

# **The ethics of prolonging life in fetuses and the newborn**

## **CONSULTATION PAPER**

**NUFFIELD  
COUNCIL <sup>ON</sup>  
BIOETHICS**

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## The terms of reference of the Council are:

- 1 to identify and define ethical questions raised by recent advances in biological and medical research in order to respond to, and to anticipate, public concern;
- 2 to make arrangements for examining and reporting on such questions with a view to promoting public understanding and discussion; this may lead, where needed, to the formulation of new guidelines by the appropriate regulatory or other body;
- 3 in the light of the outcome of its work, to publish reports; and to make representations, as the Council may judge appropriate.

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# The ethics of prolonging life in fetuses and the newborn

## Consultation paper

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## **Terms of reference of the Working Party on the ethics of prolonging life in fetuses and the newborn**

- 1 To identify and consider ethical, social, economic and legal issues arising from recent developments in fetal and neonatal medicine relating to prolonging life.
- 2 To examine scientific and medical research in these fields, considering in particular:
  - a. diagnostics;
  - b. fetal surgery;
  - c. neonatal care (including resuscitation);
  - d. recent evidence on the capacity of fetuses and the newborn to experience pain and suffering.
- 3 To examine current medical practices in these fields and their outcomes in the UK and more widely. In particular to review:
  - a. implications arising from the possibility of survival of premature babies of increasing frailty and at lower ages;
  - b. the relationship between changing survival rates and longer term outcomes
- 4 To consider issues raised by advances in research and practice, particularly:
  - a. arguments about the moral and legal status of fetuses beyond the first trimester and the newborn;
  - b. the ethical and legal basis for providing, withdrawing or withholding life-prolonging treatment;
  - c. the process of decision-making, including the relative roles of families and healthcare professionals;
  - d. the availability of support for families in the short and the long term;
  - e. resource implications for providers of healthcare, education and social care;
- 5 In light of the above, to make recommendations.

## Introduction

In developed countries, modern medicine has reached the stage where we can sustain the life of babies who, until relatively recently, might not have survived birth. While improvements in technology and care have been successful in lowering the threshold for survival to as little as 23 weeks, parents may still be faced with complex questions about what the future holds, in terms of the quality of life for their child and their family. This includes parents who may know before the birth that their baby has health problems, parents who may have an extremely premature baby or parents with a baby born at the normal time of between 37 and 42 weeks who is nevertheless very ill or has abnormalities.

In these situations, the baby may recover entirely or survive with disabilities. Many parents do not regard disability as a medical condition and there is no consensus on how we should place value on the quality of life for the developing child, the family and society. This is an area where there has been little systematic research to help parents and doctors make decisions. However, there are new findings that the increasing number of babies born extremely prematurely who survive are at particularly high risk of neurodevelopmental disabilities.

The Nuffield Council on Bioethics has established a Working Party to consider the complex and controversial ethical and legal issues that arise when deciding whether or not to prolong life in fetuses and the newborn. These issues concern whether or not life prolonging treatment should be offered to fetuses in poor health, very premature babies and the newborn who have experienced problems at birth, and how such decisions should be made. The Working Party will formulate advice that is primarily relevant to UK policy and practice, but will draw upon examples from other countries. The Council, which is an independent body, would welcome your comments on these and related issues.

This document provides some background information in the following areas relevant to prolonging life in fetuses and the newborn: clinical practice and future developments, ethical issues, social issues, economic issues, professional guidance and the law and suggests some further sources of information. Within each section, a number of questions are posed. We should like to invite you to tell us about your views and to encourage you to give the reasons behind them. You do not need to answer all of the questions. Please tell us if we have omitted any important issues. Your response will be circulated to the members of the Working Party to inform their deliberations.

We recognise that the issues we are considering touch on profoundly personal experiences for many families and professionals and acknowledge that simply reading this paper may be distressing. To help, we have tried to use clear language and to strike a balance between using technical and everyday terminology. We are sorry if, in doing so, we have omitted some context or details. A glossary is included to provide definitions of the terms that we use.

Information about how to submit your response, including the facility to respond on-line, is given at the end of this document. We should like to be able to quote your response either in print or on our Website and so we will ask you about this too.

### **Use of the terms 'fetus' and 'newborn' and other terminology**

In this paper, we use the definition of fetus to describe the stage of human development after the first eight weeks of development until birth. The Working Party is only covering those issues which arise beyond the first twelve weeks of pregnancy. (The term 'embryo' is ordinarily used for the period up to eight weeks).

We use the term 'newborn' to describe very young babies. Strictly speaking, the neonatal (or 'newborn') period, is the time within 28 complete days of delivery. The Working Party will also consider the consequences, for the infants and children who survive, of decisions made to prolong the life in the newborn period.

## **Background**

### ***What changes have made it timely to examine the issues arising from prolonging life in fetuses and the newborn?***

Progress in clinical care has meant that many more sick babies survive today than did twenty years ago. We are able to provide better care for the mother, to the benefit of her unborn child and, to a limited extent, we may be able to treat the fetus directly. The main change, however, is that the age at which the fetus can survive outside the womb has been reduced from 28 weeks to as little as 23 weeks, largely through improved methods of ventilation, nutrition and the control of infections. At the same time, diagnostic techniques and knowledge about the development of the fetus and the newborn have substantially improved. Many children overcome their difficult start in life with the help of their families and grow up to have successful adult lives. It is also the case that while a small number of children have very complex problems, their families would generally regard them as doing well and would challenge the view that disability is a medical disorder.

### ***Why do these changes raise controversial issues?***

Unfortunately, advances in the accuracy of predicting a child's longer term health have not kept pace with diagnostic and other developments. An accurate prognosis may not be established for weeks, months or even years, which means that cases of severe disability cannot always be predicted. In the case of babies of extremely low gestational age and birth weight, it is now known that the growing number of those who survive have a high risk of serious neurodevelopmental disabilities and learning difficulties during childhood.<sup>1</sup> Such findings can be expected to affect decisions about whether or not to treat the fetus or the newborn and raise complex questions about the quality of life for the developing child. This research also raises wider issues about the impact on the child's family and the role of our society.

### ***What sort of decisions are involved?***

In the case of fetuses or of very young infants, parents and healthcare professionals may be faced with a range of difficult decisions. These include whether or not a pregnancy should be terminated and whether, where possible, the fetus should be treated in the womb, or delivered early. Once born, decisions may be needed about: whether to resuscitate a newborn baby and begin treatment; whether to continue or withdraw treatment; or to provide only basic care, in the knowledge that the baby is likely to die as a result. These

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<sup>1</sup> Marlow N (2004) Neurocognitive outcome after very preterm birth *Arch Dis Child Fetal Neonatal Ed.* **89**: F224–228; See also BBC News Online (17 Sept 2004) *Miracle baby grows up*, available at: <http://news.bbc.co.uk/1/hi/programmes/panorama/3655050.stm> Accessed on: 3 Mar 2005.

decisions often have to be made when an absolute prediction of the long-term consequences for the infant is not possible.

***Is the concern about prolonging life just about premature babies?***

No. As well as babies born prematurely, babies born at full term may require intensive medical or surgical treatment to survive, because they have serious abnormalities or there are problems that arise during delivery or after birth. Technological advances have led to many conditions being identified before birth. The following points illustrate areas of concern:

- Identifying serious illnesses or abnormalities in the fetus that are likely to compromise the quality of life after birth can lead to ethical dilemmas as to how the pregnancy should be managed.
- After birth, approximately 2.5% of all babies born in the UK need intensive neonatal care. The incidence of premature delivery is rising and the gestational age at which survival is possible is falling, currently to 23-24 gestational weeks (16-17 weeks before full term).<sup>2</sup>
- Spontaneous premature birth remains one of the main causes of disability and death. Approximately 7% of births in the UK are premature, referring to babies born before the 37<sup>th</sup> week of pregnancy. The earlier a newborn infant is born, the lower their chances of survival. Fewer than 1 in 1000 babies are born extremely prematurely (before the 26<sup>th</sup> week of pregnancy). The chances that they will survive free of any disabling conditions are as follows:

11% at 23 weeks

20% at 24 weeks

32% at 25 weeks.<sup>3</sup>

- Such extreme prematurity means that affected babies need assistance because they are very small and many of their organ systems have not fully developed. In some cases, parents and doctors may question in retrospect whether they were right to initiate intensive neonatal care, particularly when, after birth, babies who initially seemed to be doing well go on to develop problems.
- At full term, babies may need intensive care because they have congenital anomalies or suffer, for example, from asphyxia during delivery, infections or blood disorders. Of these babies, a proportion will have a poor outlook.

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<sup>2</sup> For further information see the BLISS website <http://www.bliss.org.uk/>.

<sup>3</sup> For further information on extreme prematurity, see the EPICure website <http://www.nottingham.ac.uk/human-development/EPICure/index.htm>.

- Congenital anomalies occur in about 1% of the population and contribute to about 30% of perinatal deaths.<sup>4</sup>

### ***What guidance and regulation exists already?***

The UK has developed codes of practice and a framework of regulation over the years, and these are described in more detail in Section 5 and Appendix A. Judgements about whether or not to prolong the life of fetuses or the newborn have to be made on a case by case basis and doctors and families rely on professional codes of practice to guide their decisions at each stage. If doctors and parents disagree about how to treat (or how not to treat) a very premature or ill or disabled child, the courts can be asked to give a ruling about what treatment can or cannot be given. These infrequent applications are dealt with by the family courts, usually in private, but in recent months, some have been dealt with in public in the open court, at the request of the parents.<sup>5</sup> The family courts are currently considering whether family proceedings more generally should be heard in the open court.

### ***What other aspects of prolonging life need to be considered?***

In society, attitudes to medicine and surgery have been changing and we are perhaps less deferential in our attitude towards all professions, including medicine. Parents and patients are more likely to want actively to participate in decision-making about treatment and to question the decisions that are made. This perspective can lead to conflicts between parental choices and advice from clinical experts. As more lives are saved, there are more adjustments for society to make. The economic and broader societal costs of caring for children and adults with disabling conditions in the longer term may sometimes be far greater than the short term costs of providing intensive care for babies. These issues are primarily a concern of developed countries, as poorer countries often cannot provide specialist treatment and facilities.

### ***Legal definitions***

The increasing survival of the very premature newborn has recently sharpened the debate in the UK over abortion. Some children now survive who are born before the legal limit for abortion, which is currently 24 weeks of gestation (in the absence of evidence of substantial risk to the life or health of the mother or that if the child were born it would be 'seriously handicapped'). Although the Working Party will discuss the moral status of the fetus as well as of the newborn, consideration of whether or not the legal limits for abortion should be reduced is beyond our terms of reference.

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<sup>4</sup> Confidential Enquiry into Maternal and Child Health (2004) *Stillbirth, neonatal and post neonatal mortality 2000-2002*, available at: <http://www.cemach.org.uk/publications.htm> Accessed on: 3 Mar 2005.

<sup>5</sup> For example, the cases of Charlotte Wyatt and Luke Winston-Jones. The Wyatt judgement is available at: <http://www.bailii.org/ew/cases/EWHC/Fam/2004/2247.html> Accessed on: 3 Mar 2005.

## 1 Clinical practice and future developments

### *What happens in clinical practice in the UK?*

The introduction of national screening using new diagnostic procedures has meant that potential health problems in the fetus are uncovered more frequently than in the past. If problems are diagnosed before birth, several courses of action may be taken. It may be possible to terminate the pregnancy, to deliver the fetus early to allow neonatal treatment or to carry out treatment while it remains in the womb. Some clinicians would distinguish two types of situation. In cases where there is already some family experience of a disorder, it could be the case that the prospective parents find it easier to decide to seek a diagnosis and to form a view on what action, if any, to take. But when fetal health problems are detected as a result of routine screening tests, decisions may be required more urgently and may have to be made without any direct personal experience of the consequences of continuing the pregnancy. Professional guidance and counselling is available to help those who have to make these types of decision.

There can be difficulties associated with the birth itself, for example if the baby becomes deprived of oxygen because he or she is not in the normal position or has difficulty in passing down the birth canal. When an infant is born in a poor condition, the usual immediate practice in the UK would be to provide intensive care. Premature babies may need support because their organs are not fully mature; other babies may need treatment because they are ill or weak; still others may have congenital disorders associated with health problems which mean that they cannot immediately thrive. The provision of intensive care is re-evaluated over the following few weeks according to the infant's progress and parental wishes. For babies with severe problems and very poor chances of survival, an alternative approach might be adopted. This could involve providing care that ensures that the child is made comfortable, but not providing extra treatment, such as respiratory support, antibiotics or surgery.

Box 1 (opposite) describes how UK practice differs from other countries.

## **Box 1: How does UK practice differ from other countries?**

### ***Before birth***

Laws on abortion in other countries often impose earlier time limits than in the UK. There are some minor differences in the fetal treatments available before the baby is born.

### ***After birth***

Most neonatal doctors in Europe would resuscitate and start intensive care in the very premature newborn, although in some countries, including the UK, that decision might later be reversed. It is common for European doctors to set limits to the provision of intensive care for incurable conditions, but reported practice varies substantially with regard to the active withdrawal of mechanical ventilation.

Certain countries have specific policies that stipulate the gestational age at birth below which health professionals are recommended not to routinely perform intensive treatment. In the Netherlands, active intensive treatment is not routinely provided for fetuses delivered before 25-26 weeks of gestation. However, this decision may be overridden by the parents if the medical team consider the infant to be viable.<sup>6</sup> A similar situation exists in Denmark. By contrast, in the United States, generally, the options of pre-emptive abortion or withholding intensive care for severely ill fetuses or the newborn are not considered to be lawful or ethical. Standard practice in the United States is to 'treat until certainty', that is, until death or discharge from hospital. The definition of death is in itself problematic. Biologically, different organs and systems supporting life cease to function at different times, but more precise definitions, such as 'brain stem death', have been required by the law in the UK and elsewhere. In the UK, however, it is recognised that considerations other than 'brain death' are important in decision-making for young infants.<sup>7</sup>

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<sup>6</sup> Sheldon T (2001) Dutch doctors change policy on treating preterm babies *BMJ* **322**: 1383. Also in the Netherlands, there has been recent debate on euthanasia in relation to children. See Groningen Hospital Press Release (10 Dec 2004) *Paediatricians call for nationwide protocol for the ending of life of unbearably and incurably suffering newborns*, available at: <http://www.azg.nl/azg/nl/english/nieuws/45613> Accessed on: 3 Mar 2005. See also Traynor I (21 Dec 2004) *Secret killings of newborn babies trap Dutch doctors in moral maze* *The Guardian*, available at: [http://www.guardian.co.uk/uk\\_news/story/0,,1377808,00.html](http://www.guardian.co.uk/uk_news/story/0,,1377808,00.html) Accessed on: 3 Mar 2005.

<sup>7</sup> Conference of Medical Royal Colleges and their Faculties in the United Kingdom (1991) *Diagnosis of brain stem death in infants and children* (London: British Paediatric Association).

### ***What do studies on post natal decision-making show?***

It would appear that doctors working in intensive care units in the UK are more likely to involve parents in decisions regarding life prolonging treatments than in some European countries.<sup>8</sup> Some healthcare practitioners regard the ultimate responsibility of deciding to withdraw treatment from a premature baby as too great a burden for parents to bear. However, research suggests that the majority of parents wish to make the final decision.<sup>9</sup>

### ***Advances in medicine and surgery***

In general, advances have led more to improvements in diagnostic capability than they have to better treatments. As a result, parents may often be given information about the condition of the fetus without any ability to offer options other than termination, continuation of the pregnancy or early delivery. Currently there are few options for surgery on the fetus.

### ***Before birth***

Since the first open fetal surgery to remove obstructions of the urinary tract was reported in 1982, new surgical techniques have been developed, for example, to treat conditions such as spina bifida and congenital diaphragmatic hernia (see glossary for definitions). Currently in the UK, very few surgical procedures a year are carried out on the fetus while still in the uterus. This is done only when the clinical condition of a fetus poses such a threat to its viability that later intervention would be unsuccessful. Such surgery involves minimally-invasive ultrasound-guided procedures through the skin and under local anaesthesia rather than opening up the body. Examples include fetal blood transfusion, the introduction of fine plastic tubes (shunts) to by-pass obstructions, and blocking of blood vessels by laser surgery.

It may be possible in the future to use stem cells before birth to correct a congenital disorder before symptoms develop. The potential of gene therapy for treating genetic disease by implanting normal copies of defective genes in the fetus has been explored in animal models, but use in humans remains some way off.

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<sup>8</sup> Rebagliato M, Cuttini M, Broggin L *et al.* (2000) Neonatal End-of-Life Decision Making: Physicians' attitudes and relationship with self-reported practices in 10 European countries *JAMA* **284**: 2451–9; Cuttini M, Rebagliato M, Bortoli P *et al.* (1999) Parental visiting, communication, and participation in ethical decisions: a comparison of neonatal unit policies in Europe *Arch Dis Child Fetal Neonatal Ed.* **81**: F84–91; McHaffie HE (2001) *Crucial Decisions at the Beginning of Life: Parents' experiences of treatment withdrawal from infants - An Executive Summary* (Oxford: Radcliffe Medical Press).

<sup>9</sup> McHaffie HE, Laing IA, Parker M and McMillan J (2001) Deciding for imperilled newborns: medical authority or parental autonomy? *J Med Ethics* **27**: 104–9.

### ***After birth***

Advances in neonatal medicine have included improvements in methods for intensive care, such as better instrumentation for mechanical ventilation, monitoring or diagnosis, better systems for nutrition and maintaining the correct fluid balance, the use of artificial surfactants to help babies breathe unaided, and light therapy for jaundice and blood transfusions. There have been substantial improvements in the clarity of biomedical imaging techniques which have enhanced diagnosis and further developments may be expected. There have also been improvements in training and in the organisation of care, for example, providing greater opportunities for parents to be involved in their infant's care and seeking to create a more homely atmosphere in the intensive care unit.

Researchers are actively investigating techniques for protecting the injured brain, for example using brain or whole body cooling to reduce the extent of damage, including permanent disability, from oxygen deprivation at birth.

### ***The treatment of pain***

As yet, we know very little about how pain is felt by the fetus in the womb. Human infants, like other young mammals, respond strongly to painful stimulation, but in a different way to adults. These responses are processed by the basic parts of the nervous system and are not well coordinated at birth. As the baby grows, its brain gradually develops the ability to recognise and process pain in an adult way. In a healthy baby, learning from ordinary touching helps their brain to become better at distinguishing types of pain and co-ordinating a response. But when a baby's development does not follow normal patterns, perhaps because they are unwell and have a lot of procedures without pain relief, pain processing is learnt in a different way, and can lead to increased sensitivity to pain in the short term. Research in animals suggests that, in the longer term, these babies and children may be more sensitive to pain from injury but may not respond as strongly to other painful stimulation. We do not know whether these changes in pain response last into adulthood. Knowing when an ill or premature infant has pain is still very difficult and deciding which treatments are the most effective with the least risk of side effects is even more challenging. Better understanding of the risks of pain has led to a more active monitoring of infants for signs of pain, and earlier and more frequent use of strong pain killers. Practices vary widely across the UK with regard to newborn pain assessment and management.

## **Question 1**

**In cases where a fetus may suffer from serious abnormalities that are likely to be disabling in the long term, what measures may it be appropriate to take to sustain the life of the fetus or, where possible, to correct those abnormalities before birth?**

**Do you consider that there are ever circumstances when it would be appropriate to override the wishes of the pregnant woman?<sup>10</sup>**

## **Question 2**

**In which of these circumstances, if any, would it not be appropriate to use medicine and surgery to prolong the life of the newborn?**

- **When the baby is extremely premature**
- **When the baby has congenital abnormalities**
- **When the baby has poor prospects for survival because of a genetic or other disorder, or because of growth restriction during the pregnancy**
- **When the baby has acquired brain damage and is considered to be likely to have severe disabilities later in life**

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<sup>10</sup> Examples could include cases in which a fetus may suffer from serious abnormalities that are likely to be disabling in the long term, or cases where professionals consider that, by neglecting or harming herself or refusing treatment for the fetus, the mother is threatening the long term health of the fetus once born.

## **2 Ethical issues**

We recognise that, for many readers, there will be an overlap between the questions we ask about ethical and social issues. Please respond where you consider that your views fit best. It may be that you will have different views depending upon whether the context of the question is ethical or social.

Many of the ethical issues raised by the prolonging of life in the fetus and the newborn have been discussed elsewhere. They have been a feature of debates about abortion and about euthanasia in adult patients. We have highlighted some of the main issues below.

### ***What is the moral status of the fetus?***

From a scientific perspective, the origin of a new human being can be traced to the moment when the egg and sperm fuse to form the start of a new life. However, people differ in their views as to whether this event also marks the creation of a new entity with full moral status, i.e. with the same moral and legal rights that are accorded to already born living humans. Those who disagree with this concept of absolute moral status face the difficulty of stating at what stage, and why, human beings should acquire full moral status. Some argue that moral status begins at conception, others with the physical presence of basic neural structures at 54 days after conception. Yet others accord full moral status at the point of birth, or when the infant shows self-awareness, at the age of about one month.

The question of moral status bears on several practical issues, such as to what extent measures should be taken to limit fetal pain. It also critical to more fundamental issues such as whether it is ethical ever to cause or allow pain to another person; whether the unborn baby has the same interests or rights (for example, to medical care) as an adult; whether birth changes this status; and whether there is a difference between letting die, or terminating the life of a fully grown fetus at nine months and a baby of the same age. In an area such as this where many differing views are to be expected, there is a broader ethical question, of how best society should balance the varying wishes and needs of individuals.

### ***Is there a difference between acting and not acting?***

There may come a point when healthcare professionals and parents have to decide whether to begin treatment or whether to withdraw it, in circumstances where the balance between the benefits and burdens of that treatment may be uncertain. When a fetus is discovered to have a serious condition, the mother may be asked whether she wishes to continue with the pregnancy or to seek a termination. For a few conditions, treatment of the fetus while in the womb, either directly or via the mother may be an option; more usually the baby could be delivered early to allow neonatal treatment. For the newborn baby having little or no prospect of successful treatment or recovery without serious

disabilities, there could be a range of possible plans for treatment. These options are set out in Box 2 below. An important ethical question in such situations is whether acting and not acting are morally different if the consequences are the same, especially if taking action might limit suffering.

**Box 2: Acting and not acting: examples of potential care plans for newborn babies with little or no prospect of successful treatment or of recovery without serious disabilities**

- a) Providing full intensive care (ie the whole range of medical neonatal care) with appropriate relief of pain or discomfort, until in most cases the baby dies
- b) Providing fluids and nutrients and making the baby comfortable in other ways but not starting further treatment, such as respiratory support, antibiotics or surgery to combat breathing difficulties, infection or other circumstances that may threaten the baby's life
- c) Actively removing a baby from a ventilator so that it can die a 'natural' death in the arms of its mother and father
- d) Giving a large dose of analgesics or other sedatives to ease pain, appreciating that this treatment may shorten life. Note: In the UK, deliberate intervention to cause the death of an infant constitutes homicide.

**Question 3**

**In your view, are these the principal ethical questions that the Working Party should consider?**

- 1 The moral status of the fetus**
- 2 Acting and omitting to act**
- 3 Questions about the quality of life**

**Which of these or other ethical questions would you identify as the most important?**

### **3 Social issues**

As we have said, for many readers, there will be an overlap between the questions we ask about ethical and social issues. Please respond where you consider that your views fit best. It may be that you will have different views depending upon whether the context of the question is ethical or social.

#### ***How we understand disability***

Different people perceive disability in different ways. Some view disability as an 'impairment' comparable with diseases or other medical disorders. Others see it as a product of social discrimination, rather than a personal limitation. They may contend that there is a unique relationship between a person's disability and their self-identity. While accepting that disabled people may be subject to harmful and wrongful social discrimination and exclusion, others do not regard disabilities solely as an effect of discrimination. They observe that social intervention cannot remove a physical impairment or inability to do something that most others are able to. Disability might also be viewed in diverse ways by different religions, and individuals may have their own religious or spiritual perspective.

Many people's perception would be that developed societies place a high value on very young life, although questions can arise where there is disability. Some people would have difficulty in justifying prolonging the life of the very young when contrasted with prolonging the life of the elderly or the middle aged. Others might hold a different view. An important social consideration may be that the potential of a very young individual is undeveloped, whereas an older person, including an older child, will have established interactions, capabilities and responsibilities.

#### ***Quality of life***

The term 'quality of life' will mean different things to each of us. In the context of a medical condition, it usually refers to the overall effects of a combination of factors, including health and the presence of symptoms, and reflects a person's ability to function physically, psychologically and socially. The term can include subjective feelings of well-being, fulfilment or satisfaction resulting from factors beyond the specific impairment. Somebody with a disability but who is otherwise healthy might be expected to report a good quality of life, whereas someone with a troublesome and painful chronic disease that restricts what they are able to do would likely report that their quality of life is poor.

It is easier to form a view of the quality of life for another adult than it is for a baby or child who cannot answer fully for themselves. In making decisions about prolonging life, many would be sympathetic to the view that those closest to the child, who will usually be family members, are best placed to judge that child's quality of life. The family will be the most familiar with the child's environment outside the hospital and family members are also likely to become

the main carers. If this is the case, should it be the family that decides whether or not to provide a treatment that potentially will affect the child's quality of life? Who else should be involved or provide advice and are there other circumstances that should be fulfilled?

### ***How does having a disabled child affect the family?***

It is not straightforward to predict the extent of disability amongst babies who survive, even amongst those born at similar gestational ages or with similar conditions. It is the case, however, that many will need supplementary care and support, sometimes for the whole of their lives.

A surviving baby could suffer pain and repeated operations and could also suffer later in life. In severe cases, from a medical perspective, the child may have only a poor quality of life. Less severely affected children may become aware of and troubled by differences because of their condition and may experience discrimination. Their parents might have to come to terms with unexpected disappointment and resentment and may find it a physical and mental strain to care for their child's extra needs, especially if they have other children to care for. The wider circle of family and friends might well be affected emotionally or practically, and need to adapt.

Parents will usually have a deep sense of moral responsibility and want to do everything that they can for their child, realising fully that a decision about prolonging life will affect the entire family for the rest of their lives. Many parents will have positive expectations of their disabled child, but may worry that they will not receive the support they deserve from society. From their perspective, any additional social or economic costs involved are likely to seem insignificant, relative to their perceptions of how society distributes resources. What role should parental views play in debates about the allocation of resources to prolonging life?

### ***Social perceptions***

Prolonging the life of fetuses and the newborn involves many social institutions. These include the family, healthcare services, the education system, the social services, the law, professional bodies providing guidance on social, ethical and legal issues, the media, patient, disability rights and self-help groups. Such institutions differ in their spheres of influence and in access to resources. For example, state provision for health and education may be supplemented by help from charities or religious bodies. Institutions may work in a complementary way or the views of one institution may challenge the judgement or independence of another. An example would be when the law sets limits for the practice of medicine. It could be that people's perceptions of institutions may in themselves influence how those institutions operate. However there has been little systematic empirical research to help address these and related social questions.

Today, many people are prepared to question expert opinion, and medical opinion has been challenged through the courts. In a few cases, people have relinquished their privacy and sought a judgement on their case through the open court. Do people now see the law as a means of challenging medical practice? Or are the law and medical practice sometimes perceived as opposing family interests? Understanding the social factors that lead a family or health authorities to take a case to court may help clarify whether legal involvement is appropriate.

Religious and spiritual influences are likely to affect family decisions, at least in some cases. In the developed world, debate in the media could also influence people's views.

#### **Question 4**

**The Working Party has identified the following questions for discussion:**

What might we mean by 'quality of life' for a child?

How do religious and spiritual influences affect decisions?

How do the mass media influence decisions?

**In your view, are these questions that the Working Party should consider? Should any of these questions be omitted, or are there additional questions that should be included? Which social questions would you identify as the most important?**

## **Question 5**

**Who is best placed to judge the quality of life for a child?**

**When families as well as professionals are involved, whose decision should carry the most weight on whether or not to intervene to prolong the life of a fetus or a newborn baby?**

***Examples of people likely to be involved:* the mother, the father, other family members, doctors or other healthcare professionals, healthcare managers, the courts, the social services.**

**When parents are involved, whose views should take precedence? *For example:* mother, father, parents together.**

**Who else should be involved?**

**How should such decisions be made, and how should any differences in view between the parties involved be resolved?**

**When, if at all, do you think that people should use the law to challenge medical advice?**

## 4 Economic issues

There are two primary aspects to economic evaluation of health care interventions. First, there are the costs of health care interventions that are incurred by the health services, other sectors of the economy, patients, caregivers and society as a whole. Secondly, there are the consequences of health care interventions that are usually measured in natural or physical units, such as lives saved, or in terms of preference-based outcome measures, such as quality-adjusted life years (QALYs) gained (see Box 3).

### **Box 3: Assessing the cost-effectiveness of health care interventions**

The assessment of the quality of life component of QALYs (quality-adjusted life years) can be made using questionnaire or interviewer based approaches. QALY based approaches use scaling techniques, such as the rating scale, the standard gamble approach and the time trade-off approach, or multi-attribute measures, to assess health states.

The cost-effectiveness of health care interventions can be assessed within the context of randomised controlled trials or by using other methods of enquiry, such as decision-analytic modelling. Economic evaluation of health care interventions is generally presented as a ratio of cost per unit of health gain. A QALY is an example of a measure of health gain. If an intervention proves to be more effective but also more costly, a decision will be needed as to whether the health units gained (such as QALYS) are worth the extra cost incurred. Some commentators dispute the value of the QALY measure in wider decision-making for health. In the context of individuals with severe disabilities, measurement of outcomes using QALYs may differ according to individual circumstances and between different societies.

In the UK, the National Institute for Clinical Excellence (NICE) makes recommendations on clinical treatment and care using the best evidence available. The evaluation of the safety and efficacy of drugs and devices falls to the Medicines and Healthcare products Regulatory Agency (MHRA).

There have been relatively few studies on the cost-effectiveness of neonatal care. In the short term, it could be argued that neonatal care is very effective in reducing mortality, and that its cost-effectiveness compares favourably with other medical interventions. This is especially the case for newborn babies of higher birth weight or gestational age. However, the longer term costs of care for children affected with disabilities may begin to exceed the costs of care during the neonatal period as the child gets older. It has been estimated that, in

1998, it cost £125,000<sup>11</sup> to bring up a child with a severe disability, which was at least three times more than the amount required for a child without a disability. These longer-term economic implications are therefore important considerations when comparing the cost-effectiveness of neonatal care with other forms of health care.

### **Question 6**

**How much weight (if any) should be given to economic considerations in determining whether to prolong the life of fetuses or the newborn?**

### **Question 7**

**Should a quality-adjusted life (QALY) (or another measure of health gain) for a newborn child be give the same weight as a QALY for a middle aged or elderly person?**

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<sup>11</sup> Dobson B and Middleton S (1998) *Paying to care: The cost of childhood disability* (York: The Joseph Rowntree Foundation).

## 5 Professional guidance and the law

Advances in care mean that decisions about prolonging life in fetuses and the newborn can no longer be based merely on whether survival is possible. Instead, there is a range of professional and statutory guidance, which makes decision-making more complex because decisions have to be taken by third parties on behalf of the fetus or infant. Professional guidance is very important in guiding day to day clinical decisions (for examples, see Appendix A). The law provides a broad framework but the various relevant Acts were originally developed to address related issues, such as abortion or child protection. This means that careful interpretation is needed, according to the particular circumstances of a case. If there is a lack of clarity, there will need to be recourse to case law.

Separate legislation pertains to the protection of the embryo,<sup>12</sup> the fetus and the child. A pregnant woman is usually able to provide consent for her own treatment, which may affect the embryo or fetus, and her decision, in law, must be respected as long as she is mentally competent. When clinical decisions are taken as part of a research study, additional ethical and legal considerations will apply, for example over consent and liability.

### *The current legal framework in the UK: embryos and fetuses*

In English, Welsh and Scottish law,<sup>13</sup> the fetus does not acquire legal personality until born alive. Termination of pregnancy prior to 24 weeks is lawful when (among other things) it can be shown that the risk for the mother of continuing the pregnancy is greater than termination of the pregnancy. Nevertheless, the **Abortion Act (1967)** is often interpreted to allow abortion on request within the first three months. After this time the procedure is more complicated and termination may be more difficult to obtain.<sup>14</sup> Beyond six months, termination is lawful if there is a risk of grave permanent injury to the mother, or to her life, or if there is a 'substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped'. The Act offers no definition of what constitutes serious handicap.

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<sup>12</sup> The **Human Fertilisation and Embryology Act (1990)** focuses on respect for, and protection of, embryos.

<sup>13</sup> Scottish law differs on a number of issues.

<sup>14</sup> The **Abortion Act (1967)** (as amended by the **Human Fertilisation and Embryology Act (1990)**) covers England, Scotland and Wales, but not Northern Ireland and provides for the termination of pregnancy in a number of circumstances, offering a defence to prosecution under the **Offences against the Person Act (1861)**.

### ***The current legal framework in the UK: disability and disability discrimination***

As we have said, the increasing survival of premature babies has been accompanied by a greater incidence of disability. The first of two relevant Acts in relation to disability concerns parental injury during pregnancy<sup>15</sup> and the second concerns discrimination. Under the **Disability Discrimination Act (1995)**, a disability is defined as 'a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day to day activities'. 'Impairment' is not defined, but regulations clarify certain exclusions.

The Disability Discrimination Act protects disabled people (children and adults) from discrimination and less favourable treatment for a reason relating to their disability. The Disability Discrimination Bill (currently going through Parliament) will introduce a 'public sector duty' requiring all public bodies (including the NHS) to promote equality of access for disabled people. The **Children's National Service Framework** (Standard 8 on Disabled Children) expects that commissioners and providers of services will have regard to their duties under the Disability Discrimination Act. The legislation on disability discrimination increasingly is invoked in disputes around decisions to withhold or withdraw treatment.

### ***Wrongful life and wrongful birth***

Litigation involving wrongful life and wrongful birth has increased, particularly in the United States. Wrongful life refers to the situation where the child sues the mother or other people for being born, and wrongful birth refers to the situation where the mother sues other people for being burdened with a disabled child when she could have avoided this situation. In England the Court of Appeal has ruled that children cannot bring an action for wrongful life.<sup>16</sup> Claims for wrongful birth, to cover the additional costs of raising a disabled child, continue to be allowed.<sup>17</sup>

In the UK, legal decisions regarding withholding or withdrawing care from children are underpinned by the **Children Act (1989)** which emphasises the best interests of the child, and the **Human Rights Act (1998)**, which emphasises the universal right to life.

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<sup>15</sup> **The Congenital Disabilities (Civil Liability) Act (1976)** covers negligent damage to a parent during pregnancy which affects the child once born. The Act (which applies in England, Wales and Northern Ireland) provides for recovery of damage by the child where he or she has suffered as a result of a breach in a duty of care owed to the mother or the father during the pregnancy. The second Act is the **Disability Discrimination Act (1995)** which aims to protect disabled persons from discrimination.

<sup>16</sup> *McKay v Essex Health Authority* (1982) 2 *All England Reports* 771.

<sup>17</sup> *Parkinson v St James and Seacroft University NHS Hospital Trust* (2001) 3 *All England Reports* 97.

### ***The current legal framework in the UK: children***

The Children Act makes the child's welfare the paramount consideration, covering 'any harm which he has suffered or is at risk of suffering'. Parental autonomy is usually upheld when the best interests of the child are not clear and where life-prolonging treatment is only marginally beneficial.

### ***The current legal framework in the UK: human rights***

The Human Rights Act makes the provisions of the **European Convention on Human Rights (1950)** enforceable against any public authority. This has meant that NHS authorities and health professionals must take account of the fundamental rights of children and their families in their work. The dilemmas addressed in this consultation, however often deal with circumstances where rights may conflict and/or the content of any such right is far from clear. In relation to fetuses, the European Court of Human Rights has ruled that it is neither desirable nor possible to answer in the abstract whether the unborn child has a right to life.<sup>18</sup>

The mother has parental responsibility for the child if the father and mother were not married to each other at the time of the child's birth. If married, each parent has responsibility and may act alone and without the other in meeting that responsibility. An unmarried father will gain parental responsibility when he and the child's mother jointly register the birth of their newborn child.<sup>19</sup> Otherwise, in the UK, an unmarried father has few legal rights with regard to his children unless he has signed a prior, legally binding Parental Responsibility Agreement or has made a successful application through the courts.

### ***Parental disagreement***

If the parents of a child cannot agree on a decision relating to the welfare of the child then parent(s) may ask the courts to intervene. The court has the right to require parents to seek permission before they take any step in meeting parental responsibility for their child.

### ***Disagreement between parents and the healthcare team***

In cases where doctors recommend a treatment or the withholding of treatment for a child but the parent(s) are unwilling to provide their consent, doctors cannot proceed except in emergency situations.<sup>20</sup> The court may be asked to

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<sup>18</sup> European Court of Human Rights (2004) *Press release issued by the Registrar Grand Chamber Judgment in the case of Vo v. France*, available at: [http://www.echr.coe.int/Eng/Press/2004/July/GrandChamberjudgmentVovFrance080704.htm#\\_ftn1](http://www.echr.coe.int/Eng/Press/2004/July/GrandChamberjudgmentVovFrance080704.htm#_ftn1) Accessed on: 3 Mar 2005; *Vo v. France* (2004) Family Court Reports Vol 2 577.

<sup>19</sup> The **Adoption and Children Act (2002)** amends the **Children Act (1989)** to provide this condition.

<sup>20</sup> See decision of European Court of Human Rights on *Glass v. United Kingdom* (2004) ECHR 102, available at: <http://www.worldlii.org/eu/cases/ECHR/2004/102.html> Accessed on: 3 Mar 2005.

review the facts of the individual case and may, after considering the issues, decide to overrule the parents and provide the necessary consent for the proposed treatment. The court is required to pay particular attention to the welfare of the child and ensure that the decision does not contravene the European Convention on Human Rights. The **UN Convention on the Rights of the Child**<sup>21</sup> sets out a near universally-agreed set of non-negotiable standards and obligations that spell out the basic human rights for children everywhere. These are the right to survival; to develop to the fullest; to protection from harmful influences, abuse and exploitation; and to participate fully in family, cultural and social life.

### ***Recent cases***

Until recently, the majority of cases have been heard privately, but two recent cases, those of Charlotte Wyatt and Luke Winston-Jones, were heard in open court. In both these recent cases, the respective judges allowed doctors to decline resuscitation in the event that either infant suffered further breathing difficulties, although there is currently an appeal in the case of Charlotte Wyatt.<sup>22,23</sup>

### ***The legal framework for research***

Research involving fetuses or the newborn will require consideration of additional legal issues. With regard to privacy and confidentiality, the **Human Rights Act (1998)** and the **Data Protection Act (1998)** protect the rights of individuals within research and diagnostics. The **Human Tissue Act (2004)**, when it comes into operation, aims to provide a consistent legislative framework for issues relating to whole body donation and the taking, storage and use of human organs and tissue. It was drawn up partly in response to the revelations about practices of organ retention in the Bristol Interim Inquiry Report and the Redfern reports, which found that organs were taken from deceased children without adequate parental consent.<sup>24</sup>

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<sup>21</sup> United Nations (1989) *The Convention on the Rights of the Child*, Adopted by the General Assembly of the United Nations on 20 Nov 1989, Defence for Children International and the United Nations Children Fund, Geneva, available at: <http://www.unhcr.ch/html/menu3/b/k2csrc.htm> Accessed on: 3 Mar 2005.

<sup>22</sup> The Wyatt judgement is available at: <http://www.bailii.org/ew/cases/EWHC/Fam/2004/2247.html> Accessed on: 3 Mar 2005.

<sup>23</sup> See BBC News Online (8 Oct 2004) *Q&A: The Charlotte Wyatt case*, available at: <http://news.bbc.co.uk/1/hi/health/3724194.stm> Accessed on: 3 Mar 2005; BBC News Online (25 Feb 2005) *Baby Charlotte new evidence claim*, available at: <http://news.bbc.co.uk/1/hi/england/hampshire/4297801.stm> Accessed on: 3 Mar 2005.

<sup>24</sup> See The Inquiry into the management of care of children receiving complex heart surgery at the Bristol Royal Infirmary (2000) Interim Report *Removal and retention of human material*, available at: [http://www.bristol-inquiry.org.uk/interim\\_report/index.htm](http://www.bristol-inquiry.org.uk/interim_report/index.htm) Accessed on 3 Mar 2005; (2001) *The Report of The Royal Liverpool Children's Inquiry*, available at: <http://www.rlcinquiry.org.uk/> Accessed on: 3 Mar 2005.

All research studies involving fetuses and the newborn, including clinical trials, must be approved by a hospital's Research Ethics Committee. Proposals must be based on secure and reasonable information and be unlikely to pose any increased risk over and above standard treatment. Consent for participation in any trial and the option to withdraw from the research study at any point must both be voluntary (in the case of the newborn, this consent is on behalf of the subject). Ethical guidance for conducting research in children in the UK has been developed by the **Royal College of Paediatrics and Child Health** and the **Medical Research Council**.

The majority of clinical and scientific developments that have helped to prolong life would not have been possible without the consent of parents of premature and unwell newborn infants to research studies involving their children. Particular consideration and sensitivity is needed because such decisions have to take place at very difficult times. Research on fetal pain raises especially difficult ethical issues. In the UK, sensitivities about clinical research in children have been exacerbated by the findings of the Bristol and Redfern reports (see first paragraph in this section).

### **Question 8**

**Would drawing up more directive professional guidance be helpful to parents and professionals?**

**If so, should the UK follow practice in other countries and set a minimum age below which resuscitation normally would not be permitted?**

### **Question 9**

**Would drawing up new legislation in this area be helpful to parents and professionals?**

Thank you very much for considering these questions. Please now turn to page 38 in order to respond to the consultation.

## Glossary

**Abortion:** Premature expulsion of the fetus from the womb as a result of an operation or medication. The procedure is also termed termination of pregnancy.

**Biomedical imaging:** The use of imaging devices and techniques to obtain images from inside the body and to provide biochemical and physiological analysis of tissues and organs. Advanced technologies are now used to capture, store, analyse and display images at the organ, tissue, cellular, and molecular level. These technologies include magnetic resonance imaging, molecular imaging and scanning microscopy.

**Congenital anomalies:** Abnormalities or diseases which are either present at birth or show themselves soon after birth.

**Congenital diaphragmatic hernia:** A protrusion of the abdominal contents into the chest through the diaphragm.

**Disability:** The **Disability Discrimination Act 1995** (DDA) provides the following definition of a disabled person: 'A person has a disability if he or she has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day to day activities.' The DDA interprets 'long-term' as twelve months or more.<sup>25</sup>

**Embryo:** A fertilised egg up to eight weeks of development.

**Euthanasia:** A deliberate act or omission with the primary intention to end another's life. Literally, it means a gentle or easy death, but has come to signify a deliberate intervention with the intention to kill someone, who, for example, may be in pain with a terminal illness.

**Fetus:** The term used for an embryo after the eighth week of development until birth.

**Gestation:** The time from conception to birth.

**Gestational age:** The fetal age of a newborn baby, calculated from the number of completed weeks since the first day of the mother's last menstrual period to the date of birth.

**Handicap:** There is no legal definition of handicap in UK legislation. It is generally interpreted as meaning a disabled person's loss or limitation of opportunities to take part in the normal life of the community on an equal level with others, due to physical or social barriers. Physical and social barriers can include inaccessible physical environments, transport, provision of equipment and access to appropriate educational opportunities or social care.

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<sup>25</sup> The Disability Discrimination Bill (currently going through Parliament) will further clarify definitions of disability and impairment.

**Impairment:** The **Disability Discrimination Act 1995** defines impairment as the loss or limitation of physical, mental or sensory function on a long-term or permanent basis. The definition in the **Act** covers a wide range of impairments including medical conditions, such as diabetes and epilepsy. Physical impairment includes sensory impairment and mental impairment includes learning disabilities and mental health problems. The test in the **Act** of whether an impairment affects normal day to day activity is whether it relates to one or more of the following: mobility, manual dexterity, physical co-ordination, continence, ability to lift, carry or otherwise move everyday objects, speech, hearing or eyesight, memory or ability to concentrate, learn or understand and perception of risk of physical danger.

**Intensive care:** The whole range of medical neonatal care, but not necessarily all specialist services, such as neonatal surgery.

**Neonatal period:** The period within 28 complete days of delivery.

**Newborn:** A term used to describe very young babies. Strictly speaking, the 'newborn' or 'neonatal' period is the time within 28 complete days of delivery.

**Perinatal period:** The period from (usually) 24 weeks into the pregnancy until 6 completed days after birth.

**Premature birth:** Delivery of a baby before the 37th week of the pregnancy.

**Very premature:** Delivery of a baby before the 31st week of the pregnancy.

**Extremely premature:** Delivery of a baby before the 26th week of the pregnancy.

**Spina bifida:** A condition which occurs early in pregnancy, caused when the neural tube (which later forms the brain and spinal cord) does not develop properly, resulting in spinal abnormalities. Spina bifida results in symptoms which range from back pain and bowel and bladder problems to paralysis of the lower body.

**Surfactant:** A natural substance which helps to reduce the tension on the surface of the lungs and makes breathing easier. A premature baby may not produce sufficient surfactant, which can lead to respiratory distress syndrome (RDS) or hyaline membrane disease (HMD). Artificial surfactant is therefore provided when necessary.

**Term:** An infant is born at 'term' if they have a gestational age of between 37 completed weeks (259 completed days) and 42 completed weeks (294 completed days).

**Termination:** See abortion.

## Further sources of information<sup>26</sup>

**BLISS – the premature baby charity** <http://www.bliss.org.uk/>

**British Association of Perinatal Medicine** <http://www.bapm.org/>

**British Medical Association** <http://www.bma.org.uk/>

**Contact A Family** <http://www.cafamily.org.uk/>

**Department of Health *Report of the Neonatal Intensive Care Services Review Group*** <http://www.dh.gov.uk/assetRoot/04/01/87/44/04018744.pdf>

**Medical Research Council** <http://www.mrc.ac.uk/>

**NHS National Service Framework for Children**  
<http://www.nhs.uk/england/aboutTheNHS/nsf/childrensServices.cmsx>

**Resuscitation Council UK** <http://www.resus.org.uk/>

**Royal College of Obstetricians and Gynaecologists** <http://www.rcog.org.uk/>

**Royal College of Paediatrics and Child Health** <http://www.rcpch.ac.uk/>

**UK Nursing and Midwifery Council** <http://www.nmc-uk.org/>

### **The making of the unborn patient**

Monica Casper  
Rutgers University Press, 1998

### **Causing Death and Saving Lives**

Jonathan Glover  
Penguin Books, 1977

### **Ethics and Perinatology**

Edited by Goldworth, Silverman, Stevenson and Young  
Oxford Medical Publications, 1995

### **Crucial Decisions at the Beginning of Life**

Hazel McHaffie in association with others  
Radcliffe Medical Press, 2001

### **Saving Premature Babies**

Pauline Challinor Mifflin  
Books for Midwives, 2003

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<sup>26</sup> This is not a comprehensive list. Please note that the Nuffield Council on Bioethics does not endorse the content of these sites or publications.

## List of questions

### Question 1

In cases where a fetus may suffer from serious abnormalities that are likely to be disabling in the long term, what measures may it be appropriate to take to sustain the life of the fetus or, where possible, to correct those abnormalities before birth?

Do you consider that there are ever circumstances when it would be appropriate to override the wishes of the pregnant woman? <sup>27</sup>

### Question 2

In which of these circumstances, if any, would it not be appropriate to use medicine and surgery to prolong the life of the newborn?

- When the baby is extremely premature
- When the baby has congenital abnormalities
- When the baby has poor prospects for survival because of a genetic or other disorder, or because of growth restriction during the pregnancy
- When the baby has acquired brain damage and is considered to be likely to have severe disabilities later in life

### Question 3

In your view, are these the principal ethical questions that the Working Party should consider?

- 1 The moral status of the fetus
- 2 Acting and omitting to act
- 3 Questions about the quality of life

Which of these or other ethical questions would you identify as the most important?

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<sup>27</sup> Examples could include cases in which a fetus may suffer from serious abnormalities that are likely to be disabling in the long term, or cases where professionals consider that, by neglecting or harming herself or refusing treatment for the fetus, the mother is threatening the long term health of the fetus once born.

#### **Question 4**

The Working Party has identified the following questions for discussion:

What might we mean by 'quality of life' for a child?

How do religious and spiritual influences affect decisions?

How do the mass media influence decisions?

In your view, are these questions that the Working Party should consider? Should any of these questions be omitted, or are there additional questions that should be included? Which social questions would you identify as the most important?

#### **Question 5**

Who is best placed to judge the quality of life for a child?

When families as well as professionals are involved, whose decision should carry the most weight on whether or not to intervene to prolong the life of a fetus or a newborn baby? *Examples of people likely to be involved:* the mother, the father, other family members, doctors or other healthcare professionals, healthcare managers, the courts, the social services.

When parents are involved, whose views should take precedence? *For example:* mother, father, parents together.

Who else should be involved?

How should such decisions be made, and how should any differences in view between the parties involved be resolved?

When, if at all, do you think that people should use the law to challenge medical advice?

#### **Question 6**

How much weight (if any) should be given to economic considerations in determining whether to prolong the life of fetuses or the newborn?

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Should a quality-adjusted life (QALY) (or another measure of health gain) for a newborn child be give the same weight as a QALY for a middle aged or elderly person?

**Question 8**

Would drawing up more directive professional guidance be helpful to parents and professionals?

If so, should the UK follow practice in other countries and set a minimum age below which resuscitation normally would not be permitted?

**Question 9**

Would drawing up new legislation in this area be helpful to parents and professionals?

## **Appendix A: Some examples of UK guidance on prolonging life in the newborn**

The **National Service Framework for Children** provides national standards for healthcare and social services across the NHS for all children.

The **British Medical Association** provides guidance for decision-making on *Withholding and Withdrawing Life Prolonging Medical Treatment* (2001) and expects the same ethical framework for the provision or continuation of treatment to apply to babies as for children, young people and adults. The guiding principle is that the treatment should be in the child's best interests. Where there is reasonable uncertainty about the possible benefits of life-prolonging treatment, the BMA advises presumption in favour of initiating it. Criteria for determining a child's best interests include whether the child has the potential to develop awareness, the ability to interact and the capacity for self-directed action, and whether the child will suffer severe unavoidable pain and distress.

The **General Medical Council** sets out standards of practice expected of doctors when they consider whether to withhold or withdraw life-prolonging treatments in *Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making* (2002). The guidance is based on ethical principles which include doctors' obligations to show respect for human life; protect the health of their patients; and make their patients' best interests their first concern. Issues raised for consideration include: whether doctors should offer all means at their disposal to prolong a patient's life; the circumstances in which withholding or withdrawing life-prolonging treatment would be unlawful; and the responsibilities in the decision-making process of the patient, doctor, healthcare team, family members and other people who are close to the patient.

The **Royal College of Paediatrics and Child Health** has issued guidance on *Withholding or Withdrawing Life Saving Treatment in Children* (1997). It distinguishes five situations where it may be ethical or legal to consider withholding or withdrawing life sustaining or curative medical treatment: the 'brain dead' child; the 'permanent vegetative state'; the 'no chance' situation (where the child has such severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering); the 'no purpose' situation (where the patient may be able to survive with treatment, but at a cost of severe physical or mental impairment); and, the 'unbearable' situation (where the child and/or family feel that in the face of progressive illness, further treatment is more than can be borne).

The **British Association of Perinatal Medicine** has published guidelines in the form of a memorandum entitled *Fetuses and Newborn Infants at the Threshold of Viability: A Framework for Practice* (2000). The guidelines recommend that decisions on management should be based on what is perceived by the parents and their medical advisors to be in the child's best interests; medical staff have a responsibility to keep parents informed as to the likely clinical outcome of decisions and counselling must be honest and accurate. They emphasise the need, where possible, for advance liaison between members of the medical team and highlight the possibility of obtaining advance authorisation for non-resuscitation and non-provision of intensive care for infants at the extreme margins of viability.

## **Responding to the consultation**

**Please submit responses online at:**

**<http://www.nuffieldbioethics.org>**

**OR you can email your response to:**

**[bioethics@nuffieldbioethics.org](mailto:bioethics@nuffieldbioethics.org)**

**If we receive your response electronically, there is no need for you also to send a paper copy. If you should prefer to respond by post or by fax, you may send completed responses to:**

Dr Catherine Moody  
Nuffield Council on Bioethics  
28 Bedford Square  
London WC1B 3JS  
UK

Fax: +44 (0)20 7637 1712

Additional copies of this document can be downloaded from the Council's website: **<http://www.nuffieldbioethics.org>**

For printed copies, please contact the Council at the above address.

**Thank you**

**Closing date for responses: 9 June 2005**

# The ethics of prolonging life in fetuses and the newborn

## Details of respondents

Please complete and return with your response by **9 June 2005**

**Name:** \_\_\_\_\_

**Address (optional) \*** \_\_\_\_\_

\_\_\_\_\_

**Email:** \_\_\_\_\_

**Are you responding personally, on your own behalf, or on behalf of your organisation?**      **Personal / Organisation**

**This response may be published as part of an appendix to the final report**      **Yes / No / Anonymous**

**This response may be quoted in the report**      **Yes / No / Anonymous**

**This response may be made available on the Council's website when the report is published**      **Yes/ No / Anonymous**

**This response may be made available to other researchers interested in the topic**      **Yes / No**

If you have answered 'yes' to any of the above questions, please indicate your name and/or the title of your organisation as it should appear in print:

\_\_\_\_\_

**Please let us know where you heard about the consultation:**

- Web site of the Nuffield Council on Bioethics
- Sent copy by Nuffield Council on Bioethics
- Email mailing list
- Other (please state):

\_\_\_\_\_

**We should like to be able to contact you again both about this topic and future work by the Council that may be of interest to you. May we keep your contact details for this purpose? We will only use these details as specified above and will not pass them to third parties without your specific permission.**

**Yes, you may keep my contact details**

**only until the Report is published, so that you can send me a copy**

**until I notify you otherwise**

**Please do not keep my contact details**

\* Please note that if we do not have your address, we will not be able to send you a copy of the report when it is published.

**Closing date for responses: 9 June 2005**