

Chapter

Decision making:
the ethical issues

2

Decision making: the ethical issues

Introduction

2.1 The purpose of this chapter is to outline a framework within which we can consider the principal ethical issues that are raised by critical care decisions for the fetus and the newborn baby. In Chapters 4–7 this framework is applied to examples of dilemmas in current practice. We begin by considering in what sense ethical analysis can help to clarify practical problems. We then examine four issues where an analysis of ethical concepts and arguments is critically important. These are the value of human life; the role of best interests; the deliberate ending of life and the withholding and withdrawing of treatment; and the weight that should be accorded to economic and social considerations.¹ It is important to stress that ethical issues raised by critical care decisions cannot be resolved by reference to just one of these issues. All are likely to play some role in the deliberations of the different parties involved in decision-making processes. We aim to identify and appraise a range of concepts and arguments that readers of this Report could use as they consider the issues that we address, or actively participate in the difficult processes of decision making that are a central focus of this Report.

The role of ethical analysis in considering practical problems

2.2 The critical discipline of ethics or moral philosophy investigates the underlying reasons or justifications for specific moral beliefs or moral codes. It does this by various means: it seeks clarity in the uses of important terms, such as ‘quality of life’; and it requires consistency in the practical application of moral claims or values. Ethics also requires coherence in the defence of any moral framework, that is, a demonstration of how it conforms to other beliefs held to be true. This requirement leads to the formulation of ethical theories, which aim to give a systematic explanation of how arguments about moral issues can be resolved, through appeals to some general criterion according to which moral claims can be assessed.

2.3 Ethics or moral philosophy may not appear to be immediately helpful to those seeking practical solutions to the kind of dilemmas which may arise in fetal and neonatal critical care. Philosophers, like others in society, disagree over which philosophical theories are most appropriate to apply to any given situation. There are a range of competing theories, the principal ones being consequentialism, most commonly known in the form of utilitarianism; deontology or duty-based theory; and virtue ethics or character-based theory. While within each of these theories there are many nuanced positions, broadly, consequentialists judge actions according to their outcomes taken as a whole, whether good or bad. This means that they would usually assess decisions and policies in critical care in the light of the predicted outcomes for the majority of babies. In contrast, a deontological approach would hold to fundamental duties or principles in medical care that must not be breached, whatever the consequences. A rights-based theory holds that individuals have interests which are sufficiently important to justify enforcing others to respect those interests in the performance of duties. It is therefore a form of deontological theory. Rights-theorists disagree on a number of matters, including the question of who should possess rights.² For the virtue ethicist, what matters most is the character of the parents and professionals who are making the decisions.

¹ Our use of the term ‘treatment’ in this Report does not include artificial nutrition and intravenous hydration; see Glossary for full definition.

² Some, for instance, would deny that young children and the newborn can be rights-holders. There is also disagreement as to the scope or comprehensiveness of rights that people may have. All could agree, for instance, that every adult has a right to life but not all will agree that everyone has a right to the best possible healthcare. Rights-based theorists may disagree as to when, if ever, it is morally permissible to override rights. Could, for instance, avoiding very great harms befalling a very large number of people be a good enough reason to override the rights of a single person?

Another approach, termed the ethics of care,³ also has relevance to critical care decisions. From this perspective, the focus should be on the special situation of pregnant women and mothers with an emphasis on the interconnectedness of needs, the role of emotions and social relationships.

- 2.4 Those who subscribe to different ethical theories may nevertheless arrive at the same basic moral judgements about the rightness or wrongness of certain actions. A consequentialist, a deontologist, advocates of a rights-based approach, virtue theory or the ethics of care could all agree that a particular action, such as a gratuitously cruel infliction of injury, was wrong, but would have reached this view for different reasons derived from their basic theoretical commitments. However, on some matters these different commitments will lead to the making of different and incompatible moral judgements.
- 2.5 A comprehensive discussion of the different theoretical approaches to morality is outside the scope of this Report. Nevertheless, it is important to be aware of them as we examine the primary areas of concern for ethics in fetal and neonatal medicine. For, underlying the strongly held disagreements between people about what should be done in practice are often very different views on morality. This holds true for the Working Party itself. Although we have been able to agree on a number of substantive conclusions and recommendations that are informed by ethical analysis, we were not always in agreement about the frameworks by which we reached our conclusions. In addition, it is important to acknowledge at the outset that there are some issues on which different members of the Working Party would, if asked as individuals, present different judgements. We cannot and should not expect complete unanimity on issues of such fundamental moral concern. Instead we must acknowledge that there is a plurality of moral beliefs and assumptions and that each has the function of providing tools for examining the moral permissibility of certain acts. At the same time, we should try to seek agreement on substantive matters wherever possible, even if we disagree about the reasons behind these shared conclusions.
- 2.6 Given these differences in moral outlook, is the critical analysis of moral philosophy or ethics of any practical use? We believe that it is for the following reasons:
- First, by carefully examining the concepts used within different ethical theories, ethical analysis can help to clarify their scope and validity. A better understanding of the strengths and weaknesses of those concepts can reduce ambiguities and confusion. It may also reveal that there is more agreement among people than they might think.
 - Secondly, by demanding consistency, ethical analysis can reveal ways in which people may be responding instinctively or with a 'gut reaction' to some situations, rather than examining them in terms of their general moral beliefs.
 - Thirdly, by insisting that reasons or justifications for our decisions are provided, ethical analysis can lead to a shift in our views, as we come to appreciate the basis on which those with different opinions make their judgements.

Thus moral philosophy can aid informed and measured dialogue between people about morality, an essential feature, we would claim, of the genuinely moral life and of decision-making processes in critical care (see paragraphs 2.44–2.57).

³ See Gilligan C (1982) *In a Different Voice: Psychological theory and women's development* (Cambridge, MA: Harvard University Press). It should be noted that there is disagreement on whether the ethics of care should be understood as an independent normative theory, as a type of normative theory, such as virtue ethics, or merely as a supplement or critical commentary to existing normative theories. For a selection of various understandings of the ethics of care see Held V (Editor) (1995) *Justice and Care: Essential readings in feminist ethics* (Boulder, CO: Westview Press).

2.7 We recognise that moral decision making is not simply a matter of detached rationality. However, the Working Party would not go as far as some proponents of an ethics of care approach who claim that drawing on emotions allows one to exercise specific superior capacities to solve moral problems.⁴ Nevertheless we recognise that emotions play an important part in our everyday moral decision making. Decisions frequently have to be made by parents and clinical staff with little time to consider the clinical options, and often in very stressful circumstances. In our view it is essential that any discussion of ethical issues, no matter how controversial, should seek to be dispassionate, impartial and have practical relevance to those making decisions. Equally, the discussion should acknowledge the great personal significance and the very difficult choices that sometimes must be made in critical care, and consequently, the strong feelings of all who are involved. We now turn to consider the first of four areas of particular significance, the value of human life.

The value of the life of a fetus or newborn baby

2.8 One important question that all those involved in critical care decision making need to address concerns the value of the life of a fetus or a newborn baby. Is it equal to that of an adult person with fully developed mental capacity? And if not, to what extent would this matter for critical care decisions? Two important distinctions are made in the discussion that follows. First we examine the view that all human life has absolute value and that everything possible must always be done to prolong life. We then examine arguments that support the view that humans have different value (or moral status) at different developmental stages.

'Sanctity of life' or 'quality of life'?

2.9 According to the doctrine of the 'sanctity of life',⁵ taking human life is categorically wrong, as all humans are of equal intrinsic value and should be treated with the same respect. There are different interpretations that can be distinguished within the doctrine. Some people think that 'sanctity of life' means that although life is of exceptional value, there may be cases in which it can be permissible not to strive to keep a person alive. Others believe the doctrine to be sufficient to underpin an absolute right to life, in both moral and legal terms. We term this the absolutist position. Human life may be said to be sacrosanct for different reasons. Whatever interpretation is put on 'sanctity of life', the position is often defended in religious terms, although it can be held without referring to religion. One influential line of argument refers to the view that man is made in the image of God,⁶ and only God may take life.⁷ The sanctity of life view can be contrasted with a 'quality of life' view that does not recognise an absolute right to life nor a duty to preserve it, but rather judges whether a life is worth preserving (or having in the first place) in terms of its quality.⁸

2.10 Both views face inherent difficulties. For those who would place great importance upon quality of life, and that includes many consequentialists, it is difficult to make decisions on this basis as the quality of life is "hard to define and even harder to measure".⁹ Judgements of

⁴ For further details, see Tong R (2003) *Feminist Ethics*, Stanford Encyclopedia of Philosophy, available at: <http://plato.stanford.edu/entries/feminism-ethics/>, accessed on: 11 Sept 2006.

⁵ See Finnis J (1980) *Natural Law and Natural Rights* (Oxford: Oxford University Press); Kuhse H (2001) A modern myth: That letting die is not the intentional causation of death, in *Bioethics: An anthology*, Kuhse H and Singer P (Editors) (Oxford: Blackwell).

⁶ Genesis 1: 26–27, 1 Corinthians 11: 7.

⁷ 1 Corinthians 3: 16–17; Job 1: 21. See also Wyatt J (1998) When is a person? Christian perspective on the beginning of life, in *Matters of Life and Death* (Leicester: Intervarsity Press).

⁸ See Glover J (1977) *Causing Death and Saving Lives* (Penguin); Kuhse H and Singer P (1985) Is all human life of equal worth?, in *Should the Baby Live? The Problem of Handicapped Infants* (Oxford: Oxford University Press), pp18–47.

⁹ Boddington P and Podpadek T (1999) Measuring quality of life in theory and in practice, in *Bioethics: An anthology*, Kuhse H and Singer P (Editors) (Oxford: Blackwell), pp 273–82.

what constitutes a life of sufficient quality are notoriously variable. Some people would view life with severe mental or physical impairments as not worth living. However, many severely disabled individuals report that they are content with their lives, which they do not regard as having less value than the lives of others (see paragraphs 3.32 and 5.37). Thus judgements on the quality of life may reveal prejudices or conclusions based on anxieties or preconceptions. It should also be noted that disability is at least in part a socially created and conditioned state (see paragraphs 3.29 and 7.6).¹⁰

- 2.11 As we acknowledge above (paragraph 2.5), we should not expect complete unanimity on issues of fundamental moral concern and members of the Working Party hold differing personal and philosophical positions in relation to ‘sanctity’ or ‘quality’ of life. The Working Party, however, agreed that in relation to the newborn baby there are some circumstances in which imposing or continuing treatments to sustain a baby’s life results in a level of irremediable suffering such that there is no ethical obligation to act in order to preserve that life. The Working Party struggled, as have others, to identify the criteria that should determine when the degree of suffering outweighs the baby’s interest in continuing to live, and to find the appropriate language to describe the threshold at which any obligation to prolong life cedes to a duty to provide palliative care. Following deliberation, **the Working Party adopted the concept of ‘intolerability’.** **It would not be in the baby’s best interests to insist on the imposition or continuance of treatment to prolong the life of the baby when doing so imposes an intolerable burden upon him or her.**
- 2.12 In seeking to understand what may be meant by an intolerable burden the Working Party reviewed the guidance in the Framework of the Royal College of Paediatrics and Child Health (RCPCH) on withholding and withdrawing life-sustaining treatment (see Box 2.1). In considering what constitutes ‘intolerability’, we noted that the RCPCH distinguishes between three situations: ‘no chance’, ‘no purpose’ and ‘unbearable’. Where treatment offers ‘no chance’ of survival other than for a short period of time, the best interests of the baby focus on the relief of any suffering and a peaceful death. We consider that to mandate distressing and futile interventions that can do no more than delay death would be a clear case of an intolerable burden.
- 2.13 Much more difficult are cases where evidence suggests that treatments to prolong life may have either ‘no purpose’ (as defined by the RCPCH) or result in ‘unbearable’ suffering. In those cases, establishing what constitutes a level of ‘intolerability’ is more complex and controversial. The concept of ‘no purpose’ is suggested by the RCPCH for cases in which treatment may secure the survival of a baby or child but only for him or her to endure such an ‘impossibly poor’ life that it would be unreasonable to expect him or her to bear it. For example, the clinical evidence may indicate that any future existence for the baby will be a life bereft of any of those features that give meaning and purpose to human life (for example, being aware of his or her surroundings or other people). Implementing burdensome treatments when faced with such a prospect may be seen as imposing an ‘intolerable’ existence, even in the absence of evidence of great pain or distress.
- 2.14 An ‘unbearable situation’ emphasises that there may be cases where treatment secures the survival of the baby but only for him or her to endure a life of great suffering and the family believes that further treatment is more than can be borne, irrespective of medical opinion that it may be of some benefit. While the RCPCH recommends that consensus should be sought (as does the Working Party, see paragraph 2.16), the ‘unbearable’ situation would appear to give more weight to the judgement of the parents in decision making. Unlike the

¹⁰ There is a substantial literature on the ethics of disability. For an introduction to this topic, which is not addressed in this Report, see (2005) Symposium of disability *Ethics* 116 (1).

'no purpose' situation described above, babies in an 'unbearable' situation may have greater inherent awareness and potential capacities to relate to others, but suffer extreme and irremediable pain. An example of such a distressing condition might be the most severe form of the incurable inherited skin condition, junctional epidermolysis bullosa (discussed in Chapter 6, Case 8). The intractable pain and consequent disability imposed on a child with this extreme form of the condition could be said to make continuing life 'intolerable'. The Working Party concluded that in both 'no purpose' and 'unbearable' situations, continuing life-sustaining interventions could result in maintaining a life that imposed an 'intolerable' burden on the baby.

- 2.15 There are also a number of situations that are both 'no purpose' and 'unbearable'. For example, a baby may show indicators of severe and unrelievable pain that is likely to persist, and at the same time he or she may be incapable of sustaining any meaningful relations with other people and lack any potential for an independent existence. The baby's suffering is significant and there is no prospect of benefits to him or her in continuing life to offset that suffering. Cases in which the life of a baby in such a condition could continue only by means of intrusive and invasive treatments may be also described as 'intolerable'.
- 2.16 Our use of 'intolerability' embraces all three situations recognised by the RCPCH, as well as those that have features of more than one of these categories. We take 'intolerability' to encompass an extreme level of suffering or impairment which is either present in the baby or may develop in the future, and may be given more weight in the judgement of parents or doctors. In proposing 'intolerability' as a threshold to justify decisions not to insist on life-prolonging treatments, the Working Party acknowledges the fallibility of language and the uncertainty of interpretation of evidence. Reasonable people may disagree both about what constitutes 'intolerability' and/or when a particular baby's condition meets that condition. In applying this concept, we acknowledge, however, that in each case an assessment must be made of the individual baby. The Working Party regards it as crucial that assessments both of what purpose a baby may find in his or her life and of the degree of suffering endured by a baby are made jointly by parents and healthcare professionals (paragraphs 2.44–2.57). **We conclude at this stage that, although a presumption in favour of life is rightly at the root of all medical care (paragraph 2.36), it cannot be absolute in situations where there are clear indications that the life to be experienced will be an intolerable burden on the child** (for an illustration of such a situation, see Chapter 6, Case 8).

Biological development and moral status

- 2.17 The attainment of specific biological thresholds is often held to be of significance in debates about the moral status of humans at different stages of development. These thresholds are used as criteria for when moral status becomes significantly altered and certain kinds of action would be permitted (or not permitted). For example, some people hold that the human embryo from the biological moment of conception has the same moral status as a born living human person.¹¹ They place importance upon the formation of one (or more) new individuals with unique genetic identities at the point of fertilisation. For other people, the relevant threshold relates to the earliest appearance of structures needed for the central nervous system to function, around the 14th day after conception, when the 'primitive streak' forms in the embryo. Others argue that in moral terms a more developed nervous system should be the focus of concern, such as the emergence of the first components of the central nervous system, and developments in the brain that allow sustained awareness.¹² Some

¹¹ For example, see Catholic Bishops' Conference of England and Wales (2004) *Cherishing Life* (London: The Catholic Trust Society).

¹² See, for example, Sass HM (1989) Brain life and brain death: a proposal for a normative agreement *J Med Philos* 14: 45–59; Lockwood M (1985) When does a life begin?, in *Moral dilemmas in modern medicine* (Oxford: Oxford University Press).

philosophers consider that the point of birth is highly significant, as a new and in many senses independent being has been brought into existence. Others contend that full moral status is only reached when an individual possesses self-consciousness.¹³ As this does not appear to develop until some months after birth, on this view not only the embryo and fetus, but also the newborn baby and the young infant, lack the moral status of a fully self-conscious person. Central to this position is the claim that it is the capacity for self-consciousness and self-valuing that gives humans their unique status as moral agents.

- 2.18 While these various positions can be understood to suggest that full moral status is either accorded or not, there is an alternative position which can be called the ‘gradualist’ view. Here, the fetus is taken to gain increasing moral status as biological development progresses. On the criteria considered above, the moral claim of the fetus increases as pregnancy develops, with the potential for viability outside the womb representing a significant milestone. A gradualist view might be said to be implicit in legislation that permits termination of pregnancy only on increasingly serious grounds as pregnancy proceeds. It is also noteworthy that it is only from the moment of being born alive that a child is regarded as a person in the legal sense, which some might view as recognition of his or her obtaining full moral status at birth (paragraphs 4.21–4.22 and 8.2).
- 2.19 It would be naïve to suppose that divergent positions on the status of prenatal and postnatal life can be easily reconciled. As we have observed, there is wide disagreement on this issue. Similarly, **the Working Party was not able to adopt a unanimous position on the issue of the moral status of the embryo or the fetus. However, we are in agreement that arguments seeking to establish that full moral status is reached only at some point after birth are flawed, whether in the context of a gradualist view or one that recognises only one single morally relevant, empirical criterion.** There are serious dangers in seeking to define some point in postnatal development at which the life of a child begins to command full respect, and which strengthens the grounds for sustaining his or her life. Any attempt to define clearly and without prejudice the moment at which a developing child acquires full moral status is likely to fail. Assessments of capacities such as self-consciousness are very difficult to make and hence it would be challenging, if not impossible, to define a single age, or the display of a certain set of behavioural or other features as the critical stage at which the capacity in question is agreed to be present. Since every child develops at a different pace, a judgement would have to be made afresh in each individual case, with all the subjectivity that this would entail. **For these reasons, the Working Party regards the moment of birth, which is straightforward to identify, and usually represents a significant threshold in potential viability, as the significant point of transition not just for legal judgements about preserving life but also for moral ones. In this respect, and independent of gestational age, we consider, for example, a child of six days, months or years to be worthy of equal consideration.** This acknowledgment does not by itself settle the difficult ethical issues raised by critical care decisions. Nevertheless, it does mean that reasons underlying decisions not to continue providing invasive treatment need to be scrutinised with special care.
- 2.20 The question of the moral status of the developing child also raises the question of how it relates to that of the pregnant woman. We view the law, which does not allow for compelling or coercing a pregnant woman to save or attempt to improve the health of the fetus she is carrying if she decides against interventions with this aim, as acceptable.¹⁴ **Clearly a pregnant**

¹³ Tooley M (1972) Abortion and Infanticide *Philos Public Aff* 2: 37–65.

¹⁴ Within the United Kingdom there are in fact three legal systems: (1) England and Wales; (2) Scotland; and (3) Northern Ireland. See Chapter 8, Footnote 1.

woman who acts neglectfully or in a manner that is wilfully harmful to her future child is doing a wrong. However, it is another thing to follow that society should therefore coerce her to behave more responsibly. It is the view of the Working Party that although in moral terms she acts wrongly in harming her future child, it would be wrong to force her to behave rightly.¹⁵ The legal position on interventions that could benefit the fetus is discussed in paragraphs 8.3–8.4.

Best interests

2.21 The principle of the best interests of the child is central to medical practice, child protection and disputes about child custody. **The Working Party concludes that the best interests of a baby must be a central consideration in determining whether and how to treat him or her.** In legal terms the concept is enshrined in the important legislative and political instruments in the UK that are concerned with children.¹⁶ However, the interpretation and application of the principle are far from straightforward.

What does it mean to have interests?

2.22 For the purpose of this discussion, interests can be understood in terms of the factors that affect a person's quality of life.¹⁷ They are the constitutive elements of wellbeing: a person's wellbeing prospers or declines as their interests grow or wane.¹⁸ A person benefits from having their interests promoted and suffers from having their interests neglected.

2.23 In determining how to treat an individual so that their interests are promoted, we may be able to discuss possible courses of action with them and then ask them about their preferences. These preferences also form a crucial element in seeking consent in medical decision making, provided the person has a good understanding of what the treatment involves. However, there are situations where a person may be unable to express preferences, for example where they have temporarily or permanently lost the capacity to understand or to reason or, as in the case of fetuses and newborn babies, where they have not yet developed these faculties. It is in these cases that the concept of best interests has most relevance, and where it is the most challenging to apply.

Interpretation of best interests

2.24 How do we know what is in the best interests of a person who may not experience self-consciousness? Parents often talk about their baby 'fighting for her life' or, say that a baby has 'had enough'. Certainly more attention is now paid to a baby's signals and to recognising that his or her actions may indicate preferences. However, such behaviour is often held to be instinctive and not consciously formulated. It follows that adults must choose for the baby

¹⁵ Macklin R (1995) Maternal–fetal conflict II, in *Ethics and Perinatology*, Goldworth A *et al.* (Editors) (New York, Oxford and Tokyo: Oxford University Press); Bewley S (2002) Restricting the freedom of pregnant women, in *Ethical Issues in Maternal-Fetal Medicine*, Dickenson DL (Editor), (Cambridge University Press) pp131–48; Brazier M (1999) Liberty, Responsibility, Maternity, in *Current Legal Problems*, Freeman MDA (Editor) 52: 359–91.

¹⁶ For example, these instruments include in the UK the Children Act 1989, the Children (Northern Ireland) Order 1995 and the Children (Scotland) Act 1995. Internationally there is the United Nations Convention on the Rights of the Child (UNCRC) (see paragraphs 3.44 and 8.2), which gives all children a right to have their best interests be the primary consideration in matters affecting them (Article 3). It is noteworthy that the Children Act does not refer to *best interests* but only to the child's *welfare*, which might be understood to be less demanding on those who make decisions for children. The instruments also differ in the weight they accord to a child's interest: the UNCRC stipulates that the child's interests are 'a primary consideration'; the Children Act states that the child's welfare should be 'paramount'.

¹⁷ We leave aside here more subtle discussions about whether promoting someone's best interests requires promoting *all* of their interests to *the highest degree*, or promoting, for example, only a *subset* such that a basic level of wellbeing is achieved. In general when we speak of 'best interests' in this Report, we are not referring to a distinct subset of a person's interests. Rather we are saying that what is in a person's interests is promoted to the greatest extent possible and that this may be understood in several different ways.

¹⁸ Feinberg J (1984) Harm to Others, in *The Moral Limits of the Criminal Law*, Volume 1 (Oxford: Oxford University Press), p 34.

and in doing so they must attempt to determine the baby's best interests on the basis of the available information. The main types of problem that influence the interpretation of what might be in the best interests of a fetus, a newborn baby or a child are explored below. We begin by considering philosophical issues and what is meant by pain and suffering. We then examine which parties are involved and consider the interests of other parties.

- 2.25 There are fundamental philosophical and scientific issues concerning knowledge about pain and suffering in other people. Assessments of these states are of great importance in many of the situations considered in this Report. We take for granted that a life free from pain and suffering is in a person's best interests. In the case of adults, medical information, empathy and the possibility of asking a person to describe their state can support inferences about how they feel. At the same time, pain and suffering are highly subjective, and difficult to quantify in objective terms. These problems are further complicated in the case of fetuses and the newborn, where reliance is placed on information such as body temperature or blood pressure, and where empathy has limited scope. This uncertainty is particularly important in those cases where parties might argue that it is against a newborn baby's best interests to be resuscitated. Here, the implicit assumption is usually that, from the perspective of the newborn baby, it would be preferable not to continue to live. Such a view would appear to require a high degree of certainty that the state of pain and suffering is indeed intolerable. Moreover these decisions concern what will happen in the future, and often we cannot know with certainty, or indeed with any real degree of assurance, the outcome of each choice we might make.
- 2.26 There are different parties involved in the assessment of best interests, and even if they agree about the current condition of a child, they may disagree, profoundly and irreconcilably, in their judgements about whether the life the baby might have in the future would be better or worse.¹⁹ Healthcare professionals, parents and lawyers have different relationships with a fetus or newborn baby whose interests are being considered. Cases may become more complicated where, for example, the mother has a different view from the father. All parties draw on different facts and emotions in forming their decisions, and may give these attributes different weights.
- 2.27 Even if there is agreement on what is in the best interests of a fetus, a newborn baby or child, there can be conflicts with the interests of other parties, as we consider below in more detail (see paragraphs 2.29–2.30). For now, we conclude that although there are problems in interpreting and assessing best interests, it is clear that a fetus and a newborn baby have interests and that they must be taken into account. If fetuses can experience pain (itself a subject of some dispute, see paragraph 4.19) it is reasonable to assume that a fetus has an interest in reducing the negative effects of pain and that interest gives us reason not to cause it.²⁰ It also makes sense in certain circumstances to ask whether it is in the best interests of a newborn baby to continue all possible treatment, for example when death is thought to be inevitable, or when the quality of life is intolerable (see paragraph 2.16).

The weight of best interests, and interests of different parties

- 2.28 Acknowledging that a baby has interests is one matter; deciding what weight should be given to these interests is another. Should they be 'paramount' as might be implied by the Children Act 1989? If so, best interests might be said to 'trump' other principles or considerations.

¹⁹ Parker S (1994) The best interests of the child, in *The Best Interests of the Child: Reconciling Culture and Human Rights* Alston P (Editor) (Oxford: Clarendon), pp 26–41.

²⁰ Allowing that a fetus has interests in this manner is compatible with holding a range of views regarding the moral status of a fetus as compared with a newborn baby (see paragraphs 2.17–2.20). Nor does it commit us to denying our claim that it would be wrong to coerce or compel a pregnant woman to act in certain ways.

Alternatively, should they be regarded simply as ‘a primary consideration’ as suggested in provisions of the United Nations Convention on the Rights of the Child (UNCRC)? And how should the best interests of the fetus or newborn baby be considered in relation to the interests of others involved in the decision-making process?

- 2.29 Any decision in respect of a baby will have implications for his or her parents and other members of the family who also all have interests. The Working Party does not consider that the baby’s interests should invariably take precedence over the interests of these other parties. Hence our view is that those who make decisions in respect of a child must carefully consider the interests of all those who may be affected, most usually other family members, old or young, who will live with the child, care for him or her, or are dependent upon the immediate family in other ways. Consider for instance the interests of the parents of a baby who is born with a severe disability. There is no doubt that the interests of a baby are bound up with those of his or her parents, in that the degree of care that parents can devote to their child can make a very substantial difference to the quality of life that he or she can expect to enjoy. While often the adjustments that families have to make when a child has disabilities can readily be overcome, having a seriously disabled child can make a very substantial difference to the kind of life the parents can expect to enjoy (see Chapter 7). Caring for a seriously disabled child may significantly and deleteriously affect the lives of his or her parents: it can mean giving up employment, economic hardship, marital discord and divorce, great unhappiness, stress and ill health for which help from the state is limited (paragraphs 3.35 and Box 7.2). **The Working Party is clear that parents have interests and that it is reasonable for these interests to be given some weight in any relevant deliberations about critical care decisions for a child who is, or who will become, severely ill.**
- 2.30 Impartiality requires that equivalent interests of morally relevant parties of equal status have the same moral importance, and have equal weight. However, the nature of competing interests requires further scrutiny because not all of an individual’s interests are equally important. In the circumstances concerning the decisions addressed by this Report, the interests of a baby which are at stake are often those of his or her very existence, whether he or she lives or dies, and of the quality of any life he or she might enjoy. These are usually a baby’s very central or basic interests.²¹ **Thus, in according particular weight to the best interests of a baby, we are not viewing the baby as more important than other persons; rather we view his or her interests in living or dying, or in avoiding an ‘intolerable’ life (see paragraph 2.16), as more important than the interests that others may have in any significant decisions made about him or her.**
- 2.31 Decisions about whether to continue or to cease providing life-sustaining treatments are decisions between two mutually exclusive options. However, many clinical decisions are more complex and involve many possible options such as what kinds of treatment are most appropriate, and for how long should a treatment be tried. In these cases the best interests of a baby may be harder to determine and to agree upon. This does not mean that the principle of best interests ceases to be relevant, only that it is more difficult to apply.
- 2.32 If, after careful consideration, all involved in the decision-making process have come to the conclusion that it might be in the best interests of a baby to cease life-sustaining treatment, a question arises as to what may permissibly be done. Are withholding and withdrawing treatment equally acceptable options in moral terms? Do they differ from deliberately ending the life of a newborn child?

²¹ See footnote 17.

Withholding and withdrawing treatment

2.33 The Working Party examined whether there was any case to say that withholding or withdrawing treatment are morally equivalent.²² In our view, when healthcare professionals withhold or withdraw treatment in the context of critical care decisions, when guided by the best interests of a baby, they substitute one form of care for another. They may refuse to start or continue a particular treatment when they know that doing so can bring about no benefit to patients or may actively harm them. In these cases, other forms of care or palliative care would routinely be substituted. For example, when mechanical ventilation to support breathing is withdrawn in a patient whose quality of life is described as intolerable (see paragraph 2.16), the medical staff implement palliative care to minimise any discomfort associated with any ensuing difficulty in breathing. **Although many people, including clinicians, perceive a moral difference between withholding and withdrawing treatment, the Working Party concludes that there are no good reasons to draw a moral distinction between them, provided these actions are motivated in each case by an assessment of the best interests of the baby. Either withholding or withdrawing treatment would be an acceptable course of action depending on the circumstances of each case. We note that the RCPCH has reached the same conclusion (see Box 2.1).**²³

Box 2.1: Royal College of Paediatrics and Child Health framework on withholding or withdrawing life-sustaining treatment

The Royal College of Paediatrics and Child Health first published guidance on withholding or withdrawing treatment in 1997, recognising that there was a need for guidance in dealing with these difficult decisions. A revised edition was published in 2004.*

The guidance suggests five situations in which it may be ethical and legal to consider withholding or withdrawing a child's treatment:

- the brain-dead child;†
- the permanent vegetative state;
- the 'no chance' situation: "the child has such severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering. Treatment to sustain life is inappropriate";
- the 'no purpose' situation: "although the patient may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect them to bear it"; and
- the 'unbearable' situation: "the child and/or family feel that in the face of progressive and irreversible illness further treatment is more than can be borne. They wish to have a particular treatment withdrawn or to refuse further treatment irrespective of the medical opinion that it maybe of some benefit".

In a situation where the conditions for one of these categories are not met, where there is disagreement, or where there is uncertainty over the degree of future impairment, the RCPCH advises that the child's life should always be safeguarded until these issues are resolved. The guidance notes that withdrawal or withholding of life-sustaining treatment "does not imply that the child will receive no care", and highlights the need for provision of palliative care in order to ensure that the remainder of the child's life is as comfortable as possible.‡

* Royal College of Paediatrics and Child Health (2004) *Withholding or Withdrawing Life Sustaining Treatment in Children: A framework for practice*, 2nd Edition (London: RCPCH), available at: http://www.rcpch.ac.uk/publications/recent_publications/Withholding.pdf, accessed on: 12 Sept 2006.

† The guidance notes that definitions of brain death are typically not applied to young babies because of uncertainty about the maturity of the brain at this age.

‡ The guidance describes palliative care as including treatment for alleviation of symptoms and care to maintain dignity and comfort.

²² Some commentators might think discussions of 'acts and omissions' could be relevant to the discussions on end-of-life decision making in this Report. However, the Working Party takes the view that when medical staff withhold or withdraw treatment, they do not fail to act, they substitute one form of care for another. The classic critique of the acts and omissions doctrine in the context of taking life is Rachels J (1975) Active and passive euthanasia *N Engl J Med* **292**: 78–80.

²³ The RCPCH notes that "Ethically the withholding and the withdrawal of life sustaining treatment are equivalent but emotionally they are sometimes poles apart." Royal College of Paediatrics and Child Health (2004) *Withholding or Withdrawing Life Sustaining Treatment in Children: A framework for practice*, 2nd Edition (London: RCPCH). See Appendix 9.

2.34 It is important to clarify that the observations above have no bearing on when to make the decision that it would be appropriate to withhold or withdraw treatment. In practice, in many cases it will be preferable to continue to treat until healthcare professionals can decide with a reasonable degree of certainty that withholding or withdrawing treatment would be preferable.

Deliberately ending life

2.35 Viewing withholding and withdrawing treatment as morally equivalent and acceptable in certain circumstances invites the question of whether the deliberate ending of life should also be seen as equally morally acceptable, given that the outcomes of all three options may be the same. **On balance, the Working Party rejects the argument that they are equally morally acceptable, as we explain below.**²⁴ Consider the case of a seriously ill premature newborn child with no realistic prospect of survival and whose life can reasonably be thought of as one of intolerable suffering (see paragraph 2.16). Why might it be thought permissible to allow a baby to die by withdrawing or withholding life-saving treatment, but impermissible to take the life of a baby deliberately, for example by means of a lethal injection?

2.36 In principle, doctors have a professional obligation to preserve life where and when they can²⁵, using the appropriate course of action to achieve that end (see Appendix 9). By contrast, taking intentional measures to end the life of a newborn baby, even one whose condition is reasonably judged as one of intolerable suffering (see paragraph 2.16) with no prospect of survival or improvement, is commonly regarded as a violation of the duty to protect the life of the patient.²⁶ The professional guidelines of the RCPCH sanction the withdrawal of life-prolonging treatment in appropriate situations but remain opposed to “causing death by intended lethal action”.²⁷ While reference to legal and professional instruments cannot by itself be sufficient to settle the moral question of the responsibility of doctors, these guidelines appear to reflect the current UK consensus on these matters and give expression to the ethos of healthcare professionals, factors that the Working Party holds as important.²⁸ Furthermore, although we recognise that evidence on such matters is difficult to obtain, we take the view that permitting doctors to end life deliberately would be likely to have a negative impact not only upon those doctors psychologically but on how the medical profession is perceived more widely. This is especially relevant where parents may lose trust in the impartiality of advice provided by doctors during the decision-making process.

2.37 There is also a problem of ensuring consistency (see paragraph 2.2). A newborn baby cannot express his or her wishes. It is therefore appropriate to appeal to what is believed to be in his or her best interests. If it were permissible to take the life of a newborn baby on the grounds

²⁴ In what follows the Working Party must be understood to be speaking about what can reasonably be foreseen as the consequences of continuing treatment, withholding treatment, withdrawing treatment, or of actively seeking to hasten death. We are clear that the possibility of a dramatic life-saving scientific discovery does not fall within the scope of what can reasonably be foreseen. Equally if doctors act with a well-grounded conviction that a baby will die as a consequence of their actions, they cannot be condemned if the actual outcome is otherwise.

²⁵ “A physician shall always bear in mind the obligation of ‘preserving human life.’” World Medical Association (1949, as amended) *International Code of Medical Ethics*. Doctors are not obliged to provide what they consider to be futile treatment.

²⁶ For a brief introductory discussion of the intentional ending of life by a doctor see Kuhse H (1991) Euthanasia, in *A Companion to Ethics* Singer P (Editor) (Oxford and Massachusetts: Blackwell), pp 294–302 and Tooley M (2003) Euthanasia and Assisted Suicide, in *A Companion to Applied Ethics*, Frey RG and Wellman CH (Editors) (Oxford: Blackwell), pp 326–41.

²⁷ Royal College of Paediatrics and Child Health (2004) *Withholding or Withdrawing Life Sustaining Treatment in Children: A framework for practice*, 2nd edition (London: RCPCH). The RCPCH also notes that “withdrawal of life sustaining treatment in appropriate circumstances is not viewed by the courts as active killing, nor as a breach of the right of life under article 2 of the European Convention on Human Rights”.

²⁸ British Medical Association (2006) *Assisted Dying – A summary of the BMA’s position*, available at: <http://www.bma.org.uk/ap.nsf/Content/assisteddying?OpenDocument&Highlight=2,euthanasia>, accessed on: 12 Oct 2006.

that it was in his or her best interests to do so, we have to ask why would it not be permissible to kill an incompetent adult on the same grounds. Those who reject adult euthanasia but who are sympathetic to the proposition that it is permissible actively to end the life of a newborn child whose life is intolerable, would need to show that, further to the fact that the adult has had many life experiences and has entered into social relationships, there is a morally relevant difference. **In summary, the Working Party unreservedly rejects the active ending of neonatal life even when that life is 'intolerable'.**

Relieving pain and causing death: the doctrine of the double effect

2.38 Measures to end life could include the administration of a chemical that has no other purpose than to end life, such as a lethal injection of potassium chloride. Medicines such as sedatives and analgesics can also have the effect of hastening death, particularly if given at higher doses. Death may therefore occur in cases where doctors provide such treatments with the intention of reducing pain and suffering. The acceptability of administering pain-relieving drugs that may also bring about death is debated under the doctrine of double effect (see Box 2.2). **The Working Party takes the view that, provided treatment is guided by the best interests of a baby, and has been agreed in the joint decision-making process (paragraphs 2.42–2.57), potentially life-shortening but pain-relieving treatments are morally acceptable.**

Box 2.2: Doctrine of double effect

This principle governs the permissibility of actions that have two outcomes, one good and the other bad. The principle states that an action of this kind may be permissible provided the bad outcome is only foreseen, not intended, and is proportionate, that is, the bad that could be caused is not such as to outweigh the good intended.* The principal critics of the doctrine question whether there is a robust moral difference between intending and merely foreseeing an outcome, a difference which would be sufficient to show the permissibility of the act or to excuse the agent.† However, it is important to acknowledge that the principle does not permit cases in which an action has two outcomes, both intended. Thus administering a high dose of pain relief with no intention to kill but with an awareness of the possibility of it hastening death is permitted under this principle, provided the foreseen possibility of death is viewed as 'proportionate'. By contrast, administration of the same dosage of analgesic with the clear and deliberate intention of bringing about death would not be permitted. Hence if a doctor administers a high dose of pain relief to a newborn baby aiming to hasten death, then what the doctor does could reasonably be described as a deliberate act of killing. The principle of double effect would not be applicable in such a case. The British Medical Association (BMA) has noted that doctors may fear that their motives in providing pain relief could be misinterpreted, but advises that "if the intention is clearly to relieve pain and distress and the dosage provided is commensurate with that aim, the action will not be unlawful".‡ The BMA also emphasises the importance of good symptom control.

* Mason JK and Laurie GT (2005) Double effect, in *Mason and McCall Smith's Law and Medical Ethics*, 7th Edition (Oxford: Oxford University Press), pp 634–5.

† Kuhse H and Singer P (1985) The doctrine of double effect, in *Should the Baby Live? The Problem of Handicapped Infants* (Oxford: Oxford University Press), pp 85–6.

‡ British Medical Association Ethics Department (2004) *Medical Ethics Today: The BMA's handbook of ethics and law*, 2nd Edition (London: BMJ Books).

Economic and social issues

2.39 A full moral evaluation of the issues under consideration in this Report must take account of the social and economic context if the realities of decision making in critical care are to be understood. What, for instance, are the social consequences of any practice permitting the resuscitation and treatment of extremely premature babies with a high risk of moderate or severe disability? They may include the impact on families of having to care for disabled children, and the additional demands placed on social and welfare agencies. We consider the practical consequences of decision making for parents in more detail in Chapter 7. **Based on our discussion about the value of life, we conclude that just as we find no difference in the moral status of the child of six days, months or years, we find no morally relevant differences between disabled and able-bodied children and adults (paragraph 2.19). Each must be given equal consideration. It is therefore important**

that all those involved in critical care decisions, especially parents, doctors and nurses, do not feel pressured into allowing babies to die because of the risk of disability.

- 2.40 What role should economic factors, such as the costs of treatment, play in critical care decisions? Responses to our consultation showed that many people are of the view that economic factors should not be relevant, that it is both impossible and improper to put a price on human life. It would certainly be unacceptable if parents were required to take into account the costs to the health service when making a decision about the treatment of their baby, or the future additional costs of social and educational provision in the future. At the same time, there was some recognition that “the use of limited health care resources must inevitably be a consideration” (response to our consultation from the Royal College of Nursing).
- 2.41 It is important to note that economic factors are considered at different levels of decision making (see Appendix 7). At the macroeconomic or social level, decisions must be taken about the proper distribution of what will necessarily be finite resources for the purposes of the provision of healthcare. Any distribution of this kind will result in a given proportion of those resources being devoted to fetal and neonatal medicine. It is beyond the scope of this Report to consider principles affecting the distribution of resources at the macroeconomic or mesoeconomic (regional and local decision making) levels, although it is clear to us that ‘fairness’ or justice must be one of these. The Working Party is aware that there is active debate on the question of whether there is any reasonable or fair basis for judging that treatment of the very young should receive proportionately less (or more) resources than treatment of adults.²⁹
- 2.42 Provision of resources at the macroeconomic level to treat babies with a high probability of having some level of disability in the future, particularly if it is severe, has resource implications beyond the sphere of neonatal medicine. These arise from the costs of caring for disabled children as they grow up, and providing support to their families. The Working Party is clear that the State should be expected to bear some of the additional costs of supporting families in their care of these children, as it would be unreasonable to expect families to bear these costs alone. Moreover we interpret the requirement of consistency to entail that the State should not think it permissible to enable many of these babies to survive but be excused the discharge of its resultant obligation to support their care.
- 2.43 At the microeconomic level, which includes discussion about individual cases, it can be argued that decisions about the treatment of any newborn baby should not be taken on economic grounds but only on the basis of what is in the baby’s best interests. However, resource constraints arising from decisions at the national, regional or local level may not always allow healthcare professionals to do what they judge to be best for each and every child. Various situations have to be managed. A limited number of staffed cots within a neonatal intensive care unit (NICU) may mean that continued occupancy of one cot can deny full treatment to a new case at that hospital.³⁰ Sometimes a baby who is less seriously ill may have to be transferred to another hospital to make a staffed cot available for a new admission. At other times, clinicians will be unable to find a staffed cot in another nearby unit and they may have to arrange life-threatening transport over long distances. Conversely, hospitals may refuse an admission from another unit because staffed cots are unavailable. **However, the Working**

²⁹ For further information, see Mason JK and Laurie GT (2005) *Mason and McCall Smith’s Law and Medical Ethics*, 7th Edition (Oxford: Oxford University Press), pp 414–17.

³⁰ We note that it is not usually the number of cots that limits admissions but a shortfall in the number of neonatal nurses. See also BLISS – The Premature Baby Charity (2006) *Weigh Less, Worth Less? A study of neonatal care in the UK* (London: BLISS). Not only do many neonatal intensive care units fall short of the BAPM standard that there should be a 1:1 ratio of nurse to baby but also currently there are many vacancies in the posts that do exist.

Party believes that even in these circumstances decisions at the microeconomic or individual level should still be determined, not by economic considerations, but by clinical judgements of priority, which take into account the best interests of the babies concerned. It is crucial that healthcare teams can focus fully on the care of their patients.

Decision making

2.44 We have discussed four important areas which all those involved in the decision-making process will need to consider. These are the value of human life, the role of best interests, the deliberate ending of life and the withholding and withdrawing of treatment, and the weight that should be given to economic and social considerations. We now turn to the ethical issues raised by decision making in this context, paying particular attention to considerations of how one should proceed if people hold different views about substantive matters, and, because a decision needs to be made, who should be responsible for taking it, both in terms of the proposal and personal and professional acceptance of the consequences.³¹

2.45 Fair and transparent procedures are crucial for ethically acceptable decision-making processes. In principle, quite different approaches could be taken. For example, healthcare professionals could be required to make decisions based on their clinical expertise without reference to other parties. Or they might simply be asked to follow certain rules, with no flexibility of interpretation (see paragraph 2.57). However, as we explain below in more detail, in the view of the Working Party, these approaches are problematic. No single participant will usually be able to judge the many different factors and nuances that come into play in complex cases of critical care decision making. Similarly, although rules promise certainty, when they need to be applied to a range of varying situations they may be impossible to frame while retaining fairness and accuracy. By contrast, a joint decision-making process satisfies several important ethical considerations. First, the process is conducive to reaching a decision that is in a baby's best interests in that the different parties can present their views about what they hold these interests to be, and how they think those interests relate to their own. Secondly, a central ethical tenet is that several parties, each with different perspectives to bring, have responsibilities in the process that need to be acknowledged. Thirdly, if all involved are assured that their competencies have been considered appropriately in the decision-making process, there is less likelihood of later regret (of, perhaps, 'having done the wrong thing'), or if there are regrets, the parties involved can be satisfied that at the time, they had good reasons for the decisions that they made. No less important is that a recognised joint process makes it possible for parents and others to raise objections to the view of healthcare professionals.

2.46 Therefore, for reasons of procedural justice, personal and professional responsibility and the wellbeing of those most closely involved, the importance of an appropriate decision-making process cannot be overstated. We now address the ideal of decision making and clarify the roles of the different parties.

Participants in the decision-making process

Parents

2.47 In general, parents are considered to have the moral authority to make decisions in their child's best interests in all the circumstances of life. However, parents cannot make decisions on behalf of their children as if they owned them or were merely extensions of their own

³¹ For a philosophical discussion of the ethical issues of deciding for those incapable of making their own decisions see Buchanan AE and Brock DW (1989) *Deciding for Others: The ethics of surrogate decision making* (Cambridge: Cambridge University Press).

person.³² Nonetheless they are often best placed to know what is in the interests of their child because of their closeness to him or her and the special bond that they enjoy. This is a bond that begins during pregnancy and develops over time.

- 2.48 At the time that critical care decisions have to be made, there is often uncertainty about the baby's condition and prognosis which can be difficult for doctors to communicate. Written information may not be readily available. Furthermore, a parent or parents might not wish to make decisions that result in the death of their baby, preferring that the doctors should make such decisions on their behalf. **The Working Party endorses the 'partnership of care' between parents and the healthcare team recommended by the RCPCH and the British Association for Perinatal Medicine (BAPM).**³³ **We take the view that, provided healthcare professionals have made every effort to convey the relevant medical information appropriately to parents, where parents genuinely wish to allow doctors in consultation with their clinical colleagues to make decisions on their behalf, they should be allowed to do so.** Parents may also wish immediate family members or community or religious leaders to participate in the decision making. In such cases, the roles of additional participants should be discussed and agreed between parents and relevant healthcare professionals at the earliest possible opportunity.

Healthcare professionals

- 2.49 Healthcare professionals caring for the newborn child also have a responsibility to promote his or her best interests. Doctors are able to offer a prognosis based on their knowledge and experience. Nurses also have special knowledge and expertise, and are the professional group that spends the most time with parents and their baby. They are therefore well placed to provide additional insights into the best interests of both the child and his or her family (see also paragraph 3.13). Other healthcare professionals can offer opinions and prognosis about particular aspects of the baby's condition, such as his or her potential for mobility or speech. Members of healthcare teams may hold deeply personal views about moral and ethical issues which arise in their work. They may disagree with each other about what is in a baby's best interests. **In the view of the Working Party, the team of healthcare professionals should participate actively in critical care decisions and indicate what they think is best for the child. However, their command of medical knowledge does not make them able to predict the future health of a baby with complete accuracy or give them any special moral authority with regard to deciding on his or her best interests.**
- 2.50 Healthcare administrators at the national, regional or local level are not directly involved in decision making for individual babies and there is no routine involvement of individuals who, for example, have experience of disabling conditions. Clinical ethics committees (CECs) operate in some regions but are seldom involved in individual cases, and only in an advisory capacity (see paragraphs 8.48–8.51).

The process of decision making

- 2.51 **The Working Party considers that all participants in decision making should strive to reach agreement, and every effort should be made to secure consensus within the 'partnership of care'** (see paragraph 2.48). This is more likely to be achieved if all the

³² Archard D (2004) *Children, Rights and Childhood*, 2nd Edition (London: Routledge), pp 141–4.

³³ Royal College of Paediatrics and Child Health (2004) *Withholding or Withdrawing Life Sustaining Treatment in Children: A framework for practice*, 2nd Edition (London: RCPCH), available at: http://www.rcpch.ac.uk/publications/recent_publications/Withholding.pdf, accessed on: 23 Nov 2005; British Association for Perinatal Medicine (2000) *Fetuses and Newborn Infants at the Threshold of Viability: A framework for practice* available at: <http://www.bapm.org/documents/publications/threshold.pdf>, accessed on: 31 July 2006. The concept is also embedded in the policy of the National Service Framework for Children and many professional medical bodies such as the General Medical Council (GMC).

appropriate parties who wish to be are fully involved in any discussion, properly understand the facts, appreciate their significance, especially concerning statistical information about the likelihood and extent of disability, and are given the opportunity to participate in the process of deciding. This is in keeping with the normal requirements for consent (see Appendix 5). It means that the weighting given to different interests will necessarily vary from case to case, with, as we have said, the best interests of the baby remaining the main consideration.

- 2.52 Various measures can be taken to promote trust and the reaching of agreement, such as regular meetings between members of the healthcare team and the family to discuss the goals of care and to make recommendations on how these could be achieved. Good communication is essential and the Working Party later makes a recommendation for further research to find out how participants in decision making act, react and interact with each other, to provide an evidence base to inform the development of best practice in decision making (paragraph 9.48). We recognise, however, that decisions sometimes have to be taken quickly, and it may not always be possible to realise this ideal, particularly where resuscitation is involved. Moreover, agreement about what is best may not be reached, however hard and conscientiously it is sought (see Box 6.1).
- 2.53 If all possible means of resolving any disagreement between the various parties had been exhausted there would need to be, in the final analysis, a procedure to reach a decision. A clinical ethics committee or other appropriately constituted body could be approached if not already involved (see paragraph 2.50). However, in circumstances of persistent disagreement between parents and doctors or an unwillingness to use other procedures, recourse to the courts may be necessary (see Box 6.1 and paragraphs 8.50–8.51). The decisions of the courts are guided by a concern to determine what is in a child's best interests. The ideal of judicial decision making is to be, and be seen to be, impartial and dispassionate. It aims to allow all relevant parties to present their case and have it fairly scrutinised. **However, the Working Party finds it difficult to avoid the conclusion that recourse to the courts amounts to a failure, which in many cases could have been avoided by better communication.**³⁴ It is not just that an irreconcilable disagreement must now be adjudicated by a third party. A matter of profound importance and great emotional significance must be settled by professionals who are essentially strangers to the child. **We therefore take the view that every effort should be made to resolve matters without recourse to the courts. We note ways in which this might be done in Chapter 8** (paragraphs 8.56–8.62).
- 2.54 Regulations or guidelines are a way in which decision making can be distanced from the influence of the parties involved, before there is any suggestion of disagreement. This would be the case, most obviously, if doctors were required or advised not to resuscitate infants born below a certain gestational age. Such a guideline has been adopted and employed in the Netherlands (see Box 8.1) and is usually justified as follows: if it can be predicted with reasonable assurance that the substantial majority of babies born below a specified gestational age will be resuscitated and treated, only to die or be judged later as having 'intolerable lives' (see paragraph 2.16 and Table 5.1), then it would be better not to take the initial step of resuscitating such babies. Accordingly, such babies could be spared any pain and suffering caused by the life-prolonging treatment (see paragraphs 2.33–2.34). In addition, parents and doctors would be relieved of the emotional trauma of seeing the life of a baby saved only to have to face a subsequent decision about withholding or withdrawing treatment that might make the eventual process of dying more painful for the baby than it otherwise would have been.

³⁴ This view concurs with the response to our consultation by the Royal College of Obstetricians and Gynaecologists (RCOG).

- 2.55 A feature of decision making in neonatal critical care is the uncertainty that is frequently associated with making a prognosis (see paragraphs 3.6 and 5.16). In this context, not resuscitating babies born below a specific gestational age would lead to the death of a minority below the threshold who, with intervention, would not only survive but would not suffer from any significant subsequent disabilities (see Table 5.1). However, our problem is this. We cannot know with any degree of assurance which particular babies born below certain gestational ages would survive and to what extent they would develop disabilities, whether severe, moderate, mild or none. However, we do know that the lower the gestational age, the greater is the number of babies who, if resuscitated and treated, either will not survive or develop some form of disability. In other words we can predict the outcome for most or nearly all of a group born at a certain stage of pregnancy even if we cannot know with certainty what it will be for an individual baby. That is why it may be best to use a rule (here, a gestational limit for resuscitation) based on what is known about the group as a whole, even though a particular baby might fare exceptionally well.
- 2.56 In principle, the apparent harshness of a definitive rule stating that babies should not be resuscitated if born below a particular gestational age can be mitigated in several ways. First, it can be viewed as a guideline rather than an inflexible prescription. It is then possible to take account of relevant considerations in particular cases, such as increased chances of survival for extremely premature girls as compared with boys born at the same gestational age, and improved outcomes for extremely premature babies with certain ethnic backgrounds.³⁵ Secondly, parents' views can be given a greater or lesser weight in decision making within the constraints of any such rule. For example, a gestational age could be specified above which a baby would usually be resuscitated unless the parents and clinicians agree not to do so. In addition, a gestational age might be specified below which the converse presumption might be made, namely that a baby will not be resuscitated unless the parents make an informed decision that doctors may do so.
- 2.57 A rule removes from those subject to it the burdens of having to make a decision in every individual case. A rule of the form 'always do x except in the following circumstances' is weakened each time that more exceptions are added to the list. The more exceptions there are to a rule the less benefit can be derived from having it implemented as a clear and unambiguous regulation. Similarly a rule becomes more like a guideline and less of a prescription, the greater the discretion in its operation that is conceded to those subject to it. Nevertheless, in the context of making critical care decisions it is always important to avoid insisting upon an inflexible rule with no exceptions. It may be better to have a rule that states a presumption in favour of a certain course of action: a presumption that the rule can be defeated under certain circumstances or when the relevant parties are agreed that it is best not followed. **We conclude that, although insufficient by themselves, in principle, rules with certain qualifications can have an important guiding function in the decision-making process between parents and healthcare professionals. They can also be useful in signalling normal practice.** With this in mind, in our concluding chapter we develop proposals for guidelines for instituting intensive care (paragraphs 9.16–9.19).

³⁵ Morse SB, Wu SS, Ma C, Ariet M, Resnick M and Roth J (2006) Racial and gender differences in the viability of extremely low birth weight infants: a population-based study. *Pediatrics* 117: 106–12.