

# ETHICS IN CHILD HEALTH

## A PRACTICAL WORKBOOK



**EDITED BY**

**Jonathan P. Fleming, Lucy K. Shields  
and Michael D. Shields**

# Ethics in Child Health



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## *A Practical Workbook*

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Cambridge  
Scholars  
Publishing



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This book first published 2020

Cambridge Scholars Publishing

Lady Stephenson Library, Newcastle upon Tyne, NE6 2PA, UK

British Library Cataloguing in Publication Data

A catalogue record for this book is available from the British Library

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ISBN (10): 1-5275-4574-1

ISBN (13): 978-1-5275-4574-8

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# INTRODUCTION

JP FLEMING, MD SHIELDS

If the term *ethics* may be defined as “the moral principles that govern a person’s behaviour or the conducting of an activity<sup>1</sup>” then *medical ethics* may be described as the study and application of such principles, values or judgments to the practice of medicine or healthcare<sup>2</sup>. The modern science of Western medical ethics has drawn its form from centuries-old influences and practices (the Hippocratic Oath, early Christian, Jewish and Islamic teachings and scholarship) in addition to more recent debate with a necessary evolution resulting from rapid technological and healthcare advances. Medical ethics, while often regarded as a subject in and of itself, is foundational to all practitioners of healthcare and has been interwoven throughout the fabric of caring vocations since their beginning. More than two millennia ago Hippocrates swore to help the sick to the best of his ability and never with the intention of doing harm. Readers may be familiar with the Latin term *Primum non nocere*, (“First do no harm”) as one of the underlying principles of medical care. Unfortunately, the best course of action in healthcare is not always easily defined and treatment decisions may be a fine balance between benefit and harm or a source of disagreement between patient and healthcare provider.

While the study of medical theory examines what *can* be done, medical ethics in general considers what *should* be done. Most people agree that there is a difference between right and wrong and will hold to certain moral values. These values however may differ substantially and are often derived from influences such as cultural upbringing, religious belief, previous experience, personal intuition or some other source. How these values are considered and applied comprises the subject of ethics. There are of course many areas of universal moral agreement with a declaration on bioethics and human rights produced in 2005 by the United Nations Educational, Scientific and Cultural Organization (UNESCO)<sup>3,4</sup>.

Modern Western medical ethical approaches are generally and commonly based on a four-principle framework first proposed in the 1970s by Beauchamp and Childress in their seminal work *Principles of Biomedical Ethics* (currently in its seventh edition; 2013). The four principles are those



of *autonomy*, *beneficence*, *non-maleficence* and *justice*. These will be explored in the content of this book within the context of child health. There are of course many other important ethical principles which will also be discussed, such as *integrity*, *honesty*, *motives*, *confidentiality*, *consent* and *duty*<sup>5</sup>.

Medical ethical issues relevant to children and young people present their own specific directions and challenges. Until relatively recently, it had been long assumed that children and young people could not make decisions for themselves and therefore responsible adults (either the child's parents or their doctor) would make treatment decisions on their behalf. In general, this remains the practice for younger children who are unable to make informed decisions and they remain one of the most vulnerable group in society. However, many young people, while they cannot yet learn to drive, drink alcohol or even vote in elections, are perfectly capable of making informed decisions regarding their own treatment. It is not long since the cessation of the common, regularly accepted practice of allowing children with significant disabilities to die without proceeding to life prolonging or even life-saving medical treatment. Such became the subject of major public debate in the U.S.A. in the early 1980s with the public disclosure that routine, standard treatment was commonly advised against or withheld from infants with cognitive disabilities noted at birth. Several cases resulted in the passing of a federal law that came to be known as the Baby Doe Rules (an amendment to the Child Abuse Prevention and Treatment Act of 1974). One of the primary cases involved a child (Baby Doe) from Indiana, U.S.A. with Down syndrome (trisomy 21), who in 1982 died resulting from untreated oesophageal atresia and tracheoesophageal fistula. The parents, following advice from an obstetrician, chose for medical and surgical treatment to be withheld based on a perceived poor potential for success of surgery and the fact that the child had Down syndrome and cognitive impairment. The hospital brought the case before the courts but it was ruled that the child's parents had the right to decide on the withholding of treatment. The child died 6 days following birth of dehydration and pneumonia. Following the subsequent firestorm of public outrage and debate in the US, a campaign from the US Surgeon General and the involvement of President Ronald Regan, Baby Doe Rules were passed requiring that all infants be given medically beneficial treatment, regardless of disability, unless they are comatose, the treatment would merely prolong dying, or their death is imminent (without reference to the wishes of the child's parents)<sup>6,7</sup>.

The Baby Doe debate shifted the emphasis of child health from "medically beneficial treatment" to "actions should be in the best interests of the child",

which subsequently raised further significant questions. Firstly, “for what reasons did the parents and/or healthcare staff withhold potentially life-saving treatment to the child born with a disability?” Secondly, if the reason in denying such treatment is to prevent a life of suffering for both the child and their family then the question follows; “Who may decide the potential quality of life of another?”. From these stems the broader question, “Who can or should decide or define the best interest of a child?”. Considering the reasonably rigid Baby Doe Rules mentioned above, it is difficult to apply a standard of “the best interests of a child” as the rules do not consider quality of life<sup>7,8</sup>. Questions such as these can only be answered within the contexts and sensitivities of specific cases and cannot be answered universally.

If one thing is certain in the field of medical ethics, the answering of one question will undoubtedly lead to more arising. There is often (usually) no black and white answer to ethical dilemmas. What may seem the best decision in one context may be most inappropriate in another. It is the purposeful and informed process of working through the grey areas of discussion to come to a decision that is both the challenge and skill of medical ethics. This book, with an emphasis on working through cases of medical ethical dilemmas in the context of child health, does not seek to give the reader the answers to ethical problems, but hopes to assist them in learning how to approach such dilemmas and to analyse the reasons for and against different or conflicting courses of action. Specifically, it aims to raise awareness of the moral aspects of child health practice; to assist the reader to identify and examine the assumptions and values underlying their own moral beliefs and those of others and to help develop skills in identifying and critically evaluating the moral considerations in difficult medical situations. It is hoped that the book may assist the reader to broaden perspectives and foster empathy and tolerance of opposing points of view.

A wide range of issues arise where either there is no clear morally right choice or there exists a high level of disagreement or uncertainty. Individuals may believe that they have the absolute right answers to moral dilemmas based on their cultural or religious beliefs and practices. It should be borne in mind that background, experience or religious belief will significantly influence an individual’s view on how an ethical issue may be approached or on what action might be taken in aiming for a resolution. The reader is thus encouraged to consider each ethical dilemma from the varying points of view and beliefs of those involved as well as their own, even if they do not necessarily agree with them. Although this book will look at cultural and religious beliefs in the context of the ethical issues at hand, it will not attempt to discuss or portray objective moral truths. The reader should also note that this book outlines the approach to medical ethics

largely from a “Western” point of view. Other countries and cultures may have differing approaches and principles in their ethical practice.

It is hoped that this book can serve as a basic introduction to the topic of medical ethics in general, as well as a focus on the issues related to approaching ethical problems in the setting of child health. It is not an exhaustive text nor is it definitive in its scope, but it aims to assist the reader in the recognition of ethical problems (help develop ethical sensitivity) and in the development of skills in identifying and analysing the key moral considerations within difficult child health cases. This book is thus primarily aimed at those new to the topic of ethics in child health including undergraduates, medical and nursing students and other health professionals involved in the care of children<sup>9,10</sup>. However, it may also provide a useful resource for more experienced healthcare professionals who want to review their knowledge and skills in the approach to ethical issues in child health or as an aide in education.

# CHAPTER 1

## THE NATURE OF ETHICS

LK SHIELDS, JP FLEMING, MD SHIELDS

Ethics may be defined as the science of morals or moral philosophy, which are concerned with human behaviour; especially the distinctions between good and bad or right and wrong. They provide the personal framework that dictates what is right and wrong. The science of ethics seeks to evaluate human conduct and the rules and principles that are used to control it. Ethics is concerned with conscious and purposeful behaviour and with the obligations and rules that relate to it, aiming to discover what factors make actions good or bad, right or wrong both for individuals and for social groups. It is concerned both with theory and with how the various theories can be put into practice<sup>1-4</sup>.

Some frequent words used in the study of ethics are defined below. They might be regarded as part of an ethical vocabulary, and thus may be useful for reference when considering ethical cases throughout the course of reading or practice:

***Right and Wrong:*** these terms assume comparison with some absolute standard of morality outside of the action being judged.

***Good and Bad:*** to judge an action good or bad goes beyond its mere rightness or wrongness. An action can be right in the sense that it conforms to a rule but, if the motives are unworthy, it might not be regarded as a good action.

***Motives:*** motives are the desires and the intentions that move us to action. A good motive/intention can make an action better than it otherwise would be, but it cannot turn a bad or immoral action into a good one.

***Obligation/Duty:*** that which is due by the individual to meet some moral necessity. It could be duty in relation to a code of ethical behaviour imposed

by custom or religion or in relation to the inner promptings of a person's own conscience.

**Conscience:** this is a faculty within us which judges our actions or our intended actions and which seeks to direct us to produce actions it judges right or good.

**Moral Rights:** these are the entitlements of an individual to be treated in certain ways and to have his interests considered. For example, a basic human right is the *right to life*. Such a right goes beyond the *negative* concept of, "a person is entitled *not* to be deliberately or in any active way killed". It has a strong *positive* aspect that places an obligation on others, including healthcare workers, to do whatever they can to help the individual to experience and enjoy his or her life to its fullest extent. It is a *right to life* and not just a *right not to be killed*. (This will be discussed further in the next chapter). A further fundamental human right is *the right to health*, meaning that to all humans some standard of health care should be provided. This also is a *positive right*. There are however several caveats to such rights. It should be impossible to regard these rights as absolute that allow no exception and that over-ride all other moral considerations. For example, such rights do not mean that physicians and healthcare workers can or should always be required to attempt to prevent someone's death in every circumstance. In some circumstances, it may be considered as morally wrong to attempt to extend life artificially by hi-tech methods as it is to allow a life to end prematurely. In addition to this, many countries do not have robust and well-funded health care systems that provide the same rights to health as exist in the United Kingdom.

Rights arise in the context of natural, religious, national or international laws and of social and societal conventions or agreements made between fellow citizens. Often in these arrangements individuals surrender a degree of personal liberty to live in an ordered society and become entitled to certain rights in return (the principle of universality).

There are several ethical theories (perspectives) that have predominated in modern times. Each perspective advocates a different approach to addressing ethical or moral problems with the overall aim of concluding the most appropriate course of action. Ethical theories and perspectives have been debated and developed over many years, and have differed among cultures, ethnicities and societies. Important amongst the normative ethical (the study of ethical action) theories in Western philosophy are the broad groups of consequentialism, deontology and virtue ethics which will be

discussed below. Other approaches include the theory of ethics of care<sup>5</sup> (or relational ethics, which argues that moral action arises out of interpersonal relationships and the experiences of compassion and empathy) and pragmatic ethics which acknowledges the appropriateness of each ethical theory but does not take any theory as assumed. A pragmatic ethical approach is closely linked to scientific advances and focuses on society rather than on individuals<sup>6</sup>.

## Consequentialism

*Key figures: David Hume (1711-1776), Jeremy Bentham (1748-1832), John Stuart Mill (1806-1873), Peter Singer(1946-present)*

The theory of consequentialism holds that an action or course of action is morally right based solely on the outcome or consequences of the action. Consequentialism could be simplified to the maxim “*the end justifies the means*”. Thus, a consequentialist approach suggests that anything should be permitted if the overall outcome is more beneficial<sup>2,7</sup>. A modern example of consequentialism may be encountered in the controversial imprisonment and arguable torture of suspected terrorists in Guantanamo Bay. The detainees in Guantanamo have not been put on any formal trial or proven guilty of any wrong doing and have been detained against their will. A consequentialist argument would state that such action is morally justified because of the overall damage terrorism causes in the world and while keeping a few men against their will may not be good in and of itself, the benefits to society vastly outweigh the means. However, many will argue against this idea considering this to be both a major breach of human rights and morally wrong.

The most common and probably most well-known form of consequentialism is utilitarianism. Utilitarianism determines whether an action is morally right or wrong based on weighing up each potential action and assessing which will result in the most happiness for the greatest number. It may be summed up in Jeremy Bentham’s (18th Century English philosopher regarded as the founder of modern utilitarianism) famous maxim that a moral action should result in “*the greatest happiness for the greatest number*”. This could be regarded as a simple calculation and once it has been worked out it will lead to the moral action to take. According to Bentham’s term “*hedonistic calculus*”, happiness may be quantified and calculated from three standards by which happiness can be measured; intensity, duration and extent (the number of people affected)<sup>2,8</sup>.

There are several limitations with the consequentialist approach. Firstly, it is impossible to know with absolute certainty what the outcome of any course of action will be. Consequentialists would counter this argument with the belief that we can make an educated guess of an outcome based on logic and prior knowledge of results of similar actions. Secondly, consequentialism does not take into consideration the intentions (bad or good) of the person carrying out the action. The 19th Century English utilitarian philosopher and liberalist thinker John Stuart Mill argued that committing an action with a bad consequence in the belief that the action would create more pleasure than pain means that, although the action itself was wrong, the person is not bad or immoral. Consequentialists also argue that someone who solely tries to act in a way that results in the best possible outcome has good intentions even if what they do in the end of the day produced a bad outcome.

In the context of healthcare for consequentialism to be a practical guide, *expected consequences* rather than actual consequences would have to be the basis on which decisions are made. That the end justifies the means is an unsatisfactory basis for moral decision making (See introduction). For example, if it were thought to be in the best interests of a suffering disabled newborn that he/she die, would it then be morally acceptable to actively terminate their life? Clearly the common good is a desirable outcome for society, but should it be achieved by the sacrifice of an innocent individual, i.e., by paying little regard to the individual's freedom and rights or in the case of infants and young children those of its parents? It is difficult to define a good outcome, and this may vary with people's differing views. Who decides or can decide what comprises the maximum benefit?

## Deontology

*Key figures: Immanuel Kant (1724-1804),  
Thomas Nagel (1937 to present)*

It is easy to think of deontology as the opposite of consequentialism; deontology does not consider the outcome of an action to be the reason why an action can be deemed moral or immoral. In deontology, what makes a choice right is how it conforms to a moral norm<sup>2,9</sup>, these norms are universal and do not change depending on the situation.

18th Century German philosopher Immanuel Kant is regarded as the definer of deontology<sup>10</sup>. He believed that there is only one way to work out if an action is moral and that is if someone has acted in good will. For Kant,

someone acting in good will is motivated solely by doing their duty i.e. doing the right thing (whether it is deemed good or not). Kant outlines factors by which people can work out whether they have an absolute duty to perform a certain action; he called these the *categorical imperatives*. Categorical imperatives are a set of absolute duties that do not (and should not) take into account the consequences of actions.

To determine if an action is a categorical imperative (an absolute duty) you must apply the test of universality and the principle of humanity. The test of universality asks two questions. Firstly, is it possible for society to function if everybody engaged in this action (universal application)? If it cannot be universally applied, then it should never be engaged in at all. For example, if every person started lying and never telling the truth society would cease to function, people would no longer trust one another and could no longer live in communities.

Secondly, if it may be possible to universalise this action then, would it be practically inconceivable? (i.e. would it create an unbearable existence for everybody?) The principle of humanity asserts that a person acts in such a way that they always treat humanity (whether oneself or other) as the means of an action but also as an end. An example of this would be if everyone stole from each other, this would break down the ability for a human to own anything and therefore no one could steal anything anymore.

Another important aspect of deontology is the free will of the moral agents making the decisions. Kant believed we can only be held responsible for our own actions; that we cannot be held accountable for the actions of others. Thus, even if we could commit a morally wrong action that would stop another human being committing a far worse action we should not commit that action because that would be treating the other person as a creature not capable of making their own decisions.

This theory can be applied to many religious ethical frameworks. Often religions have their own set of moral laws that their followers adhere to in order to be morally righteous people. For example, the Ten Commandments in the Old Testament set out easy to follow laws that Jews and Christians can follow. The Ten Commandments tell people that certain things are prohibited in all circumstances like the examples above of stealing and lying.

One major criticism of deontology is that it is too rigid and could lead to immoral actions being taken. For example, Kant believed that we have an absolute duty to be honest at all times. As an example, this would imply that those in Nazi occupied countries during World War II who lied about the presence of Jews that they were hiding in their houses were committing immoral actions. If they had told the Nazi secret police the truth, those



whom they were hiding would have been sent to concentration camps where they would have been subjected to unimaginable cruelty and probable death. Someone holding an absolute deontological stance would thus be required to tell the truth and condemn those under their care. A utilitarian would say that it would have been immoral to tell the truth in this situation as it would not have benefitted anyone and would have added to the total pain and suffering of the world.

## Virtue Ethics

*Key figures: Aristotle (384 BC- 322BC), St Thomas Aquinas (1225-1274), Philippa Foot (1920-2010)*

While deontology is largely action based where decisions are made on the morality of an action, the virtue ethics approach suggests that morality (and thus moral decisions) are derived from a person's character or intrinsic values. The focus is thus upon *being* rather than *doing*. A right act is thus one that would be carried out by a virtuous person in the same circumstance<sup>11,12</sup>. It advocates the roles of alleviation of suffering and compassion. The key concepts of virtue ethics derive from Greek philosophy (particularly Aristotle). Aristotle asserted that the goal of human life is *Eudaimonia* ("well-being", "happiness" or the "good life") achieved by the regular practising of moral virtues such as truthfulness, temperance, courage etc and intellectual virtues such as intelligence and wisdom (especially in the resolution of moral dilemmas). It has the advantage of centring ethics around the person, including the whole of a person's life. In order to become virtuous, one must find a median between the extremes of excess and deficiency, for example the vices cowardice and rashness are the two extremes of courage.

One strand of virtue ethics is the modern approach termed ethics of care. Ethics of care, developed by feminist writers in the mid-20th Century, holds relationships, community and benevolence as central tenets. It is these along with strong emphasis of care towards family and those close that inform moral decision-making. Advocates of ethics of care do not believe that rules and principles can be used to ascertain the moral value of an action or an entire. Human relationships are deeply complex and have so many sides that fixed moral principles or universal rules cannot possibly lead to a moral action every time.

The idea of virtue ethics does however have its limitations. While it may provide general ideas on how to be a "good" person and how to grow as an ethical person, it does not provide clear guidance on how to approach or act

upon an abstracted ethical dilemma<sup>11,12</sup>. Another major point of weakness is the difficulty in defining virtues and the differing of opinions of what constitutes a virtue across cultures and ethnicities. This being the case it is argued that virtues are relative, and that virtue ethics cannot be used as a universal approach. A further criticism is that it is concerned more about the individual than any actions and may be thus regarded as self-centred rather than looking outward at those of whom an ethical action may affect. Proponents however contend that a virtue by nature must be universal in nature i.e. it is regarded as such by all cultures and societies and is therefore universal and valuable.

### A Hybrid Approach

All three theories discussed have both validity and appeal, but it is only those that acknowledge standards of morality (in the deontological group) that can provide universal absolutes. Is there a possible compromise between the theories?

Many people find deontology too restrictive, especially when Kant and others say “do not lie” even when there are lives at stake. Many find consequentialism too loose and dangerous when it could allow for innocent people to suffer or be tortured. Others find virtue ethics too subjective and relative. Some philosophers have attempted through various means to bridge the gaps between theories. *In practice, it is likely that most healthcare professionals base their ethical decisions on elements of each set of theories.* They take a “hybrid” or “blended” approach and balance what they deem to be right with the expected consequences of their actions.

One contentious issue which highlights the difficulties of taking a singular approach to an ethical dilemma is whether there is a difference in the actions of allowing a patient to die and in the active killing of a patient. There is a clear distinction between the two in British medical law; you cannot actively take measures that are primarily intended to take the life of a patient. However, you may withdraw care and allow a patient to die naturally. What are the real differences between these two courses of action, if there are any? American moral philosopher Judith Jarvis Thompson argues that the difference is not that clear. She uses the example of a man who hates his wife giving two scenarios. In one scenario, the man actively kills his wife by putting cleaning fluid into her coffee. In the second scenario, she puts the cleaning fluid into her own coffee by accident and the man, even though he possesses an antidote, lets her die<sup>13</sup>. From a legal standpoint one of these scenarios is criminal and the other not (bear in mind this is not universal, in countries such as Australia you are held legally

responsible if you let someone die when it is in your power to save them and saving them is not detrimental to your life.) From a moral or ethical standpoint is there a clear difference?

A classic illustration of the problem of two opposing ethical theories, deontology and utilitarianism when it comes to actions and omissions is the Trolley Problem. The trolley problem was posed by Oxford philosopher Philippa Foot (1967)<sup>14</sup>. Foot asks that we put ourselves in the position of a bystander who sees a runaway tram trolley hurtling down the line with no driver and with no signs of stopping. The trolley is going to hit a group of five workmen working on the tracks with heavy machinery, they cannot hear the trolley due to the noise they are making, and they are too far away for you to warn them of the impending disaster. However, beside you is a lever that switches the track so the trolley will go down a different track not hitting the five workmen but killing a single workman who is working on the other track. By doing nothing in the scenario you will let the five men die. Surely this is immoral, you should do whatever is possible to save these men? However, if you switch the track, then you are actively killing one man who would not be in any danger if it were not for you switching the tracks. Doing nothing results in five deaths by omission, whereas pulling the lever saves five men but actively kills an innocent man. For a utilitarian (consequentialist) the answer would be simple, you switch the track. The outcome of five people dying will surely be worse for the world's benefit than one person dying. A deontologist would argue however that the trolley speeding in that direction was caused by someone else, who could have foreseen the damage that it would have caused, and you have nothing to do with their action. By pulling the lever you yourself are actively getting involved and killing an innocent human being who would have survived if you hadn't been there. Someone with a virtue ethics approach would ask, "What would a virtuous person do?"

As with these general ethical problems, ethical decisions encountered in healthcare may be equally as challenging. The most prudent course of action is not easily attained.

# CHAPTER 2

## MEDICAL ETHICS AND CHILDREN

### MD SHIELDS, JP FLEMING

*Medical Ethics* may be defined as the analytic activity in which the concepts, assumptions, beliefs, attitudes, emotions, reasons and arguments underlying medico-moral decision making are examined critically and applied in governing the practice of medicine<sup>1,2</sup>. Up until relatively recently, Western healthcare was delivered with a paternalistic nature. In other words, decisions relating to medical treatment were usually made unilaterally by the medical doctor with responsibility for a patient's care. It was generally assumed that the doctor (and on occasions family members) had the absolute knowledge of the best course of actions to take for their patients (and these were always assumed to be correct no matter the consequences!). Treatment decisions did not necessarily consider the wishes of the patient and were rarely discussed or questioned. The same was generally true when ethical issues arose. It was often the medical doctor who decided what was in the best interest for their patient.

Modern Western medical ethical analysis and practice has evolved significantly and now differs considerably in its approach. Ethical problems are commonly framed around the four-principle approach postulated by Tom Beauchamp and James Childress in their 1970's seminal work entitled *Principles of Biomedical Ethics* (now in its seventh edition)<sup>3</sup>. The approach is not a rigid process or detailed method to give definitive answers but proposes four important principles each of which should be considered and measured against one another in any given problem to aid the ethical decision-making process. The four-principle approach is not without its weaknesses<sup>4</sup> and other approaches to ethical problems have been put forward. However, it remains the most widely recognised and used approach across the sphere of bioethics. The four principles are autonomy, beneficence, non-maleficence, and justice<sup>5</sup>.

## Autonomy

*“A thinking intelligent being that has reason and reflection  
and can consider itself as itself, the same thinking thing,  
in different times and places”*

—John Locke

Translated from ancient Greek, autonomy means self-governing or law. Autonomy is concerned with whether a person can make decisions regarding their own life. The quote above from the seventeenth-century British philosopher, John Locke, attempts to describe the nature of an autonomous being. Autonomy is a very important principle in both modern healthcare and medical ethics. In modern healthcare, autonomy has gained a particularly strong emphasis and the individual’s right to choose their preference in any decision pertaining to their own life or body can often override other ethical principles. To discuss the right or wrong (or good or bad) of this is a philosophical argument in and of itself and is beyond the scope of this book<sup>6</sup>.

Autonomy is a very important and serious issue in the area of ethics in child health. It poses the question, “How might it be decided if a child is capable of making a personal and fully informed decision about their own medical care free from coercion?” It also asks, “Should there be an absolute age at which a child becomes fully autonomous and thus is able to make their own decisions?”

A recent significant public example concerning the issue of childhood autonomy was the case of Hannah Jones<sup>7</sup>. Hannah Jones was a thirteen-year-old girl who had required hospital care intermittently since she was four years old for leukaemia. She required a heart transplant in order to survive; however, she did not wish to proceed with the transplant as she did not believe the process was worth it. Having spent much of her childhood in hospital, her desire was to die with dignity and suffer no longer. Although Hannah was only thirteen years old, the court ruled that she was perfectly capable of making her own decisions; in other words, Hannah was deemed fully autonomous. The healthcare trust under whom she was being treated had applied for a court order to force the transplant. Currently, in the UK a child is only automatically deemed autonomous if sixteen years of age or older. However, as the above example illustrated, many children who are younger than sixteen years old may be regarded as fully autonomous (see next chapter for more detailed explanation). How then may a child under the age of sixteen be deemed autonomous?

No legal case in the UK has brought the issue of autonomy in children under sixteen years to prominence more than that of *Mrs. Victoria Gillick*

vs *West Norfolk and Wisbech Area Health Authority* in 1984. So much so that the term *Gillick competence* is often used in defining whether a child under the age of sixteen years should be regarded as autonomous and has the ability to make his or her own decisions with regard to their medical treatment. The case concerned a mother (Mrs. Victoria Gillick) who brought her local healthcare trust to court because she believed that doctors by giving under sixteen-year-olds contraception (without the knowledge of their parents) were encouraging sexual activity amongst minors<sup>8</sup>. However, the courts ruled that doctors could prescribe contraception to anyone under sixteen years of age at their own discretion without having to tell the family of the child (see below for the case “Consent and Confidentiality” and the specific guidelines by Lord Fraser on when a health professional may give contraception to a person under the age of sixteen years). Consent to the child’s own medical treatment without parental permission or knowledge could only be given if the child was deemed able to meet three criteria. Firstly, the child needed to demonstrate the ability to understand the future implications of their actions on themselves and those around them. Secondly, they were required to have the ability to make informed decisions based on reason and rationality. And thirdly, that they had freedom from coercion when making decisions (which is often extremely difficult to determine).

## **Beneficence and Non-maleficence**

The principles of beneficence and non-maleficence in medical ethics are primarily concerned with when it is right or wrong to continue treatment. Often decision making in this area involves a healthy balance of these two principles. While similar, the terms are not exactly the same.

*Beneficence* is the idea that one should act always towards the benefit of others and is a central tenet of medical ethics. Doctors practicing beneficence would appreciate that when treating patients there is always the risk of doing some form of harm (medication side-effects for example) and thus benefits must be weighed against the risks of the treatment. Similarities can be drawn between beneficence and the theory of utilitarianism - both are concerned primarily with benefitting others.

The term *non-maleficence* is derived from the Latin phrase ‘*primum non nocere*’ meaning ‘first, do no harm’. In the world of medical ethics this means that a medical professional should avoid doing anything that could potentially be harmful to a patient.

Beneficence and non-maleficence are usually considered together as at their core they are inextricably linked. There are however differences when

considered in reality and these may emerge in their application to practice in the medical world. For example, the absolute avoidance of harm to the health of a patient (non-maleficence) would mean that many treatments could never be considered due to their side effects. In attempting to avoid harm at all costs many patients would die due to lack of medical intervention. In most cases however, the benefits (beneficence) of treatment outweigh the side effects and in treating patients the aim therefore is to provide a net benefit. The duty of non-maleficence thus requires that the potential good is not outweighed by the potential harm. It does not only apply to treatment. For example, it may not be acceptable to subject a child to a potentially harmful and painful investigation, if the resulting diagnosis will not result in any useful benefit. In contrast, always focusing on the potential benefit (beneficence) of a treatment or investigation without regard to unacceptable or potentially dangerous side effects could be regarded as equally detrimental to a patient's wellbeing.

## Justice

Justice is mainly concerned with the distribution of resources (material or otherwise) that are considered valuable or necessary for people in a society. For any society to function well and fairly, there must be a high level of importance placed on justice and the fair treatment of all citizens. The stability of political systems in modern times often reflect the extent of how just the systems are perceived to be by the subjects who are governed by them. For example, in countries where there is perceived low levels of justice there are more likely to be protests, riots and strikes. The image of justice pertained to by courts of law is a woman with scales in one hand representing fairness and a consideration of all sides, and in the other hand a sword representing the punishment for acting unjustly. She is blindfolded, meaning justice has no prejudice against any human based on their colour, creed, nationality or ability.

Justice is also a key concept in medical ethics as it asks questions such as, "Should the state pay for medical treatment?" or "Who should be treated first?" Many believe that medical treatment is a basic human right and that a country should make health care completely free while others believe that it is a business like any other and the state should not be responsible for a citizen's medical treatment. This is all underpinned within the broader question "What does the state owe us?"

Healthcare professionals also often face limited resources in addition to issues of distributive justice, i.e. to whom should these scarce resources be allocated? For example, if there is one bed left in an intensive care unit and

two children are in desperate need of a bed should the approach be simply a first come first served policy? Imagine if one of these children suffered from severe underlying medical problems and learning difficulties. Should this influence the decision made by the staff when allocating the bed space or should justice stay completely blind? Another example might be whether the state should approve a very expensive novel medical treatment for a small number of individuals or use the same amount of money or resource on giving benefit to a large number of children who require a minor inexpensive treatment<sup>9</sup> (see cases 14 and 15 later in the book for further exploration of this).

### The Four Principles of Bioethics

***Autonomy***

*The right and ability to govern oneself and make decisions independently and free from coercion*

***Beneficence***

*The act of doing good*

***Non-maleficence***

*An obligation not to inflict harm intentionally*

***Justice***

*The fair distribution of resource, risk, cost and to act fairly and evenly*

*Box 1: Adapted from Beauchamp and Childress 1978*

## Other Moral Considerations

The four principles discussed above provide the main framework of approach to ethical issues in healthcare. In any given ethical dilemma, it is likely that one or more of the four principles will have an impact on another. As patients are rightly granted more autonomy over the decisions of their own healthcare, such autonomy may influence the degree to which beneficence and non-maleficence is perceived by the patient. Furthermore, beneficence and non-maleficence when applied to a particular treatment can only be considered if that treatment is available and deemed to be fair (justice).



There are of course other moral considerations that affect and influence ethical decision making in healthcare. While these may not necessarily be considered in detail within each ethical case, they are fundamental to the understanding and wider discussion of ethics in healthcare. Let's consider these in turn.

### ***Sanctity and the Preservation of Life***

This principle enshrines the right not to be killed and implies that there is a duty to respect and conserve life. It requires that every individual is valued for his or her own sake. It could further be construed as implying a duty to provide the means and to foster the circumstances in which life is respected and conserved. Ethical dilemmas may arise that pitch this sanctity against all four of the medical ethical principles when dealing with end of life care. In other words, should the aim of healthcare be that life is preserved at all costs?

### ***Quality of Life***

Recently medical interventions have been increasingly evaluated by how they affect a patient's quality of life. For example, if an antihypertensive drug worked to lower the blood pressure, then should it be used regularly even if it made the patient feel depressed (see above beneficence and non-maleficence)? One important way of examining the "what's it worth?" question for a given health state (such as having poorly controlled diabetes or asthma) is to ask patients in that state (with that disease) how they feel both with and without the treatment. Recently there has been an increase in the published research of patient-specific measures of quality of life to allow individual patients to place different values on particular aspects of health and wellbeing. However, it is very difficult to obtain such information on young children as we must rely mostly on parental reports which introduces a degree of subjectivity. This subsequently poses the question, "can someone accurately determine the quality of life of another?" Most often the "what's it worth?" question is answered by healthy people who are deciding treatment options for their sick relatives, and their decisions are often based on the changes in health they would least like to happen to themselves.

### ***Best Interests of the Child***

The best interest standard is a fundamental principle in the making of decisions on behalf of those who lack capacity (surrogate decision making). The best interest of the child principle is based on Article 3 of the UN Convention on the Rights of the Child<sup>10</sup> which requires member states to observe the best interests of the child as a primary consideration in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies. It is thus the direction of focus for all decisions made by others on behalf of a child. In the case of a medical intervention or decision, the aim is to maximise benefits and minimize the risk of harm or detriment to the child. It is however a principle without a rigid definition, and as an overarching focus is not without its critics<sup>11,12</sup>. Arguments against the principle include that it is subjective (the values of individuals differ), ideas of best interest are often vague and indeterminate, and may lead to behaviour that is inflexible. When many are involved in the decision-making process, the question remains, “Who should decide the best interests of the child?” (see following chapter).

A child’s best interests include both the duration and quality of life (see above). The duration is a matter of time and can sometimes, though not always, be estimated with some degree of accuracy. The quality of life following treatment can be more difficult to estimate or measure. The concept of “the best interests of the child” suggests that children deserve respect as individuals separate from their parents, with their own interests and rights. A related discussion concerns whether this right extends to the unborn foetus<sup>13</sup> (see case 5).

### ***The Preference of the Child***

As children grow and develop, they acquire the capacity to make informed decisions and when this happens their choices need to be acknowledged, respected, and kept to the forefront of all decisions. Although a child’s objections are not necessarily decisive (e.g. a young child who objects to receiving injections should still receive immunizations), the child’s lack of assent should take on more weight as the child becomes more capable of making informed decisions.

### ***The Interests of Parents and Family Members***

The time and expense of caring for a sick child may compromise the rearing of other children, disrupt a parent's career prospects or jeopardize the family home or business. Should parents be expected to devote their entire lives to a sick child? Some parents may insist on an intervention that healthcare professionals regard as futile either because it is without likely benefit or because it carries significant risk for little benefit. There is no obligation on healthcare professionals to provide such care. On the other hand, unilateral decisions taken by such professionals to withhold interventions without regard to parents' treatment goals could be arbitrary and inconsistent.

### ***Interests to Society in Relation to Public Health***

Society has, and surely must have, an interest in maintaining public health. Should it then, for example, insist through legislation that all children be vaccinated against communicable diseases?<sup>14,15</sup> This is the case in much of the U.S.A. and France where children are required to produce certification of immunisation before being permitted to commence state school (see case 8).

### ***Omission and Commission***

There is a difference between stopping suffering by actively ending the life of a patient and withholding a treatment to allow the patient to die naturally.

### ***Duty***

In the field of healthcare duties may be positive or negative. Negative duties are regarded as universally binding (i.e., we should never tell a lie to a patient), but the positive duty to tell the truth is not so strong, since we have the option of remaining silent. However, while the positive duty to provide the best possible care is absolute, its outworking may be limited by the lack of the necessary resources.

### ***Integrity, Honesty and Truth-telling***

Healthcare staff have a moral duty to never give misleading or false information to patients under their care. Trust from patients relies on honesty and integrity on the part of the treating healthcare professional. While it is generally accepted across cultures that a patient should not be told a lie, there has been long debate on whether information that may cause distress should be withheld from patients. For example, it is not long ago that it was common practice for doctors not to tell their patients of a diagnosis of cancer. While this has changed significantly in the past thirty years in Western countries, in many countries it remains common practice to withhold diagnoses from patients. A recent case study<sup>16</sup> highlights the significant differences regarding disclosure of information across various cultures. In the UK the GMC<sup>17</sup> recommends that non-disclosure of information to a patient should only occur when there is reason to believe that the information could result in serious harm. Serious harm, in this case, means more than becoming upset or the fact that the patient may decide to refuse treatment.



# CHAPTER 3

## WHO SHOULD MAKE DECISIONS FOR CHILDREN?

MD SHIELDS, JP FLEMING

As discussed in the introduction of this book paternalism was the *modus operandi* of the healthcare profession until relatively recently. Paternalism is defined as interfering with the liberty of another person for one's own benefit. This is usually considered a parental duty for young children. Child health doctors have historically believed that they have the right and duty to be paternalistic – usually based on the claim that they must promote the child's health and not his/her autonomy. There is a general acceptance of the correctness of paternalism in situations when there is a high probability of serious harm, when interference with the patient's liberty is likely to prevent the harm, and when there is a reasonable likelihood that the patient when in a more mature state would want to be treated in this manner or come to appreciate it later. An example of this would be completing surgery for acute appendicitis over a young child's objections. If a child objects when prevention of harm is uncertain or minimal and the proposed action to be taken is of uncertain effectiveness, the situation is less clear.

In the UK some guidance on determining the best interests of a child or young person are given through the large body of legislation for children and young people including the Children Act 2004, The Children and Young People (Scotland) Act 2014, and The Children Order 1995 (Northern Ireland). In many situations, the course of action that is in the best interest of a young child is obvious. However, in more complex situations the course of action may not be as clear. As a result it may also be less clear who should make the decision on behalf of the child.

For children and young people who are deemed competent the situation becomes more complicated. In the UK young people aged 16 or 17 years old while not yet regarded as adults are able to consent to their own treatment independently. Unless there is sufficient evidence to suggest otherwise, young people aged 16 or 17 years of age are presumed to have

the capacity to make decisions regarding their own treatment. The term capacity means the ability to remember, use and understand information in order to make an informed decision and be able to communicate that decision<sup>1</sup>. Capacity is regarded as a functional term and is often used interchangeably with the similar more definite term competence. For the sake of clarity, the term competence will be used for the remainder of this text.

For children and young people under the age of 16 years they are only permitted to make decisions on their own treatment if they are deemed to be Gillick competent.

### **Gillick Competence**

As children mature, they develop the capacity to make informed decisions about their health care. In the UK doctors must assess whether a young person (usually an adolescent under 16 years of age) is competent to give informed consent by asking about their understanding of the proposed intervention, the alternatives, the risks/benefits of each and the likely consequences (see previous chapter Medical Ethics for some more detail on Gillick Competence). The young person must be deemed capable of remembering the information given, be capable of using it to make a measured decision and communicate this decision free from coercion<sup>2</sup>. If the young person is deemed Gillick competent then they are permitted to *consent* of treatment without the knowledge of their parents. However, a young person who has Gillick competence does not automatically have the right to *refuse* treatment in all cases. If there is an informed refusal of treatment by a competent young person that involves a potentially life-saving treatment or prevention of a permanent injury, then legal advice is usually sought by the healthcare team. The court may overrule the young person's refusal if it is considered to be in his or her best interests.

For children and young people who are not deemed Gillick competent, decisions on treatment must be taken by others with parental responsibility over them. Those who may be regarded to have parental responsibility include a child's mother or father (in the UK only if the father is married to the child's mother or listed on the child's birth certificate), a legally appointed guardian or designated local authority or individual. A mother usually acquires automatic parental responsibility for her child from birth<sup>3</sup>.

## The Parent's Role

A child's parents are presumed to be the most appropriate decision-makers for children on the basis that their love motivates them to act in the best interests of their children. Society grants parents discretion to raise their children according to their own values. Parents are permitted to decline medical interventions, when they believe the risks outweigh the benefits.

As the concept of competence is based on a patient's ability to understand the possible consequences of their decision and the available alternatives and many adolescents meet this standard (Gillick competence), potential conflicts arise when the patient is still under the supervision of their parents.

There are a few exceptions to parental decision making. These include parents who are estranged from their children, parents who lack capacity to make informed decisions (e.g., mental impairment, drug abuse, immaturity) or parents suspected of or implicated in child abuse.

In the UK it remains expected that parents make decisions for their children unless a court has appointed someone else as guardian. On occasions parents who are competent and have full responsibility disagree with routine treatment. In these rare but important situations, the issue of overriding parental decisions may arise. Examples of this would be if a parent refuses a highly effective life-saving treatment that carries little risk (e.g. antibiotics for bacterial meningitis in a previously healthy child) or a blood transfusion is refused on religious grounds. A parental refusal of treatments that are deemed to be beneficial and safe for their children does not relieve the physician of an ethical duty to the child, especially if the refusal puts the child at potential serious risk. Refusals may be overridden by the courts if deemed in the best interests of the child<sup>4,5</sup>. On the rare occasions where two parents disagree, and one parent gives consent and the other does not, then usually treatment can proceed. If the best interests of the child remain unclear, then legal advice may be necessary<sup>5</sup>.

## The Healthcare Team's Role

The healthcare team has several roles in decision making for younger patients. In an emergency, when parents are not available and thus consent is not obtainable, life-saving treatment may be initiated by the healthcare team without delay. Outside of this, the team are responsible in providing pertinent medical information (based on best evidence available), expressing their concerns, pointing out overlooked considerations and recommending what they believe is best. They also should remind everyone that the goal is



to do what is best for the child. The team should be involved in trying to persuade parents/children to accept highly effective interventions that have few side-effects. Overriding parents is usually only a last resort when all thorough discussions have occurred, and the best interests of the child are at risk<sup>6</sup>.

## **The Tavistock, UNESCO principles and the GMC requirements**

The boundaries of medical ethics have been extended to include the responsibilities of health care providers or decision makers to society and to individuals. The Tavistock Principles<sup>7</sup> were published following international collaboration between nurses, doctors, health planners, jurists, ethicists and philosophers. They formulated an agreed set of 5 ethical principles for those who shape and direct health care as follows:

1. Health care is a human right.
2. The care of individuals is at the centre of healthcare delivery but must be viewed and practised within the overall context of continuing work to generate the greatest possible health gains for groups and populations.
3. The responsibilities of the healthcare delivery system include the prevention of illness and the alleviation of disability.
4. Cooperation with each other and those served is imperative for those working within the healthcare delivery system.
5. All individuals and groups involved in health care, whether providing access or services, have the continuing responsibility to help improve its quality.

In October 2005 UNESCO published an extensive list of principles guiding professionals in issues of patient care, consent and research<sup>8</sup>. In addition, specific social responsibilities were included – a duty to the world's poor, and respect / protection of biodiversity.

Patients must be able to trust doctors with their lives and wellbeing. To justify that trust, healthcare professionals have a duty to maintain a good standard of practice and care and to show respect for human life. From the GMC (UK) guidance on the duties of a doctor, in particular a doctor must:

- make the care of the patient their first concern;
- treat every patient politely and considerately;
- respect patients' dignity and privacy;

- listen to patients and respect their views;
- give patients information in a way they can understand;
- respect the rights of patients to be fully involved in decisions about their care;
- keep their professional knowledge and skills up to date;
- recognise the limits of their professional competence;
- be honest and trustworthy;
- respect and protect confidential information;
- make sure that their personal beliefs do not prejudice your patients' care;
- act quickly to protect patients from risk, if they have good reason to believe that they or a colleague may not be fit to practise;
- avoid abusing their position as a doctor; and
- work with colleagues in the ways that best serve patients' interests.

In all these matters the doctor must never discriminate unfairly against their patients or colleagues and they must always be prepared to justify their actions to them.

### **Uncertainty in Medical Decision-making**

It should be noted that many healthcare professionals have difficulty in admitting (both to themselves and to patients) that they lack certainty as to the benefits of new or continued treatments. Determinants of best interests of a child are usually made in the presence of massive medical uncertainty as to the outcome of the proposed treatment. For example, neonatal intensive care units treating pre-term babies at the current limits of possible survival do not know with certainty what the outcome may be in terms of potential disability for a particular baby.

*“If it is hard to justify creating blind paraplegics to obtain a number of healthy survivors, it is equally hard to explain to the ghosts of the potentially healthy that they had to die in order to avoid creating blind paraplegics”*  
(Jeff Lyon, *Playing God in the Nursery*<sup>9</sup>)

Doctors may deal with this uncertainty by considering it worse to let an infant, who may have a reasonable life, die, than to save an infant who will suffer severe disability. Other doctors (likely a minority) argue that it is their duty not to hand over an infant with severe disability and a poor quality of life for parents to look after for many years to come. When faced with lack of certainty as to what is in an infant's best interests, the doctor should

discuss this and the various treatment options openly and honestly with the family.

In conclusion while there remain relatively clear guidelines on who *may* make decisions for children and young people there remains debate over who *should* decide what is the best interest for a child. Each case undoubtedly raises its own difficulties and nuances and should be regarded individually with the best interests of the child at the centre. However, this remains one of the most contentious issues in child health ethics. By nature, it is virtually impossible to accurately and objectively define the standard of best interest.

# CHAPTER 4

## AN APPROACH TO ETHICS CASES AND DILEMMAS

### JP FLEMING, MD SHIELDS

In the following chapter clinical scenarios that include ethical dilemmas are presented as short cases for thought and analysis. This chapter will consider a practical approach that may be used when facing an ethical dilemma.

An ethical dilemma is a problem that usually involves a conflict of moral principles. In child health, there may also be a conflict of opinions amongst those who are responsible for the care of the child. It is important to note that while many ethical dilemmas involve a conflict of opinions amongst caregivers, a difference of opinion does not always constitute an ethical dilemma. For example, consider a child who requires treatment for a chronic medical condition. The child's doctor and parents may disagree over the choice of two treatments. If both treatment options are commonly used, broadly similar in cost and benefit with minimal side effects then this does not necessarily constitute an ethical dilemma. Usually a discussion will occur to resolve the disagreement with a compromise obtained without any adverse effect on the child.

One method of approach to an ethical problem to arrive at a judgement (and obtain a "middle ground" between under-action and over-action) is based on what is known as the *ideal observer theory*. This theory asserts that a decision is morally acceptable if it involves five characteristics and could be approved by an ideal ethical observer:

1. The decision has included all readily available and relevant facts
2. The decision has empathetically considered the feelings of those involved
3. The decision is not based on vested interests
4. The decision is not made under conditions in which strong emotions obscure critical thinking

### 5. Similar cases are decided similarly

There is now broad agreement that the *ideal observer* does not exist, and ethically sound decisions are more likely if a multidisciplinary discussion occurs rather than if the decision were left to the parent and a personal physician alone. However, the theory does provide useful and pertinent points to be considered in helping arrive at a judgement for an ethical problem.

One of the most significant aspects drawn from the ideal observer theory is the importance of obtaining all available information and facts before any ethical judgement is made. Without thorough consideration of all information related to each ethical problem it is virtually impossible to carry out an acceptable attempt at forming a judgement or proposing any course of action. If important facts are not explored or are omitted prior to any judgement the consequences could be significant and very destructive. In addition, no individual (even those with the purest of intentions) can be totally free of vested interests or bias when coming to a judgement on an ethical problem.

On this basis, health ethics committees are now widely used to assist in resolving controversial issues and difficult ethical dilemmas. Such committees are comprised of amongst others medical doctors, nursing staff, legal professionals, lay people, members of the clergy, ethics academics and philosophers<sup>1</sup>. It is important to note that the purpose and function of such committees is not to determine the course of action or make a judgement on an ethical dilemma but to exist in an advisory role to assist healthcare professionals and those involved in the case in coming to a decision. These committees do not always make decisions but strive toward facilitating consensus among providers and parents. In the context of child health two of the most important functions appear to be improving the factual basis for decisions and determining the reasons why children/parents are making a particular decision.

When approaching the cases presented in this book it may be useful for the reader to do so as if taking part in a meeting of a local health ethics committee. If reading this book as part of a group (for example in an undergraduate tutorial) students could divide into groups and aim to explore the ethical issues from the point of view of the various individuals in each case (e.g. the child, parents, medical staff etc.). Aiming to put themselves into the shoes of the individual(s) involved and identifying each of their relevant considerations can be immensely helpful as a start to forming a reasoned ethical judgement. Each consideration should then be put into the

context of the ethical principles and underlying issues mentioned in the case introduction.

The aim of these case studies is not to provide answers or solutions, but to encourage the reader to consider and analyse the issues presented. The reader should not be disappointed if they are unable to come to a satisfactory conclusion. Many ethical dilemmas require long deliberation and, as previously mentioned, decisions are not made by an individual in isolation.

## **A Method of Approaching Ethical Dilemmas in Practice**

There are several frameworks that have been devised to assist in analysing ethical dilemmas in clinical practice. No single framework provides the definitive method for analysing ethical dilemmas, but all agree on fundamental aspects to be covered during analysis<sup>2,3,4,5</sup>. Presented below is a step by step approach that the reader may find useful when looking at the cases provided in this book.

### **Analyse and Assess**

#### ***Identify the Ethical Problem(s)***

This may sound like an arbitrary step; after all, this is a book about ethics! However, it is important to begin by taking a broad look at the problem that is presented. On occasions, medical problems may be misinterpreted, or simple misunderstandings can lead to theoretical ethical problems that may be easily resolved by finding a missing piece of information. In addition, a single ethical problem or dilemma may, in fact, be several ethical issues combined, each of which might require separate thought and action to develop the most appropriate course of action.

#### ***Identify the Clinical Facts***

Once the problem raised is identified as an ethical one, the next most important step is to attempt to gather and identify all the relevant clinical facts. While the knowledge of clinical facts informs and advises the process of judgement, the absence of the facts may potentially lead to the misidentification of an ethical problem or the significant cost (to all involved) of an ethical misjudgement. It is therefore of paramount importance that every attempt is made to attain accurate and thorough clinical information for use when approaching an ethical problem.

### ***Identify any Relevant Laws or Regulations***

After an ethical problem is identified, any relevant laws or regulations should then be consulted. These will obviously guide and direct any potential course of action but may also change an issue that may be perceived as an ethical problem to one that has only one legal course of action. Readers who are less experienced or do not have significant knowledge of medical law may need to revisit this stage of the process at a later point when all issues have been identified. If the ethical problem is particularly unusual or uncommon, the law may not be explicit. It may also become clear that legal advice is needed regarding a course of action.

### ***List the Participants Involved***

Note down who is involved within the ethical problem being analysed. It may be helpful to begin with the child and then think outwards ensuring all relevant individuals involved in the child's care are included. Participants other than the patient usually include the medical and nursing staff, allied health professionals, the child's parents or other family members, friends, religious leaders and potentially the health trust with overall responsibility of the child's care.

### ***Consider the Values and Opinions of each Participant***

Everyone involved may have a different value or a unique opinion on the best course of action for the child. It may even be such differences that are the source of the ethical dilemma. It is therefore paramount that all views are identified and considered as part of the analysis. For each participant attempt by critical thinking to discover the reasoning behind their argument.

It may be useful to write such reasons down. In the real-life clinical scenario this may require more work than in the hypothetical. It may involve lengthy discussions with all parties to ensure that all relevant concerns and issues are noted. It is never acceptable to just assume someone's value or position. The reader should not forget to reflect on how their own personal values relate to the problem being analysed and consider their own biases.

### ***Consider Professional Codes of Conduct***

The General Medical Council (GMC) and Nursing and Midwifery Council (NMC) both have guidelines on their corresponding professionals' code of conduct (practices, behaviour and professionalism). These are also

a key context within the framework of approach to any ethical problem. It is essential that every healthcare professional is aware of these and practises according to their recommendations. Patients and families must be able to trust healthcare staff with their lives and wellbeing and to justify that trust healthcare professionals have a duty to maintain a good standard of practice and care and to show respect for human life. Amongst other important requirements, the GMC's guidelines on Good Medical Practice (2013) paragraph 59 states that, "You must not unfairly discriminate against patients or colleagues by allowing your personal views to affect your professional relationships or the treatment you provide or arrange."

### ***Frame the Ethical Problem within the Four Principles of Medical Ethics and Identify any other Moral Considerations***

Take each of the four principles of medical ethics (autonomy, beneficence, non-maleficence and justice) and consider the issues that arise in each pertaining to the ethical problem. Then take any other relevant moral considerations that may not have been included in the four major principles (best interests of the child, issues of quality of life, effects to wider society etc). At this stage, the main ethical considerations should be highlighted and reflected upon in light of all the other previous considerations.

### ***Work Towards a Well-Reasoned Decision***

Ethical problems by their nature are complex and judgements made can have long-lasting consequences. It is therefore important that when making a judgement or decision on an ethical problem the reader (whether using this book or as part of a real-life ethics committee) bears a few points in mind.

Firstly, there are factors that can interfere with the accuracy of one's judgment. For example, patients, parents and healthcare staff are often under emotional stress. There may be a strong desire to believe one perspective rather than another. All participants will have a set of values that may be held dearly and can strongly influence judgements made. Opinions about ethical issues are often so strongly held that many people find it difficult to give any consideration at all to opposing views. Aim to be open and fair-minded.

Secondly, it is important not to overlook ethical principles such as autonomy or justice when considering the consequences of an option. For example, do not merely ask, "What will happen if I do this or that?" Ask also if the action/option will be supporting or breaking good ethical



principles. When it comes to deciding on a course of action consider why a decision is necessary, list the various possible courses of action and their consequences and evaluate the options and arrive at a well-reasoned decision. The following table is a suggestion of how all these steps may be recorded to assist when considering an ethical problem.

<b>The Ethical Problem(s)</b>	<i>Define the problem and separate problems if necessary</i>
<b>The Clinical Facts/Relevant Information</b>	<i>Gather all relevant facts</i>
<b>Law</b>	<i>Relevant laws may dictate the course of action</i>
<b>Professional codes and duties of conduct</b>	<i>How does following GMC or NMC (or other relevant) codes of conduct apply to the case?</i>
<b>Participants and their beliefs and values</b>	<i>Consider all involved, their views (and biases) and the weight each view might hold in decision making (including your own!)</i>
<b>The Four Ethical Principles &amp; Other Moral Considerations</b>	<i>Autonomy, beneficence, non-maleficence and justice Principles of duty, confidentiality, consent, candour, best interests etc.</i>
<b>Decision on Course of Action(s)</b>	<i>Consider potential courses of action, reasons for each, and their consequences</i>

## CHAPTER 5

### THE CASES

JP FLEMING, A BAILIE,  
C MCKENNA, G REA, MD SHIELDS

This chapter forms the main working part of this workbook. It includes a number of cases, some of which are loosely based on real-life experiences of the authors, others created for learning purposes. It is hoped that these cases may form the basis of an active learning process for the reader. The aim of each case presented is to provide enough complexity to be challenging, but at the same time be informative and stimulating. As previously stated, the goal is not to provide answers for the reader, but to assist in the development of their skills in the recognition of ethical problems, in the analysis of such problems and to develop their ability in forming a reasoned ethical argument.

Cases may be explored and analysed in detail, or if desired, may be broken up into parts to explore individual issues. They may be used as a focus for a tutorial or group discussion or simply used for personal educational development. For each, consider using the approach outlined in the previous chapter.

Each case begins with a clinical vignette. As each case is being read and studied (thus a simulated case) not all required information will be available from the vignette. Therefore, when approaching the cases, it would be beneficial to begin with asking the question, “What other information is needed?” The first case will provide an example of how a case might be approached, and as with the other cases, some short commentary notes.

## Example Case

### Saviour Sibling

*A young couple have a six-year-old son undergoing treatment for a leukaemia; it is highly likely that he will need a tissue donor for a bone marrow transplant (BMT) who is an exact match. Siblings are often used as donors because they are more likely to be tissue matches and are also likely to consent to various treatments because of their close relationship with the ill child. The couple's six-year-old son is their only child and is the only grandchild on both sides of the family. The couple are desperate and decide that they will consider using IVF (in-vitro fertilisation) to create an embryo with an exact donor match for their son with leukaemia (using pre-implantation genetic diagnosis or PGD for short).*

Consider the case above and the reflection below using the suggested approach given in the previous chapter.

<p><b>The Ethical Problem(s)</b></p>	<p>Should the parents be permitted to have IVF for the sole purpose of creating a donor for their unwell child?</p>
<p><b>The Clinical Facts</b></p>	<p>Six-year-old boy requires BMT, no matches available          The boy will die without transplant          IVF is available via NHS          What else would be necessary to know?          The method used in creating a matching donor embryo:          This involves IVF and pre-implantation genetic diagnosis (PGD) to test for compatibility (HLA) and only compatible zygotes are implanted<sup>1,2</sup>          What does bone marrow transplantation involve? Are there complications? How successful is bone marrow transplantation in children with this type of leukaemia?          Stem cells from donor (taken from umbilical cord blood at birth) are transplanted into</p>

	<p>recipient (after high dose chemotherapy to remove unhealthy bone marrow). Complications include infection, pain, thrombocytopenia and anaemia, fluid overload, respiratory distress, diarrhoea, vomiting, organ damage (all due to bone marrow suppression), and graft failure or graft v host disease. Great Ormond St figures following bone marrow transplantation for malignancies: 1 year disease free survival 43-67%</p>
<b>Relevant Laws/Regulations</b>	<p>In the UK, the Human Fertilisation and Embryo Authority (HFEA) ruled in 2008 that it is lawful to use modern reproductive technology to create a saviour sibling (involuntary organ donation not permitted)<sup>3</sup>.</p>
<b>Professional codes and duties of conduct</b>	<p>HFEA (see above) GMC - paragraph 59 and guidance notes on conscientious objection. The doctor must communicate their held beliefs and explain that they will not be recommending such a course of action or providing bone marrow transplantation, the reason and facilitate the patient in seeing another doctor who does not hold the same objection. In no way should the objection result in discrimination of the patient.<sup>4</sup></p>
<b>Participants and their beliefs and values</b>	<p>Child - unlikely to be able to fully articulate desires, possibly frightened with strong desire to be better Parents - overwhelming desire for child to be well, understandably willing to do anything and at any cost to save their child Oncology ward staff - All wish for child to be better, two staff members (including oncologist treating child) do not agree with IVF as they believe life begins at conception due to strongly held religious values. The zygotes/embryos/future saviour sibling – consider how the saviour sibling may feel in the future</p>

<p><b>The Four Ethical Principles/Other Moral Considerations</b></p>	<p>Autonomy - the six-year-old child does not have competence therefore parents have right to consent/refuse treatments</p> <p>Beneficence - Given the alternative (likely death), the bone marrow transplant would offer potentially huge benefit for the child and family as well as having a new child</p> <p>Non-maleficence - do the risks and side effects of IVF and bone marrow transplantation outweigh the potential benefits? Will the new (saviour sibling) child be regarded with equal status to the six-year-old boy?</p> <p>Justice - Given IVF and bone marrow transplant are not guaranteed to be 100% successful, could the cost of this be used to provide other treatments to children that would benefit a greater number?</p>
<p><b>Decisions/Course of Action(s)</b></p>	<p>While the responsible doctor had a conscientious objection, he facilitated the transfer of the boy's care to another oncologist so that the bone marrow transplant could be carried out following the birth of his younger sibling born following IVF. As the HPEA and law permit IVF for the purpose of creating a donor embryo there was no ethical dilemma in this case other than those of the conscientious objection. The course of action should be thus agreed with the parents.</p>

## NOTES

While in this case, the course of action was obtained with relative ease, the case poses many ethical questions that continue to garner debate. Should this couple be permitted to receive IVF with the sole purpose of creating a child that could possibly save its sibling? Is IVF ethical in itself? If IVF is regarded as ethical, is it ethical to have IVF for any purpose other than simply having a child (i.e. to create that embryo/child for the treatment of another?). Indeed, wider questions such as “When does life begin” and “Does or should an embryo have rights” add complexity to such ethical debates.

During the process of IVF often more than one fertilised embryo is created, but rarely are all the created embryos used. The surplus embryos are either frozen (for the future or for research purposes) or sluiced (destroyed); this creates an ethical problem for people who believe that human life begins at conception. Those who uphold this view believe that IVF is ethically wrong because it results in the active termination of human life. They argue that even though the IVF process in this case would result in the saving of the boy's life, it would also result in the deaths of the various embryos that were not an exact match following PGD.

The right to life is one of the most important rights in civilised society. In almost all societies, past and present, there is a high price to pay for actively ending another human being's life. So, for those who believe that a fertilised embryo is a human being, the active killing of these embryos is immoral. Allowing the six-year-old boy to die of leukaemia would not be regarded as immoral, as the only way of saving him is by actively killing several other human beings. This is the view that the lead oncologist in this case holds. A more considered debate on the differences between active termination of life and allowing to die will be included in the case about withholding and withdrawing care. For those who hold the view that a fertilised embryo is a human being, PGD is regarded as immoral because it involves the process of IVF which they inherently disagree with.

Of course not everyone holds this view of IVF or PGD. In fact, it is probably a minority view. IVF is legal in all parts of the UK and is available on the NHS if certain criteria are met. This is because many people believe that a human being becomes a person sometime after the creation of an embryo. For those who hold this belief, there is no ethical or moral problem to consider in this case. Others are in favour of IVF, but only for couples who have fertility problems, disagreeing with creating embryos and selecting a certain one based on its genetics. They believe that this is the purposeful engineering of a child to one's own desire (in other words; designing a baby) and that PGD is not a random process like IVF for infertile couples. They believe that this process could be a slippery slope towards a world where people choose their child's DNA before they are even born.

Referring to the ethical theories discussed in the chapter "The Nature of Ethics", it seems a utilitarian would be in favour of IVF because on balance it results in the most happiness in the most people. A strict utilitarian would believe that IVF and PGD would be the best way to resolve the situation because it could save the boy's life and there would be a new child in the world. If the IVF is unsuccessful, as it often is, would this lead to a decrease in the world's total amount of happiness? Those advocating a utilitarian

approach would argue that there would be no more sadness had the couple not even tried.

For a deontologist the right thing to do is save a life. Their view might thus depend on their opinion on when life begins. It would however be difficult to separate this case from the principle of humanity (see chapter Nature of Ethics). In other words, they would likely disagree on the proposed course of action on the basis that it is treating a human as a means to an end.

There is a huge variation in opinion as to exactly when life first begins. For some life begins at conception, for others a fertilised embryo is just a collection of cells and a human being develops at some point of time while in the womb. Others believe that life only begins at birth and before then the foetus should be regarded as part of the woman's body. This is a hugely controversial issue that has huge societal implications on many issues such as abortion, IVF, contraception and women's rights.

The contemporary secular utilitarian Peter Singer believes that though an embryo and a foetus are potential human beings, they are not yet "persons". Singer argues that a person is not just a member of the human species but is a rational being with a certain level of cognitive function. He argues that a human being only becomes a person at around five or six years old because they can make memories and are capable of the complex thought that separates persons from other living beings.

In contrast, many religious commentators would say that a fertilised embryo is a being that was intended by God to be created and when human beings actively end that embryo's life, they are actively killing another human being. Some secular commentators would also agree that the embryo is a potential human being with the same right to life as anyone else, irrespective of their stage of development.

In this case, some might argue that creating life for a specific purpose could be called an extremely selfish act. The parents may not have wanted a child and were not really prepared for having any more children. In addition, it does not take into consideration any burden on the younger child ("saviour sibling") who may have the feeling of uselessness when their "job is done" and they have fulfilled their purpose. Could the younger sibling feel pressure to help further in the future if their older sibling develops subsequent medical problems? It is difficult to assess the weight of this argument, as it is extremely subjective. No one can say how another person will feel; the child might grow up in a loving and supportive family, always feeling an immense sense of pride that they saved their brother or sister's life.

The reader will note that while the course of action was relatively easily obtained in this case, not everyone will agree with it. The case alludes to the fact that for some such issues are major moral dilemmas involving deeply held beliefs and their conscience, yet for others the issue does not need to be regarded an ethical one in the slightest. In addition, not all the questions posed were definitively answered, and many questions posed remain a matter of significant debate<sup>6,7,8,9</sup>. The complexities and nuances within this particularly contentious subject are beyond the scope of this book. For a literary slant on this topic the novel “My Sister’s Keeper” by Jodi Picoult explores the issue of saviour siblings.

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**CASE 1****Futile Treatment?**

*A. A baby boy weighing 0.7Kg (extremely low birth weight) is born with trisomy 13 (Patau syndrome). He has developed congestive heart failure (secondary to a VSD) and renal failure. His condition requires support by artificial ventilation. His parents are understandably upset and worried about his condition. They are aware that children with trisomy 13 will have significant disability if able to survive and have major concerns about his future. They conclude that the kindest thing in the best interests of the child would be that ventilatory support was discontinued and he is allowed to die. They ask the consultant to discontinue treatment and artificial ventilation.*

*B. A baby boy weighing 1.8Kg (low birth weight) is also born with trisomy 13. He has developed congestive heart failure (secondary to a VSD) and renal failure. His condition requires support by artificial ventilation. His parents are understandably upset and worried about his condition. They are aware that children with trisomy 13 will have significant disability if able to survive. They are devastated when they hear from the paediatrician that no treatment is being offered because “all babies with trisomy 13 die shortly after birth and certainly before the age of 12 months”. They search the internet and find that the reason babies with trisomy 13 die is due to heart failure. They tell the consultant paediatrician that they want surgery to fix the “hole in the heart” so that he can live and that they will care for him and love him greatly.*

Use the suggested approach to these cases to determine all the information you require to consider a course of action for each child. Aim particularly at answering the following questions. What further information is needed? For example, the life expectancy and prognosis of trisomy 13 and clinical symptoms and treatments etc. In case A who should determine whether the ventilator support should be withdrawn? Would it be ethical to allow the parents to make the decision to allow ventilator support to be withdrawn given that in similar circumstances other parents may request that the healthcare staff do all they could for the child? Why might the parents of the child A want to discontinue the treatment? For child B, why

do you think the parents want the opposite to that of the parents of child A? What are the ethical issues involved in going ahead with cardiac surgery for child B? Who should decide whether the surgery should proceed?

## NOTES

It is not uncommon to encounter alternative opinions on the best course of action for children with near identical clinical conditions. The parents of such children may have different views on the best interests for their child and this at times may conflict with the views of the healthcare staff. While it is not routine practice, increasingly centres are offering cardiac interventions for trisomy 13, as data on outcomes shows improved survival for select patients<sup>1,2,3,4,5</sup>. As mentioned in the introduction, it should be noted that in the past, cardiac surgery (or surgery of any type) was not considered for children with trisomy 21 (Down syndrome) on the presumption of poor outcome in addition to cognitive impairment associated with the condition. With improved medical care, many individuals with trisomy 21 survive into their fifties and many even longer. Why then should heart surgery not also routinely be offered to children with trisomy 13 or trisomy 18? And indeed, who should decide this? A recent paper<sup>1</sup> showed that the recommendation for heart surgery for children with trisomy 13 or 18 differed between specialists (cardiologists were more likely to recommend intervention than neonatologists or geneticists) and that parental wishes that “everything be done” significantly influenced all specialists’ recommendations. The principles of beneficence, non-maleficence, and justice (including allocation of resources) all are pertinent within these cases. These cases also highlight how difficult it may be to determine what is in the best interest of a child and determine who should decide this best interest.

For difficult decisions such as these it is of necessity that the parents are closely involved with the healthcare professionals engaging in detailed discussion on the clinical facts around their child’s difficulties, the best estimate of likely outcomes for potential options, and their own values towards making a decision. It is also important to note that each child and family will be uniquely affected (clinically, psychologically and spiritually)<sup>6</sup>. Obviously good communication from all members of the healthcare team is of vital importance, with the use of frameworks to help in the discussion of such a sensitive matter<sup>7</sup>.

**CASE 2****Withdrawal / Withholding of Treatment (1)**

*A. A 14-year-old girl with a history of Acute Myeloid Leukaemia (AML) is an inpatient on the paediatric oncology ward and has been in severe pain requiring high doses of opiate analgesia. She is currently comfortable but is very drowsy. Unfortunately, it has recently been confirmed that she has had a relapse of AML having previously undergone a stem cell transplantation. She has also required 2 courses of chemotherapy in the past. Given the previous chemotherapy and unsuccessful stem cell transplantation, medical staff are now "95% certain" that the girl's condition is terminal. Her parents are requesting that she undergoes further chemotherapy.*

Use the suggested approach to determine all the information you need to come to a course of action. First identify all the ethical issues involved and aim to answer the following questions. Should a third course of chemotherapy be commenced? If so, who should make this decision? Should the girl be “woken” and allowed to be in severe pain so that she may discuss her options? And if so, what influences might there be on her decision? If she was certain that she wanted a further course of chemotherapy, but her parents disagreed, how should this situation be approached?

*B. A 14-year-old boy with severe ongoing respiratory failure due to an irreversible rare chronic lung disease (bronchiolitis obliterans) is admitted to intensive care. Despite his physical problems, he is cognitively and neuro-developmentally age-appropriate and has full insight into his condition. He has been deemed not suitable for a lung transplant in the past. His condition deteriorates suddenly, and he must be sedated, intubated and ventilated. It becomes clear he is terminally ill and further ventilation is not justified. His parents wish for his sedation to be reversed so that they may say goodbye to him.*

Use the suggested approach to determine all the information you need to come to a course of action. First identify all the ethical issues involved and aim to answer the following questions in particular: If it were possible, should his sedation be reduced to allow him to have a say in his treatment and “say goodbye” to his parents, or should he continue to remain sedated and comfortable whilst respiratory support is withdrawn? Who should decide this?

## NOTES

At the core of both cases is the issue of the withdrawal or withholding of treatment. Both concern the difficulties of deciding the most appropriate action for a terminally ill child and who should make such a decision. Withdrawing, withholding or limiting life-saving treatment may be considered when the treatment is no longer in the child’s best interest. The Royal College of Paediatrics and Child Health (RCPCH) have recently published a framework for practice for making decisions to limit treatment in life-limiting and life-threatening conditions in children<sup>1</sup>. The framework proposes three sets of circumstances where limitation of treatment may be considered because it is no longer in the child’s best interest to continue. Decisions made regarding withdrawal or limitation of treatment are usually made in agreement between the child’s main carers (usually parents), the healthcare staff and if appropriate, the child themselves<sup>2,3</sup>. Such decisions should be a shared process and as in any difficult ethical situation the importance of good communication and accurate information gathering cannot be underestimated<sup>4</sup>. End of life care involving potential decisions on the withdrawal or withholding of treatments are particularly emotive in nature and unsurprisingly very difficult for all involved. For some people the idea of withdrawal or withholding of a treatment can seem unthinkable, yet for others it may seem like the most compassionate course of action given the circumstances.

There are many factors that may influence those involved in the decision-making process of withdrawal or withholding of treatment. For parents of children with terminal illnesses these include perceptions and observations of their child’s suffering, previous experience of end of life decision making, the need to protect their child and religious beliefs<sup>5</sup>. In addition, the perception of quality of life and the healthcare staff’s recommendations also influence parental decision making. For healthcare staff factors that may influence their thinking include outcome prediction, the balance between benefits and harm and the concept of futility<sup>3,4</sup>. While the term futility is defined as “pointless or useless”, it remains very

difficult to determine what constitutes futile medical intervention. Futility in this sense can be very subjective and therefore it has been suggested that futile medical intervention is defined in the context of an individual case relating to the values expressed by the participants<sup>3,4</sup>.

It has become more acceptable that families are permitted the discretion to have the ability to choose to withhold or withdraw life-sustaining treatments from critically ill children. On the most part a family's wishes and healthcare staff recommendations align, and no ethical problems arise.

### Circumstances when treatment limitation may be considered as it is no longer in a child's best interest

***When life is limited in quantity***

*Treatment is unable or unlikely to prolong life significantly including brain-stem death, inevitable death and imminent death*

***When life is limited in quality***

*Burdens associated with illness or treatment itself are not alleviated or benefits are outweighed by burdens*

***Informed competent refusal of treatment***

*In circumstances where a competent older child with extensive experience of chronic illness and aware of minimal benefits/poor outlook and in agreement with their parents may consent to withdrawal or withholding of life saving treatment. The issue is less clear cut when there is uncertainty about clinical outcome or about benefits of treatment and for those where parents may disagree.*

Adapted from Larcher et al, *Arch Dis Child* 2015;100(Suppl 2)

However, on occasions families insist on their child receiving life-sustaining treatments that are deemed by the healthcare professionals to have either minimal benefit or no benefit at all. Healthcare staff continue to have an independent ethical obligation to the child (e.g., not to provide treatments requested by parents that will only inflict pain/suffering and that have no potential benefit). Also, such treatments may carry a low likelihood of benefit (or slight possibility of benefit) in the face of considerable costs and burden to the health service. When concerned parents request continued attempts to save the life of their child and the treatments carry only an extremely remote possibility of benefit, or the outcome is uncertain, the

healthcare professional should be truthful<sup>5</sup>. They should not, however, use the language of “futility” (absolutely no hope) to force prejudiced notions against further treatment on the parents. When there is apparent or actual conflict between caregivers and parents, advice is sought from ethics committees and referral of decision making is often made to the courts<sup>1</sup>.

It is important however to note that withdrawal or limitation of treatment does not and should never mean withdrawal of care. If a decision has been made to limit life-saving treatment, the child will still have requirements for the alleviation of symptoms that may cause suffering and palliative care treatment should continue to address the ongoing needs of the child.

One aspect of symptom management is the easing of pain. Often this requires the use of opioid analgesics which have both positive and negative effects which may lead to further ethical considerations. The use of morphine in increasing doses in the dying patient, for example, alleviates pain but also potentially hastens the patient’s death through respiratory depression. The principle of double effect<sup>4,7</sup> advocates a course of action where foreseen harmful effects are inseparable from the good effects if certain criteria are met (the key difference between this practice and euthanasia being the intention of the practitioner). Firstly, it requires that the nature of the act itself is good or at least neutral. Secondly, the practitioner intends the good effect of the action and does not intend the bad effect either as a means to the good or as an end in itself. Finally, the good effect must outweigh the bad effect in circumstances severe enough to warrant causing the bad effect and the practitioner aims to minimize harm.

**CASE 3****Withdrawal / Withholding of Treatment (2)**

*An 8-year-old boy has severe cerebral palsy (spastic-quadruplegic type), severe visual impairment and severe learning difficulties. He occasionally smiles but has no recognisable speech. He develops severe dehydration during an episode of gastroenteritis and becomes anuric. Blood tests reveal kidney and liver failure. He has abnormal blood clotting and develops respiratory difficulty. Transfer is requested by his paediatrician to the regional intensive care unit because his parents want all possible treatment for their son. Transfer is hazardous, and he requires ventilatory support during the transfer. He continues to require artificial ventilation in the intensive care unit and is commenced on dialysis. He is found to have an aspiration pneumonia and profuse bloody diarrhoea has caused perianal skin breakdown. After 48 hours he is weaned off ventilatory support but 18 hours later has a respiratory arrest and is successfully resuscitated requiring ventilatory support to be recommenced. Following this he requires an increase in the level of his respiratory support. After a multidisciplinary meeting (nurses, social worker and paediatricians) his prognosis (extremely guarded with the likelihood of life significantly limited in quantity) is discussed with his parents. The healthcare team feel it would be in the boy's best interest to have a "do not resuscitate" order (DNR) in his notes as they feel he is like to have a further respiratory arrest. The problem of long-term dialysis in the event of his recovery is discussed but the prognosis for any quality of life is deemed very poor.*

Use the suggested approach to determine all the information you need to determine how you might proceed. First identify all the ethical issues involved and aim to consider the following questions. What is the general long-term prognosis of a child with severe spastic-quadruplegic type cerebral palsy? How can his quality of life be assessed and how does this relate to the child's family's quality of life? Does it appear that this boy with a severe disability with a poor prognosis have the same rights as a normal child? If this boy was in complete health (i.e. did not have cerebral palsy or associated difficulties) before having this illness, subsequent respiratory

arrest and brain injury, would you feel the same way about the withdrawal or withholding of treatment? Why or why not? What are the ethical issues involved in withdrawing or deciding to withhold further life-support from this child? In the intensive care situation how is withdrawal of life-support carried out? What are the issues about writing DNR (do not resuscitate) orders in case notes? In the unlikely event of this boy recovering, should there be preferential allocation of donated kidneys? If so, who decides on the priority?

## NOTES

In addition to case 3, this case concerns withdrawal of treatment (see case 3 for explanation on some of the ethical issues around withdrawal and futility). A decision to place a do not resuscitate (DNR) order in a patient's notes is usually made on a multidisciplinary basis. When it is decided that a DNR order is in the best interests of the child, it is then discussed with the child's parents to determine whether that is what they desire. In theory a DNR order is simply a recommendation, written in the medical notes to instruct the healthcare staff that in the event of a further arrest (cardiopulmonary) that active resuscitation should not occur on the basis that it would be extremely unlikely to be effective and would inflict unnecessary suffering on the patient. However, a DNR order is not binding, and parents should be able to change their mind and the DNR order be revoked. By its very definition DNR is an emotive term and has been mistaken to mean that care is no longer required for the patient. Some have taken it to mean that healthcare staff are "giving up" on the patient. This misconception has often resulted in confusion around what a DNR means in reality.

A recent study in the *JAMA Pediatrics* (2013)<sup>1</sup> examined clinician's attitude towards the meaning, implication and timing of the DNR order for children. It found that approximately two thirds of healthcare staff (doctors and nurses in ICU and oncology) believed that a DNR order meant only limitation of resuscitation measures in the event of cardiopulmonary arrest. The remaining third considered the DNR order to be the threshold for the limitation of treatments not related to resuscitation. Interestingly, approximately two thirds of clinicians also believed that the care of the patient changes when a DNR order is in place, including an increased emphasis towards comfort and a limitation of diagnostic or therapeutic interventions. There remains disagreement amongst healthcare staff over when discussion over a DNR order should occur (during acute illness or during period of stability). Healthcare staff reported a number of barriers to



discussion with parents over DNR orders. The main barriers included unrealistic parental expectations, lack of parental readiness to have the discussion and differences in healthcare staff and parent understanding of prognosis.

While in this case the child has significant medical difficulties, which do not appear to be responding to medical treatment, there are many cases where a recovery can be made despite poor odds and subsequent significant disability<sup>2</sup>. Subsequent disability following acute illness no doubt impacts upon a patient's quality of life. However, quality of life is extremely difficult to measure accurately and by nature is largely subjective. Difficulties in communication make this even more challenging<sup>3</sup>. In the case above, it could be argued that while the boy's quality of life before the arrest was poor, if he makes a recovery from his pneumonia and is able to leave the ICU setting his quality of life following his quality of life may not have changed significantly. His parents may feel the same<sup>4,5</sup>.

Making a recovery from his acute illness would then raise the issue of renal transplantation. Should this boy be considered to receive a renal transplant? Taking the ethical principle of justice in isolation it could be argued that he should not, based on his likely limited life expectancy and his complex medical problems and subsequent risk of rejecting the donated organ. It could be argued that someone who is likely to retain the donated kidney for a longer period would be more suitable to receive it as they would gain more benefit. However, simply because this boy has significant disability and medical problems, is he any less deserving of receiving the standard of care that others expect to receive?<sup>3</sup>

**CASE 4****Maternal and Fetal Rights**

*A. Mrs A is found to be HIV positive in her second pregnancy. She also has hepatitis B (both HBsAg and HBeAg positive). She has recently moved to the UK from a country in West Africa and plans to remain. She is now 36 weeks pregnant and you see her at the antenatal clinic to discuss the postnatal management of the baby. She says that her family, who are with her in the UK, do not know she is HIV positive and she is not ready to tell them at present. She is very keen on a normal delivery as her last baby was born this way but is willing to undergo a caesarean section if it reduces the likelihood of transmission of HIV and Hepatitis B to her baby. She is however adamant that the baby is breast fed after birth. She states that it is the expected practice in her country, where HIV is common, and her family will suspect something is amiss if the baby is formula fed.*

*You know that breast feeding will increase the risk of the baby getting HIV. She also refuses consent for the baby to get either the hepatitis vaccine or hepatitis immunoglobulin but does not give her reasons.*

Use the suggested approach to determine all the information you need to consider what action might be taken. First identify all the ethical issues involved and acquire the important information to help consider this case. What information on Hepatitis B and its transmission is needed before any course of action can be recommended?

**NOTES**

The most important ethical aspects for consideration in this case are both the mother's autonomy and beneficence towards the child (or the best interests for the child). There are many facts that should be established before any decision or course of action is made. The reader should familiarise themselves with how HIV and Hepatitis B are transmitted, what the risks are for the child of being infected including method of delivery and via vertical transmission, and what effect vaccination and/or immunoglobulin will have on these risks.

It would first be pertinent to try to discover the mother's reasons for refusing both the vaccination and immunoglobulin<sup>1</sup>. If there are any concerns or misconceptions, addressing these may lead the mother to change her mind. If she continues to refuse, then the weighing up of risk to the child versus maternal autonomy must be undertaken. The decision on the course of action may then require legal deliberation if it is felt that the refusal of vaccination and immunoglobulin represented an unacceptable risk to the child. In this case with the mother being HBeAg positive the risk of vertical transmission infection to the child is very high (up to 90%)<sup>2,3</sup>. Clearly this becomes an issue of child protection where an infant is at an extremely high risk of contracting a vaccine preventable disease with potential significant morbidity and risk of mortality (cirrhosis and liver cancer). This risk should be discussed with the mother and she may wish to change her mind. If she does not then legal advice should be taken in order to proceed and a course of action may be taken in the best interest of the child<sup>3,4,5</sup>.

Clinicians have often discouraged hepatitis B positive mothers from breastfeeding their newborns over concerns regarding breast lesions (and exposure to maternal blood) and that hepatitis B virus DNA can be detected in breastmilk. However recent evidence suggests that breastfeeding is not a risk factor for mother to child transmission of hepatitis B in infants who have undergone the recommended prophylaxis at birth (vaccination +/- immunoglobulin)<sup>6,7</sup>. It is less clear on the risk for those children who have not been vaccinated or received immunoglobulin. In the case above, it is highly likely that a court would rule that the best interests of this child would be to receive the vaccination against its mother's wishes. Therefore, breastfeeding might be encouraged.

The case is complicated given the mother's HIV positive status. Factors that increase the risk of transmission to the infant perinatally include maternal RNA viral load, current ART (antiretroviral therapy) and mode of delivery (higher risk in normal vaginal delivery than Caesarean section)<sup>8,9</sup>. It would be pertinent to determine the mother's RNA viral load and discover if she has been taking any treatment prior to arriving in the UK. Viral load and breast health are also important factors in determining the risk of HIV transmission during breastfeeding<sup>8</sup>. With low viral loads and regular antiviral treatment, the risk of transmission from breastfeeding is lower but not insignificant. As a result, many countries recommend completely avoiding breastfeeding for mothers infected by HIV. This of course is possible only in countries that are financially well-off such as the UK<sup>10</sup>. The WHO recommends that HIV positive mothers in resource-poor settings breastfeed their children exclusively up to 6 months of age with ART as the

risk of malnutrition, dehydration and infection far outweigh that of HIV transmission<sup>11</sup>. In the case above, these factors should be discussed

*B. Miss B is 38 weeks pregnant. She has an antenatal scan which shows that the baby is significantly growth restricted with an unfavourable intrauterine environment. She is advised that she should have an emergency caesarean section as the baby is at risk of stillbirth.*

*She refuses, saying that she will have the baby via normal delivery and only after spontaneous onset of labour. She gives her reasons, some of which are based on her new age beliefs. You also discover from her notes that she has previously been an inpatient in a psychiatric unit with bipolar disorder. You are very concerned that the baby will die unless she has a caesarean section in the immediate future.*

sensitively with the mother who may have cultural pressures that influence her decision whether or not to breastfeed.

Use the suggested approach to determine all the information you need to come to a course of action. For both of the above cases consider an answer to the questions, “What is the position of the unborn child within the law?” and “What rights does the fetus have?”

## NOTES

The key ethical issues that come into conflict in this case are again those of maternal autonomy and beneficence towards the fetus. There remains disagreement over when a fetus should be regarded as an individual and therefore achieve its own rights. Some argue that a fetus only becomes a person or human being at birth (or later) and prior to this should have no rights as an individual. Thus, the mother’s autonomy should completely dictate the course of any treatment choice and disregard whether it may put the fetus at risk. Others argue that life begins at conception, and that an unborn child should have as many rights as any individual. This conflict of opinion is often the centre point around which the debate over abortion revolves (not the focus of this case!)

Regardless of when it is considered for life to have begun, like a young child, a fetus or unborn child still does not have competence and thus its autonomy cannot be considered as an ethical imperative. However, the principles of beneficence and non-maleficence towards it would still apply<sup>12-14</sup>.

In most cases the mother's interests for her fetus align with her own. On rare occasions the interests of the mother and the fetus come into conflict. In the case above it appears that the best potential benefit for the fetus would be that it is delivered via Caesarean section. However, this comes into direct conflict with the mother's autonomy in her desire to have a spontaneous and normal delivery.

As with every case involving an ethical dilemma it is important to obtain as much information as possible. It would be advisable to explore in detail the mother's reason for refusing a caesarean section delivery and to discuss with her the risks to her future child associated with proceeding with a normal delivery in her case.

The fetus is not directly protected by the European convention on human rights. British law upholds the view that a fetus is not a person at any gestation<sup>13</sup>. While it does have rights, it is not recognised as being equivalent to a person. Therefore, for example, in England a mother, if competent, has the legal right to decide on treatment or refuse treatment which holds even if she or fetus might die. In this case, providing the mother is competent (important also to consider full current mental health assessment<sup>15</sup>), then her autonomy must be respected. In the past court petitions have been made from the healthcare team arguing the necessity of the mother to protect her future child, and that the state has an interest in protecting that child. However, decisions by the court have faced opposition on the basis that they limit a woman's autonomy, invade her privacy and take away her right to informed consent<sup>16,17</sup>.

## CASE 5

### Age of Consent

*A. 15 year old girl Sally attends your clinic alone. She is requesting that you prescribe the oral contraceptive pill. She mentions she has a number of sexual partners who are all boys in her school year. She maintains that she gave consent to all sexual activity. She is otherwise healthy, and you determine that she is a smart, informed and independent young girl. In the past Sally has attended for mild asthma and has always attended with her mother. Her mother is also a patient of yours, but Sally is adamant that she does not find out about her attending today and her request for oral contraceptives.*

Use the suggested approach to determine all the information you need to decide what course of action to take.

## NOTES

Sally is 15 years old and therefore cannot consent legally to sexual intercourse (in the UK<sup>1</sup>). However, the law is lenient on sexual relations between those of similar ages. There is no statutory duty to report to the police cases of consensual sexual activity involving a young person aged 13-16 years, where the other person is under 18 years old. It would be pertinent to ensure that Sally is not having sexual relations with an adult (18 years or older) as this would be child abuse and further action would be required. All attempts should also be made to rule out rape or sexual exploitation. If there is potential that a sexual crime is being committed against Sally, then confidentiality must be broken, and the police should be informed (professional duty)<sup>2</sup>. Determining Sally's sexual history is important but should be carried out in a non-judgemental and sensitive manner. It is unlikely that Sally will be open and honest without hesitation, so questions should be open and allow time for her to answer. If possible, it should be determined why she does not wish to involve her parents and she should be encouraged to inform her parents. However, if Sally is deemed Gillick competent<sup>3,4</sup> (see previous chapter: Who Should Make Decisions for Children?) and there are no child protection issues then she should be prescribed the contraceptive pill. The Lord Fraser<sup>5</sup> guidelines were laid out following the ruling of the case from which Gillick competence arose. The

Lord Fraser guidelines state that the provision of contraceptive services to under 16-year-olds without parental knowledge or permission can only occur when certain requirements are met (see below).

### Lord Fraser Guidelines (UK)

The provision of contraceptive services to under 16 year olds without parental knowledge may occur when:

- the young person will understand the advice given by the professional
- the young person cannot be persuaded to inform their parents
- the young person is likely to begin, or continue having sexual intercourse with or without contraceptive treatment
- unless the young person receives contraceptive treatment, their physical or mental health, or both are likely to suffer
- the young person's best interests require them to receive contraceptive advice or treatment with or without parental consent

If Gillick competence is a legal term that guides whether a child or young person has the maturity to make their own decisions and understand the consequences, then Lord Fraser guidelines apply this competency to the specific issue of contraceptive advice<sup>6</sup>. The more difficult aspects of the

*B. 14-year-old Emma attends your clinic alone. She presents with the complaint of a vaginal discharge and after testing it is confirmed that she has gonorrhoea. When asked about her sexual history, Emma admits that over the last few months she has had a number of different sexual partners, mostly boys from her school year. However, she also divulges to you that more recently she had engaged in a sexual relationship with an older man who is a friend of her father. She refuses to give out any other details about her past partners and she is adamant that no-one, especially not her parents, should find out about either her sexual activity or test results as this could have devastating consequences to her family. She is requesting the oral contraceptive pill.*

Fraser guidelines are determining how not receiving contraceptive treatment will affect Sally's physical or mental health and what her best interests are.

Identify and address the key ethical issues raised in this scenario. Before analysing the case in detail, what is your immediate response to Emma's request of confidentiality? What initial steps would you need to take to determine what approach to take? Using the suggested approach from the previous chapter, analyse the important ethical issues in this case, and discover the important professional guidelines and law that may influence the steps you would take.

## NOTES

The reader will have recognised that the key issues defining this case are those of autonomy in a young person under the age of 16 years, confidentiality, trust and child protection. The arguments for respecting her confidentiality include maintenance of the doctor patient relationship<sup>7</sup>, the potential family disruption and problems that may ensue, and respect for a competent patient's autonomy. However, on the contrary Emma has told you that she has been having a sexual relationship with an adult and now has a potentially serious sexually transmitted disease. Emma is fourteen years old and UK law states she cannot legally consent to sex<sup>8</sup>. The law is lenient on sexual relations between teenagers of similar ages, but you know that one of the people she is having sex with is a friend of her father's and is an adult. That is a crime, both statutory rape and child abuse<sup>8</sup>. Hopefully you will have identified this as the major issue in this case. As the doctor you have the duty to share this information appropriately as an issue of child protection (in order to protect your patient)<sup>9</sup>. In addition, she has a sexually transmitted disease and further unprotected sex could result in the harm of others.

Initial steps that may be taken in this scenario would be seeking the advice of an experienced colleague. Emma should be encouraged to involve her parents in discussion. It would be beneficial to try to determine whether or not Emma fully understands the situation, but in this case given the significance of her revelations whether she is deemed Gillick competent or meets the Fraser guidelines for contraceptive advice is irrelevant - she is a minor engaged in sexual activity with an adult and this issue needs immediate attention. It should be explained to her that although she does not want anyone to know of her relationships and/or test results that her confidentiality in this case must be broken whether she consents or not. The method and relevant person to contact will depend on local child protection procedures however it is likely that both social services and the police will need to be informed.



**CASE 6****Jehovah's Witness and Blood Transfusion**

*A 14 old girl with chronic renal failure (known to the paediatric nephrology team) presented with shortness of breath and a severe headache. She was found to be severely anaemic (haemoglobin 55 g/L) and to have fluid overload causing pulmonary oedema. She had an extremely high blood urea and creatinine. She is a Jehovah's Witness, a religion which generally forbids blood transfusion. Careful conservative management with diuretics reversed her breathing difficulties and erythropoietin injections eventually return her haemoglobin to normal. Following this, it was determined she requires dialysis support and, in the future, subsequent renal transplantation.*

*Later, following discussion, the transplant surgeons were prepared to operate, provided both the parents and the child sign legal consent refusing transfusion, and will try "bloodless surgery". They feel that transplantation is in the best interest of the girl.*

Use the suggested approach to determine all the information you need to determine how you might proceed. You should seek information on potential renal failure treatments and the method of renal transplantation and likelihood for blood transfusion during the process. What might the clinical outcomes be of not having the transplant, having the transplant without transfusion under any circumstance<sup>1</sup>, or having the transplant and receiving a transfusion. Familiarise yourself with methods to reduce blood use in surgery ("bloodless surgery")<sup>2</sup> and Jehovah's Witnesses' beliefs around blood transfusion and organ donation and if this is consistent for all Jehovah's witnesses<sup>2</sup>.

**NOTES**

Autonomy and consent are the main ethical issues encountered in this case. The healthcare staff have determined the best interest of the girl is for her to have the transplant. The girl herself has stated her wish is to have the transplant carried out with no transfusions under any circumstance. This may also be the wish of her parents and their church. Many questions arise when trying to determine this. Firstly, is the young girl competent enough

(Gillick) to be able to consent to this treatment? How much influence does (or should) the church and the young girl's parents have over her and should this be taken into consideration? To what degree is it the duty of the healthcare staff to insist and ensure that their patient has the best possible treatment available and should this override all other considerations? In an emergency, where the child requires blood in surgery, does the young girl have the right to refuse it even though it would lead to her death? Remember that Gillick competence allows consent to treatment but not necessarily refusal of treatment.

Answering these questions is a difficult task and raises the issue of the conflict between religious beliefs, parental rights, the autonomy of a young person, and the best interests of a child (under 18 years old).

Firstly, it is important to determine the exact beliefs that would have an impact on this girl's decision to refuse transfusion. Jehovah's Witnesses refuse blood transfusion on the interpretation of biblical scripture. In general, most Jehovah's Witnesses will refuse transfusion of whole blood and/or blood components (such as platelets or plasma). However, there are variances in the acceptance of blood derived products such as cryoprecipitate or albumin for example<sup>1,2,3</sup>.

Secondly, it should be noted that improving technology and surgical technique have allowed surgeons to perform many operations with minimal blood loss. Blood salvage techniques such as haemodilution or autotransfusion if available may be considered in this case. In haemodilution, blood is withdrawn from the patient prior to the operation, temporarily stored (with restoration of circulating blood volume using crystalloid or colloid solutions) and reinfused after the operation. Autotransfusion involves the collection of the patient's blood during surgery, separation of the red cells which are subsequently washed and returned to the patient. While these methods markedly reduce the potential of needing donor transfused blood (or blood products) they do not completely rule out the possibility of large intraoperative blood loss (and emergency transfusion) or the potential for requirement of blood transfusions in the post-operative period<sup>4</sup>. Methods of "bloodless surgery" should be explored and discussed with the young person and her family if they are potential options.

If the girl in this case is deemed to be Gillick competent, it would be important to confirm how much of the beliefs that she states are truly her own or are held only in the presence of her parents. While parental rights are recognised, they are not absolute. Parents may not make decisions that result in permanent harm to their children's welfare or development<sup>5</sup>. In essence, parental decision making on behalf of a child exists for the purpose of providing the child's best interest.<sup>5</sup>

It would also be important to determine any consequences to the girl if she were to receive blood in the emergency situation. Would she be rejected by her community or would she by her conscience feel she has committed a sin of which she can never be forgiven (and the potential spiritual, social and psychological consequences this may entail)<sup>3,6</sup>? Full discussion with the girl and her family should include the likelihood of success of the transplant without transfusion and explanation of the potential options should blood be required. It may be the case that the family are keen that blood is avoided, but in the emergency situation may be content that it is given (as the decision is not their own). If not, and the surgeons are not happy to carry out the transplant without transfusion as an option, then the decision of the courts would be required.

It is likely, the court will need to be involved in this case. It would be difficult to determine whether this girl is fully competent to consent to treatment independently (free from coercion) and as she is under 18 years old, she does not have the right to automatically refuse treatment and her parents become the proxy decision makers. However, her parent's wishes for refusal of transfusion appear to be at odds with the best interests of the girl. In clear cut cases where transfusion is an absolute necessity then the courts in the UK have overruled the parent's refusal and the child has been given transfusions. In this case a blood transfusion may not be required. However, the likelihood remains high and court approval should be sought to give blood during surgery if required (when all other potential options have been exhausted). If during surgery a transfusion is urgently required and there is insufficient time to get approval from the court, then blood should be given, and the young girl should not be allowed to die for lack of blood.

In the unusual circumstance of the girl being alone in refusing blood but her parents permit it then the parent's consent is adequate to make it lawful to give the transfusion without the girl's permission.

But the question overarching this case remains. Is it right or ethical to pressurise a patient on the basis of best interests (either following professional opinion or via the courts) to undergo a procedure they deem morally wrong due to a deeply held belief<sup>4</sup>?

**CASE 7****Compulsory Vaccination**

*The Public Health Department is expecting a major outbreak of polio in the next few months. They are spending large amounts of money on an immunisation programme for all 4-5 year olds at local schools using the oral (live) form of the vaccine. The success of this programme depends on getting all children immunized. The more unprotected children there are in the population, the greater the risk to the overall population.*

*You are a GP, who has been asked by the school medical officer to see the parents of Kim (one of the children in the nursery) because they are refusing to consent for Kim be vaccinated.*

Should Kim's parents be permitted to refuse vaccination of their daughter? Use the suggested approach to determine all the information you need to consider this ethical dilemma and consider to a course of action.

**NOTES**

Vaccination has undoubtedly been one of the most successful public health developments in human medical history. Vaccination has saved countless lives and significantly reduced morbidity in relation to once common infectious diseases, along with a huge reduction in healthcare related costs. As with any treatment, vaccinations are not 100% effective and are not without side effects, but despite this the benefits to any given population have been enormous. It is within the small number of individual cases where either a vaccine has been ineffective or the side effects so extreme that routine vaccinations have come under question. In the UK some parents do not consent to their children being vaccinated on the beliefs that vaccinations are either harmful, unnecessary (that the diseases are not serious) or that they do not help a child develop their own immunity. Some of these assumptions are built on false information. Consider the significant reduction in MMR (combined measles, mumps and rubella) vaccination uptake following the publication of false evidence that it was linked to the development of autism. Other assumptions are simply based on sincere parental concerns. However, many people are unaware of how the risk of

morbidity or mortality from contracting a vaccine-preventable disease significantly outweigh the risks associated with receiving the vaccination against the disease. For example, 1 in 20 children who contract measles will develop pneumonia, 1 in every 1000 will develop encephalitis (and resulting sequelae) and 1-2 in every 1000 who contract measles will die from it. In contrast, 1 in 1 million who receive the vaccination will experience a potentially severe reaction (common side effects are usually transient)<sup>1,2</sup>.

Vaccination aims to protect both the individual and the community<sup>3,4</sup>. The significant reduction of any given vaccination-preventable disease relies on the level of uptake of the vaccination. When a certain percentage of a population receives the vaccination, the population can achieve a state known as “herd immunity”. This means that when the number of people vaccinated within a population reaches a certain threshold, for those remaining unvaccinated the chance of catching the disease is negligible. As herd immunity has been achieved through routine childhood immunisation in many countries some diseases are virtually no longer seen. For parents who refuse vaccination for their children, an argument could be made that because herd immunity has been achieved, the chances of their unvaccinated child contracting a disease is so low that they do not need vaccinated<sup>5</sup>. However, a counter argument is that these parents are taking advantage of the benefit provided by every other child who has received the vaccination (and its potential side effects). In theory, if a significant proportion were to follow suit and refuse vaccination then herd immunity would be ultimately lost. The disease could increase in prevalence again resulting in increased levels of morbidity, mortality and cost to society. Therefore, consent or refusal of vaccination has an effect not only on the individual child but on the wider population<sup>6</sup>. Vaccination refusal can become an issue of justice and not just autonomy.

It is within this complex dynamic that vaccine refusal must be addressed in ethical terms. In the UK parents have the right to refuse vaccinations for their children<sup>5</sup>. In other countries, such as France and the USA, vaccination is compulsory for school attendance. The question then arises; is it ethical to enforce vaccination on children against their parent’s wishes in order to benefit public health?

In the specific case discussed above it would be important to first determine the reason behind Kim’s parent’s refusal to consent for vaccination and aim to understand their viewpoint<sup>3</sup>. It is possible that a particular concern may be easily addressed alleviating their fears. It would also be important to have the information required to ensure the parents are making an informed decision. For example, discussing the risks associated with the oral polio vaccination and to what degree it will reduce the risk of

contracting polio as well as the symptoms and potential consequences of contracting polio.

In the UK if the parents continue to refuse then their wishes should be respected. The only occasion where this may be potentially overruled is if the vaccination in question could result in protection from certain death (for example in the case of early stage rabies)<sup>5,6</sup>. In that scenario, the best interest of the child would suggest the preservation of the child's life and the healthcare worker would have a moral duty to do so despite the parent's wishes.

Consider your thoughts on this case. Do you think that all countries should follow the example of France and the USA in making childhood vaccinations compulsory?

**CASE 8****Truth Telling**

*The paediatric surgical ward doctor has just realised that he has given an 8-month-old post-operative hernia patient an incorrect dose of intravenous morphine. This was due for the older child in adjacent bed who was in a lot of pain. The 8-month-old child stops breathing (apnoea) and develops a bradycardia and requires a short period of bag and mask ventilation. The mistake is realised, and the infant is given some intravenous naloxone, which counteracts the effects of the morphine. The effects of the morphine wear off and the infant does not seem to have come to any significant harm. After this crisis the parents arrive to take the infant home. The infant now seems well but you feel you should keep him in overnight for observations. The doctor decides that to tell the truth would be too distressing for the parents and might damage his own career – he therefore makes up an alternative “half truth” (that the effects of the anaesthetic have not fully worn off) to explain why he wishes the infant to remain in hospital.*

Consider the following questions when deliberating on this case. What are the ethical issues that are raised in this case? As the infant has not come to any harm, do you think the doctor is justified in not revealing what happened to the parents? If not, what do you believe is the best course of action?

**NOTES**

Hopefully the reader will recognise the ethical issues of truth-telling and integrity from this case. As discussed in chapters 2 and 3 truth-telling and honesty are qualities expected of the modern doctor and are laid out in Domain 4 (Maintaining Trust) of the General Medical Council’s (GMC) guidelines on Good Medical Practice (2013)<sup>1</sup>. Truth telling over the disclosure of a diagnosis (such as cancer) continues to show significant variance in practice throughout the world. Barriers to truth telling of diagnoses include concern over causing significant psychological distress to an individual, a patient’s own request not to be told, the request of a patient’s family and a physician’s self-interest (avoidance of the difficulty of breaking bad news)<sup>2</sup>.

This case deals with the latter - truth-telling following a mistake where a “half-truth” is told solely in order to protect the reputation (and self-interest) of the doctor. The GMC in conjunction with the Nursing and Midwifery Council (NMC) has recently produced guidelines on the professional duty of candour building upon the existing guidelines on Good Medical Practice<sup>3</sup>. The advice states that doctors should speak to patients as soon as possible after they have realised something has gone wrong with their care. A full apology should be made with an explanation and a plan to reduce harm or address any adverse effects of the mistake. Any further action should be taken to reassure the patient that the same will not happen again and all incidents should be reported through the correct channels to prevent the same error happening to another patient. It is important to note that apologising does not mean you are admitting legal liability. However, the guidance does suggest that it may not always be beneficial to the patient or relatives to discuss with them a near miss when no harm has occurred. This should only occur when decided by the healthcare team or someone with overall clinical responsibility who deem that discussing this may cause distress that would not help recovery<sup>3</sup>.

It is often not easy to apologise to a patient or their parents. There is a sense of disappointment and potentially shame and embarrassment. Often the immediate reaction is to cover up to avoid these uncomfortable feelings. However, failing to be open or honest with a patient following an error in their care can lead to mistrust, a breakdown of the clinical relationship and legal proceedings against the healthcare staff member. It also does not help in producing a culture of learning or patient safety.

The manner of the apology is also as important as the means. Apologies should be sincere, empathetic and personal<sup>2,3</sup>.



**CASE 9****Confidentiality**

*Two paediatricians) are overheard quietly discussing a case in the lift. Another member of the healthcare staff who was also in the lift could identify the newborn as being her neighbour's newborn child. The mother had told her she had a baby boy. The staff member was quite surprised to find out from the overheard conversation that the newborn was in fact genetically a female (with ambiguous genitalia) and that the surgeon was discussing with the paediatrician what her involvement in the case might be. The neighbour then went and told the mother who was shocked and then angry to find out that her neighbour was aware of the problem.*

Identify the ethical issues of this breach of confidentiality and what effects this may have on those involved.

**NOTES**

Confidentiality is central to the relationship between a patient and their healthcare providers in the maintenance of trust and the safeguarding of the patient's welfare. Healthcare professionals are in a unique position when it comes to information sharing from others. Often a patient will share personal and sensitive information to a healthcare professional on the basis of trust and for the purpose of treatment of their condition. Improper disclosure of such information could lead to significant harm for a patient such as lost opportunity, humiliation or discrimination and a loss of trust in the healthcare profession. Both the GMC's standards of confidentiality<sup>1</sup> and the NMC's Code<sup>2</sup> highlight the importance and duty of doctors and nurses to maintain confidentiality. It is generally recognised that confidentiality should only be questioned whenever the information poses a risk to the safety of others or public health is threatened<sup>2,3</sup>.

While it is likely rare that sensitive and confidential information is shared maliciously by a healthcare team member, confidentiality breaches are common enough and may occur without the healthcare professional recognising its occurrence. Worryingly, a recent study showed that nearly half (46.7%) of all recorded confidentiality breaches in a hospital setting were classified as severe (highly sensitive information of a private nature

shared with uninvolved third parties resulting in some observable consequence). Possibly even more so, nearly 1 in 10 (9.5%) of the total confidentiality breaches were repeated and severe<sup>3</sup>. The study also showed that over a third (37.9%) of the total breaches occurred in public areas (corridors, stairs and lifts) and that doctors were by far the most likely to break confidentiality inappropriately. Another study showed that 1 in 10 breaches occurred in lifts<sup>4</sup>.

**CASE 10****Predictive Genetic Testing**

*Alice Jones is an 8 year-old girl and has been referred for investigation following a number of proven urinary tract infections (UTIs). During history taking you learn that Mr. Jones (Alice's father) and his father both have autosomal dominant polycystic kidney disease (ADPKD). Alice's kidneys have no cysts, but she has 2 older siblings (aged 15 and 17 years) who have never been told about their father's condition and have not been screened. Her father is very reluctant for them to be told about the family history or to bring them to the clinic. He is worried that, if found to have the condition, it would cause them distress and they would not be able to have a good life in the future due to potential restrictions in career choices, relationship involvement or financial planning.*

What ethical issues does this scenario raise? Consider the problems using the suggested approach and determine what current recommendations state with regards to predictive genetic testing. It would be pertinent to first aim to gather information about ADPKD.

**NOTES**

In conditions that may be diagnosed genetically in childhood but have no clinical manifestations until adulthood (predictive genetic testing) there has remained the question, "When should predictive genetic testing occur?". One such condition is Huntington's disease. It is an incurable and progressive neurological condition associated with cell loss within areas of the basal ganglia and cortex. It is an autosomal dominant inherited adult-onset condition affecting movement, cognition and behaviour leading to significant disability and premature death. As it is autosomal dominant any child of an affected parent has a 50% chance of having the dominant allele and thus developing the condition in adulthood.

A number of ethical issues arise around how a child at risk should be informed, when they should be informed and if or when they should undergo predictive genetic testing to determine their risk. Current guidelines suggest that children should be informed about genetic conditions that run

in the family, but there is differing opinions on the implementation of predictive genetic testing<sup>1,2,3</sup>.

Consensus guidelines<sup>4</sup> suggest that parents should be encouraged to defer testing of their children for adult-onset conditions until older adolescence or adulthood unless there is a clinical intervention that would be appropriate in childhood. Adolescents should be encouraged to defer predictive testing until adulthood due to the potential impact at a formative stage of their life. In some cases, testing may be reasonable in childhood, but this should be only be after considerable deliberation.

There are two main ethical arguments for deferring testing until adulthood. Firstly, it allows children to make their own fully informed decision (autonomy) on whether they wish to be tested when they reach adulthood. As discussed in chapters 2 and 3, younger children do not have capacity to make fully autonomous decisions and thus decisions regarding their welfare are often made by their primary caregivers (usually parents). Deferring testing until adulthood permits them to make a choice for themselves on something that will not directly affect them until later in life. However, current recommendations also suggest that in order to facilitate a fully informed choice in adulthood, parents should be encouraged to inform their child of the genetic condition in the family and the implications that it will have. This will allow the child to develop their knowledge of how family members may be affected and thus aid their own decision for testing in later life. Secondly, it has always been assumed that predictive testing in childhood or adolescence may result in harm for the child or young person. Harms may include significant psychological distress (e.g. depression, anxiety, suicide) especially in the formative years of a young person's life, potential discrimination in obtaining insurance, employment or a mortgage, stigmatization, or a negative influence on family dynamics<sup>4</sup>.

There are of course those who argue against deferring predictive testing until adulthood. They argue that children should be informed about the genetic condition in their family and that this involves more than just the statement of a fact. It should involve ensuring they understand what they are being told, can make sense of it and can discuss it and ask questions in a supportive and caring environment. Thus, it is argued that testing is an extension of proper disclosure and knowing whether they are positive or negative will not limit their choices but merely result in different ones<sup>5</sup>. Knowing the result removes uncertainty for the child, fear and anticipation in the parents, and allows the child to influence their own life at an earlier stage. Interestingly, a recent study shows that only 20% of the public are in agreement with the current international genetic service provider guidelines that predictive testing should be deferred until adulthood<sup>6</sup>.

In the case regarding Alice, the ethical issues raised are similar but slightly different. In ADPKD, symptoms may develop in childhood, screening may result in diagnosis and interventions may be initiated if required. There is potential that Alice's siblings may have asymptomatic clinical manifestations of the disease and potentially could be receiving treatment in order to potentially reduce long term morbidity. Should Alice and her siblings therefore be told about their father's (and grandfather's) condition and the potential risk that it may affect them in the future (presuming they are currently asymptomatic) despite their father's refusal? And if so, by whom?

In the past in the UK, unless they were exhibiting symptoms, children with a parent with ADPKD were not tested for similar reasons as those mentioned regarding Huntington's disease. However, given there is evidence showing that some children with ADPKD remain asymptomatic but have clinical findings such as hypertension<sup>7</sup>, in the future it may be recommended that pre-symptomatic testing in at risk children takes place allowing the provision of treatment to alter the progression of the disease<sup>8</sup>. Acting on the principles of beneficence and best interests of a child, it would be pertinent in this case to try to persuade Alice's father to discuss his diagnosis with his children to facilitate pre-symptomatic testing in the future (or in the present). If Alice's father refuses to inform his children what course of action should be taken?

## CASE 11

### Research

*Following a challenging but inspiring medical experience in Zambia working with children infected with HIV you are keen to return and try to help establish better medical treatment. A well-known pharmaceutical company pledges funding for a research study into a promising new anti-retroviral drug for use in children which potentially offers cost-effectiveness, once weekly dosing, and improved anti-retroviral activity. When you return to Zambia you set up the study based in a rural clinic, 80 miles from the nearest town. The study is advertised and many children arrive to take part. Some of the children have walked for many miles on their own (many are orphans as HIV/AIDS has claimed the life of their parents) as they heard about getting a “new cure” for their HIV. Others have heard there is a reward (or compensation) for enrolling and remaining in the study for its duration.*

Consider this potential scenario and the many ethical issues involved in research in the setting of a developing country. Outline both the positive and negative factors that this research may offer in order to better decide whether such a project should be carried out.

### NOTES

There are many ethical issues associated with research and before any research is carried out approval for the project is usually required from an ethics committee. A research ethics committee considers a research proposal and ensures the protection of the rights of the research participants (i.e. information to participants if provided and protecting them from potential adverse effects). It may be helpful for the reader to consider this scenario from the perspective of a research committee member. There is some important information about the research that needs to be known before the four medical ethical principles can be examined in more detail. Firstly, who is funding the research and for how long will this funding be available. Secondly, what the body funding the research wish to find out i.e. is this study to find out about efficacy of the drug or about something else such as side effects? Thirdly, will the participants be subject to any

investigations or tests? Finally, will the research result in further development and the widespread production of the medication and will it be available to the financially poor children it was trialled on<sup>1</sup>.

The answers to these questions will help in the determination of the ethical nature of the research. Ethical issues in paediatric global health (and especially in research) are complex<sup>2</sup>. The specific societal and cultural issues should be considered (differing ethical approaches) and local healthcare providers and skills should be appropriately used<sup>3</sup>.

Considering autonomy, it will be very difficult if not impossible to gain informed consent from the participants as in this case they are children (most likely not at the age of Gillick competence) and many of them do not have parents. If they do have guardians who can consent it may be impossible for them to be contacted to gain consent (limited postal or electronic communication resource or literacy rates). Therefore, if a child appears for the research voluntarily and alone should they be denied the medication based on whether a parent or guardian is present? Recruitment for this study may thus be hampered significantly, but this geographical location is where HIV/AIDS is the most prevalent and has the biggest burden upon the population.

This trial involves the active treatment of HIV/AIDS and has the potential to greatly benefit many children. From a purely beneficence point of view, it seems that the logical course of action is to enrol as many children as possible in the study to maximise the benefits. Most likely many children and families will not already be taking medication for HIV/AIDS as they will not be able to afford it. However, the trial is likely to be time limited and in the long term how does giving a short course of antiretroviral benefit a child and their family<sup>4</sup>? Some might argue due to the paucity of resources that even a short course is better than nothing and that the benefits of such medication may only ever be discovered with such research<sup>5</sup>.

Considering non-maleficence, it would be important to know that the side effects of the medication were considered and there was active procedure in order to manage any unwanted adverse effects.

Many questions around justice and fairness arise from this scenario. For example, can all participants in this research be treated fairly? Is it ever morally acceptable to offer reward or compensation to someone to enrol or remain in a research study? Does compensation such as travel costs influence a child or family to take part in a study against their best interests? A number of lines of thought could be applied to research such as this. A utilitarian might argue that new treatments or risky investigations in children would be justified on the basis that the potential benefits could be transformative for a great number of people (now or in the future). In the

past children were excluded from research as they were considered too vulnerable. However, this resulted in many children receiving treatments assumed to be safe (as they were found to be safe in the adult population) in the absence of research and this resulted in harm (on occasions significant). The challenges of research in developing countries are different from those in developed countries. Meeting tight controls to provide accurate and ethical research often proves more difficult.

What are your thoughts on how research should be carried out in developing countries?



**CASE 12****Circumcision on Religious Grounds**

*A 2 week old baby boy is brought to you (a surgeon) by his father with a request that you perform a circumcision. The boy is a healthy term infant. You note that his father comes from another cultural and religious background to his mother – his mother seems unhappy for the baby to have this procedure but her wishes are not regarded by the father.*

Consider the ethical issues involved in this scenario and determine what may influence whether or not you might carry out the procedure.

**NOTES**

There are three main reasons for consideration of newborn male circumcision. Firstly, there may be a medical indication such as to reduce the incidence of urinary tract infections in the presence of an underlying anatomical anomaly (for example, posterior urethral valves or vesico-ureteric reflux). Secondly, newborn male circumcision may be considered for cultural reasons. By this we mean it is asked for not as part of a religious act, but rather because it is the accepted cultural norm for example in North America. The third reason is as part of religious practice. Newborn male circumcision has been common practice in some areas of the world and as part of religious ritual (for example in Islam and Judaism) for many years. The medical risks and benefits are finely balanced and there is no clarity whether NMC is warranted for medical reasons. Strong arguments exist on both sides of the debate <sup>1,2,3</sup>.

Those in favour of newborn male circumcision will argue on behalf of the rights of religious freedom, the importance of the inclusion of the child in cultural and religious practices of their own community and the benefit which that provides and the recent research suggesting the health benefits. For those against the practice the arguments focus around the future autonomy of the child. In the case of newborn male circumcision to which this scenario refers, the decision is made by the parents on behalf of the infant who is not competent to consent. As newborn male circumcision is not a medical treatment per se, and has questionable benefits, should the parents be permitted to make this decision for the unaware child? Opponents

of the practice would argue that the child should be allowed to make an informed decision for themselves when they are of age and in that way the best interests of the child are maintained. In the past number of years, a German court ruled that the right of the child to physical integrity overrules the right of the parents to religious freedom<sup>2</sup>. Some have argued that newborn male circumcision is a child protection issue and that children should be protected from unnecessary procedures and the potential psychological effects when older.

The General Medical Council does not give an opinion on whether newborn male circumcision is acceptable. It does however give guidance on the standards expected if it is carried out and the obligations of a practitioner in counselling or ensuring access to an appropriate service. It allows those practitioners who disagree with newborn male circumcision to opt out.

Within the context of this case a number of questions arise. Should cultural and religious issues push you into carrying out a procedure that may be deemed unnecessary? What role does the mother have in the discussion? In the UK both parents have to consent for a cultural circumcision. For other procedures, the mother usually holds parental responsibility and can give consent unless there is a court order specifically stating she is not the guardian etc. Therefore in this case you as the practitioner should not carry out the procedure of circumcision. Nor is it your role to convince the child's mother otherwise. The GMC's guidance states that given there is parental disagreement that you must inform the parents that you cannot provide the service of male circumcision for religious reasons unless it is authorised by the courts<sup>4</sup>.

**CASE 13****Resource and Distributive Justice (1)**

*A 2-month-old infant has recently been diagnosed as having spinal muscular atrophy type 1 (SMA type 1). His parents have been told that this is a severe and life-limiting condition and that he will unlikely be alive at 12 months (prognosis based on his progress so far). His treatment has been supportive. After much thought and discussion, his parents decide to take him home with no treatment as they are keen for him to be cared for there. They decline nasogastric feeding, RSV prophylaxis or antibiotics. He dies at home during the RSV season.*

*A 2-month-old infant has recently been diagnosed as having spinal muscular atrophy type 1. His parents have been told that this is a severe and life-limiting condition and that he will unlikely be alive at 12 months (prognosis based on his progress so far). His treatment has been supportive. His parents have researched his condition on the internet and request intense management including nasogastric feeding progressing to PEG insertion, RSV prophylaxis, cough assist technology with suction and full-time non-invasive ventilation progressing to tracheostomy. He survives with a few intermittent infections, but rare hospitalisations.*

*Shortly following their diagnosis, a new treatment becomes available (Nusinersin) for those with SMA. It has been developed in the USA and has undergone preliminary trials. It is available in the UK, but use is not funded by the NHS following review by NICE (National Institute for Health and Care Excellence) due to the high expense to benefit ratio.*

Consider the clinical scenarios above and explore the ethical issues that present. Particularly seek to consider the following questions. What is the child's best interest and who should decide this? For the first child, do you feel the parents are "giving up"? Is this fair on the child? For the second child, do you feel the parents are encouraging futile treatment? Or inflicting suffering and prolonging poor quality of life? What are your thoughts on whether the new treatment Nusinersin should be offered on the NHS as a treatment? If it is not offered, do you feel it is ethical for the child's parents to pursue this treatment for their child at all costs? What are the reasons

behind your thoughts on this? (See below for more information on Nusinersin)

## NOTES

The spinal muscular atrophies (SMA) are a heterogeneous group of autosomal recessive neuromuscular disorders characterised by the progressive weakness of lower motor neurons resulting in progressive muscle weakness and atrophy. This is due to pathological loss of anterior horn cells in the spinal cord and brain stem as a result of a disruption in the SMN1 gene (survival motor neuron gene) on chromosome 5q. This gene codes for the SMN protein involved in the assembly, renewal and survival of motor neurons. There is however a second gene, SMN2, that generates 10-20% of the amount of the SMN protein and almost all SMA patients retain at least one copy of this gene. The severity of SMA symptoms is broadly related to how well the SMN2 gene (1 or more copies) can make up for the loss of function of the SMN1 gene.

There are a number of types of SMA broadly classified by the age of onset; the most common being types 1-4 (there are other variant types). SMA type 1 is also known as acute infantile or Werdnig-Hoffman disease named after the two physicians who first described the condition in the 1890's. In SMA type 1, onset of symptoms is noted between birth and 6 months of age and 95% of patients have symptoms by the age of 3 months. It occurs in approximately 1 in 10,000 live births<sup>1,2</sup>.

Infants with SMA type 1 present with severe, progressive muscle weakness (proximal > distal) and hypotonia. Approximately 60% of infants with SMA type 1 are floppy babies at birth. Bulbar dysfunction results in poor suckle, impaired swallow and difficulty coughing and clearing secretions. Other signs include a bell-shaped chest and paradoxical breathing. All lead to respiratory failure and short life expectancy with 95% of affected individuals dying due to complications by the age of 18 months. Infants with SMA often have above average IQs and are usually highly alert, aware and intelligent.

For SMA type 1 the treatment is largely based around supportive care, with a focus on airway management (assistance in secretion clearance, coughing and breathing), nutrition (feeding tubes or gastrostomy) and musculoskeletal complications (kyphosis, scoliosis). For most with SMA type 1 mechanical respiratory support is required early. This is usually in the form of non-invasive ventilation initially with many going on to require a tracheostomy and full-time ventilatory support.

The ethical issues arising from this case are, as in many dilemmas, extremely emotive. The two courses of action undertaken by the parents in the above cases highlight how contrasting the nature of the best interests of a child might be considered. Both children are in near identical clinical conditions yet the outcome for each varies greatly. But can one outcome be considered better or worse than the other? Might one course of action be deemed to be more ethical than the other? Can one course of action be deemed morally right and the other wrong, or to be more exact “more right” or “more wrong”?

The parents of the first child after careful consideration decided that treatment for their child was futile and that they wanted to reduce their child’s suffering by letting him die and not have a future life of suffering, being “trapped inside his body” and enduring invasive intervention. From this point of view, it could be argued that full time, non-invasive ventilation involving a mask followed by a tracheostomy, frequent suction, cough assist intervention and the associated hospitalisations with respiratory decompensation is too much for a child to bear. In addition, there would also be the potential of scoliosis, pain, frequent physiotherapy, gastrostomy feeding and the potential of having no speech and the inability to communicate. With this in mind, it is understandable that palliation and no active intervention in order to prolong life might be seen as an ethical course of action. Indeed, is it ethically or morally right to permit a child with such difficulty to live with such suffering, in order that they might survive a few more years than expected? As the ability to prolong survival improves with modern medicine and new technology, the benefit of improving the duration of life must be weighed against the quality of the extra years afforded, the prevention of further suffering (non-maleficence) and the cost (justice). The cost of lifetime ventilation, intensive care unit clinical care, surgical intervention and more recently drug treatment is not insignificant. Thus, the question arises over what constitutes fair allocation of resource. It might be argued that it is more humane, and in the child’s best interest, from a beneficence (not prolonging suffering), non-maleficence (actively preventing years of suffering) and justice point of view to permit and facilitate the course of action of the first parents<sup>2</sup>.

However, as has been discussed in the third chapter of this book, how can one determine the quality of life of another? For children who cannot communicate their subjective quality of life, parents and health professionals undoubtedly bring in their own subjective feelings when trying to determine this. Furthermore, it is difficult to accurately predict future quality of life. It may be that these children have a subjectively good quality of life although they may not be able to communicate this.

The second child's parents decided that everything possible should be done for their son for survival and comfort. From their point of view, they feel that keeping their son alive at all costs is better than permitting him to die. They might argue that long-term ventilation is not futile if it permits their son to survive, that if it is managed well is not a form of suffering, and that the cost of doing so is worth it<sup>3</sup>. They also might feel that suction, while uncomfortable and potentially frequent is only short lived and bearable, frequent chest infections are treatable, and cough assist technology and RSV prophylaxis while expensive are worth it.

Nusinersin is a new treatment developed in 2016 for patients with SMA. It works by modulating the function of the SMN2 gene allowing it to produce more SMN protein (allowing it to function similarly to the SMN1 gene). It is delivered by intrathecal injection and requires loading doses followed by regular intrathecal injections usually 4 months apart. It was developed with considerable investment and given the relatively small number of patients with SMA is one of the most expensive drug treatments. In the UK it costs approximately £450,000 in the first year and £225,000 per year per patient thereafter. Currently on draft guidelines<sup>4</sup> NICE (National Institute for Health and Care Excellence) does not recommend the use of Nusinersin for treating 5q SMA on the basis that the cost is too high for it to be considered a cost-effective use of NHS resource. Early trials have shown that Nusinersin for SMA type 1 patients improves survival and motor function.

Undoubtedly the development of Nusinersin has provided hope and promise for many children and families affected by SMA. For those with less severe types improvement in symptoms may be significant, transformative and life changing with the acquisition of new function. For those most severely affected, the improvements may be more subtle, and when coming from a lower baseline may not result in benefit as significant as seen in those less severely affected. Given this, Nusinersin adds a new dimension to the ethics of treating those with SMA type 1.

It could be argued that any improvement, however small, for a severe and life-limiting condition such as SMA type 1 should be welcomed unreservedly. From a deontological point of view, it could be argued that it is society's duty to provide such a treatment for such a patient. However, in a finite resource universal healthcare system (such as the NHS) the overall benefit of providing such a treatment to a small number of individuals must be balanced against the effectiveness of the treatment, and its cost to society. From a utilitarian stance it could be argued that the same amount of money could be used on treatments with greater effectiveness for a greater number and thus would confer a greater benefit to society as a whole. In such a

universal healthcare system a finite resource is shared and distributed across all areas of care. For a healthcare professional looking after a patient who requires an expensive specialist treatment the justice element of ethical decision making at the point of care does not often carry much weight. It is difficult to deny a treatment of benefit to a suffering patient. However as a result of such an expensive treatment being provided undoubtedly there will be many faceless others who will be affected due to a loss of funding in another area from which resource has been diverted. Is it even possible to measure the effect this might have on treatment waiting lists, staff numbers etc and this potential morbidity to other patients? With such high costs should it mean that all expensive treatments should be denied? How might new treatments be otherwise developed? It might be argued that western societies can be considered rich and if they don't use and encourage pharmaceutical companies to further develop unique and novel treatments for SMA then this disease will always remain a fatal condition.

The inability to obtain certain treatments on the NHS has led to many patients or families pursuing such treatments via alternative means. Personal fund raising, crowd fundraising, appealing to higher levels of government and obtaining treatment in countries outside the UK have afforded patients the ability to obtain therapies not routinely available (both legally and illegally) opening further ethical discussions.

**CASE 14****Resource and Distributive Justice (2)**

*Following IVF treatment a 29 year old mother is pregnant with sextuplets. She previously gave birth to a set of twins at 27 weeks gestation (also conceived via IVF treatment) who tragically died following severe respiratory distress syndrome (RDS). In an attempt to reduce the high risk of extreme multiple preterm delivery (which carries significant risk of death or disability) she is offered selective reduction of 4 fetuses, in the hope that 2 will survive closer to term. The parents object on the grounds of their deeply held religious conviction. 6 live infants are born at 27 weeks gestation, with an average weight of 500g. Each requires artificial ventilation. The regional neonatal intensive care unit (NICU) has 12 intensive care cots in total and already runs at 90-100% occupancy. The case attracts significant publicity and the babies are admitted to the NICU, which must draft in extra staff to be able to manage the extra cot occupancy. The unit is declared 'full' with the likelihood that it will be shut to future admissions for the next 3 months. The consultant neonatologist predicts that up to 25 babies who would otherwise have been admitted there during this period, will require transfer to units in other regions. He is concerned that the choice these parents were permitted to make risked the lives of all 6 of the newborn sextuplets and has resulted in potential considerable harm to the future infants of many other families who will require the input of the specialist neonatology team.*

Consider this case from the point of view of both the parents and the consultant neonatologist. Try to uncover all the ethical dilemmas that arise within this case and think about your own thoughts on each.

**NOTES**

The reader will note that there are several ethical issues within this case. Firstly, there are the ethical issues surrounding IVF as a procedure (see example case "Saviour Sibling" for further discussion). Secondly, there is the process of selective reduction and the ethical dilemma it presents. Selective reduction or multifetal reduction is the practice of reducing the number of fetuses in a multiple pregnancy. It is usually carried out before



12 weeks gestation by injection of potassium chloride to stop the foetal heart or by radiofrequency ablation to stop the blood flow to a fetus via the umbilical cord. It is carried out to reduce the risk of complications associated with higher order pregnancies (>3 fetuses) such as miscarriage or still birth, premature delivery and associated complications, and gestational effects such as pre-eclampsia, gestational diabetes and placental abruption. For some it is regarded as completely unethical to terminate a fetus at any gestation (see discussion in the example case “Saviour Sibling”) like the parents in this case. For others the termination of several of the fetuses is doing more good to a greater number as the risk to the mother is reduced, the potential of morbidity and mortality for a fewer number of fetuses is also reduced, and the resource required to care for a greater number of preterm infants is large.

The third issue expands this a little further; it is the issue of justice and fair distribution of resource. Some might pose the question whether following IVF, someone should be permitted to allow a high order pregnancy (more than 3 fetuses) to proceed to delivery. There is significant resource required to provide care to the mother and her infants who have a much greater chance of having multiple complications especially secondary to the highly likely preterm birth. It might be argued that by undertaking selective termination fewer resources (including cost) would be required to look after fewer (and potentially less unwell) infants, and that resource could be used to provide care for other infants (the consultant neonatologist’s opinion). This aspect of consideration is particularly relevant in the UK where there is a publicly funded universal healthcare system.

The ethical issue of justice is a difficult area to consider in individual cases because while it involves the rights of a person, it also considers the position of the individual within a society. An individual’s autonomy may be at conflict with the principle of justice. Should the mother’s autonomy in this case be respected knowing that not undergoing selective reduction (following an intervention that resulted in six viable fetuses) may result in treatment becoming unavailable for others? If justice is to be upheld, in theory then no individual should benefit at the expense of another i.e. everyone should have the right of equal access to healthcare. But how does this occur in real life? In a resource rich country such as the UK the belief that saving a life no matter what the cost may be an easier maxim to follow than in a developing country where cost is often the limiting factor. It could be argued in the case above that the high-cost and resource-intensive healthcare provided for the sextuplets could be distributed more fairly (justly) by providing lower cost treatment to a greater number of individuals and therefore provide a greater benefit overall. However, treating a greater

number of individuals does not necessarily constitute a greater overall benefit (it is quantifying benefit purely in terms of numbers). Indeed, how might benefit be quantified?

One attempt at doing this is the use of Quality of Life Adjusted Years (QALYs) to quantify the net benefit of a health intervention to allow comparison between different interventions. Interventions are measured according what they achieve in terms of the number years of extra life and increase in the quality of life. Values are assigned for both and along with the cost of intervention, cost per QALY calculations are provided for interventions so that they might be directly compared. However, this method only considers cost and does not consider an individual's need for treatment or societal expectations and values on the measure of entitlement<sup>1,2</sup>. While it is a broad tool for use in the commissioning of healthcare, it does not consider the individual case.

**CASE 15****PGD and Embryo Selection**

*A couple who are deaf, and in their early 40s, wish to have a child by in vitro fertilisation (IVF). They already have one child, also born by IVF, who is deaf. Due to the underlying genetic aetiology of their hearing impairment there is a 50% chance that any of the couple's future children will be deaf. The couple wish to have their embryos genetically screened, via pre-implantation genetic diagnosis (PGD), to ensure that their next child will also be deaf. This case is based on the experience of UK couple, Tomato Lichy and Paula Garfield, in 2007.<sup>1</sup>*

Consider the case above and seek to address the following questions. Should this couple be allowed to access PGD to ensure that their future child is deaf? What constitutes a disability, and who gets to decide this? How much control should the State have over individuals' reproductive choices?

**NOTES**

The couple and their existing child have profound sensorineural hearing loss. They have a 50% chance of having a child who will also be deaf, due to an underlying genetic variant. You would not expect this genetic variant to directly impact upon the child's health in any other way.

PGD is an established reproductive technology, typically used to select embryos who have not inherited a known pathogenic genetic variant (i.e. a "healthy" embryo). PGD is commonly used for conditions such as cystic fibrosis, Duchenne muscular dystrophy and Huntington's disease. Embryos are only screened for the known familial variant, they are not routinely screened for pathogenic variants in other genes.

The list of genetic conditions which are approved for PGD is curated by the Human Fertilisation and Embryology Authority<sup>2</sup>. Genetic causes of deafness are included on this list; therefore, it is possible for individuals with a known genetic variant that causes deafness to have PGD in order to select embryos who would not be deaf (i.e. only those embryos who had *not* inherited the genetic variant would be implanted). The embryos known to have inherited the genetic variant are discarded. Furthermore, within the UK, it is possible to terminate a pregnancy, on the grounds of genetic deafness<sup>3</sup>.

Assisted conception therapies do not always result in a live birth. The chances of a woman in her 40s having a child born after one cycle of IVF is less than 5% with PGD<sup>4</sup>.

Due to the maternal age, and already having one child via IVF in the past, the couple would have to pay privately for their fertility treatment and PGD. In this case the couple are happy to do this in order to ensure that they have an “affected” child.

Clause 14 of the 2008 Human Fertilisation and Embryology (HFE) Bill states that, in assisted reproduction, “embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that a person with the abnormality will have or develop, a serious physical or mental disability, a serious illness, or any other serious medical condition, must not be preferred to those that are not known to have such an abnormality”.<sup>5</sup> Therefore, if the couple chose to have their embryos screened, they would be obliged to implant only those that had not inherited the genetic variant for deafness and discard the “deaf embryos”. Alternately, they could proceed with IVF, without screening the embryos and have a 50% of any resultant child being deaf.

While PGD is typically used to select *against* genetic disease in embryos, it has also been used to select *for* certain traits. Schedule 2, 1ZA of the HFE Act 2008 states that “embryos can be selected to ensure that they are a compatible match for an existing child in order that that they could donate tissue to treat a serious medical condition”.<sup>6</sup> So called “saviour siblings” are explored in the example case.

There are no laws which prevent couples who have a genetic condition, or who are carriers for a genetic disease, from having offspring independently. Such laws would be a gross impingement on civil liberties. In 2002, it was reported that a deaf couple in the United States actively sought a deaf sperm donor in order to ensure that their second child would also be deaf<sup>7</sup>. The couple in this case do not view deafness as a disability. On the contrary, they see it as a key part of their culture and identity. They assert that a hearing child could not fully integrate into their family and community; they would feel isolated, “left-out” and “different”. The couple also believe that favouring “hearing embryos” places a value judgement on the life of a deaf person. They contest the notion that individuals with hearing impairment have a reduced quality of life. The couple argue that the current laws and regulations suggest that a deaf life is not worth living.

Despite the couple’s assertions, many people do consider deafness to be a disability. In response to the case of Tomato Lichy and Paula Garfield the Chief Executive of The Royal National Institute for Deaf People stated, “Deafness is a disability and we have spent a long time campaigning to

improve the lives of people who live with it. But it is certainly not a slight to the deaf to say it is better to bring a child who will face the least difficulty into the world, when there is a choice to be made”.<sup>8</sup> Some individuals may also feel that deafness is a disability which places certain pressures on society, e.g. potentially higher costs of education, healthcare and social welfare.

Should the potential child be considered in any way? Some argue that the future child could feel that deafness was inflicted upon them by their parents and that they have been deprived of one of their senses. Others would contest that if an embryo is selected for deafness, then the child’s existence and hearing impairment are inter-dependent. That is to say, if a “hearing embryo” had been selected then a different child would exist in their place.

PGD providers may support or object to the couple’s request on ethical grounds, but they will also be aware that the live birth rate from IVF is generally higher than that from PGD<sup>4</sup>. Therefore, PGD providers may advise that if the couple wish to have another child they would have a greater chance of success with standard IVF (i.e. do not genetically testing the embryos). However, the couple may contest that they only wish to extend their family with a deaf child, as opposed to a hearing one, and that they are willing to accept the lower success rate.

There may also be concerns that allowing one couple to select for a “deaf embryo” would provide precedent for other couples to do the same, for deafness, or perhaps other conditions. Decisions would have to be made about which conditions are acceptable to select for, and which are not. Some would also argue that selecting *for* a particular genetic trait sets the precedent for other forms of genetic selection (e.g. height, intelligence, gender). As mentioned above, “saviour siblings” may already be considered precedent in selecting *for* genetic traits.

The GMC’s “Duties of a Doctor” state that clinicians must “protect and promote the health of patients and the public”. The duties also require doctors to “respect the patients’ right to reach decisions with you about their treatment and care” and “treat patients fairly and with respect whatever their life choices and beliefs”. Furthermore, they must not “unfairly discriminate against patients...by allowing personal views to affect your professional relationships or the treatment you provide or arrange”.<sup>9</sup>

This considered, how much freedom should individuals have over their reproductive choices? Does this extend to accessing reproductive technologies to choose an embryo with a specific genetic trait? Does that freedom depend on who is funding the reproductive technology or “societal costs” associated with the potential child? Furthermore, should the State be

allowed to interfere in the reproductive choices of its citizens? What are the limits of this interference?

Have the parents removed autonomy from the potential child by choosing a “deaf embryo”? Is there a limit to the medical decisions that parents can make for their children, and if so, where is the “the line”?

Is a patient’s desire to have a child with a particular genetic trait, associated with disease or otherwise, a reasonable use of resources? Does this depend on who is funding the procedure? Is selecting *against* a genetic disease different from selecting *for* a genetic trait? Do the principles of fair access and non-discrimination extend to a parent’s right to choose a “deaf embryo”? Does an obligation to choose a “hearing embryo” or a “deaf embryo” imply that the life of a deaf individual is of less value or not worth living? Is choosing a “deaf embryo” the same as “making a child deaf”?

Who decides what constitutes a disability? Does this definition depend on the context of the potential child (e.g. family make-up, culture, socioeconomic status, societal provision of “disability”)? Does granting access to PGD to select a “deaf embryo” provide precedent to select for other genetic health conditions (e.g. blindness), and if so, who decides which conditions are acceptable? Does it set precedent to select for other genetic traits such as height, IQ and gender?

The couple claim that a deaf child would better integrate into their existing family and community, and thus have a better quality of life than a hearing child, in the same context. Who is the best judge of the determinants of a potential child’s happiness and quality of life?



# BIBLIOGRAPHY

## Introduction

1. <https://en.oxforddictionaries.com/definition/ethics> [accessed 1st March 2017]
2. <https://patient.info/doctor/Medical-Ethics> [accessed 1st March 2017]
3. Universal Declaration on Bioethics and Human Rights 2005, [http://portal.unesco.org/en/ev.php-URL\\_ID=31058&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html) [accessed 9th March 2017]
4. UNESCO Bioethics Core Curriculum, Section 1: Syllabus Ethics Education Programme, <http://unesdoc.unesco.org/images/0016/001636/163613e.pdf> [accessed 8th March 2017]
5. <https://www.bma.org.uk/advice/employment/ethics/children-and-young-people> [accessed 1st March 2017]
6. Resnik, Jack, "The Baby Doe Rules (1984)". *Embryo Project Encyclopedia* (2011-05-12). ISSN: 1940-5030 <http://embryo.asu.edu/handle/10776/2103> [accessed 1st March 2017]
7. White M, The End at the Beginning, *Ochsner J.* 2011 Winter; 11(4): 309–316.
8. GMC 0-18 years guidance: Assessing best interests, [http://www.gmc-uk.org/guidance/ethical\\_guidance/children\\_guidance\\_12\\_13\\_assessing\\_best\\_interest.asp](http://www.gmc-uk.org/guidance/ethical_guidance/children_guidance_12_13_assessing_best_interest.asp) [accessed 1st March 2017]
9. G M Stirrat, C Johnston, R Gillon, K Boyd on behalf of the Medical Education Working Group of the Institute of Medical Ethics and associated signatories, Medical ethics and law for doctors of tomorrow: the 1998 Consensus Statement updated, *J Med Ethics* 2010;36:55–60. doi:10.1136/jme.2009.034660
10. Lakhani SE et al, Time for a unified approach to medical ethics, *Philos Ethics Humanit Med.* 2009 Sep 8;4:13. doi: 10.1186/1747-5341-4-13.



## Chapter 1: The Nature of Ethics

1. <https://www.oxfordbibliographies.com/view/document/obo-9780195396577/obo-9780195396577-0082.xml> [accessed 17th April 2018]
2. <http://ministryofethics.co.uk/?p=4> [accessed 17th April 2018]
3. <http://www.iep.utm.edu/ethics/#H2> [accessed 21st April 2018]
4. [http://www.philosophybasics.com/branch\\_virtue\\_ethics.html](http://www.philosophybasics.com/branch_virtue_ethics.html) [accessed 10th March 2017]
5. <https://ethicsofcare.org/care-ethics/> [accessed 21st April 2018]
6. Serra JP, What Is and What Should Pragmatic Ethics Be? *European Journal of Pragmatism and American Philosophy*, II-2; 2010, <https://doi.org/10.4000/ejapap.905> [accessed 21st April 2018]
7. <https://plato.stanford.edu/entries/consequentialism/> [accessed 17th April 2018]
8. <https://www.iep.utm.edu/util-a-r/> [accessed 17th April 2018]
9. <https://plato.stanford.edu/entries/ethics-deontological/> [accessed 17th April 2018]
10. <https://www.iep.utm.edu/kantmeta/> [accessed 17th April 2018]
11. Gardiner P, A virtue ethics approach to moral dilemmas in medicine, *J Med Ethics* 2003;29:297–302
12. de Zulueta, PC, Suffering, compassion and ‘doing good medical ethics’, *J Med Ethics* 2015;41:87–90. doi:10.1136/medethics-2014-102355
13. Killing, Letting Die, and The Trolley Problem, Judith Jarvis Thompson, *The Monist*, Vol 59; 2, 1 April 1976, pg 204-217
14. The Problem of Abortion and the Doctrine of the Double Effect, Philippa Foot, *Oxford Review*, no.5, 1967

## Chapter 2: Medical Ethics and Children

1. <http://medical-dictionary.thefreedictionary.com/medical+ethics> [accessed 21 May 2017]
2. <https://patient.info/doctor/Medical-Ethics> [accessed 21 May 2017]
3. Beauchamp TL and Childress JF, *Principles of Biomedical Ethics 5<sup>th</sup> Edition*, Oxford University Press 2001
4. Gillon R, Medical ethics: four principles plus attention to scope, *BMJ*. 1994 Jul 16;309(6948):184-8.
5. Baines P, Medical ethics for children: applying the four principles to paediatrics, *J Med Ethics* 2008;34:141–145. doi:10.1136/jme.2006.018747
6. Varelius J, The value of autonomy in medical ethics, *Medicine, Health Care and Philosophy* (2006) 9:377–388, DOI 10.1007/s11019-006-9000-z
7. <http://www.independent.co.uk/life-style/health-and-families/health-news/girl-13-wins-right-to-refuse-heart-transplant-1009569.html>; [accessed 22 May 2017]
8. <https://www.nspcc.org.uk/preventing-abuse/child-protection-system/legal-definition-child-rights-law/gillick-competency-fraser-guidelines>; [accessed 22 May 2017]
9. Sheunemann LP and White DB, The Ethics and Reality of Rationing in Medicine, *Chest*. 2011 Dec; 140(6): 1625–1632.
10. [https://downloads.unicef.org/wp-content/uploads/2010/05/UNCRC\\_summary\\_1.pdf?\\_ga=2.112833408.561395167.1501494895-62137321.1501494895](https://downloads.unicef.org/wp-content/uploads/2010/05/UNCRC_summary_1.pdf?_ga=2.112833408.561395167.1501494895-62137321.1501494895)
11. Rhodes R and Holzman IR, Is the Best Interest Standard Good for Pediatrics? *Pediatrics* 2014;134;S121 DOI: 10.1542/peds.2014-1394H
12. Wilkinson D, Is it in the best interests of an intellectually disabled infant to die? *J Med Ethics*. 2006 Aug;32(8):454-9
13. Chervenak FA and McCullough LB, Ethical dimensions of the fetus as a patient, *Best Practice & Research Clinical Obstetrics and Gynaecology* (2017), <http://dx.doi.org/10.1016/j.bpobgyn.2016.12.007>
14. Gilmour J et al, Childhood Immunization: When Physicians and Parents Disagree, *Pediatrics* Nov 2011, VOLUME 128 / ISSUE Supplement 4

15. Bradley P, Should childhood immunisation be compulsory? *J Med Ethics*. 1999 Aug;25(4):330-4
16. Zahedi F, The challenge of truth telling across cultures: a case study, *J Med Ethics Hist Med*. 2011; 4: 11.
17. Good Medical Practice, General Medical Council UK (GMC 2013), [http://www.gmc-uk.org/guidance/good\\_medical\\_practice.asp](http://www.gmc-uk.org/guidance/good_medical_practice.asp)

### Chapter 3: Who Should Make Decisions for Children?

1. [http://www.gmc-uk.org/guidance/ethical\\_guidance/children\\_guidance\\_30\\_33\\_refuse\\_treatment.asp](http://www.gmc-uk.org/guidance/ethical_guidance/children_guidance_30_33_refuse_treatment.asp) [accessed 16th March 2017]
2. Larcher V and Hutchinson A, How should paediatricians assess Gillick competence? *Arch Dis Child* 2010;**95**:307–311. doi:10.1136/adc.2008.148676
3. <https://www.gov.uk/parental-rights-responsibilities/who-has-parental-responsibility> [accessed 16th March 2017]
4. Ross LF and Swota AH, The Best Interest Standard: Same Name but Different Roles in Pediatric Bioethics and Child Rights Frameworks, *Perspectives in Biology and Medicine*, Vol 60: 2; 186-197
5. <http://www.nhs.uk/Conditions/Consent-to-treatment/Pages/Children-under-16.aspx> [accessed 16th March 2017]
6. Rhodes R and Holzman IR, Is the Best Interest Standard Good for Pediatrics? *Pediatrics* 2014;134;S121 DOI: 10.1542/peds.2014-1394H
7. R Smith et al, Shared ethical principles for everybody in health care: a working draft from the Tavistock group, *BMJ* 1999 318 (7178), 248-251
8. Universal Declaration on Bioethics and Human Rights 2005, [http://portal.unesco.org/en/ev.php-URL\\_ID=31058&URL\\_DO=DO\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html) [accessed 9th March 2017]
9. Lyon, Jeff, *Playing God in the Nursery*, New York, W.W. Norton and Company, 1985

## Chapter 4: An Approach to Ethics Cases and Dilemmas

1. McLean SAM, What and who are clinical ethics committees for?, *J Med Ethics*. 2007 Sep; 33(9): 497–500.
2. Manson, H.M. (2012). The development of the CoRE-values framework as an aid to ethical decision-making. *Medical Teacher* 2012, 34(4), e258-e268.
3. Schumann JH, Alfandre D. Clinical ethical decision making: the four topics approach. *Semin Med Pract* 2008;11:36–42.
4. Daboval T and Shidler S, Ethical framework for shared decision making in the neonatal intensive care unit: Communicative ethics, *Paediatr Child Health*. 2014 Jun;19(6):302-4.
5. Larcher V, et al. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice, *Arch Dis Child* 2015;100(Suppl 2):s1–s26. doi:10.1136/archdischild-2014-306666
6. [http://www.ukcen.net/ethical\\_issues/ethical\\_frameworks](http://www.ukcen.net/ethical_issues/ethical_frameworks) [accessed 10<sup>th</sup> April 2018]

## Chapter 5: The Cases

### Example Case: Saviour Sibling

1. de Wert G et al, The future (r)evolution of preimplantation genetic diagnosis/human leukocyte antigen testing: ethical reflections, *Stem Cells*. 2007 Sep;25(9):2167-72. Epub 2007 May 24
2. Morgan ER et al, Having a Child to Save a Sibling: Reassessing Risks and Benefits of Creating Stem Cell Donors, *Pediatr Blood Cancer* 2007;48:249–253
3. <https://embryo-ethics.smd.qmul.ac.uk/tutorials/embryo-and-the-law/saviour-siblings/> [accessed 17th March 2017]
4. [http://www.gmc-uk.org/guidance/ethical\\_guidance/21177.asp](http://www.gmc-uk.org/guidance/ethical_guidance/21177.asp) [accessed 17th March 2017]
5. Singer P, *Practical Ethics*, Cambridge University Press; 2 edition (29 Jan. 1993)
6. Kamani N et al, Ethical Considerations in Pediatric BMT Donors and Recipients, *Biol Blood Marrow Transplant* 17:S132-S136, 2011
7. Spriggs M, Is conceiving a child to benefit another against the interests of the new child? *J Med Ethics* 2005;31:341–342, doi: 10.1136/jme.2003.006130
8. Samuel GN et al, Establishing the role of pre-implantation genetic diagnosis with human leucocyte antigen typing: what place do “saviour siblings” have in paediatric transplantation? *Arch Dis Child* 2009;94:317–320. doi:10.1136/adc.2008.138529
9. Pennings G et al, Ethical considerations on preimplantation genetic diagnosis for HLA typing to match a future child as a donor of haematopoietic stem cells to a sibling, *Hum Reprod*. 2002 Mar;17(3):534-8.

### Case 1: Futile Treatment?

1. Yates AR et al, Pediatric sub-specialist controversies in the treatment of congenital heart disease in trisomy 13 or 18, *J Genet Couns*. 2011 Oct;20(5):495-509. doi: 10.1007/s10897-011-9373-x. Epub 2011 May 18.
2. Maeda J et al, The impact of cardiac surgery in patients with trisomy 18 and trisomy 13 in Japan, *Am J Med Genet A*. 2011 Nov;155A(11):2641-6. doi: 10.1002/ajmg.a.34285. Epub 2011 Oct 11.

3. Kaneko Y et al, Intensive cardiac management in patients with trisomy 13 or trisomy 18, *Am J Med Genet A*. 2008 Jun 1;146A(11):1372-80. doi: 10.1002/ajmg.a.32311.
4. Peterson JK et al, Long-Term Outcomes of Children with Trisomy 13 and 18 After Congenital Heart Disease Interventions, *Ann Thorac Surg*. 2017 Jun;103(6):1941-1949. doi: 10.1016/j.athoracsur.2017.02.068. Epub 2017 Apr 26
5. Kosiv KA et al, Congenital Heart Surgery on In-Hospital Mortality in Trisomy 13 and 18, *Pediatrics*. 2017 Nov;140(5). pii: e20170772. doi: 10.1542/peds.2017-0772. Epub 2017 Oct 18
6. Jenkins KJ and Roberts AE, Trisomy 13 and 18: Cardiac Surgery Makes Sense if It Is Part of a Comprehensive Care Strategy, *Pediatrics* 2017 Nov;140(5) e20172809; DOI: 10.1542/peds.2017-2809
7. Larcher V, et al. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice, *Arch Dis Child* 2015;100(Suppl 2):s1–s26. doi:10.1136/archdischild-2014-306666

## Case 2: Withdrawal/Withholding of Treatment (1)

1. Larcher V, et al. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice, *Arch Dis Child* 2015;100(Suppl 2):s1–s26. doi:10.1136/archdischild-2014-306666
2. Vince T, Should children's autonomy be respected by telling them of their imminent death? *J Medical Ethics* 2006;32:21-23.
3. Wellesley H and Jenkins IA, Withholding and Withdrawing Life Sustaining Treatment in Children, *Paediatr Anaesth*. 2009 Oct;19(10):972-8. doi: 10.1111/j.1460-9592.2009.03027.x
4. Devictor D et al, Forgoing life-sustaining or death-prolonging therapy in the pediatric ICU, *Pediatr Clin North Am*. 2008 Jun;55(3):791-804, xiii. doi: 10.1016/j.pcl.2008.02.008
5. Basu RK, End of Life Care in Pediatrics, Ethics, Controversies, and Optimizing the Quality of Death, *Pediatr Clin N Am* 60 (2013) 725–739 <http://dx.doi.org/10.1016/j.pcl.2013.02.009>
6. Janvier A et al, Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology, *Semin Perinatol*. 2014 Feb;38(1):38-46. doi: 10.1053/j.semperi.2013.07.007.

7. <https://stanford.library.sydney.edu.au/entries/double-effect/> [accessed 14th September 2018]

### Case 3: Withdrawal/Withholding of Treatment (2)

1. Sanderson A et al, Clinician Perspectives Regarding the Do-Not-Resuscitate Order, *JAMA Pediatr.* 2013;167(10):954-958. doi:10.1001/jamapediatrics.2013.2204
2. Basu RK, End-of-Life Care in Pediatrics: Ethics, Controversies, and Optimizing the Quality of Death, *Pediatr Clin N Am* 60 (2013) 725–739
3. Larcher V, et al. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice, *Arch Dis Child* 2015;100(Suppl 2):s1–s26. doi:10.1136/archdischild-2014-306666
4. Johnson SK et al, An empirical study of surrogates' preferred level of control over value-laden life support decisions in intensive care units, *Am J Respir Crit Care Med.* 2011 Apr 1;183(7):915-21. doi: 10.1164/rccm.201008-1214OC. Epub 2010 Oct 29
5. White DB et al, Are physicians' recommendations to limit life support beneficial or burdensome? Bringing empirical data to the debate, *Am J Respir Crit Care Med.* 2009 Aug 15;180(4):320-5. doi: 10.1164/rccm.200811-1776OC. Epub 2009 Jun 4

### Case 4: Maternal and Fetal Rights

#### Part A

1. Diekema DS and the committee on Bioethics, American Academy of Pediatrics, Responding to Parental Refusals of Immunization of Children, *Pediatrics.* 2005 May;115(5):1428-31.
2. Lee C et al, Effect of hepatitis B immunisation in newborn infants of mothers positive for hepatitis B surface antigen: systematic review and meta-analysis, *BMJ.* 2006 Feb 11;332(7537):328-36. Epub 2006 Jan 27
3. Isaacs D et al, Ethical issues in preventing mother-to-child transmission of hepatitis B by immunisation, *Vaccine.* 2011 Aug 26;29(37):6159-62. doi: 10.1016/j.vaccine.2011.06.065. Epub 2011 Jun 30
4. Dawson A, The determination of 'best interests' in relation to childhood vaccinations. *Bioethics* 2005;19:188–205.
5. Isaacs D, Children have rights, too. *J Paediatr Child Health* 2009;45:627–8.



6. Chen X et al, Breastfeeding is not a risk factor for mother-to-child transmission of hepatitis B virus, *PLoS One*. 2013;8(1):e55303. doi: 10.1371/journal.pone.0055303. Epub 2013 Jan 28.
7. Shi Z et al, Breastfeeding of newborns by mothers carrying hepatitis B virus: a meta-analysis and systematic review, *Arch Pediatr Adolesc Med*. 2011 Sep;165(9):837-46. doi: 10.1001/archpediatrics.2011.72. Epub 2011 May 2
8. John-Stewart G et al, Breastfeeding and Transmission of HIV-1, *J Acquir Immune Defic Syndr*. 2004 Feb 1; 35(2): 196–202.
10. International Perinatal HIV Group, The mode of delivery and the risk of vertical transmission of human immunodeficiency virus type 1--a meta-analysis of 15 prospective cohort studies. *N Engl J Med*. 1999;340(13):977–987.
11. <https://www.cdc.gov/breastfeeding/breastfeeding-special-circumstances/maternal-or-infant-illnesses/hiv.html> [accessed 5th June 2019]
12. [https://www.who.int/elena/titles/hiv\\_infant\\_feeding/en/](https://www.who.int/elena/titles/hiv_infant_feeding/en/) [accessed 5<sup>th</sup> June 2019]

## Part B

1. Townsend S, Ethics for the Pediatrician: Obstetric Conflict: When Fetal and Maternal Interests Are at Odds, *Pediatrics in Review* 2012;33;33 DOI: 10.1542/pir.33-1-33
2. Paintin D, Ethical Issues in Maternal – Fetal Medicine, *J R Soc Med*. 2002 Jul; 95(7): 371–372
3. Chervenak FA and McCullough LB, Ethical dimensions of the fetus as a patient, *Best Practice & Research Clinical Obstetrics and Gynaecology* (2017), <http://dx.doi.org/10.1016/j.bpobgyn.2016.12.007>
4. [http://www.gmc-uk.org/guidance/ethical\\_guidance/consent\\_guidance\\_common\\_law.asp](http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_common_law.asp) [accessed 28th March 2017]
5. Fasouliotis SJ and Schenker JG, Maternal-fetal conflict, *Eur J Obstet Gynecol Reprod Biol*. 2000 Mar;89(1):101-7
6. St George’s Healthcare NHS Trust v. S [1998], <https://embryo-ethics.smd.qmul.ac.uk/tutorials/embryo-and-the-law/english-law-foetus/> [accessed 19<sup>th</sup> April 2019]

## Case 5: Age of Consent

### Part A

1. <https://www.fpa.org.uk/factsheets/law-on-sex> [accessed 29th June 2018]
2. <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years/contraception-abortion-and-sexually-transmitted-infections-stis> [accessed 29th June 2018]
3. Larcher V and Hutchinson A, How should paediatricians assess Gillick competence? *Arch Dis Child*. 2010 Apr;95(4):307-11. doi: 10.1136/adc.2008.148676. Epub 2009 Nov 29.
4. Woolley SL, The limits of parental responsibility regarding medical treatment decisions, *Arch Dis Child*. 2011 Nov;96(11):1060-5. doi: 10.1136/adc.2010.198432. Epub 2011 Jan 10.
5. <https://www.fpa.org.uk/factsheets/under-16s-consent-and-confidentiality-sexual-health-services> [accessed 29th June 2018]
6. Wheeler R, Gillick or Fraser? A plea for consistency over competence in children, *BMJ* 2006; 332:807

### Part B

1. Carlisle J et al, Concerns over confidentiality may deter adolescents from consulting their doctors. A qualitative exploration. *J Medical Ethics* 2006;32:133-7
2. <https://www.fpa.org.uk/factsheets/law-on-sex> [accessed 29th June 2018]
3. <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years/contraception-abortion-and-sexually-transmitted-infections-stis> [accessed 29th June 2018]

## Case 6: Jehovah's Witness and Blood Transfusion

1. Rollins KE et al, Major abdominal surgery in Jehovah's Witnesses, *Ann R Coll Surg Engl*. 2016 Nov;98(8):532-537. Epub 2016 Jul 14
2. Lawson T and Ralph C, Perioperative Jehovah's Witnesses: a review, *Br J Anaesth*. 2015 Nov;115(5):676-87. doi: 10.1093/bja/aev161. Epub 2015 Jun 11

3. <https://www.jw.org/en/jehovahs-witnesses/faq/jehovahs-witnesses-why-no-blood-transfusions/> accessed 22<sup>nd</sup> Feb 2018
4. Bramstedt K, Transfusion contracts for Jehovah's Witnesses receiving organ transplants: ethical necessity or coercive pact? *J Med Ethics*. 2006 Apr; 32(4): 193–195.
5. Woolley S, Children of Jehovah's Witnesses and adolescent Jehovah's Witnesses: what are their rights? *Arch Dis Child* 2005;90:715–719. doi: 10.1136/adc.2004.067843
6. Panico ML et al, When a patient refuses life-saving care: issues raised when treating a Jehovah's Witness, *Am J Kidney Dis*. 2011 Oct;58(4):647-53. doi: 10.1053/j.ajkd.2011.05.030. Epub 2011 Sep 8

### Case 7: Compulsory Vaccination

1. <https://www.cdc.gov/vaccines/vac-gen/side-effects.htm#mmr> [accessed 31st March 2018]
2. <https://www.cdc.gov/measles/about/complications.html> [accessed 31st March 2018]
3. Diekema DS, Responding to Parental Refusals of Immunization of Children, *Pediatrics*. 2005 May;115(5):1428-31
4. Verweij M and Dawson A, Ethical Principles for Collective Immunisation Programmes, *Vaccine*. 2004 Aug 13;22(23-24):3122-6
5. Bradley P, Should childhood immunisation be compulsory?, *J Med Ethics*. 1999 Aug;25(4):330-4
6. Dawson A, The determination of 'best interests' in relation to childhood vaccinations, *Bioethics*. 2005 Apr;19(2):188-205

### Case 8: Truth Telling

1. <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice> [accessed 31st March 2017]
2. Robbennolt JK, Apologies and Medical Error, *Clin Orthop Relat Res* (2009) 467:376–382 DOI 10.1007/s11999-008-0580-1
3. <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/candour---openness-and-honesty-when-things-go-wrong> [accessed 31st March 2017]

4. Shahidi J, Not telling the truth: circumstances leading to concealment of diagnosis and prognosis from cancer patients. *Eur J Cancer Care (Engl)*. 2010 Sep;19(5):589-93. doi: 10.1111/j.1365-2354.2009.01100.x. Epub 2009 Dec 3

#### Case 9: Confidentiality

1. <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality> [accessed 11th June 2018]
2. <https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf> [accessed 11th June 2018]
3. Beltran-Aroca CN et al, Confidentiality breaches in clinical practice: what happens in hospitals, *BMC Med Ethics*. 2016; 17(1): 52
4. Vigod SN et al, Privacy of patient's information in hospital lifts: observational study, *BMJ* 2003; 327; 1024-1025

#### Case 10: Predictive Genetic Testing

1. <https://www.hgsa.org.au/documents/item/272> [accessed 18th February 2018]
2. Botkin JR et al, ASHG Position Statement, Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents, *The American Journal of Human Genetics* 97, 6–21, July 2, 2015
3. Borry P et al, Presymptomatic and predictive genetic testing in minors: a systematic review of guidelines and position papers, *Clin Genet* 2006; 70; 374-381
4. Fulda KG and Lykens K, Ethical issues in predictive genetic testing: a public health perspective *J Med Ethics* 2006;32:143–147. doi: 10.1136/jme.2004.010272
5. Malpas P, Why tell asymptomatic children of the risk of an adult-onset disease in the family but not test them for it? *J Med Ethics* 2006;32:639–642. doi: 10.1136/jme.2005.015370
6. Shkedi-Rafid S et al, Genetic testing of children for adult-onset conditions: opinions of the British adult population and implications for clinical practice, *Eur J Hum Genet*. 2015 Oct; 23(10): 1281–1285.
7. Marlais M et al, Hypertension in autosomal dominant polycystic kidney disease: a meta-analysis, *Arch Dis Child* 2016;101:1142-1147

8. Harris T, Is It Ethical to Test Apparently “Healthy” Children for Autosomal Dominant Polycystic Kidney Disease and Risk Medicalizing Thousands? *Front. Pediatr.*, 19 January 2018 <https://doi.org/10.3389/fped.2017.00291>

### Case 11: Research

1. Roth D, An ethics-based approach to global child health research, *Paediatr Child Health*. 2003 Feb; 8(2): 67–71
2. Adams L et al, Ethical Issues in Pediatric Global Health, *Pediatr Clin North Am*. 2016 Feb;63(1):195-208. doi: 10.1016/j.pcl.2015.09.002
3. Nuffield Council on Bioethics, The ethics of research related to healthcare in developing countries, <http://nuffieldbioethics.org/project/research-developing-countries> [accessed 6th April 2017]
4. Weigel R et al, Supporting children to adhere to anti-retroviral therapy in urban Malawi: multi method insights, *BMC Pediatrics* 2009, 9:45 doi:10.1186/1471-2431-9-45
5. Spriggs M and Caldwell PHY, The ethics of paediatric research, *J Paediatr Child Health*. 2011 Sep;47(9):664-7. doi: 10.1111/j.1440-1754.2011.02166.x

### Case 12: Circumcision on Religious Grounds

1. American Academy of Pediatrics, Task force on circumcision, Circumcision Policy Statement, *Pediatrics* 2012; 130: 585-6
2. Jacobs AJ, The Ethics of Circumcision of Male Infants, *Isr Med Assoc J*. 2013 Jan;15(1):60-5
3. Forbes D, Circumcision and the best interests of the child, *J Paediatr Child Health*. 2015 Mar;51(3):263-5. doi: 10.1111/jpc.12853

### Case 13: Resource and Distributive Justice (1)

1. Gregoretti C et al, Survival of Patients With Spinal Muscular Atrophy Type 1, *Pediatrics* 2013, 131;5: e1509
2. Ryan MM, The use of mechanical ventilation is appropriate in children with genetically proven spinal muscular atrophy type 1: the motion against, *Paediatric Respiratory Reviews* (2008) 9, 51-54
3. Bach JR, The use of mechanical ventilation is appropriate in children with genetically proven spinal muscular atrophy type 1: the motion for, *Paediatric Respiratory Reviews* (2008) 9, 45-50

4. <https://www.nice.org.uk/guidance/gid-ta10281/documents/appraisal-consultation-document> [accessed 20th March 2019]
5. Snyder J, Mathers A, Crooks VA, Fund my treatment! : A call for ethics-focused social science research into the use of crowdfunding for medical care, *Soc Sci Med.* 2016 Nov;169:27-30

#### Case 14: Resource and Distributive Justice (2)

1. [http://www.ukcen.net/ethical\\_issues/resource\\_allocation/ethical\\_considerations3](http://www.ukcen.net/ethical_issues/resource_allocation/ethical_considerations3) accessed 20th November 2018]
2. Rutstein SE et al, Hidden Costs: the ethics of cost-effectiveness analyses for health interventions in resource-limited settings, *Glob Public Health.* 2017 October; 12(10): 1269–1281.

#### Case 15: PGD and embryo selection

1. Hinsliff G. This couple want a deaf child. Should we try to stop them? *The Guardian* 2008.  
<https://www.theguardian.com/science/2008/mar/09/genetics.medicalresearch> [accessed 11th March 2019]
2. HFEA. Approved PGT and PTT conditions  
<https://www.hfea.gov.uk/treatments/embryo-testing-and-treatments-for-disease/approved-pgd-and-ptt-conditions/2019> [accessed September 2019]
3. Stern S, et al. Attitudes of deaf and hard of hearing subjects towards genetic testing and prenatal diagnosis of hearing loss. *Journal of Medical Genetics* 2002;39(6):449-53.
4. England N. Clinical Commissioning Policy: Pre-implantation Genetic Diagnosis (PGD). Leeds: NHS England 2014
5. Legislation.gov.uk. 2008 Human Fertilisation and Embryology (HFE) Bill, claus 14 <http://www.legislation.gov.uk/ukpga/2008/22/section/142008> [accessed 13th September 2019]
6. Legislation.gov.uk. HFE Act 2008, Schedule 2, 1ZA  
<http://www.legislation.gov.uk/ukpga/2008/22/schedule/22008> [accessed 13th September 2019]
7. Teather D. Lesbian couple have deaf baby by choice. *The Guardian* 2002.  
<https://www.theguardian.com/world/2002/apr/08/davidteather> [accessed 12th September 2019]

8. Murphy C. Is it wrong to select a deaf embryo? *BBC News* 2008.  
<http://news.bbc.co.uk/1/hi/health/7287508.stm> [accessed 12th September 2019]
9. McManus I, Gordon D, Winder B. Duties of a doctor: UK doctors and good medical practice. *BMJ Quality & Safety* 2000;9(1):14-22.