "unlikely to recover", then this statement takes away from the certainty of what will happen when ventilation is discontinued in brain-dead patients. Similarly, if phrases such as "he will die after the organs are taken" are used, then previous statements that "brain death means death" have been contradicted. It might seem hard, but every word matters when we are communicating about very complex and sensitive issue with distraught relatives.

10.12 Organ Donation After the Circulatory Determination of Death (DCDD)

The concept of brain death was a revolution in medical, ethical and legal thinking, but it seems to have been a peaceful revolution. The concept became widely accepted very quickly. However, the demand for organs for transplantation exceeded the supply of organs available for donation after brain death. People then considered as donation candidate patients in the ICU who would not recover, and that the ICU treatment was therefore "futile". The question arose, "Why not find a way to harvest organs from these people?" The name applied to this in the first instance was "cardiac death", but subsequently the longer title given above came into use: donation after circulatory determination of death (DCDD).

Bernat and Robbins (2018) tell the story of a 21-year-old woman who suffered severe head trauma in a motor vehicle incident, which illustrates the process of DCDD, and some of the obvious concerns. After the injury, she was immediately ventilated. But after several days in the ICU, there were no signs of her recovery. There were still some brainstem reflexes and therefore she could not be considered brain-dead. The family understood the devastating prognosis and asked about organ donation. The team members discussed "cardiac death", what we now call DCDD, with the family. They told the family that she would be taken to the operating room, where she would be extubated, and vital signs monitored for the next 60 min. If, and only if, her heart stopped, and still remain stopped after 5 min, then irreversible cardiac death would be declared. Organ procurement would then begin. If after 5 min her heart was still beating, then she would no longer eligible to be a donor because the ischemia would have made her organs unusable. She would then be given hospice care. This process requires coordination of the ICU team and transplant teams and can obviously result in significant disappointment to the proposed recipient and possibility also to the proposed donor's family.

This process is described as "controlled" DCDD. "Uncontrolled" DCDD is carried out in some European countries, particularly Spain where the law presumes consent for organ donation. There, people who have a cardiac or respiratory arrest, and do not survive resuscitation, will still be intubated and ventilated, have cardiac compressions and intravenous fluid continued. The relatives will then be approached

for consent for donation. The issues of informed consent, as understood in the US, UK and other countries make the process of "uncontrolled" DCDD nearly impossible.

To return to our 21-year old patient whose relatives have asked about organ donation, we must consider ethics issues. The informed consent process must be conducted very carefully, especially because we have already established that in the case described above, the relatives and friends are keen that the patient who is about to die becomes an organ donor. The prognosis must be established without doubt. This is in contrast to brain death, where there is certainty in the prognosis; the patient who is dead will die in every sense of the word shortly after the ventilator is discontinued. When we are contemplating DCDD, the neurological prognosis might not be quite so certain. As in donation after brain death, the team caring for the potential donor and the team involved with organ donation must be entirely separate.

10.13 Scarlett's Story

Scarlett is an athletic 16-year-old girl who enjoyed downhill skiing. She skies in familiar mountain resorts most weekends with her family. On spring break, she went with a friend and the friend's family to a well-known ski hill in a distant resort. Near the end of the day, Scarlett skied too rapidly, lost control and collided with a tree. Help was available almost immediately, but she was already unconscious. Scarlett was taken to the bottom of the hill and transported by helicopter to a pediatric trauma center 40 kilometers away. The transport team had intubated her and started assisted ventilation. On arrival at the trauma center, Scarlett was assessed, and taken to the pediatric intensive care unit. It was clear she had a severe neurological injury.

Her friend's parents phoned her parents to tell them about this tragic turn of events. Scarlett's parents travelled to the pediatric ICU to be with their daughter. Scarlett had a 10-year-old brother, Logan, who stayed in his home where his grandparents went to be with him.

The physicians met regularly with the family to ensure they were up-to-date with the progress, or perhaps lack of progress. Over the course of 4 days, there was no evidence of improvement; all the tests confirmed brain death. The tests were repeated 24 hours later, and the results were unchanged. The physicians met with Scarlett's parents to discuss the whole situation, the reasons they had decided she was brain dead, that this finding meant she had died, and they asked the parents to consider the possibility of organ donation.

10.14 Comment on Scarlett's Story

This family went from having a vibrant and energetic daughter who was in the outdoors with friends, to receiving the sudden news that they had to drive to hospital in another town while fearing that their daughter was likely to die in the very near future. Whoever meets the family in the ICU and addresses issues that arise there must keep the suddenness and seriousness of this situation in the forefront of their mind. As stated above, every word matters when we are communicating about very complex

and sensitive issue with distraught relatives. A vital duty of medical team members in the intensive care unit is to ensure that they develop a compassionate, honest, open and trusting relationship with the parents. The parents and all of the ICU staff, including physicians, meet as strangers, but immediately are in an intense relationship dealing with intimate details of parenthood and family life. In every interaction, staff need to ensure that they tell the family what is happening, and that they are honest, without being brutally negative. The parents will direct many questions to nurses and therapists at the bedside. However, there should be regular meetings away from the bedside with the parents and physicians, usually with at least one other staff member, likely a nurse. The meeting should take place in a quiet room; the physicians should deliberately leave their cell phones and pagers with someone else. Provision of support for the parents is essential. Support needed is both emotional and instrumental. Where will the parents stay? Who will explain brain death to the sibling? These are only two of the many other immediate problems that need solving.

When brain death has been confirmed, then the ICU staff will contact the transplantation team. That team is in the best situation to detail the various options, and to explain what would happen if the parents consented to donation of their deceased daughter's organs. Depending on the jurisdiction in which the injury happened, there might be a need to notify a coroner or medical examiner. Typically, these legal authorities are supportive of transplantation, but to avoid any difficulty, they should be told what is taking place.

The parents might wonder who exactly will receive their daughter's organs. Typically, precise information (such as name and address) is not released, because of anxiety that the family of the deceased might make too many calls to the recipient and his or her family. Having said that, occasionally the identity of the recipient becomes known (and might increasingly occur because of social media), and relationships can develop between the family of the donor and the family of the recipient and the recipient himself or herself. Typically, the donor's family is told some information about the recipient but not his or her identity.

There is no doubt that all the professionals involved, and that members of society in general, are supportive of organ retrieval from brain-dead individuals. This general support does not mean that there should be shortcuts taken in the process of receiving fully informed consent from the family. The process of seeking and receiving consent must be conducted very carefully, with respect to the autonomy of the parents, who will be the decision-makers.

10.15 When a Child Dies At the Hand of a Caregiver

This chapter opened with some stories of childhood deaths announced by headlines in the media. Among the stories were homicides, and we pointed out that homicide is a rare cause of death in childhood. Having said that, homicide does occur, and the emotional impact is great on the public, and is likely to be major as well on any pediatric staff who cares for such a child as the child dies.

If the death of a child at the hand of a caregiver seems particularly horrific, many legal jurisdictions have special laws when the perpetrator is the mother. These laws create an additional crime called "infanticide", and in general the penalties are less for death caused by her mother. None of these laws apply to fathers.

Homicide of a child is most likely caused by a parent. In a report, based on the Kansas Child Death Review Board (Kajese et al. 2011), there were 170 child-abuse homicides from 1994 to 2007. Just over half (55.9%) were female, but of those killed in the neonatal period, two thirds (66.7%) were male. Most were under 2 years of age. The perpetrator was the biological mother in 24.9%, and the biological father in 26.6%. The commonest cause of death was head trauma (42.9%), asphyxia (21.8%), penetrating injury (13.5%), blunt abdominal trauma (8.2%). There was often a background of marital discord, previous child abuse, and substance abuse. The trigger was not always known, but inconsolable crying by the child was seen as one trigger.

Very similar results were seen in the review from France, in the period 1991–2008 (Makhlouf and Rambaud 2014). Whereas the Kansas report was of a multidisciplinary board, the Paris, France report was from the pathologists who investigated child death. Again, most deceased children were under 2 years of age (61.4%). Some additional information in this study is that the death of older children was more likely to be multiples, and to be associated with murder suicide. The perpetrator was the mother in 24 cases (34.3%), and the father in 27 cases (38.6%). The commonest cause again was head trauma (37.2%), gunshots (21.4%) and asphyxia 21.4%). Most (68.6%) occurred at home.

10.15.1 Russell's Story

Dr. Mark Alimba was a senior resident on a rotation in the PICU. The PICU staff physician Dr. Jocelyn Adams was talking to a parent, and Dr. Alimba was asked to hold Dr. Adams' pager so that she would not be disturbed in a sensitive conversation with parents of a patient. Dr. Alimba was of course told that if there was an emergency, he should interrupt the conversation, though the desire was to keep it uninterrupted, if at all possible. The pager went off. The emergency dispatch centre called reporting that a nine-month-old child was at that time in an ambulance on the way to the hospital. The parents had called the emergency number to say the child had suddenly collapsed, and when the paramedics reached the home the child (Russell) had no vital signs. They started resuscitation and an IV and set off for the hospital with a police escort, which was hastening the arrival of the ambulance, and bringing the mother.

Dr. Alimba interrupted Dr. Adams' meeting with a parent, and both physicians headed to the trauma bay in the emergency department, where a team was already on alert.

On arrival the child, Stephanie Williams, was as described, but there was now spontaneous heartbeat, though blood pressure was low. Ventilation was continued. The paramedics told the hospital staff that they had noticed an occipital injury and Stephanie's mother had said that this was due to a fall. Stephanie was taking to the intensive care unit; the neuro-critical care specialist was consulted, and a plan of action developed.

Shortly after Stephanie reached ICU, her mother, Vivian arrived accompanied by the police. The nurses gave Vivian a brief update, but much was happening at Stephanie's bedside, and the nurse was unable to be there immediately. CT scan confirmed an occipital fracture and marked cerebral edema. The neurosurgeon on call was informed but indicated that surgery would not be considered at that time.

Over the succeeding two days and despite everyone's best efforts, the cerebral edema did not change, there were occasional periods of heartrate dips to the 40s, and an initial brain death assessment performed. There had been frequent discussions with the mother over Stephanie's progress, but there was a constant police presence. It was clear that the police strongly suspected that the mother had caused the injury. Certainly, it was the view of the medical staff that this injury was not due to a fall, an opinion sustained by the Child Abuse team.

At this stage, it was appropriate to discuss organ donation. Dr. Adams, after a period of duty, was again on call when this discussion had to take place. She decided to request legal advice and was advised to speak to the mother who, though a suspect in the injury, retained the parental authority to make decisions for her child.

After an appropriate time interval, another assessment confirmed brain death. Vivian agreed to organ donation, and Stephanie's organs were removed for donation.

Shortly afterward, the police charged Vivian with causing the death.

Dr. Alimba had been present in the ICU on a number of shifts during Stephanie's care, and could not get out of his head the fact that her mother had probably killed her. He did his best to be supportive to the mother, and to suppress his feelings but he found it difficult. The nurses and therapists in the PICU, similarly tried to support the mother, but found it very hard.

10.15.2 Comments on Stephanie's Death

There will be an atmosphere of tension in the PICU throughout Stephanie's admission, in the immediate aftermath of her death, and likely in the long-term aftermath. Despite knowing there is a high likelihood that Stephanie's mother was the perpetrator, staff will still try to find ways to support her. This may be a heavy emotional burden, particularly on the nurses who are at the bedside minute-by-minute throughout the day. The staff will be trying to suppress their anger, as they try to support the mother. They might understand some of the factors that underlie parental homicide in general, such as a background of childhood abuse of the perpetrator, mental illness, substance abuse, or partner abuse. Even as they understand that these might be factors, they might not see them as reasons to hurt the child. They might wonder why Stephanie's mother did not reach out for help before she hit Stephanie. Specific support needs to be provided for all of the staff, including the pediatric staff and trainees throughout this period.

When it comes to making decisions about continuing or stopping Stephanie's treatment, the criteria for brain death, or indeed withdrawing ventilation for other reasons, and for considering organ donation should be the same whatever the cir-

cumstance that led to the brain injury (Arias and Weise 2012) and (Ellingson et al. 2012). Given the complexity of the legal situation, the PICU physicians should seek advice from the hospital ethics committee, the hospital legal department, and their own legal advisors. They should also involve the coroner or medical examiner. Although the coroner or medical examiner is perhaps not legally involved until the child dies, they might be concerned about the preservation of evidence during organ donation, and their cooperation and help should be sought.

The mother retains the legal ability to make decisions for Stephanie. There have been situations where parents whose actions have led to a child's death have opposed withdrawal of life-sustaining therapy, because the continued maintenance of the child's bodily functions would have prevented a charge of murder being brought against the parents (American Academy of Pediatrics et al. 2000). If such a situation arises, again legal advice should be sought to seek an alternative guardian for Stephanie.

It seems wrong to have some kind of hierarchy of deaths, but from the observation of the authors such deaths cause much more distress to PICU physicians and staff than deaths due to other reasons. This fact needs to be acknowledged, as we mentioned in the introduction to this section, by provision of extra support for the healthcare team that must continue over time.

10.16 Medical Assistance in Dying

Medical assistance in dying gives rise to two issues no matter the age of the patient. The first issue relates to language use. The practice of helping a patient to die when suffering intolerably from a terminal condition is a practice variously described as "euthanasia", "physician assistance in dying", or sometimes "physician-assisted suicide". "Euthanasia" translated literally from Greek means a "good death" and has been classified as passive euthanasia and active euthanasia. Passive euthanasia refers to death after a life-prolonging intervention was withdrawn – a phrase that is no longer used. We now consider withdrawal of assisted ventilation and allowing a natural death as a humane act and not something to be criticized. The cause of death is the underlying disease that led to the use of the life prolonging intervention, not the withdrawal of the intervention. Active euthanasia is defined as "The painless killing of a patient suffering from an incurable and painful disease or in an irreversible coma ". Again, the language has changed; the single word euthanasia is used. Physician assisted suicide means giving the patient a prescription that the patient then self-administers to commit suicide. The language of "medical assistance in dying" includes suicide, and also includes physicians administering a toxic substance to end a patient's life.

The second issue to which medical assistance in dying gives rise is related to history. While euthanasia of infants might have been considered appropriate in

ancient civilizations, it is no longer considered as such. However, the concept that it could be correct to withdraw a life-prolonging intervention is a new concept. An article in the 1970s described infants in the neonatal intensive care unit in Yale-New Haven Hospital who died after therapy was withdrawn (Duff and Campbell 1973). The article led to much public discussion and criticism even though what took place was never unreasonable. A quite different case during the same era also caused anxiety but what transpired was incorrect. Three infants with trisomy 21 had life-threatening intestinal obstructions, something that could be readily treated surgically. The physician and parents allowed two of them to die. These infant deaths became known and led again to public and professional discussion (Pence 2007).

Euthanasia of newborns is an alien concept to many, but it is a common discussion in the western world. There was great consternation when a protocol was released in the Netherlands to permit euthanasia of newborns, the so-called "Groningen Protocol" (Verhagen and Sauer 2005). When the protocol was first announced, there was doomsday-like concern that there would be very rapid increase in the number of infants deliberately killed. Verhagen (2013) explored what happened after this protocol was introduced. In fact, his data showed that there were only two cases in 5 years. What really happened was that antenatal screening improved dramatically around the time the protocol was published and there was a considerable increase in terminations of pregnancy. Therefore, many infants with significant morbidity were not born.

Medical assistance in dying (known in Canada by the unfortunate acronym "MAiD") is now legal in a number of countries. It is permitted in minors only in the Netherlands and in Belgium. The Belgian law refers to minors "who possess the capacity of discernment". MAiD became lawful in Canada in 2016. Whether it is permissible in minors is a subject under consideration. The ethical arguments in favour of allowing mature minors access to MAiD include respect for the autonomy of the minor, and beneficence (Cuman and Gastmans 2017). If MAiD can be available to a competent 25-year-old or 30-year-old, then why should it not be available to a competent 15-year-old? We have written elsewhere (Guichon et al. 2016) in support of a change in the law of Canada to permit MAiD for competent minors. We estimated that in any 1 year no more than 8 individuals aged over 14 years in the whole of Canada would be approaching death in a way that made MAiD a reasonable request. We also suggested that there be a variation in the usual approach to teenage decision-making. In most medical situations, the decision making is an either-or situation. If the minor is deemed "mature" then he or she will make decisions. Conversely if the minor is not deemed "mature", the parent will make decisions. However, in the case of possible MAiD, the minor would have been embedded in the health care system for some time, perhaps years, with parents as constant companions. Hence our suggestion that parents and child should co-approve the request.

10.16.1 Liam's Story

This story comes from a paper we co-authored on mature minors and medical assistance in dying (Guichon et al. 2016):

> *When Liam was a baby, his parents noticed that he was late to start walking. When he was about three years old, they noticed him falling frequently. After worrying for some weeks, they saw their family physician, and then a specialist who diagnosed Liam with Duchenne muscular dystrophy.*
>
> *Liam does not remember being diagnosed and accepts that muscular dystrophy affects all aspects of his life. Now aged 16, Liam has been using a wheelchair for six years. He remembers being admitted to hospital twice: at age 12 for pneumonia and at age 14 for surgery for scoliosis. These experiences are only half-remembered because he was sedated, but all the memories are difficult, such as having a tube in his throat making it impossible to speak, being suctioned down the same tube to clear secretions, and the discomfort of being turned in bed frequently. During and after his second hospital admission, he had nightmares about that experience and nightmares about his previous experience in the intensive care unit.*
>
> *After the scoliosis surgery, he began to need what the doctors called "non-invasive ventilation" at night to help him breathe. Initially he could set up the ventilator and place the mask tightly around his nose and mouth. Recently, Liam has become weaker. He has trouble swallowing and chewing so the doctors conducted surgery to place a gastrostomy tube to allow food to go directly into his stomach. Because he cannot cough effectively, a machine helps clear secretions from his lungs so that he is less likely to contract pneumonia. He sometimes has painful muscle cramps that come unpredictably; none of the doctors have found a good way to help this discomfort. Liam sees a cardiologist from time to time and knows that his heart is not strong. His parents used to come into his room at night to turn him over so that he would not get bedsores. Now, health care aides are in his home every night to do that job.*
>
> *Liam knows that his parents love him, and his nineteen-year-old sister, Olivia, is always kind and helpful. He has made friends with other boys with muscular dystrophy whom he meets at the clinic and he has friends at school.*
>
> *Liam has noticed lately at the clinic that the physicians and his parents are having private discussions. He knows he is getting more tired, in a general sense, but also feels breathless quite often every day. He asked what was going on, and his parents explained that he may need to use the breathing machine all day and not just at night. They explained that he would have a mask strapped tightly to his face that he could remove when he wanted to speak or eat. Liam's parents also explained that members of the clinic staff have suggested that he have a tracheostomy tube – an artificial breathing tube in the throat.*
>
> *Liam is aware of all these medical devices; he has seen friends who have depended on them to keep them alive and has spoken to them about what life is like being dependent on those devices.*
>
> *Liam sees all of these "helps" as a way of continuing his suffering and extreme discomfort. He believes that since he has needed a wheelchair, he has had a steady decline in what he is able to do and a very marked increase in the amount of discomfort and suffering.*
>
> *Liam assures his family that, despite the dystrophy, he has enjoyed life overall, but he is suffering a great deal from the challenges of breathing, and the lack of pleasure in using his own body to move, to eat, and even to cough. He does not want to go to the next step of needing a permanent tube to help him breathe. He tells his family that he does not want more medical intervention to continue his life. He wants help in dying.*

10.16.2 Comments on Liam's Story

Who cannot sympathize with Liam? He lives a life of suffering and sees little that is positive in his future. In terms of the specific question as to whether he might be helped to die, any options except in the Netherlands and Belgium are extremely difficult and expensive and there might be insurmountable barriers. These include going to a country where MAiD would be legal for a minor, yet that country might permit only its own citizens to have assistance in dying.

It would be more productive for the medical team to focus on exactly why Liam is so unhappy and what can be done to help improve his life. Is there conflict at home? If he is attending school, then is there bullying? Are there symptoms that can be ameliorated with some change in treatment?

Even if Liam lived in a country in which MAiD was legal, then there would still be a significant process before someone of his age could access the services. During the process of assessment, it is possible that other options such as pain relief and counseling might become obvious.

One additional point, raised above and in the Chap. 5 on confidentiality, is what we must tell children about their condition and especially the prognosis when near the end of life. We described with concern, older ideas of attempting to keep the prognosis from children and that even today people seek to withhold information from children (Sisk et al. 2016). In the past, this deception was engaged in ostensibly to "protect" children, but we suspect it was to protect parents and health care professionals from conversations they found uncomfortable. In that chapter, we describe that we strongly support openness; when parents do not want to tell their child what is happening, health care professionals should help parents see the benefits of openness. Of course, the health care professional will also need to help the parents with ways to speak to their child about approaching death. However, when children are able to read, all attempts to keep children in the dark might be moot in the internet age (Badarau et al. 2016).

The children often knew what was happening but pretended not to know as a way of protecting adults; such effort used up much of their energy. The children were often afraid to ask the adults questions about what was happening. This fear inevitably led to an environment that was far from open. The evidence accumulated from 1960 to the present day is that being open with the child is helpful and allows the child to be an "active agent" in his or her own healthcare. And contrary to the view that children will worry more, they worry less when adults are open with them.

10.17 Hope

We must often convey information to families that is unwelcome to them and that makes us uncomfortable. This "breaking bad news" is part of what we do. How we convey information is very important. Information must be conveyed empatheti-

cally but truthfully. The setting is important. We should not be standing with the parents sitting. We should all be sitting, and we should be sitting in an area with minimal distractions away from alarms, monitors, pagers, or telephones. We bring a nightmare and sadness, but if parents do not immediately believe us then we should not think there is a delusion to be crushed.

Hope is one component of a family's response to our information of a poor prognosis. Most physicians follow the disclosure of information immediately by a process of salvage (Whitney et al. 2008). By "salvage", we mean communicating to families that in the midst of the sadness, all is not lost. For example, physicians affirm to families that we will be there to support them, and that there might be some little things to be done in a positive way. In the opening chapter, we mentioned "temperance" as a very important pediatric virtue. It is extremely important in this situation to ensure that we use language carefully and avoid "undo bluntness or misleading optimism" (Mueller 2002).

The family's response might be denial, anger or acceptance, or all three in succession or even alternating. With support, we are likely to see changes in how the parents feel. The fact that parents have hope does not mean that they are unrealistic, and that we must provide them with ever more facts on how dire the situation is. Hope is not something to be avoided; hope is a quality that we need to support and perhaps re-channel. It would be wrong to be too trite in initial conversation, but there is little doubt that with the advent of effective palliative care services, we are able to give the hope of providing comfort and symptom relief to most patients. We need to think through the intricacies of each individual situation to see how we can find some hope to help families in the midst of despair.

Life-threatening illness undoubtedly brings a loss of control to life, whether the illness is in the life of a child, or in the life of an adult. The preceding paragraph should not be read as meaning that false hope should be encouraged. On the contrary, we believe that accurate information is empowering, and brings a degree of control to a very sad and difficult situation. Words that we use that lead to the destruction of hope are not likely to lead to parental acceptance that their child might die in the near future.

Some aspects of hope remain constant over time, some vary. A study of 199 parents and 158 children considered changes in their hopes for the child (Hill et al. 2018). It reported that the most common domains were quality of life, physical health, future wellbeing, and medical care. These remained the most constant domains over time, but not all were mentioned every time. The hopes that the parents had whose child had died were not significantly different from parents whose child survived. Again, an affirmation of hope is an important concept in the lives of families, and a topic for pediatricians to address at every visit.

Even as we help parents maintain hope, we might be tempted to accede to interventions that might not be justified scientifically. Some such interventions might be acceptable, but some might cause the child pain and discomfort. However difficult it is, our first duty is to the child patient; we should not 'offer the parents' anything that would hurt the child.

10.18 Reflections on Charlie Gard

Charlie Gard was the first child of unrelated parents. He showed signs of illness before the age of two months (Guichon and Mitchell 2017). *He was taken to the Great Ormond Street Children's Hospital in London, immediately admitted, and taken to the intensive care unit. Life-saving assisted ventilation was started immediately. Charlie also had advanced genetic testing in short order. The testing showed that he had the very rare mitochondrial DNA depletion syndrome. This condition is not treatable, and it was likely he would die in the near future. Charlie continued to deteriorate after admission. He needed the ventilator because of severe myopathy, but later the muscles controlling his eyelids became so weak that he could not open his eyes. He was unresponsive and almost completely deaf. There were a number of consultations including the ethics committee. The decision was made not to place a tracheostomy tube. The story reached the law courts and the media. The parents contacted a physician in America who claimed to have a therapy that might be appropriate. Please note the use of the word "might". In fact, it turned out there was no real evidence that this 'treatment' would offer any benefit. The courts forbade the parents from taking the child out of the country. Charlie was transferred to a hospice where ventilation was withdrawn, and he died very shortly afterwards.*

The publicity continues. Much of the public discussion focuses on something said to be the "rights of parents", and the alleged right to access any therapy when the situation is desperate. This is an oddly construed understanding. The medical issue is the child's wellbeing and the comfort of a dying child. Parents' rights are derivative. They have the right to make decisions for the child only to the extent that they are acting in the child's best interests.

In the continued Charlie Gard publicity, a second concept raised is the alleged "right to try" almost any remedy when facing a dire prognosis. This alleged right is not just about children, but children are mentioned. The many major advances that have improved the lives of so many children are based on carefully planned, executed, analyzed and reported research. Most countries have special arrangements to allow patients near death to be given a treatment that is likely to be approved, but under conditions similar to clinical trials, with an obligation to report results (Dresser 2015). The "right to try" movement wants much wider access, often with no reporting requirement. The argument in favour of such a practice can be summarized: "Why not? What is there too lose?" The scientific and policy responses to these questions are that there is a lot to lose. For the individual, the suffering imposed by an ineffective remedy might compound end of life suffering. (The available evidence cited by Dresser is that the remedies tried are almost always without any benefit.) For future patients, *ad hoc* use of what might be a promising intervention can make scientific proof of benefit nearly impossible and lead to its withdrawal from the market.

We do not have any easy answers to the many other issues that arose with Charlie Gard. As far as we can tell, the hospital staff took all reasonable steps immediately to save his life, to investigate the cause, and once the diagnosis and prognosis were established, to discuss these with the parents. However, conflict arose. Despite use of, for example, an ethics committee, conflict escalated, and reached the courts. Some people have since pleaded to permit parents to do what they like with their

child when the prognosis is very poor. Concerns have been raised that some other form of mediation outside court action would involve much less publicity. It is difficult to say that any action in the midst of the parents' anguish and rejection of the diagnosis and prognosis would have changed the course of Charlie Gard's life.

In a different milieu, conflict about the care of children with cancer was studied by interviewing parents and physicians about difficult relationships (Mack et al. 2017). There were many positive suggestions made by both parents and physicians regarding how these relationships might be improved. However, in one situation, "confrontational parental advocacy" in which early threats to trust led to parents taking a highly active role, resolution was rarely achieved.

Sadly, there will sometimes be conflict when we see our duty as to the child, rather than placing priority on obeying parental instructions.

10.19 Meetings with the Family After Death

All pediatric staff members are encouraged to engage with families in a friendly manner in all encounters. This encouragement contrasts with previous eras when strong encouragement was given to avoid emotional connection. Even when a child has died, trainee pediatrician, like all pediatric professionals, must have "resilience and personal resources to move on to deal with the next patient and the rest of the shift." Preparation for trainees in dealing with death might include use of simulation, preemptive discussions before the death and meetings away from the place where the child died. Careful handling of trainees during simulation training of cardio-pulmonary resuscitation might reduce feelings of guilt when such resuscitation attempts are unsuccessful. Formal, individual psychological support must be available.

The need for multidisciplinary multi professional meetings after a child death is an essential quality improvement function. These meetings should be undertaken after all deaths. Even though addressing emotions is not the main purpose, such meetings can also deal with the expression of feelings, and perhaps deal with feelings of guilt. These meetings, however, are separate from meetings specifically called to help staff recover emotionally, a subject we address next.

10.20 Self Care When a Child Is Dying or Has Died

As we come to the end of this sad section about how best to help when a child's life is ending, it is important to pause to consider one's own well-being. Trainees must be attentive to caring for themselves after a death. While their focus will be on the child and family, trainee pediatricians, like healthcare professionals in general, will experience grief when a child dies. That grief is, of course, different from the severe and long-lasting grief of parents. Nevertheless, the grief of healthcare professionals

is real, and should be addressed to avoid a number of consequences, including burnout, compassion fatigue, and even, in some cases, leaving the profession.

Indeed, the effects on pediatricians of the death of children in their care was the subject of a study conducted in Québec Canada (Plante and Cyr 2011). The study explored with healthcare professionals what made a death one that seemed special, what was the extent of the grief, and what coping strategies were used? Child death in Québec is unusual. It has a population of just over 8 million. Recent statistics show that the number of deaths in total each year is above 65,000, and in the year of the study there were 840 deaths of children. Thus, between 1% and 2% of all deaths were in children, a figure similar to other developed countries. One hundred one people responded to the questionnaire. Seventy eight percent were female. Of the 101 who completed the questionnaire, 22 were qualified physicians, and eight were residents.

The investigators reported that. in response to the question, "What makes a child's death memorable?" participants stated that a memorable death was when the death was unexpected (25%), when they had been involved with the child and family for a long time (12%), and less commonly when the death occurred on a special day such as Christmas Day. All the healthcare professionals expressed a moderate to high intensity of grief after death, but in general this was not as long lasting as has been identified in parents.

Participants reported a variety of coping strategies. Almost all study participants thought that they came to emotional acceptance after the child patient had died. The most common coping strategy employed was to talk to others (85%), positive reframing (80%), seeking out emotional support (75%), or self-distraction (57%). There were other strategies that might be perceived as negative such as self-blame (40%), denial (6%) and substance abuse (2%). "Humour" was used by 13%. It is unclear whether this is a helpful or unhelpful strategy for a physician. Most of the participants spoke with others about the death, and half spoke with family and friends. However, 19% spent time alone as a coping strategy. Forty percent would have liked more "official" support. Staff meetings after the death of a child as a form of support was not uniformly welcomed. Sixty-seven percent wanted multidisciplinary meetings after a child died, 15% wanted no meetings at all and 14% wanted them under some circumstances.

Another study of physician grief after the death of a child focused specifically on pediatric trainees, and even more specifically on the possible psychological impact, and whether meetings after the death of a child were helpful or not (Hollingsworth et al. 2018). The study was an electronic survey sent to all pediatric trainees in the UK. The authors noted that some requirements to help trainees deal with the death of a child were included in the learning curriculum. However, they suspected that some specific skills and needs such as developing resiliency, having debriefing skills, and developing strategies to ensure their welfare after an adverse event were not covered in all programs. The main objective was to study the possibility of an acute stress reaction (ASR) or posttraumatic stress disorder (PTSD) after the death of a child. The questionnaire was sent to 604 trainees. At the time of the study, one third of pediatric trainees were male, two thirds female. Eighty two percent of the

230 questionnaires returned (50% response) were by females. Ninety percent of all those who returned questionnaires had been involved with the death of a child, and 29% had been the team leader of resuscitation during which the child had died. The deaths experienced by these trainees were in the emergency department, the wards, or pediatric intensive care units. Deaths were mainly expected, some were after palliative care, and others were because of "redirection" of life-sustaining treatment. We interpret the last as indicating withdrawal of an intervention.

The study reported that after these pediatric deaths, trainees suffered. There were a range of emotional reactions. Fifty percent noted some reaction when thinking of the event. The most common reactions were: sleep disturbance 29%, vivid memories 26%, negative beliefs about oneself or others 25%, feeling emotionally numb 16%, negative thoughts about the case or consequences of the event, which are not supported by others 15%, distress when in similar situations 15%, difficulty in concentrating 14%, feeling irritable 13% and flashbacks 12%. It was concerning that 81% had some features of ASR or PTSD, though fewer had symptoms that reached formal diagnostic criteria (5 for ASR and 5% PTSD).

Most trainees (83%) felt well supported. The study specifically asked about debriefing, which took place after 48% of the deaths. 21% of those who responded could not attend debrief for reasons related to priority of clinical commitments, lack of invitation, being on leave, being on a makeshift, or some other commitment. None of the respondents responded to the option, "Did not want to attend". The conclusion about debriefing was disconcerting. There was a significant increase in prevalence of symptoms suggesting PTSD if they had attended a debrief compared with those who had not. This finding suggested that there might be an association between attendance at the debrief after child death and psychological harm. Official recommendations in Britain based on several Cochrane reviews are that one-off debrief sessions after traumatic events ought to be avoided. However, given that pediatric trainees are a vulnerable group for developing ASR and PTSD, assessment of the psychological impact of child death must be a priority, and should be taken seriously at the local level, as well as at the national level.

It is probably the case that different trainees will be helped by different strategies. In a commentary on this article, Ward Platt (2017) suggested that one of the things we need to do is "to look after one another". He makes the obvious point that no one solution is likely to meet the needs of all the trainees, given their individual personalities, and also the different ways in which they will meet children who died. To emphasize some of the points already made, children might die after "failed" resuscitation of a child who had presented moribund to the emergency department; death in the intensive care unit after highly invasive treatment has been given for some time, days or weeks; deaths on pediatric wards that might be expected or unexpected: deaths in the neonatal intensive care unit after long or short periods of treatment; and so on.

For example, we mentioned the child, Mohammed, in the chapter on children with medical complexity (Chap. 8). Mohammed was born at 24 weeks gestation and had both pulmonary and neurological damage. The neurological damage predominated, though he did require supplementary oxygen. He was looked after at home

for several months but deteriorated between ages three and 4 years. After intense treatment in hospital at that time, he went home with the support of palliative care services and died several weeks later.

In response to pediatric death, trainees doing "natural and humane things", such as a short time out of an office or meeting with colleagues over coffee, might help in achieving good outcomes for grieving trainees. Such respite acknowledges that everyone has been through an emotionally draining experience. Good professionals look after each other.

Just as it is clear that trainees need to develop skills in helping parents and children as a child approaches death, during the dying process, and afterwards, they must also develop techniques to help in their personal coping. If services for trainees are inadequate in any way, then advocacy for the trainee is needed!

10.21 Conclusion

Medical advances mean that children do not die at the rate they did in the past. But children do still die, and the major causes of death vary from society to society. In Western society, the first year of life is still the age when children are most likely to die. Many children die after interventions are deliberately withdrawn. The death of a child causes great suffering to parents and family members. While parents and family members find ways to continue their life, the suffering never goes away completely. The death of a child causes anxiety to pediatricians, and suffering, though the suffering is much less intense and much less prolonged than the suffering of parents. There are many things pediatricians can do to help, and they should focus on communication skills, compassion and empathy. The recent development of pediatric palliative care has been very welcome in helping children and families when the end of life is near, and in living with life-threatening illnesses. Unfortunately, there might be conflict, and while there are many ways of avoiding, diminishing or mediating conflict, such measures are not always successful. In all efforts at end of life, our first concern is the welfare of the child, and the second, easing the suffering of the parents and family.

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Chapter 11
Misunderstandings and Disagreements

Key Points Concerning Misunderstanding and Disagreements

- Illness is always distressing to parents and children.
- Parents will seek many ways to help their child.
  - Sometimes these ways are, at the least, unscientific or, at the most, harmful.
  - Parents might want an intervention based on their cultural background that might be harmful to the child.
  - We help these parents by respecting their beliefs, but respect for the child's health might require opposing the parents' actions.
- Parents are exposed to information from many sources on illness.
  - Physician advice might contradict more familiar advice.
  - Parents have difficulty in discerning which advice to take.
  - In such situations, clear, steady communication is important.
  - Questions require answers.
- When parents act against medical advice, pediatricians should work to "keep the door open".

11.1 Relationships with Children, Parents, and Families

When parents come to pediatricians, they have certain expectations of us. We imagine that they expect to meet someone who wants to assist them, and who will perhaps cure their child, or at least help her or him. The parents come to the interaction with their preconceptions, perhaps formed by previous encounters with physicians, what their friends and relatives have told them, what they have seen or heard on mass media, or what they have read on social media.

We come into the interaction with a scientific training, with additional training in skills such as communication, and we typically have a desire to help. We are

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_11

do-gooders. Not only do we come into the consultation with, of course, a professional background, at the same time we bring our own individual personalities, our own interpersonal issues, whether problems or celebrations. As the playwright Shakespeare wrote, "All the world's a stage, And all the men and women merely players". (Shakespeare 1564–1616) In other words, pediatricians have many different roles at different times when children are sick. As we state in Chap. 1, our contact with the child and family tends to be intermittent, whereas the family, usually, is always there for the child. Throughout our many contacts with the family and child, we need to respect the family's intimate and detailed knowledge of every aspect of the child's life. However, this respect does not nullify our professional assessment.

We all try to like the children and families. Usually it is easy to like children, and sometimes hard to like the parents. Sometimes we are seeing parents under tremendous stress, when they are reacting negatively to the situation by reacting negatively to us. Such behaviour might be discounted. But other behaviours can include demanding priority when the child's condition does not merit it, speaking badly of the child, exhibiting disdain for physicians and so on. It is possible we will dislike some parents, but we are likely to feel shame at this negative feeling.

Perhaps we think it is a duty to like everyone? In a study, researchers put this question to physicians dealing with children: "Which features cause you to feel that a parent of a child is difficult or unlikeable (in the context of your consultation or work)?" (Meadow 1992). The survey was answered by 78 of the 100 asked. As far as we can establish, such a survey has not been repeated. We would like to believe that, with effort, pediatricians could like everyone they meet, or at the least find ways of working with them. We suggest that ignoring personal feelings about parents is unwise and acknowledging to ourselves that we might have biases is a good start in our relationships with many parents.

In case you are wondering, the main perceived problems in parents that the study listed were:

- Displays of aggression,
- Non-compliance,
- Unacknowledged anxiety,
- Fixed ideas about the medical condition and its management.

We hope that current practitioners have found ways to cope with the parental behaviours the study noted, but the last, "Fixed ideas about the medical condition and its management" is probably more prevalent. Parents have ready access and frequent contact with social media and often arrive with their child with a diagnosis in hand and a proposed plan of treatment. It is difficult to know what is more annoying: the parents whose conclusions are very wide of the mark, or the parents whose ideas are spot on.

In this section, we address a selection of specific situations when there is disagreement between parents and physicians on some aspect of care. Such disagreements might arise because of misunderstandings or might cause misunderstandings. It is perhaps inevitable that these situations should feature highly in a book like this.

We suspect that most parent-pediatrician interactions go well; the few that do not cause extreme upset.

The situations we describe are far from the totality of possible misunderstandings and disagreements, many of which are scattered through the book. They are essentially the personal potpourri of one of the authors (IM). They are based on his personal experience, concerns raised by colleagues and trainees, and observations of trainees and colleagues in their interactions with families. If other situations arise as trainees look after children and interact with families, then we suggest the use of some general approaches we have discussed: patient and family interactions are likely to go well if we use good communication skills, have and display compassion and empathy, and focus on the child patient without ignoring parental anxieties or the interests of siblings.

11.2 Systemic Racism and Misunderstanding

There is ample evidence in all countries that specific racial or ethnic groups suffer because of inadequate healthcare. This fact is usually compounded by poor socioeconomic conditions. These are societal problems, and pediatricians should play their role by advocating for changes.

This chapter is about achieving empathy when the family seems different from other families. This challenge appears in areas as varied as working with Aboriginal groups with a legacy of mistrust with mainstream pediatrics, those whose cultural practices lead to requests for interventions for their child that are unacceptable in western society, and, rarely, those whose religious beliefs lead them to refuse lifesaving interventions for their child.

There is also evidence that physician interactions are often less complete with underprivileged groups, whether the child is underprivileged by colour, ethnicity or social standing. This fact is not a societal responsibility; it is a pediatrician responsibility. For outcomes to be poor because of something we do is something for us to address personally. We need to examine our own "socio-cultural competency". This is not a theoretical problem. As a recent publication states regarding approaches to black children, "pediatric residents are as susceptible as other physicians to implicit bias" (Johnson et al. 2017).

In addition to addressing our own attitudes and approaches, it is important to understand something about the beliefs of many of the different groups we meet. However, in our desire to avoid "cultural imperialism" (Macklin 1998), we should neither withhold the benefits of modern medicine nor allow parents to use unproven and possibly harmful interventions from their own culture on their sick child. Such a statement seems absolute and of course it is not. Interacting with all families, underprivileged or not, requires the cultivation of empathy, of taking an interest in families, and taking the time to explain why we do what we do.

Most modern societies are pluralistic. This fact makes it certain that many parents will have widely different views about illness and how physicians manage it.

Immigrant families in particular might have many beliefs about illness that are vastly different from the views of mainstream western society, let alone the views of western physicians. In addition, when the immigrants are refugees, their previous experiences and suffering might make them very suspicious of any authority figure, including physicians.

11.2.1 Immigrant Beliefs Impact Medical Care: Lia Lee's Story

Lia Lee was born on July 19, 1982, in Merced, California, the 14th of 15 children of her mother, Foua Yang, and her father, Nao Kao Lee. Lia Lee was their first child to be born in the United States and in hospital.

The Lees had been farmers in Laos, where there first three children had died at a young age. They arrived in the United States in 1980 after a five-year journey, during which three more of their children died. Lia Lee had a seizure when she was about 3 months old. According to her sister, Mai, speaking decades later, "My parents weren't able to convey exactly that she was having seizures. The word 'seizure' didn't come out. To them, they saw it as her soul being tampered with by something of a different realm." There were no translators for the family. The parents had a name for the condition, "qaug dab peg" translated literally as, "the spirit catches you and you fall down."

These seizures continued. After some time, the physicians diagnosed epilepsy and prescribed anti-seizure medication. But from the perspective of her parents, their daughter's spirit had left her body and she needed it to return and she was likely to have spiritual gifts. A shaman visited occasionally sacrificing a chicken or a pig. The parents thought Lia Lee might become a shaman because of such gifts.

Lia Lee's parents did not always give Lia Lee her prescribed medicine because they did not want to interfere entirely with the spirit. To encourage her soul's return, her parents gave her herbs and ornamental pieces of jewelry to ward off evil. She had 100 visits to medical facilities and 17 hospital stays. She was in foster care for 1 year against the wishes of her parents; this was a period during which the parents became distrustful of the physicians.

When Lia was 4, she had a grand mal seizure that endured nearly 2 h. Probably because of a medical procedure to bring the seizure under control, an infection developed leading to septic shock. By the time the doctors' stabilized her condition, she had lost higher brain function. For 26 years thereafter, Lia lived in a persistent vegetative state and died at age 30 in 2012. (Fox 2012)

This story is recounted in the celebrated book, **"**The Spirit Catches You and You Fall Down: A Hmong Child, her American Doctors, and the Collision of Two Cultures" (Fadiman 2012). The Hmong immigrants to the US reached the "safety" of the US, and not surprisingly retained their deeply ingrained beliefs. The pediatricians involved focused, inevitably, naturally and with concern for the child's well-being, on the seizures. The parents recognized the problem: her soul, had fled her body and must be found (Kavalier 2010). Everyone in pediatrics should read this book. It is imbued with conflict, as the pediatric and parental objectives were so far apart. The pediatricians respected the parents, and the parents respected the pedia-

tricians, but neither really heard the other. It is a tale of extreme misunderstanding based on vastly different cultural starting points. If there is a message in this book, then it is that we need to find ways to use our western medicine that also respect parental beliefs. This is not easy; if the child has a life-threatening condition then we will always want to treat as soon as possible. When the child's condition permits, a short delay to listen sincerely to the parents and to find ways to accommodate at least some cultural practices will bear fruit. However, we do not pretend these situations are easy. Had one of us (IM) been faced with this child, he might have been tempted to move quickly to initiate anticonvulsants. We hope he would have paused, however briefly, to attempt to understand the importance of the parents' beliefs.

11.2.2 Harmful Cultural Practice

A different cultural practice gives rise invariably to harm: "Female Genital Cutting" (FGC). The various procedures have also been called, "Female Genital Circumcision" and "Female Genital Mutilation". The procedure is not a circumcision, so that term is inapt. The term "mutilation" is unhelpful because offence is likely to be taken by adult women who have had the procedure. Many of these women might want to protect their daughters, even if they have been subject to the procedure; if a physician uses the term "mutilation" then an important ally might be lost. The women involved might say "cutting"; we prefer FGC as neutral term. We also mentioned this in Chap. 7 in the context of child abuse, here the focus is FGC as a cultural practice.

What are we talking about?

> "I was just seven years old when I was cut," says Leyla Hussein, a British woman of Somali origin. "The first thing I heard was my sister screaming. Then it was my turn. Four women held me down while they cut my clitoris. I felt every single cut. The pain was so intense – I blacked out."
>
> Hussein's experience of female genital mutilation (FGM) is fairly typical. The ancient rite of passage in many African and some Middle Eastern countries in which part or all of the genitals are cut off with razors or knives – often without anesthetic – is supposed to make girls "clean" and "pure", and ready for marriage.
>
> The grim reality is that an estimated 125 million women and girls living today have undergone some form of FGM – many of them suffer severe emotional and physical consequences.
>
> FGM is classified into four forms ranging from partial or total removal of the clitoris, the outer or inner vaginal lips to narrowing the vaginal opening by partially sealing it up (Shetty 2014).

FGC has many complications and no known benefits (Caring for Kids New to Canada 2018). The procedure is extremely painful (!), may result in life-threatening bleeding, infection and urinary retention. Long-term complications affect every physical aspect of genitourinary function in women, including mensturation, infer-

tility and difficulties in giving birth. Psychological sequelae are frequent (Hearst and Molnar 2013). FGC is a criminal offence in Canada and the UK, when done in these countries and also when a girl is taken abroad for the procedure. It is illegal in many US states. While most procedures are likely done by traditional "cutters", medical professionals might be involved (Baldas 2018).

FGM is recognized internationally as a violation of the human rights of girls and women (Caring for Kids New to Canada 2018). It reflects deep-rooted inequality between the sexes and constitutes an extreme form of discrimination against women. It is nearly always carried out on minors and is a violation of the rights of children. Pediatric organizations throughout the western world have requested strong action to abolish the practice. For example, the European Academy of Paediatrics has stated, "The whole paediatric community in Europe, as represented by the European Academy of Paediatrics (EAP), hereby condemns female genital mutilation and declares this as one of the most devastating forms of child abuse that must be abandoned." (Sauer and Neubauer 2014).

We agree with these opinions, and do not classify this as a cultural practice to be condoned. Nor do we think its condemnation means that western societies are displaying cultural superiority. The practice inflicts physical harm without medical benefit and leads to significant sequelae. A surrogate decision-maker (typically the parents) may not consent to such a procedure for the child because it is not in the child's medical interests. If the child would like to undergo this procedure for cultural reasons when she is a legal adult, then she is free to do so. When an instance of this practice is encountered in a girl, or when it is suspected that a girl might be taken off shore for the procedure, child protection authorities and/or police must be informed. The ethical priority is to avoid harm to a minor.

Having said that, any questioning about FGC must be conducted sensitively and respectfully. In addition, the girl's mother might have had the procedure, and might believe that her daughter's future depends on the daughter also being cut. In her cultural community, she might be correct though attitudes could be changing. On the other hand, if the child's family has immigrated to the western world, the girl will likely interact with people outside the community and might choose a partner outside her community. Conversely the mother might wish that the procedure not be done on her daughter, and we might need to help her avoid family pressure. Any long-term solution will come only by working with affected families and communities (Dixon et al. 2018).

11.2.3 Cultural Practices to Be Tolerated?

11.2.3.1 First Nation Use of Tobacco in Ceremonies

Western societies are accustomed to seeing only the many negative health consequences of tobacco use but in First Nation communities, ceremonies involving tobacco are important (Fine Maron 2018). We believe this practice is something that

can and should be accommodated. Louwagie (2008) outlined some precautions when her institution worked with First Nations patients who wished to use traditional spiritual measures. The measure suggested are:

- Arrange for the patient to be admitted into a negative airflow room.
- Prior to beginning the ceremony, temporarily disable the smoke detector associated with the patient's room.
- Close the door for privacy and smoke containment during the ceremony.
- If a caregiver is allergic to smoke, another caregiver should be assigned temporarily to assist with any urgent patient needs.
- During a ceremony, the patient and family should be allowed to have privacy and not be interrupted.
- Upon completion of the ceremony, the fire alarm system must be reactivated.

11.2.3.2 Neonatal Male Circumcision

Another cultural custom that is common in many areas of the world, including some western countries is male circumcision, also known as Male Genital Alteration (MGA). The ritual of circumcision is ancient and has been found in many societies (Doyle 2005). "Modern" rituals date to mid-nineteenth century when it was seen as a way to prevent masturbation. This ritual has persisted in USA and to a lesser extent in Canada. Practitioners alleged that it is "a simple, rapid operation with medical benefits which accrue throughout life." (Schoen 1997). It is done in the neonate much less frequently in Europe and Australasia. It has been given a veneer of medical evidence with the benefits largely in adult life and based on studies on subjects circumcised as adults. Official statements produce virulent correspondence both pro and con (Sorokan et al. 2015) and (Task Force on Circumcision 2012). (The correspondence and rebuttal and rebuttals of the rebuttals are too voluminous to cite individually.)

What are the ethical issues to consider in MGA? A subsidiary question is: "Is the ethics of FGC totally different? Why does western society treat FGC and MGA so differently?" The philosopher Earp (2015) sees both as:

> highly problematic practices, with far more overlap between them (both physically and symbolically) than is commonly understood: they should not be discussed, therefore, in hermetically-sealed moral discourses. Instead, the relevant framework is one that analyses a child's right to bodily integrity, and carefully considers how tolerant we are willing to be, in these societies, of practices which irreversibly alter a person's "private parts" in a non-trivial fashion, in the absence of medical necessity and before the person has a chance to say "no."

We do not believe that MGA can be banned by legislation; there would be extreme opposition. In addition, if it were banned it would be driven underground and the current small risks magnified. In discussing MGA with parents, it is important to stress that there is no rush; the child as an adult can make the decision. The parents might be interested to know that cultural ceremonies of welcoming the boy can occur with minimal interference with his bodily autonomy; a small 'nick' that

might heal could be the result rather than the irreparable removal of the foreskin. If the parents insist that procedure will take place, then physicians should ensure the operator is appropriately qualified and that attention given to infection control. Physicians must insist on analgesia during the procedure and for the painful days that follow.

11.3 Specific Common Disagreements

The stories we relate here concern vaccinations, use of homeopathic or naturopathy, and requests for a 'treatment' that we do not support. We also address, perhaps superficially, displays of sexism or racial prejudice in parents.

11.3.1 If Vaccination Is So Good, Then Why Isn't Every Child Fully Immunized?

"Immunization" and "vaccination" are words that have slightly different meanings but are used interchangeably. We will use vaccination to refer to the process of inserting a vaccine into the human body. The first vaccination – for smallpox – was introduced in 1721, and a clinical trial confirming benefit published in 1798 (Wilson and Marcuse 2001). Now smallpox has been eradicated. Since 1721, many vaccines have been introduced and are given to healthy people to prevent diseases that are not an immediate threat. Vaccination as a public health practice has been so successful that most in the western world hear about these preventable diseases only when hypothetical side effects are publicized. Wilson and Marcuse (2001) affirm with accuracy that, "Immunization is one of the most stunning and economically effective contributions of biomedical science to human health."

In Chap. 10 Helping at the End of Life, we noted the predominance of infectious diseases as causes of death in childhood in the developing world. Newer vaccines include those against Streptococcus pneumoniae and Hemophilus influenzae type b (Hib) have been introduced worldwide, though some developing countries have difficulties in achieving high vaccination rates. It is therefore not surprising that a recent report (Wahl et al. 2018) showed that pneumococcal deaths declined by an estimated 51% and Hib deaths by 90% from 2000 to 2015. About half of all pneumococcal deaths in 2015 occurred in four countries in Africa and Asia: India (68,700 deaths) Nigeria (49,000 deaths), the Democratic Republic of the Congo (14,500 deaths) and Pakistan (14,400 deaths) The greatest number of Hib deaths in 2015 were in India (15,600 deaths), Nigeria (3600 deaths), China (3400 deaths), and South Sudan (1000 deaths). (These data come from the paper by Wahl et al. (2018) where the methods and limitations of the data are given.)

Whereas these data demonstrated that developing countries would benefit by better vaccine coverage for their populations to prevent avoidable death from infec-

tious diseases, the developed world can be complacent. Such countries disconcertingly describe outbreaks of vaccine preventable diseases, and parent and media campaigns against new (and existing) vaccines. In 2018, regarding measles in Europe "cases in the first six months of 2018 exceeded the annual total for each of the past five years" (The Economist 2018). There were 37 deaths and more than 41,000 cases (New Scientist 2018). About half of the cases were in the Ukraine, but there were increases in Serbia, Greece and Georgia. Vaccination uptake rates have fallen. "Italy, France and Serbia, for example, have lower child-vaccinations rates than Burundi, Rwanda and Senegal" (The Economist 2018). Some decline in vaccination rates are due to disrupted supplies, but most are due to parental concerns. Italy has a law that requires children to have ten vaccinations before enrolling in state schools. Parents risk being fined up to €500 (£425; $560) if they send their unvaccinated children to school. Children under six can be turned away. The new law came in 2019 amid a surge in measles cases – but Italian officials say vaccination rates have improved since it was introduced (BBC News 2019). A March 2018 measles outbreak affected almost 5000 people and killed four (Agerholm 2018).

A vocal minority who believe in conspiracies, seem to lead opposition to the safe and effective public health measure of vaccination. The claims are sometimes based on disproven science such as an alleged link with autism or concerns about preservatives and adjuvants. Other concerns are based on incorrect science such as "vaccine overload". Newer vaccines have been opposed for other reasons. The Human Papillomavirus (HPV) was opposed in some religious circles (Guichon et al. 2013) as a public health measure that would encourage sexual promiscuity (Guichon et al. 2013) even though this claim has been disproven (Bednarczyk et al. 2012). Parents in many countries seem especially willing to distrust a vaccine that will prevent a sexually transmitted disease. The World Health Organization has presented ways of dealing in public with vaccine opposition (World Health Organization 2017). We will discuss responses to individual parents below.

11.3.2 Dr. Brooks and Juliana

Dr. Ellie Brooks was a third-year pediatric resident. She was just starting a rotation in a community practice and saw Juliana Ramirez a two-year-old child when Julia attended our "well-child" visit. Dr. Brooks reviewed Julia's chart and saw that she had never received any vaccinations. Dr. Brooks quickly reviewed the previous visits and saw that there had been no mention of any discussion of vaccination. Dr. Brooks raised the topic with Julia's mother, who told Dr. Brooks that she had done a great deal of "research" and was not sure that the vaccinations were necessary because Julia was well looked after and had a good diet with extra vitamins. In any case, Julia's mother worried about side effects.

Dr. Brooks in previous rotations had met parents whose children were not vaccinated or partially vaccinated in that they had received some of the recommended childhood vaccinations but not all. Because the children were sick at the time, Dr. Brooks considered it inappropriate to open the discussion about vaccinated at that time. She was sure she should do something but was not sure what that something would be.

11.3.3 Comments and Help for Dr. Brookes

Julia's case is a specific instance of the general problem illustrated above. It is important to stress that healthcare professionals are still able to influence most parents (Dubé et al. 2016). Therefore, Dr. Brooks should discuss vaccination with the family. It is disappointing that vaccine refusal had not been discussed before by previous physicians who cared for Julia. An important distinction can be made between parents who are now called "vaccine hesitant", compared with parents who outright refuse to have any vaccines. While, in the interest of the child, we should discuss the importance of vaccines with both groups of parents, we are more likely to be successful with the vaccine hesitant ones and most of the strategies we will describe will be directed towards these parents. This mother is concerned with safety. The evidence from her research comes from anti-vaccine websites and are judged in the "court of public opinion". Our evidence comes from science. In most cases, it is not the parents' fault that they have been misled by people who are unable or unwilling to understand the science. The parents who have been misled need assistance in understanding. As we talk to parents, we must be respectful of their anxieties and must avoid over-technical jargon; keep in mind that these parents tend to be well-educated though not, perhaps, in health science.

> While vaccine hesitancy exists in all stratums of the population, it is often associated to highly-educated parents. Studies conducted in different settings have shown that non-compliant parents appear to be well-informed individuals who have considerable interest in health-related issues and actively seek information. (Dubé et al. 2016)

There are several important strategies to deploy in helping parents understand and appreciate the importance of vaccination so that they are in a position to consent for their child. MacDonald et al. (2013) have fine suggestions to which we have added: First, we should listen carefully and non-judgmentally to identify and to address the specific concerns of this particular parent. Second, because research demonstrates that most patients see health care professionals as the most trusted relationship, it is important to preserve this relationship while tailoring communication to this particular parent. Even if the parent disagrees about vaccination, it is important to keep the door open to another conversation about vaccination. Third, throughout the discussion we must stay on message, "Vaccines are safe and effective, and serious disease can occur if your child and family are not immunized". Fourth, we should tell parents that there is a vigorous vaccine safety system; an important piece of information not well known. Fifth, we should put risk into perspective. Children, and their parents, face many risks every day as they go about their everyday life. Even if difficult to quantify, injuries when crossing the road or when driving are more likely than adverse effects from vaccines. Finally, Dr. Brooks should address the issue of pain that will occur at the injection site and describe pain reduction strategies for the body's reaction to the vaccine itself, including how fever reducing medication can prevent optimal immunogenicity.

Many physicians are concerned that unvaccinated children being seen when sick with an undiagnosed respiratory infection, fever, or rash (or all three!) might be a

risk to vulnerable children in the same waiting area. The American Academy of Pediatrics states that these parents might be dismissed from the practice as a last resort (Rucoba 2016). We do not agree even as a last resort. Dismissing the children from your practice would add punishment to the child because of a disagreement with parents. We agree with MacDonald et al. (2013) that we must raise the issue with parents stressing the importance of routine childhood vaccination and the risks to the parents' own child and to other children when parents do not agree to consent to vaccination for their child.

When the child is a mature minor, at about the age of 14, you may engage in this conversation with the adolescent who might choose to consent to vaccination. If the child has received no vaccinations at all, then you might wish to speak to that teenager about the vaccine protocol for vaccine naïve adolescents.

11.4 The Parents Want an Intervention That We Think Is Not Indicated or Might Even Be Harmful

Parents who arrive with their child at a doctor's office accompanied by a wad of articles downloaded from the Internet or, more likely, articles stored on an electronic device are a feature of modern practice. It is no longer a rare occurrence to be visited by a parent who already has fixed views on what diagnostic tests the physician should order and what treatment to prescribe. In the past, the patient would have brought to the meeting information received from relatives including grandparents; today this type of parent will have gained the information from social media. We will address only one of these demands: that for antibiotics.

The parental demand for antibiotics when a child likely has a viral infection comes from at least two sources. The first is that there is a knowledge gap between the physician and the parents. Most respiratory infections are viral, and the parent is drawing a false conclusion. Effects obviously follow causes, but not everything that follows an intervention is caused by that particular intervention. Imagine that the child was to be given a lottery ticket after the antibiotic and won the lottery on day 3; the antibiotic did not cause the win. Likewise, a child who improves after 3 days on an antibiotic probably improved because 3 days is the usual range of time to show improvement after a viral infection. Coincidence is not causation.

The second source of parent demand for antibiotics comes from the common, laudatory desire of parents to do something for the child if the child is unwell. Giving prescription medicine to the child would fulfill that parental need even though it is wrong to give medicine to a child when the medicine is not indicated and may be harmful.

Unnecessary prescription of antibiotics to individual children raises concerns for side effects such as gut superinfection, rashes, skin fungal infections, and so on. There might also be concerns for cost of a return physician visit, depending on the system of health care funding. From a whole population perspective, unnecessary

use of antibiotics will accelerate bacterial resistance to antibiotics and also increase costs. Despite these concerns there is evidence that antibiotics are "overprescribed".

This topic has been studied many times. For example, a study based in Saskatchewan, Canada used 1995 data linking physician visits, diagnostic groups, and antibiotic prescriptions (Wang et al. 1999). The investigators compared consensus guidelines on antibiotic use with the stated diagnosis and estimated that 51% of the antibiotic prescriptions might not have been indicated. The investigators expressed some sympathy with the physicians regarding difficult situations to refuse antibiotics: these included the difficulty in some cases of distinguishing viral from bacterial infections; inadequate time to discuss the role of antibiotics with the family, which lack of time might affect the physician's ability to resist strong parental pressure; and possible fear of litigation. Finally, and worse, physicians might share the belief that antibiotics are harmless.

We hope there has been improvement in physician behavior since this study was published, but perhaps not (Eckel et al. 2014).

11.4.1 Dr. Brooks and Kiera

Dr. Brooks was near the end of the rotation in community pediatrics. She had been seeing patients by herself, then after discussion with her preceptor, returning together with the preceptor to the patient's room. She saw Kiera Waldron, an 18-month-old child, who came for a visit to the clinic because she was sick. She had developed a runny nose three days before Dr. Brooke saw her and then developed a mild cough. Her mother had measured her temperature, and noted that it had been slightly raised at 38.3 °C. When Dr. Brooks examined Kiera, the temperature was now normal, Kiera was happy, there was mild inflammation in the pharynx, some nasal discharge, and her chest was clear. Dr. Brooks felt very comfortable reassuring Keira's mother that this was a viral illness, it was pursuing the normal course, and in another 2 to 4 days most of the symptoms would have gone. In the meantime, she could continue with symptomatic treatment, perhaps ibuprofen or something similar, that could be bought over-the-counter in a drugstore.

Kiera's mother said that she had seen the community pediatrician on several occasions, and each time had been prescribed an antibiotic; Kiera tended to improve within 48 hours of starting the antibiotic. She asked for a prescription for an antibiotic. Dr. Brooks was reluctant to say anything that was not in keeping with the usual practice of her preceptor but had also been at a "choose wisely" seminar when the whole issue of unnecessary antibiotic prescriptions and their dangers were mentioned. She therefore decided to tell Keira's mother that an antibiotic was not appropriate, the possible drawbacks in using them, but also said that a decision would be led left to the preceptor, and Dr. Brooks and the preceptor would return shortly to discuss things further.

11.4.2 Comments on Dr. Brooks and Kiera

You might ask, does this conversation matter? You might consider antibiotics as harmless. If a prescription is demanded, then why not prescribe it? We sympathize with Dr. Brooks. The example of the physician who had seen the child previously

does make it difficult to refuse the prescription on this occasion. On the other hand, we assume, that as a learner in the practice, she has extra time. We hope that Dr. Brooks will take time to listen carefully and to do her best to understand the concerns of the parent. It is also important that she takes time to assess the child carefully. At the end of the day, there is no ethical justification for the use of antibiotics and a prescription should not be given. It is important to know that parents learn from physicians and can take on board new information such as, "Our old practice of handing out antibiotic prescriptions has been shown to be wrong. We now prescribe them only in certain cases and fortunately your child does not have a bacterial illness." Time should be taken to reassure the mother that a physician will see her for reassessment of Kiera over the succeeding 3 days should the mother's concern continue.

There will be other demands for treatment that the physician thinks are not indicated or that might be harmful. There is, of course, no ready-made solution to the request, often phrased as a demand, except to listen carefully, to understand the parent's concerns, and to respond to these concerns patiently. We should also understand, (as a physician who had seen Kiera in the past did not understand) that if we agree to an intervention that is not indicated, then we do not help the child and make it difficult for colleagues in the future to do the right thing.

11.5 Requests for Interventions That Are Not Supported by Scientific Evidence

There is a broad range of interventions chosen by families for their child under the general rubric of "Complementary Alternative Medicine" (CAM). The fact that we have titled this section "interventions that are not supported by scientific evidence", and then go on to discuss CAM does not in any way imply that we think all of pediatrics is scientific or has a sound evidence base. Far from it! Yet there are many interventions carried out by a number of practitioners with varying types of qualifications that might or might not be university degrees and might or might not be regulated by governmental authorities. Sometime in the past, these interventions and the practitioners were seen as "alternative" to the kind of pediatrics carried out by physicians. Now the word "complementary" has been added because parents often use conventional and CAM interventions in the same situation. Some pediatricians might believe some CAM therapies are effective to some degree and might advise parents to purchase specific preparations for their child.

The boundaries between pediatric medicine and CAM therapies are not static. Some parts of what we call CAM might be fully scientific; other parts might become scientific with new evidence. With all these qualifications, we use a definition taken from the Cochrane Collaboration, as reported by Zollman and Vickers (1999):

> Complementary and alternative medicine (CAM) is a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a

> particular society or culture in a given historical period. CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting health and well-being. Boundaries within CAM and between the CAM domain and that of the dominant system are not always sharp or fixed.

Zollman and Vickers (1999) list a substantial number of CAM approaches in their paper, but such a list can never be complete. That particular list contains some interventions such as naturopathy and osteopathy - words that might be familiar to trainees in pediatrics even though they might have little information or knowledge on what is involved. Some of the interventions listed, such as massage, seem to many of us to be rather far from a therapy for acute illness, but something reasonable to use in many situations such as muscle cramps. Some others, such as "therapeutic touch", have been completely discredited (Rosa et al. 1998). Homeopathy seems scientifically unlikely (Shaw 2010) because of the degree of the dilution of the preparations, but there is some debate as to whether it might work occasionally (Fisher and Ernst 2015). Many of the adverse consequences of the use of CAM in children are listed by Polevoy (2018).

From the perspective of the trainee in pediatrics or the pediatrician in practice, one of the difficulties is that we have very little understanding of what the various modalities do. When we look at websites, we see words such as "energy force" that are unfamiliar to us. There is a temptation to make sarcastic and negative comments in the earshot of families; please resist that temptation. Whatever we might think about these therapies, they are attractive to many families and we will be unable to help families fully if we disparage their beliefs.

CAM therapies are thought to have advantages over conventional pediatrics, such as being natural, holistic, and harmless. The first of these words, "natural", is more a slogan than a meaningful response. The therapies, including herbs, used in CAM are no more natural or unnatural than therapies used by pediatricians. CAM therapists are said to spend more time with patients, listen carefully without any rush and attend to all of the contextual details that are so important to families This is probably true, but we believe that conventional pediatricians, at their best, aim to have a comprehensive approach as they deal with families, consider a diagnosis, consider safe and effective treatments, consider the views of parents, and consider how other siblings in the family might be affected. It is the claim that therapies are "harmless" that is most problematic (Polevoy 2018). There is no doubt that many interventions are harmless and specifically homeopathy is harmless, in the sense that the preparations are so diluted that there can be no active substance. Some naturopathic preparations contain active drugs that can interact with treatments used by pediatricians. The greatest potential harm from CAM intervention is that of lost opportunity. If the CAM intervention is used instead of a conventional treatment, then children might miss a chance of full recovery of a life-threatening disease by an intervention that does not work. Indeed, a child might die, as Ezekiel Stephan did at age 19 months when his parents treated him with ginger root, hot peppers, onions, garlic and horseradish and other CAM products rather than take him to medical care where a physician would have diagnosed his bacterial meningitis and treated it immediately with antibiotics (*R* v. *Stephan* 2016).

11.5.1 Dr. Riviera and Reagan

Dr. Mia Rivera saw a child, Reagan Bund, in consultation. Reagan is almost 4 years of age, and Dr. Rivera notes that she has been seen eight times in the last 15 months because of acute ear infection. She also notes that there have been discussions in the past about referral for surgery to insert tubes. On every occasion, the mother wanted to wait. On this occasion, Dr. Riviera thought she should be more forceful and strongly encouraged Reagan's mother to accept a referral to see an ENT surgeon.

The mother's response was quite disconcerting. Reagan's mother had discussed the whole topic of ear infection and surgery with her neighbour with whom she was friendly. The neighbour had had a child several years ago with a similar story and had been referred to a chiropractor. That chiropractor was still in practice locally, and Dr. Riviera was asked for a referral as the mother believed that the abnormal biomechanics of the upper spine affected the immune system. She felt that this was the reason Reagan had had so many ear infections.

11.5.2 Comments on Dr. Riviera and Reagan

The desire of Reagan's mother to avoid surgery for her daughter is very understandable. The idea of a chiropractor helping your infections is particularly disconcerting as chiropractic seems to be associated in the popular mind with manipulations of the spine associated with backache or back pain. In fact, chiropractors see themselves as having a wider remit. For example, many chiropractors believe that all newborn infants should have a course of "adjustments" to deal with the partial dislocation of the spine caused by childbirth. Many chiropractors do believe that manipulation will improve the immune system, but I am not aware there is any evidence that this is true. In the past, and perhaps occasionally today, chiropractors were particular associated with the anti-vaccine movement.

What we think Dr. Riviera should do? Firstly, while she must be disconcerted, at least a little, she must watch her body language very carefully. She should ask the mother for more information. Dr. Riviera should take the time to point out the consequences of repeated ear infections in terms of hearing, and if hearing has not been assessed already, then it should be done now, if only to establish a baseline.

It might be worth asking the mother what she believes would take place in surgery. Parents can have fears about surgery based on the experiences of people they know. Such experiences can be wholly unrelated to what this mother might reasonably expect in the proposed minor surgery for her child. When parents turn to "natural" therapies, it is often because they have significant concerns about what conventional medicine is proposing. Uncovering such parental fear and addressing it might aid the child.

Dr. Riviera must walk with Reagan's mother along a narrow path. She should work hard to maintain liaison and trust with the mother but cannot, ethically, give the referral the mother asked for. The consultation will be time-consuming, and it is possible that Dr. Riviera might want to see Reagan and her mother in 2–3 days to review the discussion.

We do not want to minimize the problem faced by Dr. Riviera, but she should not accede to this request for a referral to a chiropractor for an ear infection. However, it does not seem to us that this avoidance of recommended surgery rises to the level that we would recommend a child welfare referral. If Dr. Rivera can manage to maintain a good relationship with Reagan's mother, then follow-up can be continued and hopefully the surgery will become acceptable to the mother.

11.5.3 Dr. Cayenne and Jacob

Dr. Sadie Cayenne was reviewing a school report about 8-year-old Jacob Ouwerkerk, a boy with ADHD. She asked her mother about Jacob's progress. The mother said that he was doing extremely well, especially since she had recently seen a naturopath who had prescribed Niacin 2500 mg.

Dr. Cayenne did not know how to handle this information. She checked online sources of medical information and as far as she could tell this was a huge dose.

11.5.4 Dr. Capperelli and Peyton

Dr. Tristan Capperelli was reviewing her patient, Peyton Davis. Peyton was a seven-year-old girl who had had onset of seizures at the age of five years. No etiology had been noted and because the seizures recurred, Peyton had been started on anticonvulsants. Peyton's mother had always been uncomfortable with all medications and was always on the lookout for side effects.

On this occasion, she told Dr. Capperelli that she had stopped giving the prescribed anticonvulsant and had started mugwort. This substance had been recommended by a member of her Facebook group to support mothers of children with epilepsy.

11.5.5 Comments on Jacob and Peyton's Treatments

The treatment used in these two children was something that was unfamiliar to the physician. In Jacob's case, Dr. Cayenne was familiar with niacin but not as a treatment for ADHD. She found in the medical literature that niacin had been used as a treatment for hypercholesterolemia (Colletti et al. 1993) in doses of 500–2250 mg/daily. In that study many of the children had side effects, and she was concerned that Jacob also will have side effects.

Dr. Cayenne needs more information, which probably would come from a clinical pharmacologist or even a Poison Control Center. She should encourage the mother to stop the niacin temporarily while Dr. Cayenne collects more information. Jacob needs to be seen frequently to monitor side effects and to allow discussion on approaches to ADHD. Dr. Cayenne should avoid disparaging the naturopath and

should avoid disparaging the use of niacin given her lack of knowledge. She should, however, be very clear with the mother that there might be side effects. Once Dr. Cayenne has more information, then she should give that to the mother. Dr. Cayenne should, of course, continue monitoring Jacob.

As in many situations where parents not only reject medical advice, but also unilaterally move down a different path, the pediatrician must do a risk assessment. Should child protection services be contacted? We would suggest the child protection services not be contacted at this stage in Jacob's case with the proviso that we want Dr. Cayenne to have a continuing good relationship with Jacob's mother, and for the mother to bring Jacob for frequent evaluation. It might be helpful for Dr. Cayenne to contact a naturopath to obtain more information on the niacin and on whether he/she has used it in other patients.

The issues in dealing with Peyton are quite different. Peyton's mother has not only added a new substance (mugwort) of unknown benefit, she has stopped giving her daughter the prescribed therapy which is likely to have been at least partially effective. Peyton is at risk of uncontrolled seizures. The approach here must be quite different from the approach to Jacob's mother. Of course, the initial approach is to ensure that we maintain a good relationship with the family, but the family must be in no doubt about the risks. It is the pediatrician's duty to explain patiently that the child needs anti-epileptic therapy and the consequences of the child not taking it. The parents might not have understood the significance of refusal to administer the medication.

What if the parents are adamant that the mugwort continue? We should check first that there is no likelihood of an interaction between mugwort and the anticonvulsant prescribed. If it is clear that taking anticonvulsants and mugwort is safe, then we can encourage the mother to restart anticonvulsants and to take them in parallel with the mugwort. If she refuses to give her child the anticonvulsant medication, then it would be very reasonable to call child protection services.

In a situation such as this, there is a great temptation to use the referral to child protection services as a threat: "If you don't start the anti-epileptic, then I will report you." Such threats are never helpful and will drive a wedge between the mother and the pediatrician. It is better that the pediatrician explains that she has a personal duty to Peyton, different from the duty the mother has, but a duty nevertheless, to ask for help because Peyton is a child in need of protection. The parents might be surprised by the very idea that the physician would say such a thing. The parent might simply not understand that the child needs the anti-epileptic and the consequences of the child not taking it. It is important to help the parents understand and appreciate the consequences of what they are doing. This patient job of teaching might be needed and might prevent the need to report the situation to child welfare.

It might seem rather odd, perhaps counterintuitive, but it is possible for good relationships to continue with families even when a pediatrician asks child protection services for help with a child. Good relationships can be maintained especially when the parents understand that the pediatrician was focused on the child's wellbeing. However, even if relationships deteriorate, that is not the point. The pediatrician's principal job is not to be liked by parents but to be a good doctor to the child. The child must be protected.

11.5.6 Dr. Torres and Miles

Dr. Aubrey Torres saw Miles Young, a seven-year-old boy whom she had been seeing for several years. A diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) had been made, and in partnership with a specialist in developmental pediatrics, a number of medications have been tried with Miles. None had been really successful, and, to be candid, many had side effects that Miles' mom, and Miles found distressing.

Dr. Torres had been in contact with the specialist, had also done some further reading on ADHD, and wanted to discuss some different approaches with the mother.

The mother said that after her last visit with Dr. Torres, she spent a great deal of time learning as much as she could about ADHD. She discovered that many parents had placed their child on a gluten-free diet and that the children on this diet had benefited considerably with improvements in behaviour. In fact, Miles had been on this diet for two months, and his mother thought there was some mild improvement. She asked Dr. Torres for a note confirming the gluten-free diet was essential, because she wished to submit it with her income tax form to claim the extra expenses associated with a gluten-free diet as a medical expense.

11.5.7 Comments on Dr. Torres and Miles

There are things here in common with the previous three cases in that an intervention has been chosen and given without discussion with the pediatrician. The difference from the preceding three cases is that what has been done is to place the child on a special diet. Given that gluten-free diets are used in children with celiac disease, we have not seen harm in these children for that diet, and we know that the diet by itself will not be harmful provided the family has dietetic advice to ensure that Miles receives all essential nutrients.

The issue here is not that of Dr. Torres doing something good and helping the mother obtain a tax benefit. Who on earth can complain about paying less money in taxes? The issue here is Dr. Torres' integrity. Can she defend a strong letter of support without scientific evidence supporting the claim? The answer to the last is of course not. We know that faced with this problem and faced with a desire to continue to have good relationships with families, sometimes letters are written that seem to be supportive, but in fact are merely commentaries. By this we mean the letter may say "Miles' mother has told me that a gluten-free diet helps". In other words, we give the mother's opinion not our professional scientific opinion. What the taxation authorities want to see in a letter from a physician is a letter that says "I have assessed Miles and I am sure that a gluten-free diet is the right treatment because, (and here place scientific evidence). " The last should never be done, unless there is really strong evidence that we can find in the literature. We believe the correct thing to do is to refuse to provide a letter, but we do have some sympathy with those who write a fudging letter.

11.6 Racism and Sexism Affecting Family Choice of Physician

According to Paul-Emile, "One of medicine's open secrets is that patients routinely refuse or demand medical treatment based on the assigned physician's racial identity, and hospitals typically accede to the patient's racial preferences" (Paul-Emile 2012). This might be so, but it raises the issue of whether we are doing the morally correct thing by respecting the patient's autonomy or doing the morally wrong thing by not challenging racial biases.

In addition to requests for physicians of a different race, there might also be questions for the physician of a different gender. While the principle about dealing with prejudice due to race might be the same as dealing with prejudice due to sex, the two issues are usually handled differently. Particularly in the case of a woman in a particular ethnic or religious group who prefers a female physician, the request is usually granted provided there will not be a delay that will affect the outcome. We note this fact as a practical everyday reality, not because we think that one form of prejudice is correct and another wrong. In both forms of prejudice, the concern should be what is good for the patient not our ability to right societal wrongs. If the female patient will not accept any care from a male physician, and she needs urgent care, then we should not stand in principle, we should walk away to find a female physician who can carry out the treatment. Most physicians see racial preferences differently, but again we do not see them as absolutes. If a patient will be more likely to adhere to recommended treatment with a physician of a particular culture, then we see that as a reason to help the patient connect with a physician who will help the most. That specific action at a specific moment in time does not preclude longer-term action to deal with the underlying prejudice.

It is important also to note that rejection of a particular caregiver might not be on racial or ethnic grounds, even though the rejection might appear that way. The patient's family might have known the proposed healthcare provider socially in a manner that precludes any helpful healthcare encounter. The important matter at hand is to find a physician who can establish a working relationship with the patient and family that will benefit the patient.

11.6.1 Dr. Riviera (Again) and Declan

Dr. Mia Riviera was seeing patients late one day when she was asked to see Declan Rogers aged 9 months. Declan had arrived with his mother unannounced. Dr. Riviera saw him and noted that Declan had seen Dr. Aarav Patel the previous day with a mild upper respiratory infection thought to be viral. Dr. Riviera assumed that there had been some deterioration, and that it would be important to reassess Declan. When she saw Declan, he did not appear ill, and on further inquiry his mother had no new symptoms to report.

This situation was puzzling.

Declan's mother, after some hesitation, told Dr. Riviera that she did not believe the assessment of Dr. Aarav Patel, because he was a Muslim immigrant and she wanted to see someone she could trust.

Declan's mother is a white woman born in Canada. Dr. Patel's parents had emigrated from India and were Hindu. Dr. Patel himself had done very well at medical school in North America; his grades were always excellent.

11.6.2 Comments on Dealing with Declan's Mother

Healthcare professionals are moral actors. This statement by the mother of mistrust of the physician's assessment can cause serious upset. It appears that the mother is rejecting the advice of a physician on the grounds that the physician is Muslim. It could be that she wrongly believes Dr. Patel was trained in a country with substandard education and so she might fear that Dr. Patel does not know best practice as understood in the Western World. If the mother has then misunderstanding, then she should be helped to correct it. On the other hand, she might well believe that she cannot receive reliable medical information about her child from a person of Muslim faith. In this case, she is more to be pitied than criticized. That she is wrong (seriously wrong) is almost beside the point. The point to seize upon is that she has brought her son back. She wants reliable advice for her son's care.

The immediate action is clear, the mother needs to be told that Dr. Patel is a competent physician who is qualified by exacting standards. The details of his ethnicity are not relevant, and we do not believe they need to be shared. There is a temptation to be outraged; this should be resisted. Most people who do surprising things simply don't know how to do otherwise. We can help them. We can explain that race is not a predictor of dedication and skill in medical training and that there are many, many fine physicians in the community of a variety of races and ethnicities.

The mother might, of course, decide never to use this particular practice again, and the issue will not arise for this group of pediatricians. Hopefully, the conversation we have had with her will help her understand that race and ethnicity do not determine whether a person can give reliable medical advice and more important factors are place and quality of training. If the mother is to use this practice again and she requests to avoid Dr. Patel, then we have failed in our communication. Can she avoid Dr. Patel? Are Dr. Patel's colleagues disrespectful of the mother, and not respecting her personal autonomy, by insisting she sees whichever physician is scheduled to see emergency patients on any particular day? Creating a black list of patients and requests that will not be honoured seems at the very least, distasteful.

Dr. Riviera should be very clear with the mother that she does not support racial prejudice. Again, it is important to communicate with the mother. Was there a previous episode involving a child with a physician of a particular ethnic group that did not go well and affected her views? Was there some other life event, even if not medical, that can be discussed and resolved?

On the other hand, if we insist that Dr. Patel sees this particular child again, then there is a risk of "stereotype threat". This is anxiety in a professional that might lead to discomfort in the consultation with the possibility of reinforcing the negative stereotype (Reynolds et al. 2015).

Racial prejudice is a reality in many parts of most countries in the world. We should not support it. When faced with it, we should deal with it directly with compassionate communication directed to helping that aims to help people understand what they appear not to know.

11.7 Conclusion

This chapter is titled "Misunderstanding and Disagreements". It is about difference in knowledge, beliefs that can be unshakeable, relationships, biases, and how we interact with an enormous range of individuals, all of whom bring their own ethnicity and culture to the consultation. We do not believe that misunderstandings and disagreement will ever disappear completely. We do believe that by attention to our communication skills and by proceeding always with respect for the individuality of the parents of the children whom we see, we will minimize misunderstanding and disagreement. We believe that when misunderstanding and disagreements occur, we should be able to recognize them early and take proactive actions to resolve them as soon as possible.

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Part IV
Special Situations

Chapter 12
Oh No! I Saw a Mistake, or I Made a Mistake

Key Points Regarding Medical Error

- Medical error is experiencing harm as a result of receiving health care
- Medical error means that patients have not been kept safe
- Patient safety is "freedom from accidental injury" caused by medical care.
  - Harms or death are attributable to adverse drug events, patient misidentifications, and health care-associated or health care-acquired infections.
- Breaches of patient safety are usually due to multiple systemic problems
- Improvement in patient safety and reduction in harmful errors requires full review of all contributing circumstances and taking remedial action
- Focus on individual blame alone will not lead to reduction in errors
- Medical errors must be disclosed to children and guardians
- Disclosure is important
  - Many trainees and pediatricians find disclosure of error intellectually and emotionally difficult.
- An apology is an admission of error, accompanied by a genuine admission of regret
- Apology is essential when error has been shown to have contributed to a poor outcome
- Expressions of regret should be made immediately
- Apologies should be made once the facts are known

12.1 Chance's Story

When 6-year-old Chance Pendleton (Tarkan 2008) awoke after surgery for a wandering eye, it was obvious that something was not right. "He was crying hysterically, vomiting and kept saying, 'I wish I was dead,'" his mother, Grace Alexander, of Paris, Tex., recalled.

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_12

The boy had been through surgery before and had never reacted this way. "The nurse was quite peeved and wanted me to calm him before he disturbed anyone," said Ms. Alexander, who said Chance was denied more pain and anti-nausea medication. "She thought he was just throwing a tantrum."

After about 20 minutes, another nurse walked by, and Ms. Alexander beckoned her for help. The nurse checked the intravenous line in Chance's ankle and saw that it wasn't inserted correctly. He wasn't receiving any medication. She immediately fixed it, bringing relief to Chance in a matter of seconds.

12.2 Comment on Chance

Chance suffered pain and other severe symptoms but did not suffer permanent consequences. He was lucky! His mother was vigilant, and the second nurse responded quickly. What do we learn from the story about Chance? First, professional staff members are sometimes slow to respond to parental concerns. Second, medical errors occur in children as well as in adults.

Medical error in children can be serious and even fatal. Like adults, children can be the subject of medical error in diagnosis, choice of tests, the conduct of test and error that leads to infection and injury. Unlike adults they are physically smaller with major organs (such as the liver, kidneys and immune system) still developing. Children can be less resilient than adults when coping with medical error. For example, because children are small, and especially when they are premature infants, a very small error in medication dose can have a significant effect. Moreover, when their situation is deteriorating because of the error, children are less able to draw staff attention to the problem. They can be too small to communicate what they are experiencing, making it difficult for nurses and physicians to respond appropriately (Tarkan 2008).

12.3 Open Recognition of Medical Error

It is natural to want to hide error. After all, we are ashamed of having made a mistake, especially one that has caused harm to another person. Shame can have useful properties. As Van Vliet (2008) writes,

> The pain and adversity associated with shame also motivate individuals to increase their intellectual, physical, and social competencies. Thus, shame plays a vital role in learning and in the advancement of society as a whole.

But shame is an unpleasant experience that, according to Van Vliet (2008), can change behaviour. Shame can encourage "gaze avoidance, downward movements of the head, and hiding." These are "submissive appeasement signals that attempt to minimize the possible consequences of rejection and mitigate damage to one's social standing."

The responses to shame that encourage hiding, are not, however, beneficial to improvement in medical practice. On the contrary, openness after medical error is the best strategy to prevent such error in the future. This was the conclusion of the United States Institute of Medicine (IOM), an organization affiliated with the National Academies of Science. This not-for-profit organization which aims to provide leadership in healthcare, published a startling report in 2000 that highlighted a major problem, and proposed a solution.

The title was chosen to guarantee that it received attention: "To Err Is Human: Building A Safer Health System" (Institute of Medicine (US) and Committee on Quality of Health Care in America 2000). The report opened by describing in one sentence, three errors with devastating outcomes, one of them an 8-year-old boy who was having "minor" surgery when he died because of medication confusion.

Not only was the opening guaranteed to gain attention for the report, so was the content. The report stated that an estimate of deaths caused by medical errors per annum was 98,000. If correct, this estimate would mean that medical errors in the US are a more common cause of death than motor vehicle accidents, breast cancer or AIDS. That estimate seemed high, but now appears to have been too low.

The consequences of medical error are manifold, from lost income, lost enjoyment of life, permanent disability, increased healthcare costs, and opportunity cost. For the patients and family, there is a loss of trust, and for the professionals involved, a loss of morale. Medical errors were first identified in hospitals, but now complex procedures are often performed in outpatient surgical centres increasing the sites at which there might be error.

One major theme of the report was that hitherto there had been "silence" on the topic of errors. The report's mantra was that the silence should stop; we should be open. Only by being open can we make headway in reducing, and hopefully stopping errors.

The report encouraged readers to believe that "to err is human, but errors can be prevented". The authors agreed that healthcare professionals are motivated to do the best possible job. The authors aimed to develop a culture of safety in which everyone could learn from errors. This requires many changes in many organizations from regulators to professional organizations to patient organizations.

Since that report, errors have been identified in other countries. In a Canadian study (Baker et al. 2004) collecting data from a number of hospitals, including pediatric units, in the year 2000, the rate of adverse events was 7.5% of admissions. Extrapolated, this datum means that of the 2.5 million annual hospital admissions in Canada, 185,000 are associated with an adverse event. About 70,000 of these errors are preventable.

The American Academy of Pediatrics (AAP) reported on patient safety and used a variety of data sources to establish the significance of patient error in pediatrics (Miller et al. 2011). One estimate was 12.91 adverse events per 1000 discharges. In another review of 10,778 medication orders, 5.7% had an error, and in 1% harm was caused. They estimated that adverse events were three times more common in children than in adults. In the NICU, 45% of the errors were due to medication errors, 14% in the method of using the treatment, 11% patient identification and 7% delayed

ordering of tests and diagnosis. When we move to consider emergency departments (EDs), there were also frequent errors many of them related to communication. The communication problems were between pre-hospital and ED staff, in the ED at change of shift, between ED and inpatient staff, and between ED and families. The errors were mainly diagnostic or related to medication administration.

A study of Canadian pediatric emergency departments (Kozer et al. 2006) reported 100 prescribing errors and 31 medication administration errors per 1000 patients.

The British Medical Journal published a commentary, again with an eye-catching title, "Medical error—the third leading cause of death in the US" (Makary and Daniel 2016). It delineated the difficulties of gaining good data, including insufficient coding. In Chap. 10 on helping at the end of life, we listed causes of death based on ICD coding reported to governmental organizations. However, none of the ICD codes include medical error; only by focused studies of patient charts can we gather the kind of information we need to determine how we are improving, or not, as time goes by. The British Medical Journal commentary suggested an extra line on death certificates to allow mention of errors as contributory factors in the death.

The AAP report (Miller et al. 2011) cited earlier noted that human fallibility is real, that we must focus on the conditions within an institution that make errors possible, and that steps should be taken to avert, or at the very least to mitigate, harms. When trying to make improvements, a focus on individual blame is unlikely to be successful for at least two reasons: first, such a focus discourages people from reporting error; and second, it would prevent discovery of the truth because most errors are not rooted in individual behavior; they are rooted in multiple problems within complex systems.

The AAP report focused on what organizations should do to improve safety and suggested four requirements:

1. Reporting – collect and interpret data
2. Being just – don't punish those who report
3. Being flexible – adapt to changing circumstance
4. Learning – implement change

One consequence of medical error is that aggrieved patients or relatives will turn to litigation. We see this possibility as entirely understandable. The existence of litigation (and the costs to society) is another impetus to organizations to focus on safety. The Lancet (2018) article suggests:

- The promotion of candour;
- The advocacy of a problem-solving culture rather than one based on blaming the individual;
- Improvement in quality of a service.

These suggestions are very similar to those made by the AAP, especially the focus on system changes.

A recent report from the UK, particularly relevant to pediatricians, used "claims" information, that is litigation outcomes, to examine what led to the errors. This report focused on 50 cases of cerebral palsy (Magro et al. 2017), and the number and types of issues, that were seen across the 50 cases. These were:

- Evidence of poor-quality serious incident investigations;
- The patient and family were involved in only 40% of investigations;
- Only 32% had a review that involved an obstetrician, midwife and neonatologist;
- Only 4% had an external reviewer;
- Reports focused too heavily on individual errors;
- The most common theme was errors with fetal heart rate monitoring.
  - The underlying causes were often not related to individual misinterpretation but to systemic and human factors;
- Inadequate staff training and monitoring of competency were identified as an important issue;
- Shortcomings in informed consent were evident;
- Although this review analyses a small number of specific claims, the findings resonate with other reports with similar findings; and
- Unfortunately, the evidence suggests there has been little improvement in these areas in recent years.

In workplace safety, investigators of an incident are encouraged to ask the question "Why?" five times (iSixSigma 2018). This allows a deep exploration of the human factors involved in an incident. Sometimes, the problems can be clearly described with fewer than five whys. Such questioning can help people move from blaming the individual to fixing systems such that the error might be avoided next time. To apply this method to an individual case, why was this child anoxic? "Because the nurse did not put the oxygen prongs on the child". Why? Because the order was never written. Why was it not written? The resident was distracted by another sick child. Why? Two residents called in sick and no one tried to replace them.

This brief review has identified that errors are, sadly, far too common in pediatric practice. The errors cause enormous damage to children, a marked increase in healthcare costs, a loss of trust between the families concerned (and probably the general public) and healthcare professionals, and healthcare professionals themselves lose morale. Solutions are not straightforward, but require individual effort and commitment to safety, and a commitment as individuals to report errors to our organization. In turn, the organizations should avoid focusing on personal blame, and instead should focus on faults in the system that led to the error happening. Asking the question, "Why?" five times can help move the inquiry from the individual through to the system.

In terms of the response to families, there should be disclosure and apology. These can be and often are separated in time. Initially, it is important to tell the families that something has gone wrong and what exactly that is. Investigation is then needed before apology occurs. First comes disclosure and then apology.

12.4 Disclosure

In an era of openness, and a commitment of physicians to truth telling, it is clear that families and patients should be told when there is an error. Failure to do so is clearly deception. Failure to do so will also mislead families to agree improperly to further medical procedures, when they are not in possession of full information. Disclosure is about looking at the harm that occurred from patients and families' point of view, telling the family what has happened and addressing matters that are important to them.

Disclosure is the ethically correct thing to do. It must be done carefully so the support is provided to parents, and colleagues are not unwittingly harmed. The advice presented here is taken mostly from the website of the Canadian Medical Protective Association (CMPA) (2018), an organization with a strong interest in patient safety. Most institutions have a formal process for identifying and disclosing medical errors and trainees should learn local procedures. The language we have used up to this point has been "error", or "adverse event", but we would suggest that once you start considering disclosure, you should use a more neutral word such as "incidents". The reason for this word choice, is that in almost all cases, an investigation is required before we have all the facts in a specific event to know exactly what has happened, and what actions were taken that contributed to the undesirable outcome. We also note that the two most common reasons for apparent harm in a child's care is that the disease has progressed, or that a procedure has had a known complication. Hence, we want to encourage trainees not to prejudge the conclusion of an investigation. A poor outcome in the care of a child does not necessarily entail error.

We really do not know what actually happens during disclosure of medical incidents, but Gallagher et al. (2006) presented scenarios and asked about responses. They sent questionnaires to 4193 physicians in USA and Canada and received replies from 2637 (62.9%). They described scenarios with errors, with questions on how the physicians would respond to the scenarios. Of those who responded, 65% would definitely disclose, 29% would probably disclose, 4% would perhaps disclose, and 1% would not disclose. Given that these are theoretical scenarios, the responses might have a bias with the respondents trying to give the expected answer. In other words, fewer physicians might not disclose in real life. There are indeed barriers to physicians disclosing; these include fears of a lawsuit, physicians' personal shame that they have not met their own high standards, and lack of training in how to disclose and which exact words should be used.

From the families' perspective, if an error has occurred and harm has resulted, then they are entitled to seek financial restitution or to report the physician to the regulator. Patients who moved to litigation often claim to have done so because they have not been given an explanation, they suspect lack of honesty especially if they have had an explanation and have never received an apology.

In the study by Gallagher et al. (2006), less than half the physicians (42%) would use the word "error"; most would talk about "adverse events" using language which exculpates them from responsibility. An investigation will determine what happened. In the first instance it is important to disclose that something has happened. The parents are entitled to know.

12.4.1 First Disclosure Meeting

Therefore, there should be initial disclosure to families, at least that things are not going well, and assurance given then that there will be an investigation, and that full information will be shared with the family as soon as it is available. Most institutions have a named person who will keep in touch with the families. Some families will request transfer of their child to another institution. Such a transfer might deal with an issue, such as loss of parental trust with the first institution but is unsatisfactory in that difficulties may never be resolved. Nevertheless, if a request for transfer is made it should be acceded to if possible. However, there are fewer children's hospitals than adult hospitals, and if a child is in a PICU, he or she might be too unstable to transport over the long distances required to get to another institution. Obviously, there is an awkward situation of the parents have requested a transfer, and the physicians have said that the child is too unstable. We hope both parties will work together to act for the child.

The initial meeting will be the responsibility of the most responsible physician (MRP), and never the responsibility of the trainees. Some consideration should be given as to who should be present, what the setting will be, and what language will be used. The people to be present should be those most closely involved in the patient's care, the families, and whomever the family wishes to invite as a support. If there is a language barrier, then a trained medical translator should be employed; reliance should not be made on family members to translate. If the family wish a lawyer to be present, then the MRP should seek legal advice, and usually should also have counsel present during the meeting. This is not a common request in the early stages, and usually follows when the family thinks they are not being told the truth. The setting should be a quiet area without pagers or cell phones, and the language used by the MRP should certainly include expressions of regret, but not conclusions about blame this soon in the process. The healthcare team might be a tempted to explain all the steps they have taken to prevent such an error from occurring in the future. That temptation should be resisted in the first stage; the focus should remain on the child patient with information sharing about immediate steps to improve the child's health and the plans for future care.

12.4.2 Second Disclosure Meeting: Responsibility and Apology

After investigations have been completed, there will need to be another meeting. Typically, most health care institutions have established processes and individuals who have responsibility to communicate. Again, the communicator will not be a trainee, but if it is possible to attend such a meeting, then a trainee should request permission to do so. This meeting will be a valuable educational experience for the trainee.

This meeting should be very open in terms of disclosure, and if there are errors, then they should be disclosed. The leader of the team should:

1. State what happened;
2. Explain the effect on the child;
3. Denounce that the error was wrong,
4. Accept responsibility; and
5. Apologize sincerely on behalf of the institution.

In the preceding part of this chapter, we addressed the need to examine systemic processes that might have made an error possible. This recommendation should not be taken to assume that we are willing to ignore the role of individual actions in any adverse event.

A trainee might witness an error and realize that it has not been disclosed to the family. The family should know, but it is not the trainee's responsibility to tell the family. However, the trainee does have a responsibility to inform the MRP about what is happening. But if that physician is the one responsible for suppressing information, then the trainee should find someone else to tell. Typically, trainee pediatrician should start with their peer representative, and have the peer representative take this information to a higher level in the hospital hierarchy. We recognize the risk of retribution when trainees do the right thing, and the use of the peer representative is one way to minimize that risk.

To return to the process involved in the Second Meeting, if the incident was the result of an individual's error, then the individual should have an opportunity to apologize. Such an opportunity, if seized, will aid the person who erred and mean most to the family. There will be vulnerability on the part of the family and the person who erred, and these vulnerabilities should be protected by the person leading the meeting. In other words, sincere, heartfelt apology should be protected against an aggressive reception of that apology. Having said that, we would still counsel the need for legal advice before meeting families and offering an apology.

After apologies have taken place, the leader of the meeting should explain the steps taken to ensure that other families will be spared that error.

Given the importance of apology, we address it in some detail next.

12.5 Apologies

As stated, once an investigation has been conducted and it is known what transpired to cause the incident, an apology is in order. Families want a clear statement of the fact that an error occurred, why it occurred, an apology and explanation of how it will be prevented in the future.

An apology is an appropriate part of the disclosure process and seems to improve connections with families. An apology is not an expression of regret, such as "I am sorry that this has happened to your child". An apology is an admission of error, a statement about the role of the person making the apology and does also include an

expression of regret. Nevertheless, physicians might be fearful of apologizing, even if it is absolutely the right thing to do, because of fear of litigation, and the fear that the words will be used against them. In the context of the disclosure discussion, the physician might need to decide whether it is prudent and appropriate to apologize. Many physicians are concerned that by offering a patient an apology for an adverse event they will expose themselves to liability. Here, the surgeon bears primary responsibility, but others in the operating room (anesthesiologist, nurses, technologists) also bear some responsibility.

We quote another piece of advice from the CMPA (2013), saying.

> In the context of the disclosure discussion, the physician may need to decide whether it is prudent and appropriate to apologize. Many physicians are concerned that by offering a patient an apology for an adverse event they will expose themselves to liability.

We do not wish to minimize the fear of those who think they expose themselves to litigation by an apology, even if their concern is accurate, and even if apologizing is absolutely the right thing to do. In a number of legal jurisdictions so-called "apology legislation" has been approved or has been proposed. The idea behind such legislation is to permit apologies, and to forbid the use of an apology in any litigation that arises from the error (Macdonald and Attaran 2009). In general, such statutory protection would apply both to the evidence required if a family sued a physician because of something that happened to their child, and in disciplinary proceedings should the family report the incident to a regulatory body. To be clear, the CMPA (2013) goes on to say, "Given the novelty and general application of apology legislation, it remains unclear how the legislation will be interpreted by the courts in medical malpractice proceedings or by regulatory authorities (Colleges)."

The legal advice we have quoted above is an attempt to protect physicians from litigation. However, Nancy Berlinger (2005) in her work, "After Harm: Medical Error and the Ethics of Forgiveness" reported that physicians who disclose, take responsibility, apologize and ask for forgiveness are less likely to be sued than those who do not engage in this behavior.

We think that when someone has committed an error that has harmed a child, then that person should apologize to the child and to the child's parents. If you have any concerns about delivering a justified apology, then you should seek legal advice, but we hope that advice supports you in doing the right thing. People do make mistakes, and when they do, they owe an apology to those whom they have harmed.

12.5.1 Murray's Story

At 8 years of age, Murray was involved in every sport available. He was a keen soccer, football, baseball player and he loved wrestling and Tae Kwon Do. He complained to his Mom that he had an odd swelling in the right groin; she took him to a pediatrician who said that Murray had an inguinal hernia that required repair.

After the surgery the surgeon came out and told them that he had operated on the left side in error. He expressed his regrets and arranged to meet the family 2 weeks later to review what had happened and what should be done now. At the meeting, the surgeon entered the

room and was introduced to everyone present, the mother had brought a family friend who was a lawyer. The surgeon explained the preoperative procedures and checks that had failed. He accepted personal responsibility and apologized.

The surgeon said, "I am very sorry. I've made a mistake. Murray needs to go back into surgery to repair the hernia on the right side. I can arrange for a different surgeon to do the operation. If you trust me to do this, then I will ensure that I will operate on the correct side this time."

The mother was silent for some time. Then she said, "Everybody makes mistakes." The surgeon eventually repaired the principal hernia without complication.

12.5.2 Comments on Murray's Story

This story demonstrates the process of disclosure and apology. The surgeon immediately knew what had happened. He took time to ensure there was investigation of the incident. Operating rooms nowadays have a clear process of identifying the area of surgery with patient/guardians immediately prior to surgery; this process must not have been followed diligently here. The surgeon would have sought legal advice, and the institutions legal department would also have been involved in planning a response to the error. The surgeon knew that part of the problem was that systems had let him down, nevertheless he took full responsibility as the leader and apologised. The surgeon knew what the right thing was to do, and he did it. The story also demonstrates that families can be and often are forgiving when they are treated respectfully, honourably and forthrightly.

12.6 Challenges of Disclosure and Apology for Systematic Error: Jack Adcock and Rory Staunton

12.6.1 Jack's Story

Jack Adcock presented to hospital with diarrhea, vomiting and breathlessness (Dyer 2015). *He was admitted to hospital and his care supervised by a senior trainee in the specialty of pediatrics. She had been on maternity leave for 14 months. On her first shift back, she made an error that led to Jack's death. The trainee ordered x-rays and tests, and then started intravenous fluids. The tests showed bacterial infection, and antibiotics were also started.*

However, there was delay in the results reaching the physician because of information technology problems. The tests showed imminent renal failure that she overlooked. Later, Jack had a cardiac arrest, and the trainee made another error. The trainee ordered resuscitation to be stopped, because she thought this was the wish of the parents and that it was noted in the chart. In fact, that order was for another child, resuscitation was restarted but Jack died.

The context also matters, not only was this trainee just back after a long leave, the trainee had worked 12 h with no break. Also, there was either inadequate supervision, or no supervision whatsoever. There were problems with the IT system, and some of the results were delayed in reaching her.

What the trainee then did was something that is recommended, she admitted the error to her supervisors, and most importantly, admitted the error to herself and made notes on her reflection on the whole situation.

There seems to be no doubt that she was distraught at the death of the child.

Criminal prosecution began. The trainee was found guilty of negligent manslaughter. Her own notes, her personal reflective statement, something recommended by training organizations in "learning cultures", was used as evidence against her in the court. The regulator suspended her, and then tried to impose a lifetime ban on her practising medicine. Fortunately, a higher court overturned that ban (Dyer 2018).

12.6.2 Rory's Story

Rory Staunton (Jha 2018) *attended New York University (NYU) Hospital with vomiting and fever, a day after scraping his arm. He was sent home with an analgesic and fluids. He deteriorated, returned to the hospital, then to PICU where he died 3 days later. The white blood cell count was raised at the time of the initial visit, but results were never reviewed. NYU was found negligent for systemic errors. The media publicized his death but blamed the hospital for inadequate systems, not physicians for missing a disease (systemic sepsis) that is notoriously difficult to detect in the early stages.*

A foundation has been created in his name to publicize the early signs of sepsis and advocate for system change in hospitals.

12.6.3 Comment on Responses to Jack and Rory's Deaths

These stories are similar: early symptoms of sepsis not recognized, and ultimately two children died. There was error and responsibility for the error is diffuse. The psychologist, James Reason (2000), has been among those advocating for the examination of systems where an error occurs, rather than the scapegoating of individuals. The latter should usually be avoided. As he writes, "Blaming individuals is emotionally more satisfying than targeting institutions."

In Jack's case, the trainee was scapegoated. One might wonder why the staff pediatrician with the duty of supervising the trainee was not severely reprimanded, why the institution was not sanctioned for its poor staffing arrangements, and why its information technology service was not funded adequately. We are not minimizing what the trainee did; her errors led to the death of a child. We are trying to put her actions into perspective because other errors contributed to the death of the child.

By contrast, in Rory's case, the system was found to have failed the patient and family. In this case, we don't even know the name of the physicians involved, all the adverse publicity was directed towards the institution and its poor systems.

To return to Jack's case, the treatment of the trainee by scapegoating is very concerning. We worry that this prosecution of the trainee will lead to "cover ups" of mistakes and delay development of a "learning culture." The trainee's senior col-

leagues stated that she was "a competent and able doctor who recognizes that she missed important features of this child's illness on this occasion." (Dyer 2015).

These two sad stories make some things clear:

- Good people can make mistakes;
- Blaming individuals will happen, but won't prevent harm; and
- Improving health care and reducing errors requires looking systemically and making changes.

12.7 Summing Up: Austen's Story

Austen Sheane was the first child of unrelated parents. He was born at 39 1/2 weeks gestation; his birth weight was 3.7 kg. He was discharged home after 2 days, and his mother asked about the yellow tinge to his skin. The nurse reassured her that jaundice was common in newborn babies, and this was nothing to worry about. The nurse did say that Austen should be checked by the family physician within 2 days. The family physician did see Austen, noted he was yellow, but again did not check bilirubin. Austen was having problems feeding on the breast, and arrangements were made for the mother to see a lactation consultant. 24 h later his feeding was much worse; he had difficulty latching onto the nipple and would suckle for only a minute or two. He also seemed very floppy. The maternal grandmother was staying with the family for several weeks after birth and told Austen's mother that this was very unusual, and she should take Austen to the emergency department.

At the emergency department, the jaundice was marked, and when measured bilirubin was 471 μmol per liter. He had an immediate exchange transfusion but remained lethargic for several days before he slowly showed some improvement. Investigations did not show any etiology for the jaundice.

12.7.1 Comment on Austen

Clearly, the nurse and the physician should have checked the bilirubin level. There is no doubt that Austin is likely to have lifetime consequences of kernicterus. Some trainees may assume in an era of heightened awareness and ready availability of phototherapy, that kernicterus is a disease of the past. Unfortunately, this is untrue (Bhutani and Johnson 2009). The problems of kernicterus might be acute, with, among other problems, lethargy, feeding problems, opisthotonus seizures and sometimes death. Kernicterus can also produce chronic problems such as movement disorders, sometimes so severe the child does not develop the ability to walk, and can suffer hearing and eye problems, and impaired digestive function.

His parents might sue. A full investigation must be carried out locally, including in the family practice, to see what might be changed and improved. Not only should investigators be looking for things that might change, they should actually make changes, which might be intensified education on the importance of jaundice in the newborn.

The steps outlined above should be followed: Initial disclosure, then a second meeting explaining what happened, the results of the investigation, acceptance of responsibility, apology and explanation of preventative steps taken for the future. Austen's mother and other family members should be respectfully invited to such a meeting, and she should have a full apology preferably by the nurse and the physician involved.

She and Austin will share a lifetime of consequences of the oversight of not measuring bilirubin.

Things do not always work out well in healthcare. Sometimes, as we pointed out already, because of no fault of anyone, and not because of an error, patients suffer. Sometimes there is an error. If an error occurs, then the ethical virtues of truthfulness, and of courage in acknowledging personal failures and declaring them publicly are very important.

12.8 Ignoring Neonatal Pain, a Collective Pediatric Error?

In a recent paper about neonatal pain, the authors (Witt et al. 2016) felt it important to state:

> Newborn infants experience pain just as older children and adolescents experience pain; however, clinicians' ability and approach to assessing and managing neonates is inadequate and controversial.

The same authors also said, "They also experience long-term sequelae from pain including impaired neurologic and behavioral development." In a survey (Stevens et al. 2011) regarding painful procedures in Canadian pediatric units (October 2007–April 2008) 2987 children had at least one painful procedure. In only 844 (28.3%) was an intervention documented for painful procedure such as pain relief or being placed on the breast. Adults having a painful procedure expect to be kept comfortable and pain free. How can it be that in children, "for less than one-third of painful procedures was there documentation of one or more specific pain management interventions" (Stevens et al. 2011)?

There was a different perception almost 500 years ago, in 1656, when Wurtz wrote:

> If the skin in old people be tender, what is it you think in a new born Babe? Doth a small thing pain you so much on a finger, how painful is it then to a Child, which is tormented all the body over, which hath but a tender new grown flesh? If such a perfect Child is tormented so soon, what shall we think of a Child, which stayed not in the womb its full time? Surely it is twice worse with him? (Unruh 1992)

Rodkey and Riddell (2013) explored the history of what they called "infant pain denial", a feature of the nineteenth century care of neonates. Unfortunately, as we note above, failure to provide adequate pain relief to neonates has carried on into the twenty-first century! In the nineteenth century, when ether and chloroform became available and accepted for adults including women in labour, they were never con-

sidered for painful procedures in neonates. These authors identified four factors: the child as a "lower being", an idea derived from Darwin; extreme experimental caution, related to badly designed studies; a focus on mechanistic behaviours so that an infant's withdrawal from a painful stimulus could be seen as a "reflex" and not as evidence the child felt pain; and emphasis on brain development, with investigators overlooking responses to pain in their desire to understand brain maturation.

Moving on 100 years, to the late twentieth century, many of these attitudes persisted. In 1983, an Oxford University graduate student was a neonatology resident caring for babies after they had undergone major surgery at Oxford's John Radcliffe Hospital. Attempting to understand why they were so stressed after surgery, Kanwaljeet Anand managed to be permitted to observe neonatal surgery. He was shocked to learn that infants were not receiving anesthetic but only a paralytic to keep them still. This situation was not unique. Because physicians generally believed that newborns could not feel pain, Anand designed clinical trials to test this common understanding and earned a doctoral degree for his investigation of the ability of newborn infants to respond to surgical stress and to consider alternative methods of anesthetic management given their hormonal and metabolic response. (Anand 1985) and (Anand et al. 1985)

New York Times (Paul 2008) summarized Anand's research in this way:

> In a series of clinical trials, he demonstrated that operations performed under minimal or no anesthesia produced a "massive stress response" in newborn babies, releasing a flood of fight-or-flight hormones like adrenaline and cortisol. Potent anesthesia, he found, could significantly reduce this reaction. Babies who were put under during an operation had lower stress-hormone levels, more stable breathing and blood-sugar readings and fewer postoperative complications. Anesthesia even made them more likely to survive. Anand showed that when pain relief was provided during and after heart operations on newborns, the mortality rate dropped from around 25 percent to less than 10 percent. These were extraordinary results, and they helped change the way medicine is practiced. Today, adequate pain relief for even the youngest infants is the standard of care, and the treatment that so concerned Anand two decades ago would now be considered a violation of medical ethics.

In 1987, Berry and Gregory (1987) felt it necessary to note that neonates required anesthesia for surgery, 6 years after their landmark paper (Robinson and Gregory 1981) that demonstrated the safety of narcotic anesthesia in preterm neonates. They were pediatric anesthesiologists and were writing at a time when survival for infants born <1000 g was improving and surgery performed for patent ductus arteriosus, and insertion of ventriculoperitoneal shunts, chest tubes and feeding gastrostomy tubes. The infants were usually sick, with cardiac failure and sepsis, and fluid and electrolyte problems. Berry and Gregory (1987) were opposing the continuing common pediatric belief that term newborns did not feel pain and hence, preterm newborns were even less likely to feel pain. They describe the precautions to be taken such as ensuring appropriate fluid status, neither fluid overload nor undue fluid restriction and the choice of drugs and doses to be used.

More than 10 years later, Anand and Hickey (1987), Berry and Gregory's (1987) message that newborns feel pain seems to have been received by authors who stated, "pain experienced by infants in the neonatal period may have long-lasting effects on

future infant behaviour" (Taddio et al. 1997). However, a close reading of the paper is less reassuring. There were three groups of children in the study. One group had anesthetic cream before circumcision, a second group had placebo(!) before circumcision, and the third group did not have circumcision. These infants were then observed during subsequent vaccination. The findings were that: "Circumcised infants showed a stronger pain response to subsequent routine vaccination than uncircumcised infants." The group given analgesic cream prior to circumcision had an "attenuated [..] pain response to vaccination". They recommended "treatment to prevent neonatal circumcision pain." Duh!

In 2001, a group of investigators (Fabrizi et al. 2001) exposed infants to pain, while recording an EEG and concluded that premature infants are not able to distinguish touch from pain until approximately 35 weeks, an echo of nineteenth century pain denialism. Some ideas last across the centuries!

We hope that pediatricians take heed of the evidence presented here and ensure all of our patients, including preterm infants, have analgesia during procedures and never have surgery without anesthesia.

What are trainee pediatricians to learn from this collective error?

1. Error can occur on a grand scale;
2. Fallacious ideas have a long life;
3. Not all experiments are well designed;
4. Read more than the title of a paper;
5. If an idea seems bizarre, especially if it is cruel, then question it; and
6. Don't accept dogma without evidence.

12.9 Focus on Error or Focus on What Is Done Well?

We might have finished with a quotation from a distinguished British medical leader: "To err is human, to cover up is unforgivable, and to fail to learn is inexcusable" (Feinmann 2011). But there is something else we would like to say.

Please don't misunderstand us; we totally support the statement that error should at least be followed by learning. However, the question of learning is different. Kelly et al. (2016) address what they call "Safety-I". This is the process we have been describing: focusing on adverse event notification and investigation in essentially a reactive manner. In this process, there is always the danger of creating a "second victim", a healthcare professional who committed the "error". That person might subsequently show detachment, anxiety, or might simply no longer report incidents. These feelings and actions become worse if the person is punished.

The focus should instead be on "Safety-II": fostering positivity and resiliency. Safety-I focuses on making sure things do not go wrong and designing procedures to reduce such events. Safety-II attempts to ensure as many things as possible have the desired outcome. Some people attempt to reduce variation, on the grounds that

such variation is cause of a poor outcome. This might be true. However, there is a great deal of variation in healthcare and often times the variation leads to good outcomes.

A pilot project (Kelly et al. 2016) was conducted in a PICU in which staff members of all disciplines were encouraged to report episodes of excellent care. These reports were examined in depth in a scheduled multi-disciplinary meeting, just as adverse events were. The researchers evaluated the process and noted tangible benefits in terms of improved reporting and increased morale. However, there were other outcomes that are worth noting such as improvement in antibiotic prescribing that corresponded to the scientific evidence.

> Excellence is a better teacher than mediocrity. The lessons of the ordinary are everywhere. Truly profound and original insights are to be found only in studying the exemplary. (Bennis 2009)

Excellence in prevention is worth describing and celebrating.

12.10 Training

Trainees might not take the leadership role in communicating with families when an error has occurred. Nevertheless, they need to learn about that leadership role. A recent study (Wong et al. 2017) reviewed the disclosure skills of residents in internal medicine, pediatrics and orthopedic surgery. Participants were also asked whether they had had formal and informal training about disclosure in practice. The researchers also assessed error disclosure skills using structured role-play with standardized patients. The authors were able to compare results with a historical cohort. The data showed that there was no difference in disclosure skills across specialties, but the most recent cohort showed improvement compared with the historic court. The residents identified role modeling as one key facilitator for disclosure. The other key feature was the presence of a strong local patient safety culture.

The AAP (Committee of Medical Liability and Risk Management and Council on Quality Improvement and Patient Safety 2016) has recommended that pediatric medical educators develop and implement educational programs regarding identification and prevention of adverse events (AEs) and communication about AEs with patients and their families as part of a comprehensive patient safety curriculum. However, the AAP paper notes that additional research is needed on the consequences of various approaches to disclosure and of the effectiveness of disclosure education.

The identification of error, and then telling families that error have occurred are important. Trainees should look at their own training program. If the training program deals with disclosure, then they should participate wholeheartedly. If the training program does not deal with disclosure, then trainees should push training directors to include education in this important skill. In addition, when the issue of disclosure arises in a clinical rotation, trainees should ask to join whoever is leading the discussion with the family.

12.11 Conclusion

Not all children have a good outcome after medical treatment. Sometimes, this poor outcome is because of an error on the part of an individual, or because there are poor systems, or because of a combination of these. When an error has occurred, parents and children must be told and an apology should be made. As a caution we suggest obtaining legal advice if involved in a medical error. Whether an apology will be made, even if it is the right thing to do, might depend on the legal advice given. But as Fulghum (1986) wrote in his well-known work, "All I Really Need to Know I Learned in Kindergarten", "Say you're sorry when you hurt somebody."

The skills in disclosing such adverse events are skills that can be taught and should be part of every trainee's experience.

Human beings are fallible, and systems are imperfect. Therefore, individuals and institutions should develop a "safety culture" in which errors are much less likely to happen.

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Chapter 13
Questions About Research Involving Children

Key Points Concerning Research in Pediatrics

- Research is about investigating systematically, establishing facts and contributing to new knowledge
  - Research is essential to the future of child health
  - Children should not be denied the benefits of evidence-based healthcare
- Pediatricians have a duty to foster ethical research.
- Most countries have regulatory oversight
  - Such oversight arose because of research that did not respect the subjects, today known as "participants"
  - Children are especially vulnerable, hence pediatric research rules are stricter than the rules governing research on adults
  - Consent is usually given by parents and in writing
  - As soon as the child is capable, researchers must request and receive the assent of the child research subject.
  - Research subjects should have an opportunity to benefit from research of which they are part
- New compounds should be investigated in adults before research begins in children
  - An exception is for conditions occurring only in childhood
- Pediatric trainees might be invited to be take part in educational research

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_13

13.1 Research in Children: Introduction

The ethics of research in children is complex. We aim in this section to provide information to allow pediatricians and trainees to understand general trends in research ethics, and common pitfalls. Each country has ready access to national standards of ethics review in children. We base much of the content on the Canadian standards, with which are familiar and which are likely to be similar to those of other countries.

We recognize that some readers will need more information, perhaps as members of research ethics review committees or as researchers. Those who need more information ought to prepare themselves by reading some standard books. We recommend two books: one is called "Children in Medical Research: Access Versus Protection" (Friedman Ross 2006). The fact that sometimes children will be harmed by not being permitted to be in research is a very important concept and seems the opposite of messages we have been delivering in this chapter so far. Nevertheless, it is an important concept to explore. The second book is, "Children as Research Subjects: Science, Ethics, and Law" (Grodin and Glantz 1994).

In addition, there is a very useful on-line compendium of information called "Ethical Research Involving Children" (2018). This is a production of The UNICEF Office of Research; Child Watch International Research Network; The Centre for Children and Young People, Southern Cross University, Australia; and Children's Issues Centre, University of Otago, New Zealand (Graham et al. 2013).

13.2 History of Research in Children

Many examples of research in children in the past are well known. Perhaps the most familiar early example is that of Jenner and smallpox. In the eighteenth century, Jenner heard that someone who had had cowpox had immunity from smallpox. He inoculated his son with cowpox, and then challenged him with smallpox. Fortunately, this 'research' met with success. Jenner's son did not contract smallpox. Jenner conducted a number of other studies on the effectiveness of small pox vaccination with other children and demonstrated its success.

As we move into the nineteenth century, attitudes to children were changing dramatically. The first children's hospitals were founded. In addition, there were general trends in medicine, more specifically the use of the microscope and the identification of bacteria as important and effective agents of disease. Just as the eighteenth century closed with a successful smallpox vaccination, so the nineteenth century closed with the successful development of an antitoxin against diphtheria. The large-scale testing was conducted on foundlings, abandoned children, in Paris institutions.

In the early twentieth century, the new discovery of radiology prompted considerable use of x-rays on many normal children in studies of normal development. Use of x-ray even included shoe store use to determine whether the shoes fit

(Hempelmann 1949). Other studies examined gastrointestinal function, giving dyes and other substances to study gut motility in both healthy neonates and sick children. The researchers seemed happy that it was easy to pass a feeding tube in children compared with adults. Almost certainly this procedure was conducted on children because the adults objected vociferously and were strong enough to resist. Later in the twentieth century, from just after World War II and onwards, funding for research became a priority for most Western countries as the advantages of research became evident. There was still little concern about the problems caused to human subjects by researchers.

13.3 Has Research Made a Difference to Children?

When we teach ethics, residents and researchers have frequently commented that we focus too much on the "bad things" that happened in research and forget about the benefits. We acknowledge this criticism's validity. We strongly agree that research is important. That is why we and others engaged in oversight do what we do. But we also strongly believe that it is important to protect the people on whom research will be conducted.

The health of children in the twenty-first century is vastly better than the health of children at the start of the twentieth century. Much of this improvement is the result of factors unrelated to pediatric services. These factors are general improvements in socioeconomic status, nutrition, hygiene and cleanliness. Yet numerous medical advances have revolutionized many childhood disorders. Some such advances have been organizational with the introduction of the pediatric intensive care unit (PICU) and the neonatal intensive care unit (NICU). Some advances have improved understanding of underlying physiology and in turn therapies based on this understanding. An example here might be continuous positive airway pressure (CPAP) introduced for preterm infants, but now used widely in pediatrics, usually with specialized devices, in many contexts (and in patients of all ages!). The management of childhood malignancy has been revolutionized in only 50 years. The introduction of effective chemotherapeutic agents has changed the prognosis of acute lymphatic leukemia dramatically; what was once a death sentence, generally within a few weeks of diagnosis, is now a condition in which survival is expected. The wide range of effective vaccinations against many former lethal childhood diseases has meant that most current practitioners have not seen many of the "common" childhood infections such as measles and mumps. Anesthesia and surgery have improved, and imaging from ultrasound, via CT scanning to MRI scanning have led to a vast improvement in precise diagnosis. In addition to drugs to improve cancer treatment, there are many new anti-infective agents, and many new drugs for common disorders such as epilepsy and asthma. Careful use of epidemiology has led to a marked reduction in the number of deaths that are sudden and unexpected. In some specific conditions, such as cystic fibrosis, there has been a huge improvement in survival because of many different reasons including earlier diagnosis, new

techniques of physical therapy, new sputum clearing drugs, new antibacterial drugs, new ways of delivering antibacterial drugs, and perhaps most of all the development of multidisciplinary teams to focus on a specific condition.

All these beneficial changes are the result of research. We firmly believe children should benefit from the best possible treatment and should benefit from therapy that is based on the best evidence created by high quality research.

13.4 Is Research on Children Ethical?

We have partly addressed this question by offering some examples of how research has benefitted children. Yet it is appropriate to ask whether conducting research on children is ethical in some detail. The short answer is yes provided certain conditions are met. This entire section situates this answer in context.

The Nuremberg Tribunal (discussed in more detail in Sect. 13.8) which considered the ethics of research on humans concluded that research should occur only after the subject has consented. That rationale was the basis for early international regulations and had the effect of restricting research to competent adults. It was seen as disrespectful to children to use them in research. But if we were to say that research is ethical only if the research subject has consented, then it would follow that much research on children is unethical; many children are simply too young to understand the information about the proposed research and to agree to participate.

Over time, opinions modified somewhat; perhaps it was disrespectful to children to forbid them from taking part in research because they were not benefitting as they might from research. Shirkey (1968) described children as "therapeutic or pharmaceutical orphans". He pointed out, in an American context, that drug laws were enacted after the "thalidomide disaster". The drug thalidomide used in the late 1950s in pregnancy was thought to be safe but in fact produced major fetal anomalies. Legislation that followed regulating the use of drugs had the effect that many new drugs were marked "not for children". However, physicians still prescribed drugs to children but without the evidence base to support their safe use and without there being a way to monitor side effects.

In 1995, the AAP produced guidance on studies to evaluate drugs in pediatric populations. They (Kaufman et al. 1995) expanded on the rationale, and made the obvious points that growth, differentiation, and maturation of children will make many differences to how the body handles drugs and that the toxicities might be quite different from those seen in adults. Drug studies confined to adults cannot give meaningful information on pharmacokinetics in children. They emphasized the point made earlier by Shirkey (1968) that when a pediatrician is faced with a child with an intractable problem in which a drug approved for use in adults might help, a decision must be made whether to use the drug to help the child, even if its full scientific support in children is not known. In other words, children are likely to be harmed without research or at least exposed to unnecessary risks.

The Royal College of Paediatrics and Child Health (RCPCH) and Child Health: Ethics Advisory Committee (2000) in the UK also produced guidelines and produced a rationale. Similar to that of the AAP, the RCPCH clearly stated "children are not small adults" and also addressed safety. In other words, "research should be done in children only if comparable research done on adults could not answer the same question".

The statement from RCPCH also added a further qualification that research need not be intended directly to benefit the child subject. In the early stages of including children in research, research was conducted on a child only when there was direct benefit to the child. For many disorders that are present only in children, understanding of these disorders can be gained only by studying children with the disease.

So today, we have arrived at the result that research on children is permissible providing certain conditions are met.

In stating these conditions, it is important to distinguish between three categories of children:

1. Those who are so young or developmentally challenged that they do not understand or appreciate the proposed protocol;
2. Those who can mildly understand and appreciate the research and so can assent; and
3. Those who are mature minors because they fully understand and appreciate the proposed research.

The conditions will be dealt with in the remaining part of this chapter, but include valid consent, usually from a parent but perhaps from an older child who is mature. That consent can be given only after the parent or the mature child has been fully informed and in the absence of coercion. In addition, as with all research, an additional safeguard is that a research ethics board or committee must review fully the protocol to ensure that scientific standards are high and the study is well-designed, and that there is an appropriate balance between risk and benefit.

13.5 What Do We Call Children in Research and Does it Matter?

In the early days of research regulation, research was referred to as an experiment on humans, and patients in research were called "subjects". There has been a gradual movement to refer to "research participants" rather than "research subjects". "Research participants" is the term used in Canadian research guidelines (Canada Institutes of Health Research 2014) and in the UK National Health Service (Standing Advisory Group Consumer Involvement in the NHS Research and Development Programme 1998). One justification for using "participant" is that patients should be more involved in deciding which studies should be done, and how the studies should be done (Chalmers 1995). If the humans upon whom the research is

conducted actually do help to decide what research is undertaken and how it is conducted, then we agree that "participant" is the right word. Often, even in research involving adults, the patient being studied has had little involvement in design of the study. In the case of research on adults, the aspirational word "participant" often does not describe the situation; the adult studied is a "subject" of study.

Children and youth almost never design studies (Corrigan and Tutton 2006). In this book, we refer to the children and youth studied as "subjects" unless there is clear evidence that they are genuine participants. Whatever the name of the person upon whom it is conducted, research should be well designed, with attention to safety and always with respect for those studied.

13.6 What Types of Research Are Relevant to Children

Most parents and many pediatricians want research to be conducted that might offer immediate benefit to children in a variety of situations, and this is understandable. Chalmers et al. (2014) suggest three broad categories of research. First, is the category mentioned earlier in this paragraph, applied research, research that will have immediate applicability to clinical care and will be used in making health care policy decisions. However, some important research might be relevant to children, but perhaps not immediately. Second, basic research, whose sole aim is to advance knowledge, might seem esoteric but success at this level is the starting point for applied research. Given the disdain sometimes felt for research carried out to satisfy curiosity, we spell out why such research is important. In a classic paper, Comroe (1976) traces the practical applications of speculation about why the sky is blue. Tyndall (born 1820) showed that the sky was blue because it contained particles. Tyndall's method of demonstrating particles was used: (a) to confirm Pasteur's idea that germs were not spontaneously generated, but came from existing microorganisms; (b) to show that there were no particles in the distal airways; (c) to measure air pollution; and finally (d) to form the theoretical basis for the present range of flexible scopes used in diagnosis. A third type of research is use-inspired basic research, where the object is to advance knowledge and, at the same time, to ensure that it is applicable to practical outcomes.

Given the practical nature of this book, we focus here on applied and use-inspired research and describe the various forms of clinical trials. In terms of ethics, clinical trials require a substantial body of basic science work to determine efficacy and safety before new compounds may be studied in clinical trials in children.

Phase I studies are the first level of clinical trials in humans to consider efficacy and pharmacokinetics. These are conducted in children only in rare, specific circumstances, such as a life-threatening illness for which currently there is no treatment, or where the only current treatment has failed. In Phase II studies the focus is on safety and efficacy, in small numbers of patients, and are only rarely carried out in children. Phase III studies are the main form of large-scale randomized control study to establish whether a new intervention is effective and is safe. In Phase III, an

intervention, such as a new drug, is compared with an alternative such as a placebo, current standard therapy or another therapy. These studies are carefully planned, including determining the sample size needed to reach a clear conclusion, and specific, meaningful outcomes. In most cases, Phase III studies in children are conducted after successful conclusion of trials in adults. The practice of conducting the research in adults first necessarily delays when a new drug will be available for children. A few Phase III studies are conducted in children before being carried out in adults, but this happens almost always when the condition to be studied is seen only, or predominantly, in children. These trials in children consider efficacy, of course, but must always have a component of the study dealing with pharmacokinetics, given that children handle many substances in a very different way than do adults (Joseph et al. 2015).

Research in children is strongly recommended by Caldwell et al. (2004) partly to avoid the risks of clinicians using interventions that have not been studied in children and using data extrapolated from adults. More importantly, studies should focus on outcomes relevant to children, with attention to safety issues that matter in pediatrics. These pediatric studies should be reviewed by research ethics bodies knowledgeable in pediatrics, and that understand the nuances of consent involving parents and children. As a matter of public policy, pediatric trials must be encouraged along with education of both parents and professionals on their importance.

13.7 Who Decides What Research Is Conducted in Pediatrics?

The lone scientist using her own resources might exist; it is more likely that she is a figment of fiction. Researchers require funding for their research. The funders are many. The obvious funders are government agencies such as the National Institutes of Health (NIH) in the United States with a budget of $39.1 billion for 2019 (Kaiser 2018). The Canadian Institutes of Health Research (2019) have an annual budget of CAN $1.0 billion and the British Medical Research Council (2019) had a budget of £814.1 m in 2017–18. Most countries have created similar organizations to offer greater or lesser amounts of research funding to meet government priorities, that are a mixture of science and general areas suggested by scientific advisory councils. Governments must also meet the needs to be active in areas of concern to taxpayers, and to enhance national prestige. In terms of the latter, the British Medical Research Council, cited above, has a section on its website of awards, including Nobel prizes gained by researchers it has funded. We see nothing inherently wrong with this; taxpayers should know about successes achieved with their money.

There are innumerable other research funders, from very large foundations such as the Bill and Melinda Gates Foundation to small local charities. Small charities often give funds for focused research, usually in honour or in memory of someone who has, or who died from, a specific condition. These small charities play an

important role, but of course do not compete with the massive endowments of the large charities such as the Bill and Melinda Gates Foundation, that gave $4.6 billion in 2017, and has donated a total of $60 billion in research funding (Calfas 2017). Colleges and universities play a role in research funding by having their own grant competitions and by funding laboratories, computers, offices, assistants and so on.

Research funders will state on their websites the types of research they support including the specific topics of interest, size of grants, and application process and deadlines. Pediatric residents planning a research project as part of their training will generally need only small grants. Those residents planning a career in research might need larger grants and will require extensive support from mentors. Whatever the size of the grant, the application should meet the stated requirements and meet deadlines. University research offices are usually willing to help find an appropriate granting agency and to help in constructing a budget. Agencies will scrutinize budgets, but it is never a good idea to start a project that is underfunded.

Whether the application for funding is made by a resident at the start of a career or by an experienced investigator, the application will be reviewed initially by administrative staff to ensure it meets stated guidelines. Then qualified peer reviewers will ensure the project is well described, can be conducted by that investigator and will recommend approval or not.

While peer review of grant applications is a central tenet of the research process, it might be, sometimes, problematic. Chalmers et al. (2014) note that traditional peer review systems can have a strong bias against novelty, and that reviewers tend to support proposals similar to their own interests. In writing about editors and peer review for publication, but relevant to grant reviews, Horrobin (1990) states, "many scientist reviewers are against innovation unless it is their innovation."

Horrobin (1990) cites the example of Bob Edwards' research on IVF. We will describe what happened because this example is one of the best documented given that the evidence of the decision-making process was available in the UK Medical Research Council (MRC) archive (Johnson et al. 2010). The MRC Clinical Research Board refused to fund Dr. Edwards' research. In the 1970s, when Edwards applied for funding, the MRC "gave infertility a low priority compared with population control; assessed interventions as purely experimental rather than potential treatments, and so set the bar for safety high; feared fetal abnormalities and so wanted primate experiments first; and were antagonized by the applicants' high media profile". Edwards obtained private donations for his research and was ultimately successful, being responsible for the conception of the first infant born after IVF in 1978. Once success had been achieved, the MRC reversed its attitude, after political prompting, and offered funding. In 2010, Dr. Edwards was awarded a Nobel Prize!

In summary, individuals or organizations, according to their priorities, make decisions about what research is conducted. This is as true regarding research on pediatric topics as it is in any other group of research subjects. There is a certain moral justification to the locus of decision-making about allocation; funders are entitled to set their own spending priorities. There is also a potential for unfairness. Children cannot advocate for themselves politically. Priorities will be set according to the interests of those with money, and those interests might or might not align

with major pediatric health problems. We see no easy solution to this situation. An area of pediatric advocacy is to aim for equity in research funding, with a bias to obtaining funding for less popular but important topics.

In this section, we have not addressed funding from commercial entities. This is important in the advancement of treatment and is dealt with later in Sect. 13.12.2.

When governments or large health care organizations fund research, we see them as having a moral imperative to set priorities carefully, to pay attention to mortality and morbidity data, and to consult widely. It goes without saying that there must be transparency in their decision making.

13.8 What Research Should Be Conducted in Pediatrics?

As outlined above, setting research priorities is complicated. Rather than answer the question by listing what we think should be funded, we would answer the question by focusing on the process of allocation. Pediatricians, including trainees, should be actively engaged in setting priorities. "Pediatric research" should not be narrowly construed as relating only to medical treatment. Children can be helped by effective research in education and social services, for example, and topics in these areas are as relevant as "pediatric" research.

For these reasons, we agree with Altman (1994), "We need less research, better research, and research done for the right reasons." Altman was not talking specifically about pediatric research, but his comments are generally relevant. He highlights how clinicians can be misled by reading papers with "inappropriate designs, unrepresentative samples, small samples, incorrect methods of analysis, and faulty interpretation." If the topic of pediatric research is chosen carefully, but methods are not, children are not helped. Pediatric trainees have responsibilities at many points in research from ensuring their own research is sound to evaluating published studies whose results are used in patient management.

Pediatric research must be broadly construed. It must include basic research as well as applied research and use-inspired basic research. The many advances we see today in neonatology could not have occurred without the many preceding studies of cardio-respiratory physiology and the chemistry of surfactant.

We should also think globally about research priorities, recognizing that morbidity in many underdeveloped countries is vastly different from that seen in North America or Europe. Fortunately, attention is now being given to these children via private foundations such as the Bill and Melinda Foundation (http://www.gatesfoundation.org), support from international organizations and aid from western governments.

Hoppu et al. (2012) reviewed worldwide progress in the development of new medicines for children and whether children have access. They commend the initiatives of the United States (US), the European Union (EU), and the World Health Organization (WHO). Unfortunately, they noted patchy progress in other developed countries, with less access in poorer countries. They recognized that "Retaining and

fostering public and political interest in paediatric medicines is challenging, but pivotal for success." We echo their optimistic conclusion "that with concerted efforts and appropriate resources, change is possible but slow."

13.9 Conducting Immoral Research

The history of research ethics necessarily emphasizes research conducted in Germany before and during World War II. From the perspective of the people on whom the research was conducted and readers of that history, the research was atrocious. The research subjects tended to be prisoners who could not refuse to participate. The goals of the research were to improve Germany's success in war and to demonstrate that its ideology of Ayran superiority was based in fact. Some experiments were in sterilization procedures to reduce the populations of peoples whom the Nazis considered undesirable such as Jews and Roma. In some cases, the end point of the experiment was death. After concentration camps were liberated, the survivors began to tell stories of what had happened under the guise of medical research. One group of allies, the Americans, decided to put the physicians who conducted the horrible experiments on trial in the US occupation zone, which was in the southwestern part of Germany. Thus, the trials took place in the Bavarian town of Nuremberg beginning in 1945. The Nuremberg Trials led to a report with specific recommendations. This "Nuremberg Code" listed ten preconditions for research on humans, with a major focus on consent (Nuremburg Military Tribunals 1949).

1. The voluntary consent of the human subject is absolutely essential.

   This means that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. This latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person which may possibly come from his participation in the experiment.

   The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs or engages in the experiment. It is a personal duty and responsibility that may not be delegated to another with impunity.
2. The experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature.

3. The experiment should be so designed and based on the results of animal experimentation and a knowledge of the natural history of the disease or other problems under study that the anticipated results will justify the performance of the experiment.
4. The experiment should be so conducted as to avoid all unnecessary physical and mental suffering and injury.
5. No experiment should be conducted where there is an a priori reason to believe that death or disabling injury will occur; except perhaps, in those experiments where the experimental physicians also serve as subjects.
6. The degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment.
7. Proper preparations should be made, and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability, or death.
8. The experiment should be conducted only by scientifically qualified persons. The highest degree of skill and care should be required through all stages of the experiment of those who conduct or engage in the experiment.
9. During the course of the experiment the human subject should be at liberty to bring the experiment to an end if he has reached the physical or mental state where continuation of the experiment seems to him to be impossible.
10. During the course of the experiment the scientist in charge must be prepared to terminate the experiment at any stage, if he has probable cause to believe in the exercise of the good faith, superior skill and careful judgement required of him that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject.

The first point, that consent is absolutely necessary, implies that children could never be subjects of research because they could never give informed consent. While this injunction might have been followed, at least briefly in some countries, in general, surrogate consent by a parent or guardian is now considered sufficient.

The Nuremberg Code was followed by various regulations in different countries around the world. The World Medical Association (2013) used the Nuremberg Code as a basis for research regulations at its meeting in 1964 in Helsinki. These rules have been revised a number of times and are still called the “Helsinki Declaration”.

13.10 The Impetus for Regulation in the English-Speaking World

In the English-speaking world, Nazi research seemed to belong to another time and place and was of little relevance to scientists during the period in which it was conducted. Two publications within a year of one another changed the attitude of both the public and politicians in the English-speaking world to research, experiments, and to the moralities of researchers.

The first was a paper by an American anesthesiologist, Henry Knowles Beecher, in the prestigious New England Journal of Medicine, "Ethics and Clinical Research" (Beecher 1966). The other was a small book, "Human Guinea Pigs", by a well-known English internal medicine specialist, Maurice Henry Pappworth (1967). Beecher gave examples of unethical research he had come across, but without references. His paper had five citations, all to do with the importance of research ethics. None offered specific references to the studies. In other words, Beecher did not "name names". Beecher did cite horrific examples that involve children. As a first example, Beecher wrote,

> This study was directed toward determining the period of infectivity of infectious hepatitis. Artificial induction of hepatitis was carried out in an institution for mentally defective children in which a mild form of hepatitis was endemic. The parents give consent for the intramuscular injection or oral administration of the virus, but nothing is said regarding what was told them concerning the appreciable hazards involved.

Beecher's second pediatric example was:

> it is a question whether ureteral reflex can occur in a normal child. With this in mind, the vesicourethrography was carried out on 26 normal babies less than 48 hours old. The infants were exposed to x-rays of the bladder while the bladder was filling and during voiding. Multiple spot films were made to record the presence or absence of urethral reflux. None was found in this group, and fortunately no infection followed the catheterization. What the results of the extensive X-ray exposures will be, no one can yet say.

Dr. Pappworth (1967), however, was much more willing to name the names of researchers whose work he considered unethical. His book is full of specific references to research conducted. The references are complete citations with author's names, article title, journal name, volume, date of publication and pages. It is not clear why there should be such a difference in the approach to openness in these two publications (Gaw 2012). The difference might be related to a different legal requirement, a different attitude to freedom of publication, or simply due to the fact that one of the two was prepared to take personal risks by publicly naming and shaming.

The personal risk to Beecher might have been significantly greater than to Pappworth. Pappworth was already an outsider and had little to lose by revealing wrongdoing by physicians; he had been denied appointments for which he was qualified by the English medical establishment probably because he was Jewish. By contrast, Beecher was a professor of anesthesiology at Harvard University. Moreover, Beecher had participated in CIA-funded research on hallucinogens administered to people without their consent. As McCoy (2007) argues, Beecher "conducted experiments whose success entailed infliction of psychological pain on human subjects in violation of the Nuremberg Code."

Perhaps Beecher did not name names because people in glass houses should not throw stones? As El-Hai (2017) wrote in the Harvard Magazine:

> Beecher never publicly acknowledged his own involvement in CIA-sponsored human-subject research during the 1950s: experimentation that exposed unknowing subjects to dangerous drugs. Historians now debate the significance of his clandestine research; some have wondered whether this pioneer of modern medical ethics was a hypocrite. Or did Beecher belatedly recognize his personal errors, and determine to crusade against the unethical practices that had ensnared him?

In Pappworth's (1967) book studies are cited and so names are named. Some of the examples are horrific, just as Beecher's examples were. One study involved heart catheterization of 16 children with active rheumatic heart disease, with the conclusion that "active rheumatic heart disease interferes with the functional efficiency of the heart". Other experiments described how healthy children were catheterized to determine normal pressures in the pulmonary artery in the first few months of life. The studies were carried out on "mentally defective infants" between 2 days and 9 months.

We could offer more examples cited by Pappworth (1967), but the point is obvious that much research was happening that involved risk to the subjects, and clearly did not involve consent that was fully informed. There were other instances that received the attention, at least in the US, of politicians and the public. The US Government responded by creating the Belmont Commission produced its report in 1979 (U.S. Department of Health & Human Services 1979). There followed a series of regulatory changes mandating prior approval of research by oversight bodies that applied ethical standards to the researchers.

Since then such bodies, regulatory boards or committees, are found in all countries. The names vary, from Institutional Review Board (IRB), Research Ethics Board (REB), Ethics Committee, and so on. The membership of these boards or committee again vary, but certainly will include members of the public, someone knowledgeable in ethics, someone knowledgeable in law, and someone knowledgeable in research methodology and the topic of study. The specific rules vary again from country to country and are modified over time. However, all current rules are based on the principles established in the Belmont report: respect for persons, beneficence, nonmaleficence and justice. The implications of these "four principles" are described in more detail in Chap. 1.

13.11 Have Regulations Made a Difference?

Regulations will be successful only if researchers act with integrity. The bioethicist Carl Elliott (2017) has a course on research integrity in which he describes unethical studies of:

> children fed plutonium-laced breakfast cereal, prisoners dosed with the active ingredient in Agent Orange, mental patients given psychedelic drugs and massive electroconvulsive therapy before being sent into curare-induced paralysis and a coma.

Elliott notes that in institutions in which unethical research has occurred, many dissenters have tried to use internal mechanisms and that they rarely succeed. Many of those who notice unethical research worry that whistleblowing will be futile. Those same people are often afraid of retribution.

Where does this mean to the training in pediatrics? Being ethical, and behaving with integrity, might often be the easy choices. When we see research misconduct, we have an obligation to report what we have seen, particularly when children are harmed. This takes courage. We suggest that when pediatric trainees see unethical

research, they discuss their experience with their representative first of all and have the representative notify senior authorities in the training program and the ethics review system. Having the representative do this, means that the individual who saw the misconduct is not a target.

On the other hand, you can let the misconduct go unreported. You will not suffer any penalties because you will not be a whistleblower. You will, however, have to live with yourself.

13.12 Research and Integrity

Thank goodness we no longer blood-let febrile children. We might look disdainfully at practices of previous generations of physicians. After all, they did not have the benefit of the wealth of evidence available today including the guidance of consensus statements. Despite our advances, there is undoubtedly research conducted even today that is broadly conceived and/or badly executed. The results of this research might lead us to use treatments that are ineffective or even worse, harmful. Such research might even lead us to avoid effective and safe treatments.

Pediatrics today relies heavily on good-quality research. This book focuses on ethics, and this chapter on the ethics of research. The skill with which the research is conducted, and, for example, the choice of analytical methods used, are as of much concern to the ethicist as any other component of the research process.

13.12.1 The Researcher

We also expect the researcher to have integrity. Integrity is "the quality of being honest and having strong moral principles that one refuses to change" (www.oxforddictionaries.com). Integrity is required at every stage of research, from applying for funds, through study design, carrying out research, analyzing results, writing reports for publication and attributing authorship. We hope researchers are free of conflict of interest, "A situation in which persons are in a position to derive personal benefit from actions or decisions made in their official capacity" (www.oxforddictionaries.com).

Sadly, all is not well in the world of research; fraud and misconduct are widespread. One author (Gupta 2013) quotes a study showing that 40% of researchers were aware of misconduct but did not report it. One definition of fraud is "the knowing breach of the standard of good faith and fair dealing as understood in the community, involving deception or breach of trust, for money" (Sheehan 2007). Gupta describes research fraud as, "The fabrication, falsification, plagiarism or deception in proposing, carrying out or reporting results of research or deliberate, dangerous or negligent deviations from accepted practices in carrying out research." (Gupta 2013).

Fraud is intentional. It includes falsifying or fabricating data and producing misleading reports. Misconduct is different because it is usually negligent; it involves poor management such as failure to follow a protocol. Fraud likely has a number a number of causes. These include professional over ambition, intuitive beliefs in the "right" outcome from the research, pursuing personal interest, few or no penalties, and rewards of fraud. Sometimes there are warning signs, such as results that are "too good to be true".

Titus et al. (2008) suggest measures to prevent research fraud:

- Adopt zero tolerance: all suspected misconduct must be reported, and all allegations must be thoroughly and fairly investigated.
- Protect whistleblowers: careful attention must be paid to the creation and dissemination of measures to protect whistleblowers.
- Clarify how to report: establish clear policies, procedures and guidelines related to misconduct and responsible conduct.
- Train the mentors: researchers must be educated to pay more attention to how they work with their junior team members.
- Use alternative mechanisms: institutions need continuing mechanisms to review and evaluate the research and training environment of their institution, such as internal auditing of research records.
- Model ethical behavior: institutions successfully stop cheating when they have leaders who communicate what is acceptable behavior, develop fair and appropriate procedures for handling misconduct cases, develop and promote ethical behavior and provide clear deterrents that are communicated.

Authorship is public recognition of the researcher's work; it is the reward. Authorship must be earned. According to the International Committee of Medical Journal Editors (2018) authorship requires:

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Journals now insist that each named author on an article describes his or her contribution to the study. When trainees or junior pediatricians become involved in research, then they should raise the issue of authorship at the outset.

13.12.2 The Research Funder ("Sponsor")

Much of the activity that leads to conflict of interest in researchers and to questionable research, can be traced back to commercial entities. There is no doubt that any new product on the market intended to improve human health requires

well-designed studies that will produce results that can withstand the detailed scrutiny of the governmental approving authority. Some studies are specifically designed to have results that will be beneficial to the pharmaceutical company when advertising.

Parker et al. (2018) state that it is:

> important that health professionals and the public are educated about the promotional nature of industry activities, particularly those dressed up as research, education, or covert marketing through surrogates such as patient associations and key opinion leaders.

In addressing possible conflict of interest, we confine our remarks in this book to describing some of the ways that pediatric researchers might receive payment, ostensibly for research. We aim also to alert the trainee to larger issues of research funding from companies, often very large and multinational. As listed by Parker et al. (2018) they are:

- Classic marketing e.g. flooding or penetrating market and influencing prescribers (samples, gifts, etc.)
- Marketing through evidence
- Presenting evidence that is likely to increase drug use
- Marketing through education
- Framing promotion as medical education
- Marketing through surrogacy
- Cultivating relationships with key opinion leaders

Watkins and Kimberly (2004) used a questionnaire survey to establish knowledge about pharmaceutical marketing in their internal medicine program. The response was excellent. For residents, 85 responded out of 88 (97%) and for faculty, 86 of 109 (79%). The questions addressed the following topics:

- Familiarity with statements from professional organizations;
- Literature exploring the impact of marketing strategies on prescribing patterns;
- Efficient and critical interpretation skills of drug promotional materials;
- Potential for ethical conflicts of interest;
- Patients perception of the physician–pharmaceutical industry relationships;
- Economics of pharmaceutical marketing;
- Familiarity with marketing techniques; and
- Familiarity with pharmaceutical speakers' bureau.

Overall understanding was poor leading the authors to design a curriculum in their program to address the deficiencies.

Watkins and Kimberly wrote in 2004. Perhaps things are now better but this seem unlikely. A more recent review (Weißkircher et al. 2017) of published curricula on marketing activities reported that most participants had some deficiencies. Nevertheless, we see this publication as a good starting point for those interested in improving pediatric education in this topic.

13.13 Special Populations and Research

There are gross inequalities of health both within and between countries. Jongwook (2005) quotes a spread of life expectancy of 48 years among countries and 20 years or more within countries. These gross inequalities are not inevitable, and social factors contribute greatly to these discrepancies. These are the so-called "social determinants of health"; one would think these discrepancies would be a target of research. We will describe some of the barriers preventing what would seem to be essential research to improve health of everyone, and more specifically the health of children. As we noted in the chapter on end of life care, the infant mortality rate in developing countries is much higher than the infant mortality rate in Western countries.

Some reasons that research faces barriers relate both to research scandals and to missteps. One major research scandal was the Tuskegee study (Freimuth et al. 2001). The US Public Health Service ran the study from 1932 to 1972. It included 399 African American male subjects and 201 African-American males as controls to study the natural history of untreated syphilis. Those in the study were never told they had the disease but rather that they had "bad blood". They were offered funeral expenses to participate in the study. Penicillin became available in the 1940s; the men were not told there would be a treatment. Somewhere between 28 and 100 men died as a result of syphilis. The study was by itself grossly immoral by any standards of human decency. The legacy of the study is distrust by African-Americans of research, and a lack their willingness to participate in medical research.

In the context of Western countries, much of the concern has been on research in Indigenous peoples with high infant death rates and premature mortality in adults due to number of specific conditions, such as adult-onset diabetes and obesity. Some research has been well received (Arbour et al. 2004), and other research has aroused great criticism in aboriginal peoples in different parts of the world. A great source of criticism has been the examination of genetic profiles in the belief that identification of specific genetic differences might lead to rapid identification of specific pharmacological treatments. Such thinking, even though it uses the latest of scientific knowledge, might be simplistic and misunderstand the links between genetic findings, race, ethnicity, and health (Pearce et al. 2004).

Kowal et al. (2012) noted that in aboriginal communities, health inequalities and racial stereotypes are combined. They tell the story of a researcher who made a presentation at a conference about overrepresentation of what was called the "warrior gene" in the Maori population. The media picked up the story suggesting that the Maori were predisposed to violence. This is an example of racial stereotyping and something that could lead to other problems such as difficulties in obtaining insurance.

Indigenous communities around the world have identified many similar examples and demanded new paradigms of research in their communities (Vogel 2015) and (Cooke et al. 2007). The principles developed in Canada are described here as an example. The approach to research and ways in which Indigenous comminutes

relate to researchers show similar trends in other countries. The Canadian paradigm is known by the acronym OCAP, **O**wnership, **C**ontrol, **A**ccess, and **P**ossession (Schnarch 2004).

Ownership

Ownership refers to the relationship of a First Nations community to its cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns their personal information. It is distinct from stewardship. The stewardship or care taking of data or information by an institution that is accountable to the group, is a mechanism through which ownership may be asserted.

Control

The aspirations and rights of First Nations Peoples to maintain and regain control of all aspects of their lives and institutions extend to research, information, and data. The principle of control asserts that First Nations Peoples, their communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes which impact them. First Nations control of research can include all stages of a particular research project – from conception to completion. The principle extends to the control of resources and review processes, the formulation of conceptual frameworks, data management and so on.

Access

First Nations Peoples must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.

Possession

While ownership identifies the relationship between a people and their data in principle, possession or stewardship is more literal. Although not a condition of ownership per se, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party is in the possession of another, there is a risk of breech or misuse. This is particularly important when trust is lacking between the owner and possessor.

Most importantly, OCAP is forward-looking and pro-active. It opens up new avenues for the expression of self-determination and self-governance in the areas of research and information and provides a measure of hope for positive change.

Research in Indigenous/Aboriginal communities can be very worthwhile. Anyone in pediatrics, including trainees, contemplating conducting such research must consult leaders of the local aboriginal community at the earliest possible moment to start the process of engagement. The local research ethics board/committee might be able to identify scholars knowledgeable on research in this community.

13.14 Common Questions About Pediatric Research

The ethics of research in children is complex. Those who intend to have a career in research must prepare themselves by reading some standard books. We recommend two books: one is called "Children in Medical Research: Access Versus Protection" (Friedman Ross 2006). This book raises the issue that sometimes children will be harmed by not being permitted to be in research. This is a very important concept and seems the opposite of messages we have been delivering in this chapter so far. Nevertheless, it is an important concept to explore. The second book is, "Children as Research Subjects: Science, Ethics, and Law" (Grodin and Glantz 1994).

In addition, there is a very useful on-line compendium of information called "Ethical Research Involving Children" (2018). This is a production of The UNICEF Office of Research; Child Watch International Research Network; The Centre for Children and Young People, Southern Cross University, Australia; and Children's Issues Centre, University of Otago, New Zealand (Graham et al. 2013).

Each country has ready access to national standards of ethics review in children. We are familiar with the Canadian standards which are likely to be similar to those of other countries.

13.14.1 Comments on Consent/Permission

The issues with consent and permission are exactly the same in principle as those in clinical practice, though the details are different. As with clinical practice, research may not proceed without full information being offered by the researcher to the patient and family, there must not be any coercion, and the individual giving consent must have capacity. In most pediatric studies, authorization for a child to be in a study is given by a parent, but there is a general requirement that the child's assent is also essential.

Information given to parents (or mature children) before participating in a research study is in writing, and the consent form has been scrutinized, and approved by the ethics board/committee. That consent form must contain full information about the study, with a number of specific elements, including details of any risks, and if there are any benefits. The consent form must not contain promises of benefits that are unrealistic. The consent form must be written in plain English targeted at the educational level of Grade Six in Canada (ages 11–12 years).

Coercion can occur. Often the researcher is also the physician to the child patient, exacerbating the imbalance that already exists in that situation. While there is no easy solution to reduce that imbalance, one way is for a third party, such as a clinic nurse to explain the study in outline to the family and to seek the family's permission to meet the physician to receive full information about the study. In the previous section, we alluded to the fact that participating in research might be an important way to allow access to novel treatments. In such situations, parents might

feel pressured to give consent as the child may suffer by not having the latest treatment. In some cases, especially when cancer is advanced, the experimental treatment might be the only one that could be used. Parents of children with cancer protested a European Commission rule that permits drug companies to exclude children from cancer drug trials. “Charities including the Institute of Cancer Research and Teenage Cancer Trust say around 3,600 British children could miss out on life-saving drugs as a result” (Allen 2017). In other words, research in this context has gone from being a burden and risk to become a benefit!

Usually, the capacity of the parent or guardian to consent is assumed, but if there is any suspicion that the parent or guardian does not have capacity, then there probably should be a formal assessment.

The situation with teenage patients is more complex. There might be some instances when the teenage research subjects will be considered mature and be given information about the study for them to consider consenting on their own behalf. If this happens, then there should be documented that the teenager is mature. Whatever the age of the child, unless a very young infant, some form of assent should be requested. Even if the parent gives the formal permission by signing the consent form, the child who is the subject of the research should give assent. Such assent might be given after the child hears or reads an approved script, or more likely a brief form with basic information about the study and a place for the child to sign. If the child refuses to assent, then the research should be conducted on the child only if there is a likelihood of benefit. Even then, ignoring assent is a major breach of trust between the child and the researcher and should be recognized as such.

If the parents sign the consent form giving permission for their child to participate in the research study, does that mean they have access to all the information that applies to the child? The answer to this is clearly no, especially regarding the content of interviews given by their child. The consent form should be very clear that data collected by the researchers would not be available to families because many interviews concern sensitive data. However, the issue is more complex when the data collected concerns such issues as use of street drugs detected by blood testing, pregnancy testing, or other reproductive issues. Teenagers should be warned when such information will be collected and that there is a chance their parents might find out about it. As we mention in the Sect. 2.1 on consent and Sect. 4.3 on adolescence, it is very important that teenagers have confidentiality in these issues; without this assurance, they might not access medical services.

In many studies, including pharmaceutical studies, blood is connected for genetic analysis of one type or another and specimens are often stored. The blood might be analyzed initially to determine whether there are subsets of children who will respond to a particular drug, or subsets of children who might have side effects. The initial analysis might undercover genetic information perhaps not directly relevant to the child but relevant to the family. The consent form should state clearly what would happen to that information. If it is made clear in advance, it is quite reasonable not to pass incidental information to families. If the information is given to families, then the family needs to consider whether the information should, in turn,

be given to their extended family. When researchers plan to store specimens, they must stipulate the conditions of storage and what future use might be made of the specimen. We hope the specimens are stored in an anonymized form recognizing that it is difficult to anonymize any specimen fully. Any future use of the specimen should also be clear; this can vary from very specific studies related to the same condition as the subject of the study to general use in other studies.

13.14.2 Research on Emergency Management

If there had been no further developments in research ethics since the *Declaration of Helsinki* was first promulgated in 1964, then some research would be impossible because of the Declaration's strict requirement for consent from a competent adult. Specifically, research on emergency medical conditions, with our strict requirement for informed consent before starting the study, could not be done. In pediatrics, some situations that could not be studied would include resuscitation of the newborn, cardiopulmonary resuscitation in the emergency department, and indeed urgent management of most conditions. If the studies cannot be done, then children would be denied the benefits of evidence-based care in these and other similar situations.

The solution is straightforward but requires an extra degree of scrutiny by the ethics board/committee. In a genuine emergency situation where best management is uncertain, children can be enrolled in the study without requiring parental consent. Once the major crisis has passed, then the parents must be approached for their consent; they may agree or refuse to agree that the child continue in the study. On the face of it, such enrolment of the child in research without initial parental consent is a breach of the requirement that informed consent is an essential precondition. The ethical justification for this breach is that such a research practice will allow children access to the best treatment. The reviewing ethics board/committee will take extra care when reviewing such projects.

13.14.3 How Long Can Research Take?

Some pediatric research involves accessing health records with no further contact with the child. Other studies might be a single interview, examination or test. A few studies can take a lifetime. There are a number of long-term surveillance studies in which a cohort of children is identified, sometimes before birth, more often in the early months of years alive, and followed at intervals at least until adult life. Some of these studies continue until the original recruits are in their 40s.

In the specific studies that last into adult life, then the subjects, now adults, must give permission to continue the study.

13.14.4 Describing an "Interesting" Case in the Medical Literature

A common situation occurring in the training of pediatricians is identification of a very unusual patient situation, perhaps a rare diagnosis, an unusual presentation, or some interesting twist overall. A staff pediatrician may suggest that the resident "write up this case", with a literature review. Such case reports do not need formal ethics review but do need the consent of the parent and of the child patient. Trainees interested in writing up such reports should consult the target journal for their requirements. Many journals will stipulate written parental consent and will have an appropriate form. It goes without saying that the report should not contain identifiers.

13.14.5 What If a Study Is "Quality Improvement" (QI)

QI activities are now key to ensuring that healthcare activities are effective, that they are responding to changing circumstances, and that we believe it is always possible to do better. QI projects, like research, might be an educational requirement of some pediatric training programs. There are a number of definitions of QI, including this:

> as the combined and unceasing efforts of everyone— healthcare professionals, patients and their families, researchers, payers, planners and educators— to make the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development (learning)." (Batalden and Davidoff 2007)

Some activities included under QI are: establishing patient/family knowledge of illness, understanding the burden of illness, how well patients function and the quality of their life, what patients and families think of their care, determining the social context, and identifying whether there is unwanted and unnecessary variation in activities or outcomes.

Some QI techniques are:

- Using diagrams to illustrate flow, inter-relationships and cause-effect relationships;
- Narrative descriptions and case examples;
- Recording data over time and analyzing the data on run charts and control charts;
- Developing new, locally useful knowledge; and
- Making small tests of change such as plan-do-study-act (PDSA) cycles.

Some of these techniques are similar to some of the techniques used in research. Others, such as PDSA cycles are rarely used in research. Some QI techniques involve reviewing charts and interviewing and asking patients/families to complete questionnaires. There seems to be a need for some kind of oversight, as the risk of causing harm to patients is real. However, this should not be the current research ethics boards/committees. They are already overburdened and underfunded. In

addition, many, perhaps most, QI projects aim to give rapid feedback to the care system and to initiate immediately another cycle of improvement.

Some studies that seem to be QI might need formal review and local boards/committees should have their own criteria. Developing widespread agreement has proven difficult. Some criteria that have been used are in our opinion irrelevant, when taken out of context; these include external funding, achieving generalizable results and publishing the results in a peer reviewed journal.

We do not know of any one single factor that separates a QI activity from research, though having the authority to implement change rapidly is an important consideration that suggest the work is QI, not research. We suggest trainees, and staff pediatricians consider their endeavor overall and, if in doubt, consult someone knowledgeable about the local ethics review processes. Casarett et al. (2000) suggest that:

> a project is "research" rather than quality improvement if it is a substantial deviation from established good practices (more risk of unexpected adverse impact), has substantial funding (more risk of bias), has substantial nontherapeutic aims (more risk of investigator self-interest), has individual patients as subjects (rather than care systems or providers), or involves randomization and blinding.

Having said all of this, we believe that it is an ethical duty for pediatricians to pursue constant improvement in how we deliver care. We should never be satisfied with the status quo. Is the way we deliver care meeting our objectives? Is there a better way to provide care in any given situation? By asking these and similar questions, we are making the case that QI activities are a duty. However, attempts at "improvement" must always be undertaken in an ethical manner with the interests of patients and their protection as the first priority.

13.15 Working with Research Ethics Review Boards/Committees

Given that there are many different ways in which ethics review boards/committees are organized and run, not only in different parts of the world, but also within one country in different institutions, we will not give a catalogue of who they are and what their requirements are! We would suggest, however that pediatric trainees familiarize themselves with the process in their institution, and local standards. We would go further. We recognize that sometimes and, in some places, researchers might think that ethics oversight is an unnecessary impediment. They might think that such oversight leads to extra work for the researcher without any benefit. While it is true that oversight entails more work, there is benefit both to the researcher receiving aid to avoid problems and to the public whose interests the process aims to protect. In general, those who sit on these boards are interested in research and are motivated to help researchers. If pediatric trainees have a problem with research that they are proposing, then we suggest they meet with the chair of the local board.

13.15.1 Dr. Cox and Child in Research Program

Dr. Zachary Cox was a third-year pediatric resident, on a rotation in the emergency department. He was called urgently to see a child, Hazel Peterson, brought in by ambulance with difficult to control seizures. He attended to her airway and called his seniors. Intravenous anticonvulsants were started. The seizure stopped and she remained very drowsy. Her mother had come in with her, and said Hazel was in a research study, and gave Dr. Cox a card with contact details of the investigator and the synopsis of the study.

Dr. Cox noted that this was a double-blind placebo-controlled study using a novel compound. He was worried that child with a disease that was difficult to control should be in a study with a placebo. He was concerned that Hazel might be getting an experimental therapy without simultaneously having current accepted therapy. He was not sure what his next step should be but called the investigator urgently.

13.15.2 Comment on Dr. Cox's Patient

Children or the families might be research "participants" or "subjects". The reasons for one word or another are discussed in Sect. 13.2. All pediatricians involved in the care of these children who are in a study need to be knowledgeable about the research, particularly if a new drug is under investigation. Therefore, we agree with Dr. Cox that he should contact the investigator. The investigator might also be the physician looking after Hazel or a colleague of that physician. Dr. Cox would want to know if there are any special side effects or possible drug-drug interactions of the new drug he should know about. The researcher would want to know that Hazel has had a seizure. The fact that she has had a seizure should be notified as an adverse event to the local ethics board/committee. More importantly the onset of the seizure should be notified to an independent data monitoring board.

These independent data monitoring boards should be arm's length both from investigators and from the sponsoring pharmaceutical companies. They usually consist of experts in the field and receive information on adverse events. They have the important duty of deciding whether what is given to an individual child should be "unmasked". The data monitoring board will also decide, depending on the kind of reports received from all sites, whether the study should be stopped early or should continue. Both these decisions, the unmasking, and stopping a study early are major decisions that cannot be taken lightly. Unmasking might mean that the results from Hazel cannot be used in the study and might affect the analysis by reducing the number of children in one arm of the study. To stop the study early might be required for reasons of safety but if the new drug is showing efficacy then that proof might never emerge, and many children might be denied an effective new intervention.

Dr. Cox was surprised that this was a placebo-controlled study. It is extremely unlikely that Hazel would be receiving the new compound or the placebo with no additional therapy. Ethical standards would demand that she receive standard therapy and typically have the new compound or its placebo as extra treatment. She should receive background antiseizure medicine whether or not she is in the study. The ethics

board/committee will already have reviewed inclusion and exclusion criteria and background information on the new compound. The committee would want assurance that there is good evidence in animals that the drug might work, that it has been studied in adults, and that it is studied in children who will derive benefit from the drug. Children who have good seizure control with standard therapy would not be enrolled in the study unless they were having severe side effects from their current therapy.

Dr. Cox will maintain contact with Hazel's mother, let her know that he has been in communication with the investigator, and will tell the mother that the research team will contact her to receive more information to report this apparent adverse event.

13.15.3 Dr. Richardson's Project

Dr. Asher Richardson was a first-year pediatric resident. He had been interested in geography before he entered medical school and discussed a possible research project with the pediatric endocrinologist. They wondered if there is any specific geographic clustering of children with diabetes mellitus type I. They planned to review the records of children diagnosed with diabetes mellitus over the previous 20 years, basic demographics such as age and sex at the time of diagnosis, and postal (zip) code to produce a visual picture of where of the children lived.

The endocrinologist told the resident that this proposed study would not need ethics review.

13.15.4 Comment on Ethics Review of Dr. Richardson's Project

Pediatric trainees will be involved in research in a number of different ways. They might be required to develop a research protocol as part of their training and be involved as it passes through the process of research ethics review. They might also be involved as a "research assistant" in staff-initiated research. The comments we make here take the form of general guidance on the general principles used in research ethics and an overview of how ethics is reviewed. Involvement in research might be mandatory in some training programs. In our view, if it is not mandatory for trainees to conduct or to participate in research, then it should be!

Dr. Richardson's supervisor thought the "study" did not require ethics review, perhaps because records were being examined but there were no risky invasive procedures or untried drugs involved. Dr. Richardson reviewed the requirements for ethics review and respectfully did not agree with the endocrinologist. However, he decided to consult with a member of the research ethics board/committee. The published rules of the board/committee were that some items were exempt from ethics review, such as quality improvement/quality assurance projects or analysis of data that was already in the public arena. However, Dr. Richardson noted that the work was about deriving new information that might lead to new hypotheses concerning

diabetes mellitus type I. The information they want from the health records is not public; it is information gathered specifically for the medical care of the children. This study is research.

For this study, the ethics review board/committee would require reassurance that Dr. Richardson and his supervisor understand the possible implications of the study results. It is possible that they will find clustering of diseases. This matters. This finding might lead to stigmatizing particular areas of a city or specific ethnic groups. Is it likely that such an eventuality will happen and if it does, then how will the researchers handle it to reduce the possibility of stigma?

On the other hand, requiring consent from the parents of all the children seen over 20 years would seem onerous. A development that has occurred many decades after the Nuremberg rules was a "waiver of consent". Such a waiver is not given lightly and usually implies that the study is important enough to be done and/or that the requirement to get individual consent is impossible or impracticable. Researchers, of course, must give accurate information on how they will maintain the security of the confidential information they will obtain from the chart.

13.16 Educational Research

Pediatric trainees themselves might be research participants or subjects in educational research. This is an increasingly frequent type of research in pediatrics. Trainees must be aware of their rights as participants; such information must be provided in the consent form.

Educational research aims to ensure that the training of future pediatricians, and indeed of all healthcare professionals, is effective. The idea that we should study how we teach is relatively new but is now pervasive. Educational research might involve teachers reviewing and evaluating students, students evaluating teachers, questionnaires or interview studies, or outcomes after simulation studies. In educational research, the methodology used is not dissimilar to the various methods used in other types of healthcare research. It follows that the same ethical principles should apply and that the studies should be reviewed. Such review might be by the same board/committee that reviews other health research, or it might be conducted by a committee created specifically to deal with educational research.

The underlying principles of ensuring that there is a good research design, a prospective plan of evaluation, and that the studies are done with respect for subjects are still relevant.

There is a power imbalance between teachers and students. Eikelboom et al. (2012) claim that this imbalance is not in any way comparable to the power imbalance between physicians and patients. We disagree very strongly. Students in healthcare disciplines and physicians in training for a specialty qualification work extremely hard to achieve their qualifications. Throughout the training, they are very dependent on the evaluation of the teachers. They are aware that negative evaluations can affect their ability to complete training successfully, and that such evaluations can also impact the references they need to practice in specific areas.

When reviewing educational research, close attention must be paid to the relationship between the trainee and the researcher. The first fundamental question to be asked is: Does the researcher have a position of authority over the trainee? The second question is: How are trainees recruited? Are they recruited because they are the most relevant trainees for the specific study, or because they are available and can be conveniently recruited? During the recruitment process, is someone in authority aware which trainees have agreed to be in a study and which trainees have declined? If questionnaires are completed or interviews recorded, again is at all possible that someone responsible for assessing a trainee might have access to that information? The point is to ensure that the trainee is not coerced by concerns that participating or not, will be known to the researcher in a situation where the researcher may exercise discretion that affects the trainee's advancement.

We believe that educational research is very important, and that the next generation of healthcare professionals should always be better than previous generations. The educational techniques used must be effective, and for this to be true, the techniques must be tested. However, such evaluation must be conducted in an ethical manner, should be reviewed before the study begins, and requires the fully informed and voluntary consent of the trainee.

13.16.1 Dr. Ortiz Completes a Survey

Dr. Victoria Ortiz was an enthusiastic pediatric resident. She was particularly excited by an upcoming educational session that was going to be focused on resident wellbeing. The speaker was Dr. Lily Sanchez, the pediatric program director, and well known for her interest and knowledge of the topic.

Dr. Ortiz was slightly late, and when she arrived the other residents were completing a form. She picked up the form and entered her name on the cover. When she looked inside, she saw many multiple option questions on background information such as relationships and also feelings and emotions related to residency. There was space at the end for free text to describe a memorable experience, good or bad. She had had a very disturbed week looking after a child with end stage malignancy whose parents were insisting on continuing treatment despite the child's obvious discomfort.

Dr. Ortiz was upset but hid her feelings and completed the questionnaire. After all, it was the program director who had distributed the forms to be completed!

13.16.2 What Should Dr. Ortiz Do Now?

We hope that an appropriate body reviewed this research. That body would review the methodology and would focus particularly on issues of recruitment and consent, and the storage of what might be very sensitive information. Either Dr. Sanchez did not submit her research for review and approval, or she did not understand the precautions that had to be taken when the research subjects were individuals over whom she had authority.

It is possible for this particular study to be done in an ethical manner. Recruitment should be conducted in advance of the teaching session by an email announcement a few days before the session and be repeated perhaps the day before or the morning of the session. It should be made clear that participation is voluntary and that the program director will not know who did or did not participate. There is no reason for names to be attached to the questionnaire and the trainees should be warned that they must not include material that would identify a specific patient. The introduction to the questionnaire should contain information on the study, and by moving on and completing the questionnaire, the researcher has obtained "implicit" consent.

The storage of information gathered requires great care. It is possible that information could be collected online, in which case, information should be kept behind secure firewalls with encryption to keep information secure. If the questionnaire remains on paper, then it should be in a secure locked filing cabinet with access limited to very few people.

We sympathize with the position Dr. Ortiz is in. If she completes the questionnaire, then she exposes her feelings about an emotionally draining clinical situation to others. If she does not complete the questionnaire, then she exposes herself as perhaps, an uncooperative trainee to the program director. There is a third option. Dr. Ortiz may deliberately give misleading answers to mask her underlying emotions. This is an action that involves dishonesty and such a course of action will lead to continuing moral distress. By moving ahead in an improper manner, Dr. Sanchez creates problems for others and might also compromise her research by making dishonest answers a less distressing option than telling the truth.

Appropriate ethics review will give protection to Dr. Ortiz, just as appropriate ethics review offers protection to patients in clinical studies.

13.17 Conclusion

Research is a vital activity in pediatrics, and key to improvements in health. There have been many research scandals, leading to the development of formal research oversight. Such oversight is only partially successful; the integrity of the researcher is a key factor. We encourage trainees in pediatrics to conduct a research project at some time in their training keeping in mind that the quality of the research starts with the quality of the researcher's integrity.

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Chapter 14
Working with Adolescents

Key Points Concerning Adolescence

- Adolescents are in transition from childhood to adulthood.
  - Care should be taken in the language used because descriptors include: child, minor, youth, teen, adolescent, young adult.
  - There are subtle differences in their use and in how any one of these words might be perceived by the young person.
- Adolescents require care designed around their needs with healthcare professionals being trained and comfortable in dealing with adolescents.
  - Appropriate healthcare should continue during the phase between pediatric care and adult care, with planning designed around the needs of the individual.
- Confidentiality should be assured.
- Consent for medical care may be given by the adolescent or by the parents, depending upon the minor's maturity and the context of the decision-making.
- Termination of a pregnancy is part of reproductive freedom, but legislation or threat of shunning or violence might limit availability.
- Assent is essential in almost every case.

14.1 Samuel's Story

Samuel is now 14 years of age. Two years ago, he started having intermittent fevers, and occasional rashes. Physicians were consulted, but no diagnosis made. One year ago, he had hematuria and was seen urgently in emergency. He had raised blood pressure at that time, poor renal function and was admitted to hospital. Lupus glomerulonephritis was diagnosed after a renal biopsy and multiple blood tests. He was treated with standard therapy including cyclophosphamide with recovery of renal function, and he was told that he may

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_14

eventually require dialysis, and perhaps later renal transplant. He developed hypertension but was discharged home on therapy.

Now Samuel's hypertension persists. He has had several admissions to hospital with hypertensive crises, because he is poorly adherent to treatment. At the time of admission, Samuel's parents tell the staff that they are concerned about Samuel falling behind in school, and that the teacher has been in touch with them about some behavioural difficulties.

Samuel is the eldest of three children. His parents grew up in a remote town as members of a small strict religious sect. They married in their late 20s. They left the sect and consequently lost their relationship with their families and extended families. They left the small town and moved to a larger city when Samuel was an infant. The parents still struggle with lack of family support. Given their very strict upbringing, the parents find many aspects of modern life distressing and puzzling.

Dr. Addison is a second-year resident and is assigned Samuel during one of his admissions to control his hypertension and to assess his renal function in more detail. She takes a routine history and finds, among other items, that Samuel is experimenting with substances – "street drugs". Samuel tells the resident that his parents were very strict, and that he is worried about their response to the teacher's complaints.

Dr. Addison understands the importance of confidentiality but thinks that Samuel will be aided if Samuel's parents are alerted to some of the realities of being a teenager in a city school at the present time.

The approach of pediatricians to children and families will vary according to many circumstances, particularly by age. Adolescents are still children, The United Nations Convention on the Rights of the Child (1990) defines "child" as "a human being below the age of 18 years". Hence, a specific approach to adolescence complies with a general philosophy of pediatrics: that we pay attention to the age and developmental status of the patient. Interacting with adolescents is a part of the practice of most pediatricians at some time or another. Some pediatricians openly dread interacting with adolescents. Most pediatricians are happy to interact with adolescents and work hard to identify the strengths inherent in a particular teenager. Issues of privacy, confidentiality and consent will be dealt with in detail.

14.2 History and Overview of Medical Care of Adolescents

From the late nineteenth century through the twentieth century, some physicians gave much of their attention to children, including adolescents, in schools, or in college. There was a clinic and a training program in adolescent medicine at Boston Children's Hospital in the 1950s (Rieder et al. 2005). Now there are specialists in adolescent medicine, and specialized clinics in adolescent medicine, in most medical centers. Despite such specialization, every pediatrician should develop the basic skills required to offer excellent care to adolescents.

As noted, "Adolescent Pediatrics" is a relatively new subspecialty that recognizes the unique features of adolescents within society, and perhaps that pediatricians have not always dealt well with adolescents in the past. The World Health Organization describes adolescence as the period from about 10 years to about 19 years. This period encompasses the many changes that occur as a child transi-

tions to adult life. There are the obvious physical changes of puberty and growth but, just as importantly, there are neuro-maturational changes relevant to decision-making and social changes in the relationship of the adolescent to the family, and the world in general. In addition, mortality in pediatrics is highest in the first week or so of life, though still low, and falls throughout childhood. Mortality starts to rise again in adolescents due to non-intentional injuries (called "accidents" by some), suicide and homicide.

While we deal specifically with adolescents interacting with the healthcare system, it is important to note that society generally recognizes this group by paying special attention to it in many ways. The state addresses the growing maturity of the individual by stipulating various ages at which: a person may begin to drive a car on the highway, engage in sexual activity, purchase and consume alcohol, engage in full-time employment and vote. The processes and penalties of the criminal law are generally modified for individuals under 18. Charges and penalties are different for minors. When a custodial sentence is ordered, the focus is on rehabilitation and prevention rather than denunciation. The age at which someone is deemed an adult varies from one legal jurisdiction to another, and from one activity to another. These variations in laws do not change the ethical values to be followed, or the reality that adolescents are approaching but have not fully entered adult life. The variation in the law does change the ease with which ethical principles can be followed.

In relating the key points of this chapter, we noted that a variety of words are used such as; "child", "minor", "youth", "teen", "adolescent", "young adult". These words are not inter-changeable, and care should be taken as to which is used. The words themselves can help us see what is happening. Our choice of words will be important to the young people we deal with. For example, we might describe someone of 16 years as a "child", perhaps legally true, or as a "young adult", physically and developmentally true. Our language will let the patient know how we see him or her, and we might inadvertently put up barriers by careless use of different words.

The reality is that during the transition from childhood to adult life, part of the time the teen will depend heavily on parents to give information to pediatricians, and to give consent and authorization for treatments. At other times, the same teenager will need to be seen separately from parents and will themselves authorize treatment.

There are other concerns about adolescence that apply to a minority of patients. For example, some of the mothers of our patients will themselves be teenagers. Absent a court order, they are able to make decisions about their own children and should always be treated with respect. (This is discussed in more detail in Sect. 2.1 on consent) Also many teenagers with chronic disease will require help as they make the transition to adult care. The pediatrician has an important role in helping with this transition and will likely require skills in advocacy. There is a subset of teenagers who will be unable to lead an independent life as adults, and again the pediatrician will work with the families and with colleagues in family medicine, and internal medicine (including its subspecialties) as they help the child and family make the transition to adult care. Near the end of this chapter, we will address organizational issues that should apply to all adolescent services, and which are particularly relevant as adolescents transition to adult services.

Let us return to Dr. Addison and the interaction with Samuel. Dr. Addison has had good training in the skills involved in assessing adolescents, both in medical school and earlier in her resident training. She understands the importance of approaching Samuel in a way that ensures he is comfortable and makes it likely that she will get accurate information. She follows the HEEADSSS approach. The original mnemonic was HEADSS, **H**ome, **E**ducation / employment, peer group **A**ctivities, **D**rugs, **S**exuality, **S**uicide /depression (Goldenring and Cohen 1988). The new acronym has been expanded to include a second **E** for eating and the third **S** for safety, including violence (Goldenring and Rosen 2004). Also, it is important to explore sexuality non-judgmentally without preconceived ideas that would assume heterosexuality, so a third **S**.

14.3 Return to Samuel's Story

Dr. Addison uses HEEADSSS to take a history and finds, among other items, that Samuel is experimenting with substances. Samuel tells the resident that his parents are very strict, and that he is using substances. Dr. Addison makes a note in the chart that Samuel does not wish his parents to have this information. Despite this desire, Samuel makes it clear that his family is very important to him. Dr. Addison discusses with Samuel whether he would like a specific referral to a specialist who deals with substance abuse in teenagers. She explores why, how often, and which substances Samuel used. Samuel explained that his "friends" introduced him to the substances; these "friends" were aware that Samuel's parents were very strict, thought they were "weird", and often made fun of them. Samuel took the substances to ingratiate himself with his classmates, at the same time he is upset that he had not defended his parents more vigorously. Dr. Addison and Samuel agreed that they would defer further discussion on the next steps including the issue of a referral, and that they would continue their discussions.

Dr. Addison has met the parents on a number of occasions and finds them very warm, devoted to Samuel, but in many ways innocent. She wants to find ways to alert Samuel's parents to some of the realities of being a teenager in a city school at the present time. In trying to help them, Dr. Addison has a discussion with the unit social worker, who agrees to meet with the parents. Dr. Addison also wants to make contact with the school; the school insists on written parental consent before they will discuss Samuel. Standards regarding individual rights to confidentiality are not uniform; organizations outside healthcare can have a different perspective on a child's right to confidentiality than healthcare organizations or healthcare professionals. Dr. Addison tells the parents that she would like to speak to the school about Samuel because he is struggling with adjusting to his chronic illness. She had thought carefully about her language before she spoke to the parents to seek this permission. She believes that the reason she gave the parents was truthful because she did want to speak to the teacher about Samuel's difficulty in adjusting to his hypertension and marginal renal function. On the other hand, she did not give the

extra detail to the parents that her principal reasons for finding out about his adjustment was a confession of drug use. You can decide whether Dr. Addison has appropriately balanced confidentiality and truth telling! The authors are sympathetic to the course of action Dr. Addison took. While others might disagree, we think the information about Samuel's substance use should come from him. He is entitled to confidentiality and to raise this issue with his parents in a way and at a time when the least damage to their relationship will be done. Meanwhile, it is up to Dr. Addison to help him understand how substance use will harm him, particularly given his underlying medical issues.

In many ways, the story about a teenager adjusting to chronic disease, and also adjusting to becoming an adult in our modern society, is not unusual. As pediatricians and physicians caring for children, we have a privileged opportunity to hear the stories of the adolescents, and to offer positive help.

14.4 Reproductive Issues

14.4.1 Confidentiality and Reproduction

The following stories are variations on a theme. The variations are contained within the stories. The theme is that of respect for the adolescent as an individual, for the need for confidentiality, and for the adolescent to know that interactions will be confidential. The other theme is that adolescents are still children, and that sometimes decisions will be taken with which they do not agree. The latter means that adolescents need to be told that the confidentiality is not absolute, and that their decisions are not necessarily final.

Helena, aged 16 years, comes with her mother for a routine medical examination with Dr. Edwards. The receptionist reminds Helena and her mother of the clinic policy that patients over 14 years will be seen by the physician without the presence of a parent. The mother was already aware of this policy.

During the standard HEEADSSS assessment, Helena mentioned that she was sexually active with a steady boyfriend and that they used condoms. Helena was aware that there are more effective forms of contraception and asked for help and advice.

Dr. Edwards's first action was to assure Helena of confidentiality. This is the right thing to do because it ensures that the focus of the consultation will be the patient. This course of action also respects Helena's autonomy, is doing good and avoiding harm. In almost every legal jurisdiction, giving assurance of confidentiality is not only the ethically right thing to do, it is also legally appropriate. (Please note that there are some jurisdictions in United States where there might be legal issues for physicians who seek to make such a clear promise. Pediatricians should be clear on local legislation in the area in which they work.) Yet, when it comes to confidentiality for adolescents, there seem to be gaps in practice. In a survey of 175 (133 responded) residents in a US children's hospital, 55 (42%) had cared for an adolescent whose confidentiality had been compromised. The barriers to confiden-

tiality were: "Patient/family not knowledgeable about minor consent law (50%); trainees not knowledgeable about minor consent law (47%); and hospital discharge summary requiring parental signature (47%)" (Talib et al. 2016). The last might be specific to a particular institution, but it is a reminder that administrative procedures can obstruct good medical practice.

Confidentiality is particularly important when caring for adolescents. In a report from the Centers for Disease Control, analyzing data from the 2013 to 2015 National Survey of Family Growth, it was noted:

> 12.7% of sexually experienced youths (adolescents aged 15–17 years and those young adults aged 18–25 years who were on a parent's insurance plan) would not seek sexual and reproductive health care because of concerns that their parents might find out. Particularly concerned were persons aged 15–17 years (22.6%). Females with confidentiality concerns regarding seeking sexual and reproductive health care reported a lower prevalence of receipt of chlamydia screening (17.1%) than did females who did not cite such concerns (38.7%). (Leichliter et al. 2017)

The same survey confirmed the importance of seeing the adolescent without a parent in the room. "More adolescents aged 15–17 years who spent time alone with a health care provider (without a parent in the room) reported receipt of a sexual risk assessment (71.1%) and, among females, chlamydia testing (34.0%), than did those who did not spend time alone (36.6% and 14.9%, respectively)."

The reproductive rights of adolescents raise issues that challenge both parents and physicians and require discussion. Sexual activity at the age of 16 years is legal in most jurisdictions. If Dr. Edwards is practicing in a jurisdiction where the age is, say 17, then this fact should not stop Dr. Edwards from giving medical advice about infection and contraception, nor should it lead to any referral to child welfare or the police by itself. Again, the focus should be on the patient. In most countries there are few, if any, sanctions against consensual sexual activity between teenagers of the same age. The law in Canada is quite specific; its provisions are not unusual in the English-speaking world. In Canada, the age for consent to non-exploitative activity is 16 years. Canadian law does not accept as valid any consent by a person under 18 where:

- The sexual partner is in position of trust or authority, for example, the young person's teacher or coach
- Young person is dependent on the sexual partner, for example for care or support (*Norberg* v. *Wynrib* 1992)
- The relationship between the young person and the sexual partner is exploitative

Canadian law (Department of Justice 2018) takes into account the following factors when determining whether a relationship is exploitative of the young person:

- The young person's age
- The age difference between the young person and their partner

- How the relationship developed (for example, quickly, secretly, or over the internet)
- Whether the partner may have controlled or influenced the young person.

People under age 16 may not engage in sexual activity in Canada, though there are two "close in age" exemptions. Those aged 12 or 13 years may consent to sexual activity if the difference in age is no more than 2 years. Those aged 14 or 15 years may consent to sexual activity when the age difference is no more than 5 years. It is rare for the age of consent to be below 16, but in Nigeria the age of consent is 11 years and is 12 in the Philippines and Angola ("Legal Ages of Consent by Country" www.ageofconsent.net).

Helena's sexual activity is not unusual. About half of all high school students have been sexually active at least once (Ott et al. 2014). Once the conversation starts, Dr. Edwards must explore gently the nature of the relationship, ensure there is no coercion or exploitation, and that the partner is not in a position of authority or that there is a relationship of dependence.

14.4.2 Possibility of Absence of Lawful Consent to Sexual Activity

Some knowledge of the law as it is applied in a particular jurisdiction is important, but typically most jurisdictions would not accept that a teenager may give meaningful consent to sexual activity with someone who has authority over the teenager. Such activity falls under the general rubric of "child abuse"; once the pediatrician is aware of such a situation, then there is an imperative to act. Such situations are so complex that some legal advice is usually helpful. In general, there is no obligation to report this activity to the police. There is an obligation to involve child protection services. Unless harm is imminent, there will usually be time to discuss with hospital child abuse teams what action should be taken. Such teams are usually led by pediatricians with additional training in the area and are distinct from child welfare authorities (usually a branch of government). Dr. Edwards must maintain the confidence of Helena, and if reporting is required, tell Helena the reason for breaching confidentiality by reporting. This should be part of a general discussion with parents and children on the importance of confidentiality and its limits (Alderman 2017).

Absent any suggestion of coercion, the conversation can then move to specific medical choices, and the implications of the various alternative forms of contraception. If the choice involves a prescription, then that should be given. One further issue that requires attention is pharmacy costs, because the parents might receive from the insurance company an itemized list of prescriptions that have been funded by their policy, thus breaching the adolescent's confidentiality.

14.4.3 Physician's Duty Regarding Sexual and Reproductive Advice Is to the Adolescent

While it is ethically appropriate, and respectful, to offer Helena specific advice, possible testing and the prescription for oral contraceptives, such medical care has been challenged in a number of jurisdictions. However, the challenges have not usually been successful. One of the best-known cases arose in United Kingdom when Victoria Gillick was concerned by the fact that her daughter, aged under 16, had been prescribed oral contraceptive by a family physician. The physician was following advice given by the government, and Mrs. Gillick challenged the government's advice (*Gillick* v. *West Norfolk* 1986). It should be noted that the physician prescribed contraceptives, even though the patient was under the age of consent for such activity. The ultimate decision of the court was that a minor could give consent to medical treatment, provided some conditions were met. These are that: "children aged under 16 who have the legal capacity to consent to medical examination and treatment, providing they can demonstrate sufficient maturity and intelligence to understand and appraise the nature and implications of the proposed treatment, including the risks and alternative courses of actions" (Wheeler 2006). In the UK, these rules are now used when assessing whether someone under the age of majority may consent to medical treatment. Minors who meet these criteria are said to have "Gillick competence".

As noted earlier, sexual activity is common in high school students, that is those aged 14–18 years. Availability of accurate information might reduce the incidence of sexually transmitted disease and pregnancy. Regarding the latter, teenage pregnancy is not the inevitable outcome of increased adolescent sexual activity. It is the result of inadequate sexual education and poor access to contraceptive services (Edelman and Pittman 1986).

In the United States, the American Academy of Pediatrics (Ott et al. 2014) strongly supports provision of contraception to adolescents in a confidential manner and encourages pediatricians in private practice to establish office policies that maintain this confidentiality despite parental request for access to health records. The rationale for this recommendation is based on respect for the adolescent, respect for the relationship between the physician and the patient, and, pragmatically, to reduce the likelihood of teenage pregnancies.

Returning to the example of Helena and Dr. Edwards, as part of the discussion on sexuality and contraception, Dr. Edwards will have discussed emergency contraception. This is described as "hormonal medications taken within 72 h and up to 120 h after unprotected or inadequately protected sexual intercourse for the prevention of unintended or unplanned pregnancy" (Katzman et al. 2010). Emergency contraception is safe and well tolerated; it is available without prescriptions in many jurisdictions. Its use does not increase rates of sexual activity in adolescents. It is important that adolescents be informed of its existence, and

that it be readily available. There is no medical reason to require a prescription for emergency contraception because of the medication's safety. Having said that, its availability without the intervention of a pharmacist or physician seems to arouse strong feelings. In the Canadian Medical Association Journal, the news section reported an investigation on pharmacy practice and commented on this news story. The article reported that pharmacists had been advised by their professional association to ask for personal information, and on visiting some pharmacies, women were asked for their names and addresses (Eggertson and Sibbald 2005). A commentary on the news article noted that this request for identifiable information was a disincentive to women requesting this substance, and particularly so for adolescent girls. The Canadian Pharmacy Association was angered by the article and asked the Canadian Medical Association Journal to retract the article. The editor refused to retract the article and was dismissed.

14.4.4 Adolescent Use of Contraception and Parents: An Angry Mother

Ms. Scheuer finds both condoms and a three-month supply of oral contraceptive pills in the bedroom drawer of her daughter, Erica (age 15). The oral contraceptives have been prescribed by Dr. Bergh. Ms. Scheuer comes to Dr. Bergh's office and demands an appointment. She brings the supply of oral contraceptive as evidence and demands to know why they were prescribed without her consent.

Ms. Scheuer is in a situation similar to that of Ms. Gillick (who took issue with the health authority who had given permission for physicians to prescribe contraceptive advice to teenagers, rather than visiting the physician directly). Dr. Bergh has an array of problems to deal with, including defusing the situation. Maintaining Erica's confidentiality is not exactly straightforward, as Dr. Bergh's name is on the prescription. However, this fact that it is now known to Ms. Scheuer that Dr. Bergh saw Erica does not mean that Dr. Bergh can reveal the details of the consultation.

This situation is like many of those we deal with, in that there are a number of options that are reasonable, though no one option is absolutely correct. On the other hand, Dr. Bergh should not choose to refuse to meet with the mother. We should assume the mother is acting out of concern for her daughter, and perhaps is also concerned that her daughter chose not to confide in her. So, this anxious mother requires information and support. One way is to outline in general terms the importance of confidentiality in teenagers. In addition, Dr. Burke could, perhaps should, agree to meet Erica again to discuss with Erica how much she would like her mother to know, and whether it would be helpful for Erica, the physician, and Erica's mother to meet at the same time.

14.4.5 Pregnancy in Teens

If there is concern about prescribing contraception to teenagers, and the ready availability of emergency contraception, then you can be sure that there is even more concern about discussing all options with a pregnant teenager. Although pediatricians are not likely to encounter patients who become pregnant, this is an occurrence that physicians must manage. Teenagers might present with the knowledge that they are pregnant, but they are also likely to present pregnant, without knowing this is happening. One of the reasons is the denial that a life event that is negative for the teenager might occur. Another reason is the vague presentation with irregular menstruation rather than amenorrhea, and vague general symptoms such as nausea and general weakness. Pregnancy in a teenager leads to major adverse life outcomes for the young woman, but this outcome does not mean that there should not be a full discussion with the young woman on her circumstances, and the various choices she can make (Leslie et al. 2006).

All advice must be both accurate and accompanied by an assurance of confidentiality. If the physician seeing the pregnant teenager is uncomfortable discussing all possible options, including various forms of terminating a pregnancy, then the patient must be referred to another physician, who can offer full, nonjudgmental advice.

Before proceeding to discuss the medical options, the physician should seek to know how much support the teen has and whether the teen has told anyone. The teenager's choice regarding whether she will continue with the pregnancy and deliver, or whether she will interrupt the pregnancy, must be, in one sense urgent, because, of course the pregnancy is proceeding. And yet the decision should not be hastily taken. In counselling the teen, pediatricians have a duty to speak about all the patient's options and ensure that the teen is not coerced when making a decision among the options. When a girl or woman becomes pregnant, and absent a miscarriage, her options are limited to two: (1) She can seek an abortion; or (2) She can carry the pregnancy to term. If she opts to do the latter, then she has further decisions to take at birth: surrender the child for adoption or rear the child herself. For a teen, none of these options might seem as good as not being pregnant in the first place, but that opportunity has passed – she is pregnant.

If the pregnancy is to continue, then the best possible prenatal care is essential for the sake of the health of both the future mother and the baby. Adverse consequences, and indeed maternal mortality, do occur in this age range. Much of the discussion and counselling will not be by a physician, but the physician can at least initiate the discussion. Further detailed discussion might be with a number of individuals, depending on local resources, but would most likely be a social worker. If the young woman intends to carry the pregnancy to term and then have the baby adopted, then she needs to know what that means. It has been reported that young women often change their mind after labour and delivery, and they should be encouraged to hold the baby to ensure they are comfortable with the decision (Leslie et al. 2006).

In terms of interruption (termination, also known as abortion) of the pregnancy, the patient can be reassured that this is a safe procedure, with few if any long-term sequelae.

In the first trimester, abortion might occur with drugs (medical termination) or by minor surgery. The details of each approach, their pros and cons, will be discussed by someone expert in the procedure. Later in the pregnancy, abortion can occur only by a surgical procedure, with complexity and complications increasing with increasing gestational age. The upper gestational age when a termination may be performed legally on an otherwise normal fetus will vary from jurisdiction to jurisdiction; it is uncommon after 20 weeks, and rare after 24 weeks.

Given the strong feelings for and against abortion, we will take time to review some developments in attitudes to the procedure. These are not specific to teenagers but are relevant to them.

14.4.6 Termination of Pregnancy Generally: An Overview

Given that pediatricians must address the issue of termination of pregnancy in teens and the societal significance of the issue, it is important to pause to discuss the matter in some depth.

Termination of pregnancy is also known as "abortion" but there is a distinction between the medical and the common use of the word. In medical terminology the word," abortion" refers to the early expulsion of the fetus from the uterus, whether naturally or by medical intervention. In lay terms, when this happens spontaneously, it is called a "miscarriage". In practice, the word abortion is now used both by professional and lay people for the deliberate termination of pregnancy resulting in the intended death of the fetus prior to normal spontaneous delivery. As discussed, in Sect. 3.1 on perinatal issues, this issue is contentious and divisive. There are polarized views called "pro-life" and "pro-choice". The pro-life group gives equal weight to the rights of the fetus to be carried to term as it does to the mother's right to control her body. The pro-choice group advocates that women should be allowed to control what happens to their bodies, though in common parlance it has a more restrictive meaning of "favouring the legalization of abortion" (www.merriam-webster.com). We discuss the different attitudes to abortion later. Abortion is common, most citizens are uncomfortable with telling a woman to continue an unwanted pregnancy and at the same time become increasingly uncomfortable with the idea of abortion the further along the pregnancy this is requested.

Indeed, termination of pregnancy is not a new issue and has been a common occurrence throughout history, and likely, during prehistorical times. It has variably been legal at any time in pregnancy, legal only at certain times in pregnancy, or illegal. The person performing the termination was often unskilled and paid little attention to infection control. Illegal terminations have been performed by qualified

personnel under imperfect conditions, with secrecy and with deception. Penalties have varied but have sometimes been severe with abortion being managed by the legal system as equivalent to homicide. In the past, the procedure was dangerous; currently the procedure, as noted above, is very safe.

Today, abortion can be done safely, provided it is legal and freely available. When the law forbids abortion it continues, but in circumstances that increase the risk of both permanent damage to the reproductive tract of the woman, and to the possible death of the woman. Abortion services should be closely linked to the provision of effective contraception services. These should include emergency contraception.

Abortion is a world-wide issue because many pregnancies are, to put the matter starkly, simply not planned and not wanted. Globally, of the 200 million women who become pregnant each year, the United Nations believes that one third of the pregnancies are unintended and unwanted (Daulaire et al. 2002). One consequence for these women is death. In the developed world, while the consequences of unintended pregnancy are much less likely to lead to death, the reality in all societies is that a large number of pregnancies are unplanned. The precise number and percentage will vary from area to area. In one city in the UK, with ready availability to termination, of those women who continued pregnancy approximately two thirds had not intended to become pregnant (Lakha and Glasier 2006). A US data source identified that just under half of pregnancies were unplanned (Henshaw 1998). Given the scientific evidence for the developmental origins of later disease, and the importance of maternal and paternal disease in the peri-conceptual period (Fleming et al. 2018), there is everything, to be said for working towards every pregnancy being a wanted one.

The evidence available, on a worldwide basis, is that abortion is becoming less frequent in the developed world. Sedgh et al. (2016) collected information on incidence of abortion during the period, 1990–2014, using data from government and international agencies, about 25% of pregnancies globally ended in abortion 2010–2014. They estimated that 35 abortions occurred annually per 1000 women aged 15–44 years worldwide in 2010–2014, which was 5 points less than the 40 in 1990–94. In the developing world, they found a non-significant 2-point decline from 39 to 37. Globally, married women in 2010–2014, obtained 73% of abortions. These authors concluded that improved access to sexual and reproductive health care, including access to safe abortion, could help millions of women avoid unintended pregnancies.

More detail is available country by country. As we are presenting the numbers to help in understanding the ethics issues, we will present data from one country, Canada. The Canadian Institute of Health Information (2012) made public data for abortions performed in hospitals and clinics. In 2012, there were 83,708 abortions, 11,346 in teenagers. 47.2% had their first abortion, 17.4% their second and 10.1% their third (the numbers do not add to 100% as there were some missing data). The

complication rate was low at 2.3% with hemorrhage being the most common complication.

Women, including teenagers have abortions for a variety of reasons. In 2004, a survey of 1209 abortion patients (Finer et al. 2005) showed that the reasons were (noting some overlap as many women cite more than one reason):

74% having a child would interfere with education, work or ability to care for dependents.
73% could not afford a baby now/did not want to be a single mother.
48% having relationship problems.
40% had completed their childbearing.
30% were not ready to have a child.

The study had a qualitative part which revealed themes of responsibility to others and resource limitations, such as financial constraints and lack of partner support, recurred throughout the study. Younger women often felt ill prepared for motherhood and unsupported by a partner.

14.4.7 Legality of Abortion

The move to legalize abortion in Western countries came in the second half of the twentieth century with the recognition that elective termination achieved without safe methods was a significant cause of mortality during pregnancy. It was also seen as insulting to women, who thereby lost control over their own body. Legalization came in different forms in different countries. In the United Kingdom, a formal act of Parliament legalizing abortion was passed in 1967, and the first legal termination performed in 1968.

In Canada, abortion was legalized by act of Parliament in 1969. That act was an amendment to the Criminal Code provisions that prohibited the crime of "procuring the miscarriage of a female person". The amendment contained a complex process by which a woman was obligated to have the permission of a three person "therapeutic abortion committee". The process was eventually struck down by the Supreme Court of Canada in 1988 as unconstitutional because it violated a woman's security of the person (*R.* v. *Morgentaler* 1988). Currently abortion in Canada is regulated as a medical procedure, by institutions, and physician oversight bodies.

In the United States, the issue is much more complicated. In the famous legal *Roe* v. *Wade* case of 1973, the Supreme Court of the United States held that banning abortion was an interference in the privacy of the physician-patient relationship. As of this writing, the situation is that abortion is legal in the United States, though various states have created significant barriers to women having ready access to safe termination ("United States Abortion" www.Guttmacher.org).

14.4.8 Can Teens Consent to Abortion?

Where does all this leave teenagers? Once we accept that abortion is a medical procedure, then the usual rules governing medical practice will prevail. Whether the procedure may take place is usually governed by the answer to this question: "Is the patient who is requesting termination competent to give permission herself?" This issue was addressed in 1986 by the Alberta Court of Appeal in *J.S.C.* v. *Wren*. It is a leading decision on this issue in our jurisdiction, but the language used in the judgement seem to us to be applicable more generally. Hence we examine this case in detail.

The case concerned a pregnant girl aged 16 who wanted an abortion to which her parents objected. The parents sought an injunction against the procedure. The physician defended against the injunction and the teen intervened. In that decision, the Court took note of the poignant nature of the dispute which it described as:

> […] an obvious and painful dispute between parent and child about the appropriateness in non-medical terms of the proposed abortion. We express in that respect our sympathy both to the parents and the child for this unfortunate confrontation. (*J.S.C.* v. *Wren* 1986)

But the court went on to describe how decision-making moves over time from parents to the child:

> The real thrust of argument before us was that children should obey their parents and the courts should intervene to prevent others from interfering with parental control of those children who are committed to their custody and control. […] Parental rights (and obligations) clearly do exist and they do not wholly disappear until the age of majority. The modern law, however, is that the courts will exercise increasing restraint in that regard as a child grows to and through adolescence. (*J.S.C.* v. *Wren* 1986)

The Court then considered the governing law, citing with approval the United Kingdom House of Lords decision in *Gillick* v. *West Norfolk (*1986):

> As a matter of law, the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed. (*J.S.C.* v. *Wren* 1986)

Thus, the issue for the judges to resolve was clear. The Honourable Mr. Justice Kerans for the Court stated:

> The only real issue in the case is the capacity of the expectant mother to consent to the proposed procedure. […] The issue is not whether or not abortions are legal, let alone morally right or wrong; the issue is simply one of the capacity to consent. (*J.S.C.* v. *Wren* 1986)

The court did not accept the parents' argument that simply because the teen disagreed with her parents, she did not have sufficient intelligence and understanding to make up her own mind. Inferring that she did have sufficient and intelligence to make up her own mind, the court dismissed the appeal, which decision cleared the way for the teen to have a termination of the pregnancy.

The result for clinicians in Canada of this leading case and the reasoning upon which it is based, is that if someone under 18 requests termination of pregnancy, then it is important to establish:

1. She has been given full information about the benefits and risks of the procedure, including the common risks and the uncommon but serious risks;
2. She understands and appreciates this information and the consequences of accepting or rejecting the procedure; and
3. She is free from coercion (e.g. the male who impregnated her; her parents, or her friends).

Many jurisdictions will agree that if these three conditions obtain, then the physician may accept the young woman's permission to perform the termination.

The consent of the young person to termination of pregnancy is not the end of the dialogue between the physician and the patient, of course. The physician will want to ensure that there is support for the teenager, perhaps the parents, or some other friend. Inquiry should be made about the nature of the sexual relationship, and if it is coercive, then appropriate counselling must be given. If the pregnancy resulted from sexual assault and the young woman is at risk of this happening again, then child protection authorities should be informed. Making such determinations requires careful reflection on the part of medical staff to distinguish between the fact that young woman may give her own consent to a surgical procedure which is in her interest, and at the same time, might need to be treated as a child if she is at risk of the sexual assault occurring again. Post-abortion care is necessary including the provision of birth control.

14.4.9 Some Teen Abortion Cases

We realize that medical students, physicians, and indeed all health care practitioners are likely to show the same range of opinions about abortion as other citizens, and some will be strongly opposed to abortion. This section focuses on our duties and responsibilities as physicians. We have accepted the principle of reproductive freedom; the stories below come from three different countries and illustrate the types of cases that pediatricians might encounter. In each of these three cases, details were public though not the identity of the girl. In the first case, the girl was called "X" in the media, the second "LG" in the media, and the third "AC in the media.

Case 1 (A.G. v. X 1992) and (O'Carroll 2012)

X was a 14-year-old girl who was sexually assaulted by a man known to her and her family, and who became pregnant in 1991. Later, it was discovered that the same man had sexually abused her for the previous 2 years. The girl lived in a country where the rights of the fetus and of the pregnant woman were considered equal (Ireland); hence abortion was illegal. The girl and her parents arranged for an abortion in another country (England). The father consulted the police to ask whether the fetus could be tested after the abortion to provide

evidence for the prosecution of the rapist. The family arrived in England but had to return to Ireland as court proceedings were started to stop the abortion.

Evidence was given in court of the girl's state of mind; not surprisingly she was suicidal. Yet the judge took a week to write, "the right to life of the unborn child should not be interfered with and … the defendant [the pregnant 14-year-old] must be restrained from leaving Ireland for a period of nine months". A higher court allowed her to travel to England for the abortion. She had a miscarriage shortly after arrival in England.

Case 2 (Associated Press 2005)

LG was 13 years old and had been in the care of the state in the United States for 4 years. She ran away from the home and while away became pregnant. No issues were ever raised about rape or any suggestions about coercive nature of the sexual intercourse that led to the pregnancy. However, she did become pregnant and requested an abortion. When she was 14 weeks pregnant, the state initiated legal action against her on the grounds she was too young and immature to consent to an abortion, an action supported by the State Governor.

The judge ruled that she was competent; that she had made a decision; and that she had a right to act on that decision to have an abortion.

Case 3 (*J.S.C.* v. *Wren* 1986)

AC is described in detail above (Sect. 4.8)

These are the stories of three teenagers, a 13-year-old, a 14-year-old and a 16-year-old. The 16-year-old seems to have been able to make up her own mind, but is still vulnerable, as evidenced by the attempt by her mother to coerce her to continue the pregnancy. The other two were very vulnerable, and it is noteworthy that the government authorities took steps in both cases to ensure continuation of the pregnancy. These state actions did not seem to be based on the "best interests" of the teen and gave priority to the fetus over the young woman concerned. In the case of LG, one wonders why the state thought she was too immature to request an abortion, but mature enough to look after herself through pregnancy, give birth, and perhaps look after an infant. In all three cases the courts supported the teens' right to make decisions about themselves.

The cases illustrate the need for pediatricians to focus on the interests of their patients as they attempt to determine which of the options available to them are right for them.

14.5 Pregnancy in Adolescents

The World Health Organization (WHO) has reviewed data on pregnancy and childbirth outcomes in a population (Ganchimeg et al. 2014). It describes as adolescent mothers, a group we prefer to call "girls", who became mothers. The data comes from 29 countries (Africa, Latin America, Asia and the Middle East). There were124,446 mothers aged ≤24 years in the study. Data about those aged 20–24 years, was compared with data about girls who became mothers aged 10–19 years. The teenage mothers had "higher risks of eclampsia, puerperal endometritis, systemic infections, low birthweight, preterm delivery and severe neonatal

conditions." In addition, antenatal interventions were less likely to be used in labours at 26–34 weeks in the girls who became mothers.

In a study in 19 US hospitals of women younger than 25 years of age (Kawakita et al. 2016), there were 1189 younger adolescents (age ≤ 15.9 years), 14,703 older adolescents (age 16–19.9 years), and 27,645 young adults (age 20–24.9 years) who gave birth. Both groups of younger adolescents were more likely to have anemia and to give birth <37 weeks, but less likely than older women to have cesarean sections or NICU admissions of their infants.

As stated, most pregnancies in adolescents are unintended. The Committee on Adolescence (2014) quoted a figure of 85% unintended pregnancies in 15–17-year olds from the USA. Similar numbers are likely to be true in other countries. Issues that need to be addressed include sexual education, availability of contraceptive advice and availability of abortions. The ethics surrounding have been discussed earlier in this chapter.

14.6 Sexual Identity

Margaret comes with her mother for a routine medical examination with Dr. Haworth. The receptionist reminds Margaret and her mother of the clinic policy that patients over 14 years will be seen by the physician without the presence of a parent. The mother was already aware of this policy.

During the standard HEEADSSS assessment Margaret mentioned that she was sexually active with a steady girlfriend.

As in all other situations, Margaret must be helped to feel comfortable during this and all other interactions. We can assume there is a degree of comfort already, as lesbian, gay, bisexual, transgender, and queer or questioning (LGBTQ) youth will not "come out" to an adult if they feel that the response will be negative or judgmental. Margaret's statement about her girlfriend reveals information about sexual orientation, about Margaret's physical and emotional arousal towards others, in her case girls. This is not about gender dysphoria, which is when individuals have extreme discomfort with their natal sex.

We must offer Margaret the respect we offer all patients, and she requires reassurance that she is normal. As an aside, referral for so-called "conversion therapy" is based on the inaccurate assumption that homosexual or by-sexual orientation is a form of illness (Haldeman 2002) and has no scientific evidence that it actually achieves its misguided goal (Haldeman 1994). "Conversion therapy" is never appropriate. Moreover, if Dr. Haworth is not comfortable dealing with issues of sexual identity, then she should make a confidential referral to another physician who will be able to act as a supportive skilled physician to Margaret.

LGBTQ youth are normal in every sense of the word, and the vast majority are resilient and become fine adults. Nevertheless, these same young people are at high risk for mental health issues, suicidal ideation, substance abuse and sexually transmitted infection. Physicians must face the fact that these young people do come in contact with homophobic people who make life uncomfortable for them.

Dr. Haworth will discuss some of these things with Margaret and will seek to determine how much her parents know. Dr. Haworth will also learn whether Margaret is concerned that her parents might be homophobic. A minority of LGBTQ youth are expelled from the parental home, so any disclosure to the parents should be conducted with caution. Of course, any disclosure is Margaret's to make and never the physician's.

In terms of adolescent males engaging in sexual activity with other males, we have considerable information on the barriers to effective help, and how we can remedy them (Marcell et al. 2017). Information comes from focus groups in one specific city involving 70 young men aged 15 to 24 years. As with most studies, some of the results will be specific to that city, to this age group, but most of the results can be used in other settings. The young men raised concern that there is, at the structural level, a background of a healthcare culture focused on "women's health and [traditional] masculinity scripts". Additionally, high costs, long visits and confidentiality were seen as barriers. At a different level, the young men were concerned about being seen by people who knew them in other contexts and anxiety about the interaction with the health provider. These young men had fears and anxieties about sexually transmitted infection, including decisions about when to have HIV testing. These fears give us clues at individual levels regarding how to deal with young man seeking sexual advice, and how to broach sexual issues in young men seeking general medical help. We also have clues on how we can organize services to meet young people who might not access services readily, but who are exposed to high morbidity, and a degree of mortality.

The reader might wonder why discussing same sex activities is even mentioned in the book about ethics. Current trainees in pediatrics might not realize that extreme homophobia was routine in all parts of society, including among physicians, until very recently. There are still residual pockets of homophobia, residual effects of the homophobia, and examples of parental non-acceptance of the sexual orientation of the children. Pediatricians interested in advocacy might want to encourage gay straight alliances in schools.

14.7 Gender Dysphoria

James, aged 14 years, comes with his mother for a routine medical examination with Dr. Merkely. The receptionist reminds James and his mother of the clinic policy that patients over 14 years will be seen by the physician without the presence of a parent. The mother was already aware of this policy.

During the standard HEEADSSS assessment James mentioned that he felt as if he should have been a girl.

Dr. Merkely might feel uncomfortable with the statement and may lack the skills and knowledge to fully assess James. This does not mean that he cannot offer immediate help to James. If James has a diagnosis, it is "Gender dysphoria". This refers to James's identification with a gender not in keeping with his physical sex charac-

teristics. One of the problems is knowing which pronoun to use: should we now talk about James as "she" or continue as "he"? Inclusion of the word, "dysphoria" relates to the distress and unease experienced. The term is more specifically defined in the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (American Psychiatric Association 2013). Dr. Merkely may be forgiven for lacking full knowledge of gender dysphoria. The use of this term in PubMed identifies 238 articles. Seventeen of these articles were in the 30-year period 1974 to 2004, and 22 were in the short period January to April 2018; in other words, an increasing amount of attention is being paid to the subject.

In ethical terms, we would like Dr. Merkely to maintain friendly support of James, and seek more information from him, such as the duration of these thoughts, and whether he has shared them with his family. In that respect, Jim should be asked if he has spoken to the family, whether he wishes to do so now, and if so, whether he would like Dr. Merkely to be with him. Does James expect an angry response from the family? A negative response? Support?

Pediatricians will not be knowledgeable about every topic that arises, especially regarding concepts that are relatively new such as gender dysphoria. It is important for physicians to have confidence in their basic skills, to know the limits of their knowledge and to seek help when needed. Using the basic skills of conveying support, asking relevant questions and emphasizing the confidentiality of the interaction are essential early steps. Of course, it is important to ensure that the pediatrician's medical knowledge is up-to-date. In terms of rare situations such as gender dysphoria, there are almost always referral sources that can be identified, and that will welcome contact from Dr. Merkley to give her advice on how to proceed.

14.8 Reproduction and Developmental Delay

Monica, aged 14 years, comes with her mother for a routine medical examination with Dr. Price. The receptionist reminds Monica's mother of the clinic policy that the physician will see patients over 14 years without the presence of a parent. The mother was already aware of this policy, but requested she be present because Monica has severe developmental delay.

During the standard assessment, it became clear that Monica was sexually mature and had been menstruating for more than a year. The mother said that Monica became extremely upset with each period and requested help with suppressing menstruation. She went further. She explained her concerns that she would not always be able to care for Monica, who might be in an environment when she might be sexually assaulted, and that she wanted her sterilized, and that a hysterectomy was the best way to achieve this.

Instantly one discerns problems which this story reveals. What has happened with routine medical surveillance? Has there been no anticipatory guidance? Is the developmental disability associated with multisystem disorders, such that many specialists have seen Monica for specific system problems, but without addressing overall issues? Whatever the background, Dr. Price has to move forward. Dr. Price

might agree with the request that someone with developmental disabilities, such as Monica, be seen with a parent, at least initially. However, Dr. Price should ensure that, unless the developmental disability is extreme, Monica has an opportunity for confidential discussion.

Concerns about sexual abuse and menstruation, even if there are no menstrual abnormalities, are not unusual in the parents of young people with developmental disabilities. In a survey of 300 patients with developmental disabilities referred to a gynecological clinic, the main concerns were menstrual suppression, hygiene, caregiver burden, and menstrual symptoms (Kirkham et al. 2013). A small number, of caregivers, approximately 20, initially asked about hysterectomy, tubal ligation, endometrial ablation, and/or hysteroscopic tubal occlusion. In the whole group of 300 patients, only one hysterectomy was performed, and this was because of a marked congenital anomaly, not to achieve sterilization or menstrual suppression. There are many medical options available in terms of both contraception and menstrual management (Quint et al. 2016). It would be ethically appropriate for Dr. Price to refer Monica to a pediatric gynecology clinic. It would not be ethically appropriate to do so without discussing the mother's fears, underlying anxieties, and issues within the family. It would not be ethically appropriate to make the referral without at least a minimal discussion with Monica by herself.

Dr. Price should have access to Monica's records, and unless the developmental disability is extreme, would initiate a discussion with Monica based on the HEEADSSS mnemonic. This discussion would develop some understanding on Dr. Price's part of what Monica knows, whether she has some degree of sexual activity at present, whether there is any question of abuse, and whether she understands the consequence of childbearing and child rearing. An ethical pediatrician will take the time to explore these issues with both Monica and her mother, and while specialty clinics will be used, they will not replace general oversight of Monica's care. Dr. Price will ensure that regular follow-up is instigated and will emphasize the importance of such follow up to Monica and her mother.

There seem to be more articles in the ethical and pediatric literature on pediatric gynecological issues, than on sexuality issues in male adolescents. However, many of the issues that arise in Monica's case will arise also in a male with developmental disabilities, and the same ethical approach will apply. There should be attention to concerns of both the caregivers and the patient. However, the patient should be assured of confidentiality and should be treated with respect.

14.9 Eating Disorders

Uma, aged 17 years, comes with her mother to Dr. Walz for a routine medical examination. Uma saw Dr. Walz by herself because she and her mother knew of the clinic policy. (This story is adapted from a clinical case commentary by Dr. Garry Sigman 2005*.)*

Uma was talkative. She was doing well at school and looking forward to college. She had friends and was not sexually active. She was active in sports.

Uma had lost seven pounds since she had last been seen 6 months ago.

Physical examination was normal apart from some dental enamel erosions, mild acne, and a callous on her finger. Dr. Walz asked Uma if there is any possibility of bulimia; the reply was "no". Dr. Walz ordered urgent blood work and asked her to wait until they had preliminary results. The results showed mild hypokalemia, and increased amylase.

When the implications of these results were pointed out to Uma, she did admit that she had been "binging and purging" for the last several months.

Bulimia is one of the eating disorders, characterized by recurrent binge eating and extreme weight control behaviour such as self-induced vomiting or laxative use. The other major eating disorder is anorexia nervosa which entails an active maintenance of an unusually low and new body weight by a combination of restricted diet and extreme exercise. Both of these disorders share the characteristic of judging the self-worth mainly in terms of shape and weight. There are other atypical disorders that do not fit neatly into these definitions (Fairburn and Harrison 2003). In general, the eating disorders are described as having:

- Definite disturbance of eating habits and weight control behaviour
- Either this disturbance, or associated core eating disorder features, results in a clinically significant impairment of physical health or psychosocial functioning (core eating disorder features comprise the disturbance of eating and any associated over evaluation of shape or weight)
- The behavioural disturbance should not be secondary to any medical disorders or to any other psychiatric disorder.

Dr. Walz, like most physicians, desires to do good. She will focus initially on the physical disturbance (hypokalemia), by trying to develop a strong relationship with Uma. In this situation, as in all pediatric situations, a strong relationship between the pediatrician and the adolescent is the starting point to resolving problems. Dr. Walz will treat Uma respectfully, and assure her of privacy and confidentiality. Individuals with eating disorders are resistant to advice and are described as "treatment refractory" (MacDonald 2002). Knowledge that the eating disorders might be life-threatening understandably leads to thoughts of coercion. In trying to do good, there is certainly a temptation to move towards coercion, persuasion and manipulation; this temptation should be avoided. It is true that in some situations compulsory action needs to be taken under mental health legislation, but it is also true that such action is for extreme situations only. It is more effective to support and to guide the teen.

The assurance of confidentiality and of respect for her autonomy (even if we do not use those precise words with her), must be coupled with truth telling. In other words, Uma must be told the physical situation in which she now finds herself and the medical sequelae if her hypokalemia is not controlled. Uma must also be told that there are occasions when confidentiality will be breached in her interest, and that she might need to be treated against her wishes if she chooses not to follow medical advice and becomes very sick. Truth telling must be done in a supportive fashion, and without a coercive tone.

Adolescents who suffer from eating disorders can, and often do, live in a challenging family system. The parents might be distracted and inattentive, or overly

critical. The child might be reacting to this situation by seeking more control or seeking to disappear. There is much literature on this disorder. We find these to be helpful and creditable:

Strober M and Humphrey LL (1987) Familial contributions to the etiology and course of anorexia nervosa and bulimia. Journal of Consulting and Clinical Psychology 55(5):654. https://doi.org/10.1037/0022-006X.55.5.654

Humphrey LL (1989) Observed family interactions among subtypes of eating disorders using structural analysis of social behavior. Journal of Consulting and Clinical Psychology 57(2):206. https://doi.org/10.1037/0022-006X.57.2.206

Mimma T, Cimino S, Ballarotto G, Bracaglia F, Bottone C, and Cerniglia L (2017) Female adolescents with eating disorders, parental psychopathological risk and family functioning. Journal of Child and Family Studies 26(1):28–39. https://doi.org/10.1007/s10826-016-0531-5

It is important to keep in mind that the eating disorder in the adolescent might be happening in a complicated family system. While pediatricians have a primary responsibility to the patient, that responsibility might need to be discharged by taking further action to help any siblings and the parents. It would be within ethical norms to refer for family therapy.

14.10 Adolescents Seeking Performance Enhancing Drugs

Michael visited his physician infrequently. Most of the visits were for minor sports injuries, or to complete medical forms prior to athletic competitions. He was aged 15, was very active in sports, and was successful as a sprinter at the school level and believed that he was good enough to use this talent for college entrance.

On this occasion, Michael came by himself and told his physician that he wanted to maximize his performance. Michael had heard that steroids would help, but he was worried that if you obtain them illegally, they may be contaminated and might not be fully effective. He asks his physician to prescribe them.

We will assume that the physician wishes to obey the law. The choice then becomes one of dealing with Michael curtly, and letting him know that the physician does not want to be part of anything illegal. A more compassionate response would be to spend time with Michael, understand his anxieties, and the pressures that are occurring in his sports career.

Physicians might encounter similar, inappropriate requests for medication from adolescents who seek to perform well on examinations and believe that attention deficit disorder medications will help (DeSantis et al. 2008) and (DeSantis and Hane 2010). Again, the approach is to seek to understand the nature of the teen's anxieties and to screen for mental health concerns. Some of the teens will acquire the drug illegally, and other teens will obtain a prescription for the drug and then sell it (Bradshaw 2018). It is important for physicians to "keep the door open" such that, if the teen does act against medical advice, then he or she feels safe in returning to the physician for medical help needed because of using medication inappropriately.

14.11 Transitioning to Adult Services

Nathan had attended Dr. Wong since birth and was now aged 17 years. He had delay in walking and had been diagnosed with Duchenne muscular dystrophy when he was 18 months old. Nathan and his family received a great deal of support from a nearby pediatric centre, and they were very well aware of his current situation, and of the prognosis. Nathan had been dependent on a wheelchair for the previous 8 years and had been using noninvasive ventilation overnight for the previous 2 years. Nathan had just learned that the pediatric center had a strict policy that they did not admit anyone over the age of 18 years, and that he should plan to be followed by an adult team.

He was very concerned, indeed extremely distressed, and wanted Dr. Wong to help him stay at the pediatric center.

The anxiety is common across many chronic childhood disorders. The patients themselves, even though they are approaching adulthood or might actually be adults, and their parents, have been comfortable with the pediatric milieu and also with the specific healthcare providers. They have known no other medical care. Moving on to another set of providers, and to a different facility can be a daunting prospect. One of the first things Dr. Wong might want to do is to determine how rigid the institutional rules are, and whether exemptions are allowed. Most pediatric institutions pride themselves on being family centered, and you probably want to work with families. We would agree with the statement:

> Those responsible for providing healthcare to adolescents must allow sufficient flexibility in this age span to encompass special situations such as the emancipated minor or the young person with a chronic condition leading to delayed development or prolonged dependency.
>
> (Sacks et al. 2003)

On the other hand, we recognize the problems that pediatric institutions have in terms of availability of space, and more specifically allocating scarce space designed for children to near adults.

The qualities we are looking for in Dr. Wong are compassion but tinged with realism, managerial abilities and advocacy. The first is obvious, the second and third are necessary and the qualities required for advocacy are not so obvious. Being an advocate for a patient does not mean being automatically an advocate for everything that the patient or the family want. Dr. Wong should explore with Michael what would be in Michael's best interest. Even if Dr. Wong were able to obtain a deferment for Nathan from the pediatric institution to an older age, the deferment will not be indefinite, and the problem must be addressed sometime. The managerial skills are extremely important in identifying steps that need to be taken, formal processes that might be required, such as securing access for drugs or equipment for someone aged over 18 years, and in determining whether there are also legal steps to effect the transfer of care to an adult institution. The transfer is also an opportunity to discuss Michael's treatment goals. Michael might be aware, and is very likely to be aware, of a shortened life expectancy. On the other hand, the discussions in the past might have occurred with his parents and not with him. End-of-life discussions in this situation, as in most situations, should take place over time. The first stage is to

find information on prognosis, to clarify the options that Michael might have, and to set the agenda and timetable for the discussions.

Dr. Wong and Michael will need to collaborate on additional resources required, and though Michael is near adult, the parents have likely been very involved in his care and want to be part of the discussion. It is helpful to have formal psychological and social work help to manage the ending of relations with one institution, and the development of relationships with another institution.

It would make things very easy if Dr. Wong were to contact the pediatric institution to learn whether they have a formal process of transition.

14.12 Homeless Children

Dr. Terakita was on duty in an emergency department when the ambulance brought in Charles. He had been found injured, and unable to walk. Charles was obviously unkempt and unwilling to talk about himself or the injury. Dr. Terakita thought that Charles might be aged 15 or 16 years but was unsure. He asked Charles about his parents, with the very questions leading to distress without any reply.

The words "street children" are familiar but dated and inappropriate terminology. This name puts the focus on the "street", rather than on the individual. Current terminology varies, but one is "urban children at risk", which is perhaps cumbersome (Panter-Brick 2002). The reality is that children like Charles might sometimes sleep on the street, might occasionally return to the parental home, might sleep with friends and might be in shelters. The background of Charles is likely to be some combination of parental abuse and neglect, or perhaps parental disagreement with some aspect of appearance such as piercing body parts, religious strictures in the home, sexual orientation, or poor school performance (Hyde 2005).

Dr. Tarikita's first duty is to conduct a complete medical assessment of Charles' injury, and his general health. This assessment must be conducted respectfully and privately, and with assurances that Charles' interests will be the first priority during the whole process. Dr. Tarikita should attempt to identify, as far as is possible even though Charles might be uncooperative, whether there are major mental health issues. Identifying whether Charles has the confidence to decide on his own medical care is more difficult. However, given that he is not living with adults, there is a presumption that he alone may give consent to medical care, as an "emancipated minor".

This is a brief encounter in a facility designed for emergency care. Perhaps the most that can be done for Charles at this time is to deal with the minor injuries, and if they do not require admission, to try to make some kind of follow-up arrangements. Over and above these issues, Charles should be given an assurance of support, and addresses of shelters that might be able to help him. It would be helpful to Dr. Tarikita if his community has a shelter dedicated to the unique challenges of adolescents.

14.13 Organizing Care

The reader might wonder why such a section exists in a book devoted to ethics. Specialized adolescent clinics are orientated towards the needs of this age group of children. However, adolescents will be seen in many settings: emergency departments, walk-in clinics, subspecialty clinics, physician offices and pediatric clinics that see children of all ages. The physician seeing adolescents should ensure that, in addition to knowing about specific disorders prevalent in adolescents, they are knowledgeable about issues of consent and confidentiality. However, staff training is extremely important. Staff will require training in issues of confidentiality involving adolescents, and in the need for respect. The difficulty should not be overlooked. A receptionist who has spent the morning greeting one, two and three-year-olds with her parents, then needs to use an entirely different paradigm of interaction when a 14-year-old comes in. Nevertheless, that individual can be trained on how to greet the 14-year-old appropriately, and on the necessity for confidential health care (Riley et al. 2017) and (Adelman et al. 2016).

It is very difficult to achieve an ethically high standard of care when staff attitudes and the clinic layout deliver an unwelcome message to adolescents that they will be treated in the same way as young children.

In telling the story of Michael with developmental delay, it was clear that the physician required knowledge of transition. This is a wider question for those involved in pediatrics. During training, the focus is, not unnaturally, on medical issues of diagnosis and treatment with usually specific training in communication. Yet children and families are helped best if healthcare professionals have a good knowledge of resources that they can access to provide additional help. Such resources will include agencies beyond healthcare, including social service and psychology agencies. When dealing with adolescents, physicians need to know about services geared towards the "young adult" because adolescents will bridge services, sometimes being involved in pediatric services, sometimes being involved in adult services.

14.14 Conclusion

Adolescents are passing through a distinct developmental phase and will be leaving pediatric care. Consequently, they require a distinct approach that recognizes them as individuals who deserve and need privacy and confidentiality. This distinct approach must meet the needs of adolescents and requires staff training and often premises that offer specific arrangements for teenagers distinct from the arrangements for younger children. In most jurisdictions, adolescents are still legally minors, but are able to provide consent in many situations. Hence, assessment of their maturity and understanding is part of any medical assessment. Pediatric patients who transition successfully to adult care should be seen as successes; it is not the aim of pediatrics to keep the patients in a childlike state forever.

Suggested Reading

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Chapter 15
Why Is There So Much Talk About Cost in Health Care Today?

Key Points Concerning Resource Allocation

- Health care is funded by finite resources
- Therefore, healthcare does not have unlimited resources to meet every patient need or demand
  - More resources for health care do not necessarily mean better health
  - Priority setting and rationing are other terms used but are sometimes perceived negatively
- Resource allocation is about ensuring fairness in health care delivery in the face of competing needs and should follow consistent ethical principles
- Public attention often focuses on unusual individual cases such as access to transplant or expensive treatments
- Pediatricians engage in resource allocation activities every day
- Resource allocation might be at different levels:
  - Micro allocation – at the individual level when decisions are made about e.g. PICU admissions
  - Meso allocation - within the health care or institutional budget - in making decisions, e.g. about which health care program to support
  - Macro allocation - governmental level - when the competition is with other social services such as education and housing

15.1 Introduction

The parents of our patients, and the patients themselves, are known in modern parlance as "healthcare consumers". They need not look far to become worried about the cost of healthcare. Media reports in the US, Canada, and the United Kingdom are ubiquitous about the high cost of healthcare. One US headline that caught our

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_15

attention is, "Why health care costs are making consumers more afraid of medical bills than an actual illness". Here's another one: **"**U.S. healthcare spending to climb 5.3 percent in 2018: agency**"** (Abutaleb 2018). Total costs were expected to be $3.5 trillion, driven by an increase in Medicaid enrolment by the increasing numbers of seniors in society and by a general increase in prices of health care services and goods. One specific item listed will affect all ages and is particularly relevant in pediatrics: "higher drug prices and more use of specialty drugs such as those for genetic disorders and cancer". A recent Canadians headline reads, "Healthcare costs have skyrocketed: study" (Stevenson 2017). An article on health spending states, **"**In 2017, total health expenditure in Canada is expected to reach $242 billion, or $ 6,604 per person. It is anticipated that, overall, health spending will represent 11.5% of Canada's gross domestic product (GDP)." (Canadian Institute for Health Information 2017). In Britain, with an ostensibly publicly funded healthcare system, a headline reads "Private health insurance costs double in London" (Emery 2018). Another article claims, "Reality Check: Does UK spend half as much on health as US?" (Stevens 2018). The author makes two points: it is difficult to compare costs in one country with another and that UK health care is partly publicly funded and partly privately funded. However, even making these allowances, the US seems to spend twice as much per person on health care than does the UK.

15.2 Landen's Story

> *Six-year-old Landen lives in British Columbia, Canada and has Systemic Juvenile Idiopathic Arthritis (sJIA), a rare form of arthritis that leaves the boy in constant pain and can even cause death.*
>
> *His parents have been fighting to receive coverage for a drug called Canakinumab, which comes with an annual price tag of more than $225,000, approved by Health Canada, but not covered by British Columbia PharmaCare.* (Benning and Little 2018)

15.2.1 Comments on Landen's Story

This story appeared in a news article on January 6, 2018 and offers more details. Landen had been previously healthy, and now spent a great deal of time in bed, or in hospital, and certainly was in constant pain. His diagnosis, sJIA is a rare disorder, with inflammation of the joints; in Landen's case, adequate pain control seems difficult to achieve. sJIA is one of those conditions called a "therapeutic orphan" because it lacks good therapy; traditional therapies are not very effective and have been associated with many side effects. Canakinumab is a new biologic therapy, an anti–interleukin-1β monoclonal antibody, that is proven to be effective (Ruperto et al. 2012). The federal legislation establishing healthcare in Canada does not mandate pharmaceutical coverage, but the provinces, which administer healthcare, have programs to cover drugs. In British Columbia, the program is called PharmaCare

(British Columbia Health 2018). PharmaCare describes what drugs it will pay for and what it does not cover and also describes its process of decision-making. PharmaCare describes itself as having clinician input, public input, and produces summary reports on the decision it takes. Later in the chapter, we will discuss "accountability for reasonableness" and the process used by British Columbia PharmaCare seems to meet most of its stipulations.

Although Canakinumab might help Landen, it is clearly expensive and so approval is given only after an extra layer of scrutiny. Federal Government approval of the drug indicates that it is safe and efficacious, but Federal approval comes with no promise that the drug will be provided. British Columbia PharmaCare had decided not to approve funding for this drug for Landen. Landen's mother is convinced that it will improve his condition and is fundraising to help him. In a later news item (April 10, 2018) we learn that a charity has arranged for his transfer to a US hospital for a second opinion.

Landen's story contains many of the themes to be addressed in the chapter. New developments in medicine bring new promises to children with disorders that previously were difficult to treat. These treatments come with a high financial cost, beyond the means of most individuals to pay by themselves. Whether the healthcare program is funded by government or private insurance, there will be complex processes to decide what to approve and what not to approve both in general, and in specific cases. Not everyone will be happy with the decisions. Healthcare does not have unlimited resources to meet every patient need or demand.

In the newspaper reports, the comments were almost all supportive, and expressed surprise that the government was not providing the drug to Landen. These comments are understandable, but we don't quite have enough detail from newspaper reports to know whether there might be alternatives. It is easy to have sympathy for Landen. We are not suggesting that our sympathy lies with government agencies or insurance companies, but it is important to describe the problems they face, and some of the approaches they might use in helping to reach a decision.

A similar story is told in the UK about a child called, Joe, who is denied what is described as a life-changing drug (Buck 2018). The UK organization, National Institute for Health and Care Excellence (NICE) (see Chap. 6) had declined to approve it for any patient. The story is heart wrenching. The mother says,

> I wish they could see Joe, the people who make these decisions. They think it's about money and resources, but if they could just see Joe lying here or in hospital on a machine. He's so ill; he's like a skeleton. What if it was their child? When you know one small, pink tablet could make such a difference.

The mother was speaking about her child, but the subject concerns all patients with Cystic Fibrosis. The drug concerned is lumacaftor/ivacaftor (ORKAMBI®) used in cystic fibrosis. Sadly, the situation the mother describes is about money and resources. To explain more clearly, this drug is said to cost UK £104.000, US $136.601 per annum. The article states that 3296 patients might benefit. Because this drug is not a cure, it improves a deficiency while it is given, without lasting effects when it is stopped. This means an annual expenditure of UK £342,784,000 (US$450,236,896), in other words, hundreds of millions.

The Canadian Agency for Drugs and Technologies in Health (CADTH) reached the same conclusion as NICE re ORKAMBI®. In submissions to CADTH relevant to Joe's case, a request was made that it be funded for patients with acute deterioration. CADTH responded that this was one situation that had not been studied. (CADTH 2018)

Landen and Joe's stories are but two examples of the enormous decisions that authorities are asked to make when a new intervention is being considered. This is a major issue in bioethics we will discuss further in the Part V Conclusion. Unfortunately, it is not possible to describe ways in which expensive interventions will magically become inexpensive interventions!

15.3 Attention to Costs

Costs not only attract the attention of the media; they are the focus of elected officials and medical organizations.

It is important to state that this chapter is not isolated from the rest of the book; concerns about costs appear in almost every chapter. In Chap. 1, we described how guidelines, which are one way of constraining costs, are linked to concepts of physician autonomy. We noted in Chap. 3 that the driving force for ethics committees was concern over resource allocation, in the particular case of access to renal dialysis. In other chapters, we addressed the issue of expensive drugs for various disorders, and the fact that we now have a new population of children (children with medical complexity), who require new approaches to funding to meet their needs, needs that will continue for many years. In our description of the role of advocacy (Chap. 9), we emphasize the need for social responsibility.

This chapter is about the allocation of resources to a wide variety of healthcare activities. Here, we briefly describe various ways of delivering healthcare, some of the terms developed by economists that are useful in the ethical analysis of resource allocation and list some of the ethical considerations. This chapter is not about funding for health; it is about funding for health care. These are different. People enjoy better health than they have in the past. The improvement in health of the last century in the Western world, and in many other parts of the world, relates to general improvements in social conditions and income, improvements in education, especially the education of girls and women, improvements in hygiene and one specific healthcare intervention, vaccination.

The distinction between health and healthcare spending is made more obvious by considering how healthy a nation is and how much it spent on healthcare. To determine the health of a nation, overall measures of health are used. These are commonly assumed to be life expectancy, infant mortality, low birth weight, maternal mortality and potential life years lost. Bradley et al. (2011) reviewed health (and social spending) in 30 countries that are part of the Organization for Economic

Cooperation and Development (OECD) to determine whether better health was achieved by greater healthcare spending. In terms of strict healthcare spending, the USA spent 16% of GDP on healthcare. In the other OECD countries, the average was 9%. Despite this spending, in 2006 the USA ranked 25th in life expectancy, 29th in infant mortality and 24th in maternal mortality.

The work of Bradley and his colleagues was important because it demonstrated that pouring more money into healthcare would not necessarily achieve better health. Of course, it was already known that there is not a close relationship between health care spending and better health. But previous explanations relied too much on private financing, major disparities in quality of care, and a lack of primary care providers. Bradley et al. (2011) took another view, and reviewed spending on social services, that are known to be relevant to health. Social spending includes "income supplements, housing, unemployment coverage and other social policy targets." The data they used came from publicly available information on health and social spending. Bradley et al. (2011) had two important findings. The first was that, "health services expenditures adjusted for gross domestic product (GDP) per capita were significantly associated with better health outcomes in only two of five health indicators", life expectancy and maternal mortality. The second finding was that "social services expenditures adjusted for GDP were significantly associated with better health outcomes in three of five indicators" (life expectancy, infant mortality and potential years of life lost). The conclusion is obvious; if we wish to improve health, we cannot simply spend more on healthcare. We need to look at the broader dimensions of social policy as well as to make changes in healthcare.

This conclusion comes with a warning to all healthcare practitioners, and indeed to many of the parents of our patients: we must be careful that when we advocate for more spending on pediatric healthcare, we do not worsen the outcome for children overall by a concomitant reduction in social spending.

15.4 Health Care Systems

There is widespread concern about the costs of healthcare in all societies. Costs are seen to be rising rapidly, with little change in measured outcomes. This concern occurs whatever the "system" of healthcare in use in any particular country. Tanner (2008) writes from a US perspective and describes three types of health care systems; the single-payer system, the employment-based system, and managed competition. These are described as separate, but in fact there is considerable overlap; none of these systems is "pure". None of them covers all health care services; many include cost sharing and some limited choice of provider. We will offer an overview of these systems and return to a description of health care funding in the USA.

15.4.1 Single Payer System, Employment-Based Systems, Premiums, US Situation

In the single-payer system, the government pays for the healthcare of all citizens from taxation on income. Global budgets are established, and individual items of expenditure allocated, usually by some form of central control. The budget includes payments for individual treatments, and the payment for healthcare providers. There might or might not be private insurance, coverage of all items we would consider "healthcare", and ready access to an alternative system for which patients would pay directly.

The examples of single payer systems are Canada and UK. In Canada, a federal state, healthcare is the responsibility of individual provinces and territories. The provinces provide funding, but in fact the federal government also contributes substantially. The healthcare system in Canada focuses on physician services and hospital care, with no national drug plan system, nor any provision for publicly funded dental care. Provinces have funded developments in healthcare, such as the rise of home care, though there is no legal obligation to do so (this issue is discussed in Chap. 8 on children with medical complexity). Waiting lists for common surgical procedures and investigations have been a problem in Canada. For those with sufficient wealth, care might be accessed in the US on a personal payment basis. In the UK, healthcare includes drugs; healthcare care is free at the point of contact, though of course healthcare is not free. There is a substantial private sector, with many individuals having insurance to allow access to private care when waiting within the public system is too long for the patient.

In employment-based systems, employers must provide health insurance for employees, in a system mandated by government. In Germany, those with lower income must enroll in "sickness funds", those with higher incomes may either be enrolled in one of these funds or have private insurance. The sickness funds are partially funded by employers and partially funded by employees. The jurisdiction is split between the central government, and state governments, deciding on such items as, for example, reimbursement rates for physicians.

Healthcare premiums are costs that individuals pay for healthcare coverage. They might be regarded as a payroll tax which is remitted to some central funder, but typically providers have a great deal of independence. The main example of this mode of healthcare provision is in Switzerland. It is best described as managed competition; healthcare is private but with extensive government regulation. Swiss law insists that all citizens purchase healthcare insurance with at least basic provision. There is near universal compliance with this law, and insurance companies compete in terms of pricing and the presence or absence of various levels of deductible payments.

The US system, as described by Tanner (2008), is seen as having advantages over the other systems, though its great expense is acknowledged. The organization that sponsored Tanner's report, the Cato Institute, believes strongly in limited government involvement in the life of the citizens. In addition, this report was written before the Affordable Care Act of US President Obama was enacted, and before that healthcare system was partially dismantled by US President Trump.

Nevertheless, some of the facts about American healthcare remained true. Firstly, it is the most expensive in the world whether measured by spending per individual citizen or spending as a percentage of GDP. It is also funded to a large extent by government via Medicaid and Medicare programs, and specialized programs, such as those for Army veterans.

This brief overview of various systems is not meant to advocate for one system or another; indeed, all of the systems have problems. The problems vary from having individuals with limited access to regular healthcare, to issues with waiting lists for procedures and investigations, to a concern about the overall cost of healthcare. We recognize also that the development of the various systems is part of the culture of various countries and is not readily changed. The USA stands out as one country with public funded healthcare (Medicaid etc. mentioned earlier), but without a commitment to publicly funded health care. During the 2016 presidential election, one commentator (Callaghan 2016) stated that this situation was unlikely to change. In general, the public like the system they have and do not want to change. In addition, there are powerful interest groups, such as insurance companies that spend heavily on lobbying to prevent change. Finally, publicly funded healthcare is acceptable and indeed lauded in many developed nations, but programs described as "entitlement" are very difficult to enact in the US.

15.5 Global Aspects

This book is written for trainees in pediatrics in the Western world This chapter deals with the issues of resource allocation that arise in that world. In the preceding paragraphs we have discussed how billions and trillions of dollars might be spent. There is another part of our world in which much smaller allocation of resources would yield much greater benefits. A Lancet article details how an additional investment of five dollars per person per year until 2035 could prevent the needless deaths of five million women, 14.7 million children and 32 million stillbirths. This article addresses an investment of $30 billion per year in 74 "high burden countries" (Stenberg et al. 2014). Such health improvement could be achieved by investments in such items as better coverage for immunization and many low-cost but cost-effective interventions. The argument for such spending goes beyond the concept of "macro allocation" of healthcare in developed world countries and addresses how we might behave as citizens of the world.

15.6 Comparing Costs

When deciding whether to introduce a new intervention, whether surgery, a new drug or vaccination, a new service or something else, or whether a current intervention is economically worthwhile, we require measures of costs that allow compari-

sons with other interventions. It would be easy if new interventions saved money; alas we know of no examples. Hence, the need to be aware of the tools of health economics is important. We are not versed or qualified in the discipline of health economics but recognize its importance. Nevertheless, we introduce here some of the concepts that arise in the cost analysis of healthcare interventions.

The most fundamental concept is that of "opportunity cost, that being the benefit which could be obtained by next best use of those resources." If we minimize the opportunity costs and maximize benefits, we will achieve a degree of efficiency. In our introductory bullet for this chapter, we mentioned that the resources available for health care are finite. If we spend money on intervention A, then there might be nothing left over to pay for intervention B. Most cost-effective analyses require some sort of comparison of the new intervention compared with existing practice. It is of course important when we propose a new intervention, whatever its form, that we identify all the possible costs. These will include not just the cost of intervention itself, but also the cost of any potential adverse effects, the cost of investigating incidental findings arising from the intervention and so on.

One of the most common ways to carry out the comparison is looking at "quality adjusted life years (QALYS)" (Bravo and Sculpher 2008). These are measures that are able to combine in one metric both morbidity and mortality and are thought to reflect individual preferences. (For those interested in understanding this concept better, we suggest reading the paper by Bravo and Sculpher.) Also, we need measures that can estimate and compare benefits of a wide variety and heterogeneity of health interventions. There are criticisms of QALYS, in that the results obtained are not always consistent with the public ranking. Typically, the public will rank almost any intervention in extreme situations such as a life-and-death situation before more prosaic concerns (Neumann and Cohen 2018). There is also a concern that such measures put a monetary value on life. Some of these thoughts were expressed in online comments on Landen's care mentioned above. While we accept that it is not possible to put a monetary value on a human life, we do not think that we can ignore economic evaluation in the ethical adjudication about introducing or not introducing a specific treatment. It cannot be ethical to allow health care spending on an intervention of doubtful benefit that denies funding to a benefit of proven value.

The importance of economic analysis has widespread acceptance, but the details can vary. Most organizations have established standards of economic analysis, and in some cases, countries have a centralized process. An example would be the British National Institute for Health and Care Excellence (NICE); we would refer you to its website (www.nice.org.uk) to look at some of that organization's methodology.

15.7 Choosing Wisely

Being efficient in our use of existing resources is an obvious first step in resource allocation. If we are efficient, then we should be able to free up resources that might be allocated in more effective ways. However, we recognize that this is easier to say than to do. Recently, a campaign was started with a focus on efficiency, and discon-

tinuing unnecessary investigations and treatments. The starting point was the finding that about 30% of all medical spending in the US did not add value to care. This led the American Board of Internal Medicine to develop the "choose wisely" concept (Cassel and Guest 2012). We have already mentioned the "choose wisely" campaign in Chap. 1 in the context of overdiagnosis. There we outlined the ethical requirement to avoid doing more because of our insecurity, or because of parental demands. In this chapter, we address in more detail the concept of choosing wisely. "Choosing wisely" is now recognized internationally (Levinson et al. 2015). Individual specialty societies are examining the available evidence and compiling lists of and treatments that are of little or no value.

In Chap. 1, we identified two situations when overdiagnosis was relevant: gastroesophageal reflux in the first 6 months of life and the excessive use of pulse oximetry in acute bronchiolitis. A recent publication includes these two recommendations in the top five opportunities to improve pediatric healthcare value (Quinonez et al. 2013). The other three opportunities were to avoid: systemic corticosteroids in children under 2 years of age with lower respiratory tract infection, chest x-rays in children with asthma or bronchiolitis and bronchodilators in children with bronchiolitis.

Another study examined the concept of choosing wisely in the context of newborn medicine (Ho et al. 2015). We cite this paper because the methodology described is applicable to many different areas of pediatrics. The authors first identify, by means of a national survey, tests and treatment that might be contributing to healthcare waste because they are unnecessary. The authors then developed an expert panel (51 individuals), from a number of perinatal care organization. They used a modified Delphi process, and over three rounds identified the top five items. For interest, these recommendations were to avoid routine:

1. Use of antireflux medications for treatment of symptomatic gastroesophageal reflux disease or for treatment of apnea and desaturation in preterm infants,
2. Continuation of antibiotic therapy beyond 48 h for initially asymptomatic infants without evidence of bacterial infection,
3. Use of pneumograms for predischarge assessment of ongoing and/or prolonged apnea of prematurity,
4. Daily chest radiographs without an indication for intubated infants, and
5. Brain MRIs in preterm infants.

Of course, the specifics of these recommendations for neonates are very important, but in our view, the description of the method is of greater importance.

15.8 Ethical Aspects

The ethics of resource allocation is both simple and very complicated. In terms of it being simple, this relates to the description of "justice" provided in Chap. 1. We pointed out that ethical concepts of justice could be used to answer questions such as "Is there a right to healthcare? And how do we set priorities?" We describe vari-

ous approaches to justice but did not indicate that one approach was superior to another. We indicated sympathy with the number of concepts including some of the ideas developed by Rawls (1971) that focused on the disadvantaged, and the need to "fashion societal measures to lessen disadvantage of any kind." We express support also for the ideas developed by Powers and Faden (2006) to reduce inequality in the world. These authors pointed out the magnifying effect of inequalities, something we see in the combination of socioeconomic disadvantage and pediatric disease. They recommend that we need to attend to both health and social structures if we truly intend to achieve equality.

15.8.1 Right to Healthcare

We believe that everyone has a right to healthcare. The questions that arise are the justification for this right, who or what has the obligation to provide for this right, and what limits will be placed on the right to healthcare.

The right to healthcare is different from the right to health, and governments already have a role in protecting health. In Chap. 9 we described the governmental actions that led to deterioration in the quality of the water in Flint Michigan with extreme effects on the health of children. While some government officials and politicians argued about the facts, no one denied that the government had a role in providing safe water. Similarly, government has a role in dealing with epidemics of disease. Also, all countries have a process for reviewing the evidence on the safety and efficacy of new drugs and decide whether they can be allowed on the market in their company. Research processes (Chap. 13) are strictly regulated. We conclude that all governments accept that they have a role in the protection of health. Some of these governmental activities are related to collective protection, such as clean water, and some are related to individual protection, such as the approval of new drugs.

Governments, and society in general, have other roles in health care. The education of health care professionals is essential to the provision of health care and is at least partly funded by governments. However, patients and families also participate in education by allowing trainees to participate in their health care.

To return to the provision of healthcare: the justification for such a right would arise from almost all theories of justice. In almost all instances, ill health is something beyond the control of individuals, and brings enormous consequences to future life, and future family life. The concept of "fair opportunity" can be used to justify a right to health care.

If we agree that there is a right to healthcare and that the obligation to provide it falls to society in general, then the costs should be funded by government. However, this whole chapter is about setting priorities, and accepting the basic premise that everyone cannot have every possible healthcare intervention. So, we have already accepted the concepts of limits and that limits should apply to the right to healthcare. We would suggest that some basic level of healthcare be provided, along with

coverage for catastrophic events. This is best described as a "safety net". In those countries with government-funded healthcare, typically such extra provisions as a private room in hospital and cosmetic surgery are not provided from the public purse. Other interventions, such as advanced reproductive technology (ART) are circumscribed by regulations such as reasons for infertility and age of the prospective parents. Unlimited attempts at the intervention are generally not allowed.

There are other considerations, such as should there be ways in which the right to healthcare is forfeited. Consider the case of smoking. There is no question that smoking leads to individual ill health, and increased healthcare costs. However, smoking is generally something that starts in adolescents when people are arguably not fully autonomous and subject to strong feelings of peer pressure; moreover, it a highly addictive activity quickly making it difficult to choose not to smoke. The onset of smoking is closely related to other adverse social and environmental factors in the life of the individual. Hence, we conclude that once we accept the right to healthcare, the right should not be limited by artificial concepts of "personal responsibility". This is not to say that we do not believe in personal responsibility, but to make sense of this concept we must look at the whole context in which the person lives.

15.8.2 Utilitarian and Communitarian Concepts

These preceding ideas of justice in healthcare are presented as they apply to individual children. In terms of resource allocation, it is important to mention again the concepts of utilitarian ethics offering "the greatest happiness to the greatest number". We mentioned in Chap. 1 that some of these ideas seemed harsh, but perhaps "harsh" is the wrong word. When resource decisions are being made to advantage one child or one group, they will, of necessity, disadvantage another child or another group because health care is funded by finite resources. We don't see this result as harsh but realistic; we sympathize with those who must make such decisions. In any healthcare resource allocation decision, we will repeat what we said in Chap. 1: "the good of society, not individual rights, must be the basis of public policy."

15.9 Accountability for Reasonableness

Earlier in this book, we wrote that the ethics of resource allocation were both simple and complicated. They indeed are complicated, and, to the best of our knowledge, no one has developed a way to address the issue of resource allocation, or setting priorities, or dealing with rationing using general principles of justice. In a review of problems in the 1990s, Daniels and Sabin (1997) advanced the concept that fair procedures were one way to address major issues of resource allocation. Their publication used concepts developed from the situation in the USA, focusing on health

maintenance organizations, insurance and employers who were trying to deal with the increasing cost of healthcare by limiting access by one means or another. These authors thought that the authority of patients, with their physicians, to decide on a course of action had been taken over by external funding organizations. They did not say that this outcome was wrong and did accept that the cost of healthcare was increasing. Nevertheless, they developed four principles to guide such decision-making which are now called "accountability for reasonableness". Despite their origin in the private funding of healthcare in the US, these principles are now widely used throughout the world (Ford 2015), albeit with some quibbles about the details. They are used in publicly funded healthcare systems.

The four principles advanced by Daniel and Sabin to guide decision-making are:

1. Publicly Accessible Rationales
   There should be clarity and transparency, and details given of the evidence used to reach decisions. The decision should be consistent over time, and these conditions together should encourage confidence in their fairness.
2. Constraints on Rationales
   The decisions taken should not simply be stated: the reasons for the decisions should be given, particularly if there are particular constraints such as high-cost or low evidence, or perhaps both. Here, issues of cost-effectiveness become important, and if the constraints are accepted, then there might be voluntary compliance by physicians and patients on the outcome.
3. Dispute Resolution Procedures
   To reiterate the point made above regarding constraints, these bodies should not be authoritative. The availability of a dispute resolution procedure allows more voices to be heard, and patients and physicians can appeal decisions based on the clear evidence presented in other parts of the process.
4. Voluntary or Public Regulation

Bodies should agree to these rules, and if not, governments should legislate that they do so. Such government action is evidence of a public committing to the principle of fairness.

15.10 Political Aspects

There is no question in our mind that whatever ethical guidelines are established to evaluate healthcare interventions, there is always a political dimension (Hunter 2015). Politics in general is about who gets what, when and how. These are the specific questions we are addressing in this chapter, and health is a political issue. In the political process, the professions involved are able to speak up on healthcare issues, and we hope they do so in the interests of children and families, not in the interests of the professions. The managers, who make the resource allocation decisions we describe here, have their own interest in protecting their personal jobs. There are many community interests involved; we spoke earlier

about two conditions, in which expensive treatments are proposed, juvenile rheumatoid arthritis and cystic fibrosis. These two conditions have organizations to represent patients, and to make political arguments for treatments to benefit their members. This is not meant as criticisms of these organizations; indeed, advocacy for the individual with the particular medical condition is the rationale for their existence.

15.11 Micro Allocation

Micro allocation is about setting priorities relating to an individual patient. Every healthcare practitioner makes such decisions every day. Examples of these activities include deciding how much time to spend with an individual patient or family. Others are making decisions on admission, whether to a specific program, a hospital unit or an intensive care unit, and making decisions on discharging a child to home. Ordering tests, whether simple tests such as x-rays of the chest or limbs, or standard hematology testing, or complex testing such as MRI or CT scans or extended genetic testing should all require some consideration of their appropriateness and their priority. In surgical departments, on a daily basis, decisions are made as to which operations are performed first, based we hope on patient need.

If we order an MRI test and indicate to the imaging specialist that this is not urgent, then we are implying that the child can wait longer for this test. Conversely, if we indicate urgency when this is not the case, then we will impose a delay in being tested on some other child. The micro allocation decisions of course do crossover with decisions at the meso and macro levels. If hospital or healthcare center managers provide less resources for one service rather than another, then such provisions do affect the decisions to be taken by clinicians. For example, the PICU might be constantly full, but a decision might be made not to add further beds. This bed availability might affect the decisions taken by clinicians, decisions that are often referred to as rationing, and indeed are. At a government level, decisions might be made to transfer funding from some aspect of child healthcare, to early childhood education, which is a service that will also benefit our patients.

The reality is, therefore, that all physicians are making allocation decisions every moment of every day. How do we go about making these decisions? Strech et al. (2008) reviewed 593 references on this topic, and analyzed 10 in detail, with surveys from physicians from six different countries. The study acknowledged that rationing was a reality, and that it caused some role conflict. The conflict arose when physicians were trying to do the best possible thing for the patient before them, but there can be conflict with local guidelines. Also, there might be some difficulty with personal interests, and some of the comments indicated that time of day is a factor in some situations. One of the authors of this book (IM), was discussing demands from families for antibiotics for children with viral respiratory infections with medical students:

> We discussed many of the ethical issues, including boundary issues, and resource allocation issues. The students concluded by asking me what I would do. My response was that the time of day would matter. If this issue arose in the first consultation in the morning, I would spend time explaining the role of antibiotics, and why they were not indicated in this particular situation. If the same issue arose at the end of the day, and I had already made a commitment to do some activity with my own family, I might, with many internal misgivings, accede to the request for the prescription. Some of the students saw this is deplorable weakness on the part of their teacher, most of the students saw this as how physicians, as human beings, will act when we have many conflicting situations to address at once.

Our view is that teachers should tell the truth as they see it because the truth is the basis on which improvement can best be made.

The study by Strech et al. (2008) reported that there were three important factors influencing decision making: context factors, physician factors, and patient factors.

The context factors were the number of beds, time constraints, the available budget, and whether they had ready access to information. Other conflicts were influences from the pharmaceutical industry on the prescribing activities of physicians.

The physician factors related to a common reluctance to ration sometimes, and more frequently a lack of interest in dealing with resource issues. There is often a desire to satisfy the patient or family, and a feeling that it was an obligation to provide the best treatment, whatever the cost. Some clinicians were aware that personal involvement with the patient, by this we mean a patient that the clinician had followed over a very long time, might influence the clinician's willingness to authorize particular courses of action. Many physicians reported that they thought they lacked competence in assessing economic factors.

In the Stretch et al. (2008) study, the patient factors that related to resource allocation were the patient's ability to exercise pressure, and to be articulate. Some patients assume the role of "consumer" and demanded services, sometimes physicians acceded to the demands.

Many of the resource allocations decisions taken were implicit, such as deferring activity, deflecting requests, or simply delaying a response. Many of the physicians wanted more assistance in decision making such as access to explicit criteria, with clear rules and guidelines, perhaps involving an interdisciplinary committee. Many thought that politicians and government should be involved, along with the public and professional members.

Physicians may face most problems in individual resource allocation when the patient is facing a crisis. The imperative to do something for identified individuals who are in a great deal of trouble, regardless of cost is called the "rule of rescue". Application of this rule leads to tension between attempts to do as much good as possible with available resources, so-called cost-effectiveness. Cookson et al. (2008) quote the pioneer bioethicist Jonsen as saying:

> Should the Rule of Rescue set a limit to rational calculation of the efficacy of technology? Should we force ourselves to expunge the Rule of Rescue from our collective moral conscience? […]

15.11.1 What Should Dr. Culshaw Do?

Dr. Benjamin Culshaw was a first-year pediatric resident, and admitted a child, Julia, who was aged 4 years. Julia had been diagnosed with Hurler Syndrome and had multisystem disease. Her mother was part of a Facebook group and became aware that there was a new drug that might really help Julia. This new drug, Elaprase, cost somewhere in the range $100,000–$300,000 per year.

Julia's mother was active in the media, campaigning for the drug, in touch with politicians, and asked Dr. Culshaw to sign a petition to help her receive government funding for the drug for Julia.

Dr. Culshaw was not sure whether he should sign the petition and also unsure whether any drug that was so expensive would be funded. He wondered what the true cost of manufacturing was. On the other hand, he could see how much trouble Julia was in, and he really wanted to do everything he could to help her.

15.11.2 Comments on Dr. Culshaw's Problem

As a first-year resident, Dr. Culshaw might decide simply to deflect any decision, but we hope he gives the question thoughtful consideration. He is aware of the boundary issues (see Chap. 2) and understands the importance of continuing to have a positive relationship with Julia and her mother. He might decide to sign the petition; we would not say that this was wrong. Before he signed, he should certainly inform himself as much as possible about this particular drug, the evidence for its effectiveness, and whether there are alternatives that could help Julia.

Dr. Culshaw should take the time to explore further the role of patient advocacy groups, and whether they or professional groups have already examined the use of this drug in this particular situation. Regarding his education, Dr. Culshaw might want to identify processes used locally or regionally to decide on funding for expensive drug therapy. He would particularly want to study the ethical basis for these processes. This is undoubtedly a meso level activity, but as with many such activities, there are implications at the local institutional level, and at the regional and national level that impact on the patient level activity.

15.11.3 Triage in Priority Setting

When allocating resources in emergencies, decision-makers must triage. A general description of triage is, "The process of determining the most important people or things from amongst a large number that require attention" (www.oxforddictionaires.com). We are concerned with triage in medical situations, "the assignment of degrees of urgency to wounds or illnesses to decide the order of treatment of a large number of patients or casualties." We see triage as a form of micro-allocation that takes place in very specific situations, including mass casualties, assessing patients

for PICU care, and dealing with patients in emergency departments. Typically triage occurs during moments of crisis, involves a great deal of uncertainty, and involves decisions that might place some lives at risk. The process and effects of triage will have an effect on the emotional status of the physicians; we should be prepared to expect some distress. The situations in which triage occurs are generally chaotic, where things are moving fast, and much needs to be done at the same time. While most resource allocation has a strong basis in utilitarian philosophy, triage is almost entirely based on such a philosophy. Triage is about doing the greatest good for the greatest number, even if this means, perhaps in a mass casualty situation, not treating some patients because the severity of the illness or injury makes recovery extremely unlikely and treating these patients will deny other patients who might be helped more effectively.

These latter considerations happily are extremely rare, and usually occur only in wartime, or with large-scale disasters. More commonly, such as in an emergency department, the issue of triage is not whether someone should be treated or not, but the order in which he or she should be treated. The main ethical issue is that the decisions taken by whoever does the triage should be based on medical factors, and not on extraneous factors such as ability to complain, to speak up or to use influence.

15.12 Meso Allocation

Allocation decisions at the meso level often have an immediate identifiable impact on services. Meso level allocation is distinguished from micro and macro allocation. The consideration in micro allocation is for the individual patients; micro allocation uses criteria that might be vague or never identified. Macro level decisions might be major but lack specificity. In other words, if the government decides to reduce a healthcare budget by perhaps $500 million, and add this to an education budget, then tracking the consequences of this decision might be very difficult. Meso allocation involves individual institutions, and involves issues of politics and power differential, ability to acquire and to present data, dealing with interpersonal relationships, and sometimes difficulties in identifying who actually has authority to make decisions.

An example of meso level decision-making is whether to fund *in vitro* fertilization (IVF), a reproductive method that causes human conception to occur in a glass dish. In most jurisdictions, governments will not pay for the procedure that has a relatively low rate of success in permitting patients to take home a well child. Individual prospective parents are the principal funders of IVF, though some jurisdictions do fund IVF with specified limitations. Such private funding can cause government expenditure because the consequences of IVF therapy are multiple secondary health costs that are borne without questions. The issue of personal responsibility is particularly relevant when physicians transfer multiple embryo transfers into a woman's uterus. In this situation, there is a substantial increase in multiple births (four times, compared with natural conception), associated with increased

risk of gestational diabetes, postpartum hemorrhage, low birth rate, preterm birth, and postnatal depression (Howard 2018).

Accountability for reasonableness (Barasa et al. 2015), that is a focus on procedure, undoubtedly is used more than other approaches, but this cannot be done without dealing with issues of equity. The evidence, particularly that of cost-effectiveness is important, but such evidence must be examined also for reasonableness. Regarding allocation procedure, it is very important to have full engagement of those involved, transparency, and a degree of consistency; in other words, if the decision was A in January, then the same information presented in July, should result in the same decision.

15.12.1 A New Service?

Dr. Stella Dehaney was a pediatrician in a town of about 150,000 people. She practiced with six colleagues and had an interest in developmental issues. In the past, she had successfully advocated strongly that the hospital board fund a clinic to provide multidisciplinary care to children with developmental needs. She thought that such a clinic was essential, and that outcomes were much better now that parents and children had access to such a resource.

The hospital was facing funding problems, and specifically there had been an increase in the number of preterm infants born, requiring an increase in staffing in the NICU (level II). The hospital board wished to reduce funding to the clinic for children with developmental needs and to transfer the funding to the NICU. The implications for the clinic were that there would be a considerable reduction in the time available from both physiotherapists and social workers.

Dr. Dehaney wanted to influence the hospital board but was unsure how to do so.

15.12.2 Comment on Dr. Dehaney's Proposal

There are many constraints on the hospital some of which will be known, and some will be completely unknown. For example, there is never complete flexibility in budget allocations. There is usually only very limited flexibility because of the large number of costs that are fixed, related to such things as remuneration related to contracts, or requirements of operating buildings such as paying for utilities. Hence, Dr. Dehaney is in a competition, not for a slice of the whole budget of the hospital, but for a slice of the smaller marginal part of the budget.

Dr. Dehaney is aware of the "rule of rescue", and the fact that the hospital board might be concerned that if it did not fund the NICU appropriately, identifiable individual children might be denied admission. On the other hand, there is an obvious paradox here. An increase in number of children admitted to the NICU, will, of course, lead to a larger number of healthy survivors. It will also lead to a larger number of survivors with continuing developmental needs who might benefit from a specialized clinic, and access to, for example, physiotherapists and social workers.

In influencing the board, Dr. Dehaney must gather both information and allies. She needs as much information as possible on what the developmental clinic has already done, and the current unmet needs. She needs to gather allies both in the community, and in the local institution, without antagonizing colleagues who might be involved in the NICU. She also needs to know how the board makes decisions, and how open and transparent it is. She might want to look at key articles on "allocation for reasonableness" and encourage such a process in the local hospital board.

Decisions like this are being taken on a daily basis. We hope that the decisions are based on principles of equity, are based on verifiable information, and that they are taken with transparency, and with a mechanism for an appeal.

15.13 Macro Allocation

There is clearly a hierarchy of levels at which decisions may be taken. In terms of allocation levels, macro might be considered the "top" level. Governments must make decisions based on how much taxpayer's money will be taken to fund healthcare, as opposed to fund education services, social services, and the other responsibility of government. The next level of decisions, but still macro, are decisions made on broad approaches to health, how much to fund healthcare prevention, how much for treatment, and how much will be for acute care and how much for long term care and so on. Still at the macro level, how much funding is going to go to specific groups, such as children, the elderly, those with mental illness and so on. However, when we consider how we fund particular services (such as funds for surgery for example, or how much for drugs) we are moving to meso level.

Macro allocation is clearly the most political all of the forms of allocation. It should be the easiest to identify, but in fact governments seem to be quite successful in concealing how to make trade-offs between different departments. Some examples include a recent promise by the Government of Ontario to add PharmaCare to the publicly funded healthcare system (Sismondo 2018). As stated, drugs are not part of the Canadian healthcare system, and while most provinces have some form of coverage for healthcare, usually it is on an "insurance" basis, with patients, except the poorest, paying at least part of the cost. The government led by the Ontario Liberal Party planned to include drugs as part of the regular coverage of healthcare, as they are in the UK. We will never know if this promise would have been kept, because the Liberal Party was not elected to form the Ontario Government in the Ontario 2018 election.

A media release by the UK government announced a five-year plan for health service funding (GOV.UK 2018). This plan includes increase funding, with specified outcome measures. Most importantly, for those of us interested in issues of macro allocation, the same funding promise includes funding for social services, recognizing that social services and health services are closely entwined.

15.13.1 Paradoxes of Funding

We have described some matters considered when government and other actors allocate resources at different levels of decision-making. We have been clear that the process is political, though we strongly advocate for an ethical and equitable approach, with a focus on the transparency contained within "accountability for reasonableness". We noted earlier in this chapter the paradox that funding for the clinic for developmental needs supported by Dr. Dehaney was being cut to provide funding for NICU care. We accept fully the remarkable successes of NICU care in the last two decades, but we are also realists. One of the results of NICU care is an increase in the number of children requiring developmental support, and though many of the needs are minor compared with the needs in previous decades, they are real.

In Sect. 6.5, we told the story of a pregnant woman who had been addicted to glue sniffing. Attempts had been made by the government to apprehend her later in pregnancy to prevent her sniffing glue in the interest of protecting the fetus. In that particular case, she had sought treatment in early pregnancy for the glue sniffing but had been turned away. In many parts of the world, treatment for addictions - an important subsection of mental health care - tends not to receive a high priority (Addiction Education Society 2018).

The relevant conclusion is that some decisions are taken without much consideration including the two decisions described above. The first decision is to place no limits on NICU care, and the second is to limit access to mental health and addiction treatment. We would like both decisions to be subjected to detailed ethical analysis.

15.14 Is Crowd Funding the Solution to Funding New Intervention?

In crowd funding, small amounts of money are solicited from large numbers of people on the internet. There are various forms of crowd funding such as GiveForward, IndieGoGo, GoFundMe and YouCaring. Crowd funding is increasing in popularity, and we do not believe that this increasing use will change. In a democratic society, individuals wishing to receive help may lawfully appeal to many different resources. The major advantages of the various sources of crowd funding for most people wishing to donate are that they know exactly who they will be giving the money to, though the funding page operator takes a percentage of the donation (The Canadian Press 2018) and (GoFundMe 2018).

Is online fundraising for healthcare a solution? The clear answer must be no. Such *ad hoc* methods will deal with some funding of some interventions on a small scale, but cannot replace large-scale, continuous funding from government or insurance sources subject to detailed and ethical analysis of need.

15.15 Conclusion

Somehow, we imagine that issues of setting priorities, dealing with rationing, and working out how to allocate resources are new. Such issues have always been present in healthcare, but in the past, the main source of rationing was inadequate availability of individual funding, and a lack of commitment of government to provide healthcare. The issues are now much greater than they ever were. Such issues will increase in prominence with the availability of newer technology, and the new range of very effective and simultaneously very expensive drugs on the horizon.

Because health care is funded by finite resources, the allocation of those resources is a major issue requiring ethical analysis that will require much of our attention over the next several decades. We will also need to examine our consciences on the continuation of major inequities country-to-country (and within countries) and continent-to-continent.

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Part V
Conclusion – Looking Toward the Future

Chapter 16
Conclusion: Looking Toward the Future

It is exciting to be a pediatrician. We are in an age of almost unprecedented change in society, in relationships between patients, families and physicians, and of ever more rapid technological development. This book is intended to offer a foundation of knowledge and concepts that will help the trainee and others involved in pediatrics to navigate new problems as they arise.

This chapter addresses five specific issues covered in various ways throughout the book. We believe that these issues will be subjected to much discussion and thought in the near future. The outcome of the discussions and further advances in these various areas of knowledge will help determine how pediatrics develops.

The topics are: genetics, precision and personalized medicine, internet and social media use in pediatrics, costs of healthcare, and ensuring that pediatrics maintains a focus on the child.

16.1 Genetics

This book has offered ideas about genetics in many different sections such as prenatal and neonatal screening, in the diagnosis of complex illnesses, and as a source of treatment development. We advance here the concept that genetics is now so pervasive and important that it has become "normalized". We review a recent suggestion that all newborns should have their complete genome sequenced. We conclude this discussion of genetics with commentary on direct to consumer genetic testing, its benefits, and some cautions.

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I. Mitchell, J. R. Guichon, *Ethics in Pediatrics*,
https://doi.org/10.1007/978-3-030-22617-6_16

16.1.1 Exceptionalism Regarding Confidentiality of Genetic Information

The concept of genetic exceptionalism is that genetic information is so different and so sensitive that it must be handled differently from all other health information. Genetic information might be kept in a separate part of the medical record with extra layers of security before it can be accessed, or arrangements made for access. In the present era of electronic records, this treatment of medical information poses technical challenges, but if genetic exceptionalism is accepted, solutions to these challenges should be sought.

Please do not think that confidentiality is not important. We have already made it clear that it is a keystone of medical practice in Chap. Part 5 Confidentiality. But the issue is when is it appropriate to keep medical information from the physician or to make such information difficult to access. Has genetic information now become such an integral part of pediatric practice that the concept of genetic exceptionalism needs to be abandoned?

Genetic information is now used to make many diagnoses; information must surely be readily available to every health care practitioner caring for the child concerned. In newborn screening, the whole point is to make information rapidly available so that treatment can start as soon as possible. Genetic tests might be predictive of future health care concerns. As we acquire more information about the role of genetics in health risk assessment, it becomes clear that genetic information is only one component in risk information. Other sources of information that are just as important in risk assessment are: socioeconomic status, lifestyle issues, and behaviour.

It is true that an individual's genetic information is a unique identifier in a way that other information is not, but is it sensitive in a way different from other information? We suggest not: even today many patients might wish that their history of mental illness be kept secret from health care providers. However, we regard this as information to be treated sensitively but still to be available to health care providers to help in medical assessments. Also, what is genetic information? Is the DNA of a tumor used in planning treatment genetic information? We suggest not but use this example to highlight the many difficulties with maintaining "genetic exceptionalism" (Evans and Burke 2008). These difficulties will only increase as genetic information becomes more and more "mainstream" in pediatric practice.

We agree with Evans and Burke (2008):

> All of our medical information is precious, private and deserves vigorous protection. The trick is to provide such protection while also ensuring that legitimate medical providers have quick and reliable access to it. Instead of parsing our information by type as "genetic" or "nongenetic", we must advocate for a sensible and just health care system that protects against the inappropriate use of our medical information as a whole and ensures that all have access to the fruits of the tremendous advances that we are witnessing in modern medicine, genetic, or otherwise.

16.1.2 Routine Newborn Whole Genome Sequencing

A matter receiving attention as we write the book is the ethics of genome sequencing of all newborns. In discussing that specific technique, we rely on a recent review, (which is a good resource on the language used and definition of the terms) and material in a Hastings Centre special report. The authors find it a source of wonder that genes function on only four nitrogen bases in different combinations: adenine, thymine, guanine, and cytosine. Genome sequencing is a process of deciphering the order in which these bases appear in DNA. Determining the sequence of these bases can now occur rapidly in a process called "genome sequencing". Such sequencing is the first step in understanding the relationship between genes, genetic variations and disease. Translational genome research entails using information gained to improve pediatric care.

There are 3 billion base pairs in the whole human genome. The exome is about 1% of our genome and contains all of our known genes, including those associated with disease. Geneticists will classify genetic variants in five categories: pathogenic (in which a variant is associated with a specific disorder), benign (when the genetic variant is not disease causing and is part of normal human variation), likely pathogenic, likely benign, and uncertain/unknown.

To complicate things further, there is variable expressivity in many genetic conditions. Individuals with apparently the same condition might differ enormously in how old they are when symptoms appear, what the symptoms actual are, how severe the illness is, and whether they respond to treatment. In addition, some individuals with a specific genetic variant will never develop disease. The terms "reduced penetrance and incomplete penetrance" are used to describe these phenomena. Nevertheless, genomic testing has the potential to increase diagnostic rates in many areas of pediatrics. Specifically, in terms of rare diseases, families can undergo a long "diagnostic odyssey" that might be shortened with genomic testing. Rare diseases are of course individually rare, but collectively might affect 7% of the population. The use of complex genetic testing to make a diagnosis is an example of genetics becoming integrated into routine pediatric practice.

This now routine use of genetic tests does not come without a complex consent process. When physicians discuss the tests with parents, they should keep in mind that parents want to hear that a precise diagnosis might be achieved. The same parents will not want to hear that a precise diagnosis might not be achieved, and that genetic testing can give results that remain, with present knowledge, uncertain. There might also be genetic findings that suggest relatives might be at risk for adult onset disorders, as will the child.

However, when we consider whether whole genome testing should be part of routine neonatal screening we move into an entirely different area of genetic discussion. We discussed how neonatal screening started, and how it evolved in Chap. 6. We also listed the principles established regarding what tests should occur for all babies; these principles were enunciated by Dobrow et al. (2018). Using whole genome testing in all newborns at this time will not fit the established Dobrow prin-

ciples; new principles will be required. Specifically, use of whole genome testing will permit identification of conditions:

- Whose epidemiology and natural history are not adequately understood.
- For which tests results are not clearly interpretable and determinate.
- For which there is no clear course of action after the test has been reported to the parents.
- Where it is virtually impossible to provide "screening participants with informed choice, promoting their autonomy, and protecting their rights". In the context of routine whole genome screening of all infants, a brief statement that a proposed test could help the infant is far from the truth. A detailed explanation for all parents would require enormous human resources
- For which the balance of benefits and harms, especially of overdiagnosis are unknown.

One justification for routine newborn whole genomic testing is that it can help us understand the epidemiology and natural history of a range of disorders. Such a justification is valid, but only as a research question. If a newborn whole genomic test is understood to be research, then the consent process must be very different, and very detailed before the specimen is collected. Another justification is that there could be benefits to adults. This is already the case in terms of some existing neonatal screening tests. In CF screening, for example, a child might be identified as a carrier of the CF gene. In the past, we avoided testing minors for carrier status because such knowledge is relevant to the child only in adulthood. But the same information is immediately relevant to adults; if the child is a carrier, then at least one parent is a carrier. Such information is very relevant to the future reproductive choices of those particular parents.

Families might not be ready for the onslaught of relevant, irrelevant and confusing information that will result from newborn whole genome screening. A Canadian study of parents of symptomatic, but undiagnosed children were offered sequencing and would be told of any variants known to predict a medically significant childhood disorder. They could also ask to be told of variants associated with significant adult-onset diseases. Even when requesting these results, parents were ambiguous in their attitudes. According to the authors, "Faced with this opportunity [to receive their child's information about adult onset disease] parents felt they had no choice." Current studies in the US of newborn sequencing have reported that the vast majority of parents of healthy infants decline the tests.

We see genetic testing of all kinds becoming more prevalent, perhaps dominant, in the practice of pediatrics. While routine newborn whole genome sequencing has too many uncertainties to be conducted at present, it is also likely to happen. There is a "technological imperative" here as with other aspects of medicine, and there are powerful commercial interests that see profits to be made. (Profits by themselves are not wrong; they become wrong when they are the main objective of introducing a new medical technology). Moreover, many people advocate strongly for more expanded genetic testing.

Genetics is now, and will become, so important that every pediatrician will need to master the details of the complex information available and be able to offer basic counseling. At the same time, as genetics becomes "normalized", assiduousness with consent and confidentiality will also be the norm, and the era of genetic exceptionalism will end.

Physicians in general must become able to respond to patients who read articles with titles such as "One-off genetic test could detect heart attack risk". This article described a test that might identify people born at increased risk of heart attack. The main value of the test would be in determining who would benefit most from pharmacological interventions, long before clinical symptoms appeared. The cost stated is £40 (US$52), something the researchers who developed this test see as cheap enough for population-wide screening. Perhaps it is, but the cost of one test cannot be seen in isolation from the cumulative cost of all tests.

When parents ask pediatricians what they think about such articles, a physician can offer a response to the parents only after the physician has read the article, and not merely the press report. A detailed response, paying attention to the anxieties of the person requesting advice, will require time. We predict that more physician time will be devoted to explaining and reassuring patients and families about genetics. This allocation of physician time implies the need for more physicians, including geneticists.

16.1.3 Direct to Consumer Genetic Tests

The future of genetic knowledge and more particularly genetic determinism was depicted in the 1997 movie "Gattaca". In the film, one of the characters stated with concern, "There's no gene for fate." (IMDb 2018). It is perhaps our fate that we are now in an era of widespread genetic knowledge. In 2008, Time Magazine declared Direct to Consumer (DTC) DNA testing the invention of the year (Hamilton 2008).

The benefits of DTC genetic testing include helping the average person become aware of genetic diseases and personalized information. Many individuals welcome the fact that they do not need to see a health care provider to obtain DNA test results. The test is easy (a cheek swab) and the companies return results quickly to the consumer. The risks of such testing are that there is little oversight of the quality of the testing, and some unproven tests might be unreliable. People might make important decisions based on information that could be false; the "answers" might not be definitive. By contrast, some definitive results might be unexpected and stressful personally and on relationships. They will be received at home without a physician helping with the interpretation of the results and assisting with any distress. The results of tests could make obtaining insurance difficult. Moreover, the companies gain revenue from the development of large databanks, with the possibility of loss of genetic privacy if information is stolen or sold.

Certainly, confidentiality of genetic information related to one's identity is lost through such testing. DNA analysis companies tell people the names of those to whom they are related; the results can surprise people who learn for the first time that they were adopted or that their father is not their genetic father, whether because of donor conception or otherwise.

We believe DTC genetic testing will become so pervasive that every physician will need to have skills to respond when asked to help interpret genetic test results. In a systematic review, Covolo et al. (2015) explored what was known about the tests and their impact. They identified 473 articles and chose 118 as the most relevant. There were five categories of information; we present the main points under each heading.

- Public's Knowledge of and Attitude toward DTC Genetic Testing
- Awareness about DTC genetic testing is not great, in the range 8–50%, with those most knowledgeable having personal concerns such as risk for breast cancer. There was concern over cost and risks, but paradoxically many people were interested in using genetic tests to improve their health.
- Case Studies: Impact of DTC Genetic Testing on Users
- Most subjects emphasized the need to understand the results fully, to avoid unnecessary prevention measures, or to avoid placing too much emphasis on genetic testing in decision-making. There was also concern about adverse psychological consequences.
- Health Professionals' Point of View on DTC Genetic Testing
- Most physicians were aware of DTC tests, but at the time of the study (2014), only 7% had actually seen results. 16% of primary care physicians had confidence in assessing results, but 52% thought that DTC tests could be clinically useful. In another study used in the analysis, 80% were concerned over misinterpretation, but 60% thought the test could be clinically useful. A mixed bag of conclusions from different studies!
- Content of Websites Offering DTC Genetic Testing
- Most websites had limited information on privacy, and while some offered post-test counseling, such counseling was rare. Unsurprisingly, the companies cite many more benefits than risks. The specific risks of "genetic discrimination, emotional consequences, risk of behavior changes, and confidentiality of test results" were poorly described.
- Scientific Evidence and Clinical Utility of DTC Genetic Testing
- Many studies questioned scientific quality, clinical validity, and usefulness of DTC test. There were large variations when tests in individuals were compared company to company.

DTC testing is here to stay. The result is: patients and families will need help in interpretation, physicians will need to improve their own knowledge of the tests, and regulatory authorities should examine the scientific quality of tests.

16.2 Precision and Personalized Medicine

A consideration of precision and personalized medicine is, not surprisingly, linked to the previous section on genetics. Personalized medicine and precision medicine are related terms that are in wide use currently. Indeed, who would want generic, impersonal medicine, and imprecise diagnosis and treatment? Schleidgen et al. (2013) recognized vagueness in the term, "personalized medicine". Does this mean the best of pediatrics which is always focused on individual child? Does the term refer to comprehensive planning for the needs of one patient? Or is there a specific therapy that is targeted to stratified subgroups? We have reviewed the medical literature to achieve a definition of personalized medicine and settled on this:

> [Personalized medicine] seeks to improve tailoring and timing of preventive and therapeutic measures by utilizing biological information and biomarkers on the level of molecular disease pathways, genetics, proteomics, as well as metabolomics.

"Precision medicine" has a different connotation. As explained by Ashley (2015), the authors of a US report by the National Research Council used the word "precision" to avoid the implication that medications would be synthesized personally for single patients. Rather, they hoped to convey a broader concept that would include precisely tailoring therapies to subcategories of disease, often defined by genomics. What is intended is a radical transformation of medical care "by prevention and treatment programs more closely targeted to the individual patient." (Joyner and Paneth 2015). The sequencing of genomes is, of course, key but will become even more valuable by creating large biobanks and linking this biological information to health data. All this medical advance is facilitated by the wide spread use of electronic medical records.

Current best pediatric practice is based on careful history taking, examination, guided testing, integrated with the physician's experience and parent/child preferences. Precision medicine might provide a deeper understanding of some diagnoses. Moreover, the initiative comes at a time when some of the drawbacks of conventional randomized placebo-controlled clinical trials are being identified: for example, it is likely that a minority of subjects drive the cohort effect (Basile 2009). Hence, better selection of patients to be given a specific drug might increase overall effectiveness and decrease potential side effects. This is pharmacogenomics on a large scale!

The precision medicine initiative also comes at a time when genomics is allowing a better understanding of disease mechanisms and improves pediatric care by the development of highly specific treatments. In Chap. 15, we wrote about new drugs in cystic fibrosis (CF) that are based on the molecular defect. Patients with different CF alleles often have different mechanisms of disease and hence will need different pharmacological responses. Precision medicine will likely significantly change the face of oncology.

Precision medicine has been embraced and endorsed with great enthusiasm. However, like all interventions, its assumptions should be examined closely. Joyner and Paneth (2015) ask Seven Questions for Personalized Medicine. These questions are:

1. Does genomic knowledge improve risk prediction? The answer is no, or at least not yet; conventional risk assessment is more accurate.
2. Will the drugs developed fulfill their promise? Perhaps they will, but current cancer mortality improvements are due to screening and early detection, smoking cessation programs, environmental improvements, and (likely soon) vaccination. We hope new drugs as part of precision medicine will lead to further improvements, but we also hope that the focus on precision medicine does not result in the loss of improvements made by other means as listed above.
3. Will the new drugs based on an understanding of the molecular basis of disease be better than conventional therapy? Perhaps this is for the future. To continue with the example of CF, new therapies are coming at a time when CF survival has been steadily improving because of a variety of measures applied routinely and systematically. A report of a recent trial of ivacaftor and lumacaftor for CF of the effects on FEV_1 (a standard lung function test) stated that these expensive drugs led to changes, but the changes were "in the range of the magnitudes of change seen in studies of other cystic fibrosis therapeutics." (Wainwright et al. 2015). The therapeutics referred to were antibiotics, conventional anti-inflammatories, and hypertonic saline, all costing a fraction of the cost of ivacaftor and lumacaftor.
4. Will the quality of electronic health records be sufficient to draw powerful conclusions? We are unsure. The quality of our current electronic health records is dependent on the care of physicians in entering the data. Multiple checks are required to ensure our input data entered about patients is precise.
5. How will clinical trials be designed? These new models of investigation are still to be developed; the old model of large numbers of patients receiving an identical intervention is clearly inappropriate in the context.
6. How will conflicts of interests (COI) be managed? The focus with personalized medicine has already moved from individual investigators to institutions, which aggressively raise funds from wealthy donors and government. Hence the COI of the institutions must be declared, as individual researchers now do.
7. Will drug costs be lower? This is hardly likely because the costs for a single individualized drug will have a small market.

Having noted these questions, we do not doubt the benefit to individual patients that will arise because of the development of precision medicine. However, we have some way to go to realize these benefits (Szabo 2018) and a long way to go in achieving affordable costs for the new treatments (Shaw 2018).

16.3 Internet and Social Media Use in Pediatrics

The internet and social media are already dominant forces in society, and of course also in pediatrics. They can be very useful in many ways, and occasionally misused. An example of the latter was a recent report of a trainee in obstetrics (Torres 2018). She had just performed her first cesarean section and posted full details on Instagram. She defended what she did by noting that she had consent from the patient, as if the patient was in any position to refuse.

We might allow ourselves to be biased against social media use in medicine by such stories. But in reality, the benefits of the internet for pediatrics overall are very positive and are leading to changes in relationships between physicians and patients and families. This point was made by Moorhead et al. (2013) in a comprehensive review of 98 original research studies, focusing on "the uses, benefits, and/or limitations of social media for health communication among the general public, patients, and health professionals". The authors argue that social media, with a wide variety of sites and platforms, will allow comprehensive social networking, involving direct communication and sharing of information, often with many parties.

Social media can be used to provide health information and to provide answers to medical questions directly to patients and families. Patients might form internet groups to facilitate dialogue and support. Health professionals might use such groups to facilitate their dialogue with patients and families for health information and health prevention. There might be a place for online consultations. There are obvious advantages for communication with more widely available and accessible tailored information. Concerns remain especially with a perceived lack of reliability, uncertain quality, and lack of confidentiality and privacy. We remain surprised at the general lack of awareness in health care practitioners, patients, and family members of the risks inherent in the disclosure of their personal information including difficulty in obtaining life insurance.

The risk of seeing harmful or incorrect advice on the internet is high. One example is vaccination, discussed in Part III, Sect. 11.3.1. Inflammatory on-line reports on supposed side effects of vaccination have been a factor in declining vaccination rates. Therefore, adverse health outcomes might be one consequence of internet use. Some parents find the amount of information too much to assimilate easily and difficult to apply to their particular situation. Likewise, the safe and effective public health measure of community water fluoridation has been attacked on social media, often causing municipalities to cease fluoridation thus increasing the rate of the most common chronic disease of childhood: dental decay (McLaren et al. 2016).

We see internet use by parents, children, and pediatricians as an overall benefit. The relationships will become more collegial as the imbalance in knowledge lessens. Communication between physicians and families/patients will change dramatically, and we predict for the better. However, we see protection of privacy and confidentiality with internet and social media use as a work in progress. The full recognition of these particular risks still has not reached many professionals or families. Similarly, the risk of social media attacks on public health measures has not

been fully appreciated by public health organizations which do not have adequate defenses to repel such attacks to protect population health and thereby to benefit individual children.

16.4 Costs of Healthcare

Discussion of the cost of healthcare extends discussion of various concerns regarding costs that began in Chap. 15, Resource Allocation. Discussion of cost is, of course, related to the healthcare system with the US system of healthcare delivery being very different from, for example, the UK system. While some costs might decrease such as extended genome testing, many other costs are likely to increase. Drug development costs in an era of personalized or precision medicine are likely to rise. Given that healthcare operates with finite sums, if we decide to add an intervention, especially if it produces only small improvements, then we must consider what we are willing to give up.

The public in any country has little appetite for an increase in taxation to provide more funding for health care, nor any appetite for increases in health insurance premiums. Many difficult decisions must be made. These difficult decisions are likely to be unpopular. The reality is that every time a health system spends new or additional funds for one intervention, it must cut back on an existing intervention or not introduce a new intervention. Money from large private donations or go-fund-me pages will be insufficient to pay for all possible new interventions, though some will be covered perhaps for one or two particular patients who attract public attention. Some governments have funded very expensive drugs for individuals with very rare metabolic diseases or extremely unusual cancers. These individual decisions, while involving large sums of money for very few patients, do not have the larger impact on health care budgets of large sums for larger groups of patients. Drugs for a few patients were, however, funded and such a decision will be seen as a precedent. It is unlikely that their funding will be removed, and they will remain as an anomaly.

We in pediatrics can always play the “cute kid” card and demand more resources for our patients, who are, after all, the future of any society. However, even that approach has drawbacks because our patients, particularly those with medical complexity are ever more likely to survive to adult life with continuing medical needs. Currently, services for these young adults are patchy by disease and area; we would not want these services to be curtailed to permit more funding for pediatric patients.

It might seem that money can be liberated and used for new advances and new services by trimming administrative costs and persuading pharmaceutical companies, equipment manufacturers, and insurance companies to accept lower profits. We would not discourage any of these activities. We also support the suite of “Choose Wisely” activities that directly attempt to influence physician behavior. We do not believe any of these activities will be sufficient by themselves to reduce or even to stabilize overall health care spending. We see a time of painful financial decision-making as being very close.

16.5 Focus on the Child

This book has aimed to address many different ethical issues in pediatrics. If there has been a theme, then it is that pediatrics is about the child. Even though we have written many times throughout this text of the need to focus on the child's interest, we emphasize here that "Pediatrics is about the child!" We repeat here what we wrote in Chap. 4:

> Pediatricians do not take orders from parents but rather they care for children. Please note that the now common pediatric practice of automatically deferring to the wishes of the parents when obtaining permission for treatments or procedures on children (or accepting refusal of recommendations) is not principled. It is an action of physician convenience, not one that meets ethical standards.

Much of this section concerns children who are clearly minors. In older children, it is especially important to be certain that, in every action, we are respecting that person as an individual.

To return to younger children, Bester and Kodish (2017) reached the same conclusion that we did, using slightly different phraseology. They also point out that children are individuals.

> Children do not belong to their parents. They are not property, although throughout much of history they were considered chattel. In the 21st century, it is generally agreed that children are individuals in their own right, have interests of their own, and, in the context of health care, are the proper focus of the doctor-patient relationship. For the clinician, it is the child who is the patient.

Another theme of this book has been that of change, in all aspects of pediatrics, and society, and perhaps most importantly, in how we approach decision-making. Bioethics itself has undergone one great change, from pediatricians making decisions to pediatricians giving information to parents to help in decision making. As in many dramatic societal swings, there has been a (slight) reaction to this change in authority by using information from behavioral psychology to use "nudging". We do not see this as paternalism, rather we see it as helping parents, provided of course that such help is offered without coercion in the context of a collaborative relationship to benefit the child.

The role of parents in decision-making is key but is not unfettered. We have used the concept of "constrained autonomy", developed by Ross (1994) to describe this limitation. While there might be general acceptance of this idea, we have been concerned by recent comments in the media and in the pediatric literature about parental rights. This reached a crisis in the Charlie Gard case. Earlier in Part III, Chap. 10.18 regarding this case, we averred that parents' rights in terms of children are derivative. To quote again from Bester and Kodish (2017) regarding Charlie Gard: "one of the aspects we noticed was that many commentators seemed to be upset that parental decision making could be curtailed at all". Navin and Wasserman (2017) go further and assert that parents have significant rights that can even entail acting against the child's interest:

> Parental discretion is not merely a legal right—a right that is justified, for example, because it is impractical for the state to coerce parents to maximize their children's interests. Instead, we think it is sometimes morally permissible for parents to make decisions for their children that do not promote their children's interests, as long as they do not cross the harm threshold.

In some limited sense, we might agree with Navin and Wasserman (2017), because parents are best situated to make most, but not all, important decisions for the child. In the end, the decisions taken are not for the parent, they are for the child. We do not believe parents give informed consent for a procedure on the child; they give informed permission. This is not semantics. The difference between speaking about consent and speaking about permission is the difference between assuming parents can take decision on the child without oversight, and assuming, as we do, that the pediatrician has an important role in assessing parental reasoning. Brunnquell and Michaelson (2016) raise the important issue of moral hazard and, while accepting the extremely important role of the parents in medical decision-making, they also make the argument for monitoring parents' decisions. They describe a "situation in which a third party (the parents) makes a decision for another person (the child) to whom harms and benefits of the decision primarily flow. Parents have interests of their own that can influence their decisions for the child".

Pediatrics is changing. Yet it remains a triadic specialty that includes the child, parents and pediatricians. But, at its core, pediatrics is a medical specialty in which the physician's central interest and concern is the child.

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