

The background of the entire page is a deep teal color. Overlaid on this are several curved, overlapping lines in a lighter shade of teal, creating a sense of movement and depth. The lines are most prominent in the upper half of the page and curve downwards towards the bottom right.

**Critical care
decisions in fetal and
neonatal medicine:
ethical issues**

**NUFFIELD
COUNCIL^{ON}
BIOETHICS**

**Published by
Nuffield Council on Bioethics
28 Bedford Square
London WC1B 3JS**

**Telephone: 020 7681 9619
Fax: 020 7637 1712
Email: bioethics@nuffieldbioethics.org
Website: <http://www.nuffieldbioethics.org>**

**ISBN 1 904384 14 5
November 2006**

To order a printed copy please contact the Nuffield Council on Bioethics or visit the website.

© Nuffield Council on Bioethics 2006

All rights reserved. Apart from fair dealing for the purpose of private study, research, criticism or review, no part of the publication may be produced, stored in a retrieval system or transmitted in any form, or by any means, without prior permission of the copyright owners.

Production management by: The Clyvedon Press Ltd
95 Maes-y-Sam
Pentyrch
Cardiff CF15 9QR

Printed by: Latimer Trend & Company Ltd
Estover Road
Plymouth PL6 7PY

**Critical care decisions
in fetal and
neonatal medicine:
ethical issues**

NUFFIELD
COUNCIL ON
BIOETHICS

Nuffield Council on Bioethics

Professor Sir Bob Hepple QC FBA (Chairman)

Professor Peter Smith CBE (Deputy Chairman)

Professor Margaret Brazier OBE*

Professor Roger Brownsword

Professor Sir Kenneth Calman KCB FRSE

The Rt Rev Richard Harries DD FKC FRSL

Professor Peter Harper

Professor Søren Holm

Mr Anatole Kaletsky

Dr Rhona Knight

Professor Sir John Krebs FRS*

Professor Peter Lipton

Professor Hugh Perry

Professor Lord Plant of Highfield

Dr Alan Williamson FRSE

* co-opted members of the Council for the period of chairing the Working Parties on *Critical care decisions in fetal and neonatal medicine: ethical issues* and *Public health: ethical issues*

Secretariat

Professor Sandy Thomas (Director)

Dr Catherine Moody

Mr Harald Schmidt

Ms Julia Fox (until March 2005)

Ms Carol Perkins

Ms Catherine Joynson

Ms Caroline Rogers

Mrs Julia Trusler

Mr Mun-Keat Looi (until September 2005)

Ms Elaine Talaat-Abdalla (until June 2005)

Mrs Audrey Kelly-Gardner

Ms Claire Stephens (until March 2006)

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.

**The Nuffield Council on Bioethics is funded jointly by
the Medical Research Council, the Nuffield Foundation and the Wellcome Trust**

Foreword

This Report examines decision making in areas of medicine where emotions cannot be detached from the process of resolving painful dilemmas about how best to care for a very ill baby. Nor should they be. For hundreds of years, doctors and midwives have sometimes had to decide whether to save a mother or her baby in childbirth, and whether to attempt to treat a baby delivered in a very poor condition. In reality, until recently, there was often little doctors could do. Scientific advances have meant that doctors can now intervene. In some cases, the question becomes: *should they do so?*

Medicine has developed rapidly in the past forty years. Screening in pregnancy enables doctors to identify an increasing number of the problems that can occur during fetal development. Today, expectant mothers can sometimes be treated in pregnancy to minimise the risks to their baby. Neonatal medicine has made immense progress and enables far more babies to survive premature birth, birth with severe abnormalities, or other health problems. More babies live and thrive. Many parents in the developed world now take delight in their family when, not long ago, they would have mourned the loss of a child. These self-same advances have, however, created the dilemmas in critical care decision making which are at the heart of this Report. Medicine offers choices. Often these are not easy choices, involving as they may do decisions that could determine whether a baby lives or dies. For parents, these choices are amongst the most profound decisions that will ever affect their lives. Parents nowadays play a central role in decision making about their children and it is no longer generally assumed, or asserted by the medical profession itself, that doctors know best. Increasingly, children are accorded rights. At the same time, public controversy about such matters as the moral status of the fetus, sanctity of life and access to scarce NHS resources has rarely been as vigorous.

The Working Party embarked on its task with some trepidation. We acknowledge that the constitution of the Working Party itself influenced not just our conclusions, but the way in which we conducted our deliberations. On a number of the key ethical questions in this Report, we take different views as individuals. Each of us was influenced by our own personal and professional history. We made every effort to examine the diversity of views in the wider debate. In chairing the Working Party, I have been immensely fortunate in my colleagues. They expressed their opinions forcefully, but always with grace and respect for others. We offer the Conclusions and Recommendations in this Report as our collective view about how to approach critical care decision making in fetal and neonatal medicine. We set out our reasoning in the earlier chapters and acknowledge that in some instances we reached a unanimous conclusion on the basis of different reasoning. We hope that our recommendations represent a balanced opinion for consideration by policy makers, and to assist families and health professionals.

Writing this Report has not been easy. Any difficulties that we have faced pale into insignificance compared with the heartbreaking choices that parents and professionals have to make in these areas of medicine. Many people have contributed to our Report, through our wider consultation, at fact-finding meetings, workshops, through peer review and by correspondence. We have been privileged to observe so much good practice and devoted care of the most vulnerable babies. Our recommendations should not be taken to indicate that radical changes in the manner in which health professionals practise fetal or neonatal medicine are called for. We hope that our deliberations and conclusions can be of help to all those who, in whatever role, have to make critical care decisions.

I wish to thank all the members of the Working Party who have committed immense time and effort to this work, far beyond the call of duty. I owe a special debt of gratitude to David Archard who chaired meetings for me in my absence on more than one occasion. I thank the Nuffield Council for their support and wise advice. The counsel from Sir Bob Hepple, Chairman of Council,

was particularly appreciated. The Working Party as a whole would want to express particular thanks to Catherine Moody. As Secretary to the Working Party, she has been a model of intellectual stimulation, patience and diplomacy. We are also grateful to Professor Sandy Thomas, Director of the Nuffield Council, and other colleagues in the Secretariat, especially Harald Schmidt, Caroline Rogers, Julia Trusler and Catherine Joynson.

A handwritten signature in black ink, consisting of a stylized initial 'M' followed by the name 'Brazier'.

Professor Margaret Brazier OBE

Chair of the Working Party

Acknowledgements

The Council would like to thank the members of the Working Party for their expertise and contributions to this Report. Also greatly appreciated were the comments from a number of people who reviewed an earlier version. The reviewers were Dr Hazel McHaffie, Professor Alice Noble, Professor Bonnie Steinbock, Professor Michael Freeman, Professor Steve Robson, Professor Neil McIntosh, Professor Janet Carsten, Professor Tom Shakespeare, Professor Ciaran Phibbs and Dr Cynda Rushton. The Council also wishes to express its gratitude to the people who attended or helped to host fact-finding meetings. The discussions at these meetings provided valuable insights for members of the Working Party on issues covered in this Report. Particular thanks are extended to the parents and children that members of the Working Party met. A list of fact-finding attendees is provided in Appendix 1. The Council would like to convey appreciation and thanks to the many organisations and individuals who responded to the consultation (see Appendix 2). Members are also very grateful to those who provided advice on specific parts of the Report, including Heather Allen, Tony Allen, Dr Richard Behrman, Dr Susan Bewley, Shabnam Chaudhry, Professor Peter de Cruz, Dr Kate Fleming, Dr Ruth Graham, Professor Alison Macfarlane, Gwen Nightingale, Professor Mike Parker, Professor Sir Michael Rawlins and Dr Helen Statham.

Members of the Working Party

Professor Margaret Brazier OBE (Chair)

Professor of Law, University of Manchester

Professor David Archard

Professor of Philosophy and Public Policy, Institute of Philosophy and Public Policy, Furness College, University of Lancaster

Professor Alastair Campbell

Emeritus Professor of Ethics in Medicine, Centre for Ethics in Medicine, University of Bristol, later Chair of Medical Ethics, National University of Singapore

Professor Linda Franck

Professor and Chair of Children's Nursing Research, Centre for Nursing and Allied Health Professions Research, Institute of Child Health, University College London and Great Ormond Street Hospital for Children NHS Trust

Ms Bonnie Green

Head of External Relations (until January 2006), BLISS – The premature baby charity

Professor Erica Haimes

Executive Director, Policy, Ethics and Life Sciences Research Centre and Professor of Sociology, University of Newcastle upon Tyne

Dr Monica Konrad

Raising Fellow, Department of Social Anthropology, University of Cambridge

Professor Neil Marlow

Professor of Neonatal Medicine, School of Human Development, Queen's Medical Centre, Nottingham

Professor Catherine Peckham (Deputy Chair of the Council)

Professor of Paediatric Epidemiology, Institute of Child Health, University College London

Dr Stavros Petrou

Health Economist, National Perinatal Epidemiology Unit (NPEU), University of Oxford

Professor Charles Rodeck

Head of Department, Department of Obstetrics and Gynaecology, University College London

Dr Philippa Russell CBE

Disability Rights Commissioner; Policy Adviser for Disability, National Children's Bureau, London

Ms Anne Winyard

Partner, Leigh, Day & Company, Solicitors, London

Professor Andrew Whitelaw

Professor of Neonatal Medicine, University of Bristol Medical School

Terms of reference

- 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.

Table of contents

Council membership and terms of reference	iii
Foreword	v
Acknowledgements	vii
Members of the Working Party	ix
Working Party terms of reference	x
Executive summary	xv
Chapter 1 – Introduction	1
Chapter 2 – Decision making: the ethical issues	7
Introduction	9
The role of ethical analysis in considering practical problems	9
The value of the life of a fetus or newborn baby	11
‘Sanctity of life’ or ‘quality of life’?	11
<i>Biological development and moral status</i>	13
Best interests	15
<i>What does it mean to have interests?</i>	15
<i>Interpretation of best interests</i>	15
<i>The weight of best interests, and interests of different parties</i>	16
Withholding and withdrawing treatment	18
Deliberately ending life	19
Relieving pain and causing death: the doctrine of the double effect	20
Economic and social issues	20
Decision making	22
<i>Participants in the decision-making process</i>	22
<i>Parents</i>	22
<i>Healthcare professionals</i>	23
<i>The process of decision making</i>	23
Chapter 3 – The context for decision making in fetal and neonatal care	27
Infant survival and prevalence of low birthweight	29
The clinical context	32
<i>The impact of antenatal screening on neonatal survival and disability</i>	33
<i>The borderline of viability</i>	33
<i>Neonatal resuscitation and intensive care</i>	34
<i>Clinical trials and neonatal care</i>	36
The family and the role of professionals	36
<i>Making decisions: the perspective of parents</i>	37
<i>Making decisions: the relationship with healthcare professionals</i>	38
The wider socio-legal context	39
Consequences of decision making	41
<i>Practical issues on leaving hospital</i>	41
<i>What is disability?</i>	41
<i>Quality of life</i>	43

Economic issues	44
The legal context	45
Chapter 4 – Dilemmas in current practice: the fetus.....	49
Introduction	51
Clinical perspectives	52
<i>Decisions about when to deliver a fetus</i>	52
<i>Possibilities for fetal treatment</i>	54
<i>Possibilities for fetal surgery</i>	55
<i>Late termination of pregnancy</i>	55
<i>Fetal pain</i>	58
Some examples	58
<i>Case 1: Sarah – a fetus at risk and a dilemma for the doctor</i>	59
<i>Moral status</i>	59
<i>Best interests</i>	59
<i>Conveying information</i>	60
<i>Legal issues</i>	60
<i>Economic issues: antenatal screening</i>	60
<i>Case 2: Theresa – a fetus at risk and a dilemma for the pregnant woman</i>	61
<i>Making a decision about ending the pregnancy</i>	61
<i>Social perceptions of the fetus</i>	63
<i>Legal issues</i>	64
Chapter 5 – Dilemmas in current practice: babies born at the borderline of viability	65
Introduction	67
The clinical perspective	68
The EPICure study.....	70
UK practice for resuscitation of babies at the borderline of viability.....	74
Some examples	77
<i>Case 3: Ahmed – decision making in the delivery room</i>	78
<i>Best interests</i>	78
<i>Decision making</i>	78
<i>Implications for the healthcare team</i>	79
<i>Legal issues</i>	79
<i>Case 4: Beth – parental influences on decision making</i>	80
<i>Sanctity of life</i>	80
<i>Understanding prognoses</i>	80
<i>Perceptions of disability</i>	81
<i>Legal issues</i>	83
<i>Case 5: Callum – decision making when the parents disagree</i>	83
<i>Best interests</i>	83
<i>Decision making</i>	84
<i>Legal issues</i>	84
Economic issues at the borderline of viability	84

Chapter 6 – Dilemmas in current practice: babies needing intensive care	89
Introduction	91
The clinical perspective	91
Brain injuries in premature and term newborn babies	92
<i>The premature baby with brain injury</i>	92
<i>The full term baby who acquires brain injury</i>	93
<i>The baby born with brain abnormalities</i>	94
Other serious conditions in the newborn baby	94
Pain relief and developmental care in the neonatal intensive care unit	95
Palliative care	97
Some examples.....	99
<i>Case 6: Danielle – continuation of intensive care on the advice of doctors</i>	99
<i>Best interests</i>	99
<i>Conveying information</i>	100
<i>Legal issues</i>	100
<i>Case 7: Elliot – intensive care continued at the parents’ wishes</i>	101
<i>Sanctity of life</i>	102
<i>Best interests</i>	102
<i>Pressure on resources</i>	102
<i>Legal issues</i>	103
Economic issues relating to provision of intensive care.....	103
Further example	104
<i>Case 8: Freddie – pain relief and the consequence that death is hastened</i>	104
<i>Best interests</i>	105
<i>The doctrine of double effect</i>	105
<i>Active ending of life</i>	105
<i>Decision making</i>	105
<i>Supporting parents when a baby dies</i>	107
<i>Legal issues</i>	107
Determining outcomes	107
Chapter 7 – Living with Disability	111
Introduction	113
Perceptions of disability.....	113
Some examples.....	114
<i>The developing child with problems from birth</i>	114
<i>Case 9: Danielle – the developing child</i>	114
<i>Case 10: Gareth – coping with disability as a child grows up</i>	114
Support services	119
Education provision	120
The costs of disability.....	121
Disability legislation.....	122
<i>Legal rights of disabled children</i>	122
<i>Disability Discrimination Act</i>	123

Chapter 8 – Decision making: regulation and resolution	125
Regulation and fetal medicine	127
Regulation and neonatal medicine.....	130
The legal implications of birth	131
The duty to treat a newborn baby	132
Borderline of viability	134
Critical care decisions for babies in intensive care	135
When parents do not accept the advice of the healthcare professionals	136
<i>Parental refusals of treatment</i>	136
<i>Parental demands for treatment</i>	137
Reviewing current law	139
Acting with the intention of ending life	139
Withholding or withdrawing treatment	142
Legislation on withholding treatment: would it help?	142
A role for clinical ethics committees?	143
Resorting to the courts	144
Best interests and parental views	145
Mediation	145
Chapter 9 – Conclusions and recommendations	149
Introduction	151
Fetal medicine	152
Borderline of viability	153
<i>Proposed guidelines for deciding to institute intensive care</i>	155
Critical care decisions for babies needing intensive care.....	157
Decision making and best interests.....	159
Disputed decisions	162
Economic considerations	163
Lifelong support for the disabled child	165
Monitoring and research	165
Information, education and training	166
Appendix 1: Method of working	171
Appendix 2: Wider consultation for the Report	176
Appendix 3: Causes of neonatal and post-neonatal death	187
Appendix 4: Brain injury in the newborn baby	188
Appendix 5: Consent for treatment.....	191
Appendix 6: Randomised controlled trials in clinical medicine	192
Appendix 7: NHS organisations concerned with healthcare decision making.....	193
Appendix 8: The Quality-Adjusted Life Year (QALY).....	195
Appendix 9: Professional guidance in the UK.....	196
Appendix 10: Organisations with an interest in the fetal and neonatal area	218
Glossary	220
List of abbreviations	231
Index.....	233

Executive summary

- 1 Before the 1960s, few conditions could be diagnosed in pregnancy and there was a lack of treatments that could be offered to babies who were born very early or who were seriously ill. Most of these babies would die. Since then, major improvements in fetal diagnosis and medical care have been increasingly successful in saving the lives of extremely premature babies and in offering more hope of recovery to those born later who have health problems. Many of these babies do well but some will have a condition that limits their lifespan to a few weeks or months, with little prospect of effective treatment. Others may have major abnormalities, chronic illness or the potential for serious disability. Families and health professionals are sometimes faced with having to make complex and emotionally demanding decisions that may affect whether a baby lives or dies. The Nuffield Council on Bioethics therefore established a Working Party to provide advice on the ethical, social and legal issues that arise in critical care decision making in fetal and neonatal medicine.
- 2 The nature and complexities of decision making in critical care are a central focus of this Report. When a baby survives there may be lifelong consequences for the baby and his or her family. Decisions are made on behalf of fetuses and newborn babies who cannot speak for themselves. It is therefore crucial to examine who should make decisions on behalf of a fetus or a baby, and how his or her interests can be identified and protected. Although the circumstances of each case are different and intensely personal, uncertainty of prognosis is common. All decisions, whoever makes them and however they are made, depend on adequate and accessible information.
- 3 The ethical framework in this Report addresses several recurring issues where an analysis of ethical concepts and arguments is crucially important (Chapter 2). These are the nature and value of human life at different stages of development; the role of best interests; the deliberate ending of life and the withholding or withdrawing of treatment; and the weight that should be accorded to economic and social considerations. Personal experience, professional and social background, religious and cultural perspectives all play a role in forming people's views on these issues. All too often, there is substantial disagreement about ethical issues that arise in critical care and how they should be resolved. Within the Working Party, members themselves held diverse opinions on some of these matters.
- 4 The Report considers three clinical areas: fetal medicine (Chapter 4); the borderline of viability (babies born extremely prematurely, at or before the gestational age of 25 weeks, six days) (Chapter 5); and babies receiving intensive care (Chapter 6). In fetal medicine, despite improvements in diagnosis, the limited prospects for fetal treatment mean that critical care decisions frequently concern either the timing of delivery or termination of the pregnancy. For babies born at the borderline of viability, neonatologists are able to offer families general information about the statistical probabilities of survival and the likelihood of disability. However, doctors are frequently limited in what they are able to tell the parents about how their particular baby will fare. The Working Party considered whether there is a place for guidelines on the use of resuscitation, and the initiation of intensive care treatment, to help parents and healthcare professionals alike. The potential for further guidance to assist the determination of best interests was also considered. Once a baby is receiving intensive care, the primary ethical issue is often deciding whether it is in his or her best interests for life-sustaining treatment to continue or whether only pain relief or palliative care should be provided.
- 5 Chapter 7 describes the complex practical issues that may arise as babies with predicted disabilities enter childhood and early adulthood. The current legal framework within which

critical care decision making operates is discussed in Chapter 8. Particular attention is given to different routes for the resolution of disagreement. Finally, the conclusions and recommendations of the Working Party are presented in Chapter 9. They are also summarised below.

Background

- 6 Since the beginning of the 1980s, the proportion of babies born with extremely low birth-weights (usually premature) has increased, with the percentage doubling between 1982 and 1996.¹ The rate of survival for babies born very early has also been increasing steadily over the past few decades. However, most extremely premature babies still die. Even if an extremely premature baby survives to leave hospital, he or she is more likely to have health problems. There are also several other situations where babies may require intensive care. Babies born at any gestational age can have brain injury, which may lead to a wide range of disabilities later in life. A range of other serious conditions, such as heart, lung, bowel and kidney problems, can also arise in the newborn child.

Decision making: the ethical issues

- 7 We identified four principal issues where an analysis of ethical concepts and arguments is critically important for decision making in fetal and neonatal medicine. All are likely to play some role in the deliberations of the different parties involved in decision making.

The value of human life

- 8 An important question that those involved in critical care decision making need to address concerns the value they place on the life of a fetus or a newborn baby. There are several different views. For example, some believe that a newly formed embryo should have full moral status while others consider that this is not acquired until a baby has a capacity for self-consciousness, which does not appear to develop until some months after birth. Members of the Working Party held a range of different views on the moral status of the fetus. Collectively, however, **we regard the moment of birth, which is straightforward to identify, and usually represents a significant threshold in potential viability, as the significant moral and legal point of transition for judgements about preserving life. In this respect, and independent of gestational age, children of six days, months or years are each worthy of equal consideration (paragraph 2.19).** The issue of the moral status of the fetus also raises the question of how it relates to the status of the pregnant woman, and to her duties towards her child. We consider that the pregnant woman who has chosen to continue her pregnancy has strong ethical obligations to protect the health of her future child. **It is the view of the Working Party that although in moral terms a pregnant woman acts wrongly in harming her future child by acting neglectfully or in a manner that is wilfully harmful, as happens occasionally, it would be wrong to force a woman to behave rightly by submitting to medical or surgical interventions to benefit a fetus against her will.** To introduce laws taking away or limiting the pregnant woman's bodily integrity or liberty would be unjustifiable and impracticable as sanctions could not be related exclusively to the context of critical care decision making (paragraphs 2.20 and 8.4).
- 9 **The Working Party concluded that there are some circumstances in which imposing or continuing treatments to sustain a newborn baby's life results in a level of irreparable 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 a baby's interest in continuing to

¹ From rates of 0.2–0.4% in singletons and 1.9–3.9% for multiple births. Macfarlane A and Mugford M (2000) *Birth Counts: Statistics of pregnancy and childbirth*, 2nd Edition, Volume 2 (London: The Stationery Office), Table A6.1.1.

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. **The concept of ‘intolerability’ was adopted to describe situations where it would not be in a baby’s best interests to insist on the imposition or continuance of life-sustaining treatment when doing so imposes an intolerable burden upon the baby (paragraph 2.11).** Reasonable people may disagree both about what constitutes ‘intolerability’ and/or when a particular baby’s condition meets that condition. In applying this concept, in each case an assessment must be made of the individual baby (paragraphs 2.12–2.16).

The principle of best interests

- 10 **The Working Party agrees that the best interests of a baby must be a central consideration in determining whether and how to treat him or her. The interests of a baby often concern whether he or she will live or die, and the quality of life that might be enjoyed. In according particular weight to the best interests of a baby, the Working Party views the baby’s interests in living or dying, or in avoiding an ‘intolerable’ life, to be more important than the interests that others may have in any significant decisions made about him or her (paragraphs 2.21 and 2.28–2.32).** However, any decision will have implications for the parents and other members of the family who will live with and care for the child. Parents have interests and 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.

Withholding and withdrawing treatment and deliberate action to end life

- 11 When healthcare professionals withhold or withdraw treatment in the context of critical care decisions, when guided by the best interests of a baby, the view of the Working Party is that they substitute one form of care for another. **Our conclusion is that there are no good reasons to draw a moral distinction between withholding or withdrawing treatment, provided these actions are motivated in each case by an assessment of the best interests of the baby. Either would be an acceptable course of action depending on the circumstances of each case (paragraph 2.33).** If withholding and withdrawing treatment is seen as morally equivalent and acceptable in certain circumstances, the question arises as to whether the deliberate ending of life should be seen as equally morally acceptable, given that the outcomes of all three options may be the same. **Despite different personal views on whether any form of active ending of life could ever be ethically justifiable, the Working Party unreservedly rejects the active ending of neonatal life even when that life is ‘intolerable’.** Furthermore, **we unanimously reject the notion that there should be a law or laws expressly and exclusively allowing ending the life of newborn babies (paragraphs 2.35–2.37, 8.40 and 9.20).** Medicines such as sedatives and analgesics can have the effect of hastening death, particularly if given at higher doses. This means that death may occur in cases where doctors provide such treatments with the intention of reducing pain and suffering. **The view of the Working Party is that, provided treatment is guided by the best interests of a baby, and has been agreed in the joint decision-making process, potentially life-shortening but pain-relieving treatments are morally acceptable (paragraph 2.38).**

Economic and social issues

- 12 Opinions differ on the question of whether economic factors, such as the costs of treatment, should be taken into account in critical care decision making. At the macroeconomic 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.

Our view is that economic factors must not be the only consideration in seeking to maximise health benefits. While by no means exclusive to neonatal medicine, additional principles such as equity and justice should also be taken into account by decision makers. On grounds of consistency, the State should not think it permissible to enable many of the babies who are the subject of this Report to survive, but be excused the discharge of its resultant obligation to support their care. **The Working Party urges the UK Departments of Health; Education and Skills; and Work and Pensions to accept further responsibility for supporting families who care for disabled children and adults by providing more resources to ensure that adequate and effective services are provided uniformly across the UK. We ask the Departments of Health; and Education and Skills to provide the necessary resources to monitor this provision of care (paragraphs 2.40 and 9.46).**

- 13 Resource constraints arising from decisions at the national, regional or local levels 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. **The Working Party recommends that healthcare professionals caring for babies in neonatal intensive care units should continue to do the best possible for the ‘patient in front of them’. They should be aware of, but not driven by, the resource implications of their decisions. Those decisions should be determined by clinical judgements of priority, which take into account the best interests of the babies concerned (paragraphs 2.43 and 9.43).**

Decision making

- 14 We recognise that emotions play an important part in everyday moral decision making. Decisions frequently have to be made by parents and clinical staff with little time to consider clinical options, and often in very stressful circumstances. Any discussion of ethical issues, no matter how controversial, should seek to be dispassionate and impartial, and have practical relevance to those making decisions. Equally, the great personal significance, the often very difficult choices and consequently, the strong feelings of all who are involved must be acknowledged. In this Report, the focus of the Working Party is on not so much *what* is the ‘right’ decision, but *how* should one proceed if people hold different views concerning substantive matters raised by critical care decisions, and *who* should be responsible for taking decisions, both in terms of the proposed course of action and personal and professional acceptance of the consequences.
- 15 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. Making decisions in partnership between parents and professionals satisfies several important ethical considerations, of procedural justice, personal and professional responsibility and the wellbeing of those most closely involved. We therefore endorse the ‘partnership of care’ recommended by the Royal College of Paediatrics and Child Health (RCPCH) and the British Association for Perinatal Medicine (BAPM). Uncertainty about a baby’s condition can be difficult for doctors to communicate. Furthermore, 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 takes 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 (paragraphs 2.46–2.48).**

Fetal medicine

- 16 In fetal medicine, improvements in technology and greater understanding of how fetal development affects the future health of a child have changed the way in which pregnancies

are managed. Screening will provide reassurance for most pregnant women, but a minority will find that their unborn baby may have a serious abnormality. Most commonly, the choices will be for the woman to continue with the pregnancy, agreeing to an early delivery if appropriate, or electing to terminate the pregnancy. **The Working Party endorses the current position in the UK whereby decisions about the fetus, including the mode and timing of delivery, are made only with the consent of the pregnant woman, and that she should determine what happens in cases of dispute with her partner or her obstetrician.² Women making such decisions must be provided with comprehensive, accessible information on the risks and benefits of what is proposed, and (where possible) enabled to make their decisions with the support of their partners, their wider family or others they would like to consult, should they so wish (see paragraphs 8.3–8.4 and 9.7).**

- 17 Advances in fetal diagnosis have not been matched by prospects for effective treatment with medicine or surgery. We are aware of the development of open fetal surgery as a possible means of correcting or lessening the impact of abnormalities in a limited number of conditions although we believe that the value of such procedures remains unclear at this time. Such procedures carry a high risk to the pregnant woman. **Our view is that in the UK, new procedures in fetal surgery should be offered only within a protocol approved by a research ethics committee (see paragraphs 4.11 and 9.8).**
- 18 The Working Party does not take a position on whether the time limit for legal termination of pregnancy should be reduced since the kinds of decision making that we examine in this Report would not be affected, provided that termination on grounds of fetal abnormality continued to be permitted. In late termination of pregnancy, feticide is recommended before the initiation of labour in terminations after 21 weeks, six days of gestation to ensure that the fetus is not born alive. The procedure pre-empts the possibility of dilemmas about whether a baby born alive after a termination should be resuscitated. However, a minority of pregnant women do not wish to have feticide, whatever the diagnosis. The Working Party was advised that termination of pregnancy after 22 weeks without feticide was an issue of major concern for healthcare professionals in fetal medicine. In particular, they needed a greater understanding of the legal position. **We recommend that there should be greater uniformity of practice and interpretation of the law, which does not require all possible measures to be taken to prolong the life of a baby born alive if it is not in his or her best interests. A code of practice should be developed for healthcare professionals to achieve clarity about what the law does and does not require doctors to do.** Such a code would also help ensure that pregnant women are given sufficient information about possible outcomes if a baby is born alive following termination on grounds of fetal abnormality. **The responsibility for developing the code should be taken by a broad group of professional organisations consulting as appropriate. Where relevant, it should be made available to a woman as part of her care pathway (paragraphs 4.14–4.16, 8.7–8.8 and 9.10).**

Borderline of viability

- 19 In this Report, the term ‘borderline of viability’ is used to describe the time of birth of extremely premature babies who are born alive at or before the gestational age of 25 weeks, six days. Babies are born this early because of spontaneous labour or because they are delivered early to safeguard the health of the baby and/or the mother. At these stages of gestation, the prospects of healthy survival are reduced, often necessitating critical care decisions after birth.

² Unless her mental capacity is impaired.

- 20 Neither case law nor statute currently provides a sufficiently accurate and certain definition of 'born alive' appropriate for use in the light of modern medicine and technology. **The Working Party recommends that the Royal College of Obstetricians and Gynaecologists (RCOG) and RCPCH, together with BAPM and the Royal College of Midwives (RCM), should consult widely and develop a definition of 'born alive' which encompasses the capacity of a baby to breathe either independently, or with the support of a ventilator. Consideration should be given to incorporating such a definition in statute (paragraphs 8.13–8.16).**
- 21 The extent to which parents are consulted in advance about the initiation of intensive care appears to vary across the UK. **We strongly endorse the recommendations of the RCPCH and BAPM that, wherever possible, when the birth of a baby which is extremely premature or which is affected by significant abnormalities is expected, before the birth an experienced neonatologist should discuss options for admission to intensive care. We encourage the Royal Colleges and National Health Service (NHS) to find ways to foster a common approach by obstetricians, midwives, nurses and neonatologists (paragraph 9.12).**
- 22 Current practice in most neonatal units in the UK is usually to resuscitate a baby if the outcome is uncertain and to institute intensive care until the outlook is clearer. The legal obligation is to provide appropriate care, which does not necessarily include admission to a neonatal intensive care unit. We consider that babies should not be subjected to intensive interventions that are not likely to have any benefit and which may cause suffering. **We recommend that the RCPCH and BAPM, together with the RCOG, RCM, Royal College of Nursing (RCN) and other associated professional bodies, should consider the development of guidelines for deciding to institute resuscitation and full intensive care for babies born below 26 weeks of gestation, consulting as appropriate, including with groups that advocate for parents.³ We do not regard this as an appropriate matter for legislation in the UK. We propose below a set of guidelines to provide a basis for discussion by these bodies as we believe that clearer guidance would encourage more openness, greater consistency in practice and firmer expectations for parents (paragraphs 8.24–8.25 and 9.14–9.19).**

Proposed guidelines for deciding to institute intensive care

- 23 The guidance for deciding to institute resuscitation and full intensive care should include:
- (a) **An experienced paediatrician should be present at the delivery and make a confirmatory assessment of the gestational age and condition of the baby.**
 - (b) **At 25 weeks of gestation and above, the relatively high rate of survival and the relatively low risk of severe disability are such that intensive care should be initiated and a baby admitted to a neonatal intensive care unit, unless he or she is known to be affected by some severe abnormality incompatible with any significant period of survival.**
- Below 25 weeks of gestation, where the delivery of an extremely premature baby is anticipated and circumstances permit, the clinical team should discuss with the**

³ Broadly speaking, outcomes for premature babies at the borderline of viability improve with each additional week of gestational age. We intend our proposed week-by-week guidelines to be sufficiently flexible to take account of the variation in (1) how babies of the same age respond to treatment and (2) estimates of gestational age confirmed by ultrasound analysis, which are accurate to within five days (95% of cases) when carried out in the first trimester of pregnancy. We emphasise that a careful prior assessment of each baby and discussion with the parents, before the birth if possible, should precede any action. We recommend (paragraph 9.21) that guidelines should be reviewed regularly and revised, as needed, to reflect any future changes in outcomes.

parents in a thorough and frank fashion, the national and local statistical evidence for survival and the range of disabilities which are indicated for this age group. In the consultation with the parents, the healthcare team should make it clear that statistics indicate that most babies born below 25 weeks of gestation will die.

- (c) Between 24 weeks, 0 days and 24 weeks, six days of gestation, normal practice should be that a baby will be offered full invasive intensive care and support from birth and admitted to a neonatal intensive care unit, *unless* the parents and the clinicians are agreed that in the light of the baby's condition (or likely condition) it is not in his or her best interests to start intensive care.
- (d) Between 23 weeks, 0 days and 23 weeks, six days of gestation, it is very difficult to predict the future outcome for an individual baby based on current clinical evidence for babies born at this gestation as a whole. Precedence should be given to the wishes of the parents regarding resuscitation and treatment of their baby with invasive intensive care. However, when the condition of a baby indicates that he or she will not survive for long, clinicians are not legally obliged to proceed with treatment wholly contrary to their clinical judgement, if they judge that treatment would be futile (see paragraph 8.32). As a first step, it will be necessary to determine whether a baby is suffering, whether any suffering can be alleviated, and the likely burden placed on the baby by intensive care treatment (see paragraph 9.32). Where parents would prefer that the clinical team made the decision about whether or not to initiate intensive care, the clinicians should determine what constitutes appropriate care for that particular baby. Where there has not been an opportunity to discuss a baby's treatment with the mother (and where appropriate her partner) prior to the birth, the clinical team should consider offering full invasive intensive care until a baby's condition and treatment can be discussed with the parents.
- (e) Between 22 weeks, 0 days and 22 weeks, six days of gestation, standard practice should be not to resuscitate a baby. Resuscitation would normally *not* be considered or proposed. Only if parents request resuscitation, and reiterate this request, after thorough discussion with an experienced paediatrician about the risks and long-term outcomes, should resuscitation be attempted and intensive care be offered. The treating clinicians must concur that this is an exceptional case where resuscitation is in a baby's best interests.
- (f) Below 22 weeks of gestation, no baby should be resuscitated. For this age group, we consider current attempts to resuscitate a baby to be experimental. We recommend that attempts to resuscitate these babies should *only* take place within a clinical research study that has been assessed and approved by a research ethics committee and with informed parental consent.
- (g) When intensive care is not given, the clinical team should provide palliative care until the baby dies (paragraph 9.16).

24 At the time of writing, most babies born at 23 weeks die or survive with some level of predicted disability even if intensive care is given. Survival and discharge from intensive care for babies born between 22 and 23 weeks is rare. The Working Party has no evidence of any therapeutic developments likely to improve the prospects of survival for babies born before 22 weeks in the near future. It is our view that caution is currently required over decisions to treat babies born up to 23 weeks, six days. **We recommend that, should professional bodies choose to produce guidelines for instituting intensive care, these should be**

reviewed regularly and revised to reflect any changes in outcomes for extremely premature babies (paragraph 9.17).

- 25 The Working Party considers parental informed consent to be especially necessary for decisions to use life support for babies born between 23 and 24 weeks of gestation. If a pregnant woman is unable to consent before the birth because of her clinical condition, doctors should resuscitate the baby. Similarly, after birth, if the mother is unable to consent or if the parents should disagree, resuscitation should again proceed. Once a baby is born, a mother no longer has exclusive responsibility for decision making.
- 26 **We emphasise that our recommendation for the guidelines above is independent of concerns about limitations on resources. It rests on a judgement about what is in the best interests of a child. Just as we find no difference in the moral status of a child of six days, months or years, we find no morally relevant differences between disabled and able-bodied children and adults. 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 to allow babies to die because of the risk of disability (paragraphs 2.39 and 9.44).**

Proposed criteria for judging best interests

- 27 A more transparent and structured set of criteria for judging the best interests of a baby may be helpful to parents and doctors. We suggest below some criteria, for consideration by the Royal Colleges, and recommend that these, or similar criteria, should become part of good clinical practice (paragraphs 9.32–9.34).
- 28 **When a decision must be made by doctors whether or not to *institute life support and ventilation immediately after birth*, the following points should be considered in assessing the best interests of a baby. This assessment should be made in the light of the guidelines for instituting resuscitation and full intensive care proposed at paragraph 9.16:**
- (a) **The gestational age of the baby at birth.**
 - (b) **The evidence available indicating the likelihood of survival and incidence of severe disability among babies born at that gestational age.**
 - (c) **The evidence available from the initial assessment on:**
 - (i) **the baby's vitality at birth; and**
 - (ii) **any significant abnormalities.**
 - (d) **The views and feelings of the parents, in the light of that evidence, and accorded the significance proposed above.**
- 29 **When a decision must be made whether or not to *institute or to withhold further treatment from a baby after birth*, the following questions should be considered:**
- (a) **To what extent is it likely that the treatment in question will effect a significant prolongation of the child's life? (It will not generally be in the interests of the baby to prolong the process of dying.)**
 - (b) **What degree of pain, suffering and mental distress will the treatment in question inflict on the baby? Will there be a need for repeated, painful and distressing medical interventions? What measures can be taken to ameliorate any pain, suffering and distress?**

- (c) **What benefits will accrue to the future child from treatment in question, for example?**
- (i) **Will the child at any stage be able to survive independently of life support?⁴**
 - (ii) **Will treatment increase the chance that the child will be able to be cared for out of hospital?**
 - (iii) **Will the child be likely to be capable of establishing relationships with other people?**
 - (iv) **Will the child be likely to be able to experience pleasure of any kind?**
- (d) **Then, in the light of evidence regarding a–c:**
- (i) **Do the burdens of treatment outweigh the benefits?**
 - (ii) **What kind of support is likely to be available to provide the optimum care for the child?**
- (e) **The views and feelings of the parents as to the interests of the baby, especially in relation to (d).**

In the rare case that a baby either has no parents or has been taken into care, the local authority will often be able to exercise parental responsibility in relation to that child. However, it is important to be assured that the baby's interests are properly represented. This may be a case that would benefit from early referral to a clinical ethics committee (see paragraphs 9.37–9.39).

- 30 **When a decision must be made whether or not to *withdraw life-sustaining treatment from a baby with a limited prognosis*, the following questions should be considered:**
- (a) **For how much longer is it likely that the baby will survive if life-sustaining treatment is continued?**
 - (b) **What evidence is there that the baby is experiencing pain, suffering or distress? What measures are being, or could be taken, to ameliorate that pain, suffering or distress?**
 - (c) **Is it likely that, if life-sustaining treatment is continued, the baby will ever be able to survive independently of life support?⁵**
 - (d) **What benefits accrue to the baby from continuing life-sustaining treatment?**
 - (i) **Is he or she able to establish relationships with other people? Does he or she react to his or her surroundings?**
 - (ii) **Does he or she experience pleasure of any kind?**
 - (e) **In the light of this evidence:**
 - (i) **Do the burdens of continued life support outweigh any benefits?**
 - (ii) **Does the baby exhibit signs of effort to survive?**
 - (f) **The views and feelings of the parents as to the interests of the baby, especially in relation to (e) above.**

⁴ We note that with appropriate care, children on long-term ventilatory support can be discharged from hospital.

⁵ As footnote 4 above.

Critical care decisions for babies needing intensive care

31 After an initial decision to institute intensive care has been taken, there may subsequently come a point when parents and doctors begin discussing whether intensive care for the baby should be continued or be withdrawn. Such a point may be:

- when intensive care is proving futile, in that death appears inevitable;
- when the baby has suffered a severe brain injury and for whom there appears to a very high risk of severe disability as he or she grows up; or
- when the baby is discovered to have a serious malformation, dysplasia (abnormal development of tissues or organs) or a genetic condition with a serious outcome for which there is no treatment.

Once a decision has been made to withhold or withdraw treatment for a baby, or where there are no appropriate treatments, palliative care should be provided. However, healthcare professionals working in neonatal intensive care do not receive mandatory training in palliative care, and access to teams who specialise in palliative care is extremely limited.

32 **The Working Party proposes that the NHS, supported by the UK Departments of Health and in conjunction with the relevant professional bodies (for example the RCPCH, BAPM, RCN, Neonatal Nurses Association (NNA) and RCM), should train all neonatologists and neonatology nurses in the basic principles of palliative care so that they are applied when a need is identified. To complement this provision, the NHS should facilitate access to specialist advice in palliative care for complex cases in the same way that specialists would be consulted on complex problems in other areas of medicine (paragraph 9.23).**

33 **We conclude that oral nutrition and hydration should only be withheld from a baby when it is clear that providing it causes discomfort and pain, such as when a baby has little functioning bowel due to disease or when death is imminent. The decision should only be taken after careful assessment and as part of a planned programme of palliative care designed to minimise suffering and make the baby as comfortable as possible (paragraph 9.24).**

34 We understand that current clinical practice in terms of detection of pain and provision of pain relief varies widely across the UK. **The Working Party believes that the reduction of pain and stress for babies in neonatal units is important and suggests to the UK Departments of Health, the Healthcare Commission and relevant professional bodies that measures need to be taken to improve clinical practice through the application of current knowledge about assessment, prevention and treatment of pain in babies receiving intensive care.⁶ The UK Departments of Health and research funding bodies are encouraged to support high quality research to understand the potential developmental effects of neonatal pain and stress as well as its treatments (paragraph 9.25).**

Living with disability

35 Discussion of disability in the specific context of the long-term future of severely ill babies must pay close attention to the relationships that will be available to that individual, and broader social provision. Contemporary understanding of 'disability' means that terms such as 'impairment' and 'normal' and 'abnormal' have to be understood within a wider social context. Increasingly, disability is no longer viewed simply as something that resides in the

⁶ We note that the *National Service Framework (NSF) for Children, Young People and Maternity Services* publishes pain management standards that include babies in neonatal units.

body of a person and which has to be coped with by him or her and their family, in isolation. Disabled people, their families and many researchers tend to refer to a 'social' model of disability rather than the 'medical' model, which is embedded in much of the medical literature describing outcomes after neonatal intensive care. Parents may be presented with overly negative images of the future lives of their children, which are not balanced by more positive information about the day-to-day lives of disabled people (paragraphs 3.29–3.34 and 7.3).

- 36 Caring for a child with disabilities is likely to entail the need for support from a variety of sources, including healthcare, social services and educational systems. Many children will be cared for at home, which can place additional demands on their parents and family. It has become clear to us that accessing the relevant support or care can be very difficult, as a coordinated approach across services is not in place in the UK. Support may not be tailored to the needs of the child or the family, and information for parents on services is often inadequate (Chapter 7).

Regulation and resolution

Regulation

- 37 Legislation designed exclusively to address decisions relating to newborn babies alone would not offer the clarity and predictability that might be its objective. **The current legal principles centred on seeking agreement between parents and professionals as to the best interests of the baby are, in principle, appropriate and sufficient (paragraph 9.31).**
- 38 Further to our conclusion that it would be unethical, the Working Party concluded that to end the life of newborn babies actively would be unacceptable in the UK. It would also be very difficult to devise sufficiently stringent limits for the circumstances in which it could be permissible (paragraph 9.22).
- 39 For over 30 years, there has been extensive theoretical and policy-related debate about the concept of children's rights. The law, challenged by a potential conflict between the claims of the pregnant woman and the fetus, has, so far, declined to accord rights to the fetus. Once born, the newborn baby enjoys the same human rights to life and to appropriate medical care as any other person. In the view of the Working Party, there is no question over *whether* newborn babies have legal rights: there is no doubt that they do. The difficulty is interpreting and applying those rights when rights conflict.

Resolution

- 40 There are always likely to be cases where parents and doctors disagree about the care of a baby, for example where a parent holds that all measures must be taken to preserve life. The Working Party recommends that efforts should continue to be made to resolve disputes that may arise about the care of a baby through further discussion, initially within the neonatal unit. If disagreements remain, parents should routinely be offered access to a second medical opinion. **The NHS should explore ways to ensure that all neonatal intensive care units have rapid access to a clinical ethics committee for advice. The best mechanisms for providing such advice need to be determined and implemented on the basis of equal accessibility for parents and all professionals involved in the health or social welfare of the child. Clinical ethics committees may sometimes be able to play a limited role in resolving disputed cases. Whether a decision is disputed or not, rapid support will be needed if clinical ethics committees are to play an effective role in this area of medicine. We propose that clinical ethics committees should appoint on-call facilitators for more active resolution of differences in critical care decision making before they become entrenched as a dispute (paragraphs 9.37–9.39).**

- 41 There are potential advantages to using mediation processes in disputes about critical care decisions in neonatal medicine, for example when positions have become deeply entrenched. **We recommend that the UK Departments of Health should examine the benefits that mediation may offer, with a view to setting up a pilot study to evaluate the possible merits for critical care decision making in neonatal medicine (paragraphs 8.56–8.62 and 9.39).**
- 42 If all possible means of resolving any disagreement between the various parties has been exhausted, recourse to the courts will be necessary. There is a trend towards open hearings for disputes about the care of the newborn which is in keeping with a general trend towards more openness within the Family Division of the High Court. This has led to such disputes acquiring a much higher public profile. **We note that as the Family Division moves towards more open hearings, measures will be put in place to protect the privacy of families and professionals if this is their preference. We endorse this plan (paragraph 9.40).**

Monitoring and research

- 43 Not enough is known about variation in current practice, experience and views on critical care decision making in fetal and neonatal medicine, to provide an evidence base for identifying and applying changes to guidelines for practice, and assist with the more effective resolution of differences of opinion. **The Working Party recommends to the RCOG, the RCPCH, the RCN, the NNA and the RCM that objective, systematic data, rigorously analysed, are needed on how the different parties interact when making critical care decisions for the newborn. This information will further understanding, provide an evidence base for identifying and applying changes to guidelines for practice, and assist with the more effective resolution of differences of opinion. Sociological research is also needed to identify how wider personal, familial, social and cultural factors carry weight as individuals interact during the decision-making process (paragraphs 3.12–3.14, 3.21, 6.26 and 9.48).**
- 44 It is crucial that accurate and up-to-date evidence from research is available to doctors and parents about the risks and likely outcomes for babies in whom a birth abnormality or genetic disorder is present, as well as for extremely premature babies. Follow up is needed not only for groups of children diagnosed with health difficulties before or around the time of birth, but also for children who have minor symptoms at birth but are at risk of late-onset problems. **In the view of the Working Party, data linkage with longer-term events in later stages of a child's life, through adolescence to adulthood, captured through NHS health records and educational records, will provide crucial information on outcomes. Although the necessary electronic NHS systems are not yet in place, it is timely to consider the health-related questions that should be posed and corresponding requirements for data collection (paragraphs 5.11 and 9.49).**
- 45 Useful information can be gained from autopsy examinations for fetuses and babies who do not survive. Insights may be gained into the cause of death which may help parents in planning future pregnancies and doctors to gain a better understanding of the causes underlying clinical conditions. In turn, other parents can be given more accurate information when making decisions, and research efforts can be directed towards obtaining more precise diagnoses. **The Working Party encourages doctors to recommend and parents to consider autopsy in order to add to knowledge about causes of death (paragraph 9.50).**

Information, education and training

- 46 Good decision making in critical care depends on the quality and comprehensibility of the information available to parents and how that information is conveyed by healthcare professionals. **Parents need timely provision of accessible information, available in different languages and formats to meet the needs of different individuals. Where appropriate, this material should be provided as part of the individually based pathway of care for a pregnant woman.** It should include both national and local statistics and be updated regularly. Written information must be accompanied by face to face discussion and explanation (paragraphs 4.24, 5.36 and 9.51).
- 47 Standards for the provision of this information need to be developed and implemented by the relevant organisations (for example, the RCOG, RCPCH, BAPM, RCN, NNA and RCM). **The Working Party proposes that these organisations should liaise with groups which advocate for parents (for example, the National Childbirth Trust (NCT), BLISS – The premature baby charity and the Stillbirth and Neonatal Death Charity (SANDS), and that the Healthcare Commission should monitor delivery of the information to measurable standards. We recommend that discussions would benefit from the involvement of families and others who have direct experience of continuing specialist care at home after leaving hospital, or of what disability can mean for older children and their families. Additionally, the value and feasibility should be explored of making written or audiovisual guides available for local use by fetal medicine and neonatal intensive care units (paragraphs 9.52–9.53).**
- 48 Misunderstandings about the role of the criminal law in relation to withholding and withdrawing treatment are not uncommon. Similarly, healthcare professionals are not always well acquainted with broader ethical debates outside the general guidance offered by their professional organisations. **We recommend that the RCOG, RCPCH, RCM, RCN and the NNA should encourage medical and nursing schools to develop undergraduate and post-graduate educational programmes in the law and ethics relating to fetal and neonatal medicine, as appropriate (paragraph 9.54).**

Chapter

Introduction

1

Introduction

- 1.1 To care for a child is to express one of our most fundamental human instincts. We invest our hopes for the future in our children and want them to live healthy and fulfilling lives. In developed countries, medical care over the past 40 years has advanced dramatically so that many more babies are now born in good health, and fewer babies die in their first year of life. Before the 1960s, few problems could be diagnosed in pregnancy and there was a lack of treatments that could be offered to babies born very early or who were seriously ill. Most of these babies would die and consequently, ethical issues in fetal and neonatal¹ care were less common.
- 1.2 The number of babies born extremely prematurely is rising. Modern medical care is increasingly successful both in saving the lives of these babies and in offering more hope of recovery to babies born later who have health problems. Sometimes, however, a baby will have or develop a condition which means he or she will not live longer than a few weeks or months. Others may have major abnormalities, chronic illness or the potential for serious disability. In these situations, parents may be asked to participate in decisions involving complex ethical issues that relate to the care of their child. Part of the complexity of such decision making can arise from medical uncertainty over whether the babies who live will be seriously affected or make good recoveries. This has stimulated follow-up studies to determine outcomes in cases of extreme prematurity.² Having to make critical care decisions during pregnancy or after a baby is born places great demands, both upon the parents and the healthcare professionals who are 'partners in care' and who must decide on a baby's behalf.
- 1.3 Improved neonatal survival can be attributed to a greater understanding of fetal and neonatal development and advances in care for babies as they adapt to life outside the womb or complete their development. These improvements mean that it is sometimes decided to deliver babies early. This may be a response to complications of pregnancy that put the health of the woman or the fetus at risk, or to enable a baby with health problems to be treated. However, the major advances in fetal medicine that have allowed the diagnosis of a wide range of conditions have not been matched by new ways of treating the fetus before birth.
- 1.4 This Report examines ethical, social and legal issues that arise when making critical care decisions in fetal and neonatal medicine. First, we address critical care decision making for fetuses identified as being at risk of conditions likely to have such serious consequences as to compromise the prospect of live birth or to impair the health of a baby once born; secondly, we consider decisions on whether or not a newborn baby should be resuscitated, and admitted to neonatal intensive care; and thirdly, we address the issues of whether further treatment should be instituted after birth, withheld, or subsequently replaced with another form of care. The decisions we discuss will often affect whether a baby lives or dies. In the event of a baby surviving, there may be consequences such as severe disability which will affect a baby and their family for the rest of their lives.
- 1.5 The Working Party found that it was not always possible to offer an unequivocal answer as to what *ought* to be done in particular circumstances. We also found it necessary to address *how* a decision was made, and *who* should make it. So in our discussion of ethical issues, we explore several concepts to develop an ethical framework to help parents and professionals

¹ The neonatal period refers to the first 28 days following birth.

² See Marlow N (2005) Outcome following preterm birth, in *Robertson's Textbook of Neonatology*, Rennie JM (Editor) (London: Churchill Livingstone), Chapter 3. Currently, there is no routine collection of outcome data on a national basis.

make critical care decisions when they are faced with dilemmas created by medical uncertainty. We consider why and how an ethical analysis is helpful in this process. We discuss what is meant by concepts such as the sanctity, quality and moral status of human life before and after birth. We pay particular attention to the difficulties of balancing different interests in the decision-making process and the assessment of best interests. We also consider whether ethical distinctions can be made between withholding and withdrawing treatment, and whether there is ever a case for the deliberate ending of the life of a newborn child.

- 1.6 We have sought to make the social context for critical care decisions an integral part of the Report, even though there has been little systematic research on the issues that we address. We found social issues to be inextricably linked to ethical issues, especially in decision making where so much depends on the relationships between the different parties. When professionals and families cannot agree about what should be done, a case may need to be resolved in the courts. At a broader level, social changes have transformed attitudes to children, such that in the past decade new public policies have been put in place to assert or protect their rights.³ Similarly, the concept of 'disability' has been redefined to try to offer greater protection and social inclusion for this group.⁴ The social consequences of decisions made about the critical care of fetuses and newborn babies extend beyond the family. When children develop chronic illness or disability, the quality of their lives depends not only on the commitment of their own families, but also upon the level of community support they will receive as they grow up. A report from the Prime Minister's Strategy Unit notes that, "Since 1975, the fastest growth in numbers [of disabled people] has been for children—from 476,000 disabled children under the age of 16 in 1975 to 772,000 in 2002", an increase of 62%.⁵ Over the same period, the number of adults reporting disabilities has risen by only 22%. Although there will be other reasons,⁶ some of the incidence will be associated with critical care decisions, either for babies born prematurely or babies who have been diagnosed with a disabling condition around the normal time of birth.
- 1.7 Media attention has focused recently on the financial cost of the care both for the newborn and for children who survive with major disability.⁷ Most policy makers work on the principle that no healthcare system can provide unlimited healthcare resources and, regardless of their financing and organisation, all employ mechanisms at different levels to set priorities for spending.⁸ An important question for the Working Party was how finite healthcare resources should be allocated for the potential lifelong healthcare needs of a newborn baby starting life in intensive care.
- 1.8 We have examined the legal framework for decision making in fetal and neonatal medicine. In the UK, many of the relevant legal principles governing decision making in the context of this Report are to be found in the judgements of the courts deciding individual cases.⁹ There

³ For example, Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services*; United Nations (1989) *UN Convention on the Rights of the Child*. See also paragraphs 3.44 and 7.24.

⁴ We used the definition of disability in the Disability Discrimination Act 1995, that "a person has a disability if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities".

⁵ Prime Minister's Strategy Unit (2005) *Improving the Life Chances of Disabled People* (London: Strategy Unit).

⁶ Some of this increase (62%) in the number of disabled children can be attributed in part to higher rates of diagnosis and reporting of disability, as well as success in treating specific health problems such as head injuries or childhood cancer, which would previously have caused death.

⁷ See, for example, BBC Online (2006) *Early babies dubbed bed blockers*, 27 March, available at: <http://news.bbc.co.uk/1/hi/health/4848698.stm>; accessed on: 25 Aug 2006.

⁸ Frankel S (1991) Health needs, health-care requirements, and the myth of infinite demand *Lancet* **337**: 1588–90.

⁹ Within the United Kingdom there are in fact *three* legal systems: in (1) England and Wales; (2) Scotland; and (3) Northern Ireland. See Chapter 8, footnote 1.

is little legislation that has direct relevance, and judgements have tended to take account of the particular circumstances of each case to concentrate on the best interests of the individual baby when there are differences of opinion on care. This approach has led to a degree of flexibility and pragmatism which comes at the cost of some unpredictability. We have explored how far this flexibility is a strength, or whether new, more specific legislation should be introduced. We also examined alternative methods for resolving disputes.

- 1.9 We thought it important to elicit a wide range of views from individuals, families, patient groups and organisations engaged in medicine, nursing, law, religion and policy. Through targeted fact-finding meetings and wider consultation (see Appendices 1 and 2), we tried to capture the ‘voices’ of as many different individuals and organisations as possible. The contributions and perspectives of these participants emerge at different stages of the Report.
- 1.10 We have written this Report with a broad audience in mind. Our recommendations are directed primarily towards policy makers. Nevertheless, we hope that those with an involvement in critical care decision making, including families, doctors, midwives, nurses and others will find it relevant and helpful. We begin in Chapter 2 by considering a number of philosophical concepts to help outline an ethical framework for decision making in fetal and neonatal medicine. In Chapter 3 we set out the context in which such decisions are made. This allows us in Chapters 4–6 to examine, in turn, issues related to fetal medicine, extremely premature babies at the borderline of viability, and other babies requiring critical care, using examples. In Chapter 7 we discuss issues arising for children and families living with disability. Chapter 8 offers a discussion on regulation and the resolution of disagreements relating to critical care decision making. The main conclusions and recommendations of the Working Party are summarised in Chapter 9.

Chapter

2

Decision making:
the ethical issues

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.

Chapter

The context for decision
making in fetal and
neonatal care

3

The context for decision making in fetal and neonatal care

- 3.1 In fetal and neonatal medicine, there are several stages at which decisions have to be made that may determine whether a baby lives or dies. How such decisions are made, and the way in which ethical principles guide decision making are the focus of this Report. Yet ethical principles cannot be considered in isolation if they are to make a difference to practice. For example, we concluded in Chapter 2 that a baby's best interests are central to decision making. However, his or her interests are bound up with those of his or her family and can be difficult to determine in isolation. It is therefore essential that the medical, social and legal frameworks for critical care decisions before and after birth are well understood. That is the purpose of this chapter.
- 3.2 We begin by considering how rates of infant survival and low birthweight have changed over the past 50 years. We then set out the clinical context for pregnancy, birth, babies born at the borderline of viability,¹ and for babies where complications or abnormalities are present after birth. Following this, we consider how social and cultural factors may influence families and healthcare professionals in decision making. Some of the possible consequences of critical care decisions for a child and his or her family, including practical issues upon leaving hospital, coming to terms with possible disability, and the impact on his or her quality of life, are described. Finally, we present a brief outline of the economic and legal context.

Infant survival and prevalence of low birthweight

- 3.3 In developed countries the number of babies who die in their first year has declined in the past 40 years (see Figure 3.1 for data from England and Wales). Increased survival is likely to have arisen as a result both of general improvements in healthcare and increased standards of living, and from targeted improvements in obstetrics, midwifery and neonatal intensive care.² In England and Wales, there have been improvements in the survival rates for babies of all birthweights, particularly those classed as low birthweight (see Box 3.1 and Figure 3.2). The mortality rate for these babies decreased markedly between the 1960s and the late 1980s, and is continuing to fall. Despite these improvements, prematurity is still a major cause of neonatal death in the UK (Appendix 3).³

¹ In this Report we use the term 'borderline of viability' to refer to babies born up to 25 weeks, six days of gestation. By convention, the number of weeks of gestation refers to the period from the first to the last day of that week. For example 'at 23 weeks' means from 23 weeks to 23 weeks, six days of gestation (161–167 days of gestation).

² However, we note that it is difficult to link reductions in mortality with recorded changes in health provision. See Appleby J and Harrison A (2006) *Spending on Health Care: How much is enough?* (London: King's Fund), pp 11–13. In one study that has been carried out in the USA, two-thirds of the decrease in neonatal mortality seen in two major hospitals in Boston in 1989–90 and 1994–5 could be attributed to improvements in neonatal intensive care, see Richardson DK, Gray JE, Gortmaker SL, Goldmann DA, Pursley DM and McCormick MC (1998) Declining severity adjusted mortality: evidence of improving neonatal intensive care *Pediatrics* **102**: 893–9. This study was based on comparisons of neonatal outcomes in the two time periods taking into account birthweight and severity of illness on admission.

³ Confidential Enquiry into Stillbirth and Deaths in Infancy (2001) *8th Annual Report* (London: Maternal and Child Health Research Consortium).

Box 3.1: Birthweight and prematurity: definitions

Length of pregnancy

Full term	birth between 38 and 42 weeks of gestation
Premature (or preterm)	birth before 38 weeks, 0 days of gestation
Moderately premature	birth between 35 and 37 weeks of gestation
Very premature	birth between 27 and 34 weeks of gestation
Extremely premature	birth before 27 weeks of gestation

Weight

Low birthweight	less than 2,500 g (5.5 lb)
Very low birthweight	less than 1,500 g (3.3 lb)
Extremely low birthweight	less than 1,000 g (2.2 lb)

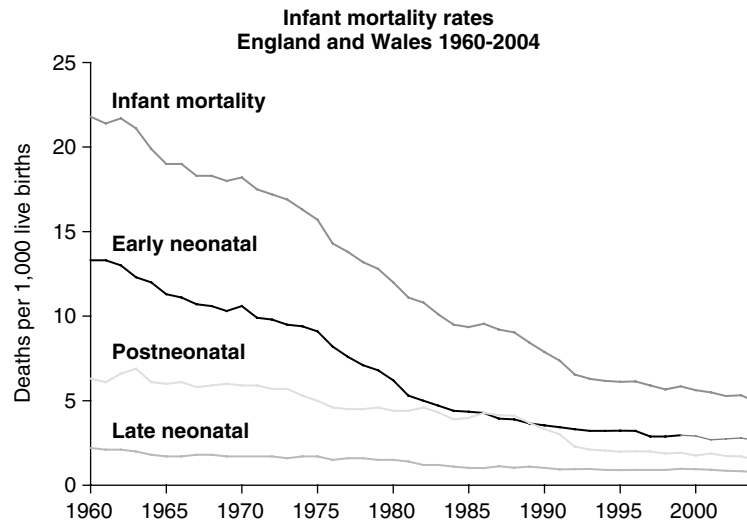
Gestational age: In the UK, the duration of gestation is measured from the first day of the pregnant woman's last menstrual period. Dates are then confirmed using ultrasound imaging in 95% of cases.

Figure 3.1: Infant mortality rates within one year after birth in England and Wales 1960–2004⁴

With kind permission from Professor Alison Macfarlane

Mortality rates are shown as deaths per 1,000 live births in the following periods after birth:

- Early neonatal: up to six completed days
- Late neonatal: between seven and 28 days
- Post neonatal: between 29 days and under one year
- Infant: under one year (total)



Source: Office for National Statistics, Mortality statistics, Series DH3
Graph by Alison Macfarlane, City University

3.4 In England and Wales, the percentage of babies born with a low birthweight has gradually increased in recent years, particularly since the mid-1980s (see Figure 3.3). This change has been attributed to several factors, including a trend towards registering a live birth for babies born at the limits of viability whose deaths might previously been classified as miscarriages or stillbirths, and a rise in multiple births.⁵ Health outcomes are poorer in multiple pregnancies, irrespective of their cause.⁶ The increase in multiple birth rates is often attributed to the

⁴ Comparable recent data are available for Scotland and Northern Ireland but definitions used differ.

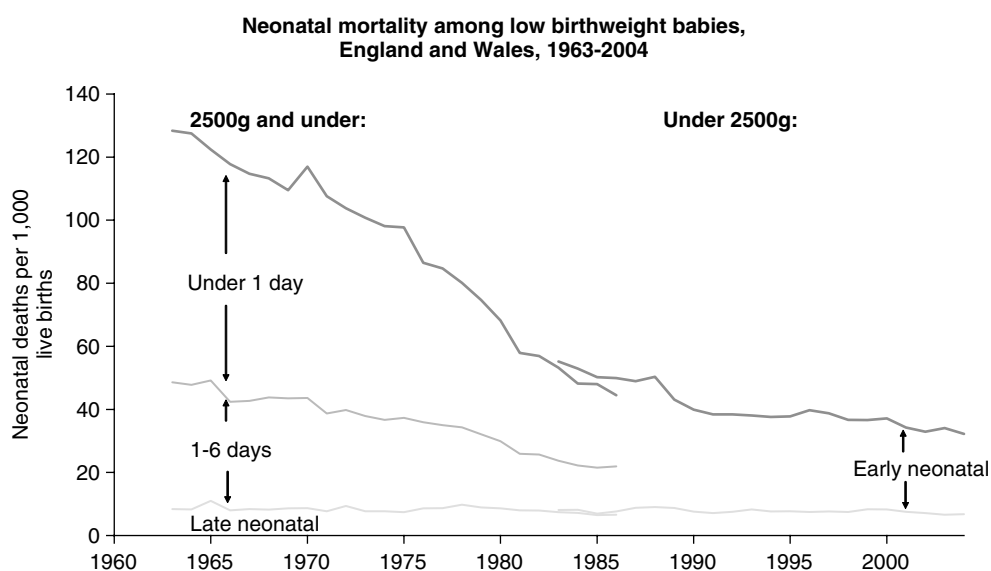
⁵ Macfarlane A and Mugford M (2000) *Birth counts: Statistics of pregnancy and childbirth*, 2nd Edition (London: The Stationery Office), Volume 1, p 55. From 1992 the gestation at which a stillbirth was registered rather than a miscarriage was lowered from 28 weeks to 24 weeks.

⁶ Marlow N (2006) Does neurodevelopment of twins and singletons differ? in *Multiple Pregnancy*, Kilby M, Baker P, Critchley H and Field D (Editors) (London: RCOG Press), pp 235–44.

Figure 3.2: Neonatal mortality among low birthweight babies within 28 days after birth in England and Wales 1963–2004

With kind permission from Professor Alison Macfarlane

The uppermost line shows the total rate of deaths of low birthweight babies within 28 days of birth. The section between this upper line and the middle line shows the proportion of this rate that is accounted for by babies under one day old; the section immediately below shows the proportion of this rate that is accounted for by babies who died at between one and six days old; and the lowermost section is the rate for babies who died between seven and 28 days after birth (the late neonatal period). Data collection changed in the mid-1980s when data on the rates of deaths under one day and between one and six days were combined. After this time, the section between the upper and lower lines represents the 'early neonatal' period. Additionally, there was also a minor change to the classification of 'low birthweight' babies to exclude babies of 2,500 g (previously the definition was 2,500 g and under). Data for the years 1989 to 1994 are unreliable because of missing birthweights.



Source: DHSS, LHS 27/1 low birthweight returns and ONS, mortality statistics, Series DH3 Birth counts, Tables A3.5.1 and A3.5.2. Graph by Alison Macfarlane

concomitant rise in *in vitro* fertility treatment since the 1980s, as there has been a tendency to implant two or more embryos.⁷ Although the prevalence of triplets has declined greatly over the past five years, the birth rate of twin pregnancies has stabilised.⁸ However, evidence that similar success rates for *in vitro* fertilisation may be achieved by implanting only single embryos is now available and in countries where this limit has been adopted, the rate of twinning has declined markedly.⁹ There have also been suggestions that the increasing tendency to delay motherhood has contributed to increases in multiple births in many developed countries, as older women are more likely to conceive multiple pregnancies than younger women.¹⁰ In addition, the UK has the highest rate of teenage pregnancy in Europe and

⁷ Macfarlane A and Mugford M (2000) *Birth Counts: Statistics of pregnancy and childbirth*, 2nd Edition (London: The Stationery Office). We note that in early 2007 the Human Fertilisation and Embryology Authority (HFEA) will hold a public consultation on ways to reduce multiple births, including the transfer of single embryos.

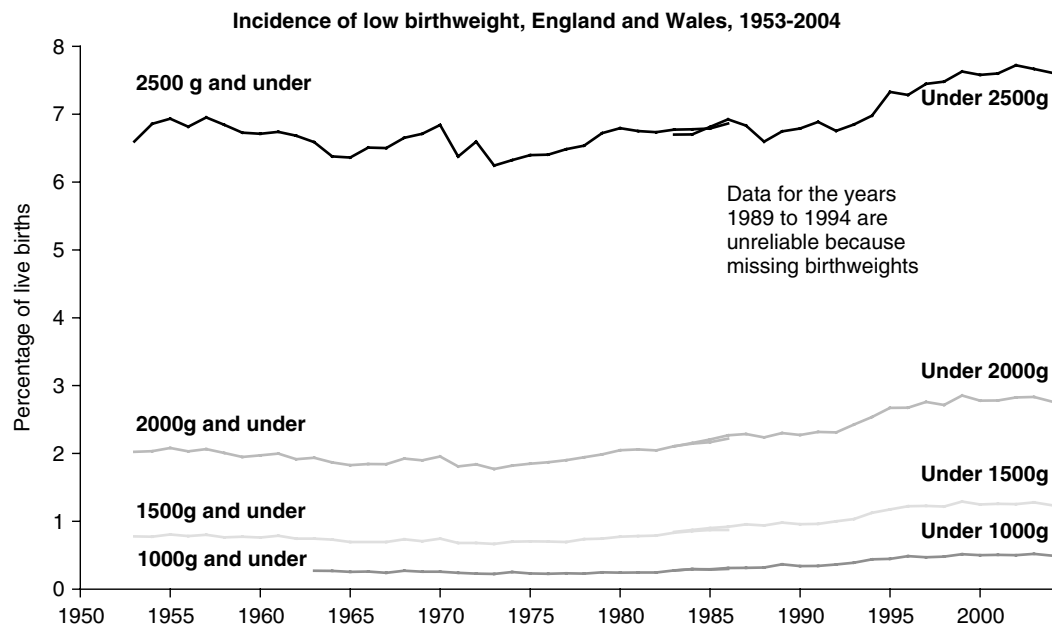
⁸ National Statistics *Birth Statistics* (London: Office for National Statistics), Series FM1 Numbers 29–33 (2000–2004).

⁹ Saldeen P and Sundström P (2005) Would legislation imposing single embryo transfer to a feasible way to reduce the rate of multiple pregnancies after IVF treatment? *Hum Reprod* 20: 4–8.

¹⁰ A biological basis for this phenomenon has recently been proposed, see Beemsterboer SN, Homburg R, Gorter NA, Schats R, Hompes PGA and Lambalk CB (2006) The paradox of declining fertility but increasing twinning rates with advancing maternal age *Hum Reprod* 21: 1531–2.

Figure 3.3: Incidence of low birthweight in England and Wales 1953–2004

With kind permission from Professor Alison Macfarlane



Source: LHS 27/1 low birthweight returns and ONS mortality statistics
Birth counts, Tables A3.4.1 and A3.4.2

teenagers are more likely to have a premature or low birthweight baby.¹¹ Increasing rates of premature birth have been recorded in other developed countries, including the USA, where a recent major study identifies prematurity as “a public health problem”.¹²

The clinical context

- 3.5 An understanding of what fetal and neonatal medicine can and cannot achieve is crucial to addressing the difficult choices that families, professionals and policy makers may have to make. The medical advances that have prompted the dilemmas discussed in this Report have occurred in three main areas. First, in fetal medicine there have been major improvements in the diagnosis of fetal abnormalities and illness. A great deal can now be discovered about the health of the fetus through the use of new technologies. Secondly, some babies born at low gestational ages respond to resuscitation and can be helped to survive. Thirdly, much more is known and continuing to be discovered about what causes babies to suffer pain or develop disabilities. Doctors are therefore better placed to make predictions about how a baby may be affected by a particular disability later in life, although usually it will be difficult to give parents precise information when asking for their consent to any treatment (see Appendix 5).
- 3.6 One feature common to these developments in fetal and neonatal medicine is that the improved ability to diagnose problems is not yet matched by the prospect of effective treatment with medicine or surgery. Another is the uncertainty of the initial prognosis for a particular baby. We shall see that in some cases doctors can give parents a reasonably certain account of whether their child is likely to survive, for how long and if he or she will have any disabilities. In many others, however, doctors may have to base their advice on statistical

¹¹ Department for Education and Skills (2005) *Teenage Pregnancy*, available at: <http://www.dfes.gov.uk/highlights/article01.shtml>, accessed on: 27 July 2006; Macfarlane A and Mugford M (2000) *Birth counts: Statistics of pregnancy and childbirth*, 2nd Edition (London: The Stationery Office), Volume 1, p 142.

¹² Institute of Medicine Committee on Understanding Premature Birth and Assuring Healthy Outcomes (2006) *Preterm Birth: Causes, consequences and prevention* (Washington, DC: IOM).

probabilities derived from studies such as EPICure (see paragraphs 5.7–5.11) and will be unable to tell parents how their baby will fare, nor predict the extent of any disability that he or she may develop.

The impact of antenatal screening on neonatal survival and disability

3.7 While routine antenatal screening is accepted by the majority of pregnant women and provides reassurance for many, it may also give the first indication that the health of a fetus or the future baby may be compromised. Screening is a public health service through which members of a defined population are offered a test. The purpose is to identify individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of a disease or its complications.¹³ Improved antenatal diagnosis of problems with fetal health has provided new challenges for pregnant women, their families, health professionals and for society as a whole. Routine screening has meant that more pregnant women now experience moral dilemmas because of the diagnosis of fetal problems which would, in the past, have been apparent only after birth.¹⁴ In the UK, the numbers of fetal abnormalities identified by the screening processes are not systematically recorded. Most are not life threatening and are dealt with after birth. The options for fetal surgery or treatment in the womb are still very limited, so when a fetus is in poor condition, the choice is often between continuing a pregnancy in the knowledge of an increased risk of the fetus or baby dying or having childhood disability, delivering the baby early or terminating the pregnancy (paragraph 4.2). A baby may be delivered early if problems have been identified. A decision is made after considering the risks for the woman and for the fetus. The immediate risks for the woman are generally resolved by delivery. When a fetus is at risk, the crucial question is whether the delivery of an extremely premature baby with consequent risks to the baby's health is justified by the seriousness of the problems (see paragraphs 4.3–4.6). Doctors have had to balance the risks of premature birth against continuation of a pregnancy since neonatal intensive care practices were first developed in the 1960s. Consequently data on outcomes are available to inform current practice (see paragraphs 5.7–5.11 and Table 5.1). Parents confronted with difficult decisions may find non-directive counselling¹⁵ helpful when facilities in National Health Service (NHS) units are available. They can also seek advice from patient support groups such as Antenatal Results and Choices (ARC).¹⁶

The borderline of viability

3.8 Birth at the borderline of viability (up to and including 25 weeks and six days of gestation) usually occurs through natural causes. More rarely, it can result from clinical intervention (see paragraph 3.7). Approximately 0.3% of all deliveries (including both live and stillbirths) in England (1,620 in 2004–5)¹⁷ occur at the borderline of viability. For babies born alive at these gestational ages, the prospects for survival are generally much less than 50% and if a baby survives, he or she is at risk of some level of disability, although as we have said, predicting the outcome for a particular baby at the time of birth is difficult (see Chapter 5). In such cases a widely used approach is for full neonatal intensive care to be instituted until the prognosis

¹³ Defined by the UK National Screening Committee.

¹⁴ Williams C, Sandall J, Lewando-Hundt G *et al.* (2005) Women as moral pioneers? Experiences of first trimester antenatal screening *Soc Sci Med* **61**: 1983–92.

¹⁵ Nuffield Council on Bioethics (1998) *Mental Disorders and Genetics: The ethical context* (London: NCOB), paragraphs 8.31–8.38.

¹⁶ See the Antenatal Results and Choices website, available at: <http://www.arc-uk.org>.

¹⁷ National Statistics (2006) *NHS Maternity Statistics, England: 2004–05*, Table 21. Data for the other countries in the UK are collected in a different way from those in England and so cannot be combined. Figures for England are included as an example. The EPICure study, however, covers the UK and the Republic of Ireland.

becomes clearer.¹⁸ This may be when the results of investigations are known or after a period when the clinical picture changes.

Neonatal resuscitation and intensive care

3.9 During the mid-1960s it became possible to save the life of a newborn baby who had stopped breathing by using mechanical ventilation. At the same time progressively more complex surgery was developed to correct life-threatening abnormalities in the newborn baby. Currently, approximately one in eight babies in the UK needs some level of special care after birth, and approximately one in 40 needs the highest level of intensive care.¹⁹ These babies need special care for a variety of reasons. They may have been born at the borderline of viability or at or near term. Most babies born before 32 weeks of gestation and/or those with a very low birth-weight will need to spend at least some time in high-dependency care.²⁰ National data on the reasons for which babies are admitted to neonatal units are not currently available.²¹ However, some insight can be gained from a report published by a neonatal intensive care unit (NICU) in the UK where babies born up to and including 32 weeks of gestation make up around a quarter of all the NICU admissions.²² Approximately one fifth of the intensive care cots in 2004–5 were occupied by babies born at 23–24 weeks of gestation, who stayed for an average of eight weeks.²³ The remaining patients were babies born at or near term who were ill because of breathing problems, congenital abnormalities, infection, brain injury, feeding difficulties or jaundice.

3.10 We concluded in Chapter 2 that certain circumstances merit discussion of whether all possible means of preserving the life of a baby should be tried. Critical care dilemmas arise in several situations. For extremely premature babies born at the borderline of viability or other babies who are unable to breathe unassisted, whether premature or born at term, decisions might have to be made about whether to begin resuscitation (see Box 3.2). When babies are dependent on artificial ventilation, the parents and doctors may have to decide whether to

¹⁸ “The greater the immaturity, the more needs to be done to support a baby’s breathing (often with mechanical ventilation), and to protect them from infection and to achieve growth equivalent to that which occurs in the womb. Thus even ‘well’ very premature babies require intensive care simply to support their organ systems until they have matured. This includes sophisticated mechanical ventilation with oxygen, intravenous feeding, and the use of incubators to control body temperature and protect from infection. It also involves treatment of illnesses which are more common in such vulnerable babies. Several weeks of intensive care may be needed for babies born prematurely, as for babies who are ill or who have congenital disorders. After that, some babies may need further weeks of high dependency or special care provided in neonatal units. Neonatal intensive care is also required for a small number of larger, more mature, babies who become ill from complications of delivery, from infection or metabolic disorders or when surgical or other treatment is required for congenital abnormalities such as congenital heart disease, disorders of the lung or gut, or of other organs.” See Department of Health (2003) Report of the Neonatal Intensive Care Services Review Group, available at: <http://www.dh.gov.uk/assetRoot/04/01/87/44/04018744.pdf>, accessed on: 15 June 2006.

¹⁹ BLISS—The premature baby charity (2005) *Special Care for Sick Babies – Choice or chance?* (London: BLISS), available at: http://www.bliss.org.uk/pdfs/Special_care.pdf, accessed on: 27 June 2006. In the UK there are 230 hospitals that provided some form of neonatal care. Approximately 20% of the neonatal units in these hospitals can be defined as level 1 units, i.e. they provide special care but do not aim to provide any continuing high dependency or intensive care. Approximately 35% of the units can be defined as level 2 units, i.e. they provide high-dependency care and some short-term intensive care; while 45% were defined as level 3 units, i.e. they provide the full range of medical neonatal care. See Redshaw M and Hamilton K (2005) *A Survey of Current Neonatal Unit Organisation and Policy* (Oxford: National Perinatal Epidemiology Unit).

²⁰ High-dependency care is a form of intensive care provided by level 2 and level 3 intensive care units and entails breathing support and intravenous nutrition, along with other care needs, depending on the individual baby. See Teamwork Management Services Limited (2005) *Neonatal Medicine: Review of intensive and high dependency care for Greater Manchester, East Cheshire and High Peak Children and Young People’s Network – Final report* (Bolton: Teamwork Management Services Limited).

²¹ However, the RCPCH and BAPM are coordinating the collection of a national dataset.

²² University of Bristol and North Bristol NHS Trust *Southmead Hospital Neonatal Medicine Annual Report 2003*, available at: <http://www.nbt.nhs.uk/services/wch/nicu/documents/Southmead%20NICU%20Annual%20Report%202003.pdf>, accessed on: 27 June 2006; University of Bristol and North Bristol NHS Trust *Southmead Hospital Neonatal Medicine Annual Report 2004*, available at: <http://www.nbt.nhs.uk/services/wch/nicu/documents/Southmead%20NICU%20Annual%20Report%202004.pdf>, accessed on: 27 June 2006.

²³ Personal communication from Professor Andrew Whitelaw, consultant neonatologist, Bristol Southmead Hospital.

continue this and other interventions that constitute treatment (see Box 3.2). For some babies, life-saving therapies will mean lifelong severe disabilities or only prolong inevitable death.²⁴ For babies with brain injuries, information from scans may be sufficient for a prognosis on which to base a discussion with parents about the withdrawal of treatment and substitution with palliative care if further intensive treatment is believed to be futile. However, for babies born with serious lung or other injuries, it can be very difficult for doctors to predict the extent of the chronic illness from which they will suffer in the future (see paragraph 3.28), and consequently decisions to withdraw treatment in such cases are rare.

Box 3.2: Medical procedures in neonatal medicine

Resuscitation

Most babies require only gentle stabilisation after birth, allowing them to start breathing while ensuring that body temperature is maintained. However, very premature babies or babies born in a poor condition may need more invasive treatment to facilitate breathing. Resuscitation will be considered for a baby born at the limits of viability and any baby who does not start breathing unaided. The procedures below may be carried out.

After birth, the baby is taken to a warm resuscitation platform or 'resuscitaire' and placed in a plastic bag to minimise evaporation and drying which make the baby cold. The baby's lungs are inflated with air (and possibly additional oxygen) using a face mask connected to a bag which is rhythmically squeezed. If the heart rate is below 60 beats per minute, inflation of the lungs is combined with rhythmic compression of the chest to improve oxygen delivery to the heart muscle and thus assist the baby's heart to pump. If he or she does not start breathing after a few breaths, or if chest inflation is ineffective using a face mask, a tube is inserted into the trachea (windpipe). Intubation is a skilled procedure carried out using a laryngoscope to visualise the trachea and the vocal cords, and may require several attempts. Once the baby has been successfully intubated, the tube is secured onto his or her face to deliver ventilation more effectively by hand or so that the tube can be connected to a mechanical ventilator. If the heart rate does not increase despite effective inflation of the lungs, chest compression is continued and adrenaline or other drugs are injected through a catheter inserted into the umbilical vein to speed up the pumping of the heart. This is also a skilled procedure that must be carried out using a sterile technique.

In some cases, the baby does not achieve a normal heart rate of 120–160 beats per minute, a pink colour, spontaneous breathing or responsiveness after carrying out these procedures. The clinician may then decide to administer injections of salt water (saline), glucose or sodium bicarbonate depending on the results of analysis of blood samples. In some cases, a blood transfusion is urgently required. Very premature babies born at under 30 weeks of gestation usually have surfactant injected into their lungs, which facilitates lung expansion.

After a baby has been resuscitated, a catheter is inserted at the earliest opportunity through the umbilical artery so that the tip lies in the aorta, the main artery of the body. Once the catheter is fixed in place it can be used to measure blood pressure, heart rate, and the composition of gases in the blood and pH levels without causing pain. Clinicians are able to use this information to guide their decisions on ventilation and further resuscitation as necessary. Although the procedures described above are very invasive and stressful for a baby, resuscitation saves lives.*

Withdrawal of life support

The most common situation where withdrawal of life support may be contemplated is when a baby is dependent on a respirator because his or her breathing has failed. Withdrawal of life support will involve removing the tube from the baby's windpipe so the ventilator is no longer inflating the lungs. Many parents will want to hold their baby when this procedure is carried out. Morphine is frequently used to provide pain relief and sedation when a baby is ventilated and this would normally be continued after ceasing ventilation to relieve any distress from difficulty in breathing. Alternatively, a decision might be made to continue ventilation but to withdraw or withhold medication being used to support the heart and blood pressure. When this is done, the reduced circulation of blood results in the baby gradually becoming unconscious. Another decision might be to not give cardiac massage or an injection of adrenaline (to try and restart the heart) if a cardiac arrest occurs. In other situations, withdrawal of life support might take the form of a decision not to treat an infection, especially pneumonia, with antibiotics. The parents and doctors might also make a decision to withhold surgery for a life-threatening condition, such as a severe heart defect (see paragraph 6.12).

In all of these examples, if the baby dies, the primary cause of death is the disease or abnormality. When life support is withdrawn, a dying baby will still receive other forms of treatment aimed at comfort and relief of symptoms, commonly termed 'palliative care' (see paragraphs 6.18–6.21).

*For further information, see Resuscitation Council (UK) (2005) *Newborn Life Support*.

²⁴ This type of case will sometimes reach the courts when parents and doctors have disagreed over the appropriateness of continuing treatment when no benefits are perceived by one of the parties (see Chapter 8).

Clinical trials and neonatal care

3.11 The care of the newborn is often integrally linked with clinical research that seeks to develop, refine and assess the impact of new technologies and methods of treatment. We recognise that clinical trials are important to identify the best forms of clinical care for these babies and to ensure that the benefits outweigh the risks of adverse effects. A description of how trials are conducted is provided in Appendix 6.

The family and the role of professionals

3.12 In this section we give an overview of the emotional and practical adjustments that families make as they reconcile their expectations with reality. When a woman or a couple embarks on a pregnancy it is generally a time of great anticipation. Parents are often very distressed to discover before or after birth that their baby has a major problem that may severely limit his or her potential for the future. Widely publicised improvements in neonatal care may lead them to have mistaken or unrealistic expectations of the likelihood of their child surviving without disability (see paragraph 3.26). Many of the parents of babies in neonatal care or intensive care will have experienced a complicated pregnancy, labour or birth. In other cases, early delivery may have occurred spontaneously with little or no warning and patients may have had little time to consider a prognosis or to prepare themselves. The baby they had imagined and had looked forward to holding may not resemble the baby whom they see in the intensive care cot or the incubator. They may be beset by uncertainty and fear for the future. There have been numerous studies identifying parental stress in the neonatal unit that have shown that parents can feel helpless, confused, frightened, angry, isolated and guilty. Their feelings are sometimes heightened by grief for the loss of the expected healthy child or anticipatory grief at the thought of their baby dying.²⁵ These are very difficult circumstances in which to ask parents, as well as for doctors and nurses, to make decisions about critical care. The consequences of decisions about the critical care of a baby may extend far beyond the hospital, especially if he or she has a severe condition which leads to disability (see Chapter 7). Often the implications will be lifelong for the child and their families, raising issues of healthcare, education and social welfare. Sensitivity and understanding are therefore crucial professional requirements.

3.13 Nurses play a crucial role within the neonatal intensive care setting, and in the decision-making process. They are the healthcare professionals who spend the most time with babies and their parents, helping them to feel and act as normal parents as much as possible in the difficult environment of the neonatal unit. They deliver treatment and closely monitor a baby's responses and are the primary source of information and support for parents. Through their close, frequent contact with parents, nurses learn about their values, beliefs, attitudes and customs and will actively encourage parents to participate as much as possible in a baby's daily care. Neonatal nurses can serve as advocates, helping parents to articulate what is important to them or helping other members of the healthcare team to appreciate the parents' perspective. Additionally, nurses assess parents' physical and psychosocial needs and can refer parents to the appropriate resources within the healthcare system, liaising with other members of the team and facilitating communication. Their special knowledge of a baby and his or her family is essential for making critical care decisions and they may be directly involved in the discussions, although this practice varies between neonatal units.²⁶ They have a professional responsibility to ensure that the rights and interests of a baby and his or her family are respected and that parents are given the information and support necessary to

²⁵ O'Shea J and Timmins F (2002) An overview of parents' experiences of neonatal intensive care *J Neonat Nurs* 8: 178–83.

²⁶ Hurst I (2005) The legal landscape at the threshold of viability for extremely premature infants: A nursing perspective, part II *J Perinat Neonat Nurs* 19: 253–62.

participate fully in decisions about their baby.²⁷ Neonatal nurses implement many of the decisions that are made to provide or withdraw life-sustaining treatments and are experts in the prevention and management of pain (see paragraphs 6.14–6.16).

- 3.14 Understanding the family's perspective is critical for the professional not only to be able to offer support and guidance when it is required but also to reconcile their own emotions should the family come to a different decision about the critical care of their baby than the one that a healthcare professional would have made. The professionals may or may not have received special training about how to deal with this situation. Some units have multidisciplinary meetings where differing views on a baby's care can be discussed, others provide access to individuals with special expertise, whereas some do not provide any formal processes for family or staff support. This variability contrasts sharply with other areas of neonatal practice, where monitoring and discussion occur regularly between neonatal units to ensure continuing improvements in quality, for example in infection control or resuscitation skills. **The Working Party noted that healthcare professionals are likely to need specific training to help them understand the perspectives of parents faced with critical care decisions and to communicate effectively with them.** This training could also help doctors and nurses reconcile decisions that are different from the choices they would have made for themselves.

Making decisions: the perspective of parents

- 3.15 The question of parental involvement in decision making about the care of the fetus or the newborn baby who has, or is likely to develop, serious health problems and disabilities is extremely important. In suggesting that there are several factors which influence parental decision making, we recognise that detailed sociological research would be required to assess their relative impact on the process. Some of these factors concern the parents' reproductive history, which may involve experience of a previous premature birth or the loss of one or more of the fetuses in a multiple pregnancy. If the mother has previously had a termination of a pregnancy, the grounds on which she did so may have a bearing on decisions about her new child. The father or the mother may have children with a previous partner, and hence have divided parenting responsibilities. A couple who had difficulties with conceiving or had experienced miscarriage, stillbirth or loss of a child or children may be initially much more concerned about a baby's survival than his or her prognosis.
- 3.16 Decision making may also be affected by expectations of family life. If both the mother and the father are new to parenthood, they are likely to have no prior experience of 'normal' childbirth and parental responsibilities. They may therefore have quite idealised views of what to expect. The parents may already have been planning to have further children or may now decide that this is what they intend. If they have older children, parents might worry about the impact of having a new child who has disabilities. They may feel obliged to take the welfare of their other children into account in decision making. In the short term at least, parental attention may be displaced towards the new child. Parents may wonder if they should involve their other children in care giving which in some cases may entail a lifelong commitment.
- 3.17 The attitudes and experiences of parents and their wider families towards pain, suffering, vulnerability, disability and death, and the influence of spirituality,²⁸ including any religious

²⁷ National Association for Neonatal Nurses (1999) *Position Statement #3015: NICU Nurse Involvement in Ethical Decisions (Treatment of Critically Ill Newborns)* (Glenview, IL: National Association of Neonatal Nurses); Nursing and Midwifery Council (2002) *Code of Professional Conduct* (London: NMC).

²⁸ Spirituality has been defined as a concern with matters of the spirit (or essence) of a person, involving a sense of connection to a much greater whole. It is a belief system that may be experienced as an alternative to religion or as an expression of personal faith within religion.

beliefs, will also have a bearing on decision making (see also paragraphs 3.23–3.24). The birth of a severely ill newborn baby in a family may undermine, strengthen, confuse or clarify preconceived notions about family ties. The actual effects in a particular family are unpredictable. Individual family members may be influenced, for example, if they have relatives or friends with disabling conditions; they may react in different ways at different points in their lives. Disagreement may occur within the family, for example, between parents, between parents and their immediate family, and between other family members. Broader social attitudes and expectations often come into play when family members find themselves directly involved in decisions about withholding or withdrawing medical treatment for another family member.

- 3.18 Over the past five years, the Internet has contributed to a significant change in the way that people communicate and make decisions about healthcare. There are far more opportunities to seek other views and opinions on a child's condition, and families who have never met each other and who are geographically many miles apart, can communicate readily. Parents sometimes form support networks or pressure groups through which they may receive help and/or channel their experiences to assist others.²⁹

Making decisions: the relationship with healthcare professionals

- 3.19 We agree with professional guidelines which advise that parents and the team of healthcare professionals should, wherever possible, jointly decide on the most appropriate treatment for a baby (see paragraphs 2.16 and 2.45 and Appendix 9). Achieving truly collaborative decision making depends greatly on the nature of the relationship between these parties. A number of sociological studies have explored what is meant by 'lay' knowledge, beliefs and experiences, and examined health and illness as it is experienced by the individual and the family.³⁰ However, there remains a need to gain a deeper understanding of the process of shared decision making in the medical context.³¹ The perspective of the family contrasts with that of the health professional, for whom the illness is the focus of their knowledge of the patient. Both are influenced by their own health status, as well as their knowledge, experience and expectations.³² Research has shown that families are generally more positive about a baby's health problems than the neonatal doctors and nurses who provide his or her care. Furthermore, as they grow up, children who develop disabilities report a more positive outlook than their carers (see paragraphs 5.37 and 7.9). It is therefore particularly important that stereotypes or prejudices against states of disability are not fostered during the decision-making process.

- 3.20 Interactions between professionals and parents take place within a broader social context that includes the nature of medical knowledge,³³ the notion of expertise,³⁴ relationships between healthcare professionals, and between them and other groups.³⁵ In the UK, the medical profession is aware that its image has changed in the public's mind in recent years. Patients are now more likely to question the judgement of healthcare professionals than they

²⁹ In a study in the USA, 56% of users of the Internet said that it had helped their relationships with family members, and 38% of users said that it had helped the way they obtained health information. See Pew Internet & American Life Project (2005) *Trends 2005: Internet: the mainstreaming of online life*, available at: http://www.pewinternet.org/pdfs/Internet_Status_2005.pdf, accessed on: 25 Jan 2006.

³⁰ For example, see Nettleton S (1995) *The Sociology of Health and Illness* (Cambridge: Polity Press); Annandale E (1998) *The Sociology of Health and Medicine* (Cambridge: Polity Press).

³¹ For further information, see Greenhalgh T and Hurwitz B (1998) *Narrative Based Medicine* (London: BMJ Books), p 259.

³² Pal DK (1996) Quality of life assessment in children: a review of conceptual and methodological issues in multidimensional health status measures *J Epidemiol Community Health* 50: 391–6.

³³ Foucault M (1976) *The Birth of the Clinic* (London: Tavistock).

³⁴ Freidson E (1986) *Professional Powers* (London: University of Chicago Press).

³⁵ Parsons T (1975) The sick role and the role of the physician reconsidered *Health Soc* 53: 257–78; Illich I (1976) *Limits to Medicine* (London: Marion Boyars).

were in the past.³⁶ Although there is a perception that this change in behaviour may have led to an increase in the level of disagreement over critical care decisions, there is a lack of robust evidence to support this view. There is also potential for conflict between different health-care professionals. For example, there may be disagreement between obstetricians and neonatologists, and between neonatologists and paediatricians, as well as between doctors and nursing staff or managers.³⁷

3.21 The influence of social factors upon decision making in the particular context of neonatal medicine has been subject to relatively little systematic research. We consider that research in this area has potentially valuable practical applications. It could provide an evidence base to explain the variations in practice and their consequences, assist the identification of good practice, and aid understanding of the issues which arise when clinical teams and parents have different views. It would also provide an evidence base for identifying and applying effective change in practice and for dispute resolution.

The wider socio-legal context

3.22 We have seen that there are a number of ethical frameworks available to help parents and healthcare professionals come to decisions about the critical care of the fetus or newborn baby. While ethical approaches are crucial to the resolution of dilemmas in neonatal critical care, emotional influences and personal experiences can also be highly pertinent, as we have seen above. For those involved in decision making, certain paradoxes that exist within the wider socio-legal context may add complexity. For example, the legal distinction between a fetus and a newborn baby (see paragraph 8.13) is at odds with the teachings of many faiths based on the scriptures and some people's moral intuitions. In another example, the late termination of pregnancy is permitted in the UK for a 'serious fetal handicap', yet once an affected baby is born, healthcare professionals often strive very hard to keep him or her alive, highlighting the "different moral status we accord to [fetuses and] neonates even of the same gestational age" (response to our consultation from the RCPCH). Another paradox concerns the prohibition of discrimination on grounds of a disabling condition, while there is inadequate social provision for the growing child and his or her family, or for when the child becomes an adult (see Chapter 7). An additional complicating factor for those involved in decision making is that what may have been judged as morally acceptable in the past may be inconsistent with current standards. For example, in certain circumstances doctors with good intentions may actively have hastened death. This occurred in the UK in the 1970s when doctors followed the criteria developed by Dr John Lorber for babies with spina bifida.³⁸

³⁶ Royal College of Physicians (2002) *NHS Day – Commentary on the NHS from the President*, available at: http://www.rcplondon.ac.uk/news/news.asp?PR_id=120, accessed on: 1 Aug 2006. Also, in response to our consultation, the RCPCH noted that "Over the past 20+ years there has been greater public desire for transparency, accountability and responsibility in all spheres of professional activity, perhaps with increasing mistrust of professionals."

³⁷ Brown SD, Truog RD, Johnson JA and Ecker JL (2006) Do differences in the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists positions on the ethics of maternal-fetal interventions reflect subtly divergent professional sensitivities to pregnant women and fetuses? *Pediatrics* **117**: 1382–7; McHaffie HE and Fowlie PW (1996) *Life, Death and Decisions: Doctors and nurses reflect on neonatal practice* (Cheshire: Hochland and Hochland (now Elsevier)). A recent study indicated that different professional groups perceive outcome for extremely premature babies differently and that this may affect their willingness to use interventions at borderline viability. See Chan KL, Kean LH and Marlow N (2006) Staff views on the management of the extremely preterm infant *Eur J Obstet Gynecol Reprod Biol* **128**: 142–7.

³⁸ In the UK in the 1960s, Dr John Lorber developed criteria for the selective non-treatment of infants with severe spina bifida and hydrocephalus. Infants who met two or more of these criteria were not offered an operation but were sedated with chloral hydrate and fed on demand. Infection such as ascending meningitis was not treated with antibiotics. These infants usually died within weeks. The 'Lorber criteria' became well known in the UK and were widely accepted by paediatricians as being a humane way of reducing suffering. Lorber J (1972) Spina bifida cystica Results of treatment of 270 consecutive cases with criteria for selection for the future *Arch Dis Child* **47**: 854–73; Lorber J (1971) Results of treatment of myelomeningocele. An analysis of 524 unselected cases, with special reference to possible selection for treatment *Dev Med Child Neurol* **13**: 279–303. The practice of active ending life in severely ill newborn infants in the Netherlands is described in Box 8.2.

In general, attitudes today have changed. The use of the Lorber criteria was discontinued when evidence became available that early surgery and physiotherapy could give an affected child a good quality of life. Even today, outside the UK, doctors and midwives may not always consult the family or other professionals before acting to withdraw treatment from newborn babies.³⁹

3.23 Historically, much of the original moral argument about decision making for a newborn baby in critical care in the UK was informed by the Judaeo-Christian tradition. Although the population in the UK is often said to be more secular than in the past, spirituality remains an important part of the lives of many people. As the diversity of our society has increased, so has the influence of other religious traditions and cultural beliefs. In addition, each person brings their own set of presuppositions, held consciously or subconsciously, consistently or inconsistently, about the basic constitution of the world.⁴⁰ While ethnicity, and other non-religious cultural factors that contribute to diversity, undoubtedly add complexity to decision making in fetal and neonatal medicine, evidence from empirical studies is lacking.⁴¹ However, we do know that orthodox religious beliefs have led to disagreements between families and healthcare professionals that have had to be resolved in the courts (see Chapter 8).

3.24 During the course of its deliberations, the Working Party held a workshop with people representing different faiths (see Appendix 1) to learn about advice that would be given to parents and doctors needing to make decisions in critical care. There was marked commonality between the different religious approaches, especially in relation to making the best interests of the child a fundamental principle. The value that predominated was that of compassion for both the child and the parents. There was also recognition that each situation was different and would require a sensitive interpretation of religious principles.⁴² The value of providing access to a religious counsellor or chaplain during periods of critical care decision making for parents with religious faith was acknowledged. While all attendees placed a high value on the sanctity of life (see paragraph 2.9), most faiths counselled that life need not be prolonged at all costs, for example in situations when treatment was futile or the pain and suffering for the child were greater than any benefit potentially gained from continuing medical intervention. Equally, all were agreed that every child had value in the eyes of God, meaning that disability in itself was not a reason for discounting the value of a God-given life.

3.25 Some of the issues discussed in this Report receive regular and widespread media coverage. It seems possible that some reporting, for example in the form of television programmes, could affect public perception of the medical problems. Research on the effects of the media on public perception in other health-related areas has been undertaken by the Glasgow University Mass Media Unit.⁴³ One particular study examined the press and television treatment of issues arising about mental health. The findings showed how ill-informed public beliefs on, for example, the association of schizophrenia with violence, could be traced directly to accounts in the media. Another study on coverage by the media on a range of scientific issues revealed that people were aware of the main themes but the knowledge that they had assimilated usually reflected those aspects that had received the most persistent coverage.⁴⁴

³⁹ Cuttini M, Nadai M, Kaminski M *et al.* (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries *Lancet* **355**: 2112–18.

⁴⁰ This is sometimes known as a 'worldview': a particular philosophy or view of life.

⁴¹ Culture has been defined as "a constellation of shared meanings, values, rituals and modes of interacting with others that determines how people view and make sense of the world".

⁴² We note that individual members of a faith group may interpret their faith differently from their religious leaders when making decisions.

⁴³ See the website of the Glasgow University Mass Media Unit, available at: <http://www.gla.ac.uk/departments/sociology/units/media.htm>.

⁴⁴ Hargreaves I, Lewis J and Speers T (2003) *Towards a Better Map: Science, the public and the media* (Swindon: ESRC).

3.26 Cases of extreme prematurity tend to receive a great deal of attention in press coverage, especially in newspapers and magazines. Numerous articles feature 'miracle babies' who survive despite being born extremely prematurely, but seldom address the implications for these children's future development, and for the lives of their families. This coverage tends to give a misleading impression that most babies born at the borderline of viability are healthy, whereas in reality, many do not survive and those who do often have disabling conditions ranging from mild to severe (Table 5.1). Reporting by the media of decision-making processes and the reasons for disputes may also be misleading. This is because those cases in which court proceedings are used as a means of resolving disputes between parents and doctors tend to make headline news, whereas those that are resolved privately do not.

Consequences of decision making

3.27 We now turn to describe the immediate practical issues for parents when they take their baby home from the hospital. We then examine what is meant by disability and quality of life.

Practical issues on leaving hospital

3.28 If a baby with a severe condition survives and is discharged from hospital, the ability of a family to manage at home is likely to be a major source of concern. We have noted that the interests of a baby are bound up with those of his or her parents and that the availability of resources affect those interests (see paragraph 2.29). Although not universal, many neonatal units now have community liaison teams to give some support to parents and families when their baby is discharged home. The majority of babies who have required intensive care will have a discharge plan which is developed during their stay in the neonatal unit. Many will be discharged with complex medical requirements such as a continuing need for oxygen therapy or special feeding needs. Very premature babies who have been treated on a ventilator are at risk of chronic lung disease. Once they no longer need the ventilator, support to the lungs may still need to be provided by continuous positive airway pressure (CPAP), and oxygen therapy. Recovery sometimes takes several months and if a baby is otherwise well, he or she may be allowed to go home with an oxygen supply. Most babies with chronic lung disease gradually improve and no longer need oxygen by 12 months of age. We consider longer-term issues of health, education and social welfare in Chapter 7.

What is disability?

3.29 Decision making in the critical care of the fetus and the newborn baby requires an understanding of the possible consequences. This is why deciding how to act in the best interests of a baby with serious medical problems demands some thought on what people perceive as 'disability' and how clinical views on a baby's health relate to the social framework in which families function. Over the past decade there has been a growing interest in the experience and the politics of disability, including studies that challenge the distinctions drawn between impairment and disability (see Glossary).⁴⁵ Various definitions of disability are currently in use. The Disability Discrimination Act (DDA) 1995 defines a person as having a disability if:

"... he has a physical or mental impairment that has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities" (see also paragraph 7.26).

Attention has been drawn to the issue of how the social organisation of everyday life (for example the design of buildings, transport, social security systems and employment legislation) has 'disabled' those with physical impairments. Estimates using the widest definition suggest that there are approximately 11 million disabled adults in the UK (i.e. one in five

⁴⁵ Barnes C, Mercer G and Shakespeare T (1999) *Exploring Disability: A sociological introduction* (Cambridge: Polity Press).

of the total adult population) and 770,000 disabled children.⁴⁶ Many of these people would not define themselves as disabled because their impairments have a low impact on their lives. This contemporary understanding of 'disability' means that discussions of disability in the specific context of the long-term future of severely ill babies must pay close attention to the relationships that will be available to that person, and broader social provision.

- 3.30 The social value and meanings attributed to notions of disability and impairment, and therefore to the very term 'disabled', are rooted in broader social, cultural and religious attitudes towards humanity. These meanings and values also derive from philosophical and historical conceptions of what it means to live a 'good life'. Striving for a 'good life' goes beyond the professional obligation upon health practitioners to do no intentional harm to their patient. The DDA 1995 and 2005 aim to protect disabled people from discrimination in every aspect of their lives, including access to health, education and social care as well as community facilities and commercial services. The Disability Rights Commission has actively promoted the rights (and potential) of disabled people to be equal citizens. Attitudes towards disability have changed markedly over the past decade and opportunities have increased. In 2006, the Government appointed a new National Director for Learning Disabilities, or 'tsar' for learning disabilities, who has a learning disability herself.⁴⁷ We return to the question of health, educational and social care for those with disabling conditions in Chapter 7.
- 3.31 Modern sociological thinking agrees that disability should no longer be viewed simply as something that resides in the body of a person and which has to be coped with by him or her and their family, in isolation. This concept remains an ideal given the current realities of discrimination and the lack of resources (see Chapter 7). Studies on the ethics of care (see paragraph 2.3) and the sociology of emotions have found that notions of burdens and of dependence are highly relative terms. Most of us are interdependent with other people, regardless of whether or not we or they have impairments.⁴⁸ The main findings arising from research on the 'sociology of the body' are that terms such as 'impairment' and 'normal' and 'abnormal' also have to be understood within a wider social context.⁴⁹ Disabled people, their families and many researchers tend to refer to this 'social' model of disability rather than the 'medical' model, which is embedded in much of the medical literature describing outcomes after neonatal intensive care.
- 3.32 Many disabled people feel that portrayals by the media do not reflect the reality of their lives. This was demonstrated by a survey which analysed over 1,000 national and local press cuttings covering disability and disabled people over an eight week period in 1999. There were over 800 occurrences of pejorative terms. The terms used most frequently were 'suffer' and 'suffers', but these terms do not reflect accurately the perceptions of disabled people about themselves.⁵⁰ It was also observed that the achievements of disabled people often went unreported.
- 3.33 These examples show why it is important that accurate information is provided for pregnant women and for parents of newborn children about the nature and prognosis of the conditions of which their baby is at risk. There have been concerns about the adequacy of arrangements for informing parents about the disabilities that their baby is likely to develop, and his

⁴⁶ Prime Minister's Strategy Unit (2005) *Improving the Life Chances of Disabled People*.

⁴⁷ Department of Health (2006) Press release: *Government announces appointment of new learning disabled tsar*, available at: <http://www.gnn.gov.uk/environment/fullDetail.asp?ReleaseID=200756&NewsAreaID=2&NavigatedFromDepartment=False>, accessed on: 10 July 2006.

⁴⁸ Bendelow G (Editor) (1998) *Emotions in Social Life: Critical themes and contemporary issues* (London: Routledge).

⁴⁹ Shilling C (2003) *The Body and Social Theory*, 2nd Edition (London: Sage).

⁵⁰ Scope (1999) *Stop Press!*, see *Stop Press! – an overview*, available at: http://www.scope.org.uk/issues/media_stoppress.shtml, accessed on: 22 Sept 2006.

or her additional needs.⁵¹ In 2000, the Department of Health and Department for Education and Skills published joint guidance for parents and professionals (*Together from the Start*).⁵² This guidance identified several barriers to effective decision making at the time of early diagnosis. These include parents' perceptions of a lack of sensitivity, misunderstandings about the implications of a diagnosis, and the subsequent impact of a disability or health need on a child and his or her family. Some of the existing definitions of disability can be particularly insensitive, especially when it is not clear whether the child will develop disabilities or what the longer-term future might be. A template for good practice in discussing early identification, diagnosis and management of a disability or other special needs developed by the charity SCOPE in 2003 was rapidly adopted, disseminated and further developed in partnership with paediatric and other child health services and partners in health, education and the voluntary sector.⁵³

3.34 It was apparent from a number of parents of young disabled children, consulted on behalf of the Working Party, that they dread any suggestion that their child is 'blocking' a bed and may interpret any advice about withdrawal of treatment or changes in regime as a judgement that their child is 'not worth treating'.⁵⁴ A crucial question for parents in this situation is what quality of life their child can expect, given individual circumstances. The approach taken by professionals in conveying the prognosis and in particular, paying attention to attitude and language used, can help parents greatly. For example, doctors refer to 'withholding or withdrawing' treatment, but parents might prefer 'changing the treatment', 'reassessing the treatment' or 'reorienting the goals of care'. Honesty, understanding, tact and timing were considered to be crucial considerations. These parents wanted a sense of the future and how their child could reach his or her full potential. They could also feel very isolated and appreciated personal support.⁵⁵

Quality of life

3.35 The concept of 'quality of life' is a fundamental issue which arises when making critical care decisions (see paragraph 2.9). In simple terms, a person's quality of life refers to their emotional, social and physical wellbeing, their intellectual capability, and their ability to perform the ordinary tasks of living within a community. Critical care decisions will often have an impact on quality of life for both a baby and their family. People have different opinions about what constitutes a 'good' quality of life; indeed, disabled children often consider their quality of life to be good (see also paragraph 3.19). However, it is very difficult to judge the quality of life experienced by a very ill, newborn baby for whom a long-term prognosis may be unclear. Evidence of the extent of physical disability may not begin to appear until a baby is a toddler, and the full extent of learning and behavioural problems may not be experienced until he or she is well into school age. Currently it is difficult to assess the quality and variety of support that is available for children and families who need it or the impact on the quality of life of the parents. Parents often experience real difficulties in obtaining information about the social care or support available to them in the community, and how to access it (Chapter 7).⁵⁶

⁵¹ Scope (2003) *Right from the Start Template: Good practice in sharing the news*.

⁵² DiES and DH (2003) *Together from the Start: Practical guidance for professionals working with disabled children (birth to third birthday) and their families*.

⁵³ Scope (2003) *Right from the Start Template: Good practice in sharing the news*.

⁵⁴ Personal communication, Dr Philippa Russell.

⁵⁵ Russell P (2005) Information from a consultation group for the Early Support Programme.

⁵⁶ Scope (2003) *Right from the Start Template: Good practice in sharing the news*.

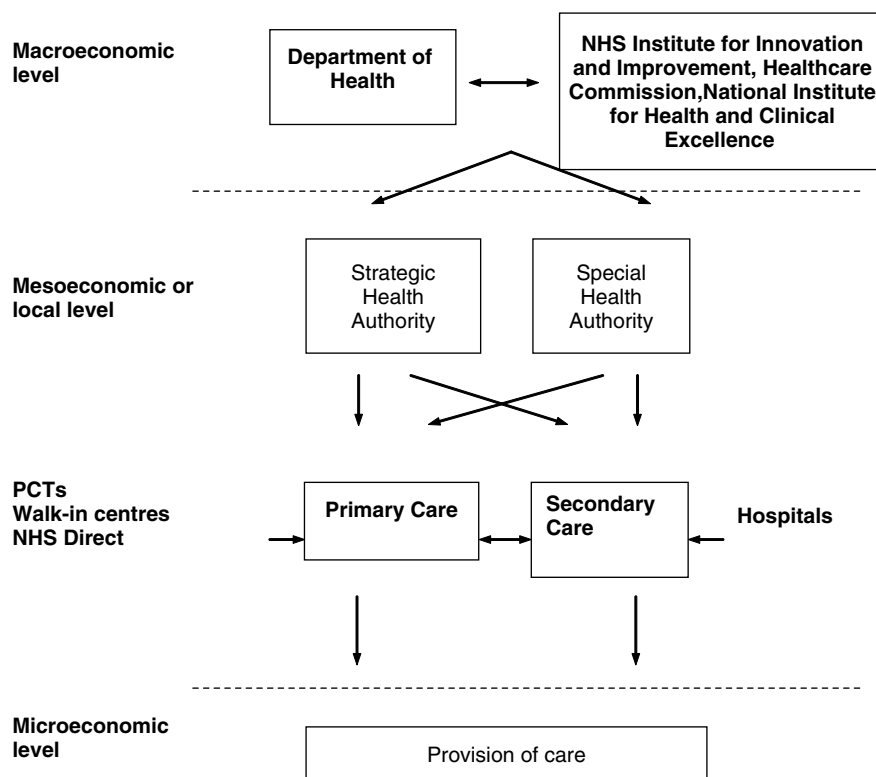
Economic issues

- 3.36 No healthcare system provides unlimited resources. The resources available for healthcare are limited compared with demand, if not need. All healthcare systems, regardless of their financing and organisation, employ mechanisms to set priorities for finite resources. Increases in funding or the removal of inefficiencies in the healthcare system which improve access to treatment are likely to be counterbalanced by other pressures on resources. Such pressures could, for example, arise from the introduction of new and more costly interventions resulting from medical advances, or from patients expecting healthcare services to do more to alleviate suffering.⁵⁷ While some commentators consider that the main economic issues concern improving expenditure on healthcare, or removing inefficiencies from the way in which it is delivered,⁵⁸ the need for setting priorities is generally perceived to be self-evident by those who have to allocate resources.
- 3.37 Given that decisions about the prioritisation of healthcare resources are unavoidable, how should we allocate finite healthcare resources in fetal and neonatal medicine? How should the lifetime costs of caring for a seriously ill newborn baby be taken into account when devising policies on whether to institute resuscitation or whether to continue treatment? Is it appropriate to invest heavily in caring for babies with poor prognoses when the resources might be directed to babies with better prognoses or elsewhere within the healthcare system? These questions are difficult to answer because there appears to be no consensus between philosophers, health economists and public health physicians about the moral basis for decisions on resource allocation.⁵⁹
- 3.38 Economic evaluation offers an explicit framework for addressing many of these divisive issues. Health economists attempt to identify the human and material inputs that combine to maximise health benefits or other measures of social welfare. Cost utility analysis is a tool, developed by health economists, that allows all health interventions to be compared in terms of their costs and the health improvements they procure. This permits healthcare resources to be allocated on a 'cost per quality-adjusted life year (QALY) gained' basis (see Appendix 8). However, numerous problems may be encountered when allocating finite resources in fetal and neonatal medicine by this method. Most notably, there is a well-recognised paucity of adequate data on the effects of fetal and neonatal interventions on survival and health-related quality of life for many conditions. In many cases, this information will also prove to be technically difficult and expensive to generate. Thus information on costs and health outcomes may be available for only a few of the range of interventions competing for priority. Moreover, little attempt has been made to test the validity, reliability, responsiveness and interpretability of the health attributes incorporated into the QALY measure in fetal and neonatal medicine. Crucially, however, allocating finite resources in fetal and neonatal medicine on a 'cost per QALY gained' basis raises a number of ethical issues. Important principles of justice may be ignored, for example if a treatment is available in one neonatal unit but not another. In addition, because neither ill health nor the distribution of healthcare resources are distributed randomly, a strategy aimed at maximising health outcomes within a limited budget may perpetuate inequalities or make them worse, and at best ignores them. In principle, this problem could be addressed by weighting the relevant data using agreed criteria for equity.
- 3.39 Broadly speaking, there are three levels at which economic issues could operate to influence decision making in healthcare. These may be described as the macroeconomic, the mesoeconomic

⁵⁷ Mooney G (1992) *Economics, Medicine and Healthcare* (London: Harvester Wheatsheaf).

⁵⁸ Frankel S (1991) Health needs, health-care requirements, and the myth of infinite demand *Lancet* **337**: 1588–90.

⁵⁹ We do not discuss the moral basis of resource allocation in this Report, but see, for example: Harvey I (1996) Philosophical perspectives on priority setting, in *Priority Setting: The health care debate*, Coast J, Donovan J and Frankel S (Editors) (Chichester: Wiley), pp 83–110.

Figure 3.4: Overview of the organisation of the NHS in England

and the microeconomic levels (see Figure 3.4; further details are provided in Appendix 7). Government agencies take decisions at the macroeconomic level, for example on the level of resource to be allocated to a particular area of clinical practice or on whether a particular treatment should be available within the NHS. The mesoeconomic level concerns regional and local decision making, such as whether or where a specialist service will be offered and the number of cots to be made available on a neonatal ward. Decisions made by healthcare professionals about a particular patient they are treating are at the microeconomic level. In practice, decision making in healthcare in the UK is affected by economic considerations at the macroeconomic and mesoeconomic levels. In our fact-finding meetings we consistently found that healthcare professionals took account only of ‘the patient in front of them’, although they could be frustrated by the difficulty, for example, of locating an intensive care bed for a very ill child. We reach some conclusions in relation to economic considerations in Chapter 2 and discuss their influence further, including the costs to families, in Chapters 4–7.

The legal context

3.40 At this point we set out some of the principal features of the law in its application to fetal and neonatal medicine. As we shall see in Chapter 8, English law distinguishes sharply between the legal status of the fetus and the newborn baby. The framework within which the law regulates decision making in fetal and neonatal medicine is equally relevant to both. The professional guidelines that are influential in shaping the law relating to decisions before, after and during birth are provided in Appendix 9.⁶⁰

3.41 On fetuses, the Abortion Act 1967 plays a major role in regulating professional practice. Other Acts of Parliament touch on dilemmas in fetal and neonatal medicine. However, much

⁶⁰ It should be noted that professional guidelines do not have a legal basis and that the following of guidelines will not give the doctor immunity from legal proceedings. Courts give some weight to guidelines but they are not treated as conclusive; see *W v Egdell* [1990] 1 All ER 835, CA; *An NHS Trust v B* [2006] EWHC 507.

of the law governing decision making in this area is based on interpretation of recent judgments of the courts, which are made on a case by case basis. In the recent decision in *An NHS Trust v B*, the judge said that his decision was “. . . not a ‘policy based’ judgment at all . . . not designed to have ‘implications’. . . . My sole and intense focus has been on this child alone, in his circumstances as they are today. . . .” This approach allows judges to take into account the circumstances of each case before them and encourages flexibility and pragmatism. That flexibility is often welcome to doctors, but some families may feel that flexible principles have led to their ‘rights’ and those of their children being overlooked. Healthcare professionals may also wish for more certainty and predictability. They may feel especially vulnerable when they could face criminal prosecution or disciplinary proceedings before the General Medical Council (GMC). These fears are not necessarily justified (see paragraph 8.8).

3.42 Legal principles reflect (whether set out in an Act of Parliament, or developed by judges) many of the ethical principles discussed in the previous chapter. One such principle is sanctity of life. However, while English law stresses the reverence for life, it does not adopt a rule that sanctity of life always demands its prolongation. Competing interests can sometimes take precedence⁶¹ and any requirement to preserve life must be balanced against the quality of that life and the burdens of proposed treatment to prolong life.⁶² Other influential principles include self-determination, or autonomy. This is crucial in fetal medicine where the English courts have concluded that like every other competent adult, the pregnant woman “. . . has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered”.⁶³ She decides whether to consent to or refuse any option for fetal surgery, early delivery or delivery by Caesarean section.⁶⁴ In law she is the arbitrator of the best interests of the fetus. However, once a baby is born alive (see paragraph 8.13), he or she has an independent legal status. The doctors’ primary duty is now owed to the baby.

3.43 Dignity is central to legal decision making especially in the case of a baby who cannot speak for him- or herself. In discussions of the law, dignity is often discussed as best interests, although it is only one aspect of the principle (see Chapter 2). One of the main legal questions concerns who should decide what is best for a fetus or baby. The law in the UK does not in theory distinguish between a newborn baby a few minutes old and older children or adults. It is a criminal offence to take active measures designed to hasten the death of a baby, however ill that baby may be. However, as in the case of older children or adults, when a baby is suffering, doctors and parents can agree to give him or her doses of pain-relieving drugs to alleviate distress even though a side effect of those drugs could be to shorten life (see paragraph 2.38).⁶⁵ The duty to care for the baby is not a duty to prolong life at all costs. Case law clearly establishes that where further treatment is futile and burdensome, the best interests of the baby may be to be allowed to die in as much comfort and dignity as possible. However, deciding when that point has been reached is very difficult. When there is uncertainty, doctors may fear that they are breaking the law in not continuing life support.⁶⁶ Where

⁶¹ *Airedale NHS Trust v Bland* [1993] AC 789 at 894.

⁶² *Re J (a minor) (wardship: medical treatment)* [1990] 3 All ER 930 at 942.

⁶³ *St George’s Hospital NHS Trust v S* [1998] 3 All ER 673.

⁶⁴ *Ibid.*

⁶⁵ *R v Adams* [1957] Crim. L. R. 365. A study of physicians working in neonatal intensive care units found that 70% of those surveyed in the UK reported having previously made a decision to administer sedatives or analgesics to suppress pain even at the risk of respiratory depression and death. It was also found that 4% reported having previously administered drugs to a newborn baby with the purpose of ending life. See Cuttini M, Nadai M, Kaminski M *et al.* (2000) End-of-life decisions in neonatal intensive care: physicians’ self-reported practices in seven European countries *Lancet* **355**: 2112–18.

⁶⁶ Personal communication to the Working Party. It has not been possible to obtain systematically collected information on the frequency of such cases reaching the courts.

parents and the professionals disagree and the case is taken to court, the judges have in the past more usually given support to professional judgement over parental views, drawing on the advice of independent professional experts.⁶⁷

3.44 The European Court of Human Rights has ruled that it is illegal for doctors to withhold, withdraw or administer a treatment against parental objection without seeking a ruling from the court except in an emergency.⁶⁸ Until recently, judges in the UK were somewhat dismissive of the notion of children's rights.⁶⁹ The Human Rights Act 1998, giving effect in domestic law to the European Convention on Human Rights, means that in all cases involving disputes about healthcare, judges must now address the question of the patient's human rights, whether he or she is an adult or a baby.⁷⁰ Parents seeking to require continuing intensive care for their baby may invoke his or her right to life reinforced by their claim as parents to the right to family life.⁷¹ Doctors may contend that continuing intrusive, intensive care is inhumane. The European Convention on Human Rights is, however, not "... designed to deal with children's claims".⁷² An international treaty, the United Nations Convention on the Rights of the Child (UNCRC) provides much more detail about children's rights.⁷³ It is not directly enforceable in the UK courts so a legal claim for breach of one of the articles of the UNCRC could not be pursued. The UNCRC articles may be used as guidance about how the law should develop. In the context of the born baby and decisions about his or her medical care,⁷⁴ the following Articles of the UNCRC are especially relevant. Article 24(1) requires that States now "recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health". Article 6 reiterates the child's "... inherent right to life" and Article 3 requires that in all decision making relating to a child, his or her best interests shall be "a primary consideration".

3.45 In England and Wales, the Children Act 1989 would be used to decide cases of disagreement over treatment for a baby. The Act states that the welfare of the child should be paramount and gives parents certain responsibilities⁷⁵ which we describe in more detail in paragraph 8.10. So far, UK courts have not given much consideration to the UNCRC in cases relating to the medical care of babies. The unequivocal recognition in UK law that a newborn baby enjoys the same status as any older child or adult reflects (if unconsciously) the rights approach of the UNCRC. A baby is recognised as having a right to life and to appropriate care determined by his or her best interests. However, the difficult decisions remain of how to interpret and apply the rights of a baby in the context of critical care decision making in fetal and neonatal medicine. In Chapter 8, we examine the constraints that the law imposes on the kinds of decisions that can be made and examine more fully the role of the law in regulation and dispute resolution. Using the models provided by clinical ethics committees, bioethics mediation and dispute resolution, we also explore how other methods of resolving disagreements justly and transparently, could be developed.

⁶⁷ *An NHS Trust v B* [2006] EWHC 507.

⁶⁸ *Glass v United Kingdom* [2004] ECHR 102.

⁶⁹ See, for example, *Re T (a minor) (medical treatment)* [1997] 1 All ER 906 at 916 per Waite L.J.

⁷⁰ See Fortin J (2003) *Children's Rights and the Developing Law* (2nd Edition) (Lexis-Nexis), Chapter 10. Article 2 (right to life), Article 3 (prohibiting inhuman (sic) treatment) and Article 8 (right to respect for privacy and family life) of the Human Rights Act are especially important in our context.

⁷¹ See *Glass v UK* (above).

⁷² Fortin J (2003) *Children's Rights and the Developing Law* (2nd Edition) (Lexis-Nexis), p 53.

⁷³ *Ibid.*, pp 31–50.

⁷⁴ *Ibid.*, pp 307–41.

⁷⁵ The Children Act 1989 applies in England and Wales. It stipulates that when a court determines matters relating to a child, the child's welfare shall be the court's paramount consideration. Similar provisions are contained in the Children (Northern Ireland) Order 1995 and the Children (Scotland) Act 1995.

Chapter

Dilemmas in current
practice: the fetus

4

Dilemmas in current practice: the fetus

Introduction

- 4.1 In this and the following two chapters we explore more fully dilemmas of decision making in fetal and neonatal medicine. We examine three stages during which decisions take place, beginning in this chapter with those made during pregnancy. In Chapter 5, we consider extremely premature babies born at the borderline of viability (up to 25 weeks and six days of gestation)¹ before turning in Chapter 6 to focus on babies whose condition has stabilised after resuscitation. Looking beyond, to the time if and when a baby leaves hospital, we discuss longer-term implications for healthcare, education and social welfare, which we consider up to early adulthood, in Chapter 7. As well as attempting to set out the issues that arise at each of these four stages, we use examples to develop our analysis of ethical and social issues and to highlight the legal implications.² It is not our intention to take a particular stance in the discussion of each of these examples, but to use the cases to illustrate the nature of the issues that can arise in critical care.
- 4.2 In fetal medicine³, improvements in technology, and greater understanding of how fetal development affects the future health of a child, have changed the way in which pregnancies are managed. Approximately 800,000 women become pregnant in England and Wales each year.⁴ During pregnancy, women are offered a range of tests, scans and screening procedures, often presented as part of a 'care pathway',⁵ which will inform them and the health professionals providing care about their health, the health of the developing baby and the progress of the pregnancy. Although screening will provide reassurance for most pregnant women, more than 35,000 per annum will be told that there is a risk that their unborn baby may have a serious abnormality.⁶ Approximately 5% of pregnant women who have blood tests for fetal abnormality will be asked if they wish to have additional diagnostic testing (see Box 4.1). In about 2% of those who are tested, the presence of a serious fetal abnormality will be confirmed and the woman will be asked how she would like to proceed.⁷ She is likely to want to discuss her options with her partner and perhaps other family members. The timing of routine scans is based on fetal development, which means that a woman may only become aware of a fetal abnormality after 20 weeks of gestation. She may need further time to consider the best course of action in her circumstances. Most commonly, the choices will be

¹ By convention, the number of weeks of gestation refers to the period from the first to the last day of that week. For example 'at 23 weeks' means from 23 weeks, 0 days to 23 weeks and six days of gestation (161–167 days of gestation).

² We use examples that are representative of what occurs in hospital. They are not based on actual clinical cases. In the discussion of each example, issues are highlighted, some of which were drawn to the attention of members of the Working Party during fact-finding meetings. We acknowledge that the choice of the issues that we discuss after each example may influence how the examples themselves are perceived by different readers, depending upon the reader's own worldview.

³ We use the term 'fetal medicine' to include surgery.

⁴ National Statistics (Summer 2006) *Population Trends No. 124*, Table 4.1.

⁵ The *National Service Framework Standard for Maternity Services*, which must be met by 2014, requires that each pregnant woman has an individual care pathway in order to ensure that all pregnant women receive the same high standard of care. The care pathway is intended to indicate a woman's progress through the variety of services available and explain how her care will be provided in particular circumstances. See Department for Education and Skills and Department of Health (2004) *Maternity Standard, National Service Framework for Children, Young People and Maternity Services* (London: Department of Health), available at: <http://www.dh.gov.uk/assetRoot/04/09/05/23/04090523.pdf>, accessed on: 31 July 2006. For further information on genetic screening programmes, see also Nuffield Council on Bioethics (2006) *Genetic Screening: a Supplement to the 1993 Report by the Nuffield Council on Bioethics* (London: NCOB).

⁶ See the website of Antenatal Results and Choices, available at: <http://www.arc-uk.org/>, accessed on: 29 Aug 2006.

⁷ In addition, there will be a small number of false-negative test results. For further information, see the website of Antenatal Results and Choices, available at: <http://www.arc-uk.org/>, accessed on: 29 Aug 2006; and Department for Education and Skills and Department of Health (2004) *Maternity Standard, National Service Framework for Children, Young People and Maternity Services* (London: Department of Health), available at: <http://www.dh.gov.uk/assetRoot/04/09/05/23/04090523.pdf>, accessed on: 31 July 2006.

whether she should accept that her child will have disabilities and continue with the pregnancy, agreeing to an early delivery if appropriate, or whether the pregnancy should be terminated.

Box 4.1: Antenatal screening programmes in the UK

The options for antenatal screening will be discussed with a pregnant woman by her doctor or midwife. Screening aims to identify pregnancies that are at high risk of congenital or genetic disorders and may be followed by confirmatory diagnostic testing. If there are fetal abnormalities, doctors will advise the woman of possible options. The development of screening programmes with high detection rates and a low incidence of false-positive test results that can be applied to all pregnant women has been given a high priority within the NHS. Conditions for which screening is routinely offered during pregnancy in the UK include Down's syndrome, fetal anomalies such as hydrocephalus or limb abnormalities, haemoglobinopathies (in certain localities), rhesus haemolytic disease (see Case 1) and Tay-Sachs disease (in some 'at-risk' populations).

For chromosome abnormalities, particularly Down's syndrome, screening is carried out by ultrasound (measurement of the nuchal translucency*) at 10–14 weeks of gestation and/or maternal blood analysis at 10–20 weeks of gestation. For other abnormalities, screening by ultrasound imaging is performed ('fetal anomaly scanning'), usually at about 20 weeks of gestation.† Pregnant women at high risk of specific fetal genetic diseases such as sickle cell disease and thalassaemia (both haemoglobinopathies) are offered a genetic test early in their pregnancy. If a woman is found to be carrying a genetic mutation responsible for either disorder, her partner may also be offered testing. If one or both of them are identified as carrying the trait, biochemical or genetic tests would be offered for the fetus.

If a high risk of a fetal abnormality is predicted or detected, fetal diagnostic tests are offered. Fetal material is obtained from samples of the placenta (chorionic villus sampling) or amniotic fluid (amniocentesis) or by direct fetal blood sampling. Each of these techniques carries a small risk (estimated at 1–2%) of miscarriage. The pregnant woman (and her partner) must be informed of this before deciding whether to undertake such a test.

* Nuchal translucency is an early ultrasound measure of the thickness of fluid at the nape of the fetal neck. An increased amount of fluid may indicate that the fetus has Down's syndrome or another chromosomal, structural or genetic abnormality.

† For further information, see Wald N and Leck (2000) *Antenatal and Neonatal Screening* (Oxford: Oxford University Press), pp 573; National Institute for Clinical Excellence (2003) *Antenatal Care: Routine care for the healthy pregnant woman* (London: NICE).

Clinical perspectives

Decisions about when to deliver a fetus

- 4.3 In parallel with advances in the detection of fetal abnormalities, there has been an improvement in identification of cases where the fetus is at high risk of dying in the womb or where early delivery is needed for other reasons. Early delivery may be necessary for the health of the pregnant woman because of intense bleeding, the development of complications of pregnancy which threaten her life, or because the fetus will be at risk if left in the womb. Decisions need to be made about which treatments should be given and when the baby should be delivered. However, the options for effective treatment with medicine or surgery are limited (see paragraphs 4.10–4.11). In addition, extreme prematurity creates its own problems (see Chapter 5).
- 4.4 The most common causes of premature birth are spontaneous preterm labour, preterm pre-labour rupture of membranes, and multiple pregnancy (see Table 4.1). Approximately 15–25% of premature births occur when a baby needs to be delivered early because of maternal or fetal complications during pregnancy.⁸ The most frequent complications are maternal hypertensive disorders such as pre-eclampsia, which can put both the woman and fetus at risk, and where the fetus is failing to grow *in utero* (fetal growth restriction) and showing signs of distress. The balance between the risk for the fetus of remaining in the womb and the risk of death and disability after premature delivery needs careful assessment.
- 4.5 When a pregnant woman is at risk of an imminent premature delivery, evidence from several clinical trials shows that a single course of steroids can help to prepare the fetal lungs for

⁸ Tucker J and McGuire W (2004) Epidemiology of preterm birth *Br Med J* **329**: 675–78.

Table 4.1: Causes of premature birth in Europe and North America

Cause of premature delivery	Frequency
Spontaneous preterm labour	31–50%
Multiple pregnancy and associated complications	12–28%
Preterm prelabour rupture of membranes	6–40%
Hypertensive disorders of pregnancy	12%
Intrauterine growth restriction	2–4%
Antepartum haemorrhage	6–9%
Miscellaneous – cervical incompetence, uterine malformation	8–9%

Source: These data are reprinted from Slattery MM and Morrison JJ (2002) Preterm delivery *Lancet* 360: 1489–97, with permission from Elsevier. The data are based on a number of studies in Europe and North America. The frequencies quoted indicate the proportion of premature births associated with each of the causes listed.

birth while causing no identifiable problems.⁹ The treatment helps to mimic the effects that occur naturally prior to delivery near full term. Steroids used in this way can reduce the risk of a premature baby dying, developing lung disease or brain injury, particularly if birth takes place 24 hours or more after a course of the medicine has been given.

- 4.6 A second intervention is to delay or arrest the onset of labour. The inhibition of contractions may be achieved by a variety of treatments. Delaying labour can benefit the fetus by allowing time for steroid treatment to be completed or for the woman to be transferred to a specialist hospital before she gives birth.¹⁰ However, some women experience adverse effects from medicines used to delay labour, and randomised trials have not demonstrated a clear benefit from their use.¹¹ Furthermore there is always the concern that delaying premature delivery could worsen the health of the woman and fetus if there is an underlying reason for the premature labour such as an infection or high blood pressure.¹² For example, chorioamnionitis, a bacterial infection of the two membranes of the placenta and the fluid around the baby, can lead to more serious maternal and fetal infections and increase the risk of other problems in the baby.
- 4.7 A better understanding of fetal health has been achieved with improved antenatal assessment. Fetal growth restriction is often caused by problems with the flow of blood through the placenta, resulting in insufficient nutrients reaching the fetus. Techniques that identify poor fetal growth and condition have improved markedly. Growth may be monitored, usually by standard and Doppler ultrasound imaging, and by recording fetal heart rhythms. A decision about early delivery is needed when there are clear signs that growth restriction is affecting fetal function, detected for example by changes in fetal behaviour, abnormal blood flow or a worsening heart trace. By the time that it is clear that the fetus will die, it may be too late to save the baby's life. Yet delivery beforehand, when there are only early signs of fetal compromise, may expose the baby to the complications of prematurity. The decision to deliver is finely balanced and different obstetricians faced with the same clinical situation may make different judgements.

⁹ Roberts D and Dalziel S (2006) Antenatal corticosteroids for accelerating fetal lung maturation for women at risk of preterm birth *The Cochrane Database of Systematic Reviews*, Issue 3.

¹⁰ Royal College of Obstetricians and Gynaecologists (2002) *Tocolytic Drugs for Women in Preterm Labour* (London: RCOG), available at: [http://www.rcog.org.uk/resources/Public/pdf/Tocolytic_Drugs_No1\(B\).pdf](http://www.rcog.org.uk/resources/Public/pdf/Tocolytic_Drugs_No1(B).pdf), accessed on: 3 Aug 2006.

¹¹ *Ibid.*

¹² Committee on Understanding Premature Birth and Assuring Health Outcomes (2006) *Preterm Birth: Causes, consequences and prevention*, Behrman RE and Stith Butler A (Editors) (Washington, DC: National Academies Press).

- 4.8 A recent trial randomly assigned pregnant women to early delivery or to deferred delivery if there was good evidence that a fetus was failing to thrive, as well as uncertainty over the best course of management (the Growth Restriction Intervention Trial, GRIT).¹³ The results showed that the overall death rates for fetuses or babies were not substantially different in the two groups. Early delivery produced more deaths on the neonatal unit whereas deferred delivery led to more deaths before birth. There were no differences in outcomes for survivors at two years of age.¹⁴
- 4.9 Dilemmas arise in the clinical management of multiple pregnancy (see paragraph 3.4) where there are significant complications or evidence that the health of one or more fetuses is being adversely affected. This may be because of an underlying abnormality, fetal growth restriction or brain injury. These complications may lead to spontaneous prematurity, and increased risks of malformation and cerebral palsy, the risks rising as the number of fetuses increases. The options for clinical management include treatment, where possible, or early delivery. Selective reduction of multiple pregnancy by fetocide is sometimes advised by doctors when the health of one or more fetuses is compromised.

Possibilities for fetal treatment¹⁵

- 4.10 A pregnant woman's options are usually limited when a condition affecting the health of the fetus(es) is identified through screening, as effective fetal treatments are available for only a small number of conditions. They include:

Ultrasound-guided procedures to obtain fetal blood samples or tissue to confirm diagnoses, or to give treatments such as transfusions.

Fetal blood transfusion if a fetus suffers from rhesus haemolytic disease, which can cause heart failure, the accumulation of fluid (hydrops), and eventual death. Transfusing blood that is compatible with the pregnant woman's blood group into the fetus can reverse the process and allow the pregnancy to progress normally.

Laser treatment by fetoscopy to correct a condition that occurs in identical twins where connections develop between the two fetal circulation systems through the placenta.¹⁶

Drainage tubes used to remove fluid that accumulates in unwanted places, especially around the fetal lungs or when the outflow of urine is blocked in the bladder. The tubes drain the accumulated fluid into the amniotic sac around the fetus. This procedure is simple to carry out and can allow the fetus to develop normally. The dilemma for doctors is whether the condition leading to the problem is reversible, or whether the damage done by the accumulating fluid, for example to the growth of the lung or kidney, is already too far advanced for the procedure to benefit the fetus.

Medicines given to a pregnant woman often cross the placenta and can be used to treat the fetus. For example, the use of digoxin or flecainide can be highly effective in preventing abnormal fetal cardiac rhythms. Untreated, this condition may be fatal. However, care must be taken to treat the fetus without producing unacceptable side effects in either the fetus or the woman.

¹³ Thornton JG, Hornbuckle J, Vail A, Spiegelhalter DJ and Levene M; GRIT study group (2004) Infant wellbeing at 2 years of age in the Growth Restriction Intervention Trial (GRIT): multicentred randomised controlled trial *Lancet* **364**: 513–20.

¹⁴ Research in this area is continuing.

¹⁵ Medical terms in this section are explained further in the Glossary.

¹⁶ Blood may flow preferentially in one direction in such cases and one fetus may fail to grow properly while the other suffers the consequences of excess circulating blood, placing both fetuses at risk of dying before birth or of developing cerebral palsy if they survive what is often very premature birth. Randomised trials have shown that using laser therapy to divide the blood vessels causing the 'twin-to-twin transfusion' can be more successful in treating this condition than other treatments. However, long-term outcomes are variable. For a review, see Harkness UF and Crombleholme TM (2005) Twin-twin transfusion syndrome: where do we go from here? *Semin Perinatol* **29**: 296–304.

Possibilities for fetal surgery

- 4.11 Open surgical operations to correct or lessen the impact of abnormalities of the fetus before birth are rare, although a number of attempts have been made over the past 20 years to repair conditions such as congenital diaphragmatic hernia or spina bifida.¹⁷ Procedures of this kind, which involve opening the pregnant woman's abdomen and uterus under general anaesthesia and partly exposing and operating on the fetus, must be considered experimental. Because the risks for the pregnant woman are high and the outcomes reported to date have been generally poor or worse than operations performed after birth, there are currently only a small number of centres in the USA that undertake open fetal surgery. Consistent with the recommendations of the Bristol inquiry,¹⁸ **the view of the Working Party is that new procedures in fetal surgery should be offered in the UK only within a protocol approved by a research ethics committee (REC).**
- 4.12 If there are no options for surgery or other treatments to treat a fetus with a serious abnormality, a woman faces a stark choice of whether to continue with her pregnancy or seek termination. For some conditions detected by testing, the outcome will be certain; examples would include anencephaly or renal agenesis. Doctors would be able to explain what is wrong with the fetus and how the baby would be affected. In other cases the outcome may be much more difficult to predict. The woman may prefer to wait for results of further tests if these are available and to defer the decision about whether or not to have a termination. If no further tests are possible, she may decide to continue her pregnancy in the knowledge that there is a risk of miscarriage, stillbirth or having a baby with health problems or disabilities. Alternatively, she may decide to terminate her pregnancy.

Late termination of pregnancy

- 4.13 In England, Scotland and Wales the Abortion Act 1967 specifies that termination of pregnancy beyond 24 weeks of gestation is only legal if either a fetus is at substantial risk of serious handicap or there is a risk of grave permanent injury to the life, or the physical or mental health of the woman.¹⁹ In England and Wales in 2004, 124 terminations were carried out after 24 weeks of gestation, out of a total of 185,415 (less than 0.1%).²⁰ Of these, 91 were for congenital malformations, 23 for chromosomal abnormalities and ten for other conditions, such as disorders related to gestation and growth. Some specialists in fetal medicine have reported that the absence of an absolute cut-off in law at 24 weeks has relieved the

¹⁷ A randomised clinical trial of fetal surgery for spina bifida is in progress in the USA. See US National Institutes of Health *Management of Myelomeningocele Study (MOMS)*, available at: <http://www.clinicaltrials.gov/show/NCT00060606>, accessed on: 20 Sept 2006. Preliminary data from the UK have recently been published on fetal surgery to correct severe congenital diaphragmatic hernia[0]. See Deprest J, Gratacos E, Nicolaides KH; FETO Task Group (2004) Fetoscopic tracheal occlusion (FETO) for severe congenital diaphragmatic hernia: evolution of a technique and preliminary results *Ultrasound Obstet Gynecol* **24**: 121–6.

¹⁸ The Bristol Royal Infirmary Inquiry (2001) *The Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984–1995: Learning from Bristol*, available at: http://www.bristol-inquiry.org.uk/final_report/the_report.pdf, accessed on: 25 Sept 2006. The recommendation made was that "Before any new and hitherto untried invasive clinical procedure can be undertaken for the first time, the clinician involved should have to satisfy the relevant local research ethics committee that the procedure is justified and it is in the patient's interests to proceed. Each trust should have in place a system for ensuring that this process is complied with." In the UK the Interventional Procedures Programme at the National Institute for Health and Clinical Excellence (NICE) is responsible for assessing and publishing guidance on the safety and efficacy of new interventions, including fetal ones, when they are first used in the NHS in England, Scotland or Wales outside of a REC-approved protocol. The Programme defines interventions as procedures "used for diagnosis or treatment that involve incision, puncture, entry into a body cavity or the use of ionising, electromagnetic or acoustic energy". See: National Institute for Clinical Excellence (2004) *The Interventional Procedures Programme – Programme manual* (London: NICE).

¹⁹ Abortion Act 1967; Mason JK and Laurie GT (2005) *Mason and McCall Smith's Law and Medical Ethics*, 7th Edition (Oxford: Oxford University Press). See also Chapter 8. Note that although the Abortion Act applies to Scotland, differences in the law in Scotland meant that the Act did not significantly alter existing policy.

²⁰ Government Statistical Service (2005) *Abortion Statistics, England and Wales: 2004*, available at: <http://www.dh.gov.uk/assetRoot/04/11/75/74/04117574.pdf>, accessed on: 13 June 2006. Note that these figures do not include 8,764 abortions performed on women who were not resident in England or Wales.

pressure for hurried decision making in a small number of patients where further investigations, consultation and/or monitoring are necessary to help establish a prognosis, or where there are delays in access to screening. While the Abortion Act 1967 does not apply to Northern Ireland, recent court cases have ruled that terminations may be permitted in some exceptional circumstances where a woman's life or physical or mental wellbeing would be at risk.²¹ Fetal abnormality alone would not be a lawful ground for termination in Northern Ireland.

4.14 Late termination of pregnancy can be traumatic for the woman, her partner, relatives and companions and for healthcare professionals²², as she ends a previously wanted pregnancy and must go into labour and give birth. In addition, at 22 weeks of gestation, a fetus (even with a fatal condition) may show signs of activity at delivery (such as a heartbeat, gasp or reflex movements). The birth of a live child has to be registered as such, which parents and professionals may find distressing when it follows termination, especially when death also has to be registered shortly afterwards.²³ The Royal College of Obstetricians and Gynaecologists (RCOG) has developed guidelines that include the recommendation that feticide (causing the death of a fetus) be carried out before the initiation of labour in terminations after 21 weeks and six days of gestation to ensure that the fetus is not born alive.²⁴ The College is also issuing new guidance about the management of pre-viable fetuses of less than 21 weeks, six days of gestation. The recommended method of feticide is an injection of potassium chloride into the fetal heart²⁵ which stops the heartbeat. It is mostly regarded as a means of causing rapid death which does not require analgesia (see paragraph 4.19). Feticide pre-empts the possibility of dilemmas about whether a baby born alive after a termination should be resuscitated. Some parents have been reported to be relieved knowing that their fetus will not suffer during induced labour or be born alive, although in other accounts parents described the procedure as particularly distressing.²⁶ Interview studies with parents have found that when the procedure is handled sensitively, reactions to feticide appear not to dominate the experience of grief at the loss of a wanted baby.²⁷

4.15 Since 2002, clinicians in England and Wales have been required to report whether feticide was performed in terminations. In 2005, 31% (approximately 800) of the terminations that took place at 20 weeks of gestation onwards in England and Wales were reported as including feticide.²⁸ The Working Party was informed that there may be some variation between

²¹ Mason JK and Laurie GT (2005) *Mason and McCall Smith's Law and Medical Ethics*, 7th Edition (Oxford: Oxford University Press), p148.

²² Royal College of Obstetricians and Gynaecologists (2001) *Further Issues Relating to Late Abortion, Fetal Viability and Registration of Births and Deaths*, available at: <http://www.rcog.org.uk/index.asp?PageID=549>, accessed on: 8 Aug 2006.

²³ McHaffie HE (2001) *Crucial Decisions at the Beginning of Life* (Abingdon: Radcliffe Medical Press), p197.

²⁴ Royal College of Obstetricians and Gynaecologists (1996) *Termination of Pregnancy for Fetal Abnormality in England, Wales and Scotland* (London: RCOG); Royal College of Obstetricians and Gynaecologists (2001) *Further Issues Relating to Late Abortion, Fetal Viability and Registration of Births and Deaths*, available at: <http://www.rcog.org.uk/index.asp?PageID=549>, accessed on: 8 Aug 2006. Feticide is discussed in several other RCOG reports and statements. One of these, from 1998, recommends the use of feticide for late terminations of pregnancy after advising that obstetricians have a duty "to protect the fetus from suffering pain in all terminations of pregnancy regardless of gestation". Royal College of Obstetricians and Gynaecologists (1998) *Late Termination of Pregnancy for Fetal Abnormality* (London: RCOG).

²⁵ Royal College of Obstetricians and Gynaecologists (2001) *Further Issues Relating to Late Abortion, Fetal Viability and Registration of Births and Deaths*, available at: <http://www.rcog.org.uk/index.asp?PageID=549>, accessed on: 8 Aug 2006.

²⁶ Statham H, Solomou W and Green JM (2001) Care in hospital for parents who terminated their pregnancy, in *When a Baby has an Abnormality: A study of parents' experiences* (Cambridge: Centre for Family Research, University of Cambridge), Chapter 6.

²⁷ Personal communication, Dr Ruth Graham, School of Geography, Politics and Sociology, University of Newcastle upon Tyne.

²⁸ This percentage may be an underestimate as routine recording only began in 2002 and the Government Statistical Service states that it is likely that feticide is still being under-reported. Government Statistical Service (2006) *Statistical Bulletin Abortion Statistics, England and Wales: 2005*, available at: <http://www.dh.gov.uk/assetRoot/04/13/68/59/04136859.pdf>, accessed on: 29 Aug 2006.

doctors on the types of condition for which feticide is offered. However, doctors would usually advise feticide where a fetus has or will develop serious abnormalities, but may live for some time without special assistance after birth, such as in the brain disorder microcephaly (usually only diagnosable very late in pregnancy). Feticide is not always considered necessary if a fetus has an unequivocally fatal condition and will die during or soon after birth.²⁹ It may also be very difficult for practical reasons, for example if the nearest fetal medicine unit is some distance away.³⁰ A minority of pregnant women do not wish to have feticide, whatever the diagnosis.³¹ They prefer to be able to hold their baby after birth and be together as a family, even if only for a short while, before the baby dies.³² The Working Party was advised that termination of pregnancy after 22 weeks without feticide was an issue of major concern for healthcare professionals in fetal medicine. In particular, they needed a greater understanding of the legal position.³³

- 4.16 This uncertainty over whether doctors are legally obliged to resuscitate any child with a serious condition who is born alive, including conditions incompatible with long-term survival, and regardless of the parents' wishes, was expressed to members of the Working Party in fact-finding meetings. Unease about this question could affect the advice that doctors provide about feticide. However, such concerns are ill-founded. There is no legal obligation to institute all possible steps to preserve life for any baby with serious abnormalities whose condition is such that it is not in his or her best interests to survive (see paragraph 8.8). Doctors should therefore feel able to respect the woman's wish if she chooses to decline feticide and not be obliged to press her to reconsider. What is essential in these circumstances however, is that there should be thorough discussions with the woman (and her partner if she wishes) about the likely outcomes, taking into account the circumstances of her case. It must be made clear that in the exceptional circumstances that a baby appears likely to live when the termination is for a non-fatal condition, neonatologists will institute treatment if they believe this to be in the best interests of the baby, having assessed his or her condition at birth. In Chapter 9 we offer some guidance for helping to decide what is in a baby's best interests. It is important that the woman should be given time to consider her decision and evaluate whether termination without feticide genuinely remains her wish. If so, she should agree a care plan in advance of the procedure that covers the possible outcomes.
- 4.17 Currently, national statistics do not include data on the extent to which feticide is offered to pregnant women. The BMA has observed that little is known about how parents make decisions following the diagnosis of severe fetal abnormality, including the kind of information and support they receive and how this affects their decision making.³⁴ Available data suggest that parents experience difficulties in deciding how to proceed after such a diagnosis, with two factors reported as being important for decision making. These are first, the impact of

²⁹ Statham H, Solomou W and Green JM (2006) Late termination of pregnancy for fetal abnormality: law, policy and decision-making in four English fetal medicine units *BJOG* (in press).

³⁰ Feticide may only be carried out in a fetal medicine unit. Royal College of Obstetricians and Gynaecologists (1998) *A Consideration of the Law and Ethics in relation to Late Termination of Pregnancy for Fetal Abnormality* (London: Royal College of Obstetricians and Gynaecologists).

³¹ A recent study reported that of 31 parents offered feticide for late termination of pregnancy, three declined; in two cases the baby had a lethal abnormality and the doctors advised that feticide was unnecessary and in the other, at 21 weeks of gestation (i.e. earlier than the limit above which feticide is advised by the RCOG), the parents decided against it. Statham H, Solomou W and Green JM (2002) Termination of pregnancy, in *When a Baby has an Abnormality: A study of parents' experiences* (Cambridge: Centre for Family Research), pp 56–106.

³² Personal communication at a fact-finding meeting of the Working Party.

³³ Personal communication from Professor Steve Robson, University of Newcastle upon Tyne.

³⁴ British Medical Association (2005) Diagnosing fetal abnormality, in *Abortion Time Limits – A briefing paper from the BMA*, available at: <http://www.bma.org.uk/ap.nsf/Content/AbortionTimeLimits~Factors~Diagnosing>, accessed on: 30 May 2006.

the abnormality on the child, on themselves and on other immediate family members (including children they wish to have in the future), and secondly, their prior attitudes and beliefs about termination. It has been suggested that parents tend not to focus on levels of risk and the options available in an objective way, but rather on their perception of their own ability to cope.³⁵ Decision making is made more complex when there is uncertainty over how seriously a child will be affected by any disability in the future.

- 4.18 The Confidential Enquiry into Maternal and Child Health (CEMACH) is currently (2006) undertaking a survey of terminations of pregnancy where a neonatal death was subsequently recorded. The survey will seek to determine the reasons for the termination of pregnancy, the method of termination and whether feticide was offered. Where possible, for terminations over 21 weeks, six days of gestation, the reasons for which feticide is not performed will be recorded, including when pregnant women declined. The Working Party supports the collection of these data for the insight they may give into current practice.

Fetal pain

- 4.19 The question of whether a fetus can feel pain is almost impossible to answer. For adults, pain involves consciousness, thought, memory and fear. In the fetus, a grimace, physical withdrawal, movement or release of stress hormones into the blood stream does not necessarily mean that pain has been consciously perceived. Scientists disagree as to when the fetus has sufficient neurological development to perceive pain and whether there might be particular characteristics of the fetal environment that inhibit conscious perception of pain *in utero*.³⁶ Even if the cerebral cortex (where pain and other sensations are perceived) is insufficiently developed before 26 weeks of pregnancy for the fetus to be conscious of pain,³⁷ there may be negative consequences from distress associated with invasive procedures which affect subsequent development. In a report on fetal pain, the RCOG suggested that the potential for it should be considered in procedures involving fetuses from 24 weeks of gestation onwards (after which it is possible that the fetus may experience pain), while bearing in mind the potential harm that analgesic drugs may cause.³⁸ The RCOG have recommended that fetal analgesia or sedation be considered for major intrauterine procedures, and (see paragraph 4.14) feticide or sedation be considered for late terminations of pregnancy.³⁹

Some examples⁴⁰

- 4.20 In the following paragraphs, we use two hypothetical examples to illustrate some of the issues that may arise when decisions affecting the survival of a child have to be made during pregnancy. The first case concerns a pregnancy where the fetus has rhesus haemolytic disease. The second concerns a woman who has been asked to decide whether to terminate her pregnancy because the fetus has a serious abnormality of brain development.

³⁵ Statham H (2002) Prenatal diagnosis of fetal abnormality: the decision to terminate the pregnancy and the psychological consequences *Fetal Matern Med Rev* **13**: 213–47.

³⁶ See Anand KJ, Aranda JV, Berde CB *et al.* (2006) Summary proceedings from the neonatal pain-control group *Pediatrics* **117**: S9–22; Derbyshire SWG (2006) Can fetuses feel pain *Br Med J* **332**: 909–12; Mellor DJ, Diesch TJ, Gunn AJ and Bennet L (2005) The importance of 'awareness' for understanding fetal pain *Brain Res Rev* **49**: 455–71; Lee SJ, Ralston HJP, Drey EA, Partridge JC and Rosen MA (2005) Fetal pain: A systematic multidisciplinary review of the evidence *J Am Med Assoc* **294**: 947–54; Glover V and Fisk NM (1999) Fetal pain: implications for research and practice *Br J Obstet Gynaecol* **106**: 881–6.

³⁷ Royal College of Obstetricians and Gynaecologists (1997) *Fetal Awareness: Report of a working party* (London: RCOG Press).

³⁸ *Ibid.*

³⁹ Royal College of Obstetricians and Gynaecologists (2001) *Further Issues Relating to Late Abortion, Fetal Viability and Registration of Births and Deaths*, available at: <http://www.rcog.org.uk/index.asp?PageID=549>, accessed on: 21 Nov 2005.

⁴⁰ See footnote 2.

Case 1: Sarah – a fetus at risk and a dilemma for the doctor**Sarah**

Sarah, who is pregnant for the second time, has a rhesus negative blood type. If she is pregnant with a rhesus positive fetus, antibodies in her blood may attack the fetus' blood cells. This will only occur if her blood has previously come into contact with rhesus positive blood, usually during the birth of a previous rhesus positive baby. Sarah's first child, who is now two years old, showed mild jaundice after birth but then recovered. In her second pregnancy, Sarah did not attend the antenatal clinic regularly although she had an ultrasound scan at 26 weeks. Her scan showed that the fetus had clear signs of rhesus haemolytic disease and anaemia caused by the incompatibility in blood groups. The skin and body tissues of the fetus showed an abnormal accumulation of fluid, caused by fetal heart failure.* Sarah's doctors now advise her that a fetal blood transfusion is urgently required. Without a transfusion, the fetus will die, but with a transfusion the survival rate for similar cases is 90%. Fetal transfusions are not without risk (1–2% risk of fetal mortality) and several would be needed. Sarah decides to refuse the treatment because she does not want to take this risk and 'everything was all right last time'. What should doctors do?

* Rodeck CH and Deans A (1999) Red cell alloimmunisation, in *Fetal Medicine: Basic sciences and clinical practice*, Rodeck CH and Whittle MJ (Editors) (Churchill Livingstone), p 785.

Moral status

- 4.21 As we have said, a presumption in favour of life is at the root of all medical care (see paragraph 2.36). Sarah's refusal of treatment for her unborn child with anti-rhesus antibodies is morally unacceptable to those for whom every possible measure should be taken to preserve life. We have described this position as an absolutist interpretation of the sanctity of life view (see paragraph 2.9). The pregnant woman might say that her refusal of the transfusion is because of the risk of death for the fetus. However, she has not appreciated the relative risks for the fetus of taking no action, as opposed to accepting the transfusion. In assuming that the outcome of the previous pregnancy will be replicated, she has not acknowledged that the risks are higher for a second pregnancy. For those who see the fetus as having a lower moral status than human life after birth, her refusal would be seen as a matter for her personal choice. A gradualist regards the fetus as gaining increasing moral status as their development progresses through the pregnancy. The fetus in Sarah's case has developed for 26 weeks of gestation and so is likely to be accorded significant status, although perhaps not the same status as a full-term baby. While there are several different approaches within consequentialism, one such view would be that the rightness or wrongness of the decision might be considered in terms of the balance between the anticipated benefits and burdens of the treatment. In this case, the risk:benefit ratio and expected outcomes would be in favour of treatment.
- 4.22 Even those who consider that the fetus has a moral status, and thus is entitled to treatment, would agree that this claim cannot be realised without involving the pregnant woman, since the treatment must pass through her body. The issue then becomes a matter of whether the claim of the fetus is such that we would be prepared to force Sarah into complying with the treatment against her wishes. To require her to undergo treatment would contravene the ethical principles of respect for patient autonomy and informed consent to treatment. As we have said, the view of the Working Party is that any attempt to save the life or to improve the health of the fetus *in utero* can be done only with the full consent of the pregnant woman (paragraphs 2.20 and 8.4).

Best interests

- 4.23 Those seeking to justify an intervention to treat the fetus, or encouragement of the pregnant woman to reconsider her position in discussion with the clinical team, are likely to appeal to the best interests of the fetus. As we observed, consideration of the various interests at stake requires an assessment of the weight that should be accorded to them. Here, the interest of the fetus to survive can be accorded considerable weight, whereas Sarah's interest to proceed as she thinks is best appears to be less important.

Conveying information

4.24 The example illustrates the importance of good communication.⁴¹ Sarah was concerned by the risk associated with fetal transfusion, but seemed to have overlooked the fact that the risk of the fetus dying in the absence of treatment was far greater. She may have wanted a totally 'natural' pregnancy and thought that the doctors wanted to interfere unnecessarily. Her lack of attendance at prenatal check-ups and completion of the ultrasound scan at 26 rather than 20 weeks are a cause for concern. Sarah's absence may be related to social or personal factors, a result of poor coordination within the health service or lack of information provided to her, or encouragement to attend. It is crucial that women in Sarah's position are given appropriate information to clarify the risks of not proceeding with treatment. Sarah should be able to ask questions as necessary and come to her own decision. She is likely to want to talk her dilemma through with her partner and perhaps friends or other family members and should be offered professional, emotional and spiritual support. This case also illustrates how perceptions of risk can vary and the difficulty of ensuring that the weight accorded to the different perspectives of all involved in the decision-making process are appropriately balanced. Some might consider that Sarah misinterpreted the information given to her and should follow the doctors' advice. However, the healthcare team would not claim to have special moral expertise on the matter. **The Working Party cannot overstate the importance of making decisions in partnership (see paragraphs 2.48 and 3.19) and ensuring that information is conveyed in a way that is appropriate to the understanding of the parents involved.** We note that the standards of the UK Government's National Service Framework (NSF) for Children, Young People and Maternity Services require that information be provided in different languages and mediums in order to meet the needs of different individuals, a policy that we support.⁴²

Legal issues

4.25 The position in English law is, in this case, straightforward. Sarah's decision is decisive (see paragraph 8.4). A pregnant woman does not have to take account of the father's wishes, should they differ, and she cannot be compelled to comply with the advice of her doctors, except if there is a question of her mental capacity. **While the requirements of the law are clear, the view of the Working Party is that doctors should make their best efforts to ensure that a woman is able to make an informed choice about her pregnancy.** This may require resort to more effective methods of communication to help her understand that the risks associated with a second pregnancy are much higher than for the first, and that the outcome without a transfusion would entail a high risk of fetal death.

Economic issues: antenatal screening

4.26 Sarah's dilemma has come to light through the application of antenatal screening. Clear economic arguments have been made in studies for some forms of routine screening for fetal infections or abnormalities.⁴³ However, such studies have tended to emphasise the potential of a fetus affected with abnormalities to incur future costs to the healthcare and other sectors of the economy, while not recognising that the fetus also has the potential to produce

⁴¹ Royal College of Physicians (1997) *Improving Communication between Doctors and Patients: A report of a working party* (London: RCP).

⁴² Department for Education and Skills and Department of Health (2004) *Maternity Standard, National Service Framework for Children, Young People and Maternity Services* (London: Department of Health), available at: <http://www.dh.gov.uk/assetRoot/04/09/05/23/04090523.pdf>, accessed on: 31 July 2006.

⁴³ Lane B, Challen K, Harris HG and Harris R (2001) Existence and quality of written antenatal screening policies in the United Kingdom: postal survey *Br Med J* **322**: 22–3.

future benefits.⁴⁴ A consistent application of methods for economic evaluation would require adjustment to take account of such benefits, which cannot be measured purely in terms of resources. Such an approach is likely to counterbalance the economic argument against many forms of antenatal screening. **The Working Party believes that economic considerations should not be central in any discourse about the value of antenatal screening programmes that often result in termination of pregnancy in cases of serious abnormality.** We discuss the economic costs of saving babies born at the borderline of viability in Chapter 5.

Case 2: Theresa – a fetus at risk and a dilemma for the pregnant woman

Theresa

Theresa is an 18-year-old woman with an unplanned first pregnancy. She discovered that she was pregnant at 23 weeks and, after she had become used to the idea, was pleased. She has just found out after a series of tests that the fetus has severe hydrocephalus due to a mutation in a gene necessary for brain development.* In this condition, some areas of the brain fail to develop and the infant will have spastic paralysis with severe learning disorders. A scan at 26 weeks of gestation showed that there was too much amniotic fluid surrounding the fetus, a condition called polyhydramnios. This fluid was distending the uterus and threatened to precipitate labour. Theresa was advised that she should consider terminating her pregnancy now because the prospects for the fetus were so severe. If born alive, the child would have the combined problems of severe prematurity and a very abnormal brain, a combination of physical disability and serious learning disorders. The doctors would carry out feticide as the first part of the termination procedure. Theresa was very upset because she would no longer have the baby she hoped for. She agreed to the termination but was thinking of refusing feticide because she could not bear the idea.

* Weller S and Gartner (2001) Genetic and clinical aspects of X-linked hydrocephalus (L1 disease): Mutations in the L1CAM gene *J Hum Mutat* 18: 1–12.

Making a decision about ending the pregnancy

- 4.27 With severe hydrocephalus of this type, the baby would be unable to develop any higher brain functions, and when older would not be able to take part in human activities or form relationships. Children with less severe forms of the condition might be less seriously affected. In Theresa's case, the loss of brain function would result in a future for her baby in which no human experience or ability to relate to the outside world would be possible. Those who hold that there is a moral obligation to preserve life at all costs could not condone termination, nor the preceding feticide. Others, however, might contend that the doctors should try as far as possible to abide by professional guidelines, which would mean not agreeing to Theresa's preferences (see paragraph 4.16). Some might think that there could be very little benefit to the baby in being born alive, and might even maintain that to preserve his or her life once born would be inhumane.
- 4.28 In considering best interests, the dilemma is to decide whether the interests of the fetus or the newborn baby should have priority. Some people may prefer to prevent the possibility of pain if the fetus should be born alive and this would incline them to accept feticide. It could be argued, however, that using anaesthesia during a medical termination⁴⁵ to reduce pain is preferable, although the outcome would be the same. However, the latter carries more risk for the pregnant woman than feticide.

⁴⁴ For example, many of the economic evaluations measure and value benefits in terms of costs averted by the screening programmes i.e. the resource savings that follow: (i) the abortion of the affected fetus; (ii) the abortion of the affected fetus less the resource costs involved with respect to any 'replacement' child; or (iii) the treatment of affected women or children.

⁴⁵ A medical procedure is used for late terminations of pregnancy after 22 weeks. Surgical terminations would in any case be carried out under general anaesthesia, thus both the woman and the fetus would receive treatment for pain.

- 4.29 Theresa may or may not hold definite views about the rightness or wrongness of termination and/or feticide. As in Case 1, **the view of the Working Party is that, whatever the decision ultimately agreed, there is no moral justification to coerce a woman to permit the feticide and/or the termination of pregnancy** (see paragraph 2.20). It would also be illegal (see paragraph 8.4).
- 4.30 Whatever she decides, this is likely to be a disturbing experience for Theresa. Receiving a prenatal diagnosis, dealing with decision making, undergoing a termination and coping afterwards can be very distressing.⁴⁶ Psychological distress is reported to be high immediately after termination of pregnancy for fetal abnormality, with most women reporting acute grief.⁴⁷ The intensity of the distress lessens over time for most women, although studies have shown that some continue to show signs of psychological distress or express feelings of sadness, guilt or anger several years later. Theresa may, for example, have concerns stemming from a strong belief in the sanctity of life, such that taking any life is morally wrong (paragraph 2.9). She may feel pressured by the doctors and nurses and feel guilty or responsible at the prospect of agreeing to terminate her pregnancy. Theresa may also have great need for social support and counselling, given that she discovered her pregnancy at an advanced stage and appears not to have close support from family or friends. Psychological and spiritual assistance could also be of value to her.
- 4.31 If Theresa should agree to feticide, she will have to cope with the death of the fetus, just as she would have to do if the baby died after birth. The longer she delays her decision on termination, the more likely it is that the baby will be born alive and could survive into infancy. If Theresa should wish the pregnancy to continue, the doctors will decide upon the best time for delivery and again, the baby is likely to survive the birth. Her ability to cope will depend on her maturity, the level of support from others, and the way that information is presented to her. It may also depend on whether she had ever previously thought about feticide and her views on it, although research suggests that parents do sometimes change their mind once they find themselves in this situation.⁴⁸ She may find that her relatives have different views if she consults them, which may cause her concern if she derives her sense of morality from the attitudes and relationships within her family (see also paragraph 3.17). She may also be influenced by the outlook of others around her, who may hold, for example, strong religious or disability rights perspectives.⁴⁹ It should not be assumed that her relative youth makes her any less capable of making decisions.
- 4.32 In this situation, parents' decisions may also be associated with socio-demographic factors. A major study in the USA on decision making following a diagnosis of fetal abnormality has shown that a number of factors correlate with the decision to terminate.⁵⁰ In particular the likelihood of termination increased with severity of abnormality and with increasing maternal age. This research cites other studies in which educational level, racial origin and household income were also found to have an effect on decisions.
- 4.33 The doctors may be unclear whether they are entitled by law to agree with Theresa's request for termination without feticide and worry that if they do agree, they would be legally

⁴⁶ Statham H, Solomou W and Chitty L (2000) Prenatal diagnosis of fetal abnormality: psychological effects on women in low-risk pregnancies *Bailliere's Clin Obstet Gynaecol* 14: 731–47.

⁴⁷ Statham H (2002) Prenatal diagnosis of fetal abnormality: the decision to terminate the pregnancy and the psychological consequences *Fet Mat Med Rev* 13: 213–47.

⁴⁸ *Ibid.*

⁴⁹ *Ibid.*

⁵⁰ Schechtman KB, Gray DL, Baty JD and Rothman SM (2002) Decision-making for termination of pregnancies with fetal anomalies: analysis of 53,000 pregnancies *Obstet Gynecol* 99: 216–22.

obliged to resuscitate the baby once born (see paragraph 4.16). They may also see a professional obligation to adhere to any local hospital guidelines and to the national guidance from the RCOG (see paragraph 4.14).⁵¹ They should clarify carefully with Theresa any issues about which she is worried and ensure that she has access to independent advice so that, for example, she can find out whether other women accept feticide in her situation. In practice, only a minority do not accept the offer of this procedure as part of a late termination.

4.34 This case also raises the issue of how the doctors perceive feticide. Recent research has shown that hospital consultants are acutely aware of both their clinical responsibility and personal involvement when carrying out feticide.⁵² They describe tolerating the procedure as a necessary part of their clinical practice and justify it for various reasons, for example to enable the parents to have 'options' available to them or to reduce suffering. It has been suggested that the emotional and personal implications for health professionals undertaking unpleasant tasks such as feticide are often not recognised and that there is a need for them to be studied.⁵³ If a doctor or other health professional has a conscientious objection to termination of pregnancy, they have the right under the Abortion Act 1967 to refuse to participate in such procedures⁵⁴ and refer the patient to another doctor.⁵⁵ This right of conscientious objection to participating in terminations is supported by the BMA.⁵⁶ However, research suggests that, while midwives involved in feticide felt that the right to object was genuinely available, consultants typically saw this right as theoretical.⁵⁷

Social perceptions of the fetus

4.35 In developed societies, people are exposed in their daily lives to powerful imagery that has increased awareness of many issues, including those related to medicine. Looking beyond this case, there are many conflicting perceptions of both the fetus⁵⁸ and the newborn baby that may affect the various parties involved in the decision-making process. For example, the image of a fetus has been used in anti-smoking campaigns. Medical imaging that visualises in three dimensions the detailed movements of the fetus inside the womb has also recently received press coverage. Such images may evoke perceptions that the fetus and the newborn baby are more similar in terms of development than in fact they are.⁵⁹ In contrast, there is greater awareness of the possibility that, in the future, scientists may be able to alter a child during development to improve his or her health, whether at the level of the gene, the pre-embryo, the embryo, the fetus or the baby. There has been speculation that the possibility of using fetal tissues in medical treatments⁶⁰ and the advent of prenatal testing to assess

⁵¹ Royal College of Obstetricians and Gynaecologists (2001) *Further Issues Relating to Late Abortion, Fetal Viability and Registration of Births and Deaths*, available at: <http://www.rcog.org.uk/index.asp?PageID=549>, accessed on: 21 Nov 2005.

⁵² Graham R, Rankin J, Haimes E and Robson S (2006) Providing feticide: An exploration of health professional perspectives *J Obstet Gynaecol* **26** (Suppl. 1): S14–16; Graham R, Robson S, Rankin J and Haimes E (2005) *Living with Feticide: A case study in tolerance and tender care*, paper presented at British Sociological Association Medical Sociology Annual Conference, September 2005.

⁵³ Graham R (2006) Lacking compassion—sociological analysis of the medical profession *Soc Theory Health* **4**: 43–63.

⁵⁴ Although not in a situation when the termination is needed to save the life of or prevent severe permanent injury to the pregnant woman.

⁵⁵ Mason JK and Laurie GT (2005) *Mason and McCall Smith's Law and Medical Ethics*, 7th Edition (Oxford: Oxford University Press).

⁵⁶ British Medical Association (1999) *The Law and Ethics of Abortion*, available at: <http://www.bma.org.uk/ap.nsf/Content/abortion-objection>, accessed on: 29 Aug 2006.

⁵⁷ Graham R, Rankin J, Haimes E and Robson S (2006) Providing feticide: An exploration of health professional perspectives *J Obstet Gynaecol* **26** (Suppl. 1): S14–16.

⁵⁸ Williams C, Alderson P and Farsides B (2001) Conflicting perceptions of the fetus: person, patient, nobody, commodity *New Genet Soc* **20**: 225–38; Williams C (2005) Framing the fetus in medical work: rituals and practice *Soc Sci Med* **60**: 2085–95.

⁵⁹ Williams C, Alderson P and Farsides B (2001) Conflicting perceptions of the fetus: person, patient, nobody, commodity *New Genet Soc* **20**: 225–38.

⁶⁰ For example transplanting fetal brain cells into the brains of patients with Parkinson's disease; see Young E (2001) Think again *New Scientist*, available at: <http://www.newscientist.com/article.ns?id=dn507>, accessed on: 22 Sept 2006.

whether a fetus is viable may foster perceptions of the fetus as an 'expendable consumer object'.⁶¹ Furthermore, the availability of prenatal testing may mean that some women view their pregnancy as tentative and do not form attachments to the unborn child until they know the results of the tests.⁶²

Legal issues

4.36 Although what is meant by a substantial risk of 'serious handicap'⁶³ to the future child so as to justify termination after 24 weeks under the Abortion Act 1967 is not defined, this type of severe hydrocephalus would definitely lead to a 'serious handicap,' and a termination of Sarah's pregnancy at 26 weeks is therefore lawful. Feticide itself is lawful if the termination of the pregnancy comes within the provision of the Abortion Act. Both feticide and the termination procedure would involve invasion of Theresa's body and therefore, under the law, require her consent. Should a termination be performed without feticide and a baby with serious health problems is born alive, there is not necessarily any obligation that the baby should be ventilated or admitted to neonatal intensive care if using all possible means to sustain his or her life is not in his or her best interests (see paragraph 8.8). The law would thus allow the doctors to act on Theresa's wishes and provide palliative care until the baby dies. Having concluded our consideration of dilemmas arising during pregnancy, we turn our attention in the next chapter to critical care at the borderline of viability.

⁶¹ Williams C, Alderson P and Farsides B (2001) Conflicting perceptions of the fetus: person, patient, nobody, commodity *New Genet Soc* 20: 225–38.

⁶² Statham H, Solomou W and Chitty L (2000) Prenatal diagnosis of fetal abnormality: psychological effects on women in low-risk pregnancies *Bailliere's Clin Obstet Gynaecol* 14: 731–47.

⁶³ The term 'handicap' is taken from the wording of the Abortion Act 1967.

Chapter

5

Dilemmas in current
practice: babies born
at the borderline of
viability

Dilemmas in current practice: babies born at the borderline of viability

Introduction

- 5.1 We use the term 'borderline of viability' to describe the time of birth of extremely premature babies who are born alive at or before the gestational age of 25 weeks and six days.¹ This limit has fallen by approximately one week every decade over the past 40 years, and may be attributed at least in part to advances in technology and care. Babies are born at this early stage of gestation because of spontaneous labour or because of early delivery to safeguard the health of the baby or mother or both. At these stages of gestation, the prospects of healthy survival are reduced and for this reason critical care decisions after birth may need to be taken. Multidisciplinary discussions between neonatal and maternity staff, including obstetricians and midwives, are of paramount importance. Plans must be made about a series of steps in clinical management that will need to be discussed with the mother and, where possible, her partner, so that the best decisions can be made for caring for her and the baby.
- 5.2 Where labour at borderline viability is likely, several practical decisions must be taken about the best way to manage care. For example, if a pregnant woman is admitted to a district general hospital, should she be transferred to a hospital with a specialist fetal medicine or a (level 3) neonatal unit?^{2,3} Is it safe to do so for her and the baby or would it be too far from her home? Is there a local Perinatal or Neonatal Network⁴ with guidelines that should be followed? A decision will also need to be made about whether a Caesarean section should be performed, bearing in mind that at this stage of pregnancy this surgical procedure is a serious and hazardous intervention for the woman that may affect her future reproductive capacity.⁵ If there is little prospect that treatment can improve the health of the baby, a decision may also need to be made about whether palliative rather than intensive care should be provided after birth (paragraphs 6.18–6.22). While these are primarily obstetric decisions,

¹ Measurements are from the first day of the pregnant woman's last menstrual period[0]. By convention, the number of weeks of gestation refers to the period from the first to the last day of that week. For example 'at 23 weeks' means from 23 weeks to 23 weeks, six days of gestation (161–167 days of gestation).

² In a level 3 neonatal unit, staff have exclusive responsibility for neonatal care and have no other paediatric responsibilities. Since 2003, Department of Health policy has been that babies with complex care needs or requiring long periods of respiratory support should be cared for initially in a level 3 unit, especially if born at 27 weeks of gestation or less. See Department of Health (2003) *Report of the Neonatal Intensive Care Services Review Group*, available at: <http://www.dh.gov.uk/assetRoot/04/01/87/44/04018744.pdf>, accessed on: 15 June 2006.

³ There is evidence that outcomes for premature babies are improved when they are born within a hospital that has a specialist neonatal unit. American Academy of Pediatrics Committee on Fetus and Newborn (2004) Policy Statement: Levels of neonatal care *Pediatrics* **114**: 1341–7; Cifuentes J, Bronstein JM, Phibbs CS, Phibbs RH, Schmitt RK and Carlo WA (2002) Mortality in low birth weight infants according to level of neonatal care at hospital of birth *Pediatrics* **109**: 745–51.

⁴ It is the policy of the Department of Health to provide all neonatal care in England within agreed managed clinical networks comprising a number of hospitals with differing types of neonatal unit (Department of Health (2003) *Report of the Neonatal Intensive Care Services Review Group*, available at: <http://www.dh.gov.uk/assetRoot/04/01/87/44/04018744.pdf>, accessed on: 15 June 2006). This strategy is encouraged by BAPM (British Association of Perinatal Medicine (2001) *Standards for Hospitals Providing Neonatal Intensive and High Dependency Care*, 2nd Edition, available at: http://www.bapm.org/media/documents/publications/hosp_standards.pdf, accessed on: 5 Sep 2006). There are 24 such networks in England, and these are called either Neonatal Networks or Perinatal Networks. (See NHS Neonatal Networks *What is a Neonatal Network?*, available at: <http://www.neonatal.org.uk/Healthcare+Professionals/About+the+Networks/>, accessed on: 18 Aug 2006.) The aim of these networks is to ensure that groups of hospitals and units work together to offer a range of levels of care and improve the services they offer. The networks are intended to facilitate the concentration of skills and expertise required within an area, and encourage transfers to local units in order to offer high-quality and appropriate neonatal care close to the mother's home.

⁵ A classical Caesarean section would be required, which involves opening the abdomen and the upper part of the uterus, unlike the operation which is usually performed at or near term in which only the lower part of the uterus is opened (lower segment Caesarean section). The uterus is more likely to rupture in a future labour if there is a scar from a previous classical Caesarean than from a lower segment Caesarean section.

they can only be made sensibly in the context of plans determined jointly between all professional groups and the parents. The clinical staff at the neonatal unit will need to determine whether there are sufficient expertise and resources available to provide optimal care of the baby. They should also ascertain whether the parents want the baby's life to be supported by active intervention, and obtain their view on what should be done if the baby is in unexpectedly good or poor condition. When labour occurs spontaneously, there may be very little opportunity to plan ahead.

- 5.3 We begin by explaining how survival rates for babies at the borderline of viability have improved, and describe current clinical practice in the UK. We then provide some examples to illustrate the kinds of dilemma that parents and health professionals may encounter when making decisions in these difficult cases. Each example is examined from ethical, social and legal perspectives, followed by a consideration of economic issues.⁶

The clinical perspective

- 5.4 There has been longstanding professional disagreement about the range of gestational ages or birthweights at which providing babies with all possible clinical interventions is justified. At borderline viability there is a 50% or less chance of survival. The estimation of fetal gestational age has become more accurate as ultrasound technology and pregnancy testing have improved. Based on the date of the woman's last menstrual period, the estimates are generally confirmed by ultrasound imaging. This method, generally considered to be more reliable than menstrual dating, is accurate to within five days in over 95% of cases when carried out in the first trimester of pregnancy.⁷ Because fetal weight cannot be measured accurately before birth, neonatologists in the UK tend to determine borderline viability by gestational criteria rather than by birthweight (the criterion being the weight at which there is a 50% or less chance of survival). However, older reports of clinical management are frequently based on birthweight because of past inaccuracies in the assessment of gestational age, and clinicians may refer to both birthweight- and gestation-based studies. The approximate equivalent of extreme prematurity is a birthweight of less than 1,000 g.
- 5.5 At present, survival at 22 weeks of gestation is very rare and, below this stage, almost unrecorded; these babies are sometimes termed 'pre-viable' for this reason. During the period of borderline viability (before 26 weeks), relatively few babies are born and most do not survive. In the past, their births would have been classified as miscarriages. Since the beginning of the 1980s, the proportion of babies that are born with an extremely low birthweight⁸ (most usually premature) has increased, with the percentage doubling between 1982 and 1996.⁹ In England, approximately 1,600 out of 584,000 estimated deliveries per year (i.e. 0.28%) are before 25 weeks, six days of gestation (see Box 5.1).¹⁰

⁶ We use examples that are representative of what occurs in hospital. They are not based on clinical cases. In the discussion of each example, issues are highlighted, some of which were drawn to the attention of members of the Working Party during fact-finding meetings. We acknowledge that the choice of the issues that we discuss after each example may influence how the examples themselves are perceived by different readers, depending upon the reader's own worldview.

⁷ Kalish RB, Thaler HT, Chasen ST, Gupta M, Berman SJ and Rosenwaks Z (2004) First- and second-trimester ultrasound assessment of gestational age *Am J Obstet Gynecol* **191**: 975–8.

⁸ See Box 3.1 for definitions. Extremely low birthweight babies weigh less than 1,000 g. Gestational age for live births has not been recorded separately in England. Birthweight, however, has been recorded over several decades in England and Wales and therefore is used to consider trends. See Macfarlane A and Mugford M (2000) *Birth Counts: Statistics of pregnancy and childbirth*, 2nd Edition, Volume 1 (London: The Stationery Office), pp55–6. The total number of deliveries (live births and stillbirths) by gestation is now recorded and the most recent figures available are included in Box 5.1.

⁹ From rates of 0.2–0.4% in singletons and 1.9–3.9% for multiple births. Macfarlane A and Mugford M (2000) *Birth Counts: Statistics of pregnancy and childbirth*, 2nd Edition, Volume 2 (London: The Stationery Office), Table A6.1.1.

¹⁰ National Statistics (2006) *NHS Maternity Statistics, England: 2004–05*, Table 21. It is not possible to give precise figures of babies born alive at these gestations because the standard data collected do not distinguish live and stillbirths. However, data on stillbirths reveal that, during 2003 in England and Wales, 3,585 babies were stillborn at 24 weeks[0] of gestation onwards until full term.

Box 5.1: Birth statistics*

In 2004–5 in NHS hospitals in England, approximately 13% of all deliveries were premature (before 37 weeks, six days of pregnancy) (the data include both live and stillbirths). The total estimated number of deliveries was approximately 584,000.

Total deliveries by weeks of gestation in England 2004–5

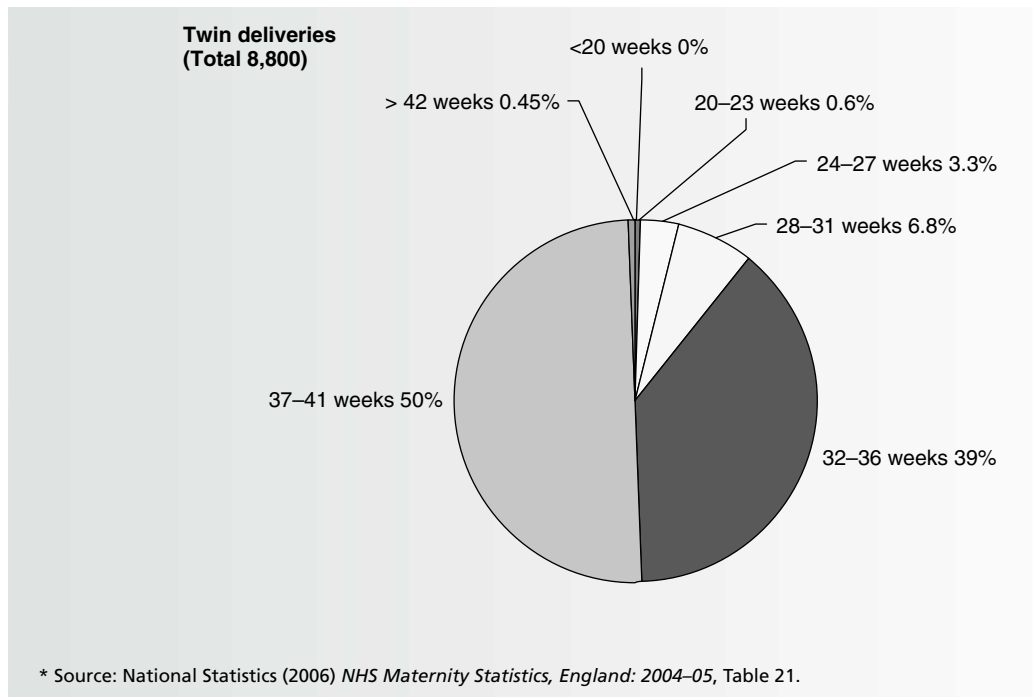
Under 20 weeks	40	< 0.01%
20 weeks	50	< 0.01%
21 weeks	80	0.01%
22 weeks	100	0.02%
23 weeks	240	0.04%
24 weeks	600	0.1%
25 weeks	500	0.1%
26 weeks	700	0.1%
27 weeks	800	0.1%
28–31 weeks	5,000	0.9%
32–36 weeks	35,100	6%
37–41 weeks	515,000	88%
42 weeks or over	26,050	4.5%
TOTAL	584,260	100%

(The number of babies delivered at the 'borderline of viability', or before 25 weeks, six days of gestation, was approximately 1,610 (0.3%.))

Deliveries by gestational age (%) for singletons and twins in England



Of these, 27% (957) were stillbirths delivered between 24 weeks and 27 weeks, six days of gestation (National Statistics (2005) *Mortality Statistics: Childhood, infant and perinatal* 2003 Series DH3 No. 36 (London: Office for National Statistics), Table 13). For Scotland in 2003, there were 260 stillbirths of singletons of which 55 occurred between 24–27 weeks of gestation (21%). At these gestational ages, 32% of all deliveries of singletons (total 174) were stillborn (NHS National Services Scotland (2003) *Scottish Perinatal and Infant Mortality and Morbidity Report* (NHS Scotland: Edinburgh), Table 22b).



5.6 Borderline viability has always been associated with the presence of disabilities in a proportion of survivors. In 1981, a review of published literature concluded that survival for babies weighing less than 1,500 g at birth (approximating to 30 weeks of gestation) had improved over time, particularly since the 1960s, whereas the proportion of babies born alive who survived with ‘handicap’ (their term) had remained stable.¹¹ Since this important study, survival rates at lower gestations have continued to improve and have played a part in the legal definition of stillbirth being changed from 28 weeks of gestation and above, to 24 weeks and above in 1992.¹² Criticism is often made of the practice of providing intensive care for babies born at the borderline of viability. However, evaluations have shown that for the relatively few babies at the borderline of viability who survive, by the age of six years, most have moderate, mild or no disabilities, rather than disabilities which are categorised as severe (see paragraph 5.8 and Table 5.1). The continued assessment of outcomes for this group is critical and was the main reason for initiating the EPICure study, to which we now turn.

The EPICure study

5.7 Extreme prematurity continues to pose serious dilemmas for parents and healthcare professionals as several disabling conditions are known to occur with much greater frequency among survivors than is the case for babies born at full term (Table 5.1 and Box 5.2). In 1995, the EPICure study was undertaken to address the paucity of data on survival and long-term outcome for extremely premature babies.¹³ The study identified all births between 20 and 25 weeks, six days of gestation in the UK and the Republic of Ireland during a ten month period in 1995. Of the 4,000 births recorded, 1,185 babies showed signs of life at birth.¹⁴ The prevalence of live birth at 23 weeks of gestation was 39%; at 24 weeks it was 60%; and at 25 weeks, 67%.¹⁵ The study has since followed the progress of the 308 babies who survived until

¹¹ Stewart AL, Reynolds EOR and Lipscomb AP (1981) Outcome for infants of very low birthweight: Survey of world literature *Lancet* **317**: 1038–41.

¹² Below 24 weeks of gestation the loss of a pregnancy is classified as a miscarriage.

¹³ See the website of the EPICure study, available at: www.epicurestudy.com, accessed on: 10 Aug 2006.

¹⁴ Wood NS, Marlow N, Costeloe K, Gibson AT and Wilkinson AR for the EPICure Study Group (2000) Neurologic and developmental disability after extremely preterm birth *N Engl J Med* **343**: 378–84.

¹⁵ Costeloe K, Hennessy E, Gibson AT, Marlow N, Wilkinson AR and the EPICure study group (2000) The EPICure study: Outcomes to discharge from hospital for babies born at the threshold of viability *Pediatrics* **106**: 659–71.

discharge from hospital, at two and a half, and approximately six years of age, and will soon report at ten years. It represents the outcome for babies born in all types of hospital across the entire geographic area, and thus broadly reflects clinical practice in 1995.¹⁶ The care of these babies ranged from the provision of full care to palliative care only. A second EPI Cure study will collect information on babies born in England during 2006 before 26 weeks, six days of gestation (thus including one more week than in the original study).

- 5.8 The outcomes for those babies who showed signs of life at birth are shown in Table 5.1. As the data are based on the performance of the children against their peers, rather than their individual quality of life, they give the most pessimistic view of outcome. Moreover, they include any disabling condition, of which many are categorised as 'mild' disabilities that do not interfere significantly with everyday life, such as the need for spectacles or having moderately low IQ scores. The table indicates the numbers and percentages of babies born alive, admitted for intensive care, and with disability at six years. At 23 weeks of gestation, for example, a total of 241 babies were born who showed signs of life, of whom just under half died in the delivery room and were not admitted for continuing care. Of those admitted to intensive care, 26 survived to discharge from hospital. Only 3% survived without any disabilities classified as severe or moderate. For the entire cohort of surviving children (born between 22 and 25 weeks, six days) who were assessed at approximately six years of age, the rates of severe, moderate and mild disability were 22%, 24% and 34% respectively. Disabling cerebral palsy was present in 30 children (12%). These high rates of disability are a cause for concern.¹⁷

Table 5.1:¹⁸ Summary of outcomes up to six years of age among children born alive at different gestational ages in the 1995 EPICure study.

In summary, the definitions of disability used in the study were as follows:

Severe disability: likely to make a child highly dependent on caregivers, and involving one or more of the following symptoms: cerebral palsy that prevented the child from walking, severe learning difficulties, * profound sensorineural hearing loss, or blindness.

Moderate disability: child typically reaching a reasonable level of independence, and involving one or more of the following symptoms: cerebral palsy (but the child could still walk), moderate learning difficulties,[†] sensorineural hearing loss that can be corrected with a hearing aid, or impaired vision without blindness.

Mild disabilities: would include mild learning problems or other impairments such as squints.

Outcome	Number (percentage of total ¹⁹) Weeks of gestation at birth			
	22 weeks ²⁰	23 weeks	24 weeks	25 weeks
Showed signs of life at birth	138 (100)	241 (100)	382 (100)	424 (100)
Admitted to intensive care	22 (16)	131 (54)	298 (78)	357 (84)
Survived to discharge from hospital	2 (1)	26 (11)	100 (26)	186 (44)
Died by the age of 6 years	136 (99)	216 (90)	284 (74)	241 (57)
Lost to follow up at 6 years of age	0	3 (1)	25 (7)	39 (9)
Remaining in study at 6 years of age: Totals	2 (1)	22 (9)	73 (19)	144 (34)
With severe disability	1 (0.7)	5 (2)	21 (5)	26 (6)
With moderate disability	0	9 (4)	16 (4)	32 (8)
With mild disability	1 (0.7)	5 (2)	26 (7)	51 (12)
With no impairment	0	3 (1)	10 (3)	35 (8)

* Defined as an IQ score more than three standard deviations below the mean.

† Defined as an IQ score between two and three standard deviations below the mean.

¹⁶ Follow up studies inevitably reflect practice at the time that data are collected and would not include the effects of recent changes, such as improvements in neonatal medicine or the reorganisation of hospital systems providing neonatal care that has occurred since 2003.

¹⁷ Marlow N, Wolke D, Bracewell MA and Samara M for the EPICure Study Group (2005) Neurologic and developmental disability at six years of age after extremely preterm birth *N Engl J Med* **352**: 9–19.

¹⁸ Table adapted from Marlow N, Wolke D, Bracewell MA and Samara M for the EPICure Study Group (2005) Neurologic and developmental disability at six years of age after extremely preterm birth *N Engl J Med* **352**: 9–19.

¹⁹ The percentages are calculated from the total number of babies born alive at each gestational age.

Box 5.2: The main categories of disability in premature babies*

- **Cerebral palsy** – particularly affects the lower limbs (diplegia), and may result from injury to the brain. Some children have severe disability with spasticity affecting all four limbs whereas others have very mild impairments which may only slightly restrict activity. Up to a quarter of extremely premature survivors may have some form of cerebral palsy but only half of these children have disability that restricts activity significantly.
- **Other motor problems** – a proportion of children without cerebral palsy may have motor difficulties that cause them to appear relatively 'clumsy' compared to their classmates at school; some will need help from an occupational or physiotherapist.
- **Visual impairment** – blindness may result from a condition called 'retinopathy of prematurity' where abnormal vessel development occurs in the back of the eye of the extremely premature baby; fortunately this outcome is rare (< 5%) and modern laser treatment can help in some cases. Less severe visual problems, such as squints and need for spectacles, are relatively common, and some are related to mild retinopathy.
- **Hearing impairment** – a small number of preterm children develop deafness and some require hearing aids.
- **Learning difficulties** – following very preterm birth, about 10–15% of children have major neurodevelopmental problems, and a further 30–40% develop less severe motor, neurodevelopmental or learning problems by school age.²¹ The cause of the major neurodevelopmental problems is thought to be damage to the white matter in the brain during the perinatal period. The cause of the less severe later problems is unclear but may be associated with reduced postnatal growth, particularly of the head.²² Children with learning difficulties require individual assessment, and support in the classroom.
- **Behavioural problems** – attention deficit disorder is found more frequently in children who have been born prematurely; individual assessment is needed but effective developmental strategies and medical treatments are available.
- **Respiratory problems** – lung development after neonatal intensive care may be compromised, particularly in extremely preterm babies. Chronic respiratory symptoms of cough and wheeze may require continuing treatment in childhood for some children.
- **Growth problems** – children born at borderline viability are often small throughout childhood but many catch up during the pubertal growth spurt.
- **Disability** – reports of outcomes following premature birth generally combine many outcomes into categories of severe, moderate, mild or no disability. Although these categories provide a convenient shorthand for describing outcome, severe disability is in fact made up of different combinations of the very different outcomes described above.

* See Marlow N (2004) Neurocognitive outcome after very preterm birth *Arch Dis Child Fetal Neonatal Ed* **89**: F224–8.

5.9 Since 1995, survival at the borderline of viability to discharge from hospital has continued to improve, primarily in children born after 24 weeks of gestation or more; for example data for the Trent region of the UK are shown in Figure 5.1. There are no current data from the Trent survey available to indicate whether the incidence of disability has altered, although some beneficial changes have been reported that are thought to have arisen through improved use of antenatal steroid therapy and surfactant treatment at delivery. There has also been a reduction in the use of ventilation and postnatal steroid treatments, both now thought to contribute to health problems. The second EPICure study (see paragraph 5.7) aims to find out if outcomes for premature babies in the UK have changed in the past decade.²³

5.10 There is evidence from other countries that the survival rate at 23 weeks of gestation has improved since the 1995 EPICure study, although caution is needed when comparing studies involving different populations. A national study of all births recorded in Norway from 1999 to 2000 showed that survival to discharge from hospital was 16% for babies born at 23 weeks and 44% at 24 weeks of gestation.²⁴ Both figures are higher than the rates recorded in the

²⁰ By this we mean 22 weeks, 0 days to 22 weeks, six days, and so forth.

²¹ Cooke RWI (2006) Are there critical periods for brain growth in children born preterm? *Arch Dis Child Fetal Neonatal Ed* **91**: F17–20.

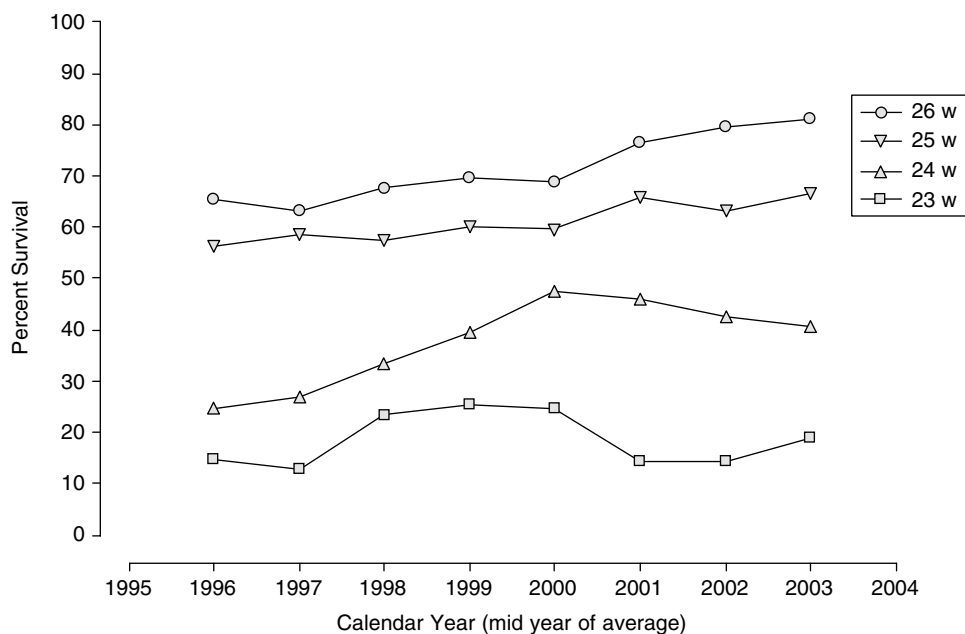
²² Cooke RWI (2006) Are there critical periods for brain growth in children born preterm? *Arch Dis Child Fetal Neonatal Ed* **91**: F17–20.

²³ See information about EPICure 2 at: <http://www.epicurestudy.com>, accessed on: 10 Aug 2006.

²⁴ Markestad T, Kaarensen PI, Ronnestad A *et al.*; Norwegian Extreme Prematurity Study Group (2005) Early death, morbidity, and need of treatment among extremely premature babies *Pediatrics* **115**: 1289–98.

Figure 5.1. Gestation-specific rates of survival to discharge from the labour ward or the neonatal unit for babies admitted for intensive care in the Trent Region of the UK 1995–2004; rolling three year averages

(Source: Trent Neonatal Survey, with permission)



EPICure study and similar to data from the Trent neonatal survey. A Swedish study of births between 1992 and 1998 showed even higher rates of survival: 43% at 23 weeks and 63% survival at 24 weeks. In this study, fetal monitoring was carried out and, if necessary, Caesarean section, at 23 weeks onwards. All infants with any signs of life were actively resuscitated and brought to the neonatal intensive care unit. Decisions to withdraw respiratory care were avoided during the first days of life and subsequent withdrawal of intensive care was rare. The Swedish data are important as they show that, even with a policy of resuscitating every baby and almost never withdrawing life support, the majority of babies at 23 weeks still died. Thirty per cent of the babies born at 23 weeks died before seven days, 20% died between seven and 28 days of age and 10% died after 28 days.²⁵ Data from an Australian study suggest that the frequency of neurosensory problems in extremely low birthweight children born in 1991–1992 remains higher than in normal birthweight children, but has dropped when compared with data from earlier decades.²⁶ Data from these studies are too limited for the Working Party to be able to conclude that disability in children surviving birth at the borderline of viability has improved. The new EPICure study²⁷ will show whether the rates of survival and disabling conditions have changed nationally over the 11 years since the first study. **In summary, the Working Party concludes that the 1995 EPICure data on the long-term developmental outcomes of babies born at the borderline of viability remain the best available for advising parents in the UK on likely outcomes in terms of disabling conditions. This is because the data were collected in a systematic way, are based on the UK and Irish population, and, by nature, require a number of years**

²⁵ Serenius F, Ewald U, Farooqi A *et al.* (2004) Short-term outcome after active perinatal management at 23–25 weeks of gestation. A study from two Swedish tertiary care centres. Part 2: infant survival *Acta Paediatr* **93**: 1081–9.

²⁶ Doyle LS, Anderson PJ and the Victorian Infant Collaborative Study Group (2005) Improved neurosensory outcome at 8 years of age of extremely low birthweight children born in Victoria over three distinct eras *Arch Dis Child Fetal Neonatal* **90**: F484–8.

²⁷ See information about EPICure 2 at: <http://www.epicurestudy.com>, accessed on: 10 Aug 2006.

to collect. By contrast, if parents are interested primarily in knowing the most up-to-date rates of survival, the survival rates reported from the EPICure study are consistently lower than those achieved now and are therefore less helpful for providing advice to parents.

- 5.11 At present, studies that assess the impact of outcomes on the child and their family and explore the relationship of outcome to perinatal management are funded through research grants. **The Working Party concludes that data from follow up should be pooled by clinical services in all hospitals,²⁸ using standardised definitions,²⁹ so that statistics can be collated year on year. Developing systems for continuous collation of data would allow routine monitoring of practice and outcome in this important area.** We discuss the question of follow up and research studies further in Chapter 6.

UK practice for resuscitation of babies at the borderline of viability

- 5.12 Where delivery at borderline viability is anticipated and time allows, most neonatologists or paediatricians will discuss whether to institute resuscitation with the parents before delivery. Consideration will also be given to the baby's need for relief of pain and discomfort (see paragraphs 6.14–6.17). The doctors will try to ascertain whether parents would want resuscitation or, if there is little chance of survival, they would prefer the baby to be given palliative care alone, allowing him or her to die without the stress and pain of attempted resuscitation and intensive care.³⁰ The decision to provide only palliative care will entail a careful assessment of the baby immediately on delivery to confirm that the estimation of gestational age is correct. The condition of the baby will then be evaluated, followed by medical and midwifery support for the baby and mother without life-prolonging medical intervention. Maximising the baby's quality of life through relief from pain and stress is an important part of palliative care (see paragraphs 6.18–6.22). This series of steps is supported by guidance from professional bodies (see Appendix 9).³¹
- 5.13 Up to 22 weeks, six days of gestation, survival to discharge from intensive care is widely regarded as highly unlikely and resuscitation is usually rejected as futile,³² even if a mother were to request it. However, a very small number of neonatologists in the UK initiate life support for babies who are born at 22 weeks. The number of survivors who live for several years remains very low and reports of follow up are limited. During its deliberations, the Working Party was not made aware of any substantive data to suggest that babies have survived following birth at less than 22 weeks of gestational age. While we are aware of therapeutic developments being investigated that could, if successful, be applied to extend viability,³³ our understanding is that this would not be at any point in the near future. Some doctors consider the institution of full intensive care below 22 completed weeks as treatment, whereas others consider it to be experimental. While experimental studies are important to advance practice, it is our view that **attempts to prolong life following birth before 22 weeks of gestation should be carried out only as part of a research study that has previously**

²⁸ BAPM (2000) *Fetuses and Newborn Infants at the Threshold of Viability: A framework for practice*, available at: <http://www.bapm.org/media/documents/publications/threshold.pdf>, accessed on: 8 Aug 2006.

²⁹ National Perinatal Epidemiology Unit/Oxford Regional Health Authority (1994) *Disability and Perinatal Care: Measurement of health status at two years* (Report of two working groups) (Oxford: NPEU/ Oxford RHA).

³⁰ Roy R, Aladangady N, Costeloe K and Larcher V (2004) Decision making and modes of death in a tertiary neonatal unit *Arch Dis Child Fetal Neonatal* **89**: F527–30.

³¹ BAPM (2000) *Fetuses and Newborn Infants at the Threshold of Viability: A framework for practice*, available at: <http://www.bapm.org/media/documents/publications/threshold.pdf>, accessed on: 8 Aug 2006.

³² By the term 'futile', we mean an intervention or treatment that would delay death but is judged to improve neither life's quality nor potential.

³³ For example, in the areas of fetal imaging and monitoring, detection and delay of premature labour, and ventilatory support.

been assessed and approved by a research ethics committee. For such a study, the parents would need to consent in advance to the resuscitation and active treatment of their baby (see also recommendation in paragraph 9.19). We say more about clinical trials in Appendix 6.

- 5.14 At gestational ages of 22–25 weeks, every effort is made to anticipate delivery once the signs are that a premature birth is likely. These plans include the presence of experienced members of the obstetric and neonatal teams at the birth to assist with the assessment of the baby and to support parents and staff in carrying out life support or palliative care.³⁴ However this level of planning may not always be possible if, for example, the birth is unexpected. The parents' wishes may influence the level of care that doctors will advise for a baby at the borderline of viability to an extent that they would not in a baby of later gestational age. Clinicians report that mothers have given different reasons for not wanting life support to be provided. Women may have stated emphatically that they do not want their baby to be subjected to prolonged intensive care, or feel that they could not cope with a disabled child, or believe that they could easily get pregnant again. In such cases, the neonatologist may be more likely to opt for palliative care for a baby born in poor condition. If, on the other hand, a mother may not have another chance to have a pregnancy (for example after extensive fertility treatment), and she is willing to accept any outcome if the child survives, the doctor is likely to use all appropriate therapy to support the baby, even if the chances of survival without some level of disability are very low.
- 5.15 Current evidence does not support the institution of active care for babies born at 22 weeks of gestation, as the chances of survival are minimal and a very high proportion of survivors are likely to be seriously disabled, although in studies the numbers of survivors have been very small. It is rare for doctors to undertake active intervention, although they will carry out a careful postnatal assessment to verify the gestational age.
- 5.16 It is at 23 weeks of gestation (the period from 23 weeks to 23 weeks, six days) where there is greatest uncertainty about the outcome for an individual baby and where the decision on whether treatment is in his or her best interests is most difficult to make. Assessing the condition of the baby in the first five minutes does not help in identifying those who will be unable to survive or those who will survive without disability.³⁵ Many doctors would only institute active care at this gestational stage if the parents were in clear agreement that they should do so. Variation in clinical practice is probably greatest at this stage of gestation and will, accordingly, affect figures for survival and almost certainly rates of disability.
- 5.17 At 24 weeks, the chances of survival improve, although there remains a high chance of some level of disability. Increasingly, it is normal practice for a baby to be offered full intensive care and support from birth, and admitted to a neonatal intensive care unit. Many doctors consider this practice appropriate. However, they would also listen carefully to the wishes of parents and give their views due weight when making decisions immediately after birth if the baby is in poor condition, or not responding to resuscitative measures.

³⁴ BAPM (2000) *Fetuses and Newborn Infants at the Threshold of Viability: A framework for practice*, available at: <http://www.bapm.org/media/documents/publications/threshold.pdf>, accessed on: 8 Aug 2006.

³⁵ Attempts to find predictors of poor outcomes have been unsuccessful. For example a recent study examined the predictive value of the APGAR score in 126 infants weighing less than 1,000 g who were born alive and resuscitated but found it was not a good predictor of outcome. Andrews B, Lagatta J, Calderelli L *et al.* (2006) Uninformed Non-Consent in the Delivery Room? Ethical implications of poor predictive value of burdensome outcome in the first minutes of life, presented at the Pediatric Academic Societies Annual Meeting, San Francisco, 2 May 2006. Guidance in the USA states that "Apgar score at 1 minute and 5 minutes is not appropriate for predicting long-term outcome", American Academy of Pediatrics, Committee on Fetus and Newborn, American College of Obstetricians and Gynecologists and Committee on Obstetric Practice (2006) Policy Statement: The Apgar score *Pediatrics* 117: 1444–7.

- 5.18 From 26 weeks of gestation and in recent years, from 25 weeks and above, the actions of the neonatologist would not normally be influenced by the parents' wishes or experiences in the way described above. The outlook for babies at this gestation is considered to be sufficiently good, in terms of survival without severe disability, that resuscitation would be judged to be in the baby's best interests without qualification, as would also be the case at later gestations.
- 5.19 Whatever the gestational age at delivery, it is the responsibility of the senior neonatologist to arrive at, and explain, the best possible assessment of what can be achieved with life support in the delivery room.³⁶ The discussion includes possible outcomes and courses of action and involves the various members of the perinatal team, who each bring a different expertise and perspective, as well as the pregnant woman and her partner if she chooses.³⁷ If there is doubt about the outcome or the correct action, or if the discussion with the parents has been inconclusive, practice in the UK is to provide support; this is in keeping with professional guidelines.³⁸ Support entails providing active resuscitation, transfer to a neonatal intensive care unit, and reassessment at a later stage. A baby may be in intensive care for varying periods depending upon his or her needs. It is extremely difficult, at around 23 weeks of gestation, for the neonatologist to identify which course of action is in an individual baby's best interests. Invasive life support may do harm because intubation, ventilation and insertion of catheters into blood vessels may prolong stress, pain and discomfort before inevitable death in the majority of babies, compared with a relatively rapid and peaceful death if no life support is given. However, active life support may increase the chances of healthy survival (albeit with a high chance of some disability) for a minority, compared with a more cautious approach.
- 5.20 Practice elsewhere differs from country to country. In the 1980s and 1990s, the approaches followed in some parts of the USA and the Netherlands appeared to be at opposite ends of a spectrum. A recent study showed that in the mid-1980s, 95% of babies born at 23–26 weeks of gestation in an area of New Jersey, USA, received mechanical ventilation in contrast to only 64% in the Netherlands (see also Box 8.1).³⁹ The proportion of babies that survived to the age of two in New Jersey was found to be double that in the Netherlands, and the proportion that had disabling cerebral palsy was five times greater in the babies from New Jersey. Among those who died, 45% of the Dutch babies had not received any ventilation compared with only 10% of the New Jersey babies. There have been several other studies that show that doctors in different countries approach critical care decision making in neonatal medicine in different ways.⁴⁰
- 5.21 The Working Party made visits to France and the Netherlands in early 2006, to hear first-hand about current practices in neonatal and fetal medicine. These two countries were chosen because the general approach differs from that followed in the UK. In the Netherlands active ending of life is more widely accepted and, for adults, is supported by legislation.⁴¹ In France,

³⁶ BAPM (2000) *Fetuses and Newborn Infants at the Threshold of Viability: A framework for practice*, available at: <http://www.bapm.org/media/documents/publications/threshold.pdf>, accessed on: 8 Aug 2006.

³⁷ McHaffie HE and Fowle PW (1996) *Life, Death and Decisions: Doctors and nurses reflect on neonatal practice* (Hale: Hochland and Hochland).

³⁸ BAPM (2000) *Fetuses and Newborn Infants at the Threshold of Viability: A framework for practice*, available at: <http://www.bapm.org/media/documents/publications/threshold.pdf>, accessed on: 8 Aug 2006.

³⁹ Lorenz JM, Paneth N, Jetton JR, den Ouden L and Tyson JE (2001) Comparison of management strategies for extreme prematurity in New Jersey and the Netherlands: outcomes and resource expenditure *Pediatrics* **108**: 1269–74.

⁴⁰ Cuttini M, Nadai M, Kaminski M *et al.* (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries *Lancet* **355**: 2112–18; Janvier A and Barrington KJ (2005) The ethics of neonatal resuscitation at the margins of viability: informed consent and outcomes *J Pediatr* **147**: 579–85.

⁴¹ M Cuttini M, Casotto V, Kaminski M, *et al.* (2004) Should euthanasia be legal? An international survey of neonatal intensive care units staff *Arch Dis Child Fetal Neonatal Ed* **89**: 19–24.

clinical practice has been characterised as paternalistic,⁴² with one study from the 1990s finding that French hospitals typically would “sound out” parent’s views and “take them into account” rather than directly including parents in decisions involving withholding or withdrawing intensive care from a baby.⁴³ The Working Party discussed policy, practices and attitudes to resuscitation, as well as the active ending of life with clinicians, ethicists and lawyers from both countries.

- 5.22 Decisions to withhold or withdraw life-sustaining treatment in the UK involve parents more often than is the case in other European countries⁴⁴ although practices are changing.⁴⁵ In France, the more traditional practice of allowing doctors to decide is beginning to give way and increasingly, more emphasis is being placed on understanding the parents’ wishes.^{46,47} Twenty years ago, resuscitation of very premature babies was routine practice, followed by re-evaluation once a firmer prognosis had been established. For babies with a poor prognosis, ventilation would be withdrawn or an injection given deliberately to end life. However, an increasing number of French neonatologists now have reservations about following this approach, and believe that common standards for practice should be agreed for use throughout the country.⁴⁸ Recently, the Fédération Nationale des Pédiatres Néonatalogistes established a review to explore these issues but the outcome is unlikely to be known for some time.
- 5.23 In the Netherlands, a consensus had been reached by 2003 that obstetricians and neonatologists at all Dutch perinatal centres should not normally resuscitate and treat extremely premature babies born before 25 weeks of gestation, because of poor outcomes (see Box 8.1). Instead, these babies are offered palliative care with their parents present, and allowed to die in the delivery room, instead of being admitted to the neonatal intensive care unit. Exceptions might, however, be made if the parents were strongly in favour of resuscitation or if the baby appeared to be particularly healthy. These criteria are currently being reviewed. There is further discussion on the practice of resuscitation in Chapter 8.

Some examples

- 5.24 We now describe several hypothetical situations⁴⁹ that help to illustrate the complex reality of decision making for babies at the borderline of viability in the UK. In the first case, a decision has been taken not to prolong life yet the baby unexpectedly survives. The circumstances of the second case involve deciding whether or not to take steps to prolong life by resuscitating the baby. In the third case, the baby’s parents disagree about what is best for him.

⁴² See for example, Orfali K (2004) Parental role in medical decision-making: fact or fiction? A comparative study of ethical dilemmas in French and American neonatal intensive care units *Soc Sci Med* **58**: 209–22.

⁴³ 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.

⁴⁴ *Ibid.*

⁴⁵ Molholm Hansen B, Hoff B and Greisen G (2003) Treatment of extremely preterm infants: parents’ attitudes *Acta Paediatr* **92**: 715–20.

⁴⁶ Personal communication to the Working Party.

⁴⁷ Comité Consultatif National d’Ethique (2000) *Opinion 65: Ethical considerations regarding neonatal resuscitation*, available at: http://www.ccne-ethique.fr/english/avis/a_065.htm#deb; accessed on: 15 Sept 2006.

⁴⁸ Pour la Fédération nationale des pédiatres néonatalogistes, Dehan M, Gold F *et al.* (2001) Dilemmes éthiques de la période périnatale: recommandations pour les décisions de fin de vie: Ethical dilemmas in the perinatal period: guidelines for end-of-life decisions and practice *Archives de Pédiatrie* **8**: 407–19.

⁴⁹ See footnote 6.

Case 3: Ahmed – decision making in the delivery room⁵⁰**Ahmed**

A 32-year-old mother of two healthy children was admitted to hospital after her waters broke at 23 weeks of gestation. A consultant neonatologist discussed the prognosis and options if delivery took place at 23 weeks. The doctor explained that most babies at this stage of gestation died and, if they survived, there was only a slim chance (3%, based on a UK study) that the baby would survive without moderate or severe disabilities. She added that the clinical team would respect the parents' wishes but that they did not normally resuscitate babies of this gestation. The situation was complicated because English was not the couple's first language but the hospital was able to provide an interpreter. The mother and her husband decided that they did not want their baby to suffer and that they did not want resuscitation. After the delivery, the baby was wrapped and held by the mother and the baby, named Ahmed, made a few weak breathing movements and his heart rate was very slow (40 beats per minute).

After 60 minutes, the neonatologist was called to make an assessment of Ahmed who had gasping respirations and a moderately slow heart rate (100 beats per minute compared with the normal rate of more than 120 beats). The neonatologist began to consider whether resuscitation should be tried after all, or if Ahmed should be treated in other ways.

Best interests

5.25 We have seen in the case of Ahmed that the neonatologist, in consultation with the parents, made the decision not to resuscitate, guided by her own and their views about Ahmed's best interests. We noted in Chapter 2 (paragraphs 2.24–2.25) that there are limitations to the usefulness of the concept of best interests. Some might say that here the principle has misled the parents and the medical professionals and precipitated a traumatic situation. However, there is always a significant degree of uncertainty involved in prognoses, and a judgement needs to be made. What this example underlines is that assessments of best interests are highly dependent on the particular circumstances of each case, which need to be conveyed in the decision-making process. Here, it was very important to make clear the uncertainties of prognosis.

Decision making

5.26 Although in Ahmed's case there was agreement between parents and the clinical team about the initial treatment options before delivery, Ahmed was assessed after birth and found to be in a poor condition and thus, in keeping with the previous decision not to intervene, palliative care was given. Had he been in good health and breathing with a fast heart rate, the neonatologist might have reconsidered the initial decision. This illustrates that there is not a single moment or process of decision making, but rather a series of decisions. As circumstances change, prior decisions may need to be revisited.

5.27 Once Ahmed had survived for about an hour, there would be several potential options for clinical management. One option, after talking to his parents, would be for the neonatologist to continue the current level of support and not intervene. Ahmed's clinical condition suggested that it was highly likely that he would die after a short while. His parents would need reassurance together with continuing emotional and practical support. Another option would be to treat Ahmed with a medicine to relieve the gasping respirations which seemed to cause him distress and were upsetting for his family to observe. A high dose of morphine, for example, would provide relief but might also quickly stop his breathing. If Ahmed should continue to breathe, a further option would be to provide non-invasive support for breathing, until it was clearer that his condition was continuing to deteriorate or he became more vigorous. Finally, the neonatologist might begin to think that, as Ahmed's condition had improved and not deteriorated as anticipated, he may have much greater potential to survive without disability than originally thought. If so, the doctor might reverse the initial decision not to intervene and propose providing every assistance. This might cause him anxiety as it would not be clear in this situation whether the delay in intervention had also worsened the eventual outcome.

⁵⁰ Cases 1 and 2 are in Chapter 3.

- 5.28 Normal practice in the UK would be for neonatologists to discuss these options openly with the parents, if this is possible. Where time permitted, doctors would review local and national guidelines and ideally talk the case through with colleagues. Some doctors might be inclined to overrule the expressed wishes of the parents and proceed with resuscitation.
- 5.29 Ahmed's case is also complicated to some extent by the fact that his parents had a limited command of the English language and required an interpreter. This raises the question of whether the parents fully understood the severity of the disability and how it would probably affect their child before agreeing that resuscitation should not be attempted. They might not have been aware that sometimes a baby can survive against the odds. Interpreters are required not only during the first consultation or while signing a consent form (see Appendix 5), but should ideally be available throughout the decision-making process. Many neonatal units are able to access and provide language support, though advance notice is needed for the interpreter to come in person.⁵¹

Implications for the healthcare team

- 5.30 Cases such as that of Ahmed are likely to cause moral distress for members of the clinical care team involved, particularly when they believe their initial decision may have been mistaken.⁵² When making decisions about resuscitation, there may be no time to consult another doctor and even if the treating neonatologist has a conscientious objection to continuing the non-interventional management, it is unlikely to be possible for the case to be passed to another doctor. Neonatologists frequently have to make complex decisions on resuscitation. Research has shown that many doctors find such decision making and/or the carrying out of the actions decided upon to be difficult. They use different coping strategies, such as detachment from the situation, seeking (informal) support from colleagues, families and friends, and pursuing personal interests to maintain a balanced life.⁵³ Within the clinical and nursing team, there can be disagreements between staff over decisions, or some individuals may have a different personal view to the lead doctor or parents, which can lead to conflicts and tensions.⁵⁴ On a fact-finding visit to a neonatal unit, the Working Party learnt that healthcare teams deal in different ways with the emotional aspect of their professional practice. A health psychologist might be employed as part of the team; sometimes the arrangements might be less formal and colleagues would counsel each other. Many neonatal teams have regular formal meetings to discuss their management of cases in retrospect, which would be facilitated in unusual circumstances by a clinical ethics committee if one is available.

Legal issues

- 5.31 Ahmed's case exemplifies the kind of circumstances that create anxieties about the law for doctors. Ahmed clearly made an effort to survive. Given his birth at 23 weeks of gestation, the decision not to resuscitate him would be unlikely to be legally questionable. However, because Ahmed struggled to breathe, the neonatologist had to re-assess what constituted appropriate care. Ahmed's long-term prospects may well mean that prolonging his life was still *not* in his best interests. But the dilemma facing the doctor is very difficult to resolve. This is a case when clearer national guidelines might well be helpful, and support from a clinical ethics committee could be constructive.

⁵¹ A recent study found that 82% of units surveyed reported the possibility of parents having access to an interpreting service. BLISS – The Premature Baby Charity (2005) *Special Care for Sick Babies – Choice or chance?* (London: BLISS).

⁵² Work-related stress among senior doctors: review of research (June 2000). Produced by the BMA Health Policy and Economic Research Unit.

⁵³ McHaffie HE and Fowlie PW (1996) *Life, Death and Decisions: Doctors and nurses reflect on neonatal practice* (Hale: Hochland and Hochland).

⁵⁴ *Ibid.*

Case 4: Beth – parental influences on decision making**Beth**

A 38-year-old woman was admitted to the labour ward in early labour at 22 weeks, six days of gestation. She had lost two pregnancies at 18 and 19 weeks, respectively, and was considered to have an 'incompetent cervix'.⁵⁵ At 14 weeks the obstetrician had placed a suture around her cervix to prevent it opening as her pregnancy progressed. She and her partner were advised that the chances of her baby surviving even with the best care were very low and that the staff had not seen a baby of this low gestation survive before. Even if the baby survived, the risk of moderate or severe disability was estimated to be more than 50%.

The parents were of religious faith and believed strongly in the sanctity of life. They clearly stated that, should their baby breathe after birth they would like all measures to preserve her life to be taken and requested the neonatal team to be present at the delivery. A baby girl named Beth, weighing 450 g (1lb) was delivered four hours later; she was resuscitated and taken to the neonatal unit. She required maximal intensive care for three days before she began to improve. On ultrasound scan it was clear she had suffered a major brain injury on one side which carried a greater than 90% risk of cerebral palsy developing. Her parents requested that intensive care should be continued because they believed everything possible should be done to keep Beth alive. Beth required two surgical operations to correct bowel problems, and received oxygen treatment for six months.

After two years her parents returned for follow up. Beth had severe cerebral palsy and was only just sitting up (normally achieved by nine months), she could feed herself a biscuit and she had two words in her vocabulary. Her parents were pleased with her progress and reaffirmed that, for them, their original decision was right.

Sanctity of life

5.32 For Beth's parents the likely degree of disability and their own capacity to deal with it was not a major concern. Their belief that everything possible should be done to enable Beth to survive came from their strong reverence for the sanctity of life (paragraph 2.9), a view consistent with the teachings of their religion. Crucially, they were content with the decision in retrospect. For Beth's parents considerations about best interests were not incompatible with her condition and their own religious outlook.

5.33 Beth's parents may have been counselled by a religious adviser. The main question for them would be not whether Beth's life was worth living but how it should best be respected. The adviser would see it as part of his or her role to help disentangle any conflicting values that parents might be experiencing, although in this case the parents were clear from the outset. An unavoidable problem in seeking to interpret religious writings to guide a couple is that the situation in which they find themselves is far removed from the context in which the writings were developed.⁵⁶

5.34 In this case, the parents' views were possibly inconsistent with the doctor's assessment of the best interests of the baby, but he nevertheless agreed to do all he could for Beth. This illustrates the importance of ensuring that there is sufficient sensitivity about the respective positions from both sides. In paragraph 3.14 the Working Party noted that doctors and nurses sometimes have to come to terms with decisions that are different from the choices they would have made for themselves and might find specific professional training beneficial to help them understand the perspective of parents and to communicate effectively with them.

Understanding prognoses

5.35 When parents are asked whether their baby should be resuscitated, they have to assess two main risks: first that of a baby dying after a period of intensive care, and secondly, the possibility of survival with disability. In the initial assessment of whether a baby may survive, less attention is given to the potential pain and distress for the baby caused by a period of unsuccessful

⁵⁵ A situation where the neck of the womb (cervix) does not close tightly, increasing the risk of infection, ruptured membranes and early labour.

⁵⁶ Personal communication, fact-finding meeting with the Working Party.

intensive care. Parents vary in their response to such a situation. For example, some parents are acutely concerned about the clinical effort required to support a child in intensive care and weigh the need for it against the chances of survival. They may conclude that they cannot subject their baby to so many procedures when he or she is likely to die. Other parents may need the reassurance that all options have been tried to assist their baby to survive, including intensive care.

- 5.36 In assessing the risks for Beth there may be confusion about what is meant by 'disability' and the extent to which the interests of the child are balanced with the interests of the family. One of the most important considerations at the borderline of viability is attitude to risk. Parents, like most people, often have difficulty in interpreting statistics about risk. They can make very different judgements about the relevance of statistics to their particular situation, especially at such a stressful time. For example, some couples might not accept a 50% risk of serious disability because of fears that they would be unable to cope with caring for a disabled child. Their perception may be different if the risk was expressed another way: that there was a one in two chance that their baby would be free from serious disability. Other parents might pin their hopes on any chance of survival, no matter how small, either disregarding or accepting the consequences. The Working Party found that although general guidance is available from the Royal Colleges and other bodies (see Appendix 9), there is an absence of written information or other aids to communication on prematurity, in particular describing possible outcomes for babies of particular gestations, together with the risks. Such information might be provided for parents where difficulties have been diagnosed during pregnancy. **The Working Party therefore recommends that a pregnant woman who presents with an imminent extremely premature birth should be given written information on prematurity, explaining the risks and the procedures that will occur. It should include information on the issues and decisions that she may encounter, so that she, if she is not too distressed or too ill, her partner or other family members, can begin to familiarise themselves with the issues. The information should be supported by the opportunity for face to face discussion. Consideration should also be given to making such information available, on request, to all pregnant women earlier in pregnancy. Any information should be available in different languages and mediums to meet the needs of different individuals, as described in the National Service Framework Standards.**⁵⁷

Perceptions of disability

- 5.37 Parents and the professionals who advise them often perceive disability in different ways. This difference of view is also reflected in the published literature.⁵⁸ Many studies measure the performance of children who were born extremely or very prematurely, against children born at full term in order to understand the impact that premature birth has on childhood development. This research is important as it indicates the nature and extent of the effect of premature birth and of its complications; it may also help doctors understand the impact that treatment after birth can have on the developing child. However, these studies will tend to emphasise a 'worst case scenario' by pooling data on serious disabilities with data on those that are less serious. What is rarely done is to distil from these data those outcomes that parents or professionals would consider to not be in the child's best interests. Often these are the conditions labelled as severe or moderate disabilities. These conditions are less common than

⁵⁷ Department for Education and Skills and Department of Health (2004) *Maternity Standard, National Service Framework for Children, Young People and Maternity Services* (London: Department of Health), available at: <http://www.dh.gov.uk/assetRoot/04/09/05/23/04090523.pdf>, accessed on: 31 July 2006.

⁵⁸ See, for example, Saigal S, Stoskopf BL, Feeny D *et al.* (1999) Differences in preferences for neonatal outcomes among health care professionals, parents, and adolescents *J Am Med Assoc* **281**: 1991–7.

is often thought.⁵⁹ Other studies try to evaluate the 'quality of life' using either self-report or 'proxy' measures completed by parents or other people involved in the child's life. Generally and significantly, a child often reports his or her health state more positively than his or her carers (see paragraph 7.9) and this view is borne out by studies that have reported adult outcomes for very low birthweight or extremely low birthweight survivors.⁶⁰ Survivors may have more health problems and achieve less academically but those without the most serious impairments generally integrate well into society.⁶¹ Thus professionals and parents who are in discussion about an extremely premature birth must be clear what is meant by the terms used to convey the likely nature of any disability.

- 5.38 Beth's parents were advised during the pregnancy that if their baby survived, there was a high risk of disability. Ultrasound diagnosis after the birth showed those risks to have increased to 90%. Their faith was a crucial factor in leading them to press for every possible step to be taken to preserve life, despite the high risk of Beth developing cerebral palsy. The loss of two previous pregnancies, and the fact that the mother was older, may have also been influential. The doctors followed the parents' wishes, though they themselves might have made different choices because they held different ethical and/or religious beliefs.
- 5.39 Although Beth did not do as well as her parents had hoped, she had survived and could experience human relationships. It is less likely that she would have been resuscitated in the Netherlands because of the practice of limiting resuscitation for babies born before 25 weeks of gestation (see Box 8.1). Even in the UK, it is possible that, had Beth been born in a different hospital or the treating clinicians had held different views, her outcome might have taken a different turn. **This variability in practice suggests a more systematic approach to decision making on resuscitation should be adopted in the UK.** Such an approach should take into account the genuine uncertainty over outcome for babies at the borderline of viability in terms of moderate or severe disability if they should survive resuscitation (see paragraph 5.16). **The most important point to communicate at the borderline of viability is that between 23 weeks and 25 weeks, six days of gestation, while survival is possible, the future for some children is bleak, yet for others it is not and doctors cannot reliably predict which group a surviving baby would fall into** (see paragraphs 5.13–5.18). For parents, the primary concern is their own baby. This is the basis of our conclusion that under certain circumstances, parents should be offered the opportunity to choose whether or not a baby is resuscitated. In Chapter 9 we develop guidelines on resuscitation and criteria to help establish the best interests of the baby. **The Working Party recommends that written information about health outcomes for premature babies should be provided for families, to be used in addition to verbal advice.** This information would also support junior members of the clinical team who might not have the benefit of experience when having to advise on resuscitation. We suggest too, that specific training may assist doctors to achieve a deeper understanding and to avoid being unintentionally directive when counselling parents.

⁵⁹ Marlow N, Wolke D, Bracewell MA and Samara M, for the EPICure Study Group (2005) Neurologic and developmental disability at six years of age after extremely preterm birth *New Engl J Med* **352**: 9–19.

⁶⁰ Hack M, Flannery DJ, Schluchter M, Cartar L, Borawski E and Klein N (2002) Outcomes in young adulthood for very low birth weight infants *N Engl J Med* **346**: 149–57; Cooke RWI (2004) Health, lifestyle, and quality of life for young adults born very preterm *Arch Dis Child* **89**: 201–6; Bjerager M, Steensberg J and Greisen G (1995) Quality of life among young adults born with very low birthweights *Acta Paediatr* **84**: 1339–43; Ericson A and Källén B (1998) Very low birthweight boys at the age of 19 *Arch Dis Child Fetal Neonatal Ed* **78**: F171–4; Dinesen S J and Greisen G (2001) Quality of life in young adults with very low birth weight *Arch Dis Child Fetal Neonatal Ed* **85**: F165–69; Watts JL and Saigal S (2006) Outcome of extreme prematurity: as information increases so do the dilemmas *Arch Dis Child Fetal Neonatal Ed* **91**: 221–25; Saigal S, Stoskopf B, Streiner D, *et al.* (2006) Transition of extremely low-birth-weight infants from adolescence to young adulthood: comparison with normal birthweight controls *J Am Med Assoc* **295**: 667–75.

⁶¹ Saigal S, Stoskopf B, Streiner D, *et al.* (2006) Transition of extremely low-birth-weight infants from adolescence to young adulthood: comparison with normal birthweight controls *J Am Med Assoc* **295**: 667–75.

Legal issues

5.40 Beth's case does not present any legal dilemmas. The doctors accepted her parents' wishes that their daughter should be given every opportunity to survive, and their view that this would be in her best interests. Had they concluded that it would not be in Beth's best interests to provide intensive care, they would have needed very strong grounds for this conclusion and would probably have had to go to court to argue that she should not be resuscitated and actively treated despite her parents' wishes to the contrary. We consider later the case of baby MB (paragraphs 8.35–8.36) whose condition was more serious than Beth's, where a judge endorsed the decision by the parents to keep him alive. In Beth's case, the outcome appears to suggest that from the present perspective of the parents, the original decisions taken were the right ones. However, there is a possibility that Beth's disabilities could in the future become so burdensome that the parents might feel that it had been wrong to resuscitate her.

Case 5: Callum – decision making when the parents disagree

Callum

A 21-year-old woman was admitted in early labour at 23 weeks, three days of gestation. The obstetrician explained to the woman and her partner that the estimated chances of a child surviving without moderate or serious disability were only 3% at the current gestation but would increase over the next week to about 20%. They discussed whether or not they should treat the woman with two injections of steroids to enhance the baby's chances if labour progressed.

The woman considered the risk of the child being disabled to be high but wanted to try and help her child after the birth. Her partner was adamant that he did not want any intensive care to be offered after birth unless the baby was delivered later, when the chances of a normal outcome were better; he had a sibling with Down's syndrome and did not want the long-term responsibility of caring for a child with disability.

The couple could not agree on a course of action. The woman was given two doses of steroids; they were then counselled by the neonatologist but neither parent changed their stance. Their baby, named Callum, was delivered at 24 weeks of gestation. The neonatal team offered intensive care because the couple could not agree a course of action and the steroid injections had been given to optimise outcome. The child, despite a difficult neonatal course, had a normal brain scan and at two years was free from cerebral palsy and had a developmental score in the normal range. The parents separated two months after Callum was discharged home.

Best interests

5.41 As we have observed above, consideration of the best interests of all involved in the decision-making process is crucial in critical care decisions. The usual assumption is that it is in a child's best interests to survive and that this has the greatest weight or is paramount. However, we have given reasons why a balancing of all interests of those involved is required (paragraphs 2.28–2.30). The case of Callum puts the feasibility of this proposal to the test as there are a number of competing interests. The mother focuses on the child's best interest, is conscious of her responsibility towards him and seeks to promote his chances of survival in every way. The father, by contrast, focuses on previous experience with his sibling. Independent of the nature of any disability by which Callum might be affected, he believes that having a healthy child should be the guiding principle, contrary to what might be in the child's, or his partner's best interest. The healthcare team decides to give priority to the mother's wishes. In cases of disagreement between parents about treatment for a baby there is often a presumption in favour of life. This can have the advantage of allowing more time for differences to be resolved. However, we have argued that there may be circumstances when it is in the best interests of a newborn baby that his or her life should not be actively supported if born alive (paragraph 2.11).

Decision making

5.42 As the limitations of applying the principle of best interests above have shown, there are many occasions where no consensus is attainable. How should decisions be made in these cases? One way of resolving this question would be to focus on cases where parents disagree solely on the best interests of the child. However, an important constraint on any option seeking to promote Callum's life is the requirement that invasive interventions require the consent of a pregnant woman, who cannot be coerced to promote the health of her child (paragraph 8.4). It is therefore imperative that advice by the medical team is non-directional and non-coercive.

5.43 However, Callum's case also shows that when the clinical team follow the wishes of the mother, the conflict may be made worse, as the father might feel excluded. This example raises the question of how a father's view should be taken into account when it differs from that of the mother. Possibly in Callum's case, if there had been time to offer independent counselling, one parent might have come to see the other's point of view. Cultural factors may have an influence. For example, in France we were told that mothers sometimes give way to the father's wishes for the sake of their relationship.⁶² Callum's father had strong opinions that were clearly influenced by his past experiences of family life. We noted earlier that parents' views may also be affected by many factors, such as their expectations of parenthood, their attitude towards illness and disability, and values influenced by religious faith (see paragraph 3.17). Socio-demographic factors including age, educational background, ethnic origin and household income are also influential (see also paragraph 4.32).

Legal issues

5.44 The decision about whether or not to accept steroid treatment is in law entirely a matter for the pregnant woman. Her partner cannot force her to accept his viewpoint. Once Callum is born, if his parents are married or register the birth together, they share parental responsibility for their new baby. Consent from one parent would be sufficient to authorise Callum's treatment and doctors can therefore proceed on the basis of Callum's mother's wishes. Often though, if parents disagree, or if doctors have a clearly different judgement about a baby's best interests, the courts may become involved. In principle, an emergency application to the court could be sought, but this would depend on whether there were any clinical measures that could be taken to keep Callum alive while the judge considered the case. Generally, however, in cases like that of Callum, decisions have to be made so swiftly that resort to court may not be feasible.

Economic issues at the borderline of viability

5.45 Resource constraints are frequently cited as important in determining whether the costs of providing intensive care to babies born at the borderline of viability can be met by the NHS. Neonatal intensive care is often described as a high-technology, high-cost and low-volume service compared with other health services.⁶³ Babies born at the borderline of viability who survive may spend protracted periods in hospital as discharge usually occurs around the original expected date of delivery; stays of 16 weeks are therefore not uncommon. This

⁶² Fact-finding meeting of Working Party to France, January 2006.

⁶³ The total spending by Primary Care Trusts in England on neonatal conditions in 2004/5 was approximately £750 million, which amounts to 1.3% of their total budget. For comparison, the disease area with the largest spend was mental health, which received ten times the amount for neonatal conditions, while the lowest spend was just over £300 million for hearing disorders. Department of Health (2006) *2004–5 National Programme Budgeting Data*, available at: <http://www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/ProgrammeBudgeting/fs/en>, accessed on: 17 Aug 2006; King's Fund (2006) *Briefing – Local variations in NHS spending priorities*, available at: http://www.kingsfund.org.uk/resources/briefings/local_variations.html, accessed on: 17 Aug 2006.

particular group of babies has the highest risk of conditions for which a prolonged period of intensive care is needed. This is reflected in the net economic cost of the initial admission for care after birth being on average highest in the least developmentally mature babies. For example, in a recent review of economic analyses of neonatal care, initial health service costs for babies born at less than 1,000 g were found to be 75% higher, on average, than for those born at 1,000–1,499 g.⁶⁴ Costs have been shown to be significantly higher in studies performed in North America compared with other countries.

- 5.46 To these costs must be added health service costs incurred after discharge from hospital (see Table 5.2). Children born prematurely are frequently readmitted to hospital in their early years, incurring significant additional health service costs (estimated for children born before 28 weeks in the former Oxford region at an average additional cost of £14,600 each over the first five years of life compared with children born at term).⁶⁵ In Merseyside, health service costs for infants of different birthweight groups who were followed up for eight to nine years were approximately £14,000 for the lowest birthweight group ($\leq 1,000$ g), £12,000 for the intermediate birthweight group (1,001–1,500 g) and £7,000 for the highest birthweight group (1,501–2,000 g) at 1998 prices.⁶⁶ Even without disability, with low birthweights ($\leq 2,000$ g), children used hospital and family practitioner services about five times more throughout the follow-up period than children in a group of controls, matched for age, sex and school class. This differential increased to 16-fold among the lowest birthweight group. Research elsewhere in England supports these trends.⁶⁷
- 5.47 We are not aware of any published studies comparing the continuing health-related costs for treating children born at the borderline of viability with those of treating children with other conditions. We have therefore provided a few examples that may give some perspective.

Table 5.2: Mean health and societal costs for children in the EPICure Study over 12 months at six years of age*

Cost category	Mean cost per child (UK£, 2003 prices)	
	Group of 241 children born extremely prematurely	Control group of 160 children born at full term
Hospital inpatient care costs	605	116
Hospital outpatient and day care costs	255	53
Community health and social care costs	422	104
Drug/medication costs	10	3
Education costs	7620	3470
Additional family expenses	573	120
Indirect costs	56	17
Total	9541	3883

* Adapted from Petrou S, Henderson J, Bracewell M, Hockley C, Wolke D and Marlow N for the EPICure Study Group (2006) Pushing the boundaries of viability: The economic impact of extreme preterm birth *Early Hum Dev* **82**: 77–84; © 2006, with permission from Elsevier.

⁶⁴ Petrou S and Mugford M (2000) Predicting the costs of neonatal care, in: Hansen TN and McIntosh N (Editors) *Current Topics in Neonatology*, Volume 4 (London: WB Saunders), pp 149–74.

⁶⁵ Petrou S, Mehta Z, Hockley C *et al.* (2003) The impact of preterm birth on hospital inpatient admissions and costs during the first five years of life *Pediatrics* **112**: 1290–7.

⁶⁶ Stevenson RC, Pharoah PO, Stevenson CJ *et al.* (1996) Cost of care for a geographically determined population of low birth weight infants to age 8–9 years. II. Children with disability *Arch Dis Child Fetal Neonatal Ed* **74**: F118–21.

⁶⁷ Petrou S, Mehta Z, Hockley C *et al.* (2003) The impact of preterm birth on hospital inpatient admissions and costs during the first five years of life *Pediatrics* **112**: 1290–7.

Healthcare costs for epilepsy, based on studies of children and/or adults in the UK, France, Italy and Germany, have been found to average between US\$100 and US\$3,000 (£60–£1,800) per individual per year, depending particularly on frequency of seizures.⁶⁸ For children with autism, health-related costs were found to be in the region of £1,300–£2,300 per year (based on 1997/98 prices),⁶⁹ depending on whether an additional learning disability was present. These studies each use different methods to calculate costs and include different components as ‘health’ costs, so that it is difficult to compare them directly. Nevertheless, it would appear from these findings that the ongoing health-related costs for children who survive following extremely premature birth are comparable with those for some other conditions that can occur during childhood.

- 5.48 Beyond the health service, there are societal costs to be considered. For healthy six-year-old schoolchildren in their seventh year, the total costs have been calculated at £3,883 for a whole year; in contrast a baby born at 25 weeks accrued £8,000 costs and a baby born before 25 weeks, £12,000.⁷⁰ Again, it is clear that the greatest costs were incurred by those babies who were least developmentally mature at birth, as has been found elsewhere.^{71,72}
- 5.49 While the costs of health services are likely to diminish over the subsequent years of life, the need for additional support at school for many extremely premature survivors with cognitive and other impairments is substantial. If we compare educational costs for extremely premature babies with those for babies born at term, we find that an extra £4,150 was incurred during their seventh year, for babies enrolled into the EPICure Study (see paragraphs 5.7–5.11).⁷³
- 5.50 The financial costs incurred directly by a family to meet additional expenses incurred as a result of a child’s disability seem relatively modest (£453 per year on average in the EPICure cohort⁷⁴), but these costs are greatest in those with the most social disadvantage and thus cannot be ignored. In practice the economic burden after leaving the neonatal unit is not evenly distributed, as a small proportion of survivors require substantial support, whereas the majority of families incur only modest costs above those of routine family life. The total economic burden for healthcare and other costs incurred as a result of survival after birth at borderline viability is likely to increase if more babies of extremely low gestation survive, because although the proportion of babies born at a given gestational age who develop disabilities may decline, the total numbers may increase. It should not be discounted, however, that interventions to reduce impairment in this group may have significant economic benefit throughout childhood and into adult life.
- 5.51 The success of neonatal intensive care has increased the pressure on resources allocated to neonatal services. For birth at the borderline of viability, long periods of intensive care and hospital stay are required. Most neonatal units to which babies are referred from other hospitals run at close to maximal capacity because of high demand. Nearly all the units that

⁶⁸ Begley CE and Beghi E (2002) The economic cost of epilepsy: A review of the literature *Epilepsia* **43** (Suppl. 4): 3–9.

⁶⁹ Jarbrink K and Knapp M (2001) The economic impact of autism in Britain *Autism* **5**: 7–22. Health-related costs were taken to be costs of medication, hospital and other health and social services.

⁷⁰ The definition of ‘societal costs’ used by the researchers was broad and encompasses impacts on social, educational and other sectors, and on families and carers. The data collected included the child’s use of hospital and community health services, social services and educational services, time taken off work by parents and informal carers as a result of the child’s ill-health and broader societal impacts that could be attributed to the child’s disability, such as additional expenses on food, bedding and child care.

⁷¹ Petrou S, Henderson J, Bracewell M, Hockley C, Wolke D, and Marlow N (2006) Pushing the boundaries of viability: The economic impact of extreme preterm birth *Early Hum Dev* **82**: 77–84.

⁷² Drotar D, Hack M, Taylor G, Schluter M, Andreias L and Klein N (2006) The impact of extremely low birth weight on the families of school-aged children *Pediatrics* **117**: 2006–13.

⁷³ Petrou S, Henderson J, Bracewell M, Hockley C, Wolke D, and Marlow N (2006) Pushing the boundaries of viability: The economic impact of extreme preterm birth *Early Hum Dev* **82**: 77–84.

⁷⁴ *Ibid.*

responded to a recent survey reported admitting more babies than they had resources or staff for, and 72% reported that they had been closed to admissions at some stage during the previous six months.⁷⁵ In the Trent region, one extra neonatal cot (including the cost of staffing that cot) was required each year over the past ten years to allow for extra activity.⁷⁶ The main reason, however, for pressure on cot availability in neonatal intensive care is a shortfall in the number of nurses available to provide the recommended level of one-to-one nursing.⁷⁷ Constraints in provision may not always allow healthcare professionals to do what they judge to be best for each and every child, and situations such as the need to transfer a baby to another hospital have to be managed. Notwithstanding such constraints, we concluded in Chapter 2 that decisions at the microeconomic or individual level should still be determined, not by resource considerations, but by clinical judgements of priority, which take into account the best interests of all babies involved.

⁷⁵ BLISS – The Premature Baby Charity (2005) *Special Care for Sick Babies – Choice or chance?* (London: BLISS).

⁷⁶ Dorling J, Draper E, Manktelow B and Field D (2006) Infants born at the threshold of viability: changes in survival and resource usage over 10 years *Arch Dis Child* **91** (Suppl.): A48.

⁷⁷ BLISS – The Premature Baby Charity (2005) *Special Care for Sick Babies – Choice or chance?* (London: BLISS). British Association of Perinatal Medicine (2001) *Standards for Hospitals Providing Neonatal Intensive and High Dependency Care*, 2nd Edition, available at: http://www.bapm.org/media/documents/publications/hosp_standards.pdf, accessed on: 5 Sept 2006; National Perinatal Epidemiology Unit (2005) *A Survey of Current Neonatal Unit Organisation and Policy*, available at: http://www.bliss.org.uk/pdfs/Special_care.pdf#search=%22Special%20Care%20for%20Sick%20Babies%20%E2%80%93%20Choice%20or%20chance%3F%22, accessed on: 27 Sept 2006.

Chapter

6

Dilemmas in current
practice: babies
needing intensive care

Dilemmas in current practice: babies needing intensive care

Introduction

6.1 We have seen in the preceding chapters that in the UK, current practice rests on a consensus that if the outcome for a baby with a serious condition is uncertain after birth, life support and full intensive care should be instituted until the prognosis becomes clearer and the situation re-evaluated. This stage may be reached when the results of investigations are known, or after a period when the clinical situation changes, or even when the baby's parents have had some time to adjust to a diagnosis and prognosis. In this chapter, we focus on the very serious conditions that can lead parents and healthcare professionals to begin discussing whether intensive care should be continued or be withdrawn. Some babies in intensive care may have started life at the borderline of viability. Others may have been born later, but with serious health problems. The relief of discomfort and pain is an important consideration, whether during intensive care or as part of palliative care when intensive care treatment has been replaced with other forms of care. As before, we use hypothetical examples to illustrate the dilemmas that parents and professionals face in making decisions when a poor prognosis for a baby has been established.¹ We highlight some economic issues relating to critical care decisions after birth, although we have not been able to find sufficient data to compare the economic costs of outcomes for children who start life with different conditions, as we would have wished. Finally, we discuss the importance of data collection and analysis to help reduce uncertainty in the prediction of health outcomes.

The clinical perspective

- 6.2 In the past, debates about critical care decisions in the newborn have focused on whether babies with specific congenital malformations should or should not have life-saving surgery or life support. In 1973, 14% of the deaths in the neonatal intensive care unit in New Haven, USA, followed decisions to withdraw treatment.² Most of these babies had severe congenital abnormalities. Subsequently, debates about withdrawal of treatment and substitution with other forms of care have broadened to include babies with acquired brain injury and premature babies at the borderline of viability. In the UK and the Republic of Ireland in 1995, among extremely premature babies, approximately half of deaths were classed as "active withdrawal of intensive care",³ and experience would suggest that the proportion is now higher.⁴
- 6.3 The situations in which parents and clinical teams come to the point of deciding whether to withdraw life-sustaining treatment, after an initial decision to begin resuscitation and other forms of treatment, fall into three broad categories:
- (a) A baby for whom intensive care is proving futile, in that death appears inevitable. In these cases, intensive care serves only to extend the process of dying.

¹ We use examples that are representative of what occurs in hospital. They are not based on clinical cases. In the discussion of each example, issues are highlighted, some of which were drawn to the attention of members of the Working Party during fact-finding meetings. We acknowledge that the choice of the issues that we discuss after each example may influence how the examples themselves are perceived by different readers, depending upon the reader's own worldview.

² Duff RS and Campbell AG (1973) Moral and ethical dilemmas in the special-care nursery *N Engl J Med* **289**: 890–4.

³ Costeloe K, Hennessy E, Gibson AT, Marlow N, Wilkinson AR and the EPICure study group (2000) The EPICure study: outcomes to discharge from hospital for infants born at the threshold of viability *Pediatrics* **106**: 659–71. The majority of deaths took place in the first seven days after admission to a neonatal intensive care unit.

⁴ Personal communication to the Working Party from Professor Neil Marlow and Professor Andrew Whitelaw.

- (b) A baby who has suffered a severe brain injury and for whom there appears to a very high risk of severe disability as he or she grows up.
- (c) A baby who is discovered to have a serious malformation, dysplasia (abnormal development of tissues or organs) or a genetic condition with a serious outcome for which there is no treatment.⁵

The first example may be considered a judgement about the timing and mode of death in terms of how care is provided. The two other examples highlight the uncertainty of outcome that complicates decision making in cases involving many neonatal conditions. We begin by considering brain injuries, which can be acquired during pregnancy or close to the time of birth and which are a major cause of later disability.

Brain injuries in premature and term newborn babies

6.4 There is an extensive body of knowledge about the origin, diagnosis and prognosis of brain injury in newborn babies. Advances in diagnostic methods mean that it is now possible to identify the nature, location and extent of brain injury even in the smallest newborn baby (see Appendix 4 for details of common types of brain injury). A range of investigations may be carried out, depending on the circumstances, and the availability of facilities. For example, a baby may have to be transported some distance to another hospital to have magnetic resonance imaging (MRI). Severe brain injuries may be manifested differently in premature and term infants, which means that understanding the predictive value of the various tests is crucial for both parents and professionals who have to make decisions about a baby in intensive care.

The premature baby with brain injury

- 6.5 In the premature baby, brain injury usually occurs in two particularly vulnerable tissues:
- (a) **The white matter** is found in an area deep inside the brain which contains mainly nerve fibres, including those that allow the brain to control movement. As the white matter surrounds the ventricles, injury within it is called periventricular leucomalacia (literally softening of the white matter around the ventricles).
 - (b) **The germinal matrix** comprises fragile tissue that lies in the base of the fluid-filled spaces or ventricles found deep in the brain. Illness in the fetal or neonatal period can lead to bleeding in this tissue. Such bleeding usually resolves without serious problems later. However, a minority of cases are complicated either by hydrocephalus (literally 'water on the brain') due to blockage of the outflow of spinal fluid from the ventricles, causing them to enlarge, or by causing adjacent areas of brain tissue to die by obstructing their blood flow (known as infarction).

⁵ Four types of birth defect are recognised: **(1) Deformations:** resulting from abnormal mechanical forces acting to distort an otherwise normal structure. These often occur quite late in gestation after normal initial formation of organs, but the growth and subsequent development of these organs or structures is hampered by the mechanical force. **(2) Disruptions:** defects caused by destruction of previously normal tissue; sometimes consequent on haemorrhage or poor blood flow during development to a particular region of the developing fetus. Disruptional abnormalities generally affect several different tissue types within a well-demarcated anatomical region. **(3) Dysplasias:** abnormal cellular organisation or function within a specific tissue type throughout the body, resulting in clinically apparent structural changes; for example a skeletal dysplasia, resulting in 'dwarfing' where the patient's short stature is caused by a major gene mutation causing a dysplasia of the cartilage, with the result that the bones do not elongate. **(4) Malformations:** abnormalities caused by failure of the embryonic process; here the development of the particular tissue or organ is arrested, delayed or misdirected, causing permanent abnormalities of the structure which prevents normal development. Many malformations are the result of genetic mutations and can affect several different body systems causing a range of different clinical signs of birth defects in the individual patient. Unlike deformations and disruptions, malformations suggest an error occurring very early in gestation, either in tissue differentiation or during the development of individual organ systems. For simplicity, throughout this Report we chose to use the more general term **abnormality** for all types of defect.

- 6.6 Although all three types of brain injury described above (leucomalacia, hydrocephalus and infarction) are associated with later disability, the extent of injuries can vary greatly between different babies, and many children with these conditions grow up free from significant problems. Trying to decide if a lesion is likely to cause disability is difficult, unless the lesion is extensive. Generally, periventricular leucomalacia or infarction which occurs in the frontal part of the brain is not associated with serious disability, but where it occurs at the back, it is much more likely to be associated with cerebral palsy. Many lesions are situated centrally and these are difficult to assess. Thus a prognosis is rarely absolutely certain; it is a matter of risk which must be communicated to the parents to help them reach a decision.
- 6.7 Extensive lesions of the brain that have a more certain adverse prognosis tend to become evident earlier in a baby's postnatal course. This coincides with the period when babies are receiving maximal intensive care and when withdrawal of that support will almost certainly lead to death. The extent of less extensive lesions of the brain takes longer to become obvious. A secure diagnosis may not be made until the period when a baby requires maximal intensive care has passed, and often when he or she may no longer require intensive care at all. For example, hydrocephalus is not usually evident until after three weeks of age and the cysts that accompany serious periventricular leucomalacia take two to three weeks to develop. By this stage, generally a baby would no longer be receiving intensive care support.

The full term baby who acquires brain injury

- 6.8 Sometimes a baby acquires brain injury as a result of a period of inadequate oxygen supply during labour or birth. This deprivation of oxygen is known as intrapartum hypoxia, or more commonly 'birth asphyxia'. After birth, a baby with this type of brain injury passes through a well-described sequence of clinical phases. The set of neurological symptoms (neurological syndrome) is termed an 'encephalopathy'.⁶ As postnatal encephalopathy can sometimes be due to problems other than intrapartum hypoxia, it requires careful evaluation.
- 6.9 The clinical phases of postnatal encephalopathy may be categorised using a grading system first described by Sarnat and Sarnat in 1975.⁷ This system allows for three categories of clinical syndrome to be defined: mild, moderate and severe:
- All babies whose category is 'mild' universally recover and long-term consequences have not been reported.
 - As with very premature babies, the 'moderate' category is more difficult to define. Around 20% of those whose clinical grade is moderate will die or develop serious disability. The remaining 80% are generally considered as having the potential to do well, although there is good evidence that in some surviving children, significant learning and behavioural problems will arise at school age.⁸
 - Babies who develop a 'severe' encephalopathy and who have not improved to a moderate grade by 48 hours either do not survive or almost always are seriously disabled. This disability usually comprises spastic or athetoid cerebral palsy⁹ affecting all limbs and trunk,

⁶ When the encephalopathy results from intrapartum hypoxia, it is sometimes termed hypoxic ischaemic encephalopathy.

⁷ Sarnat HB and Sarnat MS (1975) Neonatal encephalopathy following fetal distress *Arch Neurol* **33**: 696–705.

⁸ Robertson CM and Finer NN (1993) Long-term follow-up of term neonates with perinatal asphyxia *Clin Perinatology* **20**: 483–500; Marlow N, Rose AS, Rands CE and Draper ES (2005) Neuropsychological and educational problems at school age associated with neonatal encephalopathy *Arch Dis Child Fetal Neonatal Ed* **90**: F380–7.

⁹ Spastic cerebral palsy resulting from hypoxia is usually caused by a relatively prolonged period of partial hypoxia. In cases where the baby suffers a short period of near total lack of oxygen, as opposed to a longer period of partial hypoxia, the resulting disability will be athetoid cerebral palsy, which may be accompanied by other physical and learning disabilities, although intellect may be preserved. These babies do not always have severe neonatal encephalopathy.

severe learning disabilities, epilepsy, and severe vision and hearing impairments. These are among the most severely disabled children encountered and doctors would normally advise discontinuation of active treatment after 48–72 hours of severe encephalopathy. Infants with this condition have lost their responsiveness and consciousness and are usually, but not always, ventilator-dependent, in which case withdrawal of ventilation will result in the infant dying within minutes or hours. It is therefore critically important that the diagnosis is accurate and a careful assessment made of other possible causes for a baby's encephalopathy, including biochemical disturbances, infection and congenital anomaly (see below).

Many of the investigations that are needed to identify the nature of the injury (Appendix 4) and clarify the prognosis take time. The period when it would be possible to withdraw treatment may pass (usually the first three days) while these tests are carried out, by which time the life of the baby may no longer be dependent on technological support.

The baby born with brain abnormalities

6.10 Although rare, babies can be born with a structural abnormality of the brain that has not been recognised before birth, with evidence of a brain injury that occurred at some time before labour, or with a condition where the prognosis for normal development is well established and known to be very unlikely. These are known as congenital¹⁰ conditions. Examples include:

- A child with **polymicrogyria**, which arises from abnormal organisation of brain cells very early on in gestation; children show poor body and brain growth, and have severe cerebral palsy.¹¹
- A twin who has survived the death of his or her co-twin at mid-gestation but at the time suffered a **major failure of the blood supply** to the whole of one side of the brain, usually the left hemisphere; these babies will develop a severe cerebral palsy.
- A child born with **trisomy 13** (also known as Patau syndrome) which is a genetic condition in which three copies of chromosome 13 are in each cell instead of the usual two. Trisomy 13 is usually associated with other serious abnormalities and learning disabilities. The majority of children (80–90%) with this syndrome do not survive infancy, and long-term survivors have not been identified.

6.11 Each child with brain abnormalities is given a careful individual assessment with a range of diagnostic procedures to establish the nature of the condition, the extent of any damage and the prognosis (Appendix 4). Doctors will discuss the option of withdrawing intensive care with the family in cases where a baby is severely affected and dependent on technological support and would die without it.

Other serious conditions in the newborn baby

6.12 Life-threatening conditions other than acquired brain injury or congenital brain abnormalities can arise. These conditions require careful individual assessment prior to any decision making. For example, a baby might have an abnormality in a major organ system that was present at birth or an acquired injury, either of which makes long-term survival or independence almost impossible. This group of conditions may affect the heart, lungs, bowel or kidneys. For example, complex congenital heart abnormalities are often considered inoperable and parents may decide not to subject their child to the pain and distress of repeated episodes of surgery

¹⁰ Congenital literally means 'born with'.

¹¹ See also footnote 9.

to no benefit in the long term. Some congenital abnormalities of the lung may become obvious during intensive care, such as alveolar capillary dysplasia where gas exchange is difficult because the blood vessels in the developing lung fail to grow in proportion to the airways. In all known cases, babies with this form of dysplasia have died. A lung biopsy can be performed in an affected baby, and intensive care may subsequently be withdrawn and substituted with palliative care (see paragraphs 6.18–6.22) in confirmed cases. However, most diagnoses are made after death, usually following an autopsy (see paragraph 6.51).

6.13 In some babies, acquired injuries to the bowel pose difficult dilemmas. Babies may be found to have too little remaining gut after lengths of intestine die such as when necrotising enterocolitis (a disease affecting the wall of the newborn gut) is complicated by peritonitis, an infection that occurs when the intestine perforates and spills its contents into the abdominal cavity. A similar situation can arise when the blood supply to the gut has been compromised because the bowel twists on its supporting membrane (mesentery) which contains the blood supply. In these situations a baby may be left with less than the minimum length of bowel known to be able to regrow and support feeding. Infants with these conditions require life-long intravenous feeding to survive and many develop serious side effects and have a shortened life expectancy.¹² Bowel transplants have recently become an option in such cases. However, an affected baby would need to take immunosuppressant drugs for the rest of his or her life, meaning he or she would often be susceptible to infections. Following surgery, the incidence of illness and death remains high.¹³ Difficult dilemmas also arise when babies are born with kidney failure. To survive, these babies must begin dialysis (which is technically difficult in the newborn) to await the age when a kidney transplant may be feasible. Critical care decisions are difficult in such cases because the prognosis is poor, yet a baby may not be dependent on a ventilator. In contrast to withdrawing ventilation, which would very quickly lead to a baby's death, withholding or withdrawing intravenous nutrition (see paragraph 6.22) or dialysis may mean that a baby takes several days to die, during which time he or she should receive palliative care. We say more about methods for relieving discomfort and pain, and palliative care in the next section.

Pain relief and developmental care in the neonatal intensive care unit

6.14 While neonatal intensive care saves the lives of many babies, it can be a stressful experience for them, especially when given for long periods. Many of the procedures that are frequently performed cause discomfort or pain, such as passing a tube into the windpipe, inserting fine tubes, or cannulae, into a baby's arteries and veins, and taking blood samples. A recent study in a neonatal intensive care unit in the Netherlands found that babies were subjected to an average of 14 painful procedures per day.¹⁴ In addition, the environment, often noisy and brightly lit, can be stressful for babies. Parents of babies receiving intensive care may also find it stressful, and concern about a baby experiencing pain has been identified as one factor contributing to stress.¹⁵

6.15 Recent research has provided increasing evidence that newborn babies, including those born prematurely, show strong responses to pain¹⁶ and that experiencing painful procedures without pain relief during the neonatal period is harmful, with potential both for short- and

¹² Kato T, Tzakis AG, Selvaggi G *et al.* (2006) Intestinal and multivisceral transplantation in children *Ann Surg* **243**: 756–64.

¹³ *Ibid.*

¹⁴ Simons SHP, van Dijk M, Anand KS, Roffthoof D, van Lingem RA and Tibboel D (2003) Do we still hurt newborn babies? *Arch Pediatr Adolesc Med* **157**: 1058–64.

¹⁵ Franck L, Cox S, Allen A and Winter I (2004) Parental concern and distress about infant pain *Arch Dis Child Fetal Neonatal Ed* **89**: F71–5.

¹⁶ Slater R, Cantarella A, Gallella S *et al.* (2006) Cortical pain responses in human infants *J Neurosci* **26**: 3662–6.

long-term effects.¹⁷ These effects can include a permanently altered response to pain.¹⁸ In the past, infant pain has been poorly understood and under-treated,¹⁹ but a better understanding of the risks of pain has led to research on how to observe infants for signs of pain, and how to give pain-relieving medicines safely.²⁰ Nevertheless a survey of practice found that pain is not monitored routinely and pain relief not used widely in neonatal units in the UK, and that there is considerable variation in practice.²¹

6.16 Pain can be difficult to recognise in an ill or premature baby, and effective methods for monitoring his or her level of pain using behavioural and physiological signs are not available. Several assessment tools have been developed²² and guidelines from the Royal College of Nursing (RCN) recommend that assessment of pain should include the use of a suitable method along with consideration of a baby's health status and parental views.²³ We note that other organisations have developed guidelines for clinical practice in the UK and internationally.²⁴ While assessing a baby's discomfort or pain is difficult, deciding which treatments are most effective and with least risk is even more challenging. Many pain-relieving medicines given to adults and children can be given to babies; however, they all have disadvantages, mainly related to the way they are administered or to adverse effects. For example, some medicines that can only be given by mouth cannot be used if a baby is not able to feed. Strong analgesics such as morphine, like other medicines, may carry some risks for a baby's development if they are used for a prolonged period. There is currently little research on whether the potential developmental risks from unrelieved pain outweigh those from prolonged exposure to medicines that act on the central nervous system. New analgesics are being sought, but there is no clear consensus about which of many potential drug targets in biological pain pathways should be pursued.²⁵ Moreover it may be many years before new medicines are tested in babies. Alternative means of pain relief can be used in conjunction

¹⁷ Research in animals suggests that, in the longer term, exposure to multiple painful experiences in the newborn period leads to more sensitivity to pain from major injury and less sensitivity to minor injury. Pain in early life is also associated with later abnormalities in the stress response system: see Fitzgerald M (2005) The development of nociceptive circuits *Nat Neurosci Rev* 6: 507–20. However, much less is known about how neonatal pain might affect human children or adults. Some clinical studies suggest that untreated pain suffered in early life may affect stress hormone responses in childhood or alter how children experience pain or other sensations: see Andrews K and Fitzgerald M (2002) Wound sensitivity as a measure of analgesic effects following surgery in human neonates and infants *Pain* 99: 185–95; Grunau RE (2002) Early pain in preterm infants A model of long-term effects *Clin Perinatol* 29: 373–94; Grunau RE, Weinberg J and Whitfield MF (2004) Neonatal procedural pain and preterm infant cortisol response to novelty at 8 months *Pediatrics* 114: e77–84; Peters JWB, Schouw R, Anand KJS (2005) Does neonatal surgery lead to increased pain sensitivity in later childhood? *Pain* 114: 444–54; Schmelzle-Lubiecki B *et al.* (2005) Abstracts: 11th World Congress on Pain (Seattle: IASP Press), pp 76–7.

¹⁸ Fitzgerald M (2005) The development of nociceptive circuits *Nat Rev Neurosci* 6: 507–20.

¹⁹ International Association for the Study of Pain (2005) Why children's pain matters *Pain – Clinical Updates* Vol. XIII, No. 4, available at: <http://www.iasp-pain.org/PCU05-4.pdf>, accessed on: 27 July 2006.

²⁰ *Ibid.*

²¹ The survey found that pain scales which can be used to assess pain and an infant's responsiveness were used relatively little and that less than 60% of units regularly used analgesia for pain relief. See Redshaw M and Hamilton K (2005) *A Survey of Current Neonatal Unit Organisation and Policy: Commissioned by BLISS – The Premature Baby Charity* (Oxford: National Perinatal Epidemiology Unit), available at: http://www.npeu.ox.ac.uk/neonatalunitsurvey/neonatalunitsurvey_downloads/BLISS%20Final%20Report.pdf, accessed on: 18 July 2006.

²² Some of these tools are compared in: Royal College of Nursing Institute (1999) *Clinical Guidelines for the Recognition and Assessment of Acute Pain in Children – Technical Report* (London: RCN).

²³ *Ibid.*

²⁴ Summarised in International Association for the Study of Pain (2005) Why children's pain matters *Pain – Clinical Updates* Vol. XIII, No. 4, available at: <http://www.iasp-pain.org/PCU05-4.pdf>, accessed on: 27 July 2006. In addition see Anand KJ and the International Evidence-Based Group for Neonatal Pain (2001) Consensus statement for the prevention and management of pain in the newborn *Arch Pediatr Adolesc Med* 155: 173–80; The Royal Australian College of Physicians (2005) *Guideline Statement: Management of procedure-related pain in neonates* (Sydney: The Royal Australian College of Physicians).

²⁵ Basbaum AI (2005) The future of pain therapy: something old, something new, something borrowed, and something blue, in *The Paths of Pain, 1975–2005*, Merskey H, Loeser JD and Dubner R (Editors) (Seattle: IASP Press), pp 513–32.

with analgesics; they include giving breast milk or a dummy, and using touch, warmth and positioning of a baby's body. Such interventions have been found to provide non-painful stimulation that activate the body's own pain-relieving chemicals or divert attention from pain.²⁶

- 6.17 Decreasing the stress of the neonatal care environment for babies is another evolving area of practice. One approach that has been found to have some benefit is 'developmental care'. This comprises a broad spectrum of interventions intended to reduce the stress of the neonatal intensive care unit through modification of the care-giving environment and processes of care giving to make them more appropriate to a baby's stage of development. Developmental care uses a range of strategies, including reduced lighting, noise and handling, and non-invasive monitoring. Parents are encouraged to become more involved in the care of their babies by helping them to recognise their baby's signals and responses, and to use interventions such as baby massage and kangaroo (skin to skin) care when their baby is well enough. Research studies have shown that developmental care leads to improved growth and bone development and has reduced some adverse health outcomes, although further studies on the scale and consistency of the benefits are needed.²⁷ **The Working Party considers that the reduction of pain and stress in neonatal units is an important area for improvement in clinical practice and that more needs to be done to apply current knowledge about how to assess, prevent and treat pain for babies receiving intensive care.** Our view is that research into the potential developmental effects of neonatal pain and stress and their treatments should be encouraged.

Palliative care

- 6.18 It will not always be appropriate to continue intensive care for all babies who are seriously ill. If they have serious life-threatening or life-limiting health problems and parents and doctors agree that they are unlikely to benefit either from the initiation or continuation of intensive care, they may instead receive another form of support, known as palliative care. This is the "active, total care of patients whose disease is not responsive to curative treatment. The goal of palliative care is achievement of the best quality of life for patients and their families."²⁸ The relief of pain and other distressing symptoms caused by disease or medical treatment is the primary focus of palliative care, together with psychological, social and spiritual support to assist patients and their families at the end of the patient's life. Modern palliative care began in the 1960s within the hospice movement in the UK.²⁹ More recently the importance of the implementation and development of palliative care specifically for children has been highlighted.³⁰
- 6.19 Palliative care involves a multidisciplinary team with specialist skills, including medical and nursing staff, staff from children's services, counsellors and voluntary organisations, and can be provided in a hospice, at home or in a hospital setting. Palliative care for newborn babies is indicated in three situations: (a) when a fetal abnormality known to cause death is diagnosed prenatally, and the fetus is born alive;³¹ (b) when a decision is made in the delivery

²⁶ Franck LS and Lawhon G (1998) Environmental and behavioral strategies to prevent and manage neonatal pain *Semin Perinatol* **22**: 434–43; Leslie A and Marlow N (2006) Non-pharmacological pain relief *Semin Fetal Neonatal Med* **11**: 246–50.

²⁷ Kenner C and McGrath J (Editors) (2004) *Developmental Care of Newborns and Infants: A guide for health professionals* (Mosby).

²⁸ For the World Health Organization definition of palliative care, see: <http://www.who.int/cancer/palliative/definition/en/>, accessed on: 31 July 2006; Gale G and Brooks A (2006) Implementing a palliative care program in a newborn intensive care unit *Adv Neonatal Care* **6**: 37–53.

²⁹ Saunders C (1996) Into the valley of the shadow of death: A personal therapeutic journey *Br Med J* **313**: 1599–601.

³⁰ Association for Children with Life-threatening or Terminal Conditions and their Families and Royal College of Paediatrics and Child Health (1997) *A Guide to the Development of Children's Palliative Care Services* (Bristol and London: Association for Children with Life-threatening or Terminal Conditions and their Families and Royal College of Paediatrics and Child Health).

³¹ Breeze AC, Lees CC, Kumar A, Missfelder-Lobos HH and Murdoch EM (2006) Palliative care for prenatally diagnosed lethal fetal abnormality *Arch Dis Child Fetal Neonatal Ed* doi:10.1136/adc.2005.092122.

room that it is not in baby's best interests to be resuscitated; or (c) when it is decided that intensive care is or has become futile and treatments should be withdrawn or withheld.

6.20 Guidance from the RCPCH on this subject reads: "Withholding or withdrawing life sustaining treatment does not imply that a child will receive no care. It should rather signal a change in focus towards palliative care making sure that the rest of the child's life is as comfortable as possible."³² BAPM guidance further states: "infants for whom life-sustaining support is withdrawn or withheld should continue to be kept warm, offered oral nourishment, and treated with dignity and love (comfort care). Their parents should be encouraged to be with their child as much as possible. They should be given every support during this distressing time."³³ The Department of Health and Department for Education and Skills has also recognised the value of this type of care, by including the following in the National Service Framework (NSF) for Children: "High quality palliative care services should be available for all children and young people who need them."³⁴

6.21 We understand, however, that healthcare professionals working in perinatal and neonatal intensive care do not receive mandatory training in palliative care and that access to teams who specialise in palliative care is extremely limited. The current use of techniques in palliative care for management of pain and symptoms in babies, and the availability of support for parents, vary greatly across different settings in the UK. **The Working Party therefore recommends that the NHS should train all professionals working in neonatal medicine in the basic principles of palliative care so that these can be applied when a need is identified. To complement this provision, the NHS should also facilitate access to specialist advice in palliative care for difficult cases in the same way that specialists would be consulted on complex problems in other areas of medicine.** It may be useful to draw upon examples from other countries of different ways in which comprehensive palliative care can be provided to babies and their families.³⁵ Meanwhile, the American Academy of Pediatrics has recommended minimum standards for paediatric palliative care, including multidisciplinary training, expert palliative care assistance to be available at all times, in-patient facilities and community outreach programmes.³⁶

6.22 The BAPM guidance quoted in paragraph 6.20 above specifically states that nourishment by mouth should continue to be offered when intensive care is withheld or withdrawn.³⁷ Newborn babies all require feeding by others, and in the UK, feeding by a stomach tube for a baby who cannot suck is often considered as basic nursing care, and not medical treatment.³⁸ In many cases hunger and dehydration may add to a baby's suffering, and artificial

³² 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: 25 Sept 2006.

³³ 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.

³⁴ Department for Education and Skills and Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services: Disabled children and young people and those with complex health needs* (London: Department of Health), available at: <http://www.dh.gov.uk/assetRoot/04/09/05/56/04090556.pdf>, accessed on: 19 July 2006.

³⁵ Gale G and Brooks A (2006) Implementing a palliative care program in a newborn intensive care unit *Adv Neonatal Care* **6**: 37–53; Craig F and Goldman A (2003) Home management of the dying NICU patient *Semin Neonatol* **8**: 177–83; Stringer M, Shaw VD and Savani RC (2004) Comfort care of neonates at the end of life *Neonatal Netw* **23**: 41–6.

³⁶ American Academy of Pediatrics (2000) Palliative care for children *Pediatrics* **106**: 351–7.

³⁷ 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.

³⁸ Under UK law a distinction (in adults) has been made between artificial nutrition as a medical treatment and as a non-medical procedure when considering the permissibility of withdrawing artificial nutrition and hydration. For example, withdrawal of artificial nutrition and hydration has been held lawful in the UK in most cases in which adult patients are in PVS (a persistent vegetative state) or what has been described as near-PVS. In the case of the young man Anthony Bland (see *Airedale NHS Trust v Bland* [1993]

nutrition and hydration would need to be continued if this suffering is to be avoided. However, we also recognise that if there is a failure of gastrointestinal function as a baby dies or if their gut is absent or damaged through disease, providing food and liquid may not be appropriate and could cause additional suffering. **We therefore conclude that oral nutrition and hydration should only be withheld from a baby in the exceptional circumstances when providing it causes discomfort and pain, for example when the baby has little functioning bowel or when death is imminent. The decision should only be taken after careful assessment and as part of a planned programme of palliative care designed to minimise suffering and make the baby as comfortable as possible.**

Some examples³⁹

6.23 We consider below several different hypothetical examples to highlight some of the complexities of making decisions about treatment when the prognosis for a baby has been established. The first two examples illustrate situations in which either the doctors or the parents would like intensive care to continue while the other party disagrees. The third example describes how the use of pain relief can create a dilemma.

Case 6: Danielle – continuation of intensive care on the advice of doctors

Danielle

Danielle was the third child in her family and was born at a gestational age of 27 weeks. Although early scans suggested that she had periventricular brain lesions, these seemed to resolve. She remained at risk of cerebral palsy which made her prognosis uncertain. Danielle did not need ventilator support after the first few days following her birth. On day 24 she began receiving air through a continuous positive airway pressure (CPAP) mask to her nose because her breathing had begun to stop for short spells (apnoea). Ultrasound scans showed bilateral cystic periventricular leucomalacia, an injury to the white matter surrounding the ventricles which indicated the probable development of cerebral palsy (see Appendix 4). Danielle's parents wished to withdraw CPAP support and provide Danielle with palliative care only. They said they could cope with physical disability alone but not with mental disability. The doctor advised that her prognosis remained uncertain and that she was unlikely to die if CPAP was withdrawn. However, she might become more distressed because extra handling would be needed to curtail her apnoeic spells. He explained that it was not certain that Danielle would have serious learning disabilities in the future although she was expected to have great difficulty with sitting and walking. She would benefit from specialist treatment and support for cerebral palsy. Life support was continued and Danielle survived. At three years old Danielle had severe spastic diplegia, a form of cerebral palsy affecting the legs and mild cognitive impairment.

Best interests

6.24 In Chapter 2 we explained that doctors are under a professional obligation to preserve life where and when they can, using appropriate treatment to achieve that end. However, they are not obliged to provide life-sustaining treatments when to do so would be futile. In cases like that of Danielle, it would generally be regarded as in a baby's best interests for clinicians to continue full intensive care while the prognosis remains uncertain. For Danielle, by the time the diagnosis became clearer, she was no longer on full ventilatory support, so the option of ceasing to maintain her life by withdrawing that support had passed. In deciding to continue CPAP treatment, the doctor was using his professional judgement to act in Danielle's best interests (paragraphs 2.21–2.32). However, the parents signalled their own best interests, when they asked for the implications for themselves and other family members to be

1 All ER 821) "the court considered there was overwhelming evidence that the provision of artificial feeding by means of a nasogastric tube was 'medical treatment' and that its discontinuance was in accord with good medical practice". See Mason JK and Laurie GT (2005) *Mason and McCall Smith's Law and Medical Ethics*, 7th Edition (Oxford: Oxford University Press), p 580. The situation for paediatric practice is unclear (Royal College of Paediatrics and Child Health (2004) *Withholding or Withdrawing Life Sustaining Treatment in Children: A framework for practice*, 2nd edition (London: RCPCH)). In one case the courts have sanctioned not providing artificial feeding for a baby Re C (a minor) whose death was imminent and inevitable (wardship: medical treatment) [1989] 2 A11 ER 782 (Mason & Laurie, p 549).

³⁹ See footnote 1.

considered. We noted that there are different kinds of interest, each of which should usually be given some weight when making decisions. In an analysis based on best interests, the conflict arises not because the parents and the doctor disagree about what is best for Danielle, but because her parents see their interests as outweighing Danielle's basic interests in being alive, with the doctor deciding that Danielle's interests are the ones that should be promoted. If intolerability rather than best interests were to be used as the basis for decision making, a similar outcome would probably arise, since in Danielle's case, at the time that the decision was made, it did not seem likely that her later quality of life would be 'intolerable' (paragraph 2.16).

Conveying information

6.25 It is clear that the doctor's decision to act against the parents' wishes created tension at the moment of clinical decision making. Several factors might have affected the quality of decision making. The parents might have been given insufficient information about what it means to live with a person with physical and mental disabilities. If this was the case, they may have underestimated their capacity to care for a disabled child. Such an omission is important because their potential in this regard needs to be considered in the decision-making process. Advice should have been offered to Danielle's parents about the kinds of support and possibilities available for a family with a disabled child (see Chapter 7), including opportunities for respite care and adoption. The example of Danielle demonstrates that professionals conveying information must handle the stressful situation in which parents find themselves with great sensitivity. Danielle's parents may feel that the clinical team has not thought properly about what it will mean for their family to have a daughter with disabilities. Specialist training in the communication of sensitive issues might have helped the team to talk this or other issues through with them and identify any need for further information or counselling. In Danielle's case the doctor has the difficult task of balancing an appreciation of the concerns of her mother and father with the need to convey to them that in his view, they seem not to have given sufficient weight to Danielle's best interests.

6.26 For neonatal care, an important general question is whether any decisions that are made jointly by healthcare professionals and families are based on shared comprehension of critical choices, actions and terminology. Few common interpretations appear to exist even of terms such as 'withdrawal of treatment', 'futility', 'quality of life' or 'consent'. Understanding how these terms have been used, and the importance attached to them in the decision-making process will differ widely between different parties.⁴⁰ Research suggests that different interpretations are to be expected, especially in situations where the outcome is uncertain. It might be the case, for example, that it is precisely these often subtle differences in interpretation that lead to overt conflict between different parties and cause them to seek resolution in the courts. **We conclude that further research is needed to clarify how the different parties interact with each other to further understanding, to provide an evidence base for identifying and applying changes in practice, and for the more effective resolution of differences of opinion.**

Legal issues

6.27 Danielle's case is one that might have gone to court. Her parents could have challenged the doctor's decision and sought an order requiring withdrawal of intensive care. They would probably have maintained that the doctor acted unlawfully in continuing CPAP without either parental consent or authority from the court to act in what they believed was Danielle's best interests (see Box 6.1). However, if this case had been taken to court, the

⁴⁰ Nettleton S (1995) *The Sociology of Health and Illness* (Cambridge: Polity Press); Annandale E (1998) *The Sociology of Health and Medicine* (Cambridge: Polity Press).

judges would have been likely to support continuation of CPAP. Under the law, the likely burdens to Danielle of continuing treatment are outweighed by her interests in survival and the pleasures that life should afford her, notwithstanding her disabling condition. We note that the quality of Danielle's life will depend very much on her parents. Would they be able to argue in court for the greater say in deciding what constitutes her best interests? This case is one where the parents and the healthcare professionals might benefit from access to mediation services.

Box 6.1: Going to court

Where doctors and parents reach irreconcilable disagreement about what treatment a baby should receive, a court may be asked to decide what care is in the best interests of the baby. As well as best interests, the judge must consider broader social issues. Cases about treatment decisions are generally heard in the Family Division of the High Court and the proceedings are usually started by the NHS trust. Occasionally the family may bring Judicial Review proceedings, asking the Administrative Court (part of the High Court) to examine whether the decision (made by the doctors employed by the NHS trust) to treat (or more usually refuse treatment) was properly arrived at.

The person (or NHS trust) who commences the proceedings* is known as the 'claimant' and the other parties are called the 'defendants'. In the usual case where the trust is the claimant, the baby will be the first defendant and one or both parents and any other closely involved family members will be the second or subsequent defendants. The baby will be represented by the Children and Family Court Advisory and Support Service (CAFCASS) whose functions include not only representing the baby, but also providing information, advice and other support for the baby and his or her family. Nonetheless, the parents are likely to want their own legal representation. They will need to find a firm of solicitors who specialise in this work. Parents on low incomes may qualify for Legal Aid (now called 'Public Funding').

Though it may not appear so to the parents and the doctors involved, these court proceedings are not in the form of conventional adversarial litigation, but are a process to establish a baby's best interests. The order the court is asked to make is often referred to as a 'best interests declaration' and takes a form that depends upon whether the claimant is asking to have treatment sanctioned, withdrawn or withheld. So in a case where the NHS trust is seeking the sanction of the court, it will apply for a declaration from the court, for example, that not commencing ventilation would be in the baby's best interests, despite the parents wish for the baby to be ventilated. Conversely, when the doctors feel the baby needs a particular treatment or operation and the parents disagree, the trust will seek a declaration that the particular treatment or operation is lawful, despite the lack of parental consent, and in the baby's best interests.

Once an application has been issued, a judge will give pre-trial directions, dealing for example with disclosure of the baby's medical records, the evidence† that is needed, when it should be produced, which witnesses should attend trial for cross examination, the date of the trial and the issue of publicity. Cases concerning children are usually heard in private, but recently (for example in the cases concerning Charlotte Wyatt and Luke Winston-Jones) the court has agreed, at the request of the parents, for the hearings to take place in 'open' court, that is in public. If the case is urgent, hearings are possible at any hour of the day or night, provided clear evidence is given to the court explaining why the case is urgent, and the degree of urgency involved.

Independent expert medical evidence based upon a baby's prognosis with and without the disputed treatment is often important for the court, the baby and the parents. A breakdown of communication between parents and the doctors treating the baby is a feature in some of the cases that reach the court. Independent paediatricians or neonatologists, retained as expert witnesses, in ideal circumstances may sometimes, in the course of detailed discussions with the parents, give new or clearer explanations that lead to shared knowledge, consensus or understanding and acceptance of different views. Alternatively parents may feel the experts are there simply to support their colleagues and assert medical authority over the lay public.

* By issuing an application summarising the orders sought from the court.

† For example, factual evidence from the doctors treating the baby, and the parents and expert evidence from independent doctors.

In the next example, doctors advised discontinuation of life support but the parents disagreed.

Case 7: Elliot – intensive care continued at the parents' wishes

Elliot

A first-time mother had labour induced at 41 weeks of pregnancy and needed an emergency Caesarean section. She gave birth to a baby she named Elliot who weighed 2,700g, which is relatively small for 41 weeks. Elliot did not breathe. He was resuscitated but developed seizures after four hours. After treatment with anticonvulsant drugs his seizures stopped 12 hours later, but he remained unresponsive and ventilator-dependent after a further 96 hours. An electro-encephalogram (EEG) revealed low brain activity and an abnormal blood flow in the brain. Cerebral MRI scans indicated serious brain injuries.

All the clinical evidence, with a high degree of certainty, indicated that if Elliot survived, he would have severe quadriplegia (paralysis of all four limbs) and learning difficulties as well as severe epilepsy. The neonatologists and nurses were in agreement that further life support was not justified when the prognosis was so poor. The clinicians based their prognosis on recent published evidence and their experience. All the relevant assessments were completed by 96 hours and the evidence indicated he would be unable to sit up or eat, and would be completely dependent on carers for all functions. Life would be a series of procedures with tubes, and uncomfortable handling. The parents did not agree to the withdrawal of life support, saying that in their view, life was sacred and only God should take it away. Elliot remained on mechanical ventilation. The next critically ill infant born at that hospital had to be transferred 50 miles to another city because there were not enough nurses to staff further intensive care cots. Elliot remained in the hospital for a further three months. Eventually he developed a serious infection and died in hospital without ever breathing on his own.

Sanctity of life

6.28 The clinical management of Elliot's condition is representative of normal practice in the UK when there is disagreement over whether full treatment should be withdrawn; that is, life support was continued. Elliot's parents valued life as sacred at any cost, which was in keeping with their religious beliefs. The values they hold correspond with the absolutist stance on sanctity of life that we identified in paragraph 2.9. They may also have been reluctant to accept the prognosis given by the doctor and hoped that Elliot would improve in time. In their view, even the most uncomfortable life with very limited communication was more valuable than death. Doctors are trained to try to do their best for their patient and to ignore consequences for other patients who are not directly under their care. From the doctor's perspective, maintaining Elliot's life was not in his best interests. The healthcare team could ensure that he did not suffer by providing palliative care.

Best interests

6.29 The conflict between the parents and the medical team about how to act in Elliot's best interests could not be resolved. After Elliot died, his parents may have some consolation from knowing that they acted in accordance with their beliefs and that everything possible had been done for Elliot. Even so, the situation would have been highly traumatic for them. For the clinical team, since their professional opinion was that the burden to Elliot exceeded the benefits of continuing treatment, their agreement to maintain a treatment that they thought futile may have come at a personal emotional cost.⁴¹

Pressure on resources

6.30 In addition to raising the issue of whether continuing ventilation was in Elliot's best interests, his case raises issues of justice and fairness. Elliot's treatment in intensive care was in retrospect unsuccessful and likely to be associated with serious disability later on. This was an outcome that the doctors felt was not in his best interests. The treatment was given to Elliot rather than another baby whose chances of survival without significant disability were greater. To the doctors, it might not seem fair to allocate resources to Elliot when another child could reasonably be expected to benefit more from them. The baby who had to be transported on a ventilator to another city, risked deterioration of his or her condition because of the transfer. So long as resources such as the provision of cots and staff within intensive care units are limited, issues about their fair use can be expected to arise.⁴²

⁴¹ Hefferman P and Heilig S (1999) Giving "moral distress" a voice: ethical concerns among neonatal intensive care unit personnel *Camb Q Healthc Ethics* 8: 173–8; Stutts A and Schloemann J (2002) Life-sustaining support: ethical, cultural, and spiritual conflicts Part II: Staff support: a neonatal case study *Neonatal Netw* 21: 27–34.

⁴² In the sense that the resources available for healthcare are finite, it will always be the case that care for one patient may affect that of another. Comments to the Working Party in fact-finding meetings indicated that although doctors do not allow resource implications to affect decision making, they are aware of the implications of their decisions.

6.31 This example provides another illustration of the pressure on healthcare resources that we described in paragraphs 5.45–5.51. If mechanical ventilation for Elliot had been discontinued, the equipment might have become available for a second baby, but the motive behind the doctors' advice might be questioned. From the perspective of the parents, the advice to consider allowing Elliot to die might be misunderstood for confusing ethical with economic issues; rationing resources rather than protecting their baby's best interests. We take the view that it is important to avoid arguments about 'bed-blocking' and instead to focus on the best interests of a baby. This is consistent with our recommendation that resource considerations should not affect decision making between the doctor and the parents of the patient (paragraph 2.43).⁴³ This is not to deny that decisions in practice are affected by cost, since the treatments that may be offered will necessarily depend on the facilities and staffing skills that are available in a particular neonatal unit. The capability of a particular unit depends in turn on decision making in healthcare provision at the national or regional or local (hospital) levels (macroeconomic or mesoeconomic levels, see Figure 3.4). The Working Party would expect considerations of 'fairness' and justice to be a part of decision making on the distribution of resources (paragraph 2.41).

Legal issues

6.32 This is another case which could have been brought before a court. However, the doctors and the NHS trust chose not to challenge the parents. In our meetings with healthcare professionals we found that most are unwilling to add to parents' trauma by recommending that the trust should initiate court proceedings unless they judge that the baby is suffering severely. Had the trust challenged the decision of Elliot's parents by going to court, the sole concern would be the best interests of Elliot himself, not the impact his survival would have on NHS resources or on other critically ill babies. Questions for a court would focus on whether Elliot experienced any meaningful human interaction in his limited life. For example, did he respond to his parents? The court would also be concerned with the burdens to Elliot of treatment. Was he subject to pain and distress?⁴⁴ If Elliot gained some benefit from his life, a judge might be hesitant to overrule his parents' wishes (see Chapter 8).

Economic issues relating to provision of intensive care

6.33 In this section, we consider first, early economic evaluations of the cost-effectiveness (see also paragraphs 5.45–5.51). Secondly, we examine the cost-effectiveness of a routinely-used treatment strategy, as an example of how more recent research into the cost-effectiveness of neonatal medicine has tended to focus on specific interventions.⁴⁵ There are several outcome measures incorporated into studies of cost-effectiveness. The quality of life (QALY) measure, which we describe in Appendix 8, is often used.

6.34 Early studies have been of variable quality in terms of their evidence for the effects of neonatal intensive care on mortality. One study from Canada⁴⁶ and another from Australia⁴⁷ analysed outcomes for selected groups of the population before and after access to neonatal intensive care was expanded. For babies born weighing less than 1,000 g, the studies estimated

⁴³ See the discussion of resources for healthcare in Mason JK and Laurie GT (2005) *Mason and McCall Smith's Law and Medical Ethics*, 7th Edition (Oxford: Oxford University Press), pp 571–4.

⁴⁴ Claims made in court cases about the pain experienced by babies with serious health problems are often not substantiated by proper assessment or measurement. Nor is it always clear if adequate treatment for pain has been given.

⁴⁵ Petrou S and Mugford M (2000) Predicting the costs of neonatal care in *Current Topics in Neonatology*, Hansen TN and McIntosh N (Editors), Volume 4 (London: WB Saunders), pp 149–74.

⁴⁶ Boyle MH, Torrance GW, Sinclair JC and Horwood SP (1983) Economic evaluation of neonatal intensive care of very-low-birthweight infants *N Engl J Med* **308**: 1330–7.

⁴⁷ Kitchen WH, Bowman E, Callanan C, *et al.* (1993) The cost of improving the outcome for infants of birthweight 500–999g in Victoria *J Paediatr Child Health* **29**: 56–62.

a cost per additional survivor of between £85,000 and £174,000 (at 1998 prices). When the outcome was measured in terms of an additional year of life gained, the extra cost fell to between £4,440 and £15,790. Alternatively, measuring the outcome in terms of an additional QALY gained, gives figures of between £4,190 and £38,030.

6.35 Evaluating the effects of treatment in economic terms to determine their cost-effectiveness is a complex task. The widespread introduction into neonatal intensive care of surfactant-replacement treatment in the early 1990s for less developmentally mature babies saved lives, which led to increased periods of stay in intensive care and thus increased costs.⁴⁸ It was also associated with increased costs in caring for survivors once they left hospital. However, in the case of more mature babies for whom it is equally effective, and for whom mortality and morbidity are low, surfactant led to shorter periods of stay and a clear cost benefit.⁴⁹ In the future, it is likely that economic analysts will have to evaluate the impact of recent developments in neonatal care such as head cooling, whole body cooling, liquid ventilation, intravenous immunoglobulin therapy and high-frequency oscillation ventilation.

Further example

Case 8: Freddie – pain relief and the consequence that death is hastened

Freddie

Freddie was born by normal vaginal delivery after a nine month pregnancy. It rapidly became apparent that he had the incurable rare inherited skin condition, recessive junctional (Herlitz type) epidermolysis bullosa (EB), which is lethal in infancy. The diagnosis was confirmed by skin biopsy and DNA analysis.

Here is a description by a mother of a child with this most serious form of the condition⁵⁰:

"A child with painful wounds similar to burns covering most of his or her body. Having to wrap each tiny little infant finger with Vaseline gauze and then cover it with gauze to prevent the hand from webbing and contracting.

Never being able to hold your child tight because if you did, their skin would blister or shear off.

A child who will never know what it's like to run, skip or jump, or to play games with other children because even the slightest physical contact will injure his or her skin.

A child who screams out each time it is bathed because the water touching its open wounds creates incredible pain.

A diet of only liquids or soft foods because blistering and scarring occur in the oesophagus.

An active baby with his knees soaked in blood from the normal act of crawling."

Freddie's parents read this description, and others, on the Internet.⁵¹ They realised that the severity of the condition varied and that there were different forms. Other sufferers might not be as badly affected. However, it was clear that their son had the most serious form, which occurs in only a small proportion of babies with epidermolysis bullosa. They accepted advice from doctors, who consulted specialists in the disorder, that there was no treatment for their son's condition. It was obvious that Freddie was suffering and he was given morphine⁵² for pain relief. The dose was increased to control the pain, until the point came that his breathing started to be affected. The parents were still very concerned that their child might be in severe pain and asked the medical staff to continue to increase the dose of morphine, which was done. They did not want him to be mechanically ventilated if he stopped breathing, and the clinicians agreed to this request. The parents were present when Freddie died peacefully.

⁴⁸ Respiratory distress syndrome, which almost always occurs in babies born at less than 37 weeks of gestation, is caused by a lack of surfactant. Surfactant is needed to help keep the air sacs of the lungs open but babies who are born early do not produce enough; they rapidly develop breathing difficulties and need supplemental oxygen. Surfactant replacement therapy is given into the lungs via a breathing tube; it supplements the baby's own surfactant until he or she can make it him or herself, usually after about 3–4 days.

⁴⁹ Schumacher R, Burchfield D, Vaughan R *et al.* (1991) Economic impact of two rescue doses of Exosurf neonatal in $> = 1350$ gram infants *Pediatr Res* **29**: 264A, 1570; Mugford M, Piercy J and Chalmers I (1991) Cost implications of different approaches to the prevention of respiratory distress syndrome *Arch Dis Child* **66**: 757–64; Schwartz R, Luby A, Scanlon J *et al.* (1994) Effect of surfactant on mortality and resource use in infants weighing 500 to 1500g *N Engl J Med* **330**: 1476–80.

⁵⁰ See www.ebinfo.world.com.

⁵¹ For example DeBRA online, available at: <http://www.debra.org.uk/>. Organisations with websites such as this can provide information on particular conditions, enable people and families who are affected to establish contact, raise funds for research and raise awareness of the condition.

⁵² Morphine is widely used for pain relief in neonates. Other painkillers used for severe pain, including diamorphine, pethidine and fentanyl, would have similar effects on breathing.

Best interests

6.36 Arguments presented for Freddie's best interests were based on the concern about existing and future pain he would suffer and the poor prognosis for this incurable condition. For him, was survival worse than death? All those involved in the decision-making process agreed that Freddie's condition was 'intolerable' (paragraph 2.16). This condition is very distressing to witness, not just for the parents but also for clinical staff. It is crucially important that the diagnosis is correct and not confused with another type of the skin disorder which has a better prognosis, such as epidermolysis bullosa simplex.

The doctrine of double effect

6.37 Freddie's case illustrates the doctrine of double effect (paragraph 2.38) which becomes relevant where an action is taken with two outcomes, one good and the other bad. For such an action to be acceptable, the bad caused should not outweigh the good intended. The point at which the doctrine of double effect came to apply was when the dose of medication for pain had been increased to the point that Freddie's breathing became affected. The parents and the doctors wanted pain relief to be continued so that he should not suffer, but they also knew that increasing the dose would suppress his respiration. Here, giving morphine was intended to relieve pain but in the knowledge of the possibility of hastening death. While some people view such actions as equivalent to deliberately ending a life, others would disagree. **The Working Party takes the view that, provided the treatment in this case has been guided by the best interests of the baby, and has been agreed through joint decision making, pain-relieving treatments are morally acceptable, even if potentially life-shortening (paragraph 2.38).**

Active ending of life

6.38 Some might argue that Freddie should be given a lethal injection under sedation to allow him to die quickly. However, unlike voluntary euthanasia in adults, which is sometimes defended on the grounds that competent adults have a basic right to exercise choice, a baby cannot let his or her wishes be known. Thus any decision to end life would be on the basis of what others judged to be his or her best interests. This case also raises the question (accepting that it is not permissible by law) of whether it is ever morally acceptable actively to end life. Our position is that it is not (see paragraphs 2.37 and 8.40), and that to allow this practice would erode trust in doctors and the neutrality of their advice. There is further discussion of this issue in Chapter 8.

Decision making

6.39 All those involved in the decision-making process agreed that to continue life-sustaining treatment was not in Freddie's best interests, and arrangements were made to support his parents and for them to be with him while he was dying. Clear communication between the parents and the healthcare team about Freddie's condition and the options for clinical management was crucial to avoid later confusion or psychological distress if the parents subsequently experienced guilt in having 'allowed' Freddie to die.

6.40 This case exemplifies the complexity of decision making. First, decisions about the care of the newborn take place by means of an accumulating series of conversations, observations and interactions, sometimes quite minor, that contribute to a final decision.⁵³ Secondly, decision making does not entail a single decision that is made by the parents and doctors. In fact, a whole series of decisions need to be made, about what kind of care is given to a child at what stage and for how long.

⁵³ Decision making is understood by sociologists to be a staged process achieved through social interaction, and not a single act undertaken at one point in time by a single party.

6.41 During the decision-making process, parents sometimes complain of being deluged with conflicting information.⁵⁴ The nature of the information includes medical data about a child's diagnosis and prognosis, which is often complex and will include estimates of probabilities of particular outcomes.⁵⁵ Doctors sometimes use terminology that will not readily be understood unless it is carefully explained. Consequently parents will often fear that they have not understood it well enough to provide a basis for properly considered, informed consent (see paragraph 2.51 and Appendix 5). Further, doctors may be selective in what they tell parents, even for the best of reasons (see paragraph 6.42). How are parents to be sure they are being told everything they need to know?⁵⁶ Nevertheless, parents have also reported comprehending relevant medical information very quickly and acquiring an ability to participate in discussion of their child's condition.⁵⁷ Specifically in this case, Freddie's parents needed to gain a clear understanding of how epidermolysis bullosa can vary in severity, and that outcomes can differ between different patients. In conditions as rare as this form of epidermolysis bullosa, a specialist in palliative care would ideally be asked to advise the healthcare professionals looking after Freddie.

6.42 Some neonatal healthcare professionals believe that decisions which mean a choice between a baby surviving with a high probability of severe disability or a baby dying are too burdensome for some parents to take. Staff with these views might be inclined to present their advice in a way that leaves parents with little choice but to accept it. A study of 57 doctors reported that 58% preferred a joint approach to decision making and that only two thought that parents should take the full responsibility.⁵⁸ However, approximately 30% of the doctors considered that they alone should make decisions about critical care. The parents with whom we met⁵⁹ were clear that, whatever the magnitude of the decision, it was one that they should take as parents, although in practice decisions were jointly taken, or made by the doctors.⁶⁰ In a study involving parents for whom there had been discussion about limiting treatment for babies born at a range of gestations, 42% of parents considered that they had actually made the decision, 10% thought the decision was a joint one and 31% took the view that the doctors had decided.⁶¹ All parties need to be clear about how the decisions are being made, and each needs to be given the appropriate opportunity to participate. Nevertheless, it is entirely possible and even perhaps inevitable⁶² that when all concerned in a particular case believe that the parents were genuine partners in decision making, the parents may feel that they were led subtly towards a particular view. The balance of the information given, the tone of voice used, or the status of the person giving it can all be influential. One parent we met spoke of the "subtleties of the questions asked" (by both professionals and parents), and the complexities of the spoken words in the clinic, during a time of heightened emotion and

⁵⁴ Personal communication at fact-finding meeting (see Appendix 1).

⁵⁵ For discussion of views and experiences of parents and staff about sharing information and the care of babies with uncertain futures see Alderson P, Ehrich K, Hawthorne J, Killen M and Warren I (2004) *Foretelling futures: dilemmas in neonatal neurology* (London: Social Science Research Unit, Institute of Education, University of London).

⁵⁶ Later events may cause parents to question the adequacy of information provided at the time; see Case 6, Danielle.

⁵⁷ Personal communication from parents at fact-finding meetings (see Appendix 1).

⁵⁸ McHaffie HE and Fowle PW (1996) *Life, Death and Decisions: Doctors and Nurses Reflect on Neonatal Practice* (Hale: Hochland & Hochland Ltd).

⁵⁹ The Working Party met parents at fact-finding meetings. However, these were parents who had expressed a wish to meet the Working Party and we acknowledge that other parents might feel differently.

⁶⁰ 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.

⁶¹ McHaffie H (2001) *Crucial Decisions at the Beginning of Life* (Abingdon: Radcliffe Medical Press).

⁶² There is also an imbalance of expertise and knowledge between the parents and healthcare professionals. This is a dilemma faced by all professional givers and lay receivers of advice. Those giving the information and advice are likely to be selective about what they impart. Their selection is likely to be influenced, consciously or subconsciously, by their own views about the 'right' outcome.

changing reactions.⁶³ In one study, a parent involved in decisions about her baby with brain damage described how “It makes you *feel* like you’ve made the final choice but you haven’t made the final choice”.⁶⁴

Supporting parents when a baby dies

6.43 When a decision has been made to change current treatment to palliative care, parents will need support. Ideally, nurses and doctors in a neonatal unit will provide immediate practical and emotional help at the time of death for bereaved families, as well as facilitating links to the community for longer-term support. For many severe disorders such as epidermolysis bullosa, specialist organisations can provide help. Most neonatal units offer parents assistance with funeral arrangements, the gathering and presentation of keepsakes, answering questions and providing information about the cause of death. They also offer leaflets and other general information about the grieving process. Nurses or counsellors will usually keep in contact by telephone or on a return visit to the hospital in the first few months after a baby’s death, and parents are encouraged to contact local community support groups (see paragraph 3.18).⁶⁵

Legal issues

6.44 Whatever the ethical arguments, we restate that it would be illegal to take active steps designed to hasten Freddie’s death. Any act intended to end life constitutes the crime of murder. However, the law accepts a version of the doctrine of double effect that permits doctors to administer necessary pain relief even in doses that are known to have the incidental effect of shortening life. Giving Freddie morphine to ensure he did not suffer is lawful in the UK (see paragraph 8.18). Having concluded our discussion of the types of decision that may need to be made for babies in intensive care treatment, we turn now to the broader question, of how more comprehensive and robust data can be gained on health outcomes. This information is crucial to enable doctors to provide more robust advice to parents on the prospects for individual cases.

Determining outcomes

6.45 A consistent theme throughout this Report has been the paucity of information on the prevalence, severity and causes of disability which have their origin before or at the time of birth, in the child population. A similar paucity of data has been noted in a recent major study in the USA.⁶⁶ In the UK, national statistics are limited to routinely collected data on birth and death. We noted in Chapter 5, that as the prospects for survival and outcomes for babies born at progressively earlier gestational ages improve, there is the possibility that the absolute number of survivors with some level of disability will increase. Significantly, the lack of information on health outcomes may become an increasing problem as advances in healthcare, medicines and technologies begin to improve the prospects of children with previously untreatable conditions. This includes, for example, children with cystic fibrosis, congenital birth defects, severe respiratory or heart conditions and cancers.

⁶³ Personal communication at a fact-finding meeting.

⁶⁴ McHaffie H (2001) *Crucial Decisions at the Beginning of Life* (Abingdon: Radcliffe Medical Press).

⁶⁵ The parents may sometimes want to contact organisations such as the Child Death Helpline (<http://www.childdeathhelpline.org.uk>, accessed on: 30 March 2006) and the Stillbirth and Neonatal Death Society (SANDS) (<http://www.uk-sands.org>, accessed on: 30 March 2006) which will allow them, for example, to share their experiences with others or obtain advice on, for example, going back to work or coping with the anniversary of a baby’s death. These organisations have links to other groups that offer similar help.

⁶⁶ The Institute of Medicine report noted a paucity of information on preventing, diagnosing, treating and minimising the long-term effects specifically of preterm labour. The recommendations of the report emphasise the need for research to address these issues and for the encouragement of large-scale prospective studies. The report draws attention to one such investigation that has been proposed, the US National Children’s Study, which would follow the health and development of 100,000 children up to the age of 21.

- 6.46 Neonatal critical care decisions are particularly difficult because of the lack of information about long-term follow up on which to base predictions of future health outcomes. Follow up is needed not only for groups of children diagnosed with serious clinical problems around the time of birth or who are born at the borderline of viability, but also for children who have minor manifestations during this period but who are at potential risk of late-onset problems.⁶⁷ EPICure and other birth cohort studies have provided some information at the national level and will remain an important means of addressing more subtle aspects of outcome, including cognitive function, behavioural difficulties and assessments of the quality of life for the children affected, and their families, at different stages in their development. **We conclude that further clinical research of this type is needed to identify outcomes relating to the quality of life for the children affected and their families at different ages. We note that these studies will require consent on a case-by-case basis.**
- 6.47 However, to monitor the outcome of neonatal care at the population level, basic data relating to birth and neonatal care needs to be documented, analysed on a routine basis and linked to subsequent information collected through the NHS such as hospital admission, child health records, attendance in general practice and educational placement. Without improved data on outcomes, it will not be possible to give parents and healthcare professionals a more robust prognosis to help with decision making. Such data are also needed to improve current understanding of the relationship between clinical care and outcome. The availability of linked information of this kind would also encourage clinical trials and associated follow-up studies. **The Working Party therefore takes the view that it is crucially important that the various existing datasets comprising clinical information collected at birth and subsequently during the neonatal period, should be integrated and linked.**⁶⁸ **We further recommend to the UK Departments of Health that there should be linkage with additional data collected to record later health outcomes, not only from childhood, but including adolescence through to adulthood. These data should be captured through NHS health records and educational records and will provide crucial information on health outcomes.** We note that training of healthcare professionals will be required to help ensure a consistent knowledge base for the identification and collection of the relevant data.
- 6.48 Recently, several initiatives to begin data collection have been established. We are encouraged by the establishment of a National Neonatal Audit Programme (NNAP) for England and similar plans for Wales, as well as the Maternity Services Dataset and other datasets collecting critical clinical data at birth and during the neonatal period. The NNAP will be administered by the RCPCH on behalf of the Healthcare Commission. A clinical dataset has been identified, based on a concise range of audit information around birth and aspects of neonatal care.⁶⁹ If further funding is secured for the programme, it is hoped that follow up of infants at two years of age will be conducted to compare outcomes in relation to specific interventions and the infant characteristics of children, between those who have experienced a period of care in a neonatal unit and other children.⁷⁰

⁶⁷ For example, babies who have acquired brain injury which could result in developmental problems.

⁶⁸ The new Maternity Services Dataset, the National Neonatal Audit Programme and the Neonatal Critical Care Minimum Dataset, and data collection being undertaken by neonatal networks/groups of networks, such as SEND (South East Neonatal Data) will all collect relevant information about what happens at birth and during the neonatal period.

⁶⁹ The initial aim of the NNAP programme is to identify areas for improvement in care in relation to delivery and outcomes and to provide a mechanism for ensuring consistency of care. For more information see: <http://www.ncap.org.uk/>, accessed on: 10 Aug 2006.

⁷⁰ Personal communication from the National Neonatal Audit Programme.

- 6.49 The current development of an electronic NHS database will make routine national data collection feasible, and the recent implementation of the NHS Numbers for Babies scheme⁷¹ will ensure that the electronic record includes health information from birth onwards.⁷² The real challenges will be to identify the essential data that should be recorded from the neonatal period and in the longer term. Examples of the early data that we regard as important to collect include gestational age at birth as well as birthweight, clinical status and details of neonatal care. Other valuable information which could be recorded includes the use of pre-conception fertility treatment, as this is associated with multiple births, and consequently with prematurity (see paragraph 3.4).⁷³ Data collected at a later stage will need to include indicators of health and educational progress. Moving to a system of routine, continuous data collection based on electronic NHS systems would allow a much more complete picture of practice in neonatal medicine to be obtained. We recognise that, by their nature, data on outcomes may only partly reflect current practice by the time they are analysed. Nevertheless, there is, in the view of the Working Party, an ethical imperative to analyse outcomes for neonatal care. **In summary, although the necessary electronic NHS systems are not yet in place, the view of the Working Party is that it is timely to identify the health-related questions that should be posed and the corresponding requirements for data collection.**
- 6.50 There is a further issue that needs to be taken into account when planning the routine collection of data for possible use in research studies. Interpretation of the Data Protection Act 1998 has limited the number of studies that are able to link NHS numbers to patient records in order to obtain particular health outcomes because the Act seeks to protect the identities of individuals. Normally, if information about patients is to be used for purposes beyond the delivery of personal treatment and care (as is the case when data are used for research), the consent of patients should be sought or the information should be anonymised. Although the intention has been to ensure that personal information is handled with appropriate care and respect, in practice the outcome has created a conservative culture of governance.⁷⁴ Proposals for such studies must be referred to the Department of Health Patient Information Advisory Group, a committee that decides on behalf of the Secretary of State whether monitoring may proceed without seeking consent⁷⁵ under Section 60 of the Health and Social Care Act 2001. Certain exceptional conditions must be satisfied to justify access. Broadly, a strong public interest must exist to justify access to patient-identifiable information where consent and anonymisation are impossible or inappropriate. **The view of the Working Party is that basic studies based on data linkage are required, to complement research studies aimed at determining more subtle aspects of outcome (paragraph 6.46). Such studies do not require contact with patients or their families. In view of the strong public interest in determining outcomes from critical care decisions, we recommend that that proposals for**

⁷¹ Under this scheme, which began in 2002, babies are now assigned a unique identifier, their NHS number, at birth, rather than after civil registration up to six weeks later. For further information, see <http://www.connectingforhealth.nhs.uk/nhsnumber/nn4b/>, accessed on: 3 Oct 2006.

⁷² In 2006 expectations were that the 'National Programme for IT' (electronic health records) would be phased in over the next ten years, see <http://www.connectingforhealth.nhs.uk/>, accessed on: 26 Sept 2006.

⁷³ A need to record outcomes following the use of fertility treatment has been recommended elsewhere to enable assessment of the impact on the health of children conceived using these techniques; Medical Research Council (2004) *Assisted Reproduction: A safe sound future* (London: MRC); Human Genetics Commission (2006) *Making Babies: Reproductive decisions and genetic technologies* (London: HGC). This would require the amendment of the Human Fertilisation and Embryology Act 1990, which is currently under review.

⁷⁴ The Academy of Medical Sciences (2006) *Personal Data for Public Good: Using health information in medical research* (London: Academy of Medical Sciences), available at: <http://www.acmedsci.ac.uk/images/publication/Personal.pdf>, accessed on: 6 June 2006.

⁷⁵ See <http://www.advisorybodies.doh.gov.uk/piag/>, accessed on: 26 May 2006.

studies based solely on data linkage should be referred to the Department of Health Patient Information Advisory Group to request access to the relevant patient information. It is crucial that decisions should be based on accurate and up-to-date evidence from research about the risks to and likely outcomes for babies in whom a birth abnormality or genetic disorder has been recognised antenatally or in the newborn period, as well as for extremely premature babies.

6.51 Finally, it is important not to overlook information of a different nature that may be of future help to parents and doctors. If a baby dies, information from an autopsy can be useful in confirming an original diagnosis, establishing a cause of death and providing further information about the presence of disease or abnormality. The Human Tissue Act 2004 regulates autopsies in England, Wales and Northern Ireland, other than those ordered by a coroner. An autopsy on a newborn baby can be conducted only with explicit consent from his or her parents, unless it has been ordered by a coroner. The Human Tissue (Scotland) Act applies in Scotland and similarly requires specific parental authorisation for autopsies. Autopsy data may also provide some insights into the cause of death and help parents in planning future pregnancies. Furthermore, if doctors can gain a better understanding of the causes underlying clinical conditions, other parents can be given more accurate information when making decisions, and research efforts can be directed towards obtaining more precise diagnoses. Recent studies suggest that autopsies provide valuable additional information in 25–30% of cases of neonatal death or termination for fetal abnormality.⁷⁶ We are aware that doctors can sometimes be reluctant to ask parents for consent to carry out an autopsy for a fetus or a child who has died, and that parents may also refuse their consent.^{77,78} Good communication is essential to help parents make a genuine choice about autopsy, and the subject must be introduced sensitively and appropriately. However, even though useful information can be gained from autopsy, rates have been declining since the mid-1990s.⁷⁹ Although this decline has been attributed to a general decline in trust in the patient–professional relationship in the wake of recent enquiries, it is also the case that many regions now lack specialist paediatric pathologists to perform autopsies. It is important to overcome this practical difficulty. The benefits of providing information for the future should not be underestimated and we encourage doctors and parents to continue to consider autopsy as an option.

⁷⁶ Boyd PA, Tondi F, Hicks NR and Chamberlain PF (2004) Autopsy after termination of pregnancy for fetal anomaly: retrospective cohort study *Br Med J* **328**: 137; Brodrie M, Laing IA, Keeling JW and McKenzie KJ (2002) Ten years of neonatal autopsies in tertiary referral centre: retrospective study *Br Med J* **324**: 761–3.

⁷⁷ There have been studies on parents' reasons for giving and refusing consent for autopsies, see for example McHaffie HE (2001) *Crucial Decisions at the Beginning of Life* (Abingdon: Radcliffe Medical Press). Common reasons given by parents include wanting to avoid further invasive procedures or because the parents themselves did not have any unanswered questions. In other cases, the information gained has been reported by parents as useful in helping to understand why their baby died, see Rankin J, Wright C and Lind T (2002) Cross sectional survey of parents' experience and views of the postmortem examination *Br Med J* **324**: 816–18.

⁷⁸ In 2003, autopsies were performed in 39% of cases of fetal or neonatal death between 20 weeks of gestation, and 28 days after birth. In 61% of cases an autopsy was not performed, because consent was not given by the parents; in 38% of cases an autopsy was not offered. Confidential Enquiry into Maternal and Child Health (2005) Stillbirth, Neonatal and Post-neonatal Mortality 2000–2003 – England, Wales and Northern Ireland (London: RCOG Press), available at: <http://www.cemach.org.uk/publications/CEMACHPerinatalMortalityReportApril2005.pdf>, accessed on: 31 May 2006.

⁷⁹ Confidential Enquiry into Maternal and Child Health (2005) Stillbirth, Neonatal and Post-neonatal Mortality 2000–2003 – England, Wales and Northern Ireland (London: RCOG Press), available at: <http://www.cemach.org.uk/publications/CEMACHPerinatalMortalityReportApril2005.pdf>, accessed on: 31 May 2006; Confidential Enquiry into Stillbirths and Deaths in Infancy (2001) 8th Annual Report (London: Maternal and Child Health Research Consortium), available at: <http://www.cemach.org.uk/publications/8threport/z-Complete%20file.pdf>, accessed on: 31 May 2006.

Chapter

Living with disability

7

Living with disability

Introduction

7.1 In the preceding chapters, we have described the different stages at which critical care decisions may have to be made for fetuses or the newborn. The emphasis and structure of this chapter are different. We aim simply to provide an overview of the complex practical issues that often need to be dealt with when a child with known or predicted disabilities is finally able to leave hospital, up to early adulthood, irrespective of the cause of the disability. Caring for a child with disabilities is likely to entail the need for support from a variety of sources, including healthcare, social services and educational systems. Many children will be cared for at home, which can place additional demands on their parents and family. Our descriptions are general and we have not distinguished between disability arising as a consequence of critical care decisions and from other causes, except where we refer to studies on extremely premature or low birthweight babies. As before, we use hypothetical examples¹ to illustrate issues which may arise. We go on to describe educational and social provision, to note some of the healthcare, educational and other costs involved and explain the legal background.

Perceptions of disability

7.2 Many children do not have health difficulties after starting life in a neonatal unit. Some may have minor problems which are readily overcome. However, parents and families may have to persevere and make adjustments when a child has more significant disabilities. All parents look forward to the achievement of developmental milestones but when babies have conditions that are likely to lead to disability, parents anticipate these stages more hesitantly, not knowing if their child will eventually attain the next developmental level.

7.3 After the critical care period, the healthcare professionals involved with a baby in the perinatal or neonatal period will provide advice to families before he or she leaves hospital if there is a prognosis of disability. However, they may have little first-hand experience of the lives of disabled children and adults on which to draw. This can lead to underestimation of the achievements and quality of life which many disabled people experience. In some cases, parents may be presented with overly negative images of the future lives of their children, which are not balanced by more positive information about the day-to-day lives of disabled people.²

7.4 Once discharged from the neonatal unit, parents may find the outside environment tough and unsupportive. If they encounter difficulties in trying to get extra support from local services to improve their child's physical or mental wellbeing or help to prevent further health problems, this is likely to add to their anxieties. Research has shown that accessing the relevant support or care can be very difficult, as a coordinated approach across services is not in place in the UK.³ Support may not be tailored to the needs of the child or the family, and information for parents on services is often inadequate.⁴ Parents express concerns about increased rationing of state provision and can fear that their children might be "squeezed

¹ These examples are representative of cases that occur in real life. We acknowledge that the choice of the issues that we discuss after each example may influence how the examples themselves are perceived by different readers, depending upon the reader's own worldview.

² Wyatt J (1998) *Matters of Life and Death: Today's healthcare dilemmas in the light of Christian faith* (Leicester: Inter-Varsity Press); Jane Campbell (2005) former Chair of Social Care Institute for Excellence (SCIE) and a Disability Rights Commissioner, contributing to the Disability Rights Commission's Disability Debate; see also Eiser C (1997) Children's quality of life measures *Arch Dis Child* **77**: 350–4.

³ Joseph Rowntree Foundation (1999) *Supporting Disabled Children and their Families*, available at: <http://www.jrf.org.uk/KNOWLEDGE/findings/foundations/N79.asp>, accessed on: 14 Aug 2006.

⁴ *Ibid.*

out of services because they are too expensive".⁵ It is testing for articulate, confident parents to seek out and find support and resources, and for other parents who are not confident in or used to dealing with the authorities this can be particularly challenging. Research suggests that parents from ethnic minorities with a disabled child may encounter barriers to obtaining access to support services and are particularly poorly served.⁶

Some examples

The developing child with problems from birth

7.5 In the previous chapter we considered the example of Danielle, who was diagnosed with severe spastic diplegia cerebral palsy (see Case 6). We now revisit Danielle's situation to examine her development as she gets older. We then consider the case of Gareth who was born at 28 weeks of gestation.

Case 9: Danielle – the developing child

Danielle

Danielle had severe spastic diplegia, a form of cerebral palsy affecting the legs.* She also developed a squint and was very short-sighted. Her IQ was within the normal range. From research, and contact with local parent support groups and professionals, her parents found out that treatments including leg braces, gait analysis, botulinum toxin injections, hyperbaric oxygen treatment, could help to manage Danielle's condition. Danielle was treated and advised by various specialists, including physical therapists, paediatricians, neurologists, neurosurgeons and orthopaedic surgeons.

Danielle learnt to walk, albeit with a crouched gait, but found it difficult and had a tendency to walk on her toes. This was partly corrected with gait analysis and surgery when she was five years old. Her sight problems were overcome with surgery and special glasses. Danielle attended mainstream schools with a specially trained personal assistant who gave her one-to-one support. She was able to continue at school until she was 16, when she attended her local further education college to study information technology (IT). She went on to do a degree in IT and business studies at her local university. Both the college and the university provided coordinators to support disabled students and made arrangements to accommodate her and adapt her equipment. She was able to access a range of special allowances, including the Disabled Students' Allowance and was given individual support for her personal care needs. If Danielle fulfils her ambition to work, she will be eligible for Department of Work and Pensions support (for example, Access to Work or Pathways to Work, which can fund personal assistance, travel, and any special equipment, including equipment for the employer).

* For further information see the website of Cerebral Palsy Source:
http://www.cerebralpalsysource.com/Types_of_CP/diplegia_cp/index.html, accessed on: 15 Aug 2006.

Case 10: Gareth – coping with disability as a child grows up

Gareth

Gareth was born prematurely at 28 weeks to parents in their early 40s with one older child and no other close relatives. Initially Gareth's parents were relieved to get him home, and were especially pleased when he no longer required extra oxygen to breathe properly. However, with time, Gareth developed physical disabilities that prevented him from moving unassisted and he also had profound multiple learning disabilities. Caring for him proved to be physically very demanding. The parents found they had less time for their daughter who began to have problems at school. They failed to get any assistance from the social services or their general practitioner with caring for him because resources were scarce in their area, so they both temporarily gave up work for this purpose. Eventually Gareth's father left the family and Gareth's mother, Helen, found it very difficult to manage her son's need for personal care on her own. However, she joined a local parent support group which gave her practical advice on local services. After resuming contact with her social worker, she obtained a 'children in need' assessment by the local authority's Children with Disabilities Team. The outcome of the assessment was that Helen was offered a direct payment to pay for some extra support and a place for Gareth on a local holiday scheme.

⁵ Personal communication to Council for Disabled Children (2005).

⁶ Joseph Rowntree Foundation (1999) *Minority Ethnic Families Caring for a Disabled Child*, available at: <http://www.jrf.org.uk/knowledge/findings/socialcare/539.asp>, accessed on: 14 Aug 2006. For a detailed account of life for a child with complex needs, see Department of Health (2005) *National Service Framework for Children, Young People and Maternity Services* (London: Department of Health), Complex Disability Exemplar, available at: <http://www.dh.gov.uk/assetRoot/04/12/38/15/04123815.pdf>, accessed on: 14 Aug 2006.

Helen also asked the Local Education Authority (LEA) for an assessment of Gareth's special educational needs (SEN). The LEA decided that Gareth should have a statutory assessment and then issued a Statement of Special Educational Needs. Initially he attended a mainstream nursery school, with additional support. He subsequently moved to a special school where he could also receive regular physiotherapy, and speech and language therapy on site. The school had a good reputation for working with children with profound and multiple learning disabilities. It was developing an 'extended school' programme and offering a range of after-school activities. Helen felt that the school would benefit Gareth and enable her to return to work part-time. Their lives fell into a stable pattern for several years and Gareth made good progress.

When Gareth reached adolescence his behaviour became problematic. He started to harm himself and show signs of autistic behaviour. Helen found this very hard to cope with and became severely clinically depressed. There was a risk of the family breaking down and Gareth being taken into care, so support by a clinical psychologist and a community nurse from the local Learning Disability Team was provided. With some difficulty, the local authority found a local family with expertise in managing challenging behaviour who were willing to act as a 'link family' for Gareth and provide regular short breaks in their family home. The local authority funded these short breaks and gave additional training to the link family. Gareth enjoyed his visits and Helen began to feel much better. When Gareth was 14, the LEA initiated his Transition Plan. It was agreed that Gareth would probably remain at school until he was 19. The planning process also involved Gareth's social worker, who liaised with the relevant managers in adult services to ensure continuity of social care and support. The social worker also contacted the local Learning and Skills Council with reference to possible courses and any necessary support when Gareth left school. The local Community Mental Health and Learning Disability Teams were also consulted about options for Gareth's support in adult life.

When the family offering short-break care said they could no longer cope with Gareth, Helen became depressed again and was no longer able to care for her son who was given an emergency placement. This was in a private residential home, 200 miles away from where Helen and her daughter lived. Gareth's local authority had some concerns about the quality of care being offered, but no better option could be found.

- 7.6 We have noted previously that disability is at least partly a socially conditioned state (see paragraph 3.29). Equal respect for people with and without disability (see paragraph 2.39), and the requirement of consistency (see paragraph 2.42) demand that social policy be organised in such a way that appropriate assistance is provided to disabled people and their families to lead life with dignity. In Danielle's case this demand seems satisfied, and support has been provided through a range of medical and behavioural interventions, and social security schemes. However, in Gareth's case, the fragility of appropriate care and support shows how regional differences can have an impact on provision of services.
- 7.7 Both Danielle's and Gareth's cases illustrate how the outcomes of some critical care decisions are not confined to the neonatal unit, but are experienced by those caring for disabled people throughout their lives. Moreover decision making during the neonatal period can lead to very different outcomes that can not always be accurately predicted. Gareth's case, in particular, highlights the important role that joint decision making plays at various stages after leaving the hospital, both for clear-cut major decisions concerning Gareth's adult life (involving the Children's Services Department of the local authority, the school and LEA, and the local Community and Mental Health Service) and for a great number of smaller day-to-day decisions. For example, his mother was able to discuss Gareth's needs with staff at the special school, the clinical psychologist, the community nurse from the local Learning Disability Team and a local family with expertise in managing challenging behaviour. Thus, just as joint decision-making processes are at the core of best practice in the clinical context, they are equally important once a baby has been discharged from hospital. Despite help, Gareth's mother experienced repeated episodes of severe depression, and Gareth was finally transferred to a remote care home. There can never be a guarantee of total success, but the provision of support can provide crucial help to people in extremely difficult situations.
- 7.8 Disabled children will usually express views on their own healthcare and education. It must not be assumed that simply because they are affected by some degree of physical or mental impairment, they are any less entitled to do so. Article 12 of the UNCRC requires that those views be given " . . . due weight in accordance with the age and maturity of the child". While many adults are uneasy about the right of a child to self-determination, others believe that this right is the 'key' to all other rights, and that even young children are capable of reasoning

and forming sensible opinions and therefore should be involved in decisions affecting them.⁷ In the UK, older children acquire a right to give consent to their medical treatment once a child is sufficiently mature and intelligent to understand what is proposed.⁸ At the age of 16, all young people gain a statutory right to give consent to treatment.⁹ Paradoxically, however, the English courts have held that no minor (anyone under the age of 18) can refuse treatment¹⁰ (see paragraph 8.22). We present some views from a child's perspective below.

7.9 Assumptions are sometimes made that life with mental or physical impairments must very hard to bear. Nevertheless, as we have noted (paragraph 5.37), many individuals born prematurely or at low birthweight who have disabilities, such as Danielle, rate their quality of life as good, with, typically, positive perceptions of their health and abilities, their self esteem, and their health-related quality of life.¹¹ However, disabled children who were born prematurely have been found to have lower than average scores for cognition and academic achievement and to be at risk of various behavioural and emotional problems, including attention deficit hyperactive disorder (ADHD).¹² It is likely that Danielle's relationships with other children would be adversely affected as a result of her disability, especially if her school was some distance away, making it difficult to spend time with her school friends. Additionally she might not have been able to access the same leisure and social facilities as other children,¹³ which could discourage her and her family. Finally, if other children reacted to her because of her disability by staring or making comments, Danielle may well have found this distressing.¹⁴

7.10 While research on the experiences of children like Danielle can help us gain a better understanding of how they might be affected by disability, it is very much more difficult to gain insights into the situation of children such as Gareth, who are more severely affected and less able to communicate. It is probably not possible to appreciate what they understand of their existence and how they value it. In Gareth's case, it is fair to assume, however, that he would have been unsettled and probably adversely affected by his eventual separation from his mother.

7.11 The example of Gareth illustrates how difficult it can be for parents to cope. Depending on their family circumstances, they may be able to turn to relatives for support, as well as the local community and services, or voluntary or parent support groups. Support may be practical,

⁷ Alderson P (2000) UN Convention on the Rights of the Child: Some common criticisms and suggested responses *Child Abuse Rev* **9**: 439–43; Alderson P (1993) European Charter of Children's Rights *Bull Med Ethics* **92**: 13–15.

⁸ Gillick v West Norfolk and Wisbech Area Health Authority [1984] QB 581, [1984] 1 All ER 365; on appeal [1986] AC 112, [1985] 1 All ER 830, CA; revsd [1986] AC 112, [1985] 3 All ER 402, HL.

⁹ Family Law Reform Act 1969 s. 8.

¹⁰ Brazier M (2003) *Medicine, Patients and the Law* (London: Penguin), pp 368–70; see *Re W (a minor) (medical treatment)* [1992] 4 All ER 627, CA.

¹¹ Watts JL and Saigal S (2006) Outcome of extreme prematurity: as information increases so do the dilemmas *Arch Dis Child Fetal Neonatal Ed* **91**: 221–5; Cooke RWI (2004) Health, lifestyle, and quality of life for young adults born very preterm *Arch Dis Child* **89**: 201–6; Dinesen S J and Greisen G (2001) Quality of life in young adults with very low birth weight *Arch Dis Child Fetal Neonatal Ed* **85**: F165–9; Saigal S, Stoskopf B, Streiner D *et al.* (2006) Transition of extremely low-birth-weight infants from adolescence to young adulthood: comparison with normal birthweight controls *J Am Med Assoc* **295**: 667–75.

¹² Watts JL and Saigal S (2006) Outcome of extreme prematurity: as information increases so do the dilemmas *Arch Dis Child Fetal Neonatal Ed* **91**: 221–5; Hack M, Flannery DJ, Schluchter M, Cartar L, Borawski E and Klein N (2002) Outcomes in young adulthood for very low birth weight infants *N Engl J Med* **346**: 149–57; Bhutta AT, Cleves MA, Casey PH, Craddock MM and Anand KJS (2002) Cognitive and behavioural outcomes of school-aged children who were born preterm *J Am Med Assoc* **288**: 728–37.

¹³ Watts JL and Saigal S (2006) Outcome of extreme prematurity: as information increases so do the dilemmas *Arch Dis Child Fetal Neonatal Ed* **91**: 221–5.

¹⁴ Scottish Executive (2002) *Children's Experiences of Disability: A positive outlook* (Edinburgh: Scottish Executive), available at: <http://www.scotland.gov.uk/Resource/Doc/46951/0013975.pdf>, accessed on 24 Aug 2006.

financial, faith-based, and entail respite, counselling, and peer support. However, soon after birth when parents are usually involved in decisions about the care of their baby, it is very unlikely that they will have much insight into the support that would be available to them or how they may be affected if they have a disabled child (see Boxes 7.1 and 7.2). It takes time to seek out and assimilate this information.

Box 7.1: Living with a disabled child

There are approximately 772,000 disabled children in the UK, 90% of whom live at home with their families. The average income for families with disabled children is 24% lower than the UK average; 22% have incomes that are less than half the UK average. Only 16% of mothers with disabled children are employed, compared with 61% of other mothers. Estimates indicate that it costs up to three times as much to bring up a disabled child compared with a child without disability. With lower incomes and higher outgoings, many families with disabled children are in debt, and 55% of disabled children grow up in or almost in poverty.* The National Service Framework expresses the Government's intention that: "Children and young people who are disabled or who have complex health needs [should] receive co-ordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, enable them and their families to live ordinary lives."[†]

A survey by Contact a Family in 2003 questioned over 2,000 parents with disabled children in the UK about how their situation had affected their relationship with their partner.[‡] In this survey, 31% of parents reported that caring for their disabled child had caused some problems in their relationship and a further 13% reported that this had caused major problems. Nine per cent were separated and felt that having a disabled child had led to the separation. However, 23% of those surveyed felt that caring for their child had brought them closer.

Parents with disabled children may also report health problems associated with their role as a carer. These may be physical problems, such as back and joint pain from lifting and handling a child, or problems with mental health. A study on health problems associated with caring carried out by the Department of Health found that 30% of those caring for a child had symptoms indicating a mental disorder.[§] In total, 76% felt that caring had affected their health in some way, 71% considered that their responsibilities caused them to worry, and 32% reported depression. Problems with mental health occurred more frequently when the person being cared for had both physical and mental impairments.

Living with a disabled child can affect other siblings as well as the parents. According to the 2001 Census, about 149,000 children and young people provide unpaid care in the UK, most of them probably for a member of their family, although the survey included care for others, such as neighbours or friends. Large-scale studies have not been undertaken in the UK, but evidence suggests that they could be at a higher risk of health problems, including back pain and mental health problems. Children may also experience bullying at school as a result of their family situation and their education and social lives may be affected. The role that these 'young carers' play has only recently been recognised by government.

In 1999, the Government published its first national strategy for carers, which highlighted the need to 'care about carers'.^{**} Since then, a number of measures for carers, including new legislation (the Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004), have been introduced. It is hoped that these national policies and other initiatives will help families to cope with the pressures that result from caring for a disabled child.

* Statistics from Contact a Family press releases, available at: <http://www.cafamily.org.uk/press.html>, accessed on: 15 Aug 2006.

† Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services*, Standard 8: Disabled children and Young People and those with Complex Health Needs.

‡ Contact a Family (2004) *No Time for Us: Relationships between parents who have a disabled child*. Summary available at: <http://www.cafamily.org.uk/relationshipsurvey.html>, accessed on: 28 Oct 2005.

§ Office for National Statistics (2002) *Mental Health of Carers* (London: The Stationery Office), available at: http://www.statistics.gov.uk/downloads/theme_health/Mental_Health_of_Carers_June02.pdf, accessed on: 28 Oct 2005.

** Department of Health (1999) *Caring about Carers: A national strategy for carers* (London: The Stationery Office), available at: <http://www.carers.gov.uk/supportingcarers.htm>, accessed on: 15 Aug 2006.

7.12 There is a substantial body of research¹⁵ on the quality of life experienced by families with young disabled children. The Council for Disabled Children has provided the Working Party with comments from some parents on their experiences (Box 7.2).

¹⁵ Dobson B, Middleton S and Beardsworth A (2001) *The Impact of Childhood Disability on Family Life* (York: YPS); Joseph Rowntree Foundation (1999) *Supporting Disabled Children and their Families*, available at: <http://www.jrf.org.uk/KNOWLEDGE/findings/foundations/N79.asp>, accessed on: 14 Aug 2006; Joseph Rowntree Foundation (1999) *Minority Ethnic Families Caring for a Disabled Child*, available at: <http://www.jrf.org.uk/knowledge/findings/socialcare/539.asp>, accessed on: 14 Aug 2006.

Box 7.2: Views from parents and families on diagnosis, making decisions and managing difficult or uncertain outcomes.*

Parents and families would welcome the following:

- Up-to-date, clearly written information, available from the initial diagnosis so parents can understand their child's situation, make informed choices and obtain appropriate support. Parents can live with uncertainty if it is accompanied by a willingness to find answers. Many parents fear abandonment by professionals if there is no obvious intervention or treatment for their child.
- Emotional and practical support which is non-judgemental and which may entail introductions to other families or a parent support group.
- Recognition that their child has value even if the prognosis is poor, and that disability is not necessarily an indicator for a low quality of life.
- Recognition of the family's existing lifestyle, commitments and ambitions.
- Recognition of the importance of social, cultural and religious factors.

* Personal communication from Dr Philippa Russell. The comments were made by a number of parents with disabled children and other family members who were members of a range of parent support groups or voluntary organisations, including member organisations of the Council for Disabled Children (CDC). These comments are intended to reflect the diversity of parents' experiences and concerns.

7.13 A practical issue for parents whose baby will develop disability after leaving hospital is how they will manage their child's needs for multiple forms of care. Of particular urgency is the need to secure practical care and family support. Availability varies across the country. It is likely to depend on local policies and procedures and, in particular, on local arrangements for joint funding and pooled budgets. These sources of support may fluctuate over time or may not be available in the long term. The support available can range from home-learning programmes, such as Portage,¹⁶ to short breaks, childcare, provision of equipment and information, and assistance with applying for relevant benefits or tax credits. However, the additional costs of disability (for example, travel to specialist paediatric units, adaptation of the home, extra heating, time out of employment) can cause poverty and financial insecurity for families who might otherwise cope (Box 7.1 and paragraph 7.23).¹⁷

7.14 The National Service Framework for Children has introduced standards identifying the services and support that children and their parents should receive. Standard 8 states a requirement for coordinated high quality child- and family-centred services.¹⁸ These standards represent in many ways an ideal and at present they are neither inspected nor enforced. In 2005, the independent post of Children's Commissioner, was created. The role of the Commissioner is to provide a focus for issues concerning all children and young people, especially the disadvantaged and the vulnerable.¹⁹

7.15 The responsibility for organising support for a disabled child and their family falls to the local authority's Children's Services Department (see Box 7.3). Respite care may take a variety of forms, where it is available. For example, a child may be cared for in his or her own home, offered respite care in another family's home, as in the example of Gareth, or cared for at a specialist centre. Sometimes, it may not be possible for a disabled child to live permanently at home with his or her family. In this situation, the child would be cared for in permanent

¹⁶ Portage is a home-visiting educational service for pre-school children with additional support needs and their families. See the website of the National Portage Association, available at: <http://www.portage.org.uk/>, accessed on: 15 Aug 2006.

¹⁷ Emerson E and Hatton C (2005) *The Socio-Economic Circumstances of Families supporting a Child at Risk of Disability in Britain in 2002* (University of Lancaster); Dobson B, Middleton S and Beardsworth A (2001) *The Impact of Childhood Disability on Family Life* (York: YPS).

¹⁸ Department of Health (2001) *National Service Framework for Children, Young People and Maternity Services* (London: The Stationery Office), available: <http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/ChildrenServicesInformation/fs/en>, accessed on: 21 Oct 2005.

¹⁹ See website of the Office of the Children's Commissioner, available at: <https://www.childrenscommissioner.org/>.

foster care, at a residential children's home or at a residential school, perhaps with some home visits. In England in 2004–5, 740 children were taken into local authority care because of needs arising from their disability.²⁰

Box 7.3: Responsibilities of the local authority's Children's Services Department

Healthcare is the responsibility of the NHS. Parents must approach different agencies for other needs. The responsibility for organising support for a disabled child and his or her family falls to the local authority's Children's Services Department. All disabled children are entitled to an assessment by the relevant Children's Services Department to determine their needs and to decide which services could be provided to ensure they are met.* Assessments should be reviewed regularly, particularly when a child's circumstances change.† The local authority has a duty to provide or arrange services once needs have been identified and services to meet them have been agreed to be necessary. However, it can enforce its own criteria for eligibility and take account of resource constraints when making allocations.‡ The parents or other carers of a disabled child are also entitled to an assessment (a carer's assessment) by social services, in which their wellbeing and commitments are considered, along with any services that could be provided to make it easier for them to care for a disabled child, such as respite care.

* Department of Health and Department for Education and Skills (2000), *Framework for the Assessment of Children in Need and their Families* (HMSO); Department for Education and Skills (2006) *Common Assessment Framework: Practitioners and Managers' Guides*, available on www.everychildmatters.gov.uk.

† Contact-a-family (2006) *A Guide to Assessment and Services in England and Wales* (London: Contact a Family), available at: <http://www.cafamily.org.uk/assess.pdf>, accessed on: 24 Aug 2006; Contact-a-family (2004) *A Guide to Assessment and Services in Scotland* (London: Contact a Family), available at: <http://www.cafamily.org.uk/AssessScot.pdf>, accessed on: 24 Aug 2006.

‡ *Ibid.*

Support services

- 7.16 Care in the family home may be provided on a variety of levels depending upon the needs of the child and the family. It is usually made available on a regular basis to help the family with day-to-day life. Carers can enable parents to spend time with their other children, or allow them to go out or to have a night of uninterrupted sleep. Alternatively they may assist with catering for disabled child's particular needs, for example by helping with physiotherapy or washing, dressing and moving.
- 7.17 Families may receive short break services, typically provided in specialist residential centres or by a link family or foster carer, to enable them to take a break from caring for their disabled child from time to time. A recent report by MENCAP about children with severe learning disabilities reported that short breaks are vital in enabling families to have a good standard of family life, but that six in ten families surveyed were not receiving short breaks that met their needs.²¹ The provision of specialist centres varies across the country, and includes children's homes, children's hospices and short break centres. There are approximately 40 children's hospices and two babies' hospices in the UK, each of which provides specialist respite, emergency, palliative and end-of-life care for children with life-limiting conditions.²² There is currently under-provision of these hospice services in the UK,²³ although new Government

²⁰ Department for Education and Skills (2006) *Statistics of Education: Children looked after by local authorities, year ending 31 March 2005, Volume 1: National tables* (Norwich: HMSO), available at: <http://www.dfes.gov.uk/rsgateway/DB/VOL/v000646/vweb01-2006.pdf>, accessed on: 27 June 2006.

²¹ MENCAP (2006) *Breaking Point – Families still need a break* (London: MENCAP). Anecdotal evidence suggests that individuals with high levels of need often receive low levels of support, perhaps because finding and providing appropriate support is more difficult when a child has multiple or complex needs (personal communication, MENCAP).

²² Association of Children's Hospices (2004) *Children's Hospice Services: A guide for professionals* (Bristol: Association of Children's Hospices).

²³ According to the Association of Children's Hospices there are between 15,000 and 20,000 children aged 0–19 living in the UK with life-limiting and life-threatening conditions, of whom about 4,000 a year typically use hospice services. There are many reasons why the remainder do not use services, but there are concerns over the lack of provision and funding, see Association of Children's Hospices Factsheet, available at: <http://www.childhospice.org.uk/sections/media/documents/ACHFactSheetNov2005.pdf>, accessed on: 4 Aug 2006; Joy I (2005) *Valuing Short Lives: Children with terminal conditions* (London: New Philanthropy Capital). The two dedicated hospices for babies, based in Liverpool and Middlesbrough, are typically involved in the care of approximately 60 babies each year, most of whom live in the vicinity, although in some cases babies travel a considerable distance to use the services (personal communication, Zoe's Place Baby Hospices). The demand seen by these hospices suggests that greater provision of this type of specialist service in other areas of the country would benefit many families.

funding of £27 million for children's hospices, along with a review of the long-term sustainability and funding of children's palliative care, may go some way to address this.²⁴ Planned short breaks and placements with link families are organised by both local authorities²⁵ and charitable groups.²⁶ This type of care is thought to be beneficial in providing children with a stable family environment and for helping their families to cope and to stay together.²⁷ A recent survey of services providing foster or shared care for over 9,000 disabled children in the UK found that there were many more who could benefit, including at least 3,000 children waiting for a suitable carer to be found.²⁸ The survey highlighted problems with recruiting carers and shortages of resources and staff to support these services.

Education provision

7.18 Disabled young people are twice as likely not to be in education, employment or training aged 16 as non-disabled young people of the same age. Twenty per cent of disabled young people aged between 16 and 24 have no qualifications, compared with 9% of non-disabled people of the same age.²⁹ Children and young people with disabilities or special educational needs (SEN) have the same entitlements to education as their non-disabled peers. The Special Educational Needs and Disability Act 2001 gives parents the right to express preferences about the education of their children with disabilities or SEN and strengthens their rights to request mainstream education. It also amends the Disability Discrimination Act (DDA) 1995 to place disability discrimination duties on schools and associated education services.³⁰ The SEN Code of Practice explains the statutory framework for provision, with *Removing Barriers to Achievement* setting out the Government's strategy for children with SEN and disabilities.³¹ The strategy focuses on four key areas, namely early intervention, removing barriers to learning, raising expectations and achievement and working in partnership. The Early Support Programme is the national Government mechanism for achieving better, well coordinated services with a family focus for very young disabled children and their families across England. It has been widely endorsed by parents and professionals and will be brought into mainstream use during 2006/2007.³²

7.19 Disabled pupils may be educated in special or mainstream schools (some of which have specially resourced provision for children with SEN or disabilities). Some disabled pupils may attend independent or 'non-maintained special schools' (the majority of which offer residential provision, usually for older children with a specific impairment or SEN). Young children can attend children's centres, nursery classes and schools and take part in a range of pre-school activities. In response to legislation on disability discrimination, a growing number of schools provide after-school (extended school) and other after-hours facilities both to assist

²⁴ Department of Health (May 2006) *Press release: Government announces funding boost for children's hospices*, available at: http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4135439&chk=0ApNil, accessed on: 7 Sept 2006.

²⁵ Examples include Kent (<http://www.kent.gov.uk/NR/rdonlyres/E8F3AB27-062D-412B-9A8F-FCB85C450CEC/605/childrendisleaflet.pdf>, accessed on: 27 June 2006) and Edinburgh (<http://www.edinburgh.gov.uk/Fostering/CO/RespiteFosterCare/RespiteFosterCare.html>, accessed on: 27 June 2006).

²⁶ Examples include NCH, The Children's Charity, see: <http://www.nch.org.uk/getinvolved/index.php?i=111#28>, accessed on: 27 June 2006.

²⁷ Shared Care Network (2006) *Still Waiting? Families of disabled children in the UK waiting for short break services* (available at: http://sharedcarenetwork.org.uk/scn/files/Still_Waiting_-_Full_Report.pdf, accessed on: 27 June 2006).

²⁸ *Ibid.*

²⁹ Labour Force Survey 2004.

³⁰ Disability Rights Commission (2003), Code of Practice for Schools (Part 4 of the DDA 1995), available from www.drc-gb.org.

³¹ DfES (2001) *SEN Code of Practice* (DfES Publications); DfES (2005) *Removing Barriers to Achievement: The Government's Strategy for SEN* (DfES Publications).

³² Early Support Programme materials are available at www.earlysupport.org.uk.

working parents and to offer additional leisure, sporting, cultural and study opportunities to pupils. Disabled children and young people up to the age of 18 will have new rights to child-care and extended schools services under the Childcare Act 2006.

7.20 In January 2006, there were just over 1.5 million children in English schools with special educational needs, ranging from those with relatively minor impairments to those with severe and profound disabilities (19% of all enrolled school pupils).³³ Almost 90,000 children were enrolled at special schools. Regional variations are currently seen in the patterns of mainstream inclusion; in 2004, for example, pupils with statements of SEN in South Tyneside, the most segregated area in England, were 24 times more likely to receive a segregated education than those in Newham, London, the least segregated area.³⁴ Statistics from 2002 for 15-year-olds in England show that young people attending a special school were over ten times more likely not to have any GCSEs than those attending mainstream schools. There is debate about the wide local variations in policies on inclusion, and on the range and quality of provision available to disabled children and in the range of support services available to schools (in particular for disabled children with low incidence disabilities or SEN).³⁵

The costs of disability

7.21 The examples of Danielle and Gareth show plainly that caring for a child with disability can be very resource-intensive, not least for the child's family. As we have said, childhood disability can arise for many reasons, but a number of studies have specifically examined the consequences of prematurity and low birthweight. Premature birth increases costs for the health services, special education and social services, and the families and carers of the children. The problems arising from prematurity can be lifelong and place complex demands in an educational or work setting.³⁶ Several studies have considered the economic implications for healthcare services and educational assistance which are required to meet the needs of caring for a disabled child.³⁷ We have explained that premature or low birthweight babies are more likely to be re-hospitalised than babies born at full term or at normal birthweight, and healthcare costs in the first year are significantly higher for premature babies (see paragraphs 5.45–5.46). During childhood, premature and low birthweight children make more use of hospital and family practitioner services.

7.22 Disability in children born prematurely or at low birthweight can have other long-term consequences that require evaluation from an economic perspective. Although placing children with physical impairments or learning disabilities in institutions is practised in many countries, the costs of doing so have not been widely reported. Economic studies of premature birth

³³ Department for Education and Skills (2006) *Special Educational Needs in England – January 2006* (London: Department for Education and Skills), available at: <http://www.dfes.gov.uk/rsgateway/DB/SFR/s000661/SFR23-2006v2.pdf>, accessed on: 24 Aug 2006.

³⁴ Centre for Studies on Inclusive Education (2005). *Evidence to the Education and Skills Committee Inquiry into Special Educational Needs*, available at: <http://inclusion.uwe.ac.uk/csie/edskillscom%20sen%20inqry%20sept%2005.pdf>, accessed on: 21 Oct 2005.

³⁵ House of Commons Education and Skills Committee (July 2006) *Report on Special Educational Needs*, Third Report of Session 2005–2006.

³⁶ Hack M, Youngstrom EA, Cartar L *et al.* (2004) Behavioral outcomes and evidence of psychopathology among very low birth weight infants at age 20 years *Pediatrics* **114**: 932–40; Skuse D (1998) Survival after being born too soon, but at what cost? *Lancet* **354**: 354–5.

³⁷ Walker DB, Feldman A, Vohr BR, *et al.* (1984) Cost-benefit analysis of neonatal intensive care for infants weighing less than 1000 grams at birth *Pediatrics* **74**: 20–4; Walker DB, Vohr BR and Oh W (1985) Economic analysis of regionalized neonatal care for very low-birth-weight infants in the state of Rhode Island *Pediatrics* **76**: 69–74; Pharoah PO, Stevenson RC, Cooke RW *et al.* (1988) Costs and benefits of neonatal intensive care *Arch Dis Child* **63**: 715–18; Chaikind S and Corman H (1991) The impact of low birth weight on special education costs *J Health Econ* **10**: 291–311; Stevenson RC, Pharoah PO, Cooke RW *et al.* (1991) Predicting costs and outcomes of neonatal intensive care for very low birthweight infants *Public Health* **105**: 121–6; Javitt J, Dei Cas R, Chiang YP (1993) Cost-effectiveness of screening and cryotherapy for threshold retinopathy of prematurity *Pediatrics* **91**: 859–66; Lewit EM, Baker LS, Corman H *et al.* (1995) The direct cost of low birth weight *The Future of Children* **5**: 35–56; Stevenson RC, Pharoah PO, Stevenson CJ *et al.* (1996) Cost of care for a geographically determined population of low birth weight infants to age 8–9 years II Children with disability *Arch Dis Child Fetal Neonatal Ed* **74**: F118–21.

and low birthweight have tended to overlook the costs, for example of day-care services and respite care, as well as those borne by local authorities, voluntary organisations and by families as a result of modifications to their everyday activities.³⁸ In addition to the costs of travel, childcare and accommodation, potential costs faced by families and informal carers include additional expenditure on health goods, including alternative therapies, and non-health goods, such as food, laundry, clothing, heating utilities and repairs to the home. A study on spending by parents with disabled and non-disabled children showed that parents of disabled children spent on average £66 per week excluding food, which is almost twice as much as parents of non-disabled children.³⁹

7.23 If the local authority does not provide what is required in terms of adaptations to homes and respite care, parents will often take out loans to meet these costs (see Box 7.1).⁴⁰ Parents caring for a child with severe disabilities are less likely to be able to sustain employment, especially when there are other children to be cared for, leading to a loss of earnings. Many mothers who intended to return to work after a birth either postpone doing so, reduce their hours or leave the workforce altogether to care for their child, resulting in a reduction in family income of perhaps 20–32%.⁴¹ A recent study found that families with disabled children were four times more likely to owe over £10,000 (excluding any mortgage) than families without disabled children.⁴² The paucity of routinely collected epidemiological data makes it difficult to follow up children to provide estimates for long-term costs of premature birth and low birthweight. However, as the survival profile for premature and low birthweight children improves and further information on developmental outcomes during adolescence and adulthood becomes available, opportunities for research into economic factors should increase.

Disability legislation

Legal rights of disabled children

7.24 Over the past 30 years the law has taken an increasingly rights-based perspective on children, as exemplified in the United Nations Convention on the Rights of the Child (UNCRC) and the Children Act 1989 (see paragraphs 3.44 and 8.2). Article 23 of the UNCRC, which is legally binding in the UK although not directly enforceable in UK courts, is devoted to the rights of disabled children and is widely summarised as ‘the right of the handicapped child to special care, education and training designed to help them achieve greatest possible self-reliance and lead a full and active life in society’. The Children Act 1989 states that “Every local authority shall provide services designed (a) to minimise the effect on disabled children within their area of their disabilities; and (b) to give such children the opportunity to lead lives which are as normal as possible.”⁴³ In addition, the Disability Discrimination Act 1995 makes it unlawful to discriminate against a disabled person in access to and provision of services by treating him or her less favourably than other people without a disability.

³⁸ McCormick MC, Bernbaum JC, Eisenberg JM *et al.* (1991) Costs incurred by parents of very low birth weight infants after the initial neonatal hospitalization *Pediatrics* **88**: 533–41; Petrou S, Henderson J, Bracewell M, Hockley C, Wolke D and Marlow N, for the EPICure Study Group (2006) Pushing the boundaries of viability: The economic impact of extreme preterm birth *Early Hum Dev* **82**: 77–84.

³⁹ Dobson B, Middleton S and Beardsworth A (2001) *The Impact of Childhood Disability on Family Life* (York: YPS).

⁴⁰ Personal communication, Dr Janice McLaughlin, Policy, Ethics and Life Sciences Research Centre (PEALS), Newcastle.

⁴¹ Two studies have suggested decreases of 20–32% in total family income. See Ladden M (1990) The impact of premature birth on the family and society: transition to home Part 2. *Pediatr Nurs* **16**: 620–2, 626; Gennaro S (1996) Leave and employment in families of preterm low birthweight infants *Image J Nurs Sch* **28**: 193–8.

⁴² Harrison J and Woolley M (2004) *Debt and Disability: The impact of debt on families with disabled children* (York: Contact a Family & Family Fund).

⁴³ The wording of the Children (Scotland) Act 1995 is very similar.

7.25 However, critics argue that for children in general, despite the development of a rights-based approach and a small number of new initiatives aimed at children and their families, the UK Government is not showing a “general commitment to promoting the rights of all children”.⁴⁴ The situation for disabled children is believed to be particularly poor. Research has shown examples of various service providers, including education and social services, failing to fulfil their duties towards disabled children, suggesting that such children remain “invisible under law”.⁴⁵ This perhaps indicates that the legislation that is now in place needs to be applied more widely and consistently if children are to benefit from their newly recognised rights. Parents consulted by the Council for Disabled Children thought that recourse to the courts could be the right action when there was a lack of agreement about what was best for a child in terms of extra help from health, educational or social services.⁴⁶ One mother commented,

“if we talk about children’s rights, we sometimes have to go to Court in order to protect them. But going to lawyers doesn’t always get the best solution – they often don’t understand disability either. It becomes adversarial and people forget about the child at the centre of the battle. What matters is to get really good advice right from the start. Why not mediation? We parents often have to go to Court just to get someone to listen to us seriously – what a waste!”

However, most of the parents and families thought that with the right support and respect they could resolve any difficulties or disagreements regarding their child’s care.

Disability Discrimination Act

7.26 We noted in Chapter 3 that the Disability Discrimination Act 1995 protects disabled people (children and adults) from discrimination in access to goods and services, employment, property and estates and education (paragraph 3.30). It is amended by the DDA 2005 which further clarifies what constitutes disability.⁴⁷ Most importantly, the DDA (2005) introduces a new Disability Equality Duty (DED) for the public sector. Consequently, from December 2006, all public bodies will have a duty to promote disability equality for disabled people. Public bodies including local authorities, government departments, schools, universities and hospitals will be affected. This is a positive duty which marks a shift from a legal framework that relies on individual disabled people challenging discrimination to one in which the public sector as a whole becomes a proactive agent of change.

7.27 It is important to recognise that despite the progress made in treating babies who are premature or who have a serious condition at birth, a proportion of the survivors will have disabilities and for some of these individuals those disabilities will be severe. We take the view that the recent legislative changes will improve the chances for children such as Danielle to have a fulfilling life in the community and to prevent the deterioration of cases such as that of Gareth. **The most difficult situations that are likely to remain unaddressed are those of school leavers with complex disabilities (physical or learning) and health problems, as these disabilities have a far more severe adverse effect on life chances.** Young people affected in this way have no prospect of employment and their parents often have to cease employment work because of the lack of support. These parents can

⁴⁴ Fortin J (2003) *Children’s Rights and the Developing Law* (London: LexisNexis).

⁴⁵ Corker M and Davis JM (2000) Disabled children: (Still) invisible under law, in *Law, Rights and Disability*, Cooper J (Editor) (London: Jessica Kingsley Publishers).

⁴⁶ Personal communication to Council for Disabled Children (2005). We note that mediation processes, which we discuss in the context of resolving disagreements over critical care decision making (Chapter 8), may be of benefit here too.

⁴⁷ As we say in the Glossary, many definitions of disability exist. In this Report, we use the definition provided in the Disability Discrimination Act 1995.

become so concerned for their child's future that they come to hope that their child will die before them.⁴⁸ In the view of the Working Party, this state of affairs is unacceptable. In Chapter 2 we reached the conclusion that the State should be expected to bear some of the additional costs of supporting families in their care of children with disabilities, as it would be unreasonable to expect families to bear these costs alone. We argued on grounds of consistency that the State should not think it permissible to enable many of the babies who are the subject of this Report to survive, but be excused the discharge of its resultant obligation to support their care.

⁴⁸ Personal communication from Dr Philippa Russell.

Chapter

8

Decision making:
regulation and
resolution

Decision making: regulation and resolution

- 8.1 This chapter examines the legal framework in the UK within which critical care decisions are made for fetuses and the newborn.¹ It considers two major questions. The first is whether the constraints on decision making imposed by UK law and professional guidance are appropriate, sufficiently clear and well understood. The second is whether, when disputes do occur, there could be better means of resolving those disputes. We begin by highlighting the concept of children's rights before turning to a discussion of regulation in fetal and neonatal medicine. We analyse the legal issues arising during critical care decision making at the borderline of viability and for babies remaining in intensive care. After this, we review the current law in relation to the active ending of life, and withholding or withdrawing treatment. We conclude the chapter by raising the possibility of different mechanisms that could help improve understanding and trust between the parties involved and avoid disagreements reaching the courts.
- 8.2 For over 30 years, there has been extensive theoretical and policy-related debate about the concept of children's rights, to which, in the context of fetal and neonatal medicine, it may appear that little attention has been paid.² The law, challenged by a potential conflict between the claims of the pregnant woman and the fetus, has, so far, declined to accord rights to the fetus. Once born, the newborn baby enjoys the same human rights as any other person. We have said earlier (see paragraph 3.44), that rights are accorded to children in the United Nations Convention on the Rights of the Child (UNCRC) and protected by UK law, albeit rarely articulated. The child's "inherent right to life" (Article 6) is protected, and in determining questions about what constitutes appropriate care, the baby's best interests are the "primary consideration" (Article 3) of UK courts. The questions addressed in this chapter do not concern *whether* newborn babies have legal rights, there is no doubt that they do. The difficulty is interpreting and applying those rights when, as often happens, rights conflict. So, for example, a baby born extremely prematurely, with severe abnormalities, could perhaps be kept alive for a few days if subjected to multiple invasive procedures. The baby's 'right to life' might be said to be respected but such a decision may not be in his or her best interests. We now turn our attention to regulation in fetal medicine.

Regulation and fetal medicine

- 8.3 The fetus has no independent legal status.³ Although sometimes doctors will advise pregnant women about their conduct in pregnancy, for example, recommending that they should give up smoking or drinking, the law in the UK is clear. As we have said (paragraph 2.20), a pregnant woman cannot be compelled to submit to such advice⁴ and invasion of the woman's bodily

¹ Within the United Kingdom there are in fact *three* legal systems: (1) England and Wales; (2) Scotland; and (3) Northern Ireland. This means that both statutory law and the principles of law developed by judges with these three different jurisdictions may differ. For example, the Abortion Act 1967 does not apply in Northern Ireland. The devolved Scottish Parliament in Edinburgh has broad powers to legislate independently on the matters addressed in this Report. At the time of writing, there are few substantial differences in the law relevant to this Report within the UK; see generally Mason JK and GT Laurie (2006) *Mason and McCall Smith's Law and Medical Ethics* (7th Edition) (Oxford University Press).

² See Fortin J (2003) *Children's Rights and the Developing Law*, 2nd Edition (London: LexisNexis) pp1–68; and see paragraph 2.3 of this Report.

³ See (*inter alia*) *Paton v BPAS* [1978] 2 All ER 987. *Re MB (adult: medical treatment)* [1997] 8 Med L R 217. *In Re F (in utero)* [1988] 2 All 193, CA; *Kelly v Kelly* 1997 SC 285 (Scotland).

⁴ *Re MB (adult: medical treatment)* (above); *St George's Hwhealthcare NHS Trust v S* [1998] 3 All ER 673, CA.

integrity without her consent constitutes an assault. In all but one exceptional circumstance,⁵ the mother is granted immunity from any civil liability for prenatal injury inflicted on her child by her conduct; this means that a child cannot sue his or her mother for compensation if her conduct while pregnant causes him or her harm.⁶ There remains a slight possibility that a mother whose grossly negligent or criminal prenatal conduct results in the death of her child after birth, might face criminal sanctions.⁷ The European Court of Human Rights has not entirely dispensed with the possibility of granting some level of legal status to a viable fetus.⁸ Additionally, judges have suggested that Parliament might wish to address the question of granting some greater degree of protection to the fetus in the final trimester of pregnancy.⁹

- 8.4 The law in the UK effectively allows a pregnant woman to be the ultimate decision-maker in relation to any intervention to treat the fetus in the womb, or to deliver the baby early, or by surgery. Nothing can be done to her without her consent. Any change in the law would impose new constraints on the woman's decision-making capacity. There is no evidence that any but a tiny minority of women make decisions about the care and treatment of the fetus during pregnancy other than in what they perceive to be the best interests of the child to be. Often decisions are made that will come at some cost to the woman herself. The English courts have so far ruled that pregnancy does not abrogate the fundamental principle that *"... every person's body is inviolate"*.^{10,11} Judicial support for maternal autonomy does not depend on any overt statement about the moral status of the fetus. It derives rather from a judgement that the unique context of pregnancy should not justify coercive action against pregnant women. The argument is made that the harms ensuing from such action may well outweigh any benefits.¹² **The Working Party takes the view that, although a pregnant woman who has chosen to continue a pregnancy has strong ethical obligations with regard to the health of the future child (see paragraph 2.20), to introduce laws taking away or limiting the pregnant woman's bodily integrity or liberty would be unjustifiable and impracticable. Parliament should not accede to suggestions to grant legal status to the fetus.**
- 8.5 One caveat must be noted. The right of a pregnant woman to make her own decisions depends upon her retaining the mental capacity to consent to, or refuse, treatment. The courts have suggested that in the context of pregnancy and labour, women may sometimes be affected by 'temporary incapacity'.¹³ This notion has led to fears that judges might be tempted to manipulate the threshold of mental incapacity to protect fetal welfare by indirect

⁵ This exception is where the pregnant woman is driving a vehicle on the public road; see s. 2 of the Congenital Disabilities (Civil Liability) Act 1976. On the 1976 Act generally see Brazier M (2003) *Medicine, Patients and the Law*, 3rd Edition (London: Penguin), pp 373–86.

⁶ See s. 1(1) of the Congenital Disabilities (Civil) Liability Act 1976. See also Scott R (2005) The Uncertain Scope of Reproductive Autonomy in Preimplantation Genetic Diagnosis and Selective Abortion (2005) 13 *Medical Law Review* 291.

⁷ See *Attorney General's Reference (No. 3 of 1974)* [1997] 3 All E.R. 936, H.L.; discussed in Brazier M (1997) Parental responsibilities, foetal welfare and children's health in *Family Law: Towards the Millennium*, Bridge C (Editor) (Butterworths).

⁸ In the case of *Vo v France*, the European Court of Human Rights refused to accord independent legal status to the fetus on the facts of that case. The Court, however, did not rule out completely the possibility that in some other circumstances a viable fetus might have some claim to legal status. *Vo v France* (2005) 10 EHRR 71.

⁹ *Re F (in utero)* [1988] 2 All ER 193, CA.

¹⁰ *Collins v Wilcock* [1984] 3 All ER 374.

¹¹ Judge L.J. put it in this way in *St George's Healthcare NHS Trust v S* "... while the pregnancy increases the personal responsibilities of a woman, it does not diminish her entitlement to decide whether or not to undergo medical treatment". [1998] 3 All ER 673 at 692.

¹² *Re F (in utero)* [1988] 2 All ER 193, C.A.; see also Bewley S (2002) Restricting the freedom of pregnant women, in *Ethical Issues in Maternal-Fetal Medicine*, Dickenson D (Editor) (Cambridge: Cambridge University Press).

¹³ *Re MB (adult: medical treatment)* [1997] 8 Med. L.R. 217, CA; see also Mental Capacity Act 2005 and Adults with Incapacity (Scotland) Act 2000.

means. Certainly, judges have exhibited some reluctance to stand by and let both woman and child die when there is doubt about the woman's mental capacity or stability.¹⁴

- 8.6 The choice for a pregnant woman is constrained by the rules in the Abortion Act 1967 (which does not apply in Northern Ireland) (see paragraph 4.13). We address here only late termination of pregnancy where doctors have diagnosed an abnormality in the fetus. It is lawful to terminate the pregnancy after 24 weeks if two doctors certify that “. . . *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 law permits termination on this ground up to the very end of pregnancy. What is meant by ‘substantial risk’ and ‘serious handicap’ is unclear and has led to controversy over how serious a disability must be to permit late termination of pregnancy.¹⁵
- 8.7 The Working Party is aware that there are calls to reduce the time limit for lawful termination of pregnancy for what are often called ‘social abortions’ below the current 24 week limit, primarily in response to the increased survival of premature babies below this gestation since the beginning of the 1980s.¹⁶ **Provided termination on grounds of fetal abnormality after any reduced time limit would still be permitted, the kinds of decision making that we examine in this Report would not be affected.** Therefore we do not take a position on this issue.
- 8.8 In the UK, when a pregnancy is terminated after 21 weeks, six days of gestation, the usual practice is to perform feticide to ensure that the fetus is not born alive.^{17,18} However, a minority of women will decline it while still electing for a termination (see paragraphs 4.14–4.16 and 4.30–4.34). The practice of feticide is recommended by professional guidance¹⁹ but has been little debated outside the medical community. The Working Party was advised that healthcare professionals in fetal medicine required a greater understanding of the legal position governing termination of pregnancy after 22 weeks without feticide. The concern appears to be over cases where doctors would recommend feticide but the woman declines.²⁰ The Working Party is aware that some doctors may be unclear about what they are required to do by law, should a woman decline feticide and her baby survives the termination procedure. This may be causing unnecessary concern and lead doctors to practise late termination of pregnancy only when preceded by feticide. However, the law does not require that every baby born alive be resuscitated and admitted to intensive care (see paragraphs 4.16 and 8.14). Rather, what is done must

¹⁴ See, for example, *Bolton Hospitals NHS Trust v O* [2003] 1 FLR 824.

¹⁵ In particular, when the Reverend Joanna Jepson sought to challenge a decision by the police who did not pursue an investigation when informed that doctors had authorised an abortion of a fetus with a cleft palate after 24 weeks; see *Jepson v Chief Constable of West Mercia Constabulary* [2003] EWHC 3318. Discussed in Scott R (2005) The uncertain scope of reproductive autonomy in preimplantation genetic diagnosis and selective abortion *Med Law Rev* 13: 291–327. See also Wicks E, Wylides M and Kilby M (2004) Late termination of pregnancy for fetal abnormality: Medical and legal perspectives *Med Law Rev* 12: 285–305.

¹⁶ British Medical Association (2005) *A Briefing Paper from the BMA: Part 4 – some current proposals for law reform*, available at: <http://www.bma.org.uk/ap.nsf/Content/AbortionTimeLimits~Proposals>, accessed on: 1 Sep 2006.

¹⁷ Royal College of Obstetricians and Gynaecologists (2001) *Further Issues Relating to Late Abortion, Fetal Viability and Registration of Births and Deaths*, available at: <http://www.rcog.org.uk/index.asp?PageID=549>, accessed on: 8 Aug 2006. The legal opinion has been expressed that unless a doctor ensures that a fetus is born dead after a termination there is the possibility that his conduct could be considered to amount to the offence of murder in a court of law. Kennedy I and Grubb A (2000) *Medical Law* (London, Edinburgh and Dublin: Butterworths), pp1491–2; Wicks E, Wylides M and Kilby M (2004) Late Termination of Pregnancy for Fetal Abnormality: Medical and Legal Perspectives 12 *Medical Law Review* 285–305.

¹⁸ Another motivation is to protect the fetus from the possibility of experiencing pain during the termination. See Royal College of Obstetricians and Gynaecologists (1998) *Late Termination of Pregnancy for Fetal Abnormality: Report of the RCOG Ethics Committee* (London: RCOG). In the earlier Royal College of Obstetricians and Gynaecologists (1997) *Fetal Awareness: Report of a working party* (London: RCOG Press), fetal sedation was recommended for late terminations of pregnancy.

¹⁹ Royal College of Obstetricians and Gynaecologists (2001) *Further Issues Relating to Late Abortion, Fetal Viability and Registration of Births and Deaths*, available at: <http://www.rcog.org.uk/index.asp?PageID=549>, accessed on: 8 Aug 2006.

²⁰ We are aware that doctors might not always advise it, for example, when a baby will be anencephalic and, without ventilation, will not live for more than a few hours.

be appropriate to a baby's condition. In law, there is no requirement to ventilate a dying baby or admit him or her to intensive care. Therefore in appropriate cases, the woman's choice may safely be, and should be, respected. **Given the lack of clarity relating to feticide we recommend that a code of practice should be developed as part of professional guidelines to achieve clarity about what the law does and does not require doctors to do. A code would reassure doctors should a woman choose not to consent to feticide. A code would also help to ensure that pregnant women are given sufficient information about outcomes, which in some rare cases could include the possibility of a baby being born alive following termination on grounds of fetal abnormality and a discussion about what might happen subsequently. Such information is essential for the woman to make a fully informed choice.**

Regulation and neonatal medicine

- 8.9 Various Acts of Parliament are relevant to decision making in the care of newborn babies. Legal judgements regarding providing, withholding or withdrawing treatment from children once born must take account of the Children Act 1989 and the Human Rights Act 1998. However, many of the relevant legal principles are to be found in case law where there has been a conflict between professionals caring for a baby, and the parents. The majority of cases conclude with the judge endorsing the 'expert' opinion of the doctors.²¹ Exceptionally, in *An NHS Trust v B*,²² where the parents had strong objections, the judge refused to authorise doctors to withdraw life support from a baby, named 'MB'.
- 8.10 The Children Act 1989 emphasises the best interests of the child, stating that, when a court is asked to make any decisions regarding the upbringing of a child, "the child's welfare shall be the court's paramount consideration". Under the Act, parents have 'parental responsibility', defined as "all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child . . .". In theory the consent of one parent alone may authorise treatment. In practice, professionals would be reluctant to take decisions about giving life-sustaining treatment to a newborn baby when there is parental disagreement. A dispute between parents may have to be resolved in the courts (see below). If parents and the medical team agree on a course of action that would be in the best interests of a baby, the case is unlikely to be reviewed by any independent third party.
- 8.11 The Human Rights Act 1998 gives effect in the UK to the European Convention on Human Rights (see paragraph 3.44). The Convention (Article 2) states that the right to life is protected by law. Article 3 provides that no one shall be subjected to inhuman or degrading treatment. Although English law has always emphasised the principle of reverence for human life and prohibits measures designed to hasten death, parents and professionals are not always under an obligation to prolong an infant's life. For example, in 1990 the Court of Appeal refuted arguments from the lawyers representing a severely ill infant that life should be prolonged wherever possible unless a child was terminally ill. It was decided that there could be no such absolute rule.²³ Nor does the Act impose any such requirement. In *A National Health Service Trust v D*,²⁴ it was held that there was no breach of Article 2 in a decision not to resuscitate a baby with irreversible lung disease and multiple organ failure if that decision was taken in the baby's best interests. Article 3 required that the hospital should do what it could to allow baby D to die with dignity and not impose futile and burdensome measures to prolong his life.

²¹ An analysis of the changing perceptions of the role of expert witnesses may be found in Blom-Cooper L (Editor) (2006) *Experts in the Civil Courts* (Oxford: OUP).

²² [2006] EWHC 507.

²³ *Re J (A Minor) (wardship and treatment)* [1990] 3 All ER 930.

²⁴ [2000] 2 FLR 677.

8.12 Article 8 of the Human Rights Convention endorses a right to respect for private and family life. In *Glass v United Kingdom* the European Court of Human Rights ruled that treating a child without either the consent of the parents or the authorisation of a court violated the child's right to respect for privacy, essentially their bodily integrity. The Court endorsed a strong presumption in favour of the parents' claim to a voice in their children's care. The current legal position is clear. Only in a genuine emergency should doctors override parental wishes without a court order and where agreement is not reached, doctors cannot unilaterally override decisions of parents. There must be a hearing in court or before some independent tribunal for the final arbitration of otherwise irresolvable disputes.²⁵

The legal implications of birth

8.13 We have concluded that birth both is, and should be, the crucial threshold to legal status and the point at which a duty of care owed directly to a child arises (Chapter 2). Once born, a baby acquires the same legal status as any other human being. Killing or injuring a newborn baby is just as much murder or assault as killing or injuring his or her mother. A fetus that can lawfully be killed in the womb (by feticide)²⁶ is fully protected by the law once born. However, neither case law nor statute currently provides a sufficiently accurate and certain definition of 'born alive' appropriate for use in the light of modern medicine and technology.

8.14 There have been suggestions that where a baby is born with extremely severe abnormalities, there may be some exception to the usual rule. In the case concerning the conjoined twins born in Manchester in 2000, it was suggested that the weaker twin (Mary) should simply be viewed as non-human, a parasitic tumour on her sister.²⁷ This contention was robustly rejected by the Court of Appeal.²⁸ We agree. **We believe that any attempt to address the difficult questions about the appropriate care of even a most severely disabled newborn baby should reject any proposal that a baby, however profound his or her disability or bodily deformity, should be classified as non-human.**

8.15 So at what point is a baby 'born alive'?²⁹ Current legislation defines a stillbirth (i.e. born dead) as an infant wholly expelled from its mother that does not breathe or show any other sign of life.³⁰ Neither test helps much in our context. A fetus born at 19 weeks may have a detectable heartbeat but will not be able to survive. Under the existing definition a heart beat is a sign of life. Should this baby be registered as a live birth? A baby of 28 weeks of gestation who is capable of survival with intensive care, may not be able to breathe independently at birth. On the other hand, a baby whose condition is incompatible with more than a brief period of life after birth may draw a few gasping breaths. Case law on what was meant by 'capable of being born alive' in the Infant Life (Preservation Act) 1929 was contradictory. The Court of

²⁵ Additionally, as we have said (paragraph 8.2), rights are accorded to children in the UNCRC and protected by UK law. However, the UNCRC has no direct effect in UK law; instead lawyers might use it to reinforce an argument to advance the baby's rights. So far the UNCRC has not played a major role in cases concerning critical care decision making and newborn babies. See Fortin J (2003) *Children's Rights and the Developing Law*, 2nd Edition (London: LexisNexis), 307–41. Further information and more detail on the legal principles applied by the English courts to critical care decision making in fetuses and the newborn may be found in two recent books: Mason JK and Laurie GT (2005) *Mason and McCall Smith's Law and Medical Ethics*, 7th Edition (Oxford: Oxford University Press); Brazier M (2003) *Medicine, Patients and the Law*, 3rd Edition (London: Penguin).

²⁶ Though where injuries are unlawfully inflicted on a fetus who nonetheless is later born alive and subsequently dies, the person responsible for those injuries can be prosecuted for murder or manslaughter. See *Attorney General's Reference (No. 3 of 1994)* [1996] 2 All ER 10. But note, an obstetrician who lawfully attempts to terminate a pregnancy, but nonetheless the child is born alive to die of injuries consequent on the failed abortion, is not at risk.

²⁷ See Mason JK (2001) Conjoined Twins: A Diagnostic Conundrum *Edin L R* 5 226.

²⁸ *Re A (children) (conjoined twins: surgical separation)* [2001] Fam. 147.

²⁹ Mason JK and Laurie GT (2005) *Law and Medical Ethics* (7th Edition) (Butterworths), pp157–161. For older case-law see *R v Poulton* (1832) 5 C & P 329; *R v Handley* (1874) 13 Cox CC 79.

³⁰ See Births and Deaths Registration Act 1953 s. 41 and the Still-Birth Definition Act 1992 s. 1. The fetus must have reached 24 weeks gestation (classified as a miscarriage before this stage in the pregnancy).

Appeal adopted a negative definition. A fetus was not capable of being born alive if incapable of breathing naturally or without the aid of a ventilator.³¹ Another judge ruled that a baby, to be capable of being born alive, must be sufficiently developed to breathe unaided.³² The law remains outdated and not well suited to meet the questions posed by modern technology.³³ **We therefore recommend that the RCOG and RCPCH, together with BAPM and the Royal College of Midwives (RCM), should consult widely and develop a definition of 'born alive' which encompasses the capacity of a baby to breathe either independently, or with the support of a ventilator. Consideration should be given to incorporating such a definition in statute.**

8.16 We recognise that a definition of 'born alive' would need to be broad. It would encompass babies born with the most severe abnormalities, fetuses born alive after failed terminations and babies born at a stage of gestation when survival for any prolonged period of time is virtually impossible. Being 'born alive', however, does not of itself impose a legal duty on doctors or parents to take active measures to prolong a baby's existence, or (as will often be the case) ventilate a baby who cannot breathe naturally. The duty owed to the baby in UK law is to provide care appropriate to his or her best interests, a position that we endorse from an ethical perspective (see paragraph 2.21). Withholding or withdrawing treatments that will not promote a baby's interests is not illegal even if those treatments could prolong survival.

The duty to treat a newborn baby

8.17 Doctors may fear that their carefully considered and difficult decisions to withhold treatment, not to resuscitate a baby and institute intensive care may retrospectively be considered illegal and result in prosecution for manslaughter, or even murder. They may also worry that there may be repercussions from their actions from various sources, including parents, society, the media and pro-life organisations. Such fears could lead to unnecessary and burdensome measures being imposed on a baby or to a lack of candour with parents on the part of doctors making difficult decisions about how to care for very ill babies. Criminal law does impose constraints on what decisions may be made about extremely premature and severely disabled babies, even when doctors and parents are in complete agreement about what constitutes a baby's best interests. In our view, doctors following professional guidelines and acting in good faith, nonetheless have little to fear, as the following paragraphs indicate.

8.18 The primary constraint on what doctors and parents may decide is that any act deliberately designed to hasten the death of a baby is prohibited. Doctors who administered a lethal injection with the sole purpose of killing a baby would be guilty of murder regardless of any compassionate motive, or the full support of the baby's parents. However, as with any other patient, the law does allow doctors to provide adequate forms and dosages of pain relief even though an incidental effect of that pain relief may be to shorten a baby's life.³⁴

8.19 While the law distinguishes between acts and omissions, omitting to provide life-sustaining treatment is in some circumstances also a crime. Where the law imposes a duty to provide such care, withholding or withdrawing that treatment intending that a baby should die is as much murder as administering a lethal injection.³⁵ The crucial question, which we explore in this chapter, is therefore what kind of treatment are the doctors under a legal duty to provide to a very ill newborn baby.³⁶

³¹ *C v S* [1987] 1 All ER 1230.

³² *Rance v Mid-Downs Health Authority* [1991] 1 All ER 801.

³³ See Mason JK and Laurie GT *op cit* at p157.

³⁴ *R v Adams* [1957] Crim L.R. 365.

³⁵ For example, a father and his partner who deliberately failed to feed one of his children were convicted of her murder *R v Gibbons and Proctor* [1918] 13 Crim. App. Rep. 134.

³⁶ See Brazier M *op cit* at 340–55.

8.20 Many of the cases that come to court do so because doctors and parents cannot agree about what is in a baby's best interests. For now, we are concerned only with the legal boundaries which limit what doctors and parents can agree to.³⁷ The courts have made it clear that where there is doubt about a baby's future prognosis, there is a strong presumption in favour of treatment prolonging a baby's life. Twenty-five years ago the Court of Appeal said that the crucial question was:

*Whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die.*³⁸

In a similar vein, in *An NHS Trust v B* (2006), the judge said:³⁹

Considerable weight . . . must be attached to the prolongation of life because the individual human instinct and desire to survive is strong and must be presumed to be strong in the patient. But it is not absolute, nor necessarily decisive, and may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering or other burdens of living are sufficiently great.

In case after case, the courts have indicated that in defining the boundaries of permissible decisions to withhold treatment, a balancing exercise must be performed. The value to a child of continued survival must be balanced against both the burdens survival itself will bring, and the burdens of the means needed to promote survival. In determining whether or not to admit or retain a baby in intensive care, or to intubate a baby should breathing stop, or perform a tracheotomy to ease ventilation, due weight is given to the suffering caused. As Lord Donaldson (then President of the Court of Appeal) put it:

*. . . there will be cases in which . . . it is not in the interests of the child to subject it to treatment which will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive.*⁴⁰

8.21 When parents and doctors agree, we have seen that there is no legal obligation to institute life-saving treatment when, after assessing the benefits and burdens to the child, it is decided that the burdens outweigh the benefits. Moreover, the law also permits withdrawal of treatment if, after a period of time, it is judged that continuing that treatment confers no net benefit to the baby. Removing a baby from a ventilator and intensive care has been held not to constitute an act (or acts) hastening death.⁴¹ The legal reasoning is complex. Put simply, ventilating and subjecting a baby to the whole panoply of intensive care, is legally justifiable only if the bodily invasions, and the effects, are positively justified by the prospective benefits of what is being done. If not, the invasive procedures required by intensive care constitute assaults on the baby.

8.22 The principles governing decisions about the appropriate care of an extremely premature or very ill newborn baby are broadly similar to those applying to questions of instituting or withdrawing life support from any patient. A baby's case is distinguished from that of an older child,⁴² or an adult, by his or her inability to speak for him- or herself. So as with any

³⁷ For an analysis of the law relating to selective non-treatment of the newborn, see Mason JK and Laurie GT *op cit* at 543–9.

³⁸ *Re B (A Minor) (Wardship: Medical Treatment)* [1981] 1 WLR 1421, CA.

³⁹ See *An NHS Trust v B* [2006] EWHC 507 (Fam).

⁴⁰ *Re J (a Minor) (wardship and medical treatment)* [1990] 3 All ER 930 at 000.

⁴¹ *An NHS Trust v B* [2006] EWHC 507 and see *Airedale NHS Trust v Bland* [1993] 1 All ER 821, H.L.; discussed in Brazier M *op cit* at 443–5.

⁴² Once an older child is sufficiently mature and intelligent to understand what the treatment proposed for him or her will entail, he or she has a right to consent on his or her own behalf; see *Gillick v West Norfolk and Wisbech Health Authority* [1985] 3 All ER 402 HL; the Family Law Reform Act 1969 s. 8 grants a statutory right of consent to minors over the age of 16. However, the courts have held that no minor has a right to refuse treatment; see *Re W (a minor) (medical treatment)* [1992] 4 All ER 627, CA. Unsurprisingly, the courts show extreme reluctance to sanctioning any decision allowing a minor to die; see *Re E (a minor)* [1992] 9 BMLR 1.

other young child, the law grants power to consent on a baby's behalf to those persons who have parental responsibility.⁴³ The power, however, is limited to the power to make decisions in the best interests of a baby. In *Re J (A Minor)* the judge said:

*... it is settled law that the court's prime and paramount consideration must be the best interests of the child. This is easily said but not so easily applied. What it does involve is that the views of parents, although they should be heeded and weighed, cannot prevail over the court's view ... of best interests.*⁴⁴

Borderline of viability

8.23 Parental rights to make decisions about what treatment their child should receive, derive from the responsibilities that they owe those children. The law reflects the ethical position that parents in no sense 'own' their children and hence their decision-making powers are limited. Whatever language is used to define those limits, be it that of judges (the best interests of the child), Article 3 of the UNCRC, or the Children Act (determining the paramount consideration), applying those limits to extremely premature babies born at the borderline of viability is exceptionally difficult. Ascertaining the best interests of any particular baby depends to a large extent on an assessment of the balance of benefits and burdens generally applicable to babies of that gestational age. Drawing on evidence available from studies such as EPICure, doctors are able to advise parents of the likelihood that a baby born at 22, 23 or 24 weeks would survive, and the statistical chances that, if he or she does survive, some degree of disability will be present. However, for these stages of extreme prematurity, an assessment of a baby at delivery provides only limited help in predicting the likely outcome.

8.24 Some respondents to our consultation expressed support for guidelines on resuscitation modelled on those now operative in the Netherlands (see Box 8.1), though still more took an opposing view. Implementation of guidelines such as these in the UK would mean that babies born before a certain stage of the pregnancy would not normally be resuscitated. Respondents in favour of guidelines pointed out that they would help "to reassure parents that there was no 'postcode lottery' whereby the active resuscitation of their baby partly depended on the specific medical and nursing culture current in a particular unit." (RCOG). Those against preferred "An individual assessment . . . taking account of all relevant factors, including the views of the parents" (BMA). Guidelines, in our view, cannot dictate the proper course of action without reference to the parents' views and an assessment of each individual case. The evidence suggests that for babies born between 22 and 24 weeks of gestation there is a broad spectrum of outcomes to be expected in terms of their prospects. An absolute bar on resuscitation before, for example, 24 weeks fails to take sufficient account of the interests of a particular baby. We doubt that an inflexible rule to this effect would be lawful without new primary legislation. English law requires that the interests of the individual baby be considered and the views of parents be given due weight. Human rights law reinforces the parental claim to speak on their child's behalf.⁴⁵

⁴³ Where the child's parents are married or (if unmarried) jointly register the child's birth, they share parental responsibility for their child. In other circumstances the mother alone enjoys parental responsibility for her child unless the father enters into a formal agreement with her to share parental responsibility with her or obtains a court order to that effect; see the Children Act 1989 as amended by the Adoption and Children Act 2002. Where a child is taken into care, the local authority will share responsibility for him or her with the parents; see J Fortin (2003) *Children's Rights and the Developing Law*, 2nd Edition (London: LexisNexis), pp 485–518.

⁴⁴ *Re J (A Minor) (wardship and medical treatment)* [1990] 3 All ER 930 at 943 per Taylor LJ.

⁴⁵ *Glass v United Kingdom* (above).

Box 8.1: Dutch guidelines on resuscitation of newborn premature babies

The Nederlandse Reanimatieraad (Dutch Resuscitation Council), an advisory and educational forum comprising all the organisations involved in resuscitation, issued guidelines on resuscitation of newborn babies in March 2006,* based on those of the European Resuscitation Council.† The guidelines advise that resuscitation should not usually be undertaken for babies who are born before 25 weeks of gestation or below 500 g in weight. An experienced member of the resuscitation team should decide whether resuscitation should be stopped.

It was reported to us at a fact-finding meeting that doctors are able to exercise some flexibility when deciding whether or not to resuscitate for babies born during the period 24 weeks, 0 days and 24 weeks, six days of gestation, dependent on the vitality of the baby. For babies born between 25 and 26 weeks of gestation, treatment should only commence with the consent of the parents. We were also told that a consensus had been reached that if a baby is born before 24 weeks of gestation, then palliative care only would usually be given in the delivery room. For babies born at 24 weeks of gestation, palliative care would normally be given, unless active treatment seems more justified. For births at 25 weeks, active treatment is recommended unless palliative care seems more appropriate. Babies born at 26 weeks of gestation and over are actively treated, unless the health of the baby means that it is not believed to be justified.

* Nederlandse Reanimatieraad (2006) Reanimatie van pasgeboren baby's (in Dutch), available at: <http://www.reanimatieraad.nl/docs/Reanimatievanpasgeborenbaby%27s.pdf>, accessed on: 16 Aug 2006.

† Biarent D, Bingham R, Richmond S *et al.* (2005) European Resuscitation Council Guidelines for Resuscitation 2005, Section 6 – Paediatric life support *Resuscitation* **67**:51, 597–133, available at: http://www.erc.edu/download_gl.php?d=7, accessed on: 4 Sep 2006. The ERC Guidelines are not legally binding in the UK.

- 8.25 The evidence of poor outcomes for babies born before 24 weeks is highly relevant to the assessment of a baby's interests, and should properly be a factor in decision making. We have noted that accurate comprehensible information therefore needs to be provided (where possible) for a baby's parents (paragraph 5.39). Parents should be given all the information that a sensible, reasonable parent would need about the potential risks and benefits for their baby were intensive care to be instituted. They would then be in a position to make an informed choice.⁴⁶ Should a decision not to institute intensive care be agreed, information about palliative care to allow their baby to die with dignity should also be offered (paragraphs 6.18–6.22).
- 8.26 Cases relating to resuscitation at the borderline of viability rarely (if at all) reach the courts. The decision whether or not to initiate life-sustaining treatment must be taken swiftly. When a woman goes into extremely premature labour unexpectedly there may not be an opportunity to discuss with either parent whether or not to resuscitate a baby on delivery. In these circumstances, junior staff may prefer to initiate resuscitation to allow time for a more measured prognosis of the baby's condition and prospects.

Critical care decisions for babies in intensive care

- 8.27 As with decisions made for babies at the borderline of viability, the law requires decisions about subsequent surgery or treatment or withdrawal of existing treatment to be taken in the best interests of that baby. We reiterate that the law makes no distinction between decisions to withhold treatment (for example, not to ventilate or re-ventilate a baby) and decisions to withdraw treatment (for example, switch off a ventilator).⁴⁷ The RCPCH guidelines are clear on this point and state that "Withdrawal of life sustaining treatment in appropriate circumstances is not seen by the courts as active killing, nor as a breach of the right to life under Article 2 of the European Convention on Human Rights".⁴⁸

⁴⁶ *Pearce v United Bristol Healthcare NHS Trust* (1999) 48 BMLR 118 CA.

⁴⁷ In *An NHS Trust v B* the judge said "... there is no legal distinction between withholding and withdrawing life support and ... the best interests test applies equally to both situations". [2006] EWHC 507 at para 20. See also *Airedale NHS Trust v Bland* [1993] 1 All ER 821 at 875 per Lord Lowry.

⁴⁸ Royal College of Paediatricians and Child Health (2004) *Withholding or Withdrawing Life Sustaining Treatment in Children* 2nd Edition (London: RCPCH). Guidelines expressly endorsed in *An NHS Trust v B* [2006] EWHC 507 at para 23.

8.28 Nonetheless some clinicians express concerns that they could be vulnerable to prosecution and that this could influence their decisions about switching off a ventilator or removing a baby from intensive care (see paragraph 8.17).⁴⁹ Taking responsibility for such decisions was described to the Working Party as putting a doctor in “an unfriendly and lonely place”.⁵⁰

When parents do not accept the advice of the healthcare professionals

8.29 The most difficult cases as far as legal principles are concerned are those where parents and professionals cannot resolve a disagreement about what is best for a baby through local discussion, and one of the parties takes the case to court. This can arise either when a parent does not give consent to a treatment that health professionals believe to be in the child’s best interests, or conversely when a parent demands a treatment for their child that health professionals consider not in the child’s best interests.⁵¹ The case law suggests that two basic presumptions influence the judiciary: a strong presumption in favour of prolonging life and a weaker presumption that the views of the parents on a child’s best interests should be valued highly. Both presumptions can be rebutted and can sometimes be contradictory.

Parental refusals of treatment

8.30 Parents may refuse treatment which professionals believe to be in the interests of the baby on a number of grounds. We do not address the exceptionally rare case where parents simply abandon their disabled baby or seek to let him or her die to relieve themselves of a burden. Religious objection to particular forms of healthcare is one ground for refusal which has led to several applications to the courts. Parental refusal of life-saving treatment based *solely* on religious grounds will almost certainly be overruled. A series of cases relate to parents who are Jehovah’s Witnesses refusing consent to blood transfusions. In the cases before the court, transfusion was a part of optimal treatment (usually as an adjunct to chemotherapy) where the prospects of successful treatment were reduced without a transfusion. So far, no English judge has done other than order the transfusion against the expressed wishes of the parents. In each case, however genuine the parents’ concern for the religious interests of the child and the avoidance of an ‘ungodly act’, the physical survival and health of the child took precedence.⁵² Although recent judgements, notably *An NHS Trust v B*, demonstrated a more empathetic approach to religious faith, in a pragmatic judicial world, the balancing exercise (see paragraph 8.18) is likely to favour continued survival where a baby has a prospect of complete recovery and any objection to treatment is exclusively grounded in religion, or other personal spiritual beliefs.

8.31 The case law suggests that whatever the grounds for parental objection to proposed treatment designed to prolong a baby’s life, the courts will usually support professional judgement unless the prospects of success are low and the quality of life for the child is likely to be unbearable. In authorising surgery for an intestinal obstruction on a Down’s syndrome baby against parental wishes, the Court of Appeal⁵³ asked whether the life of the child after surgery “is demonstrably going to be so awful that in effect [she] must be condemned to die”. A judge in the Court of Appeal spoke of cases⁵⁴ “. . . of severe proved damage where the

⁴⁹ McHaffie H and Fowlie PW (1996) *Life, Death and Decisions: Doctors and nurses reflect on neonatal practice* (Hale: Hochland and Hochland).

⁵⁰ Personal communication, Professor Andrew Whitelaw, Southmead Hospital, Bristol.

⁵¹ See, for example, *Re Wyatt* [2004] EWHC 2247; [2005] EWHC 117; [2005] EWHC 693; [2005] EWHC 1181; [2005] EWHC 2902; *Re Winston Jones (A child) (medical treatment: parent’s consent)* [2004] All ER (D) 313. See also *Re C (a minor) (medical treatment)* (1997) 40 BMLR 31.

⁵² See Bridge C (1999) Religion, culture and conviction – the medical treatment of young children 11 *Child and Family Law Quarterly* 1.

⁵³ *Re B (a minor)* (1981) 1 WLR 1421, 1425.

⁵⁴ *Ibid* at 1424.

future is certain and the life of the child is . . . bound to be full of pain and suffering". However, in one significant and controversial case, *Re T*, the Court of Appeal declined to endorse the professional judgement of the best interests of a young child and accepted the mother's decision to refuse a liver transplant for her baby.⁵⁵ The medical evidence was unequivocal that the transplant was likely to be successful. In her judgement, Dame Elizabeth Butler-Sloss gave priority to a presumption of respect for parental wishes over the presumption in favour of survival. She spoke of the parent-child relationship as follows:⁵⁶

The mother and this child are one for the purposes of this unusual case and the decision of the court for consent to the operation jointly affects the mother and son and it also affects the father. The welfare of this child depends on his mother.

She concluded by saying:

I believe that the best interests of this child require that his future treatment should be left in the hands of his devoted parents.

We discuss later whether Dame Elizabeth Butler-Sloss's view should be given greater consideration.⁵⁷

Parental demands for treatment

8.32 The Working Party endorses the emphasis placed by the RCPCH and BAPM on the importance of having a 'partnership' in relation to the care of any child (paragraph 2.48).⁵⁸ The College stresses the importance of doing all that is possible to achieve consensus between parents and professionals. When parents ask for continued treatment (or particular kinds of treatment) that professionals believe not to be in the interests of the child, the College is clear that:

There is no obligation to give treatment that is futile and burdensome *indeed this could be regarded as an assault on the child*⁵⁹ (our emphasis).

8.33 However, parents asking for treatment considered futile or burdensome by professionals are not motivated by any desire to impose suffering on their baby. Rather, they want to ensure that their child receives the care that they judge best. The extent to which the law will support parental judgement is complicated by another controversial question. To what extent will the courts require doctors to provide treatment that professional opinion regards as inappropriate? As we have said, the Court of Appeal in *R (Burke) v GMC*⁶⁰ has ruled that there is no obligation to provide treatment on demand. Complicating the issue still further are implications for resources. Parents told that their baby will not continue to be offered intensive neonatal care, or will not be re-ventilated, may rightly or wrongly fear that the decision

⁵⁵ *Re T (a minor) (wardship: medical treatment)* [1997] 1 All ER 906. See Mason JK and Laurie GT *op cit* at 569–71.

⁵⁶ *Re T (a minor) (wardship: medical treatment)* [1997] 1 All ER 906 at 914–5.

⁵⁷ It should be noted that *Re T* has several unusual features including that the parents themselves were health professionals and had fled to New Zealand to avoid being forced to subject their son to a transplant. The judgement of Roch LJ suggests that this was for him the crucial factor in the 'balancing exercise'. In *Re T* although the parents agreed about refusing a transplant for their son, as they were not married, the mother alone had formal responsibility for decisions relating to the boy. The facts in *Re T* suggest that, even according greater weight to the parental views, the decision may have been wrong (see Mason and Laurie). Our concern is exclusively with the question of principle in terms of the relationship of parent and child.

⁵⁸ 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, at 2.3.1.1.

⁵⁹ Royal College of Paediatrics and Child Health (2004) *Withholding or Withdrawing Life Sustaining Treatment in Children: A framework for practice*, 2nd Edition (London: RCPCH), at 2.3.1.2, available at: http://www.rcpch.ac.uk/publications/recent_publications/Withholding.pdf, accessed on: 23 Nov 2005.

⁶⁰ [2005] EWCA 1003.

is driven in part not by their child's interests, but by a 'rationing' exercise. In one case⁶¹ the Court of Appeal overtly acknowledged the importance of resource constraints although subsequent cases of this type have been less direct.

- 8.34 In the majority of cases where parents seek treatment that doctors perceived as futile and burdensome, the courts ultimately endorsed the professionals' judgement. So in *Re C (a minor) (medical treatment)*,⁶² devout Orthodox Jewish parents opposed doctors' wishes to remove their 16-month-old daughter from ventilation support and not to resuscitate her if she then stopped breathing. The baby suffered from spinal muscular atrophy for which there is no cure, and in the view of the doctors was in the process of dying. The court authorised the action supported by the doctors. In another case, Baby D had irreversible lung disease and multi-organ failure. Doctors sought an order that they need not re-ventilate him if he stopped breathing. The judge⁶³ sympathised with his parents but said that their views "... cannot of themselves override the court's view of the [baby's] best interests". The baby's interests were to die with some dignity. In *Re Wyatt*,⁶⁴ refusing to accept the parents' request for an order that doctors must re-ventilate Charlotte Wyatt, the judge declined to replace the test of the baby's best interests with a test of 'intolerability'. Regard should be had for the parents' 'intuitive feelings' but these might well 'be projected' onto the baby. In the light of the medical evidence, the baby's interests were to be kept comfortable and should she stop breathing be allowed a "... peaceful death". In all these cases, judges, once they accepted medical evidence that there was little prospect that a baby's condition would improve and that proposed intervention would be burdensome to the baby, gave priority to a peaceful death for him or her. The parents' strong desire to do all that can be done to prolong life in the hope of obtaining a better outcome than predicted, or even for a miracle, has been subordinated to the need to avoid suffering for a baby where there is no or little chance of recovery.
- 8.35 In *An NHS Trust v B*,⁶⁵ however, the judge refused to authorise doctors to withdraw life support from a baby, MB, against the strongly voiced objections of his parents. MB was 18 months old at the time of the court proceedings. He had the most severe form of spinal muscular atrophy and breathed only with the aid of a ventilator. The doctors involved in the case viewed his death as inevitable, although they and the expert witnesses had different views on when that might be. His parents refused to consent to switching off the ventilator except as a test to see if he could breathe independently. They also wanted MB to have a tracheotomy to allow him to be ventilated outside the hospital. The doctors wanted to withdraw the endotracheal tube and, with the aid of pain-relieving medicines, allow MB a pain-free, dignified death. The medical evidence unanimously supported this course of action as did the guardian appointed by the court to represent the baby. His parents gave evidence that MB responded to them, that he enjoyed stories, songs and his favourite TV programmes. The father was a Muslim who believed the decision about when or if his baby died must be left to God. The judge refused the parents' request for an order for further invasive treatment to prolong MB's life. He also refused the doctors' request to withdraw ventilation. He attempted a balancing exercise in which the crucial feature was that MB retained some significant cognitive

⁶¹ *Re J (a minor) (wardship: medical treatment)* [1992] 4 All ER 614. At 625, Balcombe LJ said: "An order which may have the effect of compelling a doctor or health authority to make available scarce resources and to a particular child might require the health authority to put J on a ventilator in an intensive care unit, and thereby possibly deny the benefit of those limited resources to a child who was much more likely than J to benefit from them." See generally Mason JK and Laurie GT *op cit* 571–574.

⁶² (1997) 40 BMLR 1.

⁶³ *A National Health Service Trust v D* [2000] 2 FLR 677.

⁶⁴ [2004] EWHC 2247 (See also Footnote 51); discussed in Brazier M (2005) An intractable dispute: when parents and professionals disagree 13 *Medical Law Review* 412. See also *Re Winston-Jones (a child) (medical treatment: parent's consent)* [2004] All ER (D) 313.

⁶⁵ [2006] EWHC 507.

function. He was (or might be) still able to function at some level like any other infant in recognising his mother and taking simple pleasures from touch, light and sound. The suffering he might endure as a consequence of the invasive treatments keeping him alive was in the judge's view balanced by these benefits.

- 8.36 The judgement in *An NHS Trust v B* poses difficult questions if MB's cognitive function was the critical factor tipping the balance in favour of continuing to ventilate him. They include:
- MB's parents sought to keep him alive. What would be the outcome in a case where a baby has a medical condition identical to that of MB but the parents want him to be allowed to die? Would the balancing exercise be tipped the other way?
 - If MB does have sufficient cognitive function to distinguish him from earlier cases where ventilation was withdrawn, is his suffering possibly even greater?
 - What weight do we put on cognitive function? Does mental disability make a life less worth living than grave physical abnormalities?
 - Why was this case decided differently from Baby C? (See paragraph 8.35.)
 - We said earlier that judges have stated that there is no material distinction between withholding or withdrawing treatment. *An NHS Trust v B* might suggest a higher threshold is required to switch off a ventilator than to decide not to re-ventilate a baby.
- 8.37 A final matter to note is that expert medical evidence, crucial in any kind of case involving a child's care, must be shown to be 'logical and defensible'.^{66,67} It is often interpreted as evidence of fact, even though experts rarely state their opinion as certainty.⁶⁸

Reviewing current law

- 8.38 Three important questions may be asked about the current limits imposed on decision making about the care of babies who are extremely premature or who are at a high risk of developing severe disabilities. (a) Should legislation be enacted to permit doctors, in the most exceptional circumstances, actively to bring about the death of an affected baby, that is, to adopt a modified form of the Groningen Protocol? (See Box 8.2 and paragraphs 8.37–8.41.) (b) Is the current law sufficient to allow doctors and patients to make decisions designed to promote the best possible care of a baby? (See paragraphs 8.44–8.45.) (c) Is the current model of decision making that allows doctors and parents broad discretion to determine a baby's fate sufficiently sensitive to the baby's interests? (See paragraphs 8.46–8.47.)

Acting with the intention of ending life

- 8.39 In the Netherlands a protocol has been developed for the active ending of life of severely ill newborn babies and a committee established for the retrospective review of cases, to decide whether the action taken to end life was justified and whether all necessary procedures had been followed (Box 8.2).

⁶⁶ *Bolitho v City and Hackney Health Authority* [1998] AC 232; Lord Browne-Wilkinson at 242: "... the court has to be satisfied that the exponents of the body of opinion relied upon can demonstrate that such an opinion has a logical basis. In particular ... the judge before accepting a body of opinion as responsible, reasonable or respectable, will need to be satisfied that ... the experts have directed their minds to the question of comparative risks and benefits have reached a defensible conclusion on the matter".

⁶⁷ Expert evidence is also increasingly seen as fallible. Several high-profile cases have resulted in expert medical witnesses being disciplined by the General Medical Council because their evidence was subsequently found to be flawed. But see *Meadows v General Medical Council* [2006] EWHC 146 (Admin).

⁶⁸ Also, in English courts, experts, although their primary duty is to the courts (CPR 35), are usually instructed and paid by the parties in dispute, not the courts. This may cause them to be seen as partisan. Further information may be found in Blom-Cooper L (Editor) (2006) *Experts in the Civil Courts* (Oxford: OUP).

Box 8.2: Current practice in the Netherlands on the active ending of life of newborn babies who are severely ill

Actively ending the life of a baby is illegal in the Netherlands. However, in certain cases, the problems suffered by a newborn baby are considered justified grounds to carry out active termination of life and therefore doctors who have carried out this procedure have not been prosecuted.

The Groningen Protocol for the ending of life in the severely ill newborn was proposed by two Dutch paediatricians, Eduard Verhagen and Pieter Sauer.* The Protocol establishes criteria for doctors to consider when deciding to carry out this procedure. It aims to formalise the decision-making process, facilitate reporting and ensure that doctors provide all necessary information for the review of the case by the public prosecutors and therefore prevent a criminal investigation by the police.

The Groningen Protocol was established in collaboration with the district attorney following two court cases in the 1990s. In the first case, a physician ended the life of a newborn baby who had an extreme form of spina bifida. In the second case, a physician ended the life of a baby with a very severe chromosome disorder. In both cases, the doctors were acquitted. The Protocol was designed for those rare cases where a baby's condition is stable and he or she is not dependent on intensive care, but no cure is available. Most of these babies would not be expected to live for very long without further intervention.

The Protocol lists strict criteria that must be met before the ending of life can be carried out. These are as follows: the diagnosis and prognosis must be certain; hopeless and unbearable suffering must be present; these conditions must be confirmed by a least one independent doctor; both parents must give informed consent; and the procedure must be performed in accordance with the accepted medical standard. High doses of an opiate (such as morphine) and a benzodiazepine (sedative) are given to bring about death. To end life without suffering is the primary objective. A baby gradually becomes sleepy, then unconscious and dies after one to two days. Muscle relaxants to stop breathing or potassium injections to stop the heart are not used.

After the baby has died, the doctors must report the procedure to the 'prosecuting authority'. This legal body must determine whether the decision was justified and whether all necessary procedures had been followed. Twenty-two cases of active ending of life in newborn babies were reported to the legal authorities between 1997 and 2004. None of the physicians involved were prosecuted. It has been suggested, however, that most cases are not recorded or reported.†

Following calls from doctors, in November 2005, the Justice Minister and the State Secretary for Health, Welfare and Sport of the Netherlands decided to establish a committee to advise the Public Prosecution Service on matters relating to the termination of life of the newborn and late-term termination of pregnancy. Membership of the committee will comprise three physicians (who will share a single vote); an ethicist; and a lawyer in the chair. The committee will assist the prosecutor in reaching a decision on whether or not to prosecute the doctors involved. Its opinion will be sent to the College of Procurators-General, which will then assess whether the doctor acted in accordance with standards of due care.‡

The authors of the Groningen Protocol advise that following it "does not guarantee that the physician will not be prosecuted".** However, many hospitals have accepted the Protocol, or something similar, and it has the support of the Dutch Paediatric Association, which intends to transform it into a national protocol. It was reported to the Working Party that parents seldom challenged medical opinion in the Netherlands and it was rare for a case to reach the courts. In the case of any disagreement, the usual situation was for the baby to be transferred to another hospital.

* Verhagen E and Sauer PJJ (2005) The Groningen Protocol – euthanasia in severely ill newborns *N Engl J Med* **352**: 959–62.

† Verhagen E and Sauer PJJ (2005) The Groningen Protocol – euthanasia in severely ill newborns *N Engl J Med* **352**: 959–62; Verhagen AAE and Sauer PJJ (2005) End-of-life decisions in newborns: an approach from the Netherlands *Pediatrics* **116**: 736–9.

‡ Ministry of Health, Welfare and Sport of the Netherlands (2005) Press Release: *Advisory Committee on termination of life of neonates*, available at: <http://www.minvws.nl/en/press/ibe/2005/advisory-committee-on-termination-of-life-of-neonates.asp>, accessed on: 8 Dec 2005; Ministry of Justice of the Netherlands (2005) *Termination of life in newborns and late pregnancy termination: Questions and answers*, available at: <http://english.justitie.nl/currenttopics/pressreleases/archives2005/termination-of-life-in-newborns-and-late-pregnancy-termination.aspx?cp=35&cs=1578>, accessed on: 29 Sept 2006.

** Verhagen E and Sauer PJJ (2005) The Groningen Protocol – euthanasia in severely ill newborns *N Engl J Med* **352**: 959–62.

8.40 Current legal principles in the UK, which govern decisions to allow someone to die yet prohibit active steps to end life, have been attacked as morally and intellectually misshapen. John Finnis has argued:⁶⁹

What is misshapen and indefensible is a law that treats as criminal a harmful 'act', while treating as lawful (and indeed compulsory) an 'omission' with the very same intent, by one who has a duty to care for the person injured.

On this critical point, those who are opposed to all forms of euthanasia agree with proponents of the procedure. If it is lawful to cease treatment with the intent that the patient die, it is

⁶⁹ See Finnis J (1993) Bland: Crossing the Rubicon *Law Quarterly Review* **109**: 329.

illogical that it is unlawful to kill the patient directly. In paragraph 2.33, we considered this dilemma and concluded that it is ethically defensible to continue to distinguish between withholding/withdrawing life-saving treatment, and actively ending life. **Within the Working Party, we acknowledged that members held different views on whether any form of active ending of life could ever be ethically justifiable. We unanimously agreed that laws expressly and exclusively allowing ending the life of newborn babies should not be recommended.** Further, we found it difficult to envisage how laws specifically designed to allow active steps to end a newborn baby's life could be framed. Our rationale for this conclusion is presented in the following paragraphs.

- 8.41 We begin by considering what, hypothetically, the conditions might be for any law introduced in the UK to allow the active ending of the life of a baby. The first practical question would be *who* would authorise the proposal to act to end the life of the newborn child. We would envisage a minimum of four conditions as follows: (a) the parents request that doctors actively end their baby's life; (b) parents and health professionals agree that it is not in the baby's best interests to survive, and neonatal intensive care should (in any event) be withdrawn; (c) the interests of the baby are best served by ending his or her life quickly and painlessly; and (d) a second opinion has been sought which agrees with the proposal. These apparently simple hypothetical conditions raise several questions. If the justification for active steps to end life is that the welfare of a baby is best served by a swift and painless death, then reservations must be expressed about any requirement that both parents and doctors must concur in a judgement about the baby's interests. It is unrealistic to envisage legislation in the UK which did not offer doctors a right to refuse to practise euthanasia on grounds of conscience. When analogous rights of conscientious objection are granted in other legislation, it is clear that the objector is required to refer his or her patient to another clinician.⁷⁰ The difficulty of moving a baby already gravely ill may either render any 'right' to euthanasia impracticable, or render the right to conscientious objection meaningless.
- 8.42 We have assumed that parental agreement would be a prerequisite of active intervention to end life (as it is in the Netherlands, see Box 8.2). Yet if the moral case for laws permitting such intervention is the imperative to avoid suffering, it could be argued that parental objections should not be determinative. We cannot envisage legislation that authorises the killing of babies (for whatever reasons) without parental consent. The decision of the European Court on Human Rights makes it clear that acting against parental objections would constitute a violation of Article 8 of the Human Rights Convention (a right to respect for private and family life), unless authorised by an independent tribunal.⁷¹
- 8.43 The second practical question we considered was that of *what time limits would be set* within which the law would permit actively ending the life of a baby. One such limit could be the transition point at which a baby is no longer considered to be 'newborn', defined as being within 28 complete days of delivery. This definition serves a useful purpose as an indicator of a baby's stage of development, but we question whether it would be sufficiently robust to be used as a time limit to decide on whether the active ending of life is permissible. On what basis could it be lawful to permit active steps to end life at 28 days but not 29? A limit would constrain decision making and possibly put pressure on doctors and parents to make a hasty decision. If parents and doctors were permitted to end a newborn baby's life on grounds of extreme suffering, such legislation can only logically be located in laws permitting non-voluntary euthanasia for all children and mentally incapacitated adults.

⁷⁰ General Medical Council (2001) *Withholding and Withdrawing Life-prolonging Treatments: Good practice in decision-making*, paragraph 28.

⁷¹ See *Glass v UK* (above).

Withholding or withdrawing treatment

- 8.44 We have seen (paragraphs 8.18–8.20) that the legal principles governing decisions to withhold or withdraw treatment from a baby whose prognosis is poor have developed on a case by case basis. Decisions to withhold or withdraw treatment made consensually by a baby's parents and doctors are lawful providing that the decisions are made in the best interests of the baby. When doctors and parents agree what should be done, any form of external review of the decision is unlikely. This lack of independent validation of the decision to allow the baby to die has two possibly adverse results. (a) As we have said, doctors may fear that retrospectively either parents or some third party may challenge the judgement as to the interests of the child, leaving them vulnerable to criminal prosecution. (b) The baby may be said to have no-one who speaks for him or her.
- 8.45 Fears of retrospective criminal investigation should not be dismissed lightly. In the case of Dr Leonard Arthur in 1981, the doctor and the baby's parents were in complete agreement about allowing a baby who had Down's syndrome to die. It was another health professional at the hospital who reported the case to the police.⁷² Withholding food from a baby with Down's syndrome would today be seen as unjustified and unethical. The baby in Dr Arthur's care had no-one to speak for him and, unlike in more recent cases where parties and doctors disagreed, no application was made in the courts.

Legislation on withholding treatment: would it help?

- 8.46 In the debate that followed the case of Dr Arthur, a proposal for a draft Limitation of Treatment Bill was published in 1981.⁷³ It proposed that no criminal offence would be committed where a doctor refused or ceased treatment of an infant under 28 days, provided that (a) the parents gave their written consent, and (b) two doctors, both of at least seven years' standing, and one of them being a paediatrician, certified in writing that the infant suffered from severe 'physical or mental handicap' that was either irreversible or of such gravity that after receiving all reasonably available treatment the child would enjoy no worthwhile quality of life. The Bill would direct doctors to consider a number of factors in assessing the child's likely quality of life. They should consider (*inter alia*) the degree of pain and suffering likely to be endured, the child's potential to communicate, and also the willingness of the parents to care for him or her and the effect that that may have on their physical and mental health. Although the draft Bill stimulated further discussion, it was never taken forward into legislation.
- 8.47 Mason and McCall Smith originally called for similar legislation. However, in the current edition of *Mason and McCall Smith's Law and Medical Ethics*, Mason and Laurie move towards the view that legislation relating to babies, should it be needed, must be part of broader legislation addressing the law regulating withdrawal of treatment and assistance to die at any age.⁷⁴ **We agree that legislation designed exclusively to address decisions relating to newborn babies alone is not to be recommended.** Should more general legislation be introduced to regulate the kinds of decisions this Report addresses, we doubt whether it will offer the clarity and predictability that might be its objective. Whatever terminology is used there will remain room for disagreement about the criteria set in any possible statute. Parents and doctors may well continue, on occasion, to have different perceptions of when those criteria are met. **We consider that the current legal principles centred on seeking agreement between parents and professionals as to the best interests of the**

⁷² See *R v Arthur* (1981) 12 BMLR 1 discussed in Mason JK and Laurie GT *op cit* at 546–7; and see Brazier *Mop cit* at 344–5; Benyon H (1982) Doctors as Murderers *Crim L R* 17; Gunn M and Smith J C [1985] Arthur's Case and the Right to Life of a Down's Syndrome Child *Crim LR* 705.

⁷³ See D Brahams (1981) 78 *Law Soc Gaz* 1342.

⁷⁴ Mason JK and Laurie GT *op cit* at 564–5.

baby are, in principle, correct and sufficient. Some further clarification as to the criteria on which best interests are judged would be helpful and we develop this suggestion further in Chapter 9. Measures to improve the process of decision making and minimise conflict are also needed.

A role for clinical ethics committees?

- 8.48 While we consider that new legislation may not in practice offer more clarity for the resolution of cases, it might provide some reassurance to doctors that their decisions (if taken in good faith) would not retrospectively be challenged in the criminal courts. The proposed (but unpursued) 1981 proposal for a draft Limitation of Treatment Bill (paragraph 8.44) granted no additional voice to the baby. We have considered whether without legislation there are means to introduce some form of external validation of decision making designed both to reassure professionals and ensure adequate articulation of the interests of a baby and his or her family. That there might increasingly be a need for such measures was signalled to us in a number of responses to our consultation.⁷⁵ We go on to explore an expanded role for clinical ethics committees (CECs).
- 8.49 Multi-disciplinary CECs currently operate in several different types of organisation (see Box 8.3). Sometimes styled hospital ethics committees, CECs are distinct from the more formally constituted research ethics committees. A Report by the Royal College of Physicians (RCP)⁷⁶ describes the three main functions of CECs as *education* (raising awareness of ethical issues and helping health professionals develop skills to address ethical issues in their practice), *policy and guidelines* (developing policies originating from the Department of Health or the local hospital trust) and *case consultation* (assisting in individual cases). In some regions, CECs have implemented a rapid response system to deal with urgent cases. Whereas in the USA case-specific advice is provided frequently by hospital-based CECs, this practice is found much less frequently in the UK. Virtually all major hospitals in the USA have a CEC supported in most instances by one or more bioethics consultants, and clinical bioethicists. Neonatal care and the treatment of children are already areas of medicine addressed by CECs in the UK. **The view of the Working Party is that that there is scope for a greater number of UK neonatal intensive care units (and tertiary referral fetal medicine centres) to benefit from general and specific advice of a local clinical ethics committee.**

Box 8.3: Clinical ethics committees in the UK*

In the UK, clinical ethics committees are to be found most commonly within NHS trusts and hospitals. There are approximately 70 CECs in total.⁷⁷ These committees are multi-disciplinary, usually consisting of between six and 26 members with medical and nursing expertise, lay representatives and sometimes a chaplain or other religious representative. The roles of the committees vary but include providing ethical advice for the development of policy and guidelines, supporting health professionals in individual cases and facilitating ethics education for health professionals.

* Royal College of Physicians (2005) *Ethics in Practice: Background and recommendations for enhanced support* (London: Royal College of Physicians), p 27–9; General Medical Council (2001) Resolving disagreements about best interests, in *Withholding and Withdrawing Life-prolonging Treatments: Good practice in decision-making*, available at: http://www.gmc-uk.org/guidance/library/withholding_and_withdrawing/withholding_lifeprolonging_guidance.asp, accessed on: 2 Aug 2006.

⁷⁵ For example, the RCPCH commented that “The need for second opinions, ethical review and support are all becoming more apparent.”

⁷⁶ Royal College of Physicians (2005) *Ethics in Practice: Background and recommendations for enhanced support* (London: Royal College of Physicians). The Report describes the current operation of CECs in the UK in detail. It makes constructive recommendations on membership, education and working methods.

⁷⁷ A practical guide to clinical ethics support (2005), available at: <http://www.ethics-network.org.uk/reading/Guide/Guide.htm>, accessed on: 29 Mar 2006.

8.50 Other advice is available at the national level.⁷⁸ The variations in practice we have encountered in our fact-finding meetings suggest that the Royal Colleges's advice is interpreted somewhat differently across the UK. We see it as important to strike the right balance between national policy and local variation. CECS already work together within the UK Clinical Ethics Network. We would see it as important that CECs addressing fetal and neonatal medicine make particular efforts to work together. Information and views could be shared and differences in practice, or views about ethics explored. Local differences should not be considered necessarily undesirable. Hospitals serve their different local communities, and religious and cultural traditions play a major role in decision making in neonatal medicine. A CEC providing advice suitable to local needs must be aware of the religious, cultural and social profile of families in its area. **We endorse the recommendations of the RCP Working Party:**⁷⁹

“The beliefs, practices and language of the populations being served by a health care institution are important and ethics support will need to be sensitive to them. This underlines the need for local ethics support to complement national advice guidelines and support, as well as for such support to draw upon appropriate local expertise.”

8.51 Setting policy is perhaps the easier of the objectives for CECs in this field of medicine. Addressing particular cases will be more challenging. CECs could be charged to review all decisions made in relation to withdrawal of intensive care, whether such decisions are made by agreement between parents and professionals or not. Such a review would ensure an external and independent evaluation of a baby's interests. Evidence of the concurrence of the CEC would provide some protection for clinicians whose decisions are later questioned. Two particular challenges would need to be addressed. First, the CEC in its present form is primarily designed to provide ethics support for health professionals. The RCP Working Party has emphasised that the parental perspective is highly important and would advise the inclusion of lay members who may require some ethics training. But in cases of conflict, the CEC may not be perceived as sufficiently independent from the health providers. Secondly, for the kinds of dilemma addressed in this Report, there are logistical problems. Rapid advice would sometimes be required and mechanisms would be needed to achieve this. Such provision may well not be possible in all circumstances, for example with regard to decisions about resuscitation; however, one basis for such a mechanism would be for some members of existing CECs, or other facilitators, to be available on call to hospital staff.

Resorting to the courts

8.52 There is a perception that the number of cases involving the courts where parents and doctors dispute what constitutes a baby's best interests seems to be increasing, although robust evidence is lacking. Such disputes are, however, not new.⁸⁰ Conflicts aired in court attract a high degree of media attention, and on some occasions court proceedings have been conducted in a climate of acrimony and hostility. Resort to the courts is also costly. The dispute relating to the care of Charlotte Wyatt has so far involved five hearings and is reported to have cost the taxpayer £500,000.⁸¹ The polarisation of views that inevitably follows an application to court

⁷⁸ Royal College of Physicians (2005) *Ethics in Practice: Background and recommendations for enhanced support* (London: Royal College of Physicians), pp 27–9; General Medical Council (2001) Resolving disagreements about best interests, in *Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making*, available at: http://www.gmc-uk.org/guidance/library/withholding_and_withdrawing/withholding_lifeprolonging_guidance.asp, accessed on: 2 Aug 2006.

⁷⁹ Royal College of Physicians (2005) *Ethics in Practice: Background and recommendations for enhanced support* (London: Royal College of Physicians), p 38.

⁸⁰ See, for example, *Re B* [1981] IWL 1421 and see Mason JK and Laurie GT *op cit* at 546–9.

⁸¹ *The Times* (17 October 2006) Carers sought for baby Charlotte as parents part, available at: <http://www.timesonline.co.uk/article/0,,2-2406775,00.html>, accessed on: 20 Oct 2006.

may sour the relationship between the family and the doctors. However wise the judge, or right the eventual decision, there must be a sense in which the involvement of the courts is a very stressful experience for the child's family and the professionals.

8.53 As we have said, doctors cannot unilaterally override decisions of parents save in a genuine emergency (paragraph 8.10). A further important consideration is that in court a baby is given an independent voice through a guardian who is appointed exclusively to investigate and present that baby's interests. Accepting the role of the courts in truly irresolvable disputes still allows us to seek to minimise the involvement of the courts where this is possible. This could be achieved by further clarification of the legal principles governing disputed cases and by identifying alternative means of dispute resolution (see paragraphs 8.54–8.62).

Best interests and parental views

8.54 Before a healthy child can be removed from his or her parents, or other intervention by the State is permissible under the Children Act 1989, a risk of significant harm to the child must be demonstrated. So we might ask whether in disputes about the appropriate care of a newborn baby, the courts should require doctors to demonstrate an unacceptable degree of harm to the baby if the parents' wishes are allowed to prevail? Or the law could demand that the decisions of a reasonable parent be respected, the onus being on the doctors to show that any disputed decision fell outside the bounds of reasonableness? Some might say that such changes to the legal test risk overshadowing the primary consideration which is a baby's own interests. The decision of the Court of Appeal in *Re T*⁸² accorded weight to parental views of affirming the close link between parent and child, in this case not to proceed with treatment they regarded as invasive, against clinical opinion (paragraph 8.29). The judge in *An NHS Trust v B*⁸³ emphasised the baby had ". . . close relationships with a family who have spent and are able to spend very considerable time with him, and does already have an accumulation of experience and the cognition to gain pleasure from them" and required some, if not all the treatment that the parents wished, against clinical opinion (paragraph 8.33). **It is the view of the Working Party that according a greater weight to parental views of the baby's interests in cases when the outcome for their baby can reasonably be disputed could potentially minimise disputes without prejudicing the welfare of the baby. A more transparent and structured set of criteria for judging best interests might also be useful. We propose such criteria in Chapter 9.** Such criteria would identify the questions that are relevant in making such decisions.

8.55 Whatever criteria are used to determine whether a baby should continue in intensive care or receive to other measures to prolong life, disagreements will still arise. We have suggested (paragraph 8.49) that all decisions relating to withdrawal of life-sustaining care should be reviewed by a CEC. That process itself may help to minimise the incidence of disputes. However, parents may perceive a CEC as simply an adjunct of the hospital and be suspicious of its objectivity and neutrality. Committees are not generally well suited to addressing disputes. Formal hearings to allow each side to put its case would be time-consuming and could exacerbate antagonism between the parties. Another approach to the resolution of disputes entails mediation.

Mediation

8.56 We are aware of the development in the USA of a process of what is described as bioethics mediation, expressly designed for disputes between patients and their families on the one

⁸² [1997] 1 All ER 106 CA.

⁸³ [2006] EWHC 507.

hand, and doctors, other health professionals and health providers on the other.⁸⁴ Bioethics mediation is used in disputes in which neither party contemplates referral to a court, and to attempt to minimise the numbers of cases that do go to court. A sharp distinction is drawn between bioethics mediation and bioethics consultation. In the USA, the latter process may be carried out by either a CEC or a bioethics consultant. Dubler and Liebman⁸⁵ explain:

Bioethics Mediation is different from Bioethics Consultation. Bioethics Consultation refers to a directed substantive process. The consultant listens to the parties and helps move them toward a principled resolution of the dispute by explaining ethical principles and legal rules, applying them to the facts, and presenting the social consensus on the permissibility of different practices. Bioethics mediation refers to the use of classical mediation techniques to identify, understand and resolve conflicts. Bioethics mediation and bioethics consultation may both be employed in a particular case at different points in the process. Mediation is more inclusive and empowering, and consultation is more authoritarian and hierarchical; either or both may be required in any complex case, even within a single meeting.

We note that in the USA, bioethics mediation is by no means restricted to cases that might otherwise be referred to the courts. It is a process that can be embarked on at an early stage before a disagreement crystallises as a conflict.

- 8.57 When disagreements arise about the care of a very ill baby, there is rarely a 'right' answer and therefore the potential benefits of mediation merit examination. In the UK, mediation is increasingly used to assist parties in disputes that might otherwise be adjudicated in the courts. Mediation empowers the parties to a dispute to seek to resolve their disagreement themselves. Mediation has been defined as follows:

"Mediation is a flexible process conducted confidentially in which a neutral person actively assists the parties in working towards a negotiated agreement of a dispute or difference, with the parties in ultimate control of the decision to settle and the terms of resolution".⁸⁶

- 8.58 Mediation thus seeks to bring together the parties who disagree. It identifies the parties and clarifies their interests. It offers opportunities to draw in the wider family (and religious advisers). It seeks to minimise disparities in power and to find common ground. The mediator will seek to help the parties to find a "principled resolution"⁸⁷ and remain available to assist with follow up, whether or not agreement is reached, and with implementation of any agreement. Mediation will not however provide an answer to every dilemma. It may, however, facilitate better communication, reduce acrimony and narrow down the issues requiring formal adjudication in the courts. Inevitably some parties may have reservations about the process or there may be fundamental disagreement prompted by ethical concerns. For example, parents of a baby with trisomy 18 (Edwards Syndrome) whose faith requires that every possible intervention to prolong the life of their child is required are unlikely to find accord with doctors who consider that ventilating that child is futile. However, mediation may be able to help the parties understand each other better and help to reinforce and restore trust.

- 8.59 Mediation is used increasingly in legal disputes about medical practice, some of which involve ethical issues. In the context of claims for clinical negligence, the rules of the court require that parties seeking compensation consider alternative dispute resolution. Mediation is

⁸⁴ Dubler NC and Liebman CB (2004) *Bioethics Mediation: A guide to shaping shared solutions* (United Hospital Fund of New York).

⁸⁵ *Ibid.*

⁸⁶ Centre for Effective Dispute Resolution website Glossary, available at: <http://www.cedr.co.uk/index.php?location=/library/glossary.htm>; article available at: <http://www.cedr.co.uk/index.php?location=/news/archive/20041101.htm>, accessed on: 9 Oct 2006.

⁸⁷ Dubler NC and Liebman CB (2004) *Bioethics Mediation: A guide to shaping shared solutions* (United Hospital Fund of New York).

actively encouraged. Compared with litigation, it is much quicker, less expensive, less stressful and more flexible for the parties involved.⁸⁸ Mediation has been used to facilitate discussion in cases such as disputes about the costs of future care and possible withdrawal of treatment from patients in persistent vegetative state. We note that mediation achieved a successful outcome in one of the two group litigation claims arising out of the controversy in the UK on organ retention, and aided the resolution of the second.⁸⁹ We are also aware that mediation is now being piloted in the UK by the Centre for Effective Dispute Resolution for the Healthcare Commission, as a means of more effective local resolution of complaints about the NHS.

- 8.60 Mediation can be valuable in helping to resolve other kinds of disputes. In family law, it has been used effectively in disagreements between parents about the care of their children following a divorce, although it has proved to be less so when made compulsory.⁹⁰ We recognise that disputes involving family law and cases of clinical negligence present somewhat different challenges to those raised by critical care decision making in fetal and neonatal medicine. Nevertheless, there are similarities in that strong emotions are usually involved. In assessing whether mediation might play a useful role in the kinds of disputes addressed in this Report, the experience of family law mediation will also need to be addressed.
- 8.61 Mediation is a skilled process. It is not simply a question of introducing a third party to chair a round table discussion. The process recommended by the Centre for Effective Dispute Resolution is described in Box 8.4.

Box 8.4: Dispute resolution

The Centre for Effective Dispute Resolution in the UK describes the process of mediation as involving the selection of a suitable mediator (or mediators), arranging the mediation and a series of joint and private discussions with the mediator.* The mediator is usually someone who has been trained in this role and is independent of all the parties in the dispute. The mediator's primary role is to help the parties come to their own settlement rather than to come to a judgement him or herself, although his or her approach may vary from merely facilitating the discussions of the parties to intervening and proposing options for settlement. If a solution or settlement is agreed upon in the mediation, it is written up and signed by both parties and often becomes legally binding. Because the parties take up mediation voluntarily, either of them can suspend the process at any stage.

* Centre for Effective Dispute Resolution *The Mediation Process*, available at: <http://www.cedrsolve.com/index.php?location=/services/mediation/process/default.htm>, accessed on: 20 July 2006.

- 8.62 **We consider that there are potential advantages to using mediation in disputes about critical care decisions in neonatal medicine. We recommend that the UK Departments of Health examine the benefits that mediation may offer, with a view to setting up a pilot study to evaluate the possible merits for critical care decision making in neonatal medicine.**

⁸⁸ Centre for Effective Dispute Resolution *What is Mediation?*, available at: <http://www.cedrsolve.com/index.php?location=/services/mediation/default.htm>, accessed on: 20 July 2006.

⁸⁹ Allen T (2004) *Personal injury mediation: are courts and lawyers preventing its development?*, available at: http://www.cedr.co.uk/index.php?location=/library/articles/PI_mediation_are_courts_preventing.htm, accessed on: 29 Sept 06; Allen T (2006) *Working for a social business*, available at: http://www.cedr.co.uk/index.php?location=/library/articles/20060222_167.htm, accessed on: 29 Sept 06.

⁹⁰ Fortin J (2006) *Children's Rights and the Developing Law*, 2nd Edition (London: LexisNexis), pp 207–8.

Chapter

Conclusions and
recommendations

9

Conclusions and recommendations

Introduction

- 9.1 Scientific and medical developments in fetal and neonatal medicine have enabled children who previously would have died to survive and lead healthy and fulfilling lives. These same developments have also created ethical, social and legal dilemmas for those families and health professionals who are faced with making complex and emotionally demanding decisions that may have lifelong consequences. In our deliberations, we have found that the difficult questions that arise in fetal and neonatal medicine concern a number of recurring ethical issues. These include the nature and value of human life at different stages of development, distinctions between the active ending of life and death resulting from withholding or withdrawing treatment, and balancing the interests of affected children, their families and the needs of other social groups (paragraphs 2.28–2.30). All too often there is substantial disagreement about these issues and how they should be resolved. Within the Working Party, members themselves hold diverse opinions on these matters. Thus one of our challenges has been to consider, given that people hold morally diverse views, how we can arrive at sensible judgements on which to base public policy.
- 9.2 The title of our Report, *Critical Care Decisions in Fetal and Neonatal Medicine* reflects our central concern with decision making. We endorse wholly the ideal of a ‘*partnership of care*’ advanced by the RCPCH and BAPM (paragraph 2.48). In some cases, it may be that the essence of the question to be decided is what *ought* to be done. In many instances, there will not be an answer that is clearly right or wrong. Reasonable people could disagree. In this Report we often focus on not so much *what* is the ‘right’ decision, but on *how* a decision should be arrived at and *who* should make the decision. To do so, we need to know how such decisions are currently made. The fetus and the newborn baby cannot speak for themselves. Who speaks for them, and how their interests are identified and protected, are crucial questions for us.
- 9.3 All decisions, whoever makes them and however they are made, depend on adequate and accessible information. Insufficient or contradictory information impairs the decision-making process. The quality of the information and data available to professionals, families and policy makers in this challenging field is frequently inadequate or incomplete. This means that uncertainty affects many of the critical decisions that may arise in both fetal and neonatal medicine. One example is imprecision in identifying the long-term outcome for a baby in poor health. While neonatologists can offer families some information about the statistical probabilities of their extremely premature or very ill baby surviving, and the likelihood that he or she will be affected by some disability, they are limited in what they can predict for that particular baby. The paucity of information hinders doctors from answering the question that all parents ask, which is ‘what will happen to *my* baby?’.
- 9.4 Decisions in fetal and neonatal medicine such as whether to intervene to prolong life, or to withhold or withdraw certain forms of treatment arouse strong emotions. Emotional influences upon decision making must be recognised and respected both in clinical decisions about individual babies, and in national policy making. Strong emotional reactions are also aroused by questions about a fetus’ claim to rights, and perceptions of disability and disabled people. Such reactions are not confined to people with direct experience of these dilemmas. Personal experience, professional and social background, religious and cultural perspectives all play a role in forming people’s views and cannot be ignored. The Working Party has been struck by how practice varies in resolving similar dilemmas in neonatal medicine in different hospitals in the UK, and also between the UK and other countries. We begin our final discussion by presenting our conclusions and recommendations on fetal medicine, the borderline of

viability, and decisions about other babies in intensive care. We then turn to decision making, determining best interests and the resolution of disagreement. After providing our views on economic considerations and the lifelong needs of children with disabilities, we conclude by identifying needs for monitoring and research, information, education and training.

Fetal medicine

- 9.5 Members of the Working Party hold a range of different views on the moral status of the fetus, a reflection of the diversity of moral opinion among people in the UK, which is in some cases linked to religious belief. Collectively, however, **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 moral and legal point of transition for judgements about preserving life (see paragraph 2.19).**
- 9.6 **We consider that a pregnant woman who has chosen to continue her pregnancy has strong ethical obligations to protect the health of the future child.¹ We are not persuaded, however, that the law should require pregnant women to submit to medical or surgical interventions to benefit a fetus against their will (see paragraph 2.20).** Women whose conduct in pregnancy compromises the health of their child should not be subject to legal sanctions. The unique context of pregnancy is such that legal intervention to compel pregnant women to comply with medical advice would involve an unjustifiable invasion of their bodily integrity and liberty demanded of no other citizen. Nor would such sanctions be likely to achieve the desired benefit to the fetus. It is our view that sanctions would be unjustifiable and impracticable, and could not be related exclusively to the context of critical care decision making.
- 9.7 **We endorse the current position in the UK whereby decisions about interventions to benefit the fetus, including the mode and timing of delivery, are made only with the consent of the pregnant woman, and that she should determine what happens in cases of dispute with her partner or her obstetrician (unless her mental capacity is impaired). Women making such decisions must be provided with comprehensive, accessible information on the risks and benefits of what is proposed, and (where possible) enabled to make their decisions with the support of their partners, their wider family or others they would like to consult, should they so wish (see paragraphs 8.4–8.5).** Emotional and social support are particularly crucial where a woman's lifestyle puts the health of the fetus or future child at risk because she has a serious infection or because she is addicted to drugs or alcohol.
- 9.8 The Working Party is aware of the development of open fetal surgery as a possible means of correcting or lessening the impact of some abnormalities but believes that the value of such procedures remains unclear at this time. Such procedures carry a high risk to the pregnant woman and the outcomes reported to date have been generally poor or worse than operations performed after birth. **The view of the Working Party is that in the UK, new procedures in fetal surgery should be offered only within a protocol approved by a research ethics committee (see paragraph 4.11).** There should also be careful scrutiny of the potential benefits and harms of new procedures.
- 9.9 This Report addresses decisions on the critical care of fetuses at risk of developing serious conditions that are likely to compromise the prospect of live birth or to impair the health of the baby once born. Except where fetal treatment is possible, the options for a pregnant woman

¹ In the context of this Report, ethical issues arise in situations where it may be possible to treat a fetus with medicine or surgery but the pregnant woman does not give her consent (see Chapter 4, Case 1). More general circumstances of where a woman could risk the health of her future child are, for example, when a mother is HIV-positive but does not accept treatment, or when she does not modify her addictive drug-taking behaviour during pregnancy.

in this situation are between early delivery, terminating or continuing the pregnancy (paragraph 4.12). Termination of pregnancy in such cases is lawful under the Abortion Act 1967 s. 1 (1) (d) (as amended), on the grounds that “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 Working Party is aware that there are calls to reduce the time limit for lawful termination of pregnancy for what are often called ‘social abortions’ below the current 24 week limit, primarily in response to the increased survival rates of premature babies below this gestation. Provided termination on grounds of fetal abnormality after any reduced time limit would still be permitted, the kinds of decision making that we examine in this Report would not be affected. Therefore we do not take a position on this issue.

- 9.10 The late termination of pregnancy and feticide are controversial (see paragraphs 4.14–4.16). We recommend that there should be greater uniformity of practice and interpretation of the law in relation to feticide. Additionally we note that it is incorrect to interpret the law as requiring all possible measures to be taken to prolong the life of a baby born alive if it is not in his or her best interests. **We recommend that a code of practice be developed for healthcare professionals to achieve clarity about what the law does and does not require doctors to do. Such a code would also help ensure that pregnant women are given sufficient information about possible outcomes if a baby is born alive following termination on grounds of fetal abnormality. It would reassure doctors should a woman choose not to consent to feticide. The responsibility for developing the code of practice should be taken by a broad group of professional organisations² consulting as appropriate. Where relevant, the code should be made available to a woman as part of her care pathway (see paragraph 8.8).**³

Borderline of viability

- 9.11 We have endorsed birth as the crucial legal and moral threshold so that once ‘born alive’, a newborn baby has the same legal status and entitlement to respect as older children or adults. The Working Party found, however, that in the context of what can now be achieved with intensive care, legal definitions of what it means to be born alive are imprecise. A baby after 24 weeks of gestation is defined as stillborn (dead) if he or she does not breathe or show any signs of life. However, such a baby may be entirely capable of survival provided he or she is given immediate assistance with breathing. Equally, a baby about to die from a condition that is incompatible with life may nevertheless breathe for a few moments. There exists no single precise definition in use as to what constitutes ‘born alive’. **We therefore recommend that the RCOG and RCPCH, together with BAPM and the Royal College of Midwives (RCM), should consult widely and develop a definition of ‘born alive’ which encompasses the capacity of the baby to breathe either independently, or with the support of a ventilator. Consideration should be given to incorporating such a definition in statute (see paragraphs 8.13–8.16).**
- 9.12 Once a baby is ‘born alive’, the parents and the healthcare professionals in the hospital where he or she is delivered owe the baby a duty of care. Parents have interests and these must be accorded some weight. However, decisions about the care of a baby concern his or her future existence and quality of life, and the baby’s interests in these naturally carry very great

² We suggest that these might include the RCOG, the RCPCH, the Royal College of Midwives (RCM), the RCN and the Neonatal Nurses Association.

³ The *National Service Framework (NSF) for Children, Young People and Maternity Services* recommends that women should make informed choices and plan their care in partnership with professionals and that a woman should have easy access to information and support throughout her pregnancy. The NSF is based on an approach where care pathways are used to illustrate a woman’s progress through the available pregnancy services. See Department for Education and Skills and Department of Health (2004) *Maternity Standard, National Service Framework for Children, Young People and Maternity Services* (London: Department of Health), available at: <http://www.dh.gov.uk/assetRoot/04/09/05/23/04090523.pdf>, accessed on: 17 July 2006.

weight. **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 (see paragraph 2.21).** The extent to which parents are consulted in advance about the initiation of intensive care appears to vary across the UK. **We strongly endorse the recommendations of the RCPCH and BAPM that, wherever possible, when the birth of a baby who is extremely premature or who is affected by significant abnormalities is expected, before the birth an experienced neonatologist should discuss options for admission to intensive care. We encourage the Royal Colleges and the NHS to find ways to foster a common approach by obstetricians, midwives, nurses and neonatologists.**

- 9.13 Current practice in most neonatal units in the UK is usually to resuscitate a baby if the outcome is uncertain and to institute intensive care until the outlook is clearer. There is no legal obligation to provide life-sustaining treatment where parents and professionals are agreed that a baby is unlikely to survive and/or suffers from such severe abnormalities as to render it not in his or her best interests to be offered invasive intensive care. In all circumstances, including when a baby has been delivered early by intention, when a woman has gone spontaneously into premature labour, when a baby is delivered later in pregnancy suffering from severe disabilities, or when a baby is born alive after a lawful termination of pregnancy, the legal obligation is to provide *appropriate* care. Such care does not necessarily include admission to a neonatal intensive care unit (see paragraphs 8.8 and 8.17).
- 9.14 Decisions to initiate life support are especially problematic where a baby is delivered before 24 weeks of gestation because there is a high probability that the baby will die or develop some level of disability, and great uncertainty about whether treatment is in the best interests of a baby should he or she survive. We consider that babies should not be subjected to intensive interventions that are not likely to have any benefit and which may cause suffering. We have given careful consideration to whether resuscitation and intensive care should be withheld from babies born below a stipulated number of weeks of gestation or a particular birthweight. Guidelines operating in the Netherlands recommend that babies of less than 25 weeks of gestation should not be resuscitated (see Box 8.1). **We do not regard this as an appropriate matter for legislation in the UK.** We consider any complete ban upon resuscitation and continuation of intensive care to be an unjustifiable infringement of the interests of both the child and the parents, and professional responsibilities. For similar reasons we reject any absolute limit below which resuscitation is not permitted, in view of the considerable variability in outcome for babies born at the same very early age of gestation, and the possibility of variation in estimates of gestational age by up to five days (see paragraphs 2.56–2.57 and 5.4). **However, we do believe that clearer guidance would be helpful to both parents and professionals.** More clarity would assist parents in reaching a better understanding of the uncertainties about their baby's ability to survive, and subsequent state of health. It would also benefit less experienced doctors in labour wards and neonatal units when circumstances dictate that decisions on resuscitation have to be made in the absence of a senior doctor (see paragraph 8.26). It is our view that explicit guidelines will encourage more openness, greater consistency in practice and firmer expectations for parents.
- 9.15 Evidence demonstrates that the outcome of intensive neonatal care when babies are born before 24 weeks of gestation is likely to be poor (see Table 5.1). Based upon current data, if a baby is delivered before 22 weeks, six days of gestation, survival is highly unlikely. Prolonged periods of stressful and invasive treatment are likely to be required if a baby of this gestational age is to survive. In the EPICure study of children born in 1995 in the UK and Ireland, approximately 10% of the babies who were born with signs of life at 23 weeks survived to the age of six. Five out of 22 survivors born at 23 weeks of gestation were later assessed as having severe disability and eight were free from moderate or severe disabilities (see Table 5.1). It must therefore be questioned whether it is in the best interests of a baby to be subjected

to the burdens of invasive intensive care. Any presumption that the best course of action is to initiate intensive care and then to withdraw it if the prognosis is poor must take into account the uncertainty over outcomes that follow birth at such early stages of gestation. Clarity about the chances of abnormalities likely to produce later serious disability may not develop or be detected until a baby's condition improves and intensive care is no longer required. **We have concluded that there is no reason to distinguish between withdrawing treatment and deciding not to start it, provided the decision is made in the best interests of a baby (paragraph 2.33).** We acknowledge, however, that decisions to withdraw intensive care, once initiated, may be exceptionally distressing for families and healthcare staff, and that they may perceive a moral difference. Given this situation, our view is that greater clarity on whether to initiate full intensive care might be helpful. **We therefore recommend that the RCPCH and BAPM, together with the RCOG, RCM, RCN and other associated professional bodies, should consider the development of guidelines for deciding to institute full intensive care for babies born below 26 weeks of gestation, consulting as appropriate, including with groups that advocate for parents.⁴ We propose below a set of guidelines to provide a basis of discussion by these bodies.**

Proposed guidelines for deciding to institute intensive care

9.16 **The guidance for deciding to institute resuscitation and full intensive care should include:**

- (a) **An experienced paediatrician should be present at the delivery and make a confirmatory assessment of the gestational age and condition of the baby.**
- (b) **At 25 weeks of gestation and above, the relatively high rate of survival and the relatively low risk of severe disability are such that intensive care should be initiated and a baby admitted to a neonatal intensive care unit, unless he or she is known to be affected by some severe abnormality incompatible with any significant period of survival.**

Below 25 weeks of gestation, where the delivery of an extremely premature baby is anticipated and circumstances permit, the clinical team should discuss with the parents in a thorough and frank fashion, the national and local statistical evidence for survival and the range of disabilities which are indicated for this age group. In the consultation with the parents, the healthcare team should make it clear that statistics indicate that most babies born below 25 weeks of gestation will die.

- (c) **Between 24 weeks, 0 days and 24 weeks, six days of gestation, normal practice should be that a baby will be offered full invasive intensive care and support from birth and admitted to a neonatal intensive care unit, unless the parents and the clinicians are agreed that in the light of the baby's condition (or likely condition) it is not in his or her best interests to start intensive care.**
- (d) **Between 23 weeks, 0 days and 23 weeks, six days of gestation, it is very difficult to predict the future outcome for an individual baby based on current clinical evidence for babies born at this gestation as a whole. Precedence should be given to the wishes of the parents regarding resuscitation and treatment of**

⁴ Broadly speaking, outcomes for premature babies at the borderline of viability improve with each additional week of gestational age. We intend our proposed week-by-week guidelines to be sufficiently flexible to take account of the variation in (1) how babies of the same age respond to treatment and (2) estimates of gestational age confirmed by ultrasound analysis, which are accurate to within five days (95% of cases) when carried out in the first trimester of pregnancy. We emphasise that a careful prior assessment of each baby and discussion with the parents, before the birth if possible, should precede any action. We recommend (paragraph 9.17) that guidelines should be reviewed regularly and revised, as needed, to reflect any future changes in outcomes.

their baby with invasive intensive care. However, when the condition of a baby indicates that he or she will not survive for long, clinicians are not legally obliged to proceed with treatment wholly contrary to their clinical judgement, if they judge that treatment would be futile (see paragraph 8.32). As a first step, it will be necessary to determine whether a baby is suffering, whether any suffering can be alleviated, and the likely burden placed on the baby by intensive care treatment (see paragraph 9.32). Where parents would prefer that the clinical team made the decision about whether or not to initiate intensive care, the clinicians should determine what constitutes appropriate care for that particular baby. Where there has not been an opportunity to discuss a baby's treatment with the mother (and where appropriate her partner) prior to the birth, the clinical team should consider offering full invasive intensive care until a baby's condition and treatment can be discussed with the parents.

- (e) Between 22 weeks, 0 days and 22 weeks, six days of gestation, standard practice should be not to resuscitate a baby. Resuscitation would normally *not* be considered or proposed. Only if parents request resuscitation, and reiterate this request, after thorough discussion with an experienced paediatrician about the risks and long-term outcomes, should resuscitation be attempted and intensive care be offered. The treating clinicians must concur that this is an exceptional case where resuscitation is in a baby's best interests.**
- (f) Below 22 weeks of gestation, no baby should be resuscitated, except in the situation described below in paragraph 9.19.**
- (g) When intensive care is not given, the clinical team should provide palliative care until the baby dies.**

9.17 At the time of writing, most babies born at 23 weeks die or survive with some level of disability even if intensive care is given. Survival and discharge from intensive care for babies born between 22 and 23 weeks is rare. It is natural that parents may hope that their exceptionally premature baby will survive against the odds. We have no evidence of any therapeutic developments likely to improve the prospects of survival for babies born before 22 weeks in the near future. The nature of clinical advance is for doctors to seek to extend the boundaries of medicine but it is our view that caution is currently required over decisions to treat babies born up to 23 weeks, six days of gestation. **We recommend that should professional bodies choose to produce guidelines for instituting intensive care, these should be reviewed regularly and revised to reflect any changes in outcomes for extremely premature babies.**

9.18 According to our proposed guidelines, parents could refuse intensive care for their baby if he or she is born between 23 weeks and 23 weeks, six days of gestation. Because it will be the parents who live with the consequences of any decisions to resuscitate at the limits of viability, we consider parental informed consent to be especially important for decisions to use life support for babies born at this age of gestation. If a pregnant woman is unable to consent before the birth because of her clinical condition, doctors should resuscitate the baby. Similarly after birth if the mother is unable to consent or if the parents should disagree, resuscitation should again proceed. Once a baby is born, a mother no longer has exclusive responsibility for decision making. For birth below 23 weeks, normal practice would be not to resuscitate a baby.

9.19 Below 22 weeks of gestation, we consider current attempts to resuscitate a baby to be experimental. Any attempt to resuscitate babies born at this gestational age should take place only within the context of an approved research study within which the parents understand that their baby is participating in a particular project. Research may improve outcomes for babies in the future, but is highly unlikely to improve the outcome for those babies participating in

a study. **On the evidence available to us, we therefore recommend that, unless and until documented scientific evidence establishes realistic prospects that babies born at or before 21 weeks, six days could survive to be discharged from intensive care without developing severe disabilities, attempts to resuscitate these babies should *only* take place within a clinical research study that has been assessed and approved by a research ethics committee and with informed parental consent (see paragraph 5.13).**

Critical care decisions for babies needing intensive care

- 9.20 After resuscitation or admission to intensive care, it may be discovered that a baby has such profound abnormalities or his or her condition has so deteriorated that prolonging life is considered by the clinical team to be futile. Decisions will have to be made about whether to continue ventilation and other intensive care, or to offer only palliative care to alleviate pain and distress. In the UK, it constitutes neither murder nor manslaughter to cease interventions to prolong life when such measures are very unlikely to succeed and are unduly burdensome to a baby (see paragraph 8.17). We have considered carefully whether the law should be reformed to allow doctors to end the life of a baby in these circumstances, assuming that this could be done swiftly and painlessly, for example, by means of a lethal injection. Members of the Working Party held different views about whether it can ever be permissible to take active measures to end any human life. Some members would reject such measures as intrinsically unethical in any circumstances while others would consider such measures to be acceptable in principle, under certain restricted conditions. These conditions would be when a baby was enduring extreme suffering or his or her life was intolerable in other ways (see paragraph 2.16). The Working Party was aware that the latter view commands some support⁵, and that actively ending the life of a newborn baby is now sanctioned in the Netherlands. Our deliberations therefore included the question of whether legislation allowing active steps to end a newborn baby's life should be considered by Parliament. **Despite different personal views on whether any form of active ending of life could ever be ethically justifiable, the Working Party unreservedly rejects the active ending of neonatal life even when we would view that life as 'intolerable' (see paragraphs 2.16 and 2.37). Furthermore, we unanimously rejected the notion that there should be a law or laws expressly and exclusively allowing ending the life of newborn babies.**
- 9.21 From an ethical perspective, we drew a moral distinction between, on the one hand, withholding or withdrawing life-saving treatment, and on the other, actively ending the life of a baby, for reasons based on the moral responsibility of doctors and the need for ethical consistency. Many doctors are clear that they have a professional obligation to preserve life where and when they can and further, they would not be prepared to act expressly to end the lives of babies in their care. It would therefore be unacceptable to many doctors, for example, actively to take life. Furthermore, permitting doctors deliberately to end life would be likely to have a negative psychological impact, both in personal terms and from erosion of trust in the medical profession. In terms of ethical consistency, rejection of adult euthanasia while permitting the active ending of the life of a newborn baby whose life is intolerable would require demonstration of a morally relevant difference between a newborn baby and adults who are unable to consent for themselves.
- 9.22 From a legal perspective, we concluded that legislation permitting doctors to decide to end the lives of newborn babies without the consent of the parents would be unacceptable in the UK. We could envisage only very limited circumstances where a parent might even consider

⁵ For a presentation of arguments for the active ending of life in adults, see, for example, Doyal L (2006) Dignity in dying should include the legalization of non-voluntary euthanasia *Clinical Ethics* 1: 65–7.

giving consent. Finally, while in theory it would be possible to frame stringent conditions governing the circumstances in which it was permissible actively to end the life of a baby, we identified a number of objections that might make framing such legislation difficult. These included the violation of the parents' right to respect for the private and family life guaranteed by the European Convention on Human Rights if ending of life were to be permitted without parental consent, and the impossibility of setting a defensible limit for the period after birth in which ending of life of a baby was legal.⁶

- 9.23 Once a critical care decision has been made to withhold or withdraw treatment for a baby, or where there are no appropriate treatments, palliative care should be provided (see paragraphs 6.18–6.22). This is care that endeavours to relieve pain and distress in order to make the rest of a baby's life as comfortable as possible. In the context of best interests, consideration of whether a baby who is dying should be allowed to suffer led the Working Party to conclude that more could be done in the UK to provide better and more consistent access to palliative care for babies within intensive care units. The benefits of palliative care in the hospital setting are well established. During the process of dying it reduces suffering and makes a baby as comfortable as possible. However, there is little standardisation of provision, so that in the UK palliative techniques are used to a variable degree in the delivery and neonatal intensive care settings. **The Working Party therefore proposes that the NHS, supported by the UK Departments of Health and in conjunction with the relevant professional bodies (for example the RCPCH, BAPM, RCN, Neonatal Nurses Association (NNA) and RCM), should train all neonatologists and neonatology nurses in the basic principles of palliative care so that they are applied when a need is identified. To complement this provision, the NHS should facilitate access to specialist advice in palliative care for complex cases in the same way that specialists would be consulted on complex problems in other areas of medicine.**
- 9.24 We note that in the UK when intensive care is withheld or withdrawn from a baby, oral tube feeding and hydration are sometimes continued. In most cases hunger and dehydration would add to a baby's suffering; however, in babies who have a damaged gut, providing food and hydration would be impossible or would increase suffering. **We therefore conclude that oral nutrition and hydration should only be withheld from a baby when it is clear that providing it causes discomfort and pain, such as when a baby has little functioning bowel due to disease or when death is imminent. The decision should only be taken after careful assessment and as part of a planned programme of palliative care designed to minimise suffering and make the baby as comfortable as possible.**
- 9.25 If the decision is made to provide intensive care for a baby, consideration should be given to his or her continuing developmental needs. The nature and number of procedures performed on babies in these units can make intensive care a painful experience, and the bright and noisy environment can be stressful. There is increasing evidence that newborn babies, including those born prematurely, show responses to painful stimuli and that experiencing painful procedures without pain relief during the neonatal period may be harmful. We understand that current clinical practice in terms of detection of pain and provision of pain relief varies widely across the UK (see paragraphs 6.14–6.17).⁷ **The Working Party believes that the reduction of pain and stress for babies in neonatal units is important and suggests to the UK Departments of Health, the Healthcare Commission and relevant professional**

⁶ Article 8(1) of the European Convention on Human Rights.

⁷ Redshaw M and Hamilton K (2005) *A Survey of Current Neonatal Unit Organisation and Policy: Commissioned by BLISS – The Premature Baby Charity* (Oxford: National Perinatal Epidemiology Unit), available at: http://www.npeu.ox.ac.uk/neonatalunitsurvey/neonatalunitsurvey_downloads/BLISS%20Final%20Report.pdf, accessed on: 18 July 2006.

bodies that measures need to be taken to improve clinical practice through the application of current knowledge about the assessment, prevention and treatment of pain in babies receiving intensive care.⁸ The Working Party also encourages the UK Departments of Health and research funding bodies to support high quality research into the potential developmental effects of neonatal pain and stress and their treatments.

Decision making and best interests

- 9.26 UK law requires that decisions whether to initiate, withhold or withdraw treatment must be made in the best interests of a baby. Reasonable people may disagree on what this means. Healthcare professionals will perceive their infant patient differently from the parents and parents' views may differ on whether or not it is in their baby's interests to die peacefully or to continue to receive life support with an uncertain outcome. Both the law and clinical practice in the UK operate on a presumption in favour of life. The courts have suggested that unless a baby's life is likely to be 'demonstrably awful', his or her clinical care should aim to promote survival. Many people live fulfilled and valuable lives while coping with impairments so profound that others could not contemplate such a life.
- 9.27 Determining what is in the best interests of a newborn baby is difficult. A baby does not yet have developed relationships with the outside world and with others that a child will progressively acquire. By contrast, for the child who becomes critically ill at a later age, his or her parents will be able to have a greater sense of what he or she might view as a worthwhile existence. **We recognised that there are very real difficulties in knowing what is best for a baby. Nevertheless we concluded that the principle of best interests should remain a central one in decision making about newborn babies and children.** Thus, in the course of our deliberations we gave careful consideration to whether it might in some circumstances be in the best interests of a baby for intensive care to be withheld or withdrawn. We concluded that it is not in a baby's best interests to insist on the imposition or continuance of treatment to prolong life when doing so imposes an intolerable burden upon him or her. We sought to describe the features of 'intolerability', at the same time noting that reasonable people may disagree both about what it constitutes and/or when a particular baby's condition meets that condition (paragraphs 2.11–2.16).
- 9.28 We agree that, because they concern his or her very existence and quality of life, the best interests of a baby should be a central consideration and carry the greatest weight. **In according particular weight to the best interests of a baby, we do not view 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 2.30) as more important than the interests that others may have in any significant decisions made about him or her.** Furthermore, to say that the baby's interests are of central importance does not mean his or her interests are the exclusively relevant consideration. Nor can a baby be viewed in isolation from his or her parents. The welfare of the baby is inextricably linked with the ability of the parents to care for and support him or her. The views and feelings of the parents should therefore be accorded considerable weight. Their views carry weight in two different senses. First, in the light of their close bond with the baby, the parents have a strong claim to speak for him or her. Secondly, the potential quality of the life in prospect for the baby is significantly affected by the parents' ability to provide an environment within which he or she can achieve his or her full potential. For this they may require state support.

⁸ We note that the *National Service Framework for Children, Young People and Maternity Services* publishes pain management standards that include babies in neonatal units.

- 9.29 Parents also have interests that are distinct from those of their baby. Caring for a baby with serious disabilities may harm their health, their relationship with a spouse or partner, and the welfare of any existing siblings. Similarly, parents have interests in their own emotional well-being and/or their belief system which may include religious faith. In some cases, parental interests may make it difficult for parents to accept that it is in their baby's best interest for his or her life to be prolonged. For example, the demands on other family members may be perceived as too onerous. In other cases, parental interests may render it equally difficult for parents to accept that it may not be in a baby's best interests to continue to take all measures to keep him or her alive. For example, some parents may interpret their faith as requiring that all life should be preserved, regardless of the futility and demanding nature of treatment. In such cases where there is potential for parental interests to conflict with a baby's interests, these parental interests should not be wholly disregarded but should carry much less weight than those parental interests directly addressing the welfare of the baby. **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 baby who has, or who will develop, a serious condition (paragraph 2.29). Furthermore, careful consideration should be given to the interests of all potentially affected persons, who most usually would be other family members who will live with the child and either care for him or her, or themselves depend on the immediate family for support.**
- 9.30 Doctors, nurses and other members of the healthcare team also have interests that may conflict with their ability to represent the best interests of a baby. Their own emotional wellbeing may be affected by carrying out treatments they perceive as futile or by concerns about their additional responsibilities to care for other babies in their charge. Their willingness to accept a different view of the baby's best interests from parents may be influenced accordingly.
- 9.31 **The view of the Working Party is that the current legal principles centred on seeking agreement between parents and professionals as to the best interests of the baby are, in principle, appropriate and that further legislation designed exclusively to address decisions relating to newborn babies alone is not to be recommended.** We doubt that more general legislation introduced to regulate the kinds of decisions that this Report addresses would offer the necessary clarity and predictability to criteria developed in order to judge best interests, since different interpretations of the criteria defined in any possible statute are likely to occur. **However, we propose that clarification of the criteria by which best interests may be judged would be helpful. We therefore develop such criteria below, with the recommendation that they, or similar criteria, should become part of good practice.** These criteria are intended to help parents and professionals alike assess best interests when deciding the threshold for instituting, withholding or withdrawing treatment from newborn babies. The criteria are not weighted in any way. They are intended as a guide and no single criterion should be the sole influence upon decision making. In all cases the important question is whether it is in the best interests of a baby to receive treatment.
- 9.32 **When a decision must be made by doctors whether or not to institute life support and ventilation immediately after birth, the following points should be considered in assessing the best interests of a baby. This assessment should be made in the light of the guidelines for instituting resuscitation and full intensive care proposed above at paragraph 9.16:**
- (a) **The gestational age of the baby at birth.**
 - (b) **The evidence available indicating the likelihood of survival and incidence of severe disability among babies born at that gestational age.**

(c) The evidence available from the initial assessment on:

- (i) the baby's vitality at birth; and*
- (ii) any significant abnormalities.*

(d) The views and feelings of the parents, in the light of that evidence, and accorded the significance proposed above.

9.33 When a decision must be made whether or not *to institute or to withhold further treatment from a baby after birth*, the following questions should be considered:

(a) To what extent is it likely that the treatment in question will effect a significant prolongation of the child's life? (It will not generally be in the interests of the baby to prolong the process of dying).**(b) What degree of pain, suffering and mental distress will the treatment in question inflict on the baby? Will there be a need for repeated, painful and distressing medical interventions? What measures can be taken to ameliorate any pain, suffering and distress?****(c) What benefits will accrue to the future child from the treatment in question, for example:**

- (i) Will the child at any stage be able to survive independently of life support?⁹*
- (ii) Will treatment increase the chance that the child will be able to be cared for out of hospital?*
- (iii) Will the child be likely to be capable of establishing relationships with other people?*
- (iv) Will the child be likely to be able to experience pleasure of any kind?*

(d) Then, in the light of evidence regarding (a)–(c):

- (i) Do the burdens of treatment outweigh the benefits?*
- (ii) What kind of support is likely to be available to provide the optimum care for the child?*

(e) The views and feelings of the parents as to the interests of the baby, especially in relation to (d).

In the rare case that a baby either has no parents or has been taken into care, the local authority will often be able to exercise parental responsibility in relation to that child. However it is important to be assured that the baby's interests are properly represented. This may be a case that would benefit from early referral to a clinical ethics committee (see paragraphs 9.37–9.39).

9.34 When a decision must be made whether or not *to withdraw life-sustaining treatment from a baby with a limited prognosis*, the following questions should be considered:

(a) For how much longer is it likely that the baby will survive if life-sustaining treatment is continued?**(b) What evidence is there that the baby is experiencing pain, suffering or distress? What measures are being, or could be taken, to ameliorate that pain, suffering or distress?**

⁹ We note that with appropriate care, children on long-term ventilatory support can be discharged from hospital. For an example, see *Best Practice Guidance: Care pathway for the discharge and support of children requiring long term ventilation in the community*, National Service Framework for Children, Young People and Maternity Services. This example in turn is taken from Noyes J and Lewis M (2005) *From Hospital to Home: Guidance on discharge management and community support for children using long-term ventilation* (Barnardo's).

(c) Is it likely that, if life-sustaining treatment is continued, the baby will ever be able to survive independently of life support?¹⁰

(d) What benefits accrue to the baby from continuing life-sustaining treatment?

(i) Is he or she able to establish relationships with other people? Does he or she react to his or her surroundings?

(ii) Does he or she experience pleasure of any kind?

(e) In the light of this evidence:

(i) Do the burdens of continued life support outweigh any benefits?

(ii) Does the baby exhibit signs of effort to survive?

(f) The views and feelings of the parents as to the interests of the baby, especially in relation to (e) above.

Disputed decisions

9.35 No matter how clearly any criteria express the basis on which decisions about the care of a baby *should* be made, professionals and parents will sometimes disagree. **As we have said, we endorse wholly the ideal expressed in Guidelines from the RCPCH that a 'partnership of care', should be one of the fundamental principles behind decisions on withholding and withdrawal of treatment.**¹¹ However we recognise that there is a need for greater consideration to be given to how disputed cases can be resolved.

9.36 **The Working Party recommends that efforts should continue to be made to resolve disputes about the care of a baby by agreement.** Often this will be possible through further discussions within the neonatal unit. A member of the unit or hospital staff with knowledge of the neonatal unit can often be useful as a facilitator in discussions aimed at reaching agreement. Frequently, parents or clinical staff may simply need more time. There may be misunderstandings or miscommunications that can be resolved with local discussion. **If disagreements remain after further discussion, parents should routinely be offered access to a second medical opinion.**

9.37 There is a perception that the courts are being asked to resolve a growing (though still small) number of disputes.¹² In most (but not all cases) the courts are asked to decide where a dispute arises between those responsible for a baby. We consider that there is a role for a forum to assist parents and professionals making these difficult decisions even when there is no dispute. **We therefore recommend that NHS trusts should explore ways to ensure that all neonatal intensive care units have rapid access to a clinical ethics committee, available to families and staff.** Such committees can play a crucial role in resolving the different views held by parties in dispute, and in developing local guidelines appropriate for the community served by the neonatal intensive care unit (see paragraphs 8.48–8.49).

9.38 In the UK, clinical ethics committees are still at an early stage of development. We anticipate that adaptation of existing models will be required and that new committees may have to be set up to ensure that all units have access. Emphasis should be placed upon fostering common approaches in fetal and neonatal medicine and upon consultation with parents.¹³ The NHS is primarily responsible for providing this service to its staff and customers. **The Working Party recommends that the NHS should identify the best mechanisms for the operation of clinical ethics committees able to provide advice on ethical dilemmas in fetal and**

¹⁰ As footnote 9 above.

¹¹ The other principles listed by RCPCH are the duty of care (under which the parents and healthcare team should enter a 'partnership of care' in order to serve the best interests of the child), legal duty and respect for children's rights.

¹² The Working Party was unable to obtain data because records are not kept in a systematic or centralised way.

¹³ The national Patient Advice and Liaison Service (PALS) is a possible source of contact with parents.

neonatal medicine. The chosen model(s) should be implemented on the basis of equal accessibility for parents and all professionals involved in the health or social welfare of the child. In some cases, clinical ethics committees may be able to play a limited role in resolving disputed cases. Whether a decision is disputed or not, rapid support will be needed if clinical ethics committees are to play an effective role in this area of medicine. **We propose that clinical ethics committees should appoint on-call facilitators for more active resolution of differences in critical care decision making before they become entrenched as a dispute.**

9.39 We consider that misunderstandings lie at the heart of many disputes and that providing routes for swift and effective resolution will be best for all parties. We acknowledge that in a limited number of cases, clinical ethics committees may not be a suitable means of resolving differences. If positions have quickly become deeply entrenched there may be little prospect for resolution. Approaching a committee could even add to frustration or delay the case reaching court. In such cases, we propose that mediation may be beneficial, to help the parties work towards a negotiated agreement of their dispute or difference as an alternative to litigation. The mediator will seek to help the parties to find a 'principled resolution' and remain available to help with follow up, whether or not agreement is reached, and with implementation of any agreement. Even if resolution is ultimately not possible, mediation may improve communication and reduce acrimony, leading to a better mutual understanding of the issues that remain to be resolved by the courts. The substantial human and economic costs of taking a case to court should not be underestimated. **The view of the Working Party is that there are potential advantages to using mediation in disputes about critical care decisions in neonatal medicine. We recommend that the UK Departments of Health should examine the benefits that mediation may offer, with a view to setting up a pilot study to evaluate the possible merits for critical care decision making in neonatal medicine (paragraph 8.62).**

9.40 There will always be cases where resort to the courts cannot be avoided. The European Court of Human Rights made it clear in *Glass v UK* that, except in an emergency, doctors wishing to treat or withhold treatment from a child without parental consent act unlawfully if they act without judicial authority. We can envisage no other forum where all parties would feel confident of a dispassionate and objective ruling and consider that they had been given an adequate opportunity to put their case forward. However, the added ordeal of litigation adds to the responsibility already borne by a baby's parents as well as the professionals involved. Publicity and media coverage can add to that ordeal. There is a trend towards open hearings for disputes about the care of the newborn which is in keeping with a general trend towards more openness within the Family Division of the High Court. This has led to such disputes acquiring a much higher public profile. **We note that as the Family Division moves towards more open hearings, measures will be put in place to protect the privacy of families and professionals if this is their preference. We endorse this plan.**

Economic considerations

9.41 The limitation of resources for healthcare is a major topic of debate in the UK, especially where the lives of babies are at stake. There is now much broader public awareness of the need for difficult choices to be made by the providers of national healthcare. We have discussed the difficult economic issues which have to be managed in neonatal medicine because more babies are able to survive than in the past. We noted that the current national (macro-economic) level of provision of neonatal intensive care does not always meet demand and a baby in need of intensive care may have to be moved hundreds of miles from the hospital in

¹⁴ Work by Dr M Redshaw and Dr K Hamilton published in the BLISS Baby Report 2006.

which he or she was born.¹⁴ Health outcomes may thus be put at risk. Contentiously, this has caused questioning of whether funds spent on resuscitating or prolonging the life of babies where the prognosis is very poor are spent appropriately. Can this be reconciled with the aim of healthcare professionals to treat ‘the baby in front of them’? There is also an overarching issue of how policy makers should allocate finite healthcare resources for the lifelong healthcare needs of a newborn baby starting life at high risk of serious disabilities. **The view of the Working Party is that economic factors must not be the sole consideration in seeking to maximise health benefits. Although by no means exclusive to neonatal medicine, additional principles such as equity and justice should also be taken into account by decision makers (see paragraphs 2.39–2.43).** For example, there remain wide differences in infant mortality between different parts of the country and low birth-weights are more prevalent in lower socioeconomic groups.¹⁵

- 9.42 Supply does not necessarily meet demand. Policy makers and managers responsible for providing resources to neonatal units (the mesoeconomic level of decision making) are aware that comprehensive provision may not be possible without cuts to other services so that, for example, spending more on the very young may reduce the amount available to help the elderly or vice versa. We take the view that policy makers and managers should be fair when distributing resources. We are aware that there is wide-ranging debate, but no consensus, on whether there is any reasonable or fair basis for judging that the age of a patient should be a relevant consideration in any such distribution. We consider that devolution by central government of all responsibility for provision of services to local commissioners is inequitable, as it is unjust that a baby’s chances of receiving appropriate intensive care or subsequent continuing care should depend on where he or she is born. **We conclude that the economic dilemmas posed by the provision of neonatal intensive care highlight the need for a much broader independent analysis of the use of NHS resources, with a view to providing national guidance on allocating resources for healthcare in an efficient and equitable manner.**¹⁶
- 9.43 In the context of fetal and neonatal medicine, decisions at the microeconomic level about critical care of a fetus or baby are made by members of healthcare teams with parents. **At the microeconomic level of decision making, the Working Party recommends that parties should be aware of, but not driven by, the resource implications of their decisions. Such decisions should be determined, not by economic considerations, but by clinical judgements of priority, which take into account the best interests of the babies concerned. Healthcare professionals caring for babies in neonatal intensive care units should therefore continue to do the best possible for the ‘patient in front of them’ (see paragraphs 2.39 and 2.43).**
- 9.44 We have proposed the use of guidelines for the initiation of intensive care in babies for whom critical care decisions need to be made. **We emphasise that our justification for the use of guidelines is not constrained by concerns about limitations on resources. It rests on a judgement about what is in the best interests of a child. Furthermore we wish to reiterate firmly that, just as we find no difference in the moral status of a child of six days, months or years, we find no morally relevant differences between disabled and able-bodied children and adults. Each must be given equal consideration. It is therefore important that all those involved in critical care decisions, especially**

¹⁵ *Ibid.*; Moser K, Li L and Power C J (2003) Social inequalities in low birthweight in England and Wales: trends and implications for future and implications for future population health *J Epidemiol Community Health* 57: 687–91.

¹⁶ We note that the National Institute for Health and Clinical Excellence (NICE) has published guidelines for judgements concerning social values that should be incorporated into processes used to develop NICE guidance. These guidelines are primarily concerned with the judgements that are involved in developing conclusions about cost-effectiveness and particularly those that have implications for priority setting and resource allocation. See National Institute for Health and Clinical Excellence (2005) *Social Value Judgements: Principles for the development of NICE guidance*.

parents, doctors, and nurses, do not feel pressured to allow babies to die because of the risk of disability (paragraph 2.39).

Lifelong support for the disabled child

- 9.45 At the macroeconomic level, any decision to provide intensive care for babies at risk of severe disability if they survive has resource implications beyond the sphere of neonatal medicine. These arise from the costs of caring for children as they grow into adults and providing support to families with disabled children. Advances in medicine and technology have meant that each year many children survive who would not otherwise have done so. Some of these children will require lifelong healthcare, social and educational support to be able to enjoy a reasonable quality of life. Yet in the UK, current support for disabled people and their families is uneven at best and, without adequate support, disabled children are unlikely to reach their full potential.
- 9.46 In the UK the law currently prohibits active measures to end the life of the newborn, a position which, as we have said, the Working Party endorses. Clinical guidelines impose very strict conditions limiting when treatment for life support can be withdrawn from a baby. There is also legislation to protect disabled people from discrimination (see Chapter 7). In other words, UK practice is to save life where possible and to protect the quality of that life. It is our view that consistency in this regard is essential. Adequate support for the lives of those people whose existence we endorse through decisions taken at or shortly after birth must be provided. By default, the current inadequacies of provision have a negative impact on the quality of life, not only for the child, but also their family. In this context we note the importance of specialist short- and long-term foster care for seriously disabled children.¹⁷ **We endorse Standard 8 of the National Service Framework for Children which states a requirement for families to be provided with a range of appropriate family support services that are flexible and responsive to their needs, and recommend that this should apply to all national governments and assemblies responsible for the different countries of the UK.¹⁸ In this regard we urge the UK Departments of Health; Education and Skills; and Work and Pensions to accept further responsibility for supporting families who care for disabled children and adults by providing more resources to ensure that adequate and effective services are provided uniformly across the UK. We also ask the Departments of Health; and Education and Skills to provide the necessary resources to monitor this provision of care.**

Monitoring and research

- 9.47 It is the view of the Working Party that measures are required to help reduce the uncertainty currently associated with making decisions during pregnancy on the critical care of a fetus or, after birth, about a baby. We identify two broad areas for action: improved processes of communication and the need for more data on outcomes.
- 9.48 We gained valuable information and insight from experienced clinical teams working in this field, from parents who shared their experiences of critical care decisions made for their baby (see Appendix 1), from the research data that are available (see Chapter 5) and from our wider consultation (see Appendix 2). However, while first-hand experiences convey some sense of many of the issues, they cannot be seen as definitive and may miss some of the complexity of how different parties view those issues. To help to identify variations in practice, experience and views, further research is required. **The Working Party therefore recommends to the RCOG, the RCPCH, the RCN, the NNA and the RCM that objective, systematic (obser-**

¹⁷ The Department of Health announced a review on the long-term sustainability of children's hospices on 29 May 2006.

¹⁸ See Disabled Child Standard, *National Service Framework for Children, Young People and Maternity Services*, available at: <http://www.dh.gov.uk/assetRoot/04/09/05/56/04090556.pdf>, accessed on: 17 July 2006.

vational and interview) data, rigorously analysed, are needed on how the different parties interact when making decisions to resuscitate babies who are critically ill or born at the borderline of viability, and also decisions to withdraw intensive care. This information will further understanding, provide an evidence base for identifying and applying changes to guidelines for practice, and assist with the more effective resolution of differences of opinion (paragraph 6.26). There is also little evidence available on how prior experience influences either clinical teams or parents, in terms of wider personal, familial, social and cultural factors (paragraph 3.21). **Sociological research is needed to identify these factors and the extent to which they carry weight as individuals interact during the decision-making process.**

- 9.49 Neonatal critical care decisions are particularly difficult because of the lack of information from long-term follow up on which to base predictions of future health outcomes. It is crucial that accurate and up-to-date evidence from research is available to doctors and parents about the risks to and likely outcomes for babies in whom a birth abnormality or genetic disorder has been recognised antenatally or in the newborn period, as well as for extremely premature babies. Follow up is needed not only for groups of children diagnosed with health difficulties before or around the time of birth, but also for children who have minor symptoms at birth but are at potential risk of late-onset problems.¹⁹ **Our view is that data linkage with longer-term events in later stages of a child's life, through adolescence to adulthood, captured through NHS health records and educational records, will provide crucial information on outcomes. Although the necessary electronic NHS systems are not yet in place, it is timely to consider the health-related questions that should be posed and corresponding requirements for data collection (see paragraphs 6.45–6.50).** We recommend that proposals for studies based solely on data linkage, that do not require contact with patients or their families, should be referred to the Department of Health Patient Information Advisory Group to request access to the relevant patient information, on grounds that it would be strongly in the public interest to determine outcomes from critical care decisions.²⁰
- 9.50 In addition to the follow up of babies for whom critical care decisions had to be made at the fetal or neonatal stage, our view is that, provided the subject is introduced sensitively and appropriately and there is parental consent, useful information can be gained from autopsy examinations for fetuses and babies who do not survive. Autopsy data may provide some insights into the cause of death and help parents in planning future pregnancies. Furthermore, if doctors can gain a better understanding of the causes underlying clinical conditions, other parents can be given more accurate information when making decisions, and research efforts can be directed towards obtaining more precise diagnoses. **Therefore the Working Party encourages doctors to recommend and parents to consider autopsy in order to add to knowledge about causes of death (see paragraph 6.51).**

Information, education and training

- 9.51 Good decision making in critical care depends on the quality and comprehensibility of the information available to parents and how that information is conveyed by healthcare professionals. **Parents need timely provision of accessible information on the nature of potential disability and long-term consequences of decisions made in fetal and neonatal med-**

¹⁹ The Working Party notes that a similar need for long-term follow up of children has been identified in the USA, and in other areas where there is a potential but unanticipated risk of late-onset problems, for example arising from acquired brain injury.

²⁰ See <http://www.advisorybodies.doh.gov.uk/piag/>, accessed on: 26 May 2006.

²¹ The NSF for Children recommends that women should make informed choices and plan their care in partnership with professionals and that a woman should have easy access to information and support throughout her pregnancy. The relevant NSF care pathway is at: <http://www.dh.gov.uk/assetRoot/04/09/05/23/04090523.pdf>, accessed on: 17 July 2006.

icine. We propose that, where appropriate, this material should be provided as part of the individually based pathway of care for a pregnant woman.²¹ For example, pregnant women for whom an extremely premature birth is imminent should, where practicable, be given written information on prematurity, explaining the risks and the procedures that will occur.²² **The information needs to be available in different languages and formats to meet the needs of different individuals, as specified in the Standards of the National Service Framework for Children.²³ It should include both national and local statistics and be updated regularly. We emphasise that written information must be accompanied by face to face discussion and explanation with the expectant mother and her partner or others who are there to support her (if she wishes).**

- 9.52 **We recommend that standards for the provision of such information need to be developed and implemented by the relevant organisations. We propose that such organisations (for example, the RCOG, RCPCH, BAPM, RCN, NNA and RCM) should liaise with groups that advocate for parents (for example, the National Childbirth Trust (NCT), BLISS – The premature baby charity and the Stillbirth and Neonatal Death Charity (SANDS)) and that the Healthcare Commission should monitor delivery of this information to measurable standards. We recommend that any discussions about the provision of information would benefit from the involvement of families and others who have direct experience of continuing specialist care at home after leaving hospital or of what disability can mean for older children and their families.** Account should be taken of the NICE standards for information-giving during pregnancy and the neonatal period and the RCPCH standards required for professional competency in neonatal medicine, which cover communication skills.²⁴
- 9.53 **As part of this proposed collaboration on standards for information giving, we recommend that the relevant organisations should develop, and evaluate the value and feasibility of, making written or audiovisual guides available for local use by fetal medicine and neonatal intensive care units. These guides would promote continuing education in fetal and neonatal medicine by setting out how healthcare professionals should approach critical care decision making.** We note that healthcare professionals are likely to need specific training to help them understand the perspectives of parents faced with critical care decisions and to communicate effectively with them. This training could also help doctors and nurses reconcile decisions that are different from the choices they would have made for themselves.
- 9.54 Misunderstandings about the role of the criminal law in relation to withholding and withdrawing treatment are not uncommon. Similarly, healthcare professionals are not always well acquainted with broader ethical debates outside the general guidance offered by their professional organisations. **We therefore recommend that the RCOG, RCPCH, RCM, RCN and the NNA should encourage medical and nursing schools to develop undergraduate and postgraduate educational programmes in the law and ethics relating to fetal and neonatal medicine, as appropriate.**

²² We acknowledge that a woman who is about to give birth will not necessarily be in a state of mind to read or digest written information. Nevertheless, it may be valuable to her later; and if a partner, family member or friend is with her, they may find it helpful.

²³ Department for Education and Skills and Department of Health (2004) *Maternity Standard, National Service Framework for Children, Young People and Maternity Services* (London: Department of Health), available at: <http://www.dh.gov.uk/assetRoot/04/09/05/23/04090523.pdf>, accessed on: 31 July 2006.

²⁴ National Collaborating Centre for Women's and Children's Health, Commissioned by the National Institute for Clinical Excellence (2003) *Antenatal Care: Routine care for the healthy pregnant woman* (London: RCOG Press); National Institute for Clinical Excellence (2006) *Routine Post-natal Care of Women and their Babies*, available at: <http://www.nice.org.uk/page.aspx?o=CG37>, accessed on: 28 Sept 2006; Royal College of Paediatrics and Child Health Specialist Advisory Committee for Neonatal Medicine (2001) *Competency Framework for Sub-Specialty Training in Neonatal Medicine* (London: RCPCH).

Appendices



Appendix 1: Method of working

In 2003, the Council held a workshop to discuss ethical issues raised by prolonging life. The Council subsequently established a Working Party to focus on ethical issues surrounding critical care decisions in fetal and neonatal medicine in October 2004. This Report is the result of ten meetings of the Working Party, additional fact-finding meetings including visits to hospitals, and an interfaith workshop. Brief details about these meetings are provided below. The Council also held an external consultation between March and June 2005, details of which are in Appendix 2.

During the progress of the Working Party, the Council worked with Ecsite-UK, the UK Network of Science Centres and Museums, to develop workshops for young people on the issues surrounding the treatment of premature babies. The Working Party provided advice on the content of the workshop materials and individual members took part as guest speakers. A total of 659 people aged 14–19 were involved in six debates in schools and science centres around the country between October 2005 and March 2006. A summary of the discussions, which can be found on the Council's website, was presented to the Working Party in April 2006.

The Working Party and the Council are extremely grateful to all those who have contributed to this study by providing valuable insights and information.

Fact-finding meetings

11 February 2005, Nottingham

Fact-finding meeting to consider the ethical dilemmas encountered in different areas of fetal and neonatal medicine

Mr Zarko Alfirevic, Fetal Medicine Specialist, Liverpool

Mrs Sally Boxall, Midwife, Southampton

Ms Rachel Chittick, Neonatal Nurse Practitioner, Liverpool

Mrs Anne Coleman, Neonatal Nurse and Counsellor, Nottingham

Dr Ian Laing, Neonatologist, Edinburgh

Dr Chris Packham, Consultant in Public Health Medicine, Nottingham

Ms Alison Challenger, Directorate of Health Equality, Nottingham

Programme

- Presentations and discussion of ethical issues in dealing with fetal abnormalities
- Presentations and discussion of ethical issues in managing extreme prematurity
- Presentations and discussion of ethical issues in end-of-life decisions after birth
- Optional tour of the neonatal intensive care unit

23 March 2005, Manchester

Fact-finding meeting at the Department of Neonatal Medicine, St Mary's Hospital, Manchester

Dr Anthony Emmerson, Director of Neonatal Services

Dr Ngozi Edi-Osagie, Consultant Neonatologist

Ms Debbie Roberts and Mr Andrew Clark, parents of Corey Roberts

Sisters Marion Pass and Vivien Evans, Neonatal Medical Unit Bereavement Team

Professor Malcolm Chiswick, Medical Director, Manchester Royal Infirmary

Dr Michael Maresh, Consultant, Obstetrics and Gynaecology Department

Programme

- Tour of the department
- Discussion with neonatologists
- Discussion with parents
- Discussion with members of the Neonatal Medical Unit Bereavement Team
- General discussion
- Discussion with obstetrician

21 July 2005, London

Fact-finding meeting at the neonatal unit at Homerton Hospital, Hackney, London

Professor Kate Costeloe, Professor of Paediatrics and Consultant Neonatal Paediatrician

Dr Shad Husain, Clinical Director and Consultant Neonatal Paediatrician

Ms Nancy Hallett, Medical Director of the Trust

Dr Narendra Aladangady, Consultant Neonatal Paediatrician

Dr Swee Fang, Consultant Neonatal Paediatrician

Ms Olga Kurtianyk, Operations Manager

Ms Jane Steele, Counsellor

Sister Johnette Brown, Counsellor

Reverend Russell Ogston, Assistant Chaplain

Ms Amrik Devgun, Advocacy Team Leader

Programme

- Tour of neonatal unit
- Meeting with senior clinicians
- Meeting with nursing staff and counsellors
- Closing discussion

31 August 2005, London

Fact-finding meeting with representatives from BLISS – The premature baby charity and parents of children born prematurely

Ms Bonnie Green, Head of Professional and Public Affairs, BLISS – The premature baby charity (also a Member of the Working Party)

Ms Shanit Marshall, Head of Information and Support, BLISS – The premature baby charity

Mrs Pearl and Mr Glynn Pope, parents, and their daughter Heather

Mr Matthew Henson, parent

Mrs Carrie Barker, parent

Programme

- Contributions from parents
- Contributions from representatives from BLISS
- Open discussion

8 September 2005, London

Workshop to consider faith-based perspectives on critical care decisions in fetal and neonatal medicine

Mr Bimal Das, General Secretary, National Council of Hindu Temples (UK)

Sister Vivien Evans, St Mary's Hospital and University of Manchester

Ms Claire Foster, Policy Adviser, Church of England Community and Public Affairs Board

Canon Robin Gill, Department of Theology and Religious Studies, University of Kent at Canterbury

Professor Peter Harvey, Professor of Buddhist Ethics, University of Sunderland

Dr David Jones, Catholic Bishops Conference

Mr Eli Kernkraut, family adviser for the Jewish community

Reverend Dr Neil Messer, Faculty of Theology and Religious Studies, University of Wales, Lampeter, and United Reformed Church

Dr Syed Aziz Pasha, General Secretary, Union of Muslim Organisations of UK and Eire

Rabbi Dr Jonathan Romain, Maidenhead Synagogue

Dr Peter Saunders, General Secretary, Christian Medical Fellowship

Reverend Prebendary Peter Speck, Honorary Visiting Research Fellow at Southampton University

Programme

- Opening remarks and introduction
- Scenario-based discussion
- General discussion
- Concluding remarks

10 November 2005, London

Fact-finding meeting with the Director of Antenatal Results and Choices (ARC)

Ms Jane Fisher, Director

Programme

- Presentation on parental decision making and the work of ARC
- General discussion

10 January 2006, London

Fact-finding meeting at Ickburgh School, Clapton, a federated school for children with severe or profound learning disabilities aged two to 18 years

Mrs Shirleyanne Sullivan, Head Teacher

Various members of staff and therapists

Pupils

Programme:

- Background to the school
- Discussion of issues relating to education and long-term prospects for children with disabilities
- Tour of the school

31 January 2006, Paris, France

Fact-finding meeting with members of the CCNE and Espace Ethique of Assistance Publique Hopitaux de Paris to discuss current practices in neonatal and fetal medicine in France

Professor Didier Sicard, President, CCNE, and Professor of Internal Medicine, Cochin Hospital
Madame Marie-Helen Mouneyrat, General Secretary, CCNE
Professor Marc Guerrier, Vice Director, de l'Espace Ethique de l'AP-HP
Professor Guy Moriette, Head of neonatal services at Port-Royal Hospital
Dr Laurence Caeymaex, premature baby specialist, Henri Mondor Hospital

Programme

- Clinical practice in France and the UK
- Ethical issues in France and the UK
- Regulation and guidance in France and the UK
- General discussion

2 February 2006, London

Fact-finding meeting with healthcare commissioners and managers

Dr Daphne Austin, Consultant in Public Health, West Midlands Specialised Services Agency
Mr Simon Brake, Lead Commissioning Manager, West Midlands Specialist Services Agency
Dr Bryan Gill, Consultant in Neonatology, Leeds General Infirmary
Ms Ruth Moore, Network Manager, Staffordshire, Shropshire and Black Country Network University Hospital

Programme

- Presentations by participants on their experiences of commissioning and managing maternal, neonatal and paediatric services
- Discussion

17 March 2006, Amsterdam, the Netherlands

Fact-finding meeting with clinicians, lawyers and ethicists to discuss current practices in neonatal and fetal medicine in the Netherlands

Dr Arie Bos, Neonatologist, Groningen
Dr Hens Brouwers, Neonatologist, Utrecht
Professor Dr John Griffiths, Faculty of Law, Groningen
Professor Dr Govert den Hartogh, Ethicist, Amsterdam
Dr Agnes van der Heide, Epidemiologist, Rotterdam
Professor Dr Evert van Leeuwen, Ethicist, Amsterdam

Dr Eduard Verhagen, Neonatologist, Groningen

Professor Ruud ter Meulen, Ethicist, Bristol

Programme

- Presentations on euthanasia in the Netherlands and on withholding and withdrawing treatment from babies in the Netherlands, and comparisons with the UK, followed by discussion
- Presentations on the Groningen Protocol, and a comparison with the UK, followed by discussion
- Presentations on ethics before and after birth, and a comparison with the UK, followed by discussion

24 May 2006, Manchester

Fact-finding meeting to discuss the operation of mediation processes

Mr Tony Allen, Director, Centre for Effective Dispute Resolution (CEDR)

Mrs Heather Allen, CEDR Mediator

1 June 2006, London

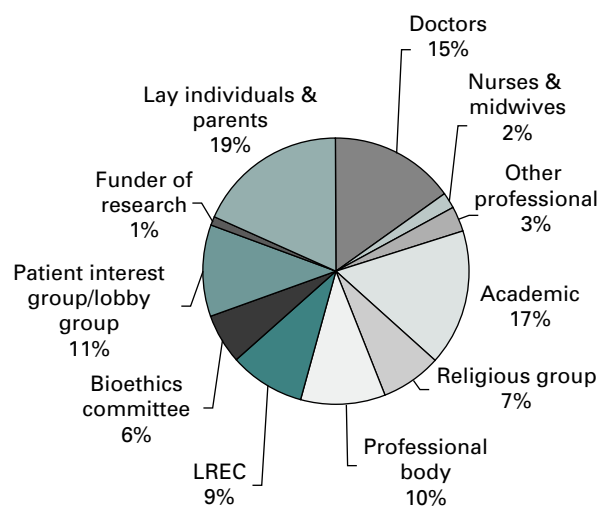
Fact-finding meeting about the operation of clinical ethics committees (CECs)

Professor Mike Parker, Director of the Ethox Centre and Professor of Bioethics, University of Oxford

- Presentation about the operation of CECs to resolve disputes
- Discussion

Appendix 2: Wider consultation for the Report

A consultation was held between March and June 2005. This was based on a consultation paper which contained background information and a set of nine questions for respondents to answer if they wished. The Council disseminated 1,200 copies of the Paper to relevant individuals and organisations and it was also available online. Organisations and members of the public were invited to reply. Approximately 100 responses to the consultation were received, 53% of which were from individuals and 47% from organisations. Respondents fell broadly into the following categories:



The Council is grateful for the responses and found them to be thoughtful and comprehensive. Members of the Working Party used the points raised to inform their deliberations and would like to thank everyone who contributed. The questions, a summary of the responses and the list of respondents are provided in this Appendix. The views we have included in the summary were selected either to display the range of different comments or to highlight particularly interesting perspectives. It is not a systematic selection. Many respondents agreed to make their submissions available on the Council's website.

Questions in the Consultation Paper

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?¹

¹ 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 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?

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?

Question 7

Should a quality-adjusted life year (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?

Summary of responses

On measures to sustain the life of the fetus

Some respondents took the view that all possible measures to prolong life should be taken because no human being is in a position to judge if a life may or may not be 'worth' living. There was more reluctance, however, to perform serious, risky procedures on the fetus, which necessarily involved entering the body of the pregnant woman, than there was to performing such procedures on the infant after birth. There were several references to the need to balance the chance of significantly improving the condition of the fetus against the risk of the procedure to the mother.

Overriding the wishes of the pregnant woman

The overwhelming majority of respondents were of the view that a pregnant woman's wishes should not be overridden, except in the most exceptional of circumstances. One respondent believed that there is no reason why a mother should not be allowed to sacrifice herself to preserve a viable baby if she wished to do so. A medical professional raised the question of who should have authority when an otherwise healthy fetus is in distress at the time of birth and the mother refuses a Caesarean or delivery using vacuum suction or forceps. Another correspondent also highlighted this difficulty, and commented that some women later report regret at not having consented to proven medical interventions. This decision might be one that needs to be made quickly, possibly in frightening circumstances for the mother. It was suggested again that the balance between the mother's wishes and the baby's interests could be considered on the basis of the invasiveness and risk to the mother. A similar situation also arises if the mother is not mentally competent to make a decision at the time.

There were several respondents who wished to see some pregnant women act in what they would regard as a more morally responsible way towards their fetus. One, for example, thought that if healthcare professionals believed strongly that a woman's lifestyle choices might negatively affect fetal development, this could be sufficient reason to override her wishes. Some people saw this issue as being linked with that of deciding the appropriate 'moral status' of the fetus. Certain respondents were in favour of giving 'rights' to fetuses even if this would result in conflict between professionals and pregnant women whose actions might compromise the health of their fetus. Others thought that pregnant women should not be coerced into undergoing procedures against their wishes, even if they were risking the health of the developing fetus.

Causes of prematurity and disability

There was concern about the causes of the rise in the rate of premature births and it was proposed that they needed to be investigated. Certain groups that are opposed to termination linked the procedures involved to an increase in risk of prematurity in subsequent pregnancies. Some respondents highlighted the need to consider disabilities caused by factors other than prematurity, including by medical procedures close to the time of birth.

Prolonging the life of the newborn

An ethics committee, responding to the consultation, recommended that, when deciding whether or not to resuscitate and ventilate extremely premature babies, the UK should adopt the usual US approach of treating until there was certainty of prognosis. Many respondents expressed their belief that all possible measures should be taken to prolong the life of newborn babies. Some were parents of premature babies who had survived. There was a suggestion that medical professionals were unaware of the more positive outcomes of children who grew up to be healthy after a poor prognosis. Several wrote to us with accounts of their prematurely born babies who had later thrived, as in the case of the twin brothers, Jett and Seth:

“My 23 week twin boys had undergone much medicine and many more surgeries. We were told that the lung disease alone may take the life of one and they were sure he [Jett] would need to go home on oxygen. He is now home after 4 months in the NICU and he has not needed oxygen since he was 3 months old. There is no way to tell how a baby will come out of a situation . . . each baby is different.”

Josh and Andrea Quigg

The second twin Seth only lived for six days. These parents felt strongly that the babies should be enabled to survive if at all possible and that their treatment should not be discontinued. With regard to critical care decisions involving the artificial ventilation of babies having ‘serious abnormalities’, our attention was drawn to the difficulties of defining what is meant by the term. ‘Serious abnormalities’ is used to describe a range of medical problems experienced by very premature or very ill babies. Some respondents considered the term as vague and open to interpretation and the following qualification was suggested:

“[the term ‘serious abnormalities’] includes conditions that combine profound physical and likely cognitive impairment with poor or limited prognosis but note that in some instances this is a changing territory”.

*Dr Simon Woods and Dr Tom Shakespeare,
Policy Ethics and Life Sciences Research Institute (PEALS),
Newcastle University, UK*

The religious beliefs of some respondents led them to the conclusion that all human life is important, regardless of subjective views of the quality of that life. However, not all the correspondents who expressed their religious views thought that life should be prolonged whatever the circumstances. Two Christian organisations stated that intensive life support should not have the purpose of prolonging life if there would never be the prospect of recovery.

Some respondents who identified themselves as medical professionals were very concerned about performing highly invasive and intensive treatment on babies who had acquired brain damage and who were considered likely to have severe disabilities in the future. A proposal was made that when repeated efforts to treat or resuscitate a newborn baby were thought to be causing too much suffering, it would be reasonable to withhold further treatment. It was thought preferable for the parents to be in agreement with the decision. Another respondent suggested that, in very serious cases, it could be beneficial for parents if active treatment was continued until they accepted that the situation was futile or intolerable. It was noticeable that medical professionals emphasised the need to consider issues about the future quality of life when making treatment decisions, whereas many of the parents who responded, and an ethics committee, were cautious about making quality of life decisions on behalf of others. One response considered that questions about the future quality of life for a baby should not be decided by a committee, in isolation from any actual medical case. It was suggested that the Working Party could interview teenagers and adults who had been through life-threatening experiences in fetal or neonatal life, and obtain their views.

Some respondents emphasised that medical professionals needed to understand that parents' personal, religious and cultural beliefs would affect their decision making. There was recognition that quality of life for a child could be assessed differently by different people. Those who thought that consideration of the future quality of life for a very ill baby was important regarded the following as important contributing factors: communication potential; prospect for an independent life; suffering; and life expectancy. A contrasting view was that long-term issues about the quality of life were in fact irrelevant because it was possible that new treatments might be developed in the future.

Several respondents were in favour of case-by-case assessment in the way that is already prevalent in the UK. A different view was expressed by a neonatologist from the Netherlands, who submitted his hospital's guidelines on the resuscitation of very premature babies born between 24 and 28 weeks of pregnancy. He thought that intensive care treatment should not be offered to babies born earlier than 25 weeks of gestation due to the poor survival rates and the very high risk of serious neurodevelopmental disabilities in those who do survive. If babies are born at this stage and show signs of life, the neonatologist would admit them to the unit and administer fluids, nutrients and antibiotics but would not start respiratory support. He drew attention to the benefit of discussing this approach with the parents before birth where it was possible. A paediatric registrar from the UK drew attention to what he interpreted as the present uncertainty over whether to begin resuscitation of a premature baby at birth when the mother has requested that this should not be done.

It was suggested that it would be preferable if parents could make decisions about treatment with a better knowledge of the support, services and therapies that are available to help them care for babies likely to develop disease or disability in the long term. However, there was concern from the Foundation for People with Learning Disabilities that any such information must include a balanced view of disability.

"Too often the birth of a disabled child is presented as a tragedy, whereas the reality is that disabled people often lead full lives, greatly loved by their families."

The Foundation for People with Learning Disabilities

This view was supported by another respondent who pointed out that many people with severe disabilities viewed their lives as having a greater value than that attributed to their lives by others. Disability was recognised as being part of the human condition, whereby many people are 'destined' to experience disability. In contrast, one respondent suggested that prolonging the life of very ill babies was in response more to the availability of medical technology, than because parents held a deep moral imperative that the life of babies otherwise incapable of independence should be sustained.

The differences between countries such as the UK, which has the resources to save the lives of very premature and ill babies, and countries where, owing to a lack of expertise and equipment, such babies might not have the opportunity of treatment were also highlighted.

Ethical questions

We asked correspondents to comment on whether three questions relating to ethical issues were those that should be considered by the Working Party (see Question 3). Many respondents identified questions about the quality of life as particularly important, and members of a local research ethics committee suggested that the aim of critical care decisions should be to limit suffering rather than trying to decide what is right or wrong.

Acting and omitting to act

A range of views were expressed on this doctrine, ranging from respondents who believed there was no difference between acting and omitting to act and those who thought that omissions could be easier to justify than actions that led to the same results. One respondent thought that some

doctors would prefer not to initiate potentially beneficial treatment as its later withdrawal would be an 'act' and therefore more likely to be controversial.

One clinician stated that:

“. . . 'Acting and omitting to act' is the most pressing ethical and legal issue that is constantly faced. Perhaps the Working Party can consider [. . .] how the neonatal intensive care units can establish the mechanisms to enable the staff looking after a baby for whom the discontinuation of active treatment is a possibility, to discuss the ethical considerations amongst themselves in a structured way . . . [involving staff on different shifts].”

Dr Paul de Keyser

The influence of the media

There was limited comment on the role of the media on medical decision making, other than the opinion that the media should not have influence. In general this aspect was not singled out as an important area for the deliberations of the Working Party. Two respondents thought that the influence of the media could not be changed or avoided, and that any analysis would not be a useful objective for the Working Party.

Decision making in critical care situations

It was observed that today many people are no longer as prepared to accept expert advice without questioning it. Many respondents took the view that parents should have the opportunity to make critical care decisions, most often for the reason that they would be most affected by those decisions. There was also a view that the family would be in the best position to judge the quality of life for a child. It was pointed out that the view that the parents' opinions should take precedence was supported by findings from interviews with bereaved parents.

In contrast, some respondents were concerned that parents should not have sole responsibility for making a decision not to continue intensive care. In their view, doctors could be more directive in their advice if they thought it appropriate. One respondent considered that part of the doctor's role was to relieve parents of the guilt that they might feel when a decision had been made to let a baby die, whereas death might have been inevitable. This situation has become more complex as more babies who were very ill or very premature survive.

Some respondents thought that parents should not always have the authority to make decisions about their children. It was suggested that the experience of others was also very important in determining a baby's best interests. For example,

“In situations where the consensus of all agencies suggests that the parent's views do not take the child's best interests into account there must be the ability to override the parental view as the child once born has an independent moral status.”

Mr Richard N Brown, Consultant Obstetrician and Gynaecologist

In situations where parents disagreed, most of our respondents considered that a mother's opinion should have more weight; indeed members of a local research ethics committee thought that this view was widely accepted in the UK. However, others thought that the opinions of mothers and fathers were equally important and that the healthcare team might need to help them find agreement.

There was strong support both from medical professionals and others for the need for consensus. Several responses, including those from professional and parents' organisations, suggested that some parents might be assisted by a trained mediator, an arbitrator or religious or spiritual advisers. One respondent wished to see the development of guidance regarding the most appropriate role

for social workers in critical care decision making. However, a significant number of respondents thought it was necessary for some cases to be taken to the courts, and accepted, with regret, that this sometimes was unavoidable.

The need for good information for parents on health outcomes for very ill and very premature babies was highlighted. However, problems inherent in obtaining that information were identified, such as the difficulty in maintaining its relevance in a changing field.

Economic issues

Several respondents thought that economic issues should not influence decision making involving individual babies. Other respondents were concerned that treatment of the newborn in intensive care was very expensive and suggested that it might be more equitable if the funds were spent on disease prevention or treatment in older people. However, one parent suggested that babies should be provided with whatever treatment they needed as they were not responsible for their condition, whereas economic restrictions may be more appropriate for some adults who require treatment largely as a consequence of their own lifestyle choices. Some respondents pointed out that economic issues already play a part in the treatment of babies and cannot be ignored; as for example when of babies are transferred between neonatal intensive care units when there are shortages of cots.

The use of the QALY, or other similar measures, to inform decision making was rejected by many respondents, who objected to its limitations. Several people felt strongly that QALYs or other similar measures should not be used as the basis for considering whether to treat older people compared with the newborn.

Professional guidance

There was support for drawing up professional guidance for making decisions in critical care, accompanied by a strong sense that it should not be too restrictive. Advisory or 'directive' guidance would be welcomed by some professionals, provided they could retain the flexibility to use their own clinical judgement. For example, the response from the South Manchester Clinical Ethics Committee stated that:

“Such guidance should allow consistency of approach and the development of standards of decision making while still permitting professionals and parents to negotiate freely.”

A few respondents, however, did not see the need for guidance, in some cases viewing this as 'unwarranted interference'. One respondent considered that it might be useful to set out the situation with regard to recourse to the courts when parents and doctors did not agree.

On setting a minimum age at birth below which resuscitation would not be attempted, there were strongly held opinions that this could only ever be arbitrary and the suggestion was referred to as “dangerous” by one respondent. It was observed that strict limits might cause more distress to the medical staff especially if a baby under the limit should show signs of life. However, there were some respondents who would welcome setting a minimum age, mostly to establish 'normal practice', although most who commented, thought that such a guideline should be advisory rather than compulsory. One proponent suggested that professional guidance and a limit for resuscitation would reduce the feeling by parents that they had been subject to the luck of the draw. However, it was also pointed out that it was not always possible to assess accurately the exact length of the pregnancy. Others felt that setting a limit presupposed that all fetuses developed at the same rate, which was not the case. One respondent took the view that limits would become outdated in a very few years due to technical advances in care and treatment. Another considered that it was erroneous to presume that not resuscitating a baby born before a specific limit would inevitably result in death. It

was argued that in some cases, a baby could survive and be at greater risk of disability than if resuscitation had been carried out. There was also a concern that a legal limit for resuscitation could lead to a deterioration in the relationship between parents and the doctors as parents would be likely to prefer assessment on a case-by-case basis.

In conclusion, there was concern from parents of extremely premature babies who had survived, that the introduction of wide-ranging guidelines on the provision of treatment would not have allowed their baby to be considered as an individual case. We did not have any responses from parents who regretted a decision (either their own or the medical team's) to continue treatment for their very ill baby. As we have said, it was noticeable that medical professionals were most concerned about the future quality of life for the babies in their care. However, in most cases this did not override the obligation that they felt to comply with the wishes of the parents. Recognition that it was the parents who would live with the consequences of whatever decisions were made was influential in this regard. Several respondents who work in the field commented that they thought it was important that the most appropriate decisions for each particular family were reached.

New legislation

There was some objection to the introduction of new legislation that would establish criteria for the level of treatment that should be provided as a result of critical care decisions in the newborn. There was strong preference for guidelines as they were more flexible and would allow case-by-case decisions. Members of one clinical ethics committee thought that current legislation was probably inadequate. However, it was also believed that the adoption of more stringent legislation would risk introducing new legal constraints to the current pragmatic and flexible process of decision making.

Life after the neonatal intensive care unit

Several respondents expressed concern for those families where a baby leaves an intensive care unit facing long-term health or development problems. One respondent proposed that if the critical care decisions made by a family were influenced by wider moral expectations, it was unfair to expect all of the costs of disabilities that might affect any children to be borne by the family alone. It was suggested that the Working Party could consider the level of provision that should be made by the state for the care of children with special needs. One parent commented that families were "often in the dark" in terms of the level of support and care to expect on a longer-term basis. The charity Contact a Family drew our attention to the financial costs to a family of bringing up a disabled child; stating that 16% (only 3% full time) of mothers of a disabled child were in employment compared with 61% of other mothers. The charity reported that families with a disabled child were much more likely to experience debt, including arrears in mortgage and rent payments. Another respondent commented that having a disabled child in a family also has consequences for their siblings.

List of respondents

Organisations

Antenatal Results and Choices (ARC), UK

Barking & Havering Local Research Ethics Committee, UK

BLISS – The premature baby charity, UK

British Association of Perinatal Medicine

British Humanist Association

British Medical Association

Bromley Research Ethics Committee, UK

Burnley General Hospital (Peter Ehrhardt, Consultant Paediatrician), UK
Joint Ethico-Medical Committee of The Catholic Union of Great Britain and the Guild of Catholic Doctors
Centre for Ethics in Medicine, University of Bristol, UK
The Children's Trust, UK
Christian Medical Fellowship, UK
The Church of England Mission and Public Affairs Council
Comment on Reproductive Ethics (CORE)
Jerzy Brusilo, Commission of Bioethics, Collegium Medicum of the Jagiellonian University, Poland
(responding both personally and on behalf of the organisation)
Contact a Family, UK
European Bioethical Research, UK
Faculty of Health and Social Care, University of Hull, UK
The Foundation for People with Learning Disabilities, UK
Genetic Interest Group, UK
Hellenic National Bioethics Commission
Professor Dr Francesco Abel, Dr Juan Antonio Camacho, Dr Fco. Jose Cambra, Dra Victoria Cusi,
Professor Nuria Terribas, Institut Borja de Bioetica, Ramon Llull University, Spain
Israel National Council of Bioethics
The Lawyer's Christian Fellowship, UK
LIFE, UK
The Little Foundation, UK
The Mauritius Association of Biomedical Analysts
The Mauritius Institute of Health
Medical Ethics Alliance, UK
Medical Research Council, UK
National Council of Women of Great Britain
National Spiritual Assembly of the Bahá'ís of the United Kingdom
Peruvian Bioethics Association
Dr Simon Woods and Dr Tom Shakespeare, Policy Ethics and Life Sciences Research Institute
(PEALS), Newcastle University, UK
Portsmouth Hospitals NHS Trust Clinical Practice Ethics Committee, UK
Royal College of General Practitioners, UK
Royal College of Midwives, UK
Royal College of Nursing, UK
Royal College of Obstetricians and Gynaecologists, UK
Royal College of Paediatrics and Child Health, UK
Royal College of Physicians, UK

Patient and Carer Network of the Royal College of Physicians, UK

Faculty of Public Health, Royal Colleges of Physicians of the United Kingdom

South Manchester Clinical Ethics Committee

Sub-group of North Nottinghamshire Local Research Ethics Committee, and additional comments from Sherwood Forest Hospitals, UK

Wakefield Local Research Ethics Committee

Individuals

Anonymous (11)

Michael Abrams, Member of the Open Section Council, Royal Society of Medicine, UK

John Adams, Lecturer, UK

Dr Pauline Adiotomre, Consultant Paediatrician, UK

Dr Jayapaul Azariah, All India Bioethics Association, India

Miss Emma Baird, UK

Mr A Beauchamp, South West Devon Research Ethics Committee, UK

KA Bergman MD, Consultant Neonatologist, Department of Paediatrics, Beatrice Children's Hospital, Groningen, The Netherlands

Mr Hugh Bliss, Chairman, West Essex Local Research Ethics Committee, UK

Mrs Andrea J Blood, UK

Dr Richard N Brown, Consultant Obstetrician and Gynaecologist, UK

Dr Alan M Calverd, member of a Local Research Ethics Committee, UK

Dr Carine de Beaufort

Dr Paul de Keyser, Specialist Paediatric Registrar, UK

Jan Deckers, Lecturer, UK

Professor Ames Dhai, Chair of Research Ethics Committee and Head of Bioethics, University of KwaZulu-Natal South Africa

Joanie Dimavicius, UK

Dr David Ferguson, Consultant Paediatrician, UK

John Goodden, UK

Dr Ruth Graham and Dr Judith Rankin, School of Population and Health Sciences, Newcastle University, UK

Mr R J Hall, Member of Ethics Committee, UK

Dr Mark Houghton, General Practitioner, UK

Dr Rosemarie Hutchinson, UK

Ms Claire Jauffret, UK

Dr Ian Jessiman, UK

Professor Shirley R Jones, UK

Jeantine Lunshof, Bioethicist, the Netherlands

Mrs Jayne McCoy, Vice Chair of local branch of the National Childbirth Trust, UK

Jillian Mounter, UK

Staff of the National Perinatal Epidemiology Unit, University of Oxford, UK

Mrs Nicola O'Connor, Mother, UK

Miss Mari Owen, UK

Revd Canon Dr Maureen F Palmer, Sub Dean and Canon Pastor, The Cathedral Church of the Holy Spirit, Guildford, UK

Alexis Picton, UK

Mr Kevin Power, Principal Lecturer, School of Nursing and Midwifery, De Montfort University, Leicester, UK

Josh and Andrea Quigg, Parents, USA

Dr H Rabe, Consultant Neonatologist, Brighton and Sussex University Hospitals, UK

Dr John Smyth, Consultant Neonatologist, Brighton and Sussex University Hospitals, UK

Helen Statham, Senior Research Associate, Centre for Family Research, University of Cambridge, UK

Dr Brenda L Stather-Dunn, Retired Psychiatrist, UK

Dr Chantal Steward, Department of Obstetrics and Gynaecology, University of Cape Town, South Africa

Dame Marilyn Strathern FBA, William Wyse Professor Social Anthropology, University of Cambridge, UK and Member of the Nuffield Council on Bioethics

Mrs Patricia Tan, UK

Dr J H Tripp, Consultant Paediatrician and Senior Lecturer in Child Health; Mrs D Smith Ringer, Research Midwife, Dr M Kealy, Consultant in Communicable Diseases, and Mrs L Trevelyan, Senior Midwifery Manager; all of the Exeter Confidential Enquiry into Perinatal and Early Childhood Deaths, UK

Professor Zephne M van der Spuy, Department of Obstetrics and Gynaecology, University of Cape Town, South Africa

Baroness Mary Warnock, UK

Appendix 3: Causes of neonatal and post-neonatal death

Death certificates record the underlying cause of death of an individual. For neonatal and post-neonatal cases, these causes of death are grouped by the Office of National Statistics into ten main groups. The table below gives the number of deaths assigned to each group for babies born in England and Wales in 2002; the total number of live births in England and Wales in this year was 596,122. Neonatal death refers to death 0–27 days after birth; post-neonatal death refers to death 28–364 days after birth.

Cause of death	Number of neonatal deaths	Number of post-neonatal deaths
Congenital anomalies	523	341
Antepartum infections	39	12
Immaturity-related conditions	1,255	165
Intrapartum asphyxia, anoxia or trauma	237	10
External conditions	10	52
Infections	25	108
Other specific conditions	19	31
Sudden infant deaths	36	144
Other conditions	41	110
Total	2,185	973

Source: Office for National Statistics (2006) Mortality Statistics: Childhood, Infant and Perinatal. Review of the Registrar General on Deaths in England and Wales, 2004 (London: Office for National Statistics). Crown copyright material is reproduced with the permission of the Controller of HMSO and the Queen's Printer for Scotland.

Appendix 4: Brain injury in the newborn baby

Diagnosis of brain injury in the newborn baby

There are three major tools used alongside clinical examination to assess the brain of a newborn baby for abnormalities:

- Ultrasound scanning sends high frequency sound waves into tissue and measures the reflection of sound back (similar to naval sonar). The scanner detects changes that indicate bleeding, enlargement of the normally slit-like fluid-filled spaces (ventricles), and areas of brain injury, often comprising cystic changes which represent areas where brain cells have died. Doppler ultrasound can also be used to measure the speed of blood flow inside blood vessels and is more useful in assessing brain injury in the term baby.
- Magnetic resonance imaging (MRI) involves placing the baby in a powerful magnetic field and reversing the polarity of the magnet, causing tiny radio signals to be emitted by the body which are picked up by a sensitive receiver. With MRI, doctors can now identify areas of injury due to lack of blood supply or lack of oxygen (infarction) with more definition than ultrasound and can better define the details of congenital malformations of the brain and spine.²
- Electroencephalography (EEG) measures the spontaneous electrical activity of the brain. In newborn babies EEG can accurately identify seizures and abnormalities in background brain electrical activity which relate to long-term outcome. In addition the cerebral function monitor (a simple form of EEG) is used to monitor EEG activity over a long period of time and these records have proved usefully predictive of later development.³

Other forms of clinical examination have been developed (some using long periods of video recording) that have proved helpful in predicting if a poor outcome is likely. Other techniques such as computerised (axial) tomography (CT) scanning (computerised scan involving a large dose of X-rays) and testing of specific brain pathways for vision, hearing, sensation and movement are occasionally used, although not in routine practice.

Common forms of brain injury

Periventricular leucomalacia (PVL, literally 'softening of the white matter around the ventricles') is the term used to refer to the usually bilateral injury to the white matter of the brain that occurs in premature babies. The white matter contains mainly nerve fibres, including those which allow the brain to control movement. More severe forms of PVL can be detected by ultrasound scanning, and are usually identified in the neonatal period. Less severe forms cannot be diagnosed on ultrasound at all and appear as changes on MRI scans when investigating an infant with neurological signs later in childhood.

Depending on the site and extent of the brain injury, the risk of later serious disability varies from close to 0% to around 100%. Where there is extensive damage towards the back of the brain, as occurs in 3–5% of those with birthweights below 1,500 g, all surviving children will develop severe

² Biagioni E, Mercuri E, Rutherford M *et al.* (2001) Combined use of electroencephalogram and magnetic resonance imaging in full-term neonates with acute encephalopathy *Pediatrics* **107**: 461–8.

³ *Ibid.*

(spastic) cerebral palsy affecting all limbs and the trunk.⁴ In addition, many affected infants also have serious learning disability, epilepsy, impaired vision and limited communication. Less severe bilateral white matter injury in the same area is followed by cerebral palsy affecting primarily the legs and trunk (spastic diplegia) and is associated with outcomes ranging from dependency to independence.

Germinal matrix haemorrhage (GMH) involves bleeding in and around the ventricles or cavities of the brain, which are filled with cerebrospinal fluid and linked by ducts so the fluid can circulate. It is a common complication of being born very early and occurs in about 25% of babies born with birthweight below 1,500 g.⁵ In premature babies, the fragile blood vessels that supply the germinal matrix near the lining of the ventricles are prone to bleeding. Many haemorrhages are of mild or moderate severity and by themselves may not increase the risk of disability. Large haemorrhages (about 25% of all haemorrhages) and those with complications increase the risk of cerebral palsy.

If GMH is followed by blockage of the drainage channels for the cerebrospinal fluid, the ventricular system can enlarge and hydrocephalus may develop. This is a condition where fluid under pressure expands the brain and head relentlessly.⁶ It is a rare condition and occurs in about one in 3,000 infants in the south west of England for example. Hydrocephalus is frequently associated with a higher risk of cerebral palsy and multiple disabilities although up to 50% of the children may not develop later disability. Whereas the acute haemorrhage can usually be diagnosed within three days of birth, hydrocephalus following GMH may take up to four weeks to develop.

If GMH is associated with local venous obstruction, the area of brain where the blood supply is impeded may become injured as back pressure stops blood flowing through tissue. This condition is termed haemorrhagic parenchymal infarction and the area affected by the infarction will determine the outcome. The effects vary from causing hemiplegia (stiffness, or spasticity, and reduced control of certain limbs) but with good overall function (the child walking independently and having intelligence in the normal range)⁷ to severe spastic cerebral palsy and learning difficulties.

An **encephalopathy** is any disease or disorder affecting the brain and especially chronic degenerative conditions. After birth complicated by intrapartum hypoxia (a critical period of lack of oxygen to the fetus at term during labour and delivery) an encephalopathy may typically occur. This is sometimes termed hypoxic-ischaemic encephalopathy and occurs in 1–2 out of 1,000 full-term deliveries.⁸ The baby does not breathe at birth and requires resuscitation with ventilation. Within hours, encephalopathy becomes obvious with reduced responsiveness, abnormal postures and movements and, in many cases, seizures. Babies who deteriorate to the level of being unresponsive and losing all reflexes for more than 72 hours will have disabilities if they survive. Babies who retain some of their reflexes and responses but are still abnormal at ten days of age will nearly always be disabled.⁹ The type of disability is usually a mixed athetoid (involuntary movements interfering with voluntary movements) and spastic (stiff contracted muscles resistant to passive movement) cerebral palsy in which involuntary movements interfere with normal movement. All four limbs and the trunk are affected. In severe cases, sucking and swallowing might be impaired

⁴ De Vries LS, Van Haastert IL, Rademaker KJ, Koopman C and Groenendaal F (2004) Ultrasound abnormalities preceding cerebral palsy in high-risk preterm infants *J Pediatr* **144**: 815–20; Larroque B, Marret S, Ancel PY *et al.* (2003) White matter damage and intraventricular hemorrhage in very preterm infants: the EIPAGE study *J Pediatr* **143**: 477–83.

⁵ Sheth RD (1998) Trends in incidence and severity of intraventricular hemorrhage *J Child Neurol* **13**: 261–4.

⁶ Whitelaw A, Thoresen M and Pople I (2002) Posthaemorrhagic ventricular dilatation *Arch Dis Child Fetal Neonatal Ed* **86**: F72–4.

⁷ Volpe JJ (1989) Intraventricular hemorrhage and brain injury in the premature infant. Diagnosis, prognosis, and prevention *Clin Perinatol* **16**: 387–411.

⁸ Smith J, Wells L and Dodd K (2000) The continuing fall in incidence of hypoxic-ischaemic encephalopathy in term infants *Br J Obstet Gynaecol* **107**: 461–6.

⁹ Volpe JJ (2001) *Neurology of the Newborn* 3rd Edition (Philadelphia: Saunders).

and/or the growth of the whole brain is reduced with associated **microcephaly** (a small head size for age), resulting in severe learning disability. Epilepsy is also common.

Brain death in the newborn baby

The concept of 'brain death' is established in UK law and medical practice. In the UK, brain death requires a firm clinical diagnosis as to the cause of brain injury and the loss of brain stem responses including spontaneous respiration.¹⁰ However, using this term is understood to be inappropriate for babies below 37 weeks of gestation because of differences in the brain at this early stage in development. In babies between 37 weeks of gestation to two months of age it is rarely possible to confidently diagnose brain stem death.¹¹ It is very unusual for a newborn baby with the common types of neonatal brain injury and abnormality that are observed at birth to meet the formal criteria for brain death, even after severe brain injury.¹² We note therefore that when withdrawal of life support is considered for critically ill babies, the child is not brain dead but legally alive.¹³

¹⁰ Pallis C (1980) Diagnosis of brain death *BMJ* **281**: 1491–2; *Re A* [1992] 3 Med LR 303. Additional criteria that rest on the velocity of cerebral blood flow velocity in the diagnosis of neonatal brain death have been suggested.

¹¹ British Paediatric Association (1991) *Diagnosis of brain stem death in infants and children* (London: British Paediatric Association).

¹² Guidance suggests that at this stage in development decisions on whether to continue treatment should be based on 'an assessment of the likely outcome of the condition, after close discussion with the family'. British Paediatric Association (1991) *Diagnosis of brain stem death in infants and children* (London: British Paediatric Association).

¹³ British Paediatric Association (1991) *Diagnosis of brain stem death in infants and children* (London: British Paediatric Association); Royal College of Paediatrics and Child Health (2004) *Withholding or Withdrawing Life Sustaining Treatment in Children: A framework for practice* (London: RCPCH).

Appendix 5: Consent for treatment

It is a general legal and ethical principle that valid consent must be obtained before examining or treating a patient whenever possible. This principle reflects the right of an individual to determine what is done to their own body. For consent to be valid, it must be:

- informed, that is, given after explanation of the procedure involved
- given by someone who has the capacity to consent, that is, given by someone able to understand and retain the information provided about the procedure
- given voluntarily.

In the case of babies and infants, consent for treatment is normally provided by someone with parental responsibility for the child.¹⁴ In providing consent, parents are required to consider what they judge to be in their child's best interests (see paragraph 8.20).¹⁵

Issues relating to consent may arise when a relative is not available to provide consent for the treatment of a child, for example when urgent treatment is needed after birth when a mother may herself be receiving medical attention. Guidance documents issued by the Department of Health, the British Medical Association (BMA) and the General Medical Council (GMC) suggest that in an emergency a doctor would be justified in providing treatment for a child without consent if the treatment was urgently required and in the child's best interests (see Appendix 9). The British Association of Perinatal Medicine (BAPM) specifically comments on the case of the newborn: "In emergency, if consent cannot be obtained, e.g. because nobody with parental responsibility is available or the parents are too distressed to give valid informed consent, treatment may lawfully be started if clinicians believe it to be in the child's best interests." The Association notes that "It should always be possible later to justify that action to the parents, and to reassure them that what was done was in the best interests of the baby." In other situations where it is not possible to gain consent, it advises health professionals to contact Social Services and, if necessary, seek legal advice.¹⁶

Consent can be obtained in different ways depending on the situation and procedure involved. In some cases a parent complying with a health professional's request, for example to open the child's mouth for their throat to be examined, would be considered to be consent (sometimes called implicit consent). In other cases, usually where the treatment is more complex or where significant risks or side effects are involved, consent is given explicitly, either verbally or by signing a form. BAPM has produced a list of common neonatal investigations and interventions and suggests whether or not explicit consent should usually be required.¹⁷

¹⁴ The Children Act 1989 sets out persons who may have parental responsibility. Depending on the circumstances this may be one or both parents, a legally appointed guardian, or a Local Authority. For further details see Department of Health (2001) *Reference Guide to Consent for Examination or Treatment*, available at: <http://www.dh.gov.uk/assetRoot/04/01/90/79/04019079.pdf>, accessed on: 25 May 2006.

¹⁵ Department of Health (2001) *Consent – What You Have a Right to Expect: A guide for parents*, available at: <http://www.dh.gov.uk/assetRoot/04/11/73/53/04117353.pdf>, accessed on: 27 July 2006.

¹⁶ British Association of Perinatal Medicine (2004) *Consent in Neonatal Clinical Care: Good practice framework*, available at: <http://www.bapm.org/publications/>, accessed on: 17 Nov 2005.

¹⁷ *Ibid.* It should be noted that the judgement in the recent case of *Glass v UK* endorsed a strong presumption in favour of a parent's claim to a voice in their children's care and that parental wishes should not be overruled without a hearing in court (see paragraph 8.10 of this Report).

Appendix 6: Randomised controlled trials in clinical medicine

Doctors often must decide between a new treatment or procedure which may or may not be superior compared with the standard one. It is rarely obvious that one treatment is very much better than another. It is also known that different individuals respond to the same treatment differently (for example males and females may have different responses). In order to determine whether a treatment is better than the standard treatment (that is the one usually given) a process known as a randomised controlled trial (RCT) is used.

The aim of a randomised trial is to compare outcomes for two groups of patients, one of which receives the new treatment, and the other the standard treatment. Each group is sufficiently large to account for the differences between individuals and to demonstrate the desired effect of the treatment, if it is successful. The process of random allocation to the standard treatment or a new treatment is done to ensure that each group will randomly contain individuals with different responses (for example equal numbers of males and females) so that the treatment can be used in the future across all patients.

The process of deciding which treatment an individual gets is done by a sophisticated technique of randomisation, which in essence is like tossing a coin: that is, which side ends upwards is a matter of chance. A doctor can only enter a patient into a trial if the patient (or parent) gives permission for the doctor to do so, except in very special circumstances where permission would be impossible, for example during resuscitation when the patient is unconscious.

All studies are reviewed by members of a research ethics committee who must satisfy themselves that the study is well designed, that it will contain enough patients to be able to detect a potential difference between treatments and that the study procedure does not place undue pressure on patients to consent to the trial. Patients are always free to withdraw from the trial at any time. Most trials are also externally monitored to ensure they are not producing unexpected results, in which case the trial should be curtailed.

This system of using randomised trials is thought to be fair and allows medicine to move forward in the confidence that its treatments are effective. People almost always make the assumption that any 'new' treatment is necessarily better, but in many trials the differences may be less than expected and in some trials unexpected adverse effects occur. A patient cannot request or insist on a new treatment, which is usually only available within the context of the randomised trial, until it is effective and safe. Once this has been established, the medicine is normally licensed by the appropriate authorities.

Cochrane Reviews are analyses of randomised trials and other relevant evidence in certain areas of medicine that aim to determine the effectiveness and appropriateness of a given treatment. These are published in the Cochrane Database of Systematic Reviews (www.cochrane.org); there are currently over 190 reviews in the library relating to trials carried out on babies.

Appendix 7: NHS organisations concerned with healthcare decision making

The macroeconomic level (see Figure 3.4)

The Government, through the UK Departments of Health, is responsible for leading the direction of the NHS. At the macroeconomic level, decisions are made about how much to allocate to the NHS as against competing demands on public resources such as education, social security, defence and the other ministries of central government.

Two agencies that operate at the macroeconomic level and have had increasing importance in the last few years are the National Institute for Health and Clinical Excellence (NICE) and the Healthcare Commission. In England and Wales, NICE has the role of assessing medicines and medical devices based on evidence about their clinical effectiveness and cost-effectiveness.¹⁸ One of the reasons for establishing NICE was to curb 'postcode prescribing' (patients in different geographical areas receiving different treatments or services based on their location). Since April 2005, NICE has also taken on the role of evaluating public health interventions. The Healthcare Commission is essentially an inspectorate, since it is responsible for evaluating the performance of NHS institutions in England and monitoring adherence to government policy, such as the National Service Frameworks (NSFs), which specify good practice in different specialised areas. In addition, the Healthcare Commission is responsible for the 'annual health check', which involves assessing and rating the performance of all NHS healthcare organisations in England each year. The assessment takes into account performance in relation to new and existing national targets, the attainment of certain core standards and improvement in the previous year.

The mesoeconomic level

At the mesoeconomic level, decisions are made on behalf of the local population about the amount of money that should be assigned to programmes or to specialties. Strategic Health Authorities (SHAs), of which there are now ten covering the whole of England,¹⁹ develop strategies for the NHS and performance manage their local NHS organisations, involving overseeing activities among Primary Care Trusts (PCT) and Trusts (or hospitals).²⁰ Special Health Authorities, of which there are around 15 in England, including NHS Blood and Transplant (formed from a merger of the National Blood Authority and UK Transplant), provide health services to the whole of England, rather than specifically to a local community. NHS healthcare is organised into separate systems for Scotland, Wales and Northern Ireland.

Below the SHA and Special Health Authorities, Primary Care Trusts (PCTs) are responsible for providing and commissioning local services, as well as developing primary and community health services and improving health in their areas (where an area typically consists of about 100,000 people). PCTs generally commission from secondary care trusts. For example they pay for neonatal intensive and

¹⁸ National Institute for Clinical Excellence (2004) *Guide to the Methods of Technology Appraisal* (London: NICE).

¹⁹ Initially there were 28 SHAs but this was reduced in June 2006 with the aim of "delivering stronger commissioning functions, leading to improved services for patients and better value for money for the taxpayer". NHS England (2006) *Strategic Health Authorities*, available at: <http://www.nhs.uk/England/AuthoritiesTrusts/Sha/Default.aspx>, accessed on: 17 Aug 2006.

²⁰ Department of Health (2003) *Improvement, Expansion and Reform: The next 3 years, priorities and planning framework 2003–2006*.

high dependency care; they are responsible for ensuring that services they offer are delivered to a high quality.

Formal policy at the local level is largely guided through Local Delivery Plans (LDPs), which focus on the health and social care priorities set out in the three yearly planning framework for improving outcomes.

The microeconomic level

At the microeconomic level, healthcare professionals, such as general practitioners and hospital doctors, make decisions about the treatment of individual patients, involving decisions about who to treat and what treatment or services they should receive (in line with the policy of their local PCT). Furthermore, groups of general practitioners have clinical and financial responsibility, since they must make prescribing and referral decisions within their budget.

Appendix 8: The quality-adjusted life year (QALY)

A quality-adjusted life year (QALY) is a measure of both the quantity and the health-related quality of life gained by particular treatments or interventions. A year of perfect health is valued at 1 QALY, whereas a year expected to be spent at less than perfect health is valued at less than 1. Death is valued at zero using this measure, and some very serious health conditions may be considered to have negative scores. The main purpose of the QALY is to provide a common measure to assess the benefits gained from different health interventions. The incremental cost of providing 1 QALY can then be compared for different treatments in order to assess their cost-effectiveness.

For example:

Treatment A gives a patient 6 years in a health state valued at 0.5 = 3 QALYs

Treatment B gives a patient 6 years in a health state valued at 0.25 = 1.5 QALYs

Therefore, Treatment A generates 1.5 additional QALYs than Treatment B and this figure could be compared with the difference in costs between the two treatments.

A number of approaches have been used to generate the values for 'health states' (the figures 0.5 and 0.25 in the example above). For example, a large sample of patients might be asked to indicate their state of health in terms of different domains, such as physical, social and cognitive function, psychological wellbeing, symptoms and pain. The answers could then be used to create average health-related quality of life scores for different conditions and health problems.

QALYs have various limitations, including the subjectivity of health-related quality of life assessments and variations in the way that the same person may assess their health-related quality of life at different times of their lives. It is also the case that once a person is in a particular health state, they may assess it differently than those who are not in that health state. Furthermore, little attempt has been made to assess the appropriateness of the QALY measure for childhood.

See Drummond MF, Sculpher MJ, Torrance GW, O'Brien B, Stoddart GL (2005) *Methods for the economic evaluation of health care programmes*, 3rd Edition (Oxford: Oxford University Press).

Appendix 9: Professional guidance in the UK

The following table outlines much of the national professional guidance in the UK on matters relating to critical care of the fetus and the newborn. Most of the guidance presents guidelines to be followed, for example that of the Royal Colleges and the British Medical Association; however, other guidance presents goals, in particular the National Service Framework for Children, Young People and Maternity Services, which gives standards to be reached by 2014.

We have presented the guidelines according to topics addressed within the Report.

Abbreviations: BAPM, British Association of Perinatal Medicine; BMA, British Medical Association; DH, Department of Health; GMC, General Medical Council; MRC, Medical Research Council; NICE, National Institute for Health and Clinical Excellence; NSF, National Service Framework for Children, Young People and Maternity Services; RCM, Royal College of Midwives; RCOG, Royal College of Obstetricians and Gynaecologists; RCP, Royal College of Physicians of London; RCPCH, Royal College of Paediatrics and Child Health.

Organisation	Guidance	Reference
Best Interests		
RCOG	<p>"In an emergency and in the absence of an advance directive the obstetrician should act in the best interests of the mother."</p> <p>"if the patient has an advance directive which specifies refusal of treatment during pregnancy this should be honoured even at the expense of the fetus."</p> <p>"if the advance directive does not mention pregnancy specifically, then more weight may be given to the interests of the fetus unless the mother's condition was such that she was expected to recover within a reasonable time."</p>	<p><i>Supplement to 'A Consideration of the Law And Ethics in Relation to Court-Authorised Obstetric Intervention'</i> (1996), available at: http://www.rcog.org.uk/index.asp?PageID=1198#supplement, accessed on: 21 Nov 2005. Reproduced with permission of the RCOG.</p>
RCPCH	<p>"The doctor's primary duty is to act in the child's best interest. If there is conflict between doctor and parents or parents and child, then the child's needs are paramount."</p> <p>"All published guidance on the moral responsibilities of doctors reaffirms their fundamental duty to act in their patients' best interests. The scope of a doctor's duty is wider than the simple consideration of whether or not a given intervention is clinically more beneficial than harmful. It also includes:</p> <ul style="list-style-type: none"> • preserving life, restoring health and preventing illness • listening to children and respecting their autonomy • respecting human rights and dignity • performing these duties justly, fairly and to an acceptable standard." <p>"Parents are expected to make health care decisions for the children based on what they feel is in a child's 'welfare' or 'best interests'."</p>	<p><i>Responsibilities of Doctors in Child Protection Cases with regard to Confidentiality</i> (2004), available at: http://www.rcpch.ac.uk/publications/recent_publications/Confidentiality.pdf, accessed on: 25 Nov 2005. Reproduced with permission of the RCPCH.</p>
DH		<p><i>Consent – What You Have a Right to Expect: a Guide for Parents</i> (2001), available at: http://www.dh.gov.uk/assetRoot/04/11/73/53/04117353.pdf, accessed on: 22 Nov 2005. Reproduced under the terms of the Click Use Licence.</p>
BMA	<p>"In an emergency, where consent cannot be obtained, doctors should provide medical treatment that is in the patient's best interests and is immediately necessary to save life or avoid significant deterioration in the patient's health."</p> <p>Factors that should be taken into account when considering a patient's best interests, not all of which are relevant to children, include:</p> <ul style="list-style-type: none"> • "the patient's own wishes and values (where these can be ascertained), including any advance statement; • clinical judgment about the effectiveness of the proposed treatment, particularly in relation to other options; • where there is more than one option, which option is least restrictive of the patient's future choices; • the likelihood and extent of any degree of improvement in the patient's condition if treatment is provided; • the views of the parents, if the patient is a child; • the views of people close to the patient, especially close relatives, partners, carers or proxy decision makers about what the patient is likely to see as beneficial; and • any knowledge of the patient's religious, cultural and other non-medical views that might have an impact on the patient's wishes." 	<p><i>Consent Tool Kit</i>, 2nd Edition (2003), available at: http://www.bma.org.uk/ap.nsf/Content/consenttk2/\$file/toolkit.pdf, accessed on: 23 Nov 2005.</p>

GMC

“Where a child under 16 years old is not competent to give or withhold their informed consent, a person with parental responsibility may authorise investigations or treatment which are in the child’s best interests. This person may also refuse any intervention, where they consider that refusal to be in the child’s best interests, but you are not bound by such a refusal and may seek a ruling from the court. In an emergency where you consider that it is in the child’s best interests to proceed, you may treat the child, provided it is limited to that treatment which is reasonably required in that emergency.”

“In deciding what options may be reasonably considered as being in the best interests of a patient who lacks capacity to decide, you should take into account:

- options for treatment or investigation which are clinically indicated;
- any evidence of the patient’s previously expressed preferences, including an advance statement;
- your own and the health care team’s knowledge of the patient’s background, such as cultural, religious, or employment considerations;
- views about the patient’s preferences given by a third party who may have other knowledge of the patient, for example the patient’s partner, family, carer, tutor-dative (Scotland), or a person with parental responsibility;
- which option least restricts the patient’s future choices, where more than one option (including non-treatment) seems reasonable in the patient’s best interest.”

Seeking Patients’ Consent: *The ethical considerations* (1998), available at: <http://www.gmc-uk.org/guidance/library/consent.asp>, accessed on: 23 Nov 2005.

Consent to treatment during pregnancy

RCOG

Regarding consent to any treatments, interventions or operations on a woman:

- Ensure woman is informed about her condition, the treatment and any alternatives, and any uncertainties are discussed, before seeking consent;
- Follow good practice principles on consent;
- “give information and obtain consent at a time and in a manner that is appropriate . . . Women should not be given important information or asked to make decisions at the same time as undergoing gynaecological examinations.”
- If a woman’s capacity to consent is in doubt or where differences or opinion about her best interests cannot be resolved, advice from experienced colleagues and, if appropriate, legal advice, should be sought.

Regarding consent relating to pregnancy:

- In consent for screening it is essential that the woman is made aware of the purpose, uncertainties and implications of screening, since findings may potentially have serious medical social or financial consequences for the individual and for her relatives;
- With women in pain or in labour, care must be taken in obtaining valid consent for treatment or research purposes (suggested procedures for a number of scenarios are outlined);
- For an emergency caesarean section, written consent should ideally be obtained, as for all operations requiring anaesthesia, but if this is not possible verbal consent should be consultation obtained. “If a competent woman refuses delivery by caesarean section, even after full and explanation of the consequences for the fetus, her wishes must be respected;

Clinical Governance Advice No. 6: *Obtaining Valid Consent* (2004), available at: http://www.rcog.org.uk/resources/Public/pdf/CGA_No6.pdf, accessed on: 21 Nov 2005.

Reproduced with permission of the RCOG.

-In the case of a woman becoming incompetent after refusing consent to a treatment following previous discussion during pregnancy, even if this is at the expense of the fetus, her wishes should be respected. Where there is substantial doubt as to whether the woman foresaw the present circumstances when making her wishes known, then the doctor would be wish to apply to the court.

RCOG

"Obstetricians must respect the woman's legal liberty to ignore or reject professional advice, even to her own detriment and that of her fetus."
 "The law provides no restriction on a woman's freedom on account of her pregnancy. Any medical action requires her informed consent."
 "It is the doctor's duty to provide appropriate information so that the pregnant woman can make an informed and thoughtful decision."
 "Where conflict arises the doctor should seek help and advice from other professional colleagues and, with the patient's agreement, it may be appropriate to involve other members or friends of her family."
 "We conclude that it is inappropriate, and unlikely to be helpful or necessary, to invoke judicial intervention to overrule an informed and competent woman's refusal of a proposed medical treatment, even though her refusal might place her life and that of her fetus at risk."

A Consideration of the Law and Ethics in Relation to Court-Authorised Obstetric Intervention (1994), available at: <http://www.rcog.org.uk/index.asp?PageID=1198>, accessed on: 21 Nov 2005. Reproduced with permission of the RCOG.

RCOG

"In an emergency and in the absence of an advance directive the obstetrician should act in the best interests of the mother."
 "If the patient has an advance directive which specifies refusal of treatment during pregnancy this should be honoured even at the expense of the fetus."
 "If the advance directive does not mention pregnancy specifically, then more weight may be given to the interests of the fetus unless the mother's condition was such that she was expected to recover within a reasonable time."
 "When the obstetrician has doubt or reservations then early consideration should be given to seeking legal advice."

Supplement to 'A Consideration of the Law And Ethics in Relation to Court-Authorised Obstetric Intervention' (1996), available at: <http://www.rcog.org.uk/index.asp?PageID=1198#supplement>, accessed on: 21 Nov 2005. Reproduced with permission of the RCOG.

DH (NSF)

"Women require information in a medium or language which suits their needs. In early pregnancy, they need to decide which, if any, screening tests they wish to have. It is particularly important that women give properly informed consent to have any tests before these procedures take place."
 The decision of a woman to request or decline services or treatment should be respected.

National Service Framework for Children, Young People and Maternity Services: Maternity Standard (2004), available at: [http://www.dh.gov.uk/PublicationsAndStatistics/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4089101&chk=Kuk%2BDw](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4089101&chk=Kuk%2BDw), accessed on: 22 Nov 2005. Reproduced under the terms of the Click-Use Licence.

GMC

"Wherever possible, you must be satisfied, before you provide treatment or investigate a patient's condition, that the patient has understood what is proposed and why, any significant risks or side effects associated with it, and has given consent."

Good Medical Practice (2001), available at: http://www.gmc-uk.org/guidance/good_medical_practice/index.asp#Relationships%20with%20patients, accessed on: 23 Nov 2005.

GMC

"You must respect patients' autonomy – their right to decide whether or not to undergo any medical intervention even where a refusal may result in harm to themselves or in their own death . . . This right to decide applies equally to pregnant women as to other patients, and includes the right to refuse treatment where the treatment is intended to benefit the unborn child."

Seeking Patients' Consent: The Ethical Considerations (1998), available at: <http://www.gmc-uk.org/guidance/library/consent.asp>, accessed on: 23 Nov 2005 ff

Organisation	Guidance	Reference
	<p>"You must ensure that anyone considering whether to consent to screening can make a properly informed decision. As far as possible, you should ensure that screening would not be contrary to the individual's interest. You must pay particular attention to ensuring that the information the person wants or ought to have is identified and provided. You should be careful to explain clearly:</p> <ul style="list-style-type: none"> • the purpose of the screening; • the likelihood of positive/negative findings and possibility of false positive/negative results; • the uncertainties and risks attached to the screening process; • any significant medical, social or financial implications of screening for the particular condition or predisposition; • follow up plans, including availability of counselling and support services." 	
Consent to treatment of the newborn		
RCP	<p>"Significant investigations or treatment of children should only be carried out with the informed consent of their parents."</p>	<p><i>Improving Communication Between Doctors and Patients: A report of a working party (1997)</i> (London: RCP). Reproduced with permission of the RCP.</p>
DH (NSF)	<p>"Hospitals should follow the Department of Health guidance on consent and the associated report on working with children. Trusts' policies on consent should specifically address the needs of children and young people. Consent policies . . . need to address the situation where health care professionals believe that a particular treatment is crucial, perhaps life-saving, for a child but parents refuse to give consent."</p>	<p><i>Getting the right start: National Service Framework for Children: Standard for Hospital Services (2003)</i>, available at: http://www.dh.gov.uk/assetRoot/04/06/72/51/04067251.pdf, accessed on: 22 Nov 2005. Reproduced under the terms of the Click-Use Licence.</p>
- by whom, and what to do if they are unavailable or incompetent		
BAPM	<p>Consent should be obtained from someone with parental responsibilities; this will usually be the parents. "However, in neonatal practice there are frequently occasions, particularly soon after birth, when there is no-one available to provide consent and the clinician has to initiate treatment [in the absence of consent]. It should always be possible later to justify that action to the parents, and to reassure them that what was done was in the best interests of the baby." "In emergency, if consent cannot be obtained, e.g. because nobody with parental responsibility is available or the parents are too distressed to give valid informed consent, treatment may lawfully be started if clinicians believe it to be in the child's best interests."</p>	<p><i>Consent in Neonatal Clinical Care: Good Practice Framework (2004)</i>, available at: http://www.bapm.org/publications/, accessed on: 17 Nov 2005. Reproduced with permission of BAPM.</p>
RCM	<p>"Examination of the newborn baby should always be carried out in the mother's presence after obtaining her consent, and should always be accompanied by a comprehensive explanation of the procedure, reason for it and the findings."</p>	<p><i>Evidence Based Guidelines for Midwifery-Led Care in Labour: Midwifery Practice Guidelines (2005)</i>, available at: http://www.rcm.org.uk/data/education/data/_Toc89671202, accessed on: 22 Nov 2005. Reproduced with permission of the RCM.</p>

DH	<p>Guide for parents gives the following information:</p> <p>Parents are entitled to give consent to treatment on behalf of children for whom they have parental responsibility. "Mothers automatically have parental responsibility for their children. Fathers also have parental responsibility if they were married to the mother when the child was conceived or born. . . . Unmarried fathers do not automatically have parental responsibility for their child, but a court order or a 'parental responsibility agreement' can give it to them. People looking after your child, like childminders or grandparents do not have parental responsibility, but you can authorise them to take medical decisions for your child, if you wish."</p>	<p><i>Consent – What You Have a Right to Expect: a Guide for Parents</i> (2001), available at: http://www.dh.gov.uk/assetRoot/04/11/73/53/04117353.pdf, accessed on: 22 Nov 2005. Reproduced under the terms of the Click-Use Licence.</p>
DH	<p>A more detailed publication provides further information, as follows.</p> <p>People with 'parental responsibility' also include: "the child's legally appointed guardian", "a local authority designated in a care order"; and "a local authority or other authorised person who holds an emergency protection order in respect of the child".</p> <p>Consent for treatment is needed from someone who has parental responsibility for the child, unless it is an emergency and it would be unreasonable to wait.</p> <p>It is lawful to provide immediately necessary treatment on the basis that it is in the child's best interests if there is no-one able to give consent or if someone is available to consent but is unable to because they are distressed or not competent. If mother is under 16 "she will only be able to give valid consent for her child's treatment if she herself is 'Gillick competent' to take the decision in question".</p>	<p><i>Seeking Consent – Working with Children</i> (2001), available at: http://www.dh.gov.uk/assetRoot/04/06/72/04/04067204.pdf, accessed on: 22 Nov 2005. Reproduced under the terms of the Click-Use Licence.</p>
BMA	<p>"Those with parental responsibility for a baby or young child are legally and morally entitled to give or withhold consent to treatment. Their decision will usually be determinative unless they conflict seriously with the interpretation of those providing care about the child's best interests."</p>	<p><i>Withholding and Withdrawing Life-prolonging Medical Treatment – Guidance for decision making</i> (2001) (London: BMJ Books).</p>
BMA	<p>For treatment of a child, anyone with parental responsibility for the child can provide consent. "if, however, treatment is required urgently and nobody with parental responsibility is available, doctors can proceed with treatment that is in the young person's best interests." A definition of who has 'parental responsibility' is given, which agrees with that given by the DH (above). In addition, clarification is given that "if there is any doubt about whether the person giving consent is legally entitled to do so, legal advice should be sought."</p>	<p><i>Consent Tool Kit</i>, 2nd Edition (2003), available at: http://www.bma.org.uk/ap.nsf/Content/consenttk2/\$file/toolkit.pdf, accessed on: 23 Nov 2005.</p>
GMC	<p>"A person with parental responsibility may authorise investigations or treatment which are in the child's best interests. This person may also refuse any intervention, where they consider that refusal to be in the child's best interests, but you are not bound by such a refusal and may seek a ruling from the court. In an emergency where you consider that it is in the child's best interests to proceed, you may treat the child, provided it is limited to that treatment which is reasonably required in that emergency."</p> <p>"Where differences of opinion . . . cannot be resolved satisfactorily, you should consult more experienced colleagues and, where appropriate, seek legal advice on whether it is necessary to apply to the court for a ruling."</p>	<p><i>Seeking Patients' Consent: the Ethical Considerations</i> (1998), available at: http://www.gmc-uk.org/guidance/library/consent.asp, accessed on: 23 Nov 2005.</p>

Organisation	Guidance	Reference
- the situations in which consent is required		
BAPM	<p>"It is a legal and ethical requirement to gain valid consent before examining and initiating any investigation and treatment for any patient."</p> <p>Implicit consent and explicit consent are considered acceptable, depending on the nature and risks of the intervention. A list of common neonatal interventions and whether explicit or implicit consent should usually be required is provided with the leaflet. For example, explicit consent should be required for a biopsy, surgery and genetic testing, whereas it is not usually required for examining and assessing the patient, taking x-rays and blood transfusions.</p>	<p><i>Consent in Neonatal Clinical Care: Good Practice Framework (2004)</i>, available at: http://www.bapm.org/publications/, accessed: 17 Nov 2005.</p> <p>Reproduced with permission of BAPM.</p>
DH	<p>Consent is needed for healthcare of any kind for a child, from helping a child get dressed to carrying out major surgery.</p> <p>"Sometimes, during an operation, it may become clear that the child would benefit from an additional procedure, for which consent has not been obtained. You must obtain further consent for this procedure before going ahead, unless the delay involved in doing so would genuinely put the child's life or health at risk."</p>	<p><i>Seeking Consent – Working with Children (2001)</i>, available at: http://www.dh.gov.uk/assetRoot/04/06/72/04/04067204.pdf, accessed on: 22 Nov 2005.</p> <p>Reproduced under the terms of the Click-Use Licence.</p>
- the nature of the consent required		
BAPM	<p>Depends on nature of intervention, and whether explicit or implicit consent is acceptable.</p> <p>All procedures should be explained to parents and understood by them. Information should be provided to parents on the implications and options should consent be withheld, and they should understand that they can withdraw consent for interventions not yet completed.</p> <p>"Consent may be written, verbal or implied."</p> <p>"It will not usually be necessary to document consent to routine and low risk procedures."</p> <p>"If treatment is complex, or involves significant risks or side effects, explicit consent must be gained and it is good practice for this to be signed."</p>	<p><i>Consent in Neonatal Clinical Care: Good Practice Framework (2004)</i>, available at: http://www.bapm.org/publications/, accessed: 17 Nov 2005.</p> <p>Reproduced with permission of BAPM.</p>
DH	<p>Guide for parents gives the following information.</p> <p>Consent varies according to the intervention. An example of 'simple' consent is given as encouraging a young child to open his or her mouth to allow the doctor to look at their throat.</p> <p>"For something more complicated like an operation, you [the parent] . . . will be asked to sign a form agreeing to the treatment."</p>	<p><i>Consent – What You Have a Right to Expect: a Guide for Parents (2001)</i>, available at: http://www.dh.gov.uk/assetRoot/04/11/73/53/04117353.pdf, accessed on: 22 Nov 2005.</p> <p>Reproduced under the terms of the Click-Use Licence.</p>
DH	<p>A more detailed publication provides further information, as follows:</p> <ul style="list-style-type: none"> • For consent to be valid, the person (child or parent) giving consent must be: • capable of taking that particular decision ('competent') • acting voluntarily (not under pressure or duress from anyone) • provided with enough information to enable them to make the decision." <p>Information should include:</p>	<p><i>Seeking Consent – Working with Children (2001)</i>, available at: http://www.dh.gov.uk/assetRoot/04/06/72/04/04067204.pdf, accessed on: 22 Nov 2005.</p> <p>Reproduced under the terms of the Click-Use Licence.</p>

<ul style="list-style-type: none"> • “the benefits and the risks of the proposed treatment • what the treatment will involve • what the implications of not having the treatment are • what alternatives may be available • what the practical effects on their lives of having, or not having, the treatment will be.” 	<p>GMC</p> <p>“To determine whether patients have given informed consent to any proposed investigation or treatment, you must consider how well they have understood the details and implications of what is proposed, and not simply the form in which their consent has been expressed or recorded.”</p> <p>Consent may be expressed orally or in writing, or implied. Written consent should be obtained in cases where:</p> <ul style="list-style-type: none"> • the treatment or procedure is complex, or involves significant risks and/or side effects; • providing clinical care is not the primary purpose of the investigation or examination; • there may be significant consequences for the patient’s employment, social or personal life; • the treatment is part of a research programme. 	<p>Seeking Patients’ Consent: <i>The Ethical Considerations</i> (1998), available at: http://www.gmc-uk.org/guidance/library/consent.asp, accessed on: 23 Nov 2005.</p>
<p>- if parents disagree with doctors or one another</p>	<p>BAPM</p> <p>If parents withhold or withdraw consent and the clinicians believe this is not in the interests of the baby the clinicians “should discuss this with the parents and may need to take advice, which is the first instance should be from the hospital’s senior management team and/or Social Services.”</p>	<p>Consent in Neonatal Clinical Care: <i>Good Practice Framework</i> (2004), available at: http://www.bapm.org/publications/, accessed: 17 Nov 2005. Reproduced with permission of BAPM.</p>
<p>BAPM</p> <p>“When the parents do not agree with each other, or when they do not accept their doctor’s advice on whether or not to withhold or withdraw care, treatment should be pursued until a change in the baby’s status or further counselling and discussion clarifies the situation. Only as a last resort and in exceptional circumstances after all other options have been exhausted, should the problem be referred to the Courts.”</p>	<p><i>Fetuses and Newborn Infants at the Threshold of Viability: A Framework for Practice</i> (2000), available at: http://www.bapm.org/media/documents/publications/threshold.pdf, accessed on: 24 Nov 2005. Reproduced with permission of BAPM.</p>	<p>Consent – <i>What You Have a Right to Expect: a Guide for Parents</i> (2001), available at: http://www.dh.gov.uk/assetRoot/04/1173/53/04117353.pdf, accessed on: 22 Nov 2005.</p>
<p>DH</p> <p>Guidance for parents explains that health professionals cannot usually go ahead with treatment if parents disagree, and encourages parents to continue discussions with health professionals in order to reach an agreement. On rare occasions when there is a disagreement, the parents or the health practitioner may take the case to court.</p>	<p>Consent – <i>Working with Children</i> (2001), available at: http://www.dh.gov.uk/assetRoot/04/06/72/04/04067204.pdf, accessed on: 22 Nov 2005. Reproduced under the terms of the Click-Use Licence.</p>	<p>Consent – <i>What You Have a Right to Expect: a Guide for Parents</i> (2001), available at: http://www.dh.gov.uk/assetRoot/04/1173/53/04117353.pdf, accessed on: 22 Nov 2005.</p>
<p>DH</p> <p>A more detailed publication provides further information, as follows. “The consent of any one person with parental responsibility is sufficient for treatment lawfully to be given, even if another person with parental responsibility does not agree. Consensus between those with parental responsibility should be achieved if at all possible.” However, the guidance states that there are a small number of important decisions that should not be taken by one person with parental responsibility against the wishes of another.</p>	<p>Consent – <i>Working with Children</i> (2001), available at: http://www.dh.gov.uk/assetRoot/04/06/72/04/04067204.pdf, accessed on: 22 Nov 2005. Reproduced under the terms of the Click-Use Licence.</p>	<p>Consent – <i>Working with Children</i> (2001), available at: http://www.dh.gov.uk/assetRoot/04/06/72/04/04067204.pdf, accessed on: 22 Nov 2005. Reproduced under the terms of the Click-Use Licence.</p>

Organisation	Guidance	Reference
BMA	<p>"Where the proposed intervention is controversial, agreement between parents is desirable. If this cannot be achieved, ethical and legal advice should be sought. The courts have held that there is a small group of controversial procedures, such as male infant circumcision for non-medical reasons, which should only be carried out with the consent of both parents or the approval of a court."</p> <p>"If a parent refuses consent to [HIV] testing, and the doctor believes that person's judgement to be distorted, for example because he or she may be the cause of the child's infection, the doctor must decide whether the medical interests of the child override the wishes of those with parental responsibility. Legal advice should be sought if testing is medically necessary, but parental consent is refused. The GMC also advises doctors to consult with an experienced colleague."</p>	<p><i>Consent Tool Kit</i>, 2nd Edition (2003), available at: http://www.bma.org.uk/lap.nsf/Content/consenttk2/\$file/toolkit.pdf, accessed on: 23 Nov 2005.</p>
Threshold of viability		
RCOG	<ul style="list-style-type: none"> • "The management of fetuses and newborn infants at the threshold of viability should be in accordance with the British Association of Perinatal Medicine's Framework for Practice." • Registration responsibilities are also outlined for situations in which baby does not survive: • If baby is born before 24 weeks of gestation and did not breathe or show any signs of life, there is no requirement for the event to be registered and a funeral can proceed once doctor or midwife certifies that baby was born before legal age of viability; • If baby is born after 24 weeks of gestation and does not breathe or show any signs of life, he/she is considered to be stillborn and must be registered; • If baby is born alive but subsequently dies, regardless of the gestational age, both the birth and death are registered. 	<p>Further Issues Relating to Late Abortion, <i>Fetal Viability and Registration of Births and Deaths</i> (2001), available at: http://www.rcog.org.uk/index.asp?PageID=549, accessed on: 21 Nov 2005. Reproduced with permission of RCOG.</p>
BAPM	<p>"Infants born 22 – <28 weeks gestation (approx. equivalent to 500–1,000 g) have been termed as having "threshold viability", though in developed countries this term is more often used in reference to infants of <26 weeks."</p> <p>"The increasing potential risk of residual disability or early death associated with decreasing gestational age (especially < 26 weeks) raises serious ethical dilemmas in respect to appropriate management. These include whether elective delivery for fetal indication is appropriate or whether intensive care should be provided following delivery, or, alternatively, whether comfort care is more appropriate (warmth, offer of oral nourishment and human contact)."</p> <p>"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, uninfluenced by the child's gender or by religious, eugenic, demographic or financial factors."</p> <p>"Medical staff have a responsibility to keep parents informed as to the likely clinical outcome resulting from the decisions in which the parents need to participate. Counselling must be honest and accurate. Parents may have unrealistic expectations not only as to what is medically possible but also as to future prospects for their infant whatever treatment is proposed."</p> <p>"Perinatal mortality, morbidity and future outcome relate closely to gestational age at birth."</p>	<p><i>Fetuses and Newborn Infants at the Threshold of Viability: A Framework for Practice</i> (2000), available at: http://www.bapm.org/media/documents/publications/threshold.pdf, accessed on: 24 Nov 2005. Reproduced with permission of BAPM.</p>

There needs to be an agreed policy for the antenatal estimation of the expected date of delivery. This is usually based on early ultrasound measurements and the menstrual history. Physical examination of the infant after birth may lead to a revision of the original estimate. This needs to be explained in advance to parents who otherwise may be confused or feel that an error has been made.”

“The perinatal team need to be aware of up-to-date national statistics on infant mortality and morbidity outcome according to gestational age, as well as the results of local audit. This should include the incidence and severity of disability amongst survivors at the age of 2 years or more.”

“Threshold viability infants should be followed-up carefully for a minimum of two years (preferably five years) in order to detect disabilities and also to enable the audit of outcome to be completed.”

Resuscitation of the newborn

RCOG	<p>“It is professionally acceptable not to attempt to support life in fetuses below the threshold of viability. It is extremely important to distinguish between physiological movements and signs of life, as well as being aware that observed movements may be of a reflex nature and not necessarily signs of life or viability.”</p>	<p><i>Further Issues Relating to Late Abortion, Fetal Viability and Registration of Births and Deaths</i> (2001), available at: http://www.rcog.org.uk/index.asp?PageID=549, accessed on: 21 Nov 2005. Reproduced with permission of the RCOG.</p>
RCPCH	<p>“Neonates should almost always be resuscitated in the labour ward, particularly if there has been no prior discussion.”</p> <p>“In acute situations it is always necessary to give life-sustaining treatment first and to review this when enough information is available, from more experienced opinion or following the evolution of the clinical state or in the light of investigations.”</p>	<p><i>Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice</i>, 2nd Edition (2004), available at: http://www.rcpch.ac.uk/publications/recent_publications/Withholding.pdf, accessed on: 23 Nov 2005. Reproduced with permission of the RCPCH.</p>
RCM	<p>Directs midwives to the guidelines of Resuscitation Council UK (below).</p>	<p><i>Evidence Based Guidelines for Midwifery-Led Care in Labour: Midwifery Practice Guidelines</i> (2005), available at: http://www.rcm.org.uk/data/education/data/_Toc89671202, accessed on: 22 Nov 2005.</p>
BAPM	<p>“Following counselling on the likely prognosis, some parents may wish to give advance authorisation for the non-resuscitation and non-provision of intensive care for infants at the extreme margin of viability. While appreciating their wishes, such authorization cannot be considered binding on the healthcare team. For example, the newborn infant maybe found to be more mature and vigorous than expected.”</p> <p>“Because of the difficulty, complexity and seriousness of management decisions concerning the appropriateness of resuscitation and the use of intensive care, the birth of a threshold-viability infant should be regarded as a major emergency requiring the presence of very experienced members of the obstetric and paediatric teams in the delivery room.”</p> <p>“It may be appropriate to institute intensive care to threshold-viability infants at birth until the clinical progress of the infant and further consultation with the parents has clarified whether it is better to continue or withdraw this form of medical care.”</p>	<p><i>Fetuses and Newborn Infants at the Threshold of Viability: A Framework for Practice</i> (2000), available at: http://www.bapm.org/media/documents/publications/threshold.pdf, accessed on: 24 Nov 2005. Reproduced with permission of BAPM.</p>

Organisation	Guidance	Reference
	<p>In a list of guidelines, BAPM also refers to a Thames Regional Perinatal Group publication – <i>Guidelines Relating to the Birth of Extremely Immature Babies (22–26 Weeks Gestation)</i> (2000), available at: http://www.bapm.org/media/documents/publications/immature.pdf, accessed on: 24 Nov 2005.</p>	
Resuscitation Council UK	<p>“Newborn life support is designed to provide help [to newborn babies having breathing difficulties] and it comprises the following elements: drying and covering the newborn baby to conserve heat, assessing the need for any intervention, airway opening, lung inflation, rescue breathing, chest compressions and, very rarely, the administration of drugs.” A flow diagram (algorithm) is given for the process of newborn life support. If the baby is not breathing, the clinician should control the airway and support breathing, and if there is no response, further steps are suggested.</p>	<p><i>Newborn Life Support Resuscitation Guidelines</i> (2000), available at: http://www.resus.org.uk/pages/nls.htm, accessed on: 22 Nov 2005.</p>
DH (NSF)	<p>One of the standards to be reached by 2014: “All staff who attend a woman in childbirth or who deal with newborn babies, irrespective of the place of delivery, have been trained in neonatal life support and have up-to-date skills in the techniques of neonatal resuscitation and the thermal care of infants at resuscitation.”</p>	<p><i>National Service Framework for Children, Young People and Maternity Services: Maternity Standard</i> (2004), available at: http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4089101&chk=Kuk%2BDw, accessed on: 22 Nov 2005. Reproduced under the terms of the Click-Use Licence.</p>
Withholding and withdrawing treatment		
RCPCH	<p>“The background to all treatments . . . must be that they should be in the child’s best interests.” “There are some circumstances in which the continuation of medical attempts to cure are either manifestly futile or inflict unbearable suffering on the child. Professionals, trained to restore health, often feel that they have failed patients whose problems persist despite active treatment. However, in some circumstances, to continue life sustaining treatment is to offer care that is no longer in the child’s best interest.” “The Ethics Advisory Committee of the Royal College of Paediatrics and Child Health has defined five categories in which the withholding or withdrawal of life sustaining medical treatment might be appropriate and in which the goals of care are redirected.” These five categories are: The ‘Brain Dead’ Child The ‘Permanent Vegetative State The ‘No Chance’ Situation The ‘No purpose’ Situation The ‘Unbearable’ Situation.</p> <p>“In situations that do not fit with these five categories, or where there is uncertainty about the degree of future impairment or disagreement, the child’s life should always be safeguarded in the best way possible.”</p>	<p><i>Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice</i>, 2nd Edition (2004), available at: http://www.rcpch.ac.uk/publications/recent_publications/Withholding.pdf, accessed on: 23 Nov 2005. Reproduced with permission of the RCPCH.</p>

"Withholding or withdrawing life sustaining treatment does not imply that a child will receive no care. It should rather signal a change in focus towards palliative care making sure that the rest of the child's life is as comfortable as possible.
 "Ethically the withholding and the withdrawal of life sustaining treatment are equivalent but emotionally they are sometimes poles apart. If the decision from the outset is that any treatment other than palliative care would not be in the child's interests, then the decision requires that no resuscitative action is taken. On the other hand if the decision is taken after treatment intended to continue life has been instituted, the decision will lead to a change in the treatment plan with active withdrawal of life sustaining treatment with emphasis on palliative care. Some paediatricians and parents find the second course psychologically and emotionally the more difficult but on the other hand in this situation it may be easier for the parents to believe that everything possible has been done.
 "In acute situations it is always necessary to give life-sustaining treatment first and to review this when enough information is available, from more experienced opinion or following the evolution of the clinical state or in the light of investigations."
 Three fundamental principles that apply to the situation are discussed:

- Duty of Care and the Partnership of Care
- The Legal Duty
- Respect for Children's Rights

BAPM

"When a decision has been taken to electively deliver a threshold-viability fetus or to withhold or withdraw neonatal life-sustaining care, all actions taken and the reasons for them, as well as the clinical course of the child and the views of the parents, should be carefully documented by the medical team.
 "Infants from whom life-sustaining support is withdrawn or withheld should continue to be kept warm, offered oral nourishment, and treated with dignity and love (comfort care). Their parents should be encouraged to be with their child as much as possible. They should be given every support during this distressing time."

Fetuses and Newborn Infants at the Threshold of Viability: A Framework for Practice (2000), available at: <http://www.bapm.org/media/documents/publications/threshold.pdf>, accessed on: 24 Nov 2005.
 Reproduced with permission of BAPM.

BMA

The BMA Guidance states that the ethical framework underlying the provision or continuation of treatment in children, young people and adults should also apply to babies. The guiding principle is that the treatment should provide a net benefit to the patient (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.
 "Although emotionally it may be easier to withhold treatment than to withdraw that which has been started, there are no legal, or necessary morally relevant, differences between the two actions."

Withholding and Withdrawing Life-prolonging Medical Treatment – Guidance for decision making (2001) (London: BMJ Books).

GMC

Guiding principles and a good practice framework for doctors faced with decisions about withholding and withdrawing life-prolonging treatments are provided. Key principles include the respect for life, the best interests of the patient and the obligation to protect the health of a patient. Specific guidance on artificial nutrition and hydration, and on cardiopulmonary resuscitation is also given.

Withholding and Withdrawing Life-prolonging Treatment: Good Practice in Decision-making (2003), available at: http://www.gmc-uk.org/guidance/library/standards/withholding_lifeprolonging_guidance.asp#introduction, accessed on: 23 Nov 2005.

Organisation	Guidance	Reference
	<p>The guidance also raises concerns over starting and then stopping a treatment: "Although it may be emotionally more difficult for the healthcare team, and those close to the patient, to withdraw a treatment from a patient rather than to decide not to provide a treatment in the first place, this should not be used as a reason for failing to initiate a treatment which may be of some benefit to the patient. Where it has been decided that a treatment is not in the best interests of the patient, there is no ethical or legal obligation to provide it and therefore no need to make a distinction between not starting the treatment and withdrawing it."</p> <p>"Where patients lack capacity to make decisions about treatment, and there is a reasonable degree of uncertainty about the appropriateness of providing a particular treatment, treatment which may be of some benefit to the patient should be started until a clearer assessment can be made. It must be explained clearly to all those involved in caring for the patient that the treatment will be reviewed, and may be withdrawn at a later stage, if it is proving to be ineffective or too burdensome for the patient."</p> <p>"This is particularly important where time is needed for consultation and a more detailed assessment, in emergencies, and also where there is doubt about the severity of a condition, the likelihood of recovery, or the ability of a particular treatment to benefit the patient."</p> <p>Regarding children the following guidance is given:</p> <ul style="list-style-type: none"> • "All the advice in this booklet . . . also applies to decision making in cases involving children. This includes premature babies and children with disabilities where the decisions may be particularly difficult for everyone involved.²¹ • "In all cases you, and others involved in making decisions on behalf of a child, have a duty to consider what is in the child's best interests on the basis of an assessment of the benefits, burdens and risks for the child. • "Where a child lacks capacity to make his or her own decision, you should note that authorisation given by one person with parental responsibility cannot be vetoed by a refusal from another person who also holds parental responsibility. In such circumstances you should do your best, in the child's interest, to try to achieve a consensus between those with parental responsibility. <p>It is important that you work sensitively, and in partnership with the child (where that is possible), those who have parental responsibility for the child, members of the healthcare team and other carers, and aim to achieve consensus with them about the best course of action.</p> <ul style="list-style-type: none"> • "Where there is disagreement between those with parental responsibility and the healthcare team and this cannot be resolved satisfactorily through informal review, you should seek legal advice about obtaining a ruling from the courts. • "Where none of those holding parental responsibility are willing to authorise treatment, you should consider yourself bound by their refusal unless you obtain a ruling from the court." 	

Decision making and providing information

RCM	<p>"One of the key principles of midwifery-led care is the right of pregnant women to be provided with good information and to be involved in decisions about their own care and that of their babies. Failure to pay attention to the quality of that information, and an over-optimistic view of interventions, can have serious consequences in terms of iatrogenic harm, unnecessary costs and increased dissatisfaction."</p> <p>"Respect for a woman's wishes and her involvement in decision making is essential to her care in pregnancy and labour."</p>	<p><i>Evidence Based Guidelines for Midwifery-Led Care in Labour: Midwifery Practice Guidelines</i> (2005), available at: http://www.rcm.org.uk/data/education/data/_Toc89671202, accessed on: 22 Nov 2005. Reproduced with permission of the RCM.</p>
RCPCH	<p>"It is the duty of the parents to act for the child and in the best interests of the child. The parents will always be participants in the care and decision making." "Ultimately, the clinical team carries the corporate moral responsibility for decision making, which is an expression of their moral and legal duties as health care professionals." "There may however be circumstances when an independent consultation with another clinician or ethics committee may be helpful." "Many major medical decisions require a second opinion for legal reasons as well as clinical assurance, e.g. termination of pregnancy, brain stem death. Obtaining a second opinion as to the advisability of withdrawing life sustaining treatment is not a legal requirement but there may be circumstances in which it may highlight the appropriateness of the process of decision making."</p>	<p><i>Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice</i>, 2nd Edition (2004), available at: http://www.rcpch.ac.uk/publications/recent_publications/Witholding.pdf, accessed on: 23 Nov 2005. Reproduced with permission of the RCPCH.</p>
RCP	<p>"In clinical medicine, communication between doctor and patient is the basis of accurate history taking and diagnosis and of successful medical outcome. Patients' experience of illness and medical care is undoubtedly improved by good communication." "In both the young and the old, where another person – parent, child or other carer – is involved in giving and receiving information, there is the danger that the carer's own ideas and worries will intrude into the factual history of the patient's problems. The doctor/carer/patient relationship is vulnerable and may be highly charged with emotion because of hopes for the young and fears for the old. Careful explanation of investigation and treatment is thus critical . . . It is important to realise that carers also have needs and should be treated with understanding."</p>	<p><i>Improving Communication Between Doctors and Patients: A report of a working party</i> (1997) (London: RCP). Reproduced with permission of the RCP.</p>
DH (NSF)	<p>"Mothers must have the support and the information they need to make the best choices for them and their baby. Children, young people and pregnant women need to be listened to and to be involved in all decisions about their care." "The majority of women will want to be active participants in planning their care. Most will want to be involved in decisions about which type of care or offers of screening best suits their needs and wishes, and to share responsibility for managing their pregnancy in partnership with their professional care providers." Maternity service providers are expected to ensure that:</p> <ul style="list-style-type: none"> • pregnant women are offered clear information on matters relating to antenatal and postnatal care and screening; • "Women are given enough time between receiving information and making choices to reflect upon the information, consider their options and seek additional information and advice where they wish to"; 	<p><i>National Service Framework for Children, Young People and Maternity Services</i> (2004), available at: http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/ChildrenServicesInformation/ChildrenServicesInformationArticle/fs/en?CONTENT_ID=4089111&chk=U8Ecln, accessed on: 22 Nov 2005. Reproduced under the terms of the Click-Use Licence.</p>

Organisation	Guidance	Reference
DH	<ul style="list-style-type: none"> • "In addition to providing support and advice for women, maternity services seek to engage fathers." <p>"The way in which health professionals present bad or difficult news is an important factor in how it is received, understood and dealt with. Such news must be shared with children and parents in a sensitive, non-hurried fashion, away from possible interruptions. A consistent theme from parents is the need for more information. Time must be set aside for careful and detailed explanations, repeated as often as requested, and in different forms, including written, with ample opportunity to ask questions."</p>	<p><i>Seeking Consent – Working with Children</i> (2001), available at: http://www.dh.gov.uk/assetRoot/04/06/72/04/04067204.pdf, accessed on: 22 Nov 2005. Reproduced under the terms of the Click-Use Licence.</p>
NICE	<p>"Pregnant women should be offered evidence-based information and support to enable them to make informed decisions regarding their care. Information should include details of where they will be seen and who will undertake their care. Addressing women's choices should be recognised as being integral to the decision-making process."</p>	<p><i>Antenatal Care: Routine Care For The Healthy Pregnant Woman. Clinical Guideline 6</i> (2003), available at: http://www.nice.org.uk/pdf/CG6_ANC_NICEguideline.pdf, accessed on: 22 Nov 2005.</p>
GMC	<p>"You must respect the right of patients to be fully involved in decisions about their care."</p>	<p>Good Medical Practice (2001), available at: http://www.gmc-uk.org/guidance/good_medical_practice/index.asp#Relationships%20with%20patients, accessed on: 23 Nov 2005.</p>
GMC	<p>"Effective communication is the key to enabling patients to make informed decisions. You must take appropriate steps to find out what patients want to know and ought to know about their condition and its treatment. Open, helpful dialogue of this kind with patients leads to clarity of objectives and understanding, and strengthens the quality of the doctor/patient relationship. It provides an agreed framework within which the doctor can respond effectively to the individual needs of the patient. Additionally, patients who have been able to make properly informed decisions are more likely to co-operate fully with the agreed management of their conditions."</p>	<p><i>Seeking Patients' Consent: The Ethical Considerations</i> (1998), available at: http://www.gmc-uk.org/guidance/library/consent.asp, accessed on: 23 Nov 2005.</p>
Research and clinical trials during pregnancy and early life		
RCOG	<p>"Consent to participate in research should not normally be obtained in labour." Exceptions are made if the woman has been fully informed prior to labour and for important therapeutic research that cannot be done in any other way and that has full ethics committee approval.</p>	<p><i>Clinical Governance Advice No. 6: Obtaining Valid Consent</i> (2004), available at: http://www.rcog.org.uk/resources/Public/pdf/CGA_No6.pdf, accessed on: 21 Nov 2005. Reproduced with permission of the RCOG.</p>
RCPCH	<p>Guidelines are given for "everyone involved in the planning, review, and conduct of research with children." "These guidelines are based on six principles: (1) "Research involving children is important for the benefit of all children and should be</p>	<p>Guidelines for the ethical conduct of medical research involving children (2000), <i>Arch Dis Child</i> 82:177–182, available at: http://adc.bmjournals.com/cgi/reprint/82/2/177, accessed on: 23 Nov 2005</p>

(subscription required). Reproduced with permission from the BMJ Publishing Group.

- supported, encouraged and conducted in an ethical manner
- (2) "Children are not small adults; they have an additional, unique set of interests Research should only be done on children if comparable research on adults could not answer the same question
- (4) "A research procedure which is not intended directly to benefit the child subject is not necessarily either unethical or illegal
- (5) "All proposals involving medical research on children should be submitted to a research ethics committee
- (6) "Legally valid consent should be obtained from the child, parent or guardian as appropriate. When parental consent is obtained, the agreement of school age children who take part in research should also be requested by researchers."
- The guidelines recognise that "Medical research involving children is an important means of promoting child health and wellbeing."
- "Research and innovative treatment on humans should only be undertaken after adequate basic research. Research with children should be undertaken only if work with adults is clearly not feasible. When a choice of age groups is possible, older children should be involved in preference to younger ones, although much valuable research can only be done with younger children and babies."
- "As assessment of benefit and harm is complex, children are best protected if projects are reviewed at many levels, by researchers, funding and scientific bodies, research ethics committees, the research assistants and nurses working with child subjects, the children, and their parents."
- "If the child is insufficiently mature to consent, then valid parental consent must be obtained."
- "A general exception to the requirement for consent is the provision of medical care in an emergency. If emergency medical, surgical, and neonatal care are to be improved, research is necessary. On many, but not all, such occasions, it may be impracticable, or meaningless, to attempt immediately to obtain informed consent for the proposed research procedures from parents or guardians."
- "Provided, therefore, that the specific approval of a research ethics committee has been obtained for the project overall, it would be ethical to carry out research on children on such occasions of extreme urgency without obtaining consent. It is possible, however, that it would still be unlawful if the research were not expected to benefit the child in question, although legal action would be unlikely. The parents or guardians and, where appropriate, the child must be informed about the research as soon as possible afterwards: a requirement in ethics as in courtesy."

Safeguarding Informed Parental Involvement in Clinical Research Involving Newborn Babies and Infants: A position statement (1999)
(London: RCPCH).

- RCPCH
- "All paediatricians work within and are committed to the Declaration of Helsinki which includes the statement that concern for the interests of the subject must always prevail over those of science and society."
- "It would be unethical not to do important clinical research on newborn babies and infants."
- "Research should only be carried out on neonates and infants if meaningful data for the management and care cannot be obtained by extrapolation from equivalent research in older age groups."
- "All trial protocols must be sanctioned by a properly constituted and independent Research Ethics Committee."

Organisation	Guidance	Reference
	<p>“Good practice, with regard to clinical trials, requires that informed assent or consent is obtained from a parent of the infant prior to entry to a trial.”</p> <p>“The involvement of infants and children in properly conducted research is justified because it generates evidence on which treatment of future generations will be based.”</p> <p>“Information enhancing the understanding of the value of scientific research should be given to all mothers attending antenatal clinics. Such information should be written and might include: what randomisation means; what a randomised controlled trial is; what therapeutic equipoise is; what independent Research Ethics Committees do; and what consent is and how to opt in and opt out of research studies.”</p>	<p><i>Consent – What You Have a Right to Expect: a Guide for Parents</i> (2001), available at: http://www.dh.gov.uk/assetRoot/04/11/73/53/04117353.pdf, accessed on: 22 Nov 2005.</p>
DH	<p>There are different types of research that may involve children, all of which will have been approved by a Research Ethics Committee before any child is asked to take part. Some research will involve a new or different treatment and sometimes a child may only be able to get a certain treatment as part of a research trial because it has not been properly tested yet. Parents should receive information about any research project and have the opportunity to ask questions before deciding on whether their child should taking part.</p>	<p><i>Seeking Consent – Working with Children</i> (2001), available at: http://www.dh.gov.uk/assetRoot/04/06/72/04/04067204.pdf, accessed on: 22 Nov 2005.</p>
DH	<p>Further details provided.</p> <p>Information given to parents cover the following:</p> <ul style="list-style-type: none"> • there is no pressure to take part, and they can withdraw consent at any time, without the rest of the child's care being affected; • if the research is a clinical trial, the nature of the trial, and the information available so far on the therapy's effectiveness and side effects; • if the research is a randomised controlled trial, the fact that their child will be randomly assigned to the standard treatment, the new treatment or (if applicable) the placebo. <p>People with parental responsibility can consent to a non-therapeutic intervention on a child as long as that intervention is not against the interests of the child and imposes only a minimal burden.</p>	<p><i>National Service Framework for Children, Young People and Maternity Services: Maternity Standard</i> (2004), available at: http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4089101&chk=Kuk%2BDw, accessed on: 22 Nov 2005.</p> <p>Reproduced under the terms of the Click-Use Licence.</p>
DH (NSF)	<p>One of the standards to be reached by 2014:</p> <p>“Maternity units actively engage in well-designed, ethical, clinical research that aims to improve care for pregnant and recently pregnant women and their babies.”</p>	<p><i>National Service Framework for Children, Young People and Maternity Services: Medicines for Children and Young People</i> (2004), available at: http://www.dh.gov.uk/assetRoot/04/09/05/63/04090563.pdf, accessed on: 22 Nov 2005.</p> <p>Reproduced under the terms of the Click-Use Licence.</p>
DH (NSF)	<p>“Evidence suggests that medication safety needs to be improved, particularly in babies and young children . . .</p> <p>In 2004, the Government recognised the need for high quality research in children and young people and resolved to establish a national research network to study medicines for children.”</p>	<p><i>National Service Framework for Children, Young People and Maternity Services: Medicines for Children and Young People</i> (2004), available at: http://www.dh.gov.uk/assetRoot/04/09/05/63/04090563.pdf, accessed on: 22 Nov 2005.</p> <p>Reproduced under the terms of the Click-Use Licence.</p>

BMA	<p>There is general agreement that participation by immature minors in “non-therapeutic” research is not necessarily unethical provided that: the research carries no more than minimal risk; it does not entail any suffering for the child; parental and LREC agreement is obtained; and the child does not appear to object. Nonetheless, researchers should be aware that the law is unclear and therefore legal advice should be sought.</p>	<p><i>Consent Tool Kit</i>, 2nd Edition (2003), available at: http://www.bma.org.uk/ap.nsf/Content/consenttk2\$file/toolkit.pdf, accessed on: 23 Nov 2005.</p>
GMC	<p>“If you participate in research you must put the care and safety of patients first. You must ensure that approval has been obtained for research from an independent research ethics committee and that patients have given consent. You must conduct all research with honesty and integrity.”</p>	<p><i>Good Medical Practice</i> (2001), available at: http://www.gmc-uk.org/guidance/good_medical_practice/index.asp#Relationships%20with%20patients, accessed on: 23 Nov 2005.</p>
GMC	<p>“Research involving children and young people is important in promoting their health and to validate in them the beneficial results of research conducted with adults.” “When involving children and young people in research you must protect their ethical, physical, mental and emotional rights and ensure that they are not exploited. It is important to assess carefully the potential benefits and harm to them, at all stages of any research.” “You must always ensure that you have obtained consent before undertaking any research on children and young people. If they are not competent, independently, to consent to treatment then they should not participate in research without the consent of someone with parental responsibility.”</p>	<p><i>Research: The Role and Responsibilities of Doctors</i> (2002), available at: http://www.gmc-uk.org/guidance/library/research.asp#Children%20and%20young%20people, accessed on: 23 Nov 2005.</p>
MRC	<p>The MRC guidelines discuss the importance and the ethical consideration of research involving children, particularly focusing on consent, confidentiality, safety and ethical review. Regarding research involving babies, the following points are made: “A parent/guardian’s informed consent is necessary for the involvement of babies in research. When a baby is seriously ill and a decision about treatment is required quickly, the pressure on parents is high and the difficulty of obtaining truly informed consent is recognised.”</p>	<p><i>MRC Ethics Guide: Medical Research Involving Children</i> (2004), available at: http://www.mrc.ac.uk/pdf-ethics_guide_children.pdf, accessed on: 23 Nov 2005.</p>
Pain		
RCOG	<p>Report discusses current practice and current opinion in this area, and considers medical interventions for diagnosis and treatment of the fetus, for termination of the pregnancy and during labour. Three recommendations were made: i) “that practitioners who undertake diagnostic or therapeutic surgical procedures upon the fetus at or after 24 weeks’ gestation consider the requirements for fetal analgesia and sedation”; ii) “that practitioners who undertake termination of pregnancy at 24 weeks or later should consider the requirements for feticide or fetal analgesia and sedation”; iii) “further research be undertaken in a number of areas identified”.</p>	<p><i>Fetal Awareness: Report of a working party</i> (1997) (London: RCOG Press). Reproduced with permission of the RCOG.</p>
MRC	<p>Discusses the main recommendations of the RCOG working party report and the feasibility of further research in the areas highlighted.</p>	<p><i>Report of the MRC Expert Group on Fetal Pain</i> (2001), available at: http://www.mrc.ac.uk/pdf-fetal.pdf, accessed on: 25 Nov 2005.</p>

Organisation	Guidance	Reference
DH (NSF)	"Hospital policies for managing children's pain should apply to all children in every hospital department, including newborns in neonatal units."	<i>Getting the right start: National Service Framework for Children: Standard for Hospital Services</i> (2003), available at: http://www.dh.gov.uk/assetRoot/04/06/72/51/04067251.pdf , accessed on: 22 Nov 2005. Reproduced under the terms of the Click-Use Licence.
DH (NSF)	"Children . . . have a right to appropriate prevention, assessment and control of their pain. Pain is unpleasant, delays recovery, and adds to the trauma of illness, injury and clinical procedures. Historically, pain has been underestimated and under treated in children and particularly babies. There is still evidence that pain is inadequately dealt with for children, requiring better prevention, assessment and treatment."	<i>National Service Framework for Children, Young People and Maternity Services: Children and Young People who are Ill</i> (2004), available at: http://www.dh.gov.uk/assetRoot/04/10/40/32/04104032.pdf , accessed on: 22 Nov 2005. Reproduced under the terms of the Click-Use Licence.
Responsibilities and attitudes to the fetus, the newborn and the woman		
RCOG	"Although obligations to the fetus in utero increase as it develops, UK law does not grant it personal legal status. This comes from the moment of birth." "The maternal-fetal relationship is unique. There are two patients with access to one through the other. For the duration of the pregnancy the woman is the only person who can directly control what is done to her fetus. Others can advise and encourage but she alone takes direct responsibility during every minute of every day for some nine months." "The fetus is totally reliant on the mother so long as it remains in utero. The protection of the fetus stands on her performance of her moral obligations, not on any legal right of its own." "The unique relationship between a mother and her embryo or fetus places on her a responsibility which increases as the pregnancy advances. The welfare of the child may well be dependent on her commitment to this unique obligation." "The aim of those who care for pregnant women must be to foster the greatest benefit to both the mother and fetus with the least risk to both." "Obstetricians must recognise the dual claims of the mother and her embryo or fetus, and inform and advise the family, utilising their training and experience in the best interests of both parties. Almost always, when medical information and the possible options are communicated sensitively and effectively, both the decision and the responsibility for it can be shared by the mother and her obstetrician." "The law and the ethics of the obstetrician are at one in recognising a duty towards the welfare of the fetus, which only exceptionally conflicts with the vital interests of the mother and her freedom of choice. It is in the common interest for society, and it is the object of obstetric care in particular, to assist the mother to fulfil her obligation."	<i>A Consideration of the Law and Ethics in Relation to Court-Authorised Obstetric Intervention</i> (1994), available at: http://www.rcog.org.uk/index.asp?PageID=1198 , accessed on: 23 Nov 2005. Reproduced with permission of the RCOG.
RCOG	"Obstetricians must respect the woman's legal liberty to ignore or reject professional advice, even to her own detriment and that of her fetus." "The law provides no restriction on a woman's freedom on account of her pregnancy. Any medical action requires her informed consent."	<i>A Consideration of the Law and Ethics in Relation to Court-Authorised Obstetric Intervention</i> (1994), available at: http://www.rcog.org.uk/index.asp?PageID=1198 , accessed on: 21 Nov 2005. reproduced with permission of the COG.
RCM	"The newborn should be treated with kindness and respect" "In all situations, it is important that women understand who has responsibility for their care,	<i>Evidence Based Guidelines for Midwifery-Led Care in Labour: Midwifery Practice Guidelines</i> (2005), available at:

http://www.rcm.org.uk/data/education/data/_Toc89671202, accessed on: 22 Nov 2005.
Reproduced with permission of the RCM.

<p>RCPCH</p>	<p>"The doctor's primary duty is to act in the child's best interest. If there is conflict between doctor and parents or parents and child, then the child's needs are paramount."</p>	<p><i>Responsibilities of Doctors in Child Protection Cases with regard to Confidentiality</i> (2004), available at: http://www.rcpch.ac.uk/publications/recent_publications/Confidentiality.pdf, accessed on: 25 Nov 2005. Reproduced with permission of the RCPCH.</p>
<p>DH (NSF)</p>	<p>"Children and young people are important. Nothing matters more to families than the health, welfare and future success of their children. They deserve the best care because they are the life-blood of the nation and are vital for our future economic survival and prosperity." "Healthy mothers produce healthy babies who become healthy children and adults." Standards to be reached by 2014 include:</p> <ul style="list-style-type: none"> • "The health and well-being of all children . . . is promoted and delivered through a coordinated programme of action, including prevention and early intervention wherever possible, to ensure long term gain, led by the NHS in partnership with local authorities." • "All children . . . who are ill, or thought to be ill, or injured will have timely access to appropriate advice and to effective services which address their health, social, educational and emotional needs throughout the period of their illness." • "Children . . . who are disabled or who have complex health needs receive coordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives." • "All agencies work to prevent children suffering harm and to promote their welfare, provide them with the services they require to address their identified needs and safeguard children who are being or who are likely to be harmed." • "Parents or carers are enabled to receive the information, services and support which will help them to care for their children and equip them with the skills they need to ensure that their children have optimum life chances and are healthy and safe." • "Women have easy access to supportive, high quality maternity services, designed around their individual needs and those of their babies." 	<p><i>National Service Framework for Children, Young People and Maternity Services</i> (2004), available at: http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ChildrenServices/ChildrenServicesInformation/ChildrenServicesInformationArticle/fs/en?CONTENT_ID=4089111&chk=U8Eclh, accessed on: 22 Nov 2005. Reproduced under the terms of the Click-Use Licence.</p>
<p>NICE</p>	<p>"Women and their families should always be treated with kindness, respect and dignity."</p>	<p><i>Routine Post-natal Care of Women and their Babies</i>, (2006) available at: http://www.nice.org.uk/page.aspx?o=CG37, accessed on: 28 Sept 2006.</p>
<p>GMC</p>	<p>"Patients must be able to trust doctors with their lives and well-being. To justify that trust, we as a profession have a duty to maintain a good standard of practice and care and to show respect for human life."</p>	<p><i>Good Medical Practice</i> (2001), available at: http://www.gmc-uk.org/guidance/good_medical_practice/Index.asp#Relationships%20with%20patients, accessed on: 23 Nov 2005.</p>

Organisation	Guidance	Reference
Consideration of social, cultural and religious background		
RCOG	"The General Medical Council's Duties of a Doctor says that doctors must make sure that their 'personal beliefs do not prejudice patient care'"	<i>About Abortion Care</i> (2001) (London: Royal College of Obstetricians and Gynaecologists). Reproduced with permission of the RCOG.
RCOG	"Some women may have a clear preference for women doctors . . . This may be due to ethnic, religious or cultural background or may be related to previous trauma."	<i>Clinical Governance Advice No. 6: Obtaining Valid Consent</i> (2004), available at: http://www.rcog.org.uk/resources/Public/pdf/CGA_No6.pdf , accessed on: 21 Nov 2005. Reproduced with permission of the RCOG.
BAPM	"The doctor counselling parents should be careful not to impose his or her own cultural and religious convictions on those whose beliefs may be different, bearing in mind the requirements of the law." "Frequently an important part of counselling parents is to try as sensitively as possible to gain insight into their wishes and concerns, in order to spare them avoidable stress and feelings of guilt, rather than trying to seek an outright decision." "Parents facing difficult decisions should be encouraged to seek advice from others such as family members or religious advisors. They should be offered the opportunity of seeking additional professional advice."	<i>Fetuses and Newborn Infants at the Threshold of Viability: A Framework for Practice</i> (2000), available at: http://www.bapm.org/media/documents/publications/threshold.pdf , accessed on: 24 Nov 2005. Reproduced with permission of BAPM.
RCPCH	"Each hospital should have a policy in place for when a child dies and provide information which should be readily available for staff which includes details about asking for post mortems, the needs of different cultures and the provision of mementos for the family." "If there is anxiety about the degree of certainty behind the medical facts it should be considered whether any further investigation might help to resolve this. Input from religious advisors or other important sources of support to the family may be helpful. However, personal beliefs may dictate that some individuals decide in a particular way whatever the circumstances."	<i>Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice</i> , 2 nd edition (2004), available at: http://www.rcpch.ac.uk/publications/recent_publications/Withholding.pdf , accessed on: 23 Nov 2005. Reproduced with permission of the RCPCH.
RCP	"Good communication with parents is essential in obtaining the history and educational and social background and to help inform the child and to receive informed consent." "Patients who speak little or no English or whose idiomatic use of English differs from that of the doctor pose special problems, particularly if they also belong to a different ethnic group. Their ideas and understanding about illness and its implications may lead to misunderstanding . . . A greater understanding of the culture and practices of different so-called minority populations is necessary and attention needs to be given to this aspect of medicine in undergraduate and postgraduate education."	<i>Improving Communication Between Doctors and Patients: A report of a working party</i> (1997) (London: RCP). Reproduced with permission of the RCP.
RCP	"The beliefs, practices and languages of the populations being served by a health care institution are important and ethics support will need to be sensitive to them."	<i>Ethics in Practice: Background and recommendations for enhanced support</i> (2005) (London: RCP). Reproduced with permission of the RCP.

DH (NSF)	<p>Recognition that: "Each pregnancy is different and each woman has different social, physical and emotional needs as well as specific clinical factors that may affect her pregnancy." Target to provide: "high quality midwifery, obstetric and neonatal services in a culturally sensitive way."</p>	<p><i>National Service Framework for Children, Young People and Maternity Services: Maternity Standard (2004)</i>, available at: http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4089101&chk=Kuk%2BDw, accessed on: 22 Nov 2005. Reproduced under the terms of the Click-Use Licence.</p>
NICE	<p>"The views, beliefs and values of the woman, her partner and her family in relation to her care and that of her baby should be sought and respected at all times."</p>	<p><i>Routine Post-natal Care of Women and their Babies, (2006)</i> available at: http://www.nice.org.uk/page.aspx?o=CG37, accessed on: 28 Sept 2006.</p>
BMA	<p>"Where the parents hold strong views in favour of either withdrawing or continuing treatment, these, together with the reasons for their views, should be given serious consideration as part of the decision-making process."</p>	<p><i>Withholding and Withdrawing Life-prolonging Medical Treatment – Guidance for decision making (2001)</i> (London: BMJBooks).</p>
GMC	<p>The investigations or treatment you provide or arrange must be based on your clinical judgement of patients' needs and the likely effectiveness of the treatment. You must not allow your views about patients' lifestyle, culture, beliefs, race, colour, gender, sexuality, disability, age, or social or economic status, to prejudice the treatment you provide or arrange.</p>	<p><i>Good Medical Practice (2001)</i>, available at: http://www.gmc-uk.org/guidance/good_medical_practice/index.asp#Relationships%20with%20patients, accessed on: 23 Nov 2005.</p>

Appendix 10: Organisations with an interest in the fetal and neonatal area

We describe below some organisations that are involved in fetal and neonatal medicine and care for babies and children.²²

Antenatal Results and Choices (ARC) (<http://www.arc-uk.org/>)

Antenatal Results and Choices (ARC) is a national charity that aims to provide support and information to parents making decisions about antenatal testing and dealing with the diagnosis of an abnormality. It does this through publishing literature for parents, running a helpline and email support group, and organising parent meetings. ARC also works with medical professionals to improve the care that parents receive at this time.

BLISS – The premature baby charity (<http://www.bliss.org.uk/>)

BLISS is a national charity that was founded in 1979. Its aim is to give every baby the chance of an equal start in life and it seeks to do this in three main ways by: (1) campaigning for improvements in neonatal care; (2) supporting affected parents and families; and (3) promoting new developments and innovations in care.

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

The British Association of Perinatal Medicine (BAPM) was set up 30 years ago by around 20 neonatal paediatricians with the aim of improving the standard of perinatal care in the British Isles. The group now has around 800 members and maintains the same core aim. The work of the Association includes establishing standards and guidelines, organising scientific meetings, advising the Government and other bodies, and facilitating and supporting research.

Council for Disabled Children (<http://www.ncb.org.uk/Page.asp?sve=785>)

The Council for Disabled Children provides a national forum for the discussion and development of a range of policy and practice issues relating to service provision and support for disabled children and young people, and those with special educational needs. It works with parents of disabled children and disabled children themselves, among others, to collate and share examples of good practice in children's services and other types of support. The Council believes that children with disabilities should have equality of opportunity and the right to have their views heard.

Disability Rights Commission (<http://www.drc-gb.org/>)

The Disability Rights Commission (DRC) is an independent body established in April 2000 by Act of Parliament to prevent discrimination and promote equality of opportunity for disabled people. The goal of the DRC is "a society where all disabled people can participate fully as equal citizens". The DRC is involved in a variety of activities, including giving advice and information to disabled people and their employers, campaigning to strengthen the law, and producing policy statements and research on disability issues. The work of the DRC will be integrated into the new Commission for Equality and Human Rights (CEHR) when it is launched in October 2007.

National Childbirth Trust (<http://www.nct.org.uk/>)

The National Childbirth Trust (NCT) is a charity concerned with pregnancy, birth and early parenthood in the UK. It aims to ensure that parents' needs are represented to policy makers at both national and local levels. The NCT also offers educational courses and provides information and telephone helplines for parents and delivers training for healthcare professionals.

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

The Royal College of Obstetricians and Gynaecologists (RCOG) was founded as the British College of Obstetricians and Gynaecologists in 1929, and later was awarded a Royal Charter. There are currently around 11,000 members of the College, many of whom are international. The role of the College is “the encouragement of the study and the advancement of the science and practice of obstetrics and gynaecology”. Its aim is “setting standards to improve women’s health”. The College is involved in education and examinations, promoting and publishing research, and establishing standards and guidelines.

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

The Royal College of Paediatrics and Child Health (RCPCH) was founded as the British Paediatric Association in 1928. It now has over 6,000 members, most of whom are hospital or community paediatricians. The main objectives of the College are to advance the art and science of paediatrics, improve standards of medical care to children, and to educate and examine doctors in paediatrics. In addition, the College has a role in providing information to the public on the healthcare of children. The functions and responsibilities of the RCPCH currently include overseeing postgraduate training and examinations, conducting paediatric research, organising meetings and conferences, and publishing papers and guidelines relevant to paediatric practice.

Stillbirth and Neonatal Death Charity (SANDS) (<http://www.uk-sands.org/>)

The Stillbirth and Neonatal Death Charity (SANDS) is a UK-wide charity, established in 1975. It aims to support parents and others who have been affected by a baby’s death. The organisation also works towards improving care for pregnant and bereaved parents by, for example campaigning for more research into the medical causes of stillbirth, trying to ensure parents receive appropriate care when their baby has died and raising awareness of stillbirth and neonatal deaths in the wider community.

Tommy’s – The baby charity (<http://www.tommys.org/>)

Tommy’s is a national charity founded in 1991 and concerned with health during pregnancy and birth. Central to the charity’s work is its belief that every baby deserves the best start in life. It has two main areas of work: firstly, providing information on healthy pregnancy and birth for parents and health professionals; and secondly funding medical research into premature birth, stillbirth, miscarriage and complications during pregnancy.

Wellbeing of Women (<http://www.wellbeingofwomen.org.uk/>)

Wellbeing of Women is a national charity funding vital research into all aspects of women’s reproductive health. Its aim is to “put an end to fear and suffering from women’s reproductive problems”. The areas of research funded by Wellbeing include gynaecological cancers, pregnancy and birth, and other quality of life problems. The charity also provides information on and raises awareness of good reproductive health in women.

WellChild (<http://www.wellchild.org.uk/>)

WellChild is a national charity founded over 25 years ago that works to improve the health of children in the UK. WellChild’s three aims are: to make every child as healthy as possible, to support every family with a sick child and to raise awareness of children’s health and healthcare. It achieves these aims through research, information and support for families, and education of professionals.

Glossary

Abnormality: An anomaly, deformity, malformation, **impairment** or dysfunction.

Abortion: See **Termination of pregnancy**.

Acardiac twinning: Twins where only one twin has a heart, and that twin pumps blood through them both.

Amniocentesis: A procedure that involves removing a sample of fluid from the **amniotic sac** surrounding the **fetus** using a needle using **ultrasound** guidance. The sample is then used for laboratory tests to inform an assessment of whether the fetus has certain conditions. Amniocentesis is the most common prenatal test used to diagnose **chromosomal** and genetic birth defects.

Amniotic sac: A thin membrane around the **fetus** that is filled with amniotic fluid.

Anaemia: A deficiency in the blood involving a lack of red blood cells or haemoglobin (the molecule that transports oxygen in the blood).

Analgesic: A compound that relieves pain by altering the perception of painful stimuli without producing anaesthesia or loss of consciousness.

Anencephaly: An developmental **abnormality** in which most or all of the brain is absent. This condition is incompatible with life and may be detected by tests during pregnancy.

Antenatal: During pregnancy.

Antepartum infection: Infection in the period before **labour** or childbirth.

Anoxia: Lack of oxygen, especially of such severity as to result in permanent damage.

Aorta: Large blood vessel that carries blood from the heart to be circulated around the body.

APGAR: A scoring system used to evaluate the condition of a newborn baby based on a rating of 0, 1 or 2 for each of the five characteristics of colour, heart rate, response to stimulation of the sole of the foot, muscle tone, and respiration.

Ascending meningitis: Bacterial infection entering via an opening in the spine (**spina bifida**) and spreading to the fluid and membranes around the brain.

Autonomy: Self-governance or self-determination.

Best interests: Principle that requires that in all matters affecting a child his or her best interests should be an important consideration. Although there are different interpretations of scope and status, the principle is central to medical practice, child protection and disputes about child custody.

Bilateral: On both sides (e.g. of the brain or body).

Borderline of viability: Extremely **premature** babies who are born alive at or before 25 weeks, six days of gestation (measured from the first day of the **pregnant** woman's last menstrual period).

Brain death: Irreversible cessation of all functions of the entire brain, including the brain stem.

Caesarean section: Procedure in which the **fetus** is removed from the mother after surgical incision through the abdominal wall and the uterus, rather than being born vaginally. A classical Caesarean section involves opening the abdomen and the upper part of the uterus, unlike the operation which usually can be performed at or near term in which only the lower part of the uterus is opened (lower segment Caesarean section).

Care: The activity of providing treatment for or looking after someone.

Catheter: A tube inserted into the body usually through a natural passage to remove (or introduce) fluid, such as urine from the bladder through the urethra.

Cerebral palsy: A general term for permanent but non-progressive disorder or abnormality of movement and posture arising from injury to the immature brain. See also **Spastic diplegia**.

Cerebrospinal fluid: Clear fluid produced in the ventricles of the brain and which flows through channels to be reabsorbed on the outside of the brain.

Chorioamnionitis: An infection of the chorion and the amnion, the two membranes enclosing the **fetus** and **amniotic fluid**, which can lead to more serious infections in both the mother and baby. This condition increases the risk of other problems in the baby and can cause **pre-mature** birth.

Chorionic villus sampling: A biopsy of part of the placenta during pregnancy to obtain a sample that can be used for diagnosis of chromosomal or genetic disorders in the **fetus**.

Chromosome: Within the nucleus of each cell of the human body, the genetic material (DNA) is arranged in 46 string-like chromosomes. The chromosome complement of an individual is determined when the sperm fertilises the egg.

Chromosomal abnormality or disorder: A condition in which extra or missing **chromosome** material leads to abnormalities, for example Down's syndrome.

Chronic lung disease of prematurity: Persistent abnormality of the lungs of **premature** babies which prolongs the need for help with breathing and oxygen. In most cases this condition gradually improves over months or after one or two years.

Cognitive impairment: **Impairment** of mental processes used in rational thinking, for example, learning, judging, knowing, analysis, etc.

Complication: A disease or disorder that occurs during the course of (or because of) another disease.

Congenital diaphragmatic hernia: A protrusion of the abdominal contents into the chest through a defect in the diaphragm.

Congenital disorders: Abnormalities or diseases that involve the way a baby has developed during pregnancy. They may be present at birth or become apparent soon after birth.

Consent: It is a general legal and ethical principle that valid agreement must be obtained before examining or treating a patient, whenever possible. The purpose is to ensure absence of coercion, force or duress (see Appendix 5).

Consequentialism: An ethical approach that judges right and wrong primarily on the basis of the consequences of a given action.

Continuous positive airway pressure (CPAP): Air is made to flow through fine tubes placed in the baby's nose to assist breathing. This slightly raises the pressure and prevents the lungs from collapsing.

Critical care decision: A decision that potentially affects whether a patient will live or die. This Report deals with three particular areas of medical decision-making: (1) about the care of the **fetus** and the mother-to-be during her pregnancy; (2) whether to resuscitate a **premature** or ill newborn baby, and admit him or her to neonatal intensive care; and (3), whether to institute further treatment after birth, or to withhold, or even withdraw treatment.

Cyst: An abnormal sac in part of the body that contains gas, fluid or a semi-solid material and has a membrane lining.

Deontology: Philosophical approach in which the rightness or wrongness of certain actions is defined by a formal system, independently of their outcomes.

Diagnostic technique or test: Technique or test used to establish or confirm a diagnosis.

Disability: Various definitions of disability are currently in use. The **Disability Discrimination Act (DDA) 1995** (as amended 2005) provides the following definition of a disabled person: “A person has a disability . . . if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.” The courts have interpreted ‘substantial’ as meaning neither petty nor trivial. Long-term is generally interpreted as meaning 12 months or longer. The **EPICure Study** (see Chapter 5) distinguishes between severe, moderate and mild disability using the following criteria. A severe disability would be likely to make a child highly dependent on care-givers, and involve one or more of: cerebral palsy that prevented the child from walking, an IQ score considerably lower than average, profound sensorineural hearing loss, or blindness. With a moderate disability reasonable independence would be likely to be achieved and one or more of the following would be involved: cerebral palsy (but the child could still walk), an IQ score lower than average, sensorineural hearing loss that can be corrected with a hearing aid, or impaired vision without blindness. Mild disabilities would include mild learning problems or other **impairments** such as squints. See also **Impairment**.

Doppler ultrasound: Investigation of the speed and direction of blood flow in the **fetus, placenta** and uterus using **ultrasound** waves.

Down’s syndrome (or trisomy 21): A condition in which there is an extra **chromosome 21** (three instead of two) in (usually) every cell, leading to learning disabilities. Other abnormalities occur in some cases, including problems with the heart, intestine and muscles.

Duodenal blockage: Blockage of the intestine immediately beyond the stomach.

Duty of care: Once a baby is ‘born alive’ the healthcare team legally owe the baby a duty of care. This duty will be to sustain the patient’s life and restore him or her to health, where possible and appropriate, and, in all cases, to prevent pain and suffering, and comfort the child.¹

Electroencephalography (EEG): The recording of the electrical activity of the brain to identify seizures (convulsions and fits) and abnormalities of background brain activity.

Embryo: Name given to the stage of development of a fertilised egg until classified as a **fetus** at around 12 weeks of gestation.

Empirical research: Knowledge built up by direct observation and by testing to see if theories can be disproven.

Encephalopathy: Any disease or disorder affecting the brain and especially chronic degenerative conditions.

Endoscopy: (literally ‘looking in’) involves the insertion of a narrow telescope into the body. Endoscopic procedures are often referred to as ‘keyhole surgery’.

Epidermolysis bullosa: A group of inherited skin diseases in which the skin blisters and erodes easily when knocked or rubbed. Different diseases within this group affect the body in slightly different ways and affect the severity of the disease, from being lethal in early life to allowing the person to lead a near-normal life for many years.

Epilepsy: A persistent disorder of the brain caused by sudden electrical disturbance in which an individual experiences disturbances of brain function affecting movement and consciousness.

¹ Royal College of Paediatrics and Child Health (2004) *Withholding or Withdrawing Life Sustaining Treatment in Children: A framework for practice*, 2nd Edition, available at: http://www.rcpch.ac.uk/publications/recent_publications/Withholding.pdf, accessed on: 23 Nov 2005.

Fertility treatment: A term used to describe all the treatment methods that are used to help a couple achieve a pregnancy when they are having difficulty conceiving. Treatments are available for both male and female infertility problems, and include *in vitro* fertilisation (IVF).

Fetal blood transfusion: Procedure carried out if the **fetus** suffers from **rhesus haemolytic disease** that involves transfusing blood into the fetus to correct fetal **anaemia**.

Fetal growth restriction: Condition in which the **fetus** fails to achieve its growth potential, usually due to an inadequate supply of nutrients and oxygen by the **placenta**.

Fetal medicine: The branch of medicine that deals with the growth, development, care, and treatment of the **fetus** and with environmental factors that may harm the fetus. (See also **Open fetal surgery; percutaneous surgery**.)

Feticide: The action or process of causing the death of a **fetus**. The guidelines of the Royal College of Obstetricians and Gynaecologists (RCOG) recommend that feticide be carried out before **termination** of a pregnancy after 21 weeks, six days of gestation to ensure that the fetus is born dead.² The recommended method of feticide is injection of potassium chloride into the fetal heart.

Fetoscopy: Use of an endoscope introduced through the mother's abdominal wall into the uterus to view the **fetus** and the fetal surface of the **placenta**, for diagnostic or therapeutic purposes.

Fetus: The name given to the unborn baby usually from the end of the 12th week of gestation until birth.

Futile: An intervention or treatment that would delay death but is judged to improve neither life's quality nor potential.³

Gene: The fundamental physical and functional unit of heredity consisting of a sequence of DNA, occupying a specific position on a **chromosome**.

Genetic screening: Screening is a public health service in which members of a defined population, who do not necessarily perceive they are at risk of, or are already affected by a disease or its complications, are asked a question or offered a test, to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of a disease or its complications.

Genetic testing: Testing an individual for the genetic change (mutation) underlying a condition or abnormality that may be suggested by other evidence.⁴

Gestation: The duration of the pregnancy from first day of the woman's last menstrual period to birth.

Gestational age: The duration of gestation is measured from the first day of the **pregnant** woman's last menstrual period. Conception will usually occur around two weeks after this date.

Gradualism: In the context of this Report, the view that the **fetus** gains increasing **moral status** as biological development progresses.

Gynaecology: The science of the physiological functions and diseases of women and girls, in particular those affecting the reproductive system.

² Royal College of Obstetricians and Gynaecologists (2001) *Further Issues Relating to Late Abortion, Fetal Viability and Registration of Births and Deaths*, available at: <http://www.rcog.org.uk/index.asp?PageID=549>, accessed on: 8 Aug 2006.

³ Royal College of Paediatrics and Child Health (2004) *Withholding or Withdrawing Life Sustaining Treatment in Children: A framework for practice*, 2nd Edition, available at: http://www.rcpch.ac.uk/publications/recent_publications/Withholding.pdf, accessed on: 23 Nov 2005.

⁴ See Nuffield Council on Bioethics (2006) *Genetic Screening: A supplement to the 1993 Report by the Nuffield Council on Bioethics* (London: NCOB).

Haemorrhage: Heavy or uncontrolled bleeding.

Handicap: No legal definition of handicap exists in UK legislation. It is term that is no longer widely used, 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.

Heart failure: Inability of the heart to pump enough blood for the needs of the body's organs.

Hemiplegia: Brain injury affecting one side of the brain that results in stiffness, or spasticity, and reduced control of the arm and leg on the opposite side of the body.

High-dependency care: A level of neonatal care which often involves intravenous feeding and some assistance with breathing, along with other care needs.

Hospice: Centre that provides specialist respite, emergency, palliative and end-of-life care for individuals with life-limiting conditions, either within the centre, or in their own home.⁵

Hydrocephalus: A condition in which an abnormally large amount of **cerebrospinal fluid** is present. The fluid causes certain areas of the brain to swell, which puts pressure on the surrounding tissue and causes enlargement of the brain and skull. The effects of the condition vary greatly, but when it is detected during pregnancy the outlook is generally poor. It can also occur after birth if the channels for draining cerebrospinal fluid become blocked. In around 50% of such cases a disability such as cerebral palsy will result.

Hypoxia: A lack of oxygen which is severe enough to stop cells working normally and cause cell death.

Hypoxic-ischaemic encephalopathy: A type of brain injury that typically occurs after a critical lack of oxygen supplied to the **fetus** at term during **labour** and delivery. The baby does not breathe at birth and requires **resuscitation** with **ventilation**. Within hours, brain injury becomes obvious with reduced responsiveness, abnormal postures and movements, and, in many cases, seizures.

Imaging: The use of 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, ultrasound**, molecular imaging and scanning microscopy.

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. 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 coordination, 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. See also **Disability**.

Incubator: A piece of medical equipment that a baby is kept inside to keep him or her warm. Some incubators also regulate humidity.

⁵ Association of Children's Hospices (2004) *Children's Hospice Services: A guide for professionals* (Bristol: Association of Children's Hospices).

Inherited disorder: A disease that is determined by an individual's genetic make-up. Examples include cystic fibrosis, sickle cell anaemia and muscular dystrophy.

(Neonatal) intensive care: The whole range of medical neonatal care, but not necessarily all specialist services, such as neonatal surgery.

Intervention: The act or method of interfering with the outcome or course of a condition or process, usually to prevent harm or improve function.

Intolerable: In this Report we take 'intolerability' to encompass an extreme level of suffering or **impairment** which either is present in the baby or may develop in the future.

Intrapartum asphyxia: A lack of oxygen during **labour** and birth.

Intrauterine: Within the uterus (womb).

Intrauterine growth restriction: See **Fetal growth restriction**.

Intraventricular haemorrhage: Bleeding in and around the ventricles or cavities of the brain, which are filled with cerebrospinal fluid and linked by ducts so the fluid can circulate. This is a common complication of being born very prematurely and occurs in about 25% of babies with a birthweight below 1,500 g. Large haemorrhages (about 25% of all haemorrhages) increase the risk of cerebral palsy.

Intubation: Inserting a breathing tube into the windpipe so that artificial **ventilation** can be given.

Invasive: Referring to a procedure that requires insertion of an instrument or device into the body through the skin or a body orifice.

Jaundice: A yellowish colouring of the skin, tissues, and certain body fluids that usually results from either excessive breakdown of red blood cells (for example after internal haemorrhage or in various haemolytic states) or problems with the liver that affect the production and discharge of bile.

Justice: Principle that requires the fair, equitable and impartial treatment of all persons.

Labour: The process of delivery of a baby, involving contraction of the uterus, dilatation of the cervix and expulsion of the **fetus** and **placenta** from the mother's uterus.

Learning disability: A condition that either prevents or hinders somebody from learning basic skills and/or acquiring information.

Lesion: General term encompassing damage to, or abnormality of a tissue or organ.

Live birth: A baby who shows signs of life at birth.

Magnetic resonance imaging (MRI): A technique that allows observation of internal structures of the body using magnetism and a computer to generate images. For the scan, adult patients lie flat on a bed, while babies are placed inside a special incubator to keep them warm. The bed or incubator is moved into a horizontal tube that is surrounded by a large circular magnet. These scans are painless and have an advantage over X-rays as there is no exposure to radiation. They are useful for assessing development of the brain and the extent of any brain damage in newborn babies. See **Imaging**.

Microencephaly: A condition in which the brain is abnormally small.

Miscarriage: Spontaneous expulsion of the **fetus** and **placenta** from the **pregnant** woman before the 24th week of gestation.

Moral status: The intrinsic value (in the context of this Report) of humans at different stages of development.

Morbidity: A diseased state.

Mortality: A fatal outcome. Mortality rates refer to the rate of death in a given population.

Multiple birth: A single **pregnancy** resulting in two or more births (e.g. twins).

Negligence: A lack of proper care and attention. In the medical field this may include technical failure of equipment and failure of a medical professional to carry out his or her duties to the expected standard.

Neonatal medicine: The branch of medicine that is concerned with the diagnosis and treatment of ill **newborn** babies.

Neonatal period: The period within 28 days of birth.

Neurodevelopmental: Of or relating to the development of the nervous system, which includes the brain and spinal cord.

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

Non-invasive fetal treatment: Treatment of a **fetus** that involves giving the **pregnant** woman medicines that cross the **placenta** and have a therapeutic effect on the fetus.

Obstetrics: The clinical specialism involving the care of women and their **fetuses** during pregnancy and **labour** and of the mothers in the period after birth).

Open fetal surgery: Surgical procedures that involve opening the mother's abdomen and uterus under general anaesthesia. The **fetus** is partially exposed and operated on. Compare **Percutaneous surgery**. Sometimes known as 'true' fetal surgery.

Oxygen therapy: Air contains 21% oxygen but babies with lung disease may need a higher percentage to achieve adequate levels within the body. This may be given via a ventilator or, more commonly, via a nasal tube. Compare **Continuous positive airway pressure**.

Paediatrics: The clinical specialism in the care of children.

Palliative care: Defined by the World Health Organization as the "active, total care of patients whose disease is not responsive to curative treatment. The goal of palliative care is achievement of the best quality of life for patients and their families".⁶ Compare **Treatment**.

Paraplegia: Paralysis from the waist down, resulting from injury or abnormality of the spinal cord.

Pathological: In a diseased or injured state.

Percutaneous surgery: Procedure performed without surgical incision of the skin, by introducing an endoscope (fetoscope) or cannula and trocar under ultrasound guidance. Compare **Open surgery**.

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

Periventricular leucomalacia (PVL): Injury, usually **bilateral**, to the white matter surrounding the ventricles in the brain.

Placenta: An organ that develops from the fertilised egg and is therefore a fetal tissue. It is attached to the wall of the womb and is connected to the **fetus** by the umbilical cord. The placenta mediates transfer of nutrition and oxygen from mother to fetus and excretory products from fetus to mother. It also has an important hormone function. After birth, the placenta is expelled; at this stage it is disc-shaped, about 18 cm across and has the umbilical cord attached roughly at the centre.

⁶ Gale G and Brooks A (2006) Implementing a palliative care program in a newborn intensive care unit *Adv Neonatal Care* 6: 37–53.

Pneumonia: Infection in the lung.

Pre-eclampsia: Complication of pregnancy involving raised blood pressure and excess protein in mother's urine. The **pregnant** woman becomes progressively more ill with high blood pressure, poor kidney function and fluid retention. If no action is taken, she may eventually develop eclampsia, characterised by seizures, strokes and eventually death. In such cases the baby will also be at risk.

Pre-embryo: Early stage of development from fertilisation to implantation of the **embryo** in the lining of the womb at seven days post-fertilisation.

Pregnant: Having a child developing in the uterus (womb).

Premature birth: Birth of a baby before 38 weeks, 0 days of gestation.

Moderately premature: Birth of a baby between 35 and 37 weeks of gestation.

Very premature: Birth of a baby between 27 and 34 weeks of gestation.

Extremely premature: Birth of a baby before 27 weeks of gestation.

Preterm birth: See **Premature birth**.

Pre-viable fetus: A fetus before the age of gestation at which independent existence is possible. Even with full neonatal support, babies born before this age (currently defined as 21 weeks, six days of gestation) are unable to survive.

Primitive streak: A structure that forms in the **embryo** at around 14 days after conception in humans. It is the first clearly recognisable stage in embryonic development.

Prognosis (plural prognoses): Prediction of the outcome of a disease or injury.

Quality-adjusted life year: A quality-adjusted life year (QALY) is a measure of both the quantity and the health-related quality of life gained by particular treatments or interventions. A year of perfect health is valued at 1 QALY, whereas a year expected to be spent at less than perfect health is valued at less than 1. See Appendix 8.

Randomised controlled trial (RCT): An experiment in which, with consent, investigators randomly allocate eligible participants into control and intervention groups to receive one or more treatments that are being tested. The results are assessed by comparing outcomes of the two groups (see Appendix 6).

Recessive junctional epidermolysis bullosa: A genetic disease that causes the skin to blister and erode. It is rare for a child with a severe form of this condition to live beyond a few months. See **Epidermolysis bullosa**.

Renal agenesis: Developmental absence of both kidneys, leading to death of the baby at birth. Survival is the norm when only one kidney is absent.

Respiratory distress syndrome (RDS): A syndrome in which breathing difficulties in newborn babies are caused by a lack of lung surfactant. This syndrome almost always occurs in babies born at less than 37 weeks of gestation, and the more **premature** the baby, the greater the risk. It is also more likely to occur when the baby's mother is diabetic.

Resuscitation: Revival from potential or apparent death. Resuscitation will be considered for a baby born at the limits of viability and any baby who does not start breathing unaided after birth. Resuscitation involves inflating the baby's lungs with air (and possibly with additional oxygen) and sometimes using chest compression or drugs to speed up the pumping of the heart. Further measures may be needed if the baby does not respond. See Box 3.2.

Retinopathy of prematurity: Babies born before 28 weeks of gestation have a significant risk of developing an eye disease that can result in loss of vision.

Rhesus haemolytic disease: Disease in which a **fetus** suffers from **anaemia** caused by **rhesus incompatibility** with the blood group of the mother.

Rhesus incompatibility: Rhesus factor is a protein that is present on the red blood cells of some people, according to their genes. When this factor is present in the **fetus** but not in the mother, there is incompatibility and a serious reaction can occur if antibodies from the mother cross the placenta and attack the red blood cells of the fetus. This can cause anaemia, hydrops (accumulation of watery fluid) and fetal death.

Rights-based theory: A rights-based theory holds that individuals have interests that are sufficiently important to justify enforcing others in the performance of duties to respect those interests. This is a type of deontological theory. See **Deontology**.

Rupture of membranes: The **pregnant** woman experiences vaginal loss of amniotic fluid because of a hole in the membrane of the gestation sac (amnion and chorion).

Sanctity of life: A doctrine that usually holds that taking human life is categorically wrong, as all humans are of equal intrinsic value and should be treated with the same respect.

Selective reduction of pregnancy: A technique for **intrauterine** termination of one or more **fetuses** while leaving one or more other fetuses undisturbed, usually in pregnancies with fetal anomalies or with several fetuses.

Self-determination: See **Autonomy**.

Seizure: A sudden disturbance of consciousness or movement resulting from an electrical disorder in the brain.

Singleton: A baby who is the sole **live birth** or **stillbirth** from a pregnancy.

Sociology: The study of the development, structure and functioning of human society.

Spastic diplegia: A form of **cerebral palsy** which primarily affects the legs and the trunk rather than the arms.

Spasticity: Involuntary muscle contractions that occur in many people with **cerebral palsy**, and those who suffer severe head injuries.

Special care: This lower level of **care** may involve tube-feeding, some additional **oxygen therapy** and light therapy (phototherapy) as appropriate for each individual baby. Compare **(Neonatal) Intensive care**.

Spina bifida: A condition in which the spinal column fails to close around the spinal cord, leading to abnormal spinal cord development often associated with paralysis of the lower limbs. The muscles that control the bowel and bladder function can be affected and some babies have **hydrocephalus**.

Stillbirth: A baby who is born after the 24th week of gestation and did not at any time breathe or shown any signs of life after being born.

Surfactant: A natural substance that 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: A baby is born at 'term' if they have a **gestational age** of between 38 weeks and 42 weeks at birth.

Termination of pregnancy: The deliberate ending of a pregnancy with the intention that the **fetus** does not survive, typically using medication or surgical removal of the fetus from the womb.

Trachea: The windpipe, or airway, that carries air from the larynx (voice box) to the lungs.

Tracheotomy: An operation to make an artificial opening in the front of the windpipe to enable a patient to breathe if the upper airway is blocked.

Trauma: An injury, physical or mental. Birth trauma refers to a physical injury to a baby during birth.

Treatment: The medical or surgical management of a patient. The aims of different treatments include curing, ameliorating or preventing onset of a condition or the symptoms of a condition, and alleviating pain and distress associated with a condition or medicines taken for a condition. Palliative treatments are those that are intended to alleviate pain and distress associated with a health condition, and in this Report we use the term **palliative care** where a patient receives palliative treatments but not active treatments, for example where the active treatments have been withheld or withdrawn. There is some debate as to whether artificial feeding and hydration procedures should be considered as treatment; however, in this Report by treatment we do not include artificial nutrition and intravenous hydration, considering it instead as basic nursing care.

Trisomy 18 (Edwards syndrome): A severe **chromosome abnormality** in which there is an extra chromosome 18 in (usually) every cell of the body. Different types of the syndrome have varying severities, of which the most serious means that babies do not usually live beyond infancy. Characteristic features include growth deficiency, bone abnormalities, hernias, skin mottling, heart defects, feeding and breathing problems and **learning disabilities**.

True fetal surgery: See **Open fetal surgery**.

Ultrasonography: A method for studying internal structures that involves scanning with high frequency ultrasound waves and measuring the reflected waves to produce an image. This technique is routinely used to monitor the growth and development of the baby before birth. Scans before 16 weeks of gestation can be used to date the pregnancy and can detect some major malformations. Detailed scans are usually carried out at 18–21 weeks of gestation and should reveal most major malformations and some minor ones.

Ultrasound: See **Ultrasonography**.

Utilitarianism: A form of **consequentialism**, in which the focus is on measuring the value of actions by the overall degree of happiness they generate.

Ventilation: Treatment by which a medical device breathes for the baby, inflating the lungs to produce each breath. Some ventilators assist the baby's own efforts. Sometimes the baby is passive and inflation of the lungs is achieved entirely by the ventilator. Ventilation requires that the baby has a tube inserted into the **trachea**. See Box 3.2.

Ventricles: Four fluid-filled spaces within the brain which communicate with the brain's exterior.

Viability: Being capable of living outside the womb.

Virtue ethics: In virtue ethics what matters most is to develop excellence in moral action and to display and express this excellence in one's character.

White matter: The white matter is found in an area deep inside the brain which contains mainly nerve fibres, including those which allow the brain to control movement. In **premature** babies, white matter is immature and very vulnerable to injury.

Withdrawal of treatment: Ceasing active medical **treatment** for a given child in a situation where this is considered to be, for example, **futile**, burdensome or not in their **best interests**. When treatment is withdrawn, the child will still receive other forms of treatment aimed at comfort and relief of symptoms (see **Palliative care**).

Withholding treatment: To not initiate medical **treatment** that could be provided for a given child in a situation that is considered to be, for example, **futile**, burdensome or not in their **best interests**. When such treatment is withheld, the child will still receive other forms of treatment aimed at comfort and relief of symptoms (see **Palliative care**).

Worldview: A particular philosophy or view of life that an individual may hold.

List of abbreviations

BAPM	British Association of Perinatal Medicine
BMA	British Medical Association
CEC	Clinical ethics committee
CEMACH	Confidential Enquiry into Maternal and Child Health
CPAP	Continuous positive airway pressure
CT scanning	Computerised (axial) tomography scanning
DDA	Disability Discrimination Act 1995, 2005
DH	Department of Health
EEG	Electroencephalography
GMC	General Medical Council
HFEA	Human Fertilisation and Embryology Authority
LEA	Local education authority
MRC	Medical Research Council
MRI	Magnetic resonance imaging
NCT	National Childbirth Trust
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NICU	Neonatal intensive care unit
NNA	Neonatal Nurses Association
NNAP	National Neonatal Audit Programme
NSF	National Service Framework
PCT	Primary care trust
PVL	Periventricular leucomalacia
QALY	Quality-adjusted life year
RCM	Royal College of Midwives
RCN	Royal College of Nursing
RCOG	Royal College of Obstetricians and Gynaecologists
RCP	Royal College of Physicians
RCPCH	Royal College of Paediatrics and Child Health
RCT	Randomised controlled trial
(L)REC	(Local) Research ethics committee
SANDS	Stillbirth and Neonatal Death Charity
SEN	Special educational needs
SHA	Strategic Health Authority
UNCRC	United Nations Convention on the Rights of the Child

Index

- abnormal 42
- abnormalities 92
 - see *also* congenital abnormalities;
 - fetal abnormalities
- abortion see termination of pregnancy
- Abortion Act 1967 45–6, 55–6, 63, 64, 129, 153
- absolutist interpretation, sanctity of life
 - 11, 59
- acts and omissions 18, 132, 140–1
- administrators, healthcare 23
- advances, medical 32, 51
- alveolar capillary dysplasia 95
- American Academy of Pediatrics 98
- amniocentesis 52
- anaesthesia, in late terminations 61
- analgesia see pain relief
- analgesics
 - causing death as side-effect 20, 46
 - in neonatal intensive care 96
- anencephaly 55
- Antenatal Results and Choices (ARC) 33, 218
- antenatal screening 33, 51, 52, 60–1
- APGAR score 75
- Arthur, Dr Leonard 142
- attention deficit disorder 72, 116
- autism 86
- autonomy, pregnant woman xix, 46, 128, 152
- autopsies xxvi, 110, 166

- BAPM see British Association for Perinatal Medicine
- 'bed blocking' 43, 103
- behavioural problems 72, 115, 116
- benzodiazepines 140
- bereavement support 107
- best interests xvii, 15–17, 159–62
 - babies at borderline of viability 77–8, 83, 153–4
 - conflicting 16, 160
 - declaration (by a court) 101
 - of different parties 17, 160
 - fetus 59
 - impact of resource constraints 21–2
 - interpretation 15–16
 - in intolerable situation 105
 - in late terminations 61, 64
 - legal perspective 46–7, 130, 133–4, 145
 - in neonatal intensive care 99–100, 102
 - parents' views and 145, 159
 - proposed criteria for assessing xxii–xxiii, 160–2
 - UK professional guidance 197–8
 - weight 16–17, 59, 159
- bioethics consultation 146
- bioethics mediation 145–6
- birth
 - legal implications 14, 46, 131–2
 - live see born alive
 - moral and legal significance xvi, 14, 152
 - statistics by gestational age 69–70
- birth asphyxia 93
- birthweight
 - data collection 109
 - to determine borderline viability 68
- blindness see visual impairment
- BLISS – The Premature Baby Charity
 - xxvii, 167, 218
- blood transfusion
 - fetal 54, 59–61
 - refusal of consent 136
- BMA see British Medical Association
- Bolitho v City and Hackney Health Authority* [1998] 139
- borderline of viability, babies at xix–xxii, 29, 33–4, 67–87
 - best interests 77–8, 83, 153–4
 - birth statistics 68, 69–70
 - case examples 77–84
 - clinical perspective 68–70
 - conclusions and recommendations 153–7
 - economic issues 84–7
 - implications for healthcare team 79
 - legal issues 79, 83, 84, 134–5
 - professional guidance 204–5
 - resuscitation and intensive care xx–xxii, 34–5, 74–7
 - case examples 77–84
 - conclusions and recommendations 154–7
 - legal aspects 134–5
 - need for guidelines xx, 134–5, 154
 - in other countries 73, 76–7, 135
 - outcomes 71, 73
 - proposed guidelines xx–xxii, 155–7
 - research needs 74–5, 156–7
 - UK practice xviii, 74–7, 82
 - survival and outcomes 68–74, 154–5
 - see *also* extremely premature babies

- born alive
 - need for definition xx, 131–2, 153
 - at termination of pregnancy 56, 64, 129–30
 - see *a/so* birth
- bowel
 - obstruction, surgery against parent's wishes 136–7
 - serious acquired injuries 95
 - transplants 95
- brain death 190
- brain injuries xxiv, 35, 92–4, 188–90
 - acquired, in term babies 93–4
 - case example 101–3
 - common forms 188–90
 - congenital abnormalities 94
 - diagnosis 188
 - in premature babies 92–3
- Bristol Royal Infirmary Inquiry (2001) 55
- British Association for Perinatal Medicine (BAPM) 218
 - on babies at borderline of viability 154, 204–5
 - on consent to treatment 191, 200, 202, 203
 - on neonatal resuscitation 205–6
 - on palliative care 98
 - 'partnership of care' concept xviii, 23, 137
 - recommendations to xx, xxiv, 132, 153, 155, 158, 167
 - on social, cultural and religious issues 216
 - on withholding and withdrawing treatment 207
- British Medical Association (BMA)
 - on best interests 197
 - on consent to treatment 191, 201, 204
 - on doctrine of double effect 20
 - on fetal abnormalities 57
 - on research and clinical trials 212–13
 - on social, cultural and religious issues 217
 - on withholding and withdrawing treatment 207
- burdensome treatment 12, 46–7, 137, 157
- Butler-Sloss, Dame Elizabeth 137
- Caesarean section 67, 73
- cardiac rhythms, abnormal fetal 54
- care pathways, maternity services 51, 153
- carers
 - assessment 119
 - disabled children 117
 - provision of 119
 - see *a/so* parents
- Carers (Equal Opportunities) Act 2004 117
- Carers and Disabled Children Act 2000 117
- Centre for Effective Dispute Resolution 147
- cerebral palsy 72
 - after continuation of neonatal intensive care 99–101
 - athetoid 93–4, 189
 - babies at borderline of viability 71, 76, 80, 82
 - brain injuries underlying 93–4, 189
 - caring for developing child with 114
 - spastic 93–4, 189
- cervical incompetence 80
- chaplains 40
- character-based ethics 9–10
- Childcare Act 2006 121
- Child Death Helpline 107
- children
 - consent by 133
 - rights 4, 47, 127
- Children Act 1989 15, 47, 122, 130, 145
- Children (Scotland) Act 1995 15, 47
- Children and Family Court Advisory and Support Service (CAFCASS) 101
- Children (Northern Ireland) Order 1995 15, 47
- Children's Commissioner 118
- chorioamnionitis 53
- chorionic villus sampling 52
- chromosomal abnormalities 52, 55
- chronic lung disease 41, 72
- clinical context, decision making 32–6
- clinical ethics committees (CECs) 23, 24, 143–4
 - babies at borderline of viability 79
 - recommendations xxv, 162–3
 - review of withdrawal of life-sustaining care 145
- Clinical Ethics Framework 144
- clinical negligence 146–7
- clinical trials 36, 192
 - professional guidance 210–13
- Cochrane Database of Systematic Reviews 192
- cognitive function 139
- communication
 - about disability 43
 - importance of good 24, 60, 110
 - training needs 37, 82, 100, 167
 - see *a/so* information, provision

- community leaders 23
- community liaison teams 41
- community mental health services 115
- Confidential Enquiry into Maternal and Child Health (CEMACH) 58
- congenital abnormalities 34, 91, 94–5, 131
- congenital heart abnormalities 94–5
- conjoined twins 131
- conscientious objection 63, 141
- consent
- to autopsy 110
 - to data collection 109
 - to feticide before late termination 64
 - by minors 133
 - by parents 134, 191
 - professional guidance 197–204
 - for treatment 191, 198–204
 - treatment without 191
 - when parents disagree 84, 203–4
- consequentialism 9, 59
- continuing education 167
- continuous positive airways pressure (CPAP) 41, 99–101
- coping strategies, healthcare professionals 79
- corticosteroids *see* steroids
- cost-effectiveness studies, neonatal intensive care 103–4
- cost per quality-adjusted life year (QALY) gained 44
- costs
- babies born at borderline of viability 85–6
 - court proceedings 144–5
 - disability 117, 121–2
 - see also* economic issues
- cost utility analysis 44
- Council for Disabled Children (CDC) 117–18, 123, 218
- counselling 33, 62
- courts
- avoiding recourse to 24, 162–3
 - on children's rights 123
 - judgements 4–5, 46
 - parental demands for treatment 137–9
 - parental refusal of treatment 136–7
 - procedures 101
 - protection of privacy xxvi, 163
 - recourse to xxvi, 101, 144–5, 163
 - scenarios for possible involvement 83, 84, 100–1, 103
- criminal law xxvii, 46, 132, 142, 167
- cultural factors 40, 84, 216–17
- data
- collection, requirements xxvi, 108–9, 165–6
 - linkage xxvi, 108, 109–10, 166
 - paucity of adequate 107, 151
 - see also* information
- Data Protection Act 1998 109
- deafness *see* hearing impairment
- death
- causes 187
 - neonatal *see* neonatal death
- DeBRA 104
- decision making xviii, 22–5
- at borderline of viability 78–9, 84
 - clinical context 32–6
 - conclusions and recommendations 159–62
 - consequences 41–3
 - context 29–47
 - economic issues 44–5
 - ethical issues xvi–xviii, 3–4, 9–25
 - legal framework *see* legal framework
 - pain relief with life-shortening effect 105–7
 - parents' perspective 37–8
 - participants in process 22–3
 - process 3–4, 23–5
 - professional guidance 209–10
 - regulation and resolution xxv–xxvi, 127–47
 - research requirements xxvi, 100, 166
 - role of emotions xviii, 11, 151
 - shared 22, 38–9, 60, 106–7
 - socio-demographic factors influencing 62, 84
 - staged process 105
 - termination for fetal abnormality 61–3
 - wider socio-legal context 39–41
- deformations 92
- deliberate ending of life *see* ending of life, active
- delivery
- babies at borderline of viability 67
 - early *see* premature delivery
- deontology 9
- Department for Education and Skills 43, 98
- recommendations to xviii, 165

- Department of Health (DH) 43, 98, 193
 - on best interests 197
 - on consent to treatment 191, 199, 200, 201, 202–4
 - data collection/linkage 108
 - on decision-making and information provision 209–10
 - Patient Information Advisory Group 109–10, 166
 - recommendations to xviii, xxiv, xxvi, 147, 158–9, 163, 165
 - on research and clinical trials 212
- Department of Work and Pensions xviii, 114, 165
- depression 115
- developmental care 97, 158–9
- dialysis 95
- diaphragmatic hernia, congenital 55
- dignity 46
- digoxin 54
- disability xxiv–xxv, 41–3, 113–24
 - assessment of risk 81
 - babies at borderline of viability 33, 70, 71, 73–4
 - in brain injuries 93–4
 - categories in premature babies 72
 - conclusions and recommendations 165
 - costs 117, 121–2
 - definitions 4, 41
 - impact of antenatal screening 33
 - legislation 122–4
 - media reporting 42
 - mild 71
 - moderate 71, 81–2
 - perceptions of 81–2, 113–14
 - severe 71, 81–2
 - social and medical models xxv, 42
 - social context 4, 20–1
 - sociology of 42
 - stereotypes or prejudices 38
 - wider socio-legal context 39
- Disability Discrimination Acts (DDA) 1995 and 2005 41, 42, 120, 122, 123–4
- Disability Equality Duty (DED) 123
- Disability Rights Commission 42, 218
- disabled children 113–24
 - case examples 114–15
 - education provision 120–1
 - financial burden on family 86, 118, 122
 - impact on parents' interests 17
 - legal rights 122–3
 - living with 117–19
 - numbers 4, 41–2
 - quality of life 43, 82, 116
 - recommendations 165
 - support for families *see under* support, family
- disabled people
 - moral status xxii, 20–1, 164–5
 - numbers 41–2
 - rights 42, 115–16
 - value of life 12
- disabled young people 123–4
- dispute resolution xxv–xxvi, 144–7
 - conclusions and recommendations 162–3
 - in the courts 101, 144–5, 162, 163
 - by mediation 145–7, 163
 - role of clinical ethics committees 162–3
 - see also* parents, disagreement with doctors
- disruptions 92
- distress *see* stress/distress
- doctors
 - acceptance of parents' wishes 80
 - conveying information 60, 100, 106
 - decision making role 23, 106–7
 - disagreement with parents *see* parents, disagreement with doctors
 - interests 160
 - perspective on active ending of life 141, 157
 - perspective on feticide 63
 - public image 38–9
 - training 37, 82
 - see also* neonatologists
- double effect, doctrine of 20, 105, 107
- Down's syndrome 52, 136–7, 142
- drainage tubes, fetal 54
- duty-based ethics 9
- dysplasias xxiv, 92
- Early Support Programme 120
- economic issues xvii–xviii, 20–2, 44–5
 - antenatal screening 60–1
 - at borderline of viability 84–7
 - conclusions and recommendations 163–5
 - neonatal intensive care 103–4
 - see also* costs
- education
 - costs, babies at borderline of viability 86
 - disabled children 114, 120–1
 - healthcare professionals xxvii, 167
- Edwards syndrome 146

- electroencephalography (EEG) 188
 electronic NHS database xxvi, 109, 166
 embryo, moral status 13–14
 emotional distress *see* stress/distress
 emotions, role in decision making xviii, 11, 151
 employment
 disabled young people 114, 123–4
 parents of disabled child 114, 117, 122
 encephalopathy, neonatal 93–4, 189–90
 ending of life, active xvii, 19–20, 46
 conclusions and recommendations 157–8
 distinction from withholding/
 withdrawing treatment 140–1, 157
 in intolerable situation 105, 157
 legal issues xxv, 132
 reviewing current law 139–42
 time limits 141–2
 EPICure study 70–4, 85, 86, 154
 epidermolysis bullosa, junctional 13, 104–7
 epilepsy 86, 94
 equity xviii, 164
 see also fairness and justice
 ethics xv, xvi–xviii, 3–4, 9–25
 of care approach 10, 11
 education 167
 plurality of beliefs and assumptions
 xv, 10
 role in considering practical problems
 10–11
 theoretical approaches 9–10
 ethics committees *see* clinical ethics commit-
 tees; research ethics committees
 ethnicity
 access to support services and 114
 decision making and 40
 viability of extremely premature babies
 and 25
 European Convention on Human Rights 47,
 130–1, 158
 European Court of Human Rights 47, 128,
 131, 141, 163
 euthanasia *see* ending of life, active
 expert medical witnesses 101, 139
 extremely low birthweight babies xvi,
 30, 68
 costs of care 85, 103–4
 outcomes 70, 73
 extremely premature babies 3, 33–4
 birth statistics 68, 69–70
 birthweight equivalent 68
 at borderline of viability *see* borderline
 of viability, babies at
 coping with disability as child grows up
 114–15
 decisions about delivery 33, 52–4
 definition 30
 information for parents 81, 82
 media coverage 41
 resuscitation 24–5, 34–5, 74–7
 see also very premature babies
 fairness and justice
 decision making 22
 resource allocation xvii–xviii, 21, 102–3, 164
 family
 decision making context 36–9
 financial costs of disabled child 86
 involvement in decision making 23, 62
 support *see* support, family
 see also parents
 Fédération Nationale des Pédiatres
 Néonatalogists 77
 feeding *see* nutrition
 fertility treatment 31, 109
 fetal abnormalities
 antenatal screening 33, 51, 52, 60–1
 diagnosis 51, 52
 maternal choices xix, 51–2, 55, 61–2,
 152–3
 termination of pregnancy xix, 55–8,
 61–4, 129–30
 treatment *see* fetal treatment
 fetal blood transfusion 54
 refusal 59–61
 fetal growth restriction 52, 53–4
 fetal medicine xv, xix, 51–64
 advances in 32, 51
 case examples 58–63
 conclusions and recommendations 152–3
 regulation 127–30
 role for clinical ethics committees 143–4
 fetal medicine units 57, 67
 clinical ethics committees 143
 information provision 167
 fetal surgery xix, 3, 33, 55, 152
 fetal treatment xix, 3, 33, 54
 refusal (case example) 59–61
 feticide
 before late terminations xix, 56–8, 64
 doctors' perspective 63
 proposed code of practice xix, 130,
 153
 refusal by woman 57, 61–4, 129–30
 selective, in multiple pregnancy 54

- fetus 51–64
 - guidance on responsibilities and attitudes to 214–15
 - law relating to 45–6
 - legal status xxv, 127–8, 131
 - moral status xvi, 13–15
 - gradualist view 14, 59
 - pain perception 58, 213
 - social perceptions 63–4
 - timing of delivery 52–4
 - value of life 11–15
 - viability see viability
- flecainide 54
- foster care 118–19, 120, 165
- France
 - babies at borderline of viability 76–7
 - disagreement between parents 84
- futile treatment xxiv, 46–7, 74, 91, 137, 157
- gender differences, viability of extremely premature babies 25
- General Medical Council (GMC)
 - on best interests 198
 - on consent to treatment 191, 199–200, 201–2, 203
 - on decision-making and information provision 210
 - on research and clinical trials 213
 - on responsibilities and attitudes to women and babies 215
 - on social, cultural and religious issues 217
 - on withholding and withdrawing treatment 208
- general practitioners 194
- germinal matrix haemorrhage (GMH) 92, 189
- gestational age
 - birth statistics by 69–70
 - data collection 109
 - estimation methods 68
 - late termination of pregnancy 55–6
 - resuscitation based on 24–5, 74–6, 134
 - terminology 29, 30, 51, 67
- Glass v United Kingdom* 131, 163
- GMC see General Medical Council
- ‘good life,’ striving for a 42
- gradualist view, moral status of fetus 14, 59
- Groningen Protocol 140
- growth problems 72
- Growth Restriction Intervention Trial (GRIT) 54
- guidelines
 - at borderline of viability, need for 79, 134–5
 - decision making based on 24–5
 - flexibility 25
 - national professional, overview 196–217
- haemoglobinopathies 52
- Health and Social Care Act 2001 109
- healthcare administrators 23
- Healthcare Commission xxvii, 158–9, 193
- healthcare costs
 - babies at borderline of viability 84–6
 - disability 121–2
- healthcare professionals
 - acceptance of parents’ wishes 80
 - continuing education 167
 - decision making role 23, 36–9, 194
 - disagreement between 39
 - education xxvii, 167
 - impact of decisions at borderline of viability 79
 - interests 160
 - perceptions of disability 113
 - perspective on feticide 63
 - relationship with parents 38–9
 - training see training
 - see *also* doctors; neonatologists; nurses
- healthcare resources see resources, healthcare
- health problems, parents of disabled children 117
- hearing impairment 72, 94
- high-dependency care 34
- hospices 119–20
- hospital
 - discharge from 41, 86
 - transfer of pregnant woman 67
- hospital ethics committees see clinical ethics committees
- Human Fertilisation and Embryology Act 1990 109
- human life see life
- human rights see rights
- Human Rights Act 1998 47, 130
- Human Tissue (Scotland) Act 110
- Human Tissue Act 2004 110
- hydration, in palliative care xxiv, 98–9, 158
- hydrocephalus 61–4, 92, 93, 189
- hypertensive disorders of pregnancy 52
- hypoxia, intrapartum 93
- hypoxic ischaemic encephalopathy 93, 189

- impairment 41, 42
- income, families with disabled children 117, 122
- Infant Life (Preservation Act) 1929 131–2
- infants
 - moral status 14
 - mortality rates 30
 - survival 29–32
- infarction, brain 92, 93, 189
- information 165–6
 - paucity of adequate 42–3, 107, 151
 - provision xxvi–xxvii, 42–3, 165–6
 - need for standards xxvii, 167
 - parents of babies in intensive care 100, 106
 - pregnant women xix, xxvii, 60, 81, 166–7
 - on prematurity 81, 82
 - professional guidance 209–10
 - see also communication
 - see also data
- Internet 38, 104
- interpreters 78, 79
- intestine see bowel
- intolerability xvii, 12–13, 105, 157, 159
- intrapartum hypoxia 93
- in vitro* fertilisation 31

- Jehovah's Witnesses 136
- Jepson v Chief Constable of West Mercia Constabulary* [2003] 129
- Judaeo-Christian tradition 40
- justice see fairness and justice

- kangaroo care 97
- kidney failure 95

- labour, delaying 53
- language, English, difficulties with 78, 79
- laser treatment, fetal 54
- law see legal framework
- learning disabilities 72, 94
 - in brain injuries 102
 - costs 121–2
 - National Director (tsar) for 42
 - severe, case example 114–15
 - support services 115, 119
- Learning Disability Team 115
- legal framework xxv, 4–5, 45–7, 127–47
 - at borderline of viability 79, 83, 84, 134–5
 - disability 122–4
 - education of healthcare professionals 167
 - fetal medicine 127–30
 - fetal treatment 60
 - late termination of pregnancy 55–6, 62–3, 64, 129–30
 - neonatal intensive care 100–1, 103, 135–6
 - neonatal medicine 130–9
 - pain relief with life-shortening effect 107, 132
 - reviewing current law 139–43
 - see also courts
- legal status
 - fetus xxv, 127–8, 131
 - newborn baby xxv, 14, 46, 47, 131
- life
 - actively ending see ending of life, active
 - quality of see quality of life
 - reverence for 46, 130
 - right to 11, 47, 127, 130
 - sanctity of see sanctity of life
 - value of xvi–xvii, 11–15
- Limitation of Treatment Bill, draft (1981) 142, 143
- link families 115, 119, 120
- liver transplant, refusal 137
- local authority
 - care 119, 134
 - Children's Services Department 118, 119
 - disability support 114, 115, 118–19, 120
 - parental responsibility 134, 161
- Local Delivery Plans (LDPs) 194
- Local Education Authority (LEA) 115
- Lorber, Dr John 39–40
- low birthweight babies
 - costs 121–2
 - definitions 30
 - high-dependency care 34
 - neonatal mortality 29–30, 31
 - prevalence/incidence 29–32
 - see also premature babies
- lungs
 - chronic disease 41, 72
 - congenital abnormalities 95

- macroeconomic level 21, 44–5, 163–4, 193
- magnetic resonance imaging (MRI) 92, 188
- malformations xxiv, 92
- manslaughter 132, 157

- Mason and McCall Smith's Law and Medical Ethics* (Mason and Laurie) 142
- massage, baby 97
- Maternity Services Dataset 108
- MB, baby *see An NHS Trust v B*
- media coverage 4, 40–1
- disability 42
 - fetus 63–4
- mediation 145–7
- bioethics 145–6
 - definition 146
 - recommendations xxvi, 163
- medical profession *see* doctors
- Medical Research Council (MRC) 213
- medicine, advances in 32, 51
- medicines
- fetal treatment 54
 - see also* analgesics; sedatives
- mental health, parents of disabled children 115, 117
- mental incapacity, pregnant woman 128–9
- mesoeconomic level 21, 44–5, 164, 193–4
- micro(en)cephaly 57, 190
- microeconomic level 21–2, 45, 164, 194
- midwives, perspective on feticide 63
- miscarriage 68
- monitoring xxvi, 165–6
- moral philosophy *see* ethics
- moral status
- at different stages of development 13–15
 - disabled people xxii, 20–1
 - fetus xiv, 13–15, 59
 - newborn baby xvi, 14
- morphine 35, 78, 96, 104, 105, 107, 140
- motor problems 72
- multiple pregnancy 31, 54
- see also* twins
- murder 107, 129, 131, 132, 157
- nasogastric tube feeding 98, 99
- National Childbirth Trust (NCT) xxvii, 167, 218
- National Health Service (NHS)
- electronic database xxvi, 109, 166
 - organisation 45, 193–4
 - recommendations to xx, xxiv, xxv, 158, 162–3
- A National Health Service Trust v D* [2000] 130, 138
- National Institute for Clinical Excellence (NICE) 164, 193
- on information provision 167, 210
- Interventional Procedures Programme 55
- on responsibilities and attitudes to women and babies 215
 - on social, cultural and religious issues 217
- National Neonatal Audit Programme (NNAP) 108
- National Service Framework (NSF) for Children, Young People and Maternity Services
- care pathways in maternity services 51, 153–4
 - consent to treatment 199, 200
 - decision-making and information provision 60, 167, 209–10
 - disability 117, 118, 165
 - neonatal resuscitation 206
 - pain management 214
 - palliative care 98
 - research and clinical trials 212
 - responsibilities and attitudes to newborn 215
 - social, cultural and religious issues 216–17
- National Service Frameworks (NSFs) 193
- necrotising enterocolitis 95
- negligence, clinical 146–7
- Neonatal Critical Care Minimum Dataset 108
- neonatal death
- autopsy after xxvi, 110, 166
 - causes 187
 - support for parents after 107
- neonatal encephalopathy 93–4, 189–90
- neonatal intensive care xv, xxiv–xxv, 34–5, 91–110
- best interests 99–100, 102
 - at borderline of viability *see under* borderline of viability, babies at
 - brain injuries 92–4
 - case examples 99–103, 104–7
 - clinical perspective 91–2
 - conclusions and recommendations 157–62
 - determining outcomes 107–10
 - developmental care 97, 158–9
 - discontinuation *see* withholding and withdrawing life-sustaining treatment
 - economic issues 103–4
 - information provision 100, 106
 - legal issues 100–1, 103, 135–6

- other serious conditions 94–5
- resource constraints 21–2, 84–5, 86–7, 102–3, 163–4
- sanctity of life 102
- neonatal intensive care units (NICU) (level 3 neonatal units) 34
 - clinical ethics committees xxiv, 143, 162
 - information provision 167
 - pain relief xxiv, 95–7, 158–9
 - palliative care provision 158
 - reasons for admission 34
 - stressful nature 36, 80–1, 95
 - stress reduction xxiv, 97, 158–9
 - transfer of pregnant woman 67
- neonatal medicine
 - advances in 32
 - conclusions and recommendations 153–62
 - disagreements between parents and doctors 136–9
 - regulation 130–6
 - reviewing current law 139–43
 - role for clinical ethics committees 143–4
- neonatal mortality rates 29–30, 31
- Neonatal Networks 67
- Neonatal Nurses Association (NNA) xxiv, xxvi, xxvii, 158, 165–6, 167
- neonatal resuscitation 34–5
 - after late termination of pregnancy 57, 64
 - babies at borderline of viability see *under* borderline of viability, babies at
 - best interests considerations 16
 - criteria for assessing best interests xxii–xxiii, 160–1
 - gestational age limits 24–5, 74–6
 - parents' wishes 75, 76
 - procedure 35
 - professional guidance 205–6
- neonatal units
 - classification 34
 - discharge from 41, 113
 - dispute resolution within 162
 - level 3 see neonatal intensive care units
- neonates see newborn babies
- neonatologists
 - determination of borderline viability 68
 - impact of decisions at borderline of viability 79
 - management at borderline of viability 74, 75–6, 77–9
 - resuscitation after late terminations 57
- nervous system, stage of development 13–14
- Netherlands
 - active ending of life 139, 140
 - resuscitation at borderline of viability 24, 76, 77, 82, 135
- newborn babies
 - best interests see best interests
 - at borderline of viability see borderline of viability, babies at
 - brain death 190
 - brain injuries see brain injuries
 - consent to treatment 200–204
 - deliberately ending life see ending of life, active
 - duty to treat 132–4, 153–4
 - guidance on responsibilities and attitudes to 214–15
 - impact of antenatal screening on survival 33
 - legal rights 47, 127
 - legal status 14, 46, 47, 131
 - moral status xiv, 14
 - pain perception 95–6
 - serious conditions 92–5
 - survival 29–30, 31
 - value of life 11–15
 - see also low birthweight babies; premature babies
- NHS see National Health Service
- NHS Numbers for Babies Scheme 109
- NHS Trusts 193
- An NHS Trust v B* [2006] (baby MB) 46, 83, 130, 133, 135, 136, 138–9, 145
- NICE see National Institute for Clinical Excellence
- NNA see Neonatal Nurses Association
- 'no chance' situation, RCPCH framework 12, 18
- 'no purpose' situation, RCPCH framework 12, 13, 18
- normal 42
- Norway, babies at borderline of viability 72–3
- NSF see National Service Framework
- nuchal translucency 52
- nurses
 - acceptance of parents' wishes 80
 - decision making role 23, 36–7
 - interests 160
 - shortages of neonatal 21, 87
 - training 37

- nutrition
 - artificial, withdrawal 98–9
 - intravenous, withholding or withdrawing 95
 - oral, in palliative care xxiv, 98–9, 158
- opiates 140
- oxygen therapy, home 41
- pain xxiv
 - assessment 96
 - and best interests 16
 - caused by neonatal intensive care 80–1
 - fetal 58
 - perception by newborn babies 95–6
 - professional guidance 213–14
 - severe and unrelievable 13
- pain relief (analgesia)
 - fetal 58
 - with life-shortening effect xvii, 20, 46, 104–7, 132
 - medications see analgesics
 - in neonatal intensive care unit xxiv, 95–7, 158–9
 - non-drug methods 96–7
- palliative care xxiv, 18, 97–9
 - after withdrawal of life-sustaining treatment 35, 95
 - babies at borderline of viability 67–8, 74, 75, 77, 78–9
 - baby born alive after late termination 64
 - case example 99
 - definition 97
 - indications 97–8
 - recommendations xxiv, 158
 - support for parents 107
- parental responsibility 130, 134, 161
- parents
 - bereaved, support 107
 - consent by 134, 191
 - decision making 22–3, 25, 36, 37–8, 106–7
 - disagreement between 83–4, 130, 203–4
 - disagreement with doctors 131, 136–9
 - case examples 99–103
 - parental demands for treatment 137–9
 - parental refusal of treatment 136–7
 - professional guidance 203–4
 - resolution see dispute resolution
 - health problems 117
 - impact of child's disability 17
 - information provision see information, provision
 - interests in relation to baby's 17, 160
 - involvement in baby's care 97
 - legal rights 47
 - perspective, clinical ethics committees 144, 145
 - relationship problems 117
 - relationship with healthcare professionals 38–9
 - socio-demographic factors affecting decisions 62
 - stress 36, 95
 - support for disabled child see *under* support, family
 - support groups 38, 107
 - understanding of prognoses 80–1
 - wishes/views
 - active ending of life 141, 157–8
 - autopsy 110
 - at borderline of viability xx, xxii, 75, 76, 77, 78–9, 80–3, 156
 - weight accorded to 145, 159
- 'partnership of care' approach xviii, 23–4, 60, 137, 151, 162
- Patau syndrome 94
- Patient Information Advisory Group 109–10, 166
- Perinatal Networks 67
- peritonitis 95
- periventricular leukomalacia (PVL) 92, 93, 99, 188–9
- polyhydramnios 61
- polymicrogyria 94
- Portage 118
- postmortems see autopsies
- post-neonatal death, causes 187
- potassium chloride injections 56
- poverty, families with disabled children 117, 118, 122
- pre-eclampsia 52
- preferences, ability to express 15
- pregnant woman
 - autonomy xix, 46, 128, 152
 - care pathway 51, 153
 - choices in fetal abnormality 51–2, 55, 61–2, 152–3
 - coercion xvi, 15, 59, 62, 127–8, 152
 - consent to treatment 198–200
 - early delivery see premature delivery

- guidance on responsibilities and attitudes to 214–15
- information provision xix, xxvii, 60, 81, 166–7
- legal rights 46, 60, 84, 127–9
- mental incapacity 128–9
- moral obligations to fetus xvi, 14–15, 152
- refusal of fetal treatment 59–61
- refusal of feticide before late termination 57, 61–4, 129–30
- prejudices 38
- premature babies
- brain injuries 92–3
 - categories of disability 72
 - costs 121–2
 - definitions 30
 - information for parents 81, 82, 167
 - pain perception 95–6
 - survival 29, 31
 - see *also* borderline of viability, babies at; extremely premature babies; low birthweight babies
- premature delivery 52–4
- causes 52, 53
 - decision making 3, 33, 52, 53–4
 - interventions 52–3
- prenatal diagnosis 51, 52
- press coverage see media coverage
- pre-viable babies 68
- Primary Care Trusts (PCT) 193–4
- prognosis
- brain injuries 93
 - conveying information about 43
 - uncertain nature 25, 32–3, 78, 82, 151
 - understanding by parents 80–1
- psychological distress see stress/distress
- quality-adjusted life years (QALYs) 44, 103, 104, 195
- quality of life 11–13, 43
- disabled children 82, 116
 - families with disabled children 117–18
- randomised controlled trials (RCTs) 192
- RCM see Royal College of Midwives
- RCN see Royal College of Nursing
- RCOG see Royal College of Obstetricians and Gynaecologists
- RCP see Royal College of Physicians
- RCPCH see Royal College of Paediatrics and Child Health
- Re C (a minor) (medical treatment)* [1997] 138
- regulation xxv–xxvi, 127–47
- flexibility 25
 - guiding decision making 24–5
 - see *also* legal framework
- Re J (A Minor) (wardship and medical treatment)* [1990] 134
- Re J (A minor) (wardship: medical treatment)* [1992] 138
- religious advisors 23, 40, 80
- religious influences
- at borderline of viability 80–3
 - decision making 37–8, 40
 - guidance on consideration for 216–17
 - in neonatal intensive care 102
 - parental demands for treatment 138–9
 - parental refusal of treatment 136
 - views on sanctity of life 11
- renal agenesis 55
- research xxvi, 165–6
- decision-making process xxvi, 100, 166
 - neonatal pain and stress xxiv, 159
 - outcomes of neonatal intensive care 108, 166
 - professional guidance 210–13
 - resuscitation at borderline of viability 74–5, 156–7
- research ethics committees xix, 75, 152, 192
- residential care, disabled children 115, 119
- resolution, dispute see dispute resolution
- resources, healthcare
- allocation 4, 44–5, 164
 - constraints on xviii, 21–2, 84–5, 86–7, 102–3, 137–8, 163–5
 - fairness of distribution xvii–xviii, 21, 102–3, 164
 - finite nature 44
 - implications of decisions 164–5
 - organisations responsible for 193–4
- respiratory distress syndrome 104
- respiratory problems
- chronic 41, 72
 - palliative care 78
- respite care 118, 119–20, 122
- resuscitation, neonatal see neonatal resuscitation
- Resuscitation Council UK 206
- Re T (a minor) (wardship: medical treatment)* [1997] 137, 145

- retinopathy of prematurity 72
- reverence for life 46, 130
- Re Wyatt* [1997] 138
- rhesus haemolytic disease 54, 59–61
- rights 47
 - children 4, 47, 127
 - disabled children 122–3
 - disabled people 42, 115–16
 - fetus xxv
 - newborn babies xxv, 47, 127
 - parents 47
 - pregnant women 46, 60, 84, 127–9, 152
- rights-based ethics 9
- risk, perceptions 60, 81
- Royal College of Midwives (RCM)
 - on consent to treatment 200
 - on decision-making and information provision 209
 - on neonatal resuscitation 205
 - recommendations to xx, xxiv, xxvi, xxvii, 153, 155, 165–6, 167
 - on responsibilities and attitudes to women and babies 214
- Royal College of Nursing (RCN)
 - on assessment of pain 96
 - recommendations to xx, xxiv, xxvi, xxvii, 155, 158, 165–6, 167
- Royal College of Obstetricians and Gynaecologists (RCOG) 219
 - on best interests 197
 - on consent to treatment 198–9
 - on fetal pain 213
 - on fetal perception of pain 58
 - on late termination of pregnancy 56
 - on neonatal resuscitation 205
 - recommendations to xx, xxvi, xxvii, 132, 153, 155, 165–6, 167
 - on research and clinical trials 210
 - on responsibilities and attitudes to women and babies 214
 - on social, cultural and religious issues 216
 - on threshold of viability 204
- Royal College of Paediatrics and Child Health (RCPCH) 219
 - on babies at borderline of viability 154
 - on best interests 197
 - data collection 108
 - on decision-making and information provision 209
 - on deliberately ending life 19
 - on neonatal resuscitation 205
 - 'partnership of care' concept xviii, 23, 137, 162
 - recommendations to xx, xxiv, xxvi, xxvii, 132, 153, 155, 158, 165–6, 167
 - on research and clinical trials 210–12
 - on responsibilities and attitudes to newborn 215
 - on social, cultural and religious issues 216
 - on withholding and withdrawing treatment 12–13, 18, 98, 135, 206–7
- Royal College of Physicians (RCP)
 - on clinical ethics committees 143, 144
 - on consent to treatment 200
 - on decision-making and information provision 209
 - on social, cultural and religious issues 216
- R (Burke) v GMC* [2005] 137
- sanctity of life 11–13
 - absolutist interpretation 11, 59
 - babies at borderline of viability 80
 - babies in neonatal intensive care 102
 - legal principles 46
- SANDS see Stillbirth and Neonatal Death Society
- school leavers 123–4
- schools 86, 120–1
 - after-hours facilities 120–1
 - mainstream 114, 115, 120
 - special 115, 120, 121
- SCOPE 43
- screening, antenatal see antenatal screening
- sedation, fetal 58
- sedatives
 - to actively end life 140
 - causing death as side-effect 20, 46
- self-consciousness 14
- self-determination see autonomy
- short break services 115, 119–20
- siblings, impact of disability on 114, 117
- sickle cell disease 52
- social issues xvii–xviii, 4, 20–2, 39
 - disability xxiv–xxv, 4, 20–1
 - professional guidance 216–17
- social perceptions, fetus 63–4
- social services 114, 115
- societal costs, babies at borderline of viability 85, 86

- socio-demographic factors, affecting decision making 62, 84
- socio-legal context, wider 39–41
- sociological research xxvi, 166
- spastic diplegia 114
- special care, neonatal 34
- special educational needs (SEN) 115, 120, 121
- Special Educational Needs and Disability Act 2001 120
- Special Health Authorities 193
- special schools 115, 120, 121
- spina bifida 39–40, 55
- spinal muscular atrophy 138–9
- spirituality 37–8, 40
- stereotypes 38
- steroids
- antenatal 52–3, 72, 83, 84
 - postnatal 72
- stillbirth 131, 153
- Stillbirth and Neonatal Death Society (SANDS) xxvii, 107, 167, 219
- Strategic Health Authorities (SHAs) 193
- stress/distress
- babies in intensive care 80–1, 95
 - healthcare team 79
 - parents of babies in intensive care 36, 95
 - reduction, in neonatal units xxiv, 97, 158–9
 - women after termination for fetal abnormality 62
- suffering
- and best interests 16
 - intolerable xvi–xvii, 12–13
 - unbearable 12–13
 - weight given to, in legal decisions 133
 - see *also* pain
- support, family
- after death of baby 107
 - disabled child 21, 41, 43, 119–20
 - case example 114–15
 - conclusions and recommendations 165
 - difficulties in accessing xxv, 113–14, 115
 - recommendations xviii, 165
 - responsibility for organising 118–19
 - sources 116–17
 - variations in availability 118, 165
 - disabled young people 123–4
- support groups, parental 38, 107
- surfactant treatment 35, 72, 104
- surgery
- fetal xix, 3, 33, 55, 152
 - newborn babies 34
 - against parent's wishes 136–7
- Sweden, babies at borderline of viability 73
- teenage pregnancy 31–2
- television programmes 40–1
- termination of pregnancy
- autopsy after 107
 - late xix, 39, 55–8
 - decision making 61–3, 153
 - feticide before xix, 56–8
 - legal issues 55–6, 62–3, 64, 129–30
 - proposed code of practice xix, 130, 153
 - refusal of feticide before 57, 61–4, 129–30
 - resuscitation of babies born alive 57, 64
 - maternal choices 55, 153
- thalassaemia 52
- threshold of viability, babies at see *borderline of viability, babies at*
- Together from the Start* 43
- Tommy's 219
- training xxvii, 167
- communication with parents 37, 82, 100, 167
 - palliative care xxiv, 98, 158
- Trent Neonatal Survey 72, 73
- trisomy 13 94
- trisomy 18 146
- twins
- after death of co-twin 94
 - conjoined 131
 - see *also* multiple pregnancy
- twin-to-twin transfusion 54
- ultrasound
- antenatal screening 52
 - diagnosis of brain injuries 188
 - gestational age estimation 68
 - guided fetal treatment 54
- umbilical artery catheterisation 35
- 'unbearable' situation, RCPCH framework 12–13, 18
- uncertainty, of prognosis 25, 32–3, 78, 82, 151
- UNCRC see United Nations Convention on the Rights of the Child

- United Nations Convention on the Rights of the Child (UNCRC) 15, 17, 47, 115–16, 122, 127, 131
- United States (USA)
 - babies at borderline of viability 76
 - bioethics mediation 145–6
 - clinical ethics committees 143
- utilitarianism 9
- value of life xvi–xvii, 11–15
- ventilation, mechanical 34–5
 - babies at borderline of viability 72, 76
 - withdrawal 35, 133, 136, 138–9
- very premature babies
 - care after discharge from hospital 41
 - definition 30
 - neonatal intensive care 34
 - resuscitation procedures 35
 - see *also* extremely premature babies
- viability
 - babies at borderline of see borderline of viability, babies at
 - gender and ethnic differences 25
 - moral status in relation to 14
- virtue ethics 9–10
- visual impairment 72, 94
- welfare, child's 15
- wellbeing 15
- Wellbeing of Women 219
- WellChild 219
- white matter injury, premature babies 92
- Winston-Jones, Luke 101, 136, 138
- withholding and withdrawing life-sustaining treatment xvii, 18–19
 - in brain injuries 94
 - clinical ethics committees and 145
 - concept of intolerability 12–13
 - criteria for assessing best interests xxii–xxiii, 160–2
 - disabled children 43
 - distinction from active ending of life 140–1, 157
 - legal equivalence 135
 - legal issues 46–7, 132–9
 - Lorber criteria 39–40
 - moral equivalence xv, 18, 155
 - in neonatal intensive care unit 91–2, 97–9, 100–1, 102
 - procedures 35
 - professional guidance 206–8
 - RCPCH framework 12–13, 18
 - reviewing current law 142–3
 - see *also* palliative care
- Working Party
 - method of working 171–5
 - wider consultation 176–86
- Wyatt, Charlotte 101, 136, 138, 144–5
- young carers 117
- young people, disabled 123–4