Medico-Legal Decision Making for Incapacitated Neonates

by

Neera Bhatia

LLB (Hons), LLM

Submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

Deakin University

October 2013
I am the author of the thesis entitled: Medico-Legal Decision Making regarding Incapacitated Neonates

submitted for the degree of Doctor of Philosophy

This thesis may be made available for consultation, loan and limited copying in accordance with the Copyright Act 1968.

'I certify that I am the student named below and that the information provided in the form is correct'

Full Name: NEERA BAHRIA
(Please Print)

Signed: [Signature Redacted by Library]

Date: 20TH FEB 2014
DEAKIN UNIVERSITY
CANDIDATE DECLARATION

I certify the following about the thesis entitled Medico-Legal Decision making regarding Incapacitated Neonates

submitted for the degree of Doctor of Philosophy

I am the creator of all or part of the whole work(s) (including content and layout) and that where reference is made to the work of others, due acknowledgment is given.

a. The work(s) are not in any way a violation or infringement of any copyright, trademark, patent, or other rights whatsoever of any person.

b. That if the work(s) have been commissioned, sponsored or supported by any organisation, I have fulfilled all of the obligations required by such contract or agreement.

I also certify that any material in the thesis which has been accepted for a degree or diploma by any university or institution is identified in the text.

"I certify that I am the student named below and that the information provided in the form is correct"

Full Name: Neera Banerija
(Please Print)

Signed: [Signature Redacted by Library]

Date: 20th Feb 2011
ACKNOWLEDGMENTS

I thank Deakin University School of Law for giving me the opportunity to re-locate to Australia and initially pursue this PhD via an International scholarship, which later transitioned to a full-time Law lectureship within the school. I am grateful to all my colleagues and friends within the school for their continued support.

In particular, I am indebted to my supervisor and Head of School, Professor Mirko Bagaric, for his guidance, encouragement and valuable feedback on my drafts. I also extend my gratitude to Professor Danuta Mendelson and Associate Professor Samantha Hepburn.

Finally, I thank my family, who, although thousands of miles away, have never allowed me to feel their absence. I thank them for their encouragement and constant belief in me—Skype truly is an amazing invention.
**TABLE OF CONTENTS**

DEAKIN UNIVERSITY CANDIDATE DECLARATION...... Error! Bookmark not defined.

ACKNOWLEDGMENTS..........................................................................................................ii

TABLE OF CONTENTS.....................................................................................................iii

LIST OF ABBREVIATIONS............................................................................................vi

ABSTRACT .......................................................................................................................vii

CHAPTER ONE: INTRODUCTION .................................................................................1

I: Medicine, technology and the law.............................................................................1

II: Concepts of life and death and the law.................................................................3

III: Individual autonomy.............................................................................................4

IV: Why is neonatal end-of-life decision making a matter of importance? ..........6

V: Historical development of neonatology.................................................................11

VI: Thesis purpose.....................................................................................................13

VII: Research methodology.......................................................................................14

VIII: Thesis outline...................................................................................................15

IX: Conclusion...........................................................................................................17

CHAPTER TWO: DOES THE BEST INTEREST PRINCIPLE FUNCTION EFFECTIVELY? .................18

I: Summary..................................................................................................................18

II: Introduction............................................................................................................18

III: Sanctity of life perspectives...............................................................................19

(A) Judeo-Christian tradition..................................................................................19

(B) Greco-Roman principles and the Hippocratic Oath.......................................22

(C) Declaration of Geneva......................................................................................25

IV: What is the best-interests principle?..................................................................28

V: The undefinable concept of futility....................................................................31

VI: Early case law involving neonates: Inconsistency in case decisions .............32

VII: The legal and ethical challenges: *Airedale NHS Trust v Bland*....................40

(A) Sanctity of life...................................................................................................42

(B) Substituted judgment test.................................................................................44

(C) Reliance on the medical profession.................................................................45

(D) Acts and omissions.........................................................................................50

(E) Does withdrawal of nutrition and hydration amount to starving to death?...53

VIII: Seminal English decisions involving neonates and young infants: The *Re: J and Re: C* cases ..........................................................56

IX: The turn of the millennium: *Re A (Conjoined Twins)* ................................68

X: Recent decisions—Scoreboard of benefits and burdens............................73

XI: Australian case law concerning incapacitated neonates or young infants.....88

XII: The effectiveness of the best-interests principle.............................................100

XIII: Conclusion.......................................................................................................102

CHAPTER THREE: DO CLINICAL GUIDELINES PROVIDE CONSISTENCY AND UNIFORMITY TO DECISIONS TO END-OF-LIFE DECISION MAKING? .........................................................................................................................................................104

I: Summary.................................................................................................................104
II: Introduction ......................................................................................................105
III: The threshold of viability ..............................................................................105
IV: Clinical guidelines: United Kingdom ............................................................108
V: Royal College of Paediatrics and Child Health: Withholding or withdrawing life-sustaining treatment in children: A framework for practice. 109
VI: British Medical Association: Withholding and withdrawing life-prolonging medical treatment: Guidance for decision making ..................114
VII: General Medical Council: Treatment and care towards the end-of-life: Good practice in decision making .................................................................117
VIII: EPICure Studies ..........................................................................................119
(A) EPICure Study 1: 1995 ................................................................................119
(B) EPICure Study 2: 2006 ................................................................................121
IX: British Association of Perinatal Medicine: The management of babies born extremely pre-term at less than 26 weeks’ gestation—A framework for clinical practice at the time of birth .........................................................124
X: Bliss and the National Institute of Clinical Excellence ................................126
XII: The Royal Australasian College of Physicians—Paediatrics and child health division: Decision making at the end-of-life in infants, children and adolescents (2008) ..............................................................................135
XIII: Perinatal care at the borderlines of viability: A consensus statement based on New South Wales and Australian Capital Territory consensus workshop (2005): Another missed opportunity? ................................................139
XIV: Conclusion ..................................................................................................142

CHAPTER FOUR: THE ROLE, IMPACT AND IMPORTANCE OF KEY STAKEHOLDERS IN DECISIONS TO WITHDRAW OR WITHHOLD LIFE-SUSTAINING TREATMENT ........................................................................146
I: Summary ...........................................................................................................146
II: Introduction ......................................................................................................147
III: Parents: Conflicting interests and views ..........................................................149
(A) The influence of media, development of medical science and technology 150
(B) Religious and cultural beliefs ........................................................................156
(C) The common denominator: Hope .................................................................158
(D) Parental ethnicity .........................................................................................160
(E) Pain and suffering of the child .....................................................................164
(F) The length of the ‘dying process’ ..................................................................168
(G) Perceptions and realities of disability ............................................................170
(H) Relationships of trust and confidence with the medical team .......................175
(I) Do parents carry guilt and the burden of responsibility in decision making? .........................................................................................................178
(J) Are parents the ultimate decision maker or is it an illusion? .........................184
IV: Doctors: Subjectivity, conflicting interests and views ...................................188
(A) Religious beliefs and cross-country attitudes ..............................................191
(B) Doctors’ perceptions of death, disability and decision making .................195
(C) Different parents, different treatment—Are parents treated differently by doctors? .................................................................................................199
(D) Are pre-term infants treated differently to other patients? .........................201
(E) The framing effect .......................................................................................202
(F) The roster lottery ..........................................................................................207
(G) Should doctors be considered as functionaries? ........................................208
**LIST OF ABBREVIATIONS**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>Australian Capital Territory</td>
</tr>
<tr>
<td>BAPM</td>
<td>British Association of Perinatal Medicine</td>
</tr>
<tr>
<td>BMA</td>
<td>British Medical Association</td>
</tr>
<tr>
<td>CEMACH</td>
<td>Confidential Enquiry into Maternal and Child Health</td>
</tr>
<tr>
<td>ELBW</td>
<td>Extremely Low Birth Weight</td>
</tr>
<tr>
<td>GDP</td>
<td>Gross domestic product</td>
</tr>
<tr>
<td>IQ</td>
<td>Intelligence quotient</td>
</tr>
<tr>
<td>IVF</td>
<td>In-vitro fertility</td>
</tr>
<tr>
<td>LST</td>
<td>Life sustaining treatment</td>
</tr>
<tr>
<td>NCOB</td>
<td>Nuffield Council on Bioethics</td>
</tr>
<tr>
<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute of Clinical Excellence</td>
</tr>
<tr>
<td>NICU</td>
<td>Neonatal intensive care unit</td>
</tr>
<tr>
<td>NSW</td>
<td>New South Wales</td>
</tr>
<tr>
<td>PDA</td>
<td>Patent Ductus Arteriosus</td>
</tr>
<tr>
<td>PVS</td>
<td>Permanent vegetative state</td>
</tr>
<tr>
<td>QALY</td>
<td>Quality adjusted life years</td>
</tr>
<tr>
<td>QoL</td>
<td>Quality of life</td>
</tr>
<tr>
<td>RACP</td>
<td>Royal Australasian College of Physicians</td>
</tr>
<tr>
<td>RCOG</td>
<td>Royal College of Obstetricians and Gynaecologists</td>
</tr>
<tr>
<td>RCPCH</td>
<td>Royal College of Paediatrics and Child Health</td>
</tr>
<tr>
<td>TAC</td>
<td>Transport accident commission</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
</tbody>
</table>
ABSTRACT

This thesis examines and analyses factors and practices that are applied in end-of-life decision making for extremely premature and critically impaired neonates in the United Kingdom and Australia.

It explores the application of the best-interests principle by the courts and the medical profession in deciding whether life-sustaining medical treatment can lawfully by withdrawn or withheld. This thesis also examines the effectiveness of clinical guidelines, and the role and impact of key stakeholders—chiefly parents, medical practitioners and the courts—in the decision-making process for impaired neonates.

This thesis finds that current practices in end-of-life decision making for impaired and extremely premature neonates are ambiguous and arbitrary; primarily being driven by the subjective sentiments of the decision maker.

The central contention of this thesis is that there is a need for more transparency and objectivity in end-of-life decision making for imperilled neonates. To achieve this greater objectivity, the allocation of finite public healthcare resources, and corresponding quality of life, should be a principal consideration in treatment decisions for impaired neonates.
CHAPTER ONE: INTRODUCTION

I: Medicine, technology and the law

During their life span, most human beings will require the intervention of medicine and possible care. In comparison with other areas of law, medical law profoundly affects people throughout their lives, from the period of pre-conception through to organ donation and the possible withdrawal or withholding of treatment at the end of life.¹

Medical law is an area of research, practice and, increasingly, litigation.² Over the past three decades, it has been the topic of considered and intense academic and legal discussion.³ During the course of its development, issues that have required medical, ethical and legal debate have become increasingly complex, and topics that were once considered almost science fiction have now become a reality.⁴ The rapid advancement of medicine has brought these issues to the fore; correspondingly increasing the public’s expectations of medicine, in terms of both the simple treatment and management of illness, and the hope for a complete cure of illness.⁵

⁵ Note, ‘Developments in the Law’, above n 1, 1523.
Advancements in medical technology and research require a parallel development of the law governing ethics, policies and regulation of medical issues. In Australia and the United Kingdom (UK), matters relating to issues such as human fertilisation and embryology, abortion and human tissue have been legislated. However, there continue to be areas governed under medical law that remain largely unlegislated.

The traditional, conservative foundations of the law and its retrospective nature have observed the development of a widening gulf between the realised and possible achievements of medical science and any corresponding legislation. Put simply, the law has been unable to keep up and, consequently, medical law, while attempting to accommodate developments in medical science, remains an area with little statutory intervention, dominated largely by case law.

Evidence of this lag can be found in *Airedale NHS Trust v Bland*, in which Lord Mustill poignantly recognised:

…the law has been left behind by the rapid advances of medical technology. By starting with a clean slate the law would be freed from the piecemeal expedients to which courts throughout the common law world have been driven when trying to fill the gap between old law and new medicine.

---

7 This is not an exhaustive list. For a comprehensive compilation of medical law legislation in the UK see Anne E Morris and Michael A Jones (eds) *Blackstone’s Statutes on Medical Law* (Oxford University, 7th ed, 2011).
8 These include issues such as euthanasia and withdrawal or withholding of life-sustaining treatment in both adults and infants.
9 *Airedale NHS Trust v Bland* [1993] 1 ALL ER 789, 888. Balcombe LJ made a similar comment in *Re C (a minor) (wardship: medical treatment)* [1989] 2 ALL ER 782, 789 stating: ‘This is a problem of a kind with which, as a result of advances in medical science, the courts in this and other jurisdictions are increasingly being faced’.
II: Concepts of life and death and the law

Western society has observed a shift from divinity to secularity in relation to the contemplation and understanding of concepts of life and death. Once considered to be beyond human control and the preserve of religious leaders, matters of life and death have increasingly become the topic of regular discourse in hospitals and courtrooms as well as in less formal settings, such as talkback radio and internet blogs. Issues surrounding life and death, such as the withdrawal or withholding of life-sustaining treatment, are often discussed in the public arena with individuals and stakeholder groups expressing strong, often divergent opinions.

That such issues and the ethical dilemmas they present arouse significant public interest is understandable. The finality and irreversibility of life and death decisions, such as the withdrawal or withholding of life-sustaining treatment, are of ultimate importance. It is critical that the law facilitates and guides these decisions in the most appropriate moral and ethical context. While moral, ethical, religious and sociological issues tend to dominate decisions of this kind, individual notions of rights, entitlements and personal autonomy have become a significant feature of western society and, consequently, have also influenced the development of medical ethics and law.

---

10 See generally, Charles Taylor, A Secular Age (Harvard University Press, 2007).
12 The role, opinion and views of the stakeholders (parents, doctors and the judiciary) are discussed in Chapter Four of this thesis.
The recognition of a right to life and protection from harm is one of the main ideals in a civilised society, and thus it has the protection of law.\textsuperscript{13} As appropriate, the law will intervene when called upon in life and death situations. However, in many of these instances, the very right demanded is the right to die—a right that is not expressly endorsed by law in Australia or the UK.

Both medical practitioners and the judiciary are placed in a difficult moral dilemma when deciding the legal permissibility of decisions to withdraw or withhold medical treatment essential to maintaining the existence of an incapacitated patient. There are, inevitably, conflicts of opinion in this area, and it is fraught with moral quandaries.

\section*{III: Individual autonomy}

Although the religious and philosophical tenets of western society underpin the principle of sanctity of life, there is no absolute medical obligation to preserve human life at all costs.\textsuperscript{14} In matters of life and death, individual autonomy provides a basis for individuals to decide what shall or shall not be done to their person, and this autonomy is often a cardinal and determinative principle. The seminal application of this principle can be found in \textit{Schloendorff v New York Hospital}, in which Justice Cardozo famously stated: ‘every human being of adult years and sound mind has the right to...

\footnotesize{\textsuperscript{13} For example, in the UK: \textit{The Human Rights Act 1998} art 2: ‘Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law’. See further, European Convention on Human Rights 1950. In Victoria, Australia see \textit{Charter of Human Rights and Responsibilities Act 2006} s 9: ‘Right to life—Every person has the right to life and has the right not to be arbitrarily deprived of life’.

\textsuperscript{14} An example of the sanctity of life principle can be found in in Christianity, where it is recognised and founded on Genesis 9:6: ‘whoever sheds the blood of man, by man shall his blood be shed for God made man in his image’. See generally, Robert L Barry, \textit{The Sanctity of Human Life and its Protection} (University Press of America, 2002). The sanctity of life principle is considered in greater detail in Chapter Two of this thesis.}
determine what shall be done with his body; and a surgeon who performs without the patients consent commits an assault’.15

In *Schloendorff*, the principle of personal autonomy concerned an adult individual’s rights to and freedoms from non-consensual medical intervention. Individual autonomy is often regarded as being of such importance that in many cases it surpasses competing cardinal virtues, including the sanctity of life, patient welfare, altruistic paternalism and medical best advice and opinion.16 However, no principle is always paramount, and even patient autonomy will sometimes yield to other competing imperatives. Thus, voluntary euthanasia continues to remain illegal in most jurisdictions.17

Although patient autonomy is an important and empowering principle for competent individuals, neonates cannot express their rights, values or choices.18 That is not to suggest that life and death decisions for those who have never and may never be able to express their autonomy are straightforward.19 This issue is one of the most profound ethical, legal and medical minefields of our time.

15 *Schloendorff* v *New York Hospital* (1914) 211 NY 125, 126. See also, *Re R (a minor) (wardship: medical treatment)* [1991] 4 ALL ER 177 CA 183, in which Lord Donaldson stated: ‘…a doctor is not entitled to treat a patient without the consent of someone who is authorised to give that consent. If he does so, he will be liable in damages for trespass to the person and may be guilty of a criminal assault’.


17 Currently, the jurisdictions that allow lawful voluntary euthanasia include the Netherlands, Belgium, Luxembourg and Switzerland.

18 As neonates lack patient autonomy, they cannot declare their wishes and treatment decisions are generally made on their behalf by parents or medical practitioners. Leading academic Peter Singer states, ‘…a newborn is not an autonomous being, capable of making choices, and so to kill a newborn baby cannot violate the principle of respect for autonomy’. See especially, Peter Singer, *Practical Ethics* (Cambridge University Press, 2nd ed, 1993) 175–218.

19 Neonates cannot declare their treatment wishes.
As the model of the western demographic nation-state progresses, topics once considered taboo or intractable are increasingly being discussed and resolved. Life and death decisions concerning neonates is one issue that deeply impacts modern medicine and society, and which therefore requires considered attention.

IV: Why is neonatal end-of-life decision making a matter of importance?

For the purposes of this thesis, a neonate is defined as a newborn infant in the first 28 days of life.\(^{20}\) This thesis focuses on decisions to withdraw or withhold life-sustaining treatment from neonates that are born pre-term, prior to a full gestational pregnancy of 37–42 weeks.\(^{21}\) In particular, this thesis concentrates on withdrawal or withholding of life-sustaining treatment from neonates considered to be extremely premature \(^{22}\) and suffering debilitating medical conditions.\(^{23}\)

Approximately 8 per cent of neonates are born pre-term in Australia each year, before the 37-week gestation period.\(^{24}\) Birth weights of premature neonates vary, from very low (2,500 grams) to extremely low (less than 1,000 grams).\(^{25}\) In 2010, in Australia, approximately 8 per cent of neonates are born pre-term in Australia each year, before the 37-week gestation period. Birth weights of premature neonates vary, from very low (2,500 grams) to extremely low (less than 1,000 grams). In 2010, in Australia,

---


\(^{21}\) However, the case law examined in Chapter Two of this thesis examines cases concerning neonates and very young infants. See further, William A Engle, ‘A Recommendation for the Definition of “Late Preterm” (Near-Term) and the Birth Weight–Gestational Age Classification System’ (2006) 30(1) Seminars in Perinatology 2–7. Also see, Alan R Fleischman, Motoko Oinuma and Steven L Clark, ‘Rethinking the Definition of “Term Pregnancy”’ (2010) 116(1) Obstetrics & Genecology 136–139.

\(^{22}\) This is generally between 23–25 weeks + 6 days gestation. See further, Nuffield Council on Bioethics, ‘Background: Extremely Premature Babies’, [http://www.nuffieldbioethics.org/neo-natal-medicine/neo-natal-medicine-background-extremely-premature-babies/].

\(^{23}\) There is no discussion or examination of abortion or the concept of personhood.


8.3 per cent of live births were pre-term babies.\(^{26}\) Of those born in 2010, 6.2 per cent weighed less than 2,500 grams.\(^{27}\) Figures from the UK highlight similar rates of premature birth; roughly 8 per cent of neonates are born pre-term.\(^{28}\) Statistics from the UK also illustrate that approximately 6 per cent of premature births occur between 23–27 weeks’ gestations. Neonates born at 23 weeks’ gestation are often referred to as being born ‘at the borderline of viability’. This is likely to be the earliest point at which a baby can be delivered alive with a possibility of survival with life-sustaining treatment.\(^{29}\)

The information age has engendered public awareness of medical technology. Consequently, parents of premature, critically ill neonates are often encouraged by the use of the digital age to request life-sustaining treatment from medical practitioners to attempt to prevent their pre-term neonate from death.\(^{30}\)

Such requests are often made by parents even when the medical prognosis for the premature neonate is extremely poor.\(^{31}\) This is confirmed by Lantos and Meadows, who have described the perception that many parents have of the neonatal intensive...
care unit (NICU) as being ‘a saviour, a place where miracles will happen and babies are snatched from the jaws of death’. Arguably, this particularly reflects the attitudes of parents with strong religious beliefs who ‘wait for such miracles’ to occur, or those who request the continuation of medical treatment even where doctors consider such treatment to be futile. Where such disagreements cannot be resolved, parents or doctors may seek judicial guidance as to whether treatment can or should be withdrawn.

Decisions regarding the desirability of treatment in cases concerning critically ill neonates are extremely complex, involving multi-faceted considerations and competing principles and interests. While there is an abundance of case law on the matter, particularly in the UK, there is a corresponding and notable absence of

---


33 See especially, Joe Brierley, Jim Linthicum and Andy A Petros, ‘Should Religious Beliefs be Allowed to Stonewall a Secular Approach to Withdrawing and Withholding Treatment in Children?’ (30 March 2012) *Journal of Medical Ethics* 100–104. The authors conducted a study about the importance of religion to the family unit in end-of-life decision making for children in paediatric intensive care. The study was conducted over a three-year period in the UK. The study found that, of the 203 cases reviewed, ‘11 (65%) involved explicit religious claims that intensive care should not be stopped due to expectation of divine intervention and complete cure together with conviction that overly pessimistic medical predictions were wrong’. The authors concluded that, ‘While it is vital to support families in such difficult times, we are increasingly concerned that deeply held belief in religion can lead to children being potentially subjected to burdensome care in expectation of “miraculous” intervention’. For the other side of the discussion see, Steve Clarke, ‘When they Believe in Miracles’ (2013) 39(9) *Journal of Medical Ethics* 582–583 and The Week, ‘Waiting for a Miracle: Is it Inhumane for Religious Parents to Prolong Treatment of Sick Kids?’ *The Week* (Online), 17 August 2012 <http://theweek.com/article/index/232122/waiting-for-a-miracle-is-it-inhumane-for-religious-parents-to-prolong-treatment-of-sick-kids#>. Similar views are held by parents of premature and critically ill neonates. This is considered in Chapter Four of this thesis.

34 This is a view often held by parents that have strong religious beliefs, or feel their baby is not ‘ready’ to die. This is considered in Chapter Four of this thesis. The concepts of futility and quality of life are discussed in greater detail in Chapter Two. For a general discussion about the nature and application of the concept of futility see, eg, Robert D Truog, Allan S Brett, and Joel Frader, ‘The Problem with Futility’ (1992) 326(23) *New England Journal of Medicine* 1560–1564.

35 As will be considered in Chapter Four of this thesis, individuals with strong religious beliefs may not face any dilemmas in making treatment decisions, as they are guided by their religious view that all human life is sacred so life-sustaining treatment should not be withdrawn or withheld. See, eg, Rebagliato et al, ‘Neonatal End-of-life Decision Making: Physicians’ Attitudes and Relationship with Self-Reported Practices in 10 European Countries’ (2000) 284(19) *Journal of American Medical Association* 2451–2459; Roy et al, ‘Decision Making and Modes of Death in a Tertiary Neonatal Unit’ (2004) 89(6) *Archives of Disease Child Fetal, Neonatal Edition* 527–530.
statutory provision and parliamentary intervention. One of the recommendations of this thesis is that decisions to withdraw or withhold life-sustaining treatment from extremely premature, critically ill neonates should be governed, or at the very least guided by a clear and authoritative legislative framework.\textsuperscript{36} This thesis identifies the need for more structured and unified decision making with regard to withdrawing or withholding life-sustaining treatment from extremely premature, critically ill neonates.

Decisions to withdraw or withhold treatment in cases of severely incapacitated neonates are fraught with inconsistency and lack of transparency. This is demonstrated in hospital clinical guidelines and case law from the UK, where the courts have been required to consider the withdrawal or withholding of life-sustaining treatment. In comparison, in Australia, over the past three decades, there have only been three cases requiring legal intervention, with two of these cases being heard in 2011 and 2012.\textsuperscript{37} As medical technology has advanced over the latter decades of the twentieth century, the instances in which newborn lives can be saved or extended have greatly increased.\textsuperscript{38} Accordingly, the legal and medical professions are facing ever more situations that the inadequate regulatory framework struggles to address.

\textsuperscript{36} Professor Skene supports the view that there is a need for greater legal or procedural clarity in decisions to withdraw or withhold life-sustaining treatment from critically ill neonates. See especially, Loane Skene, ‘Legal Issues in Treating Critically Ill Newborn Infants’ (1993) 2(3) \textit{Cambridge Quarterly of Healthcare Ethics} 295–308. This is explored further in Chapters Five and Six of this thesis.

\textsuperscript{37} See, eg, \textit{Re F: F v F} (Unreported, Supreme Court of Victoria, Vincent J, 2 July 1986); \textit{Baby D (No 2)} [2011] Fam CA 176; \textit{TS \& TD v Sydney Children’s Hospital (‘Mohammed’s case’)} [2012] NSWSC 1609. Case law from the UK and Australia are discussed in greater detail in Chapter Two of this thesis.

\textsuperscript{38} See, eg, Callie Watson, ‘With Technological Advances, Most Premature Babies Survive against the Odds’, \textit{The Australian} (Online), 4 November 2012, \textless http://www.thaustralian.com.au/news/most-premature-babies-survive-against-the-odds/story-e6fr6g6n6-1226510132523\textgreater . See also, the EPICure Studies of survival of extremely premature neonates, conducted in the UK in 1995 and 2006. These studies are discussed in further detail in Chapter Three of this thesis. See especially, Lantos and Meadow, above n 32.
While adult patients lacking mental capacity may be able to exercise some patient autonomy, neonates are entirely dependent on the will of others; principally doctors, parents and the courts. This dependency places neonates in an extremely vulnerable position: they are subject to the withdrawal or withholding of life-sustaining treatment, based on individual stakeholder subjectivity. There is no clear approach to decisions in this area, and clarity is unlikely to be achieved within the existing framework given the difficulty in reconciling factors that are often complicated by subjective social, cultural, religious and ethical beliefs. These subjective beliefs often cloud judgments by decision makers.

---

39 Often adult patients may declare their treatment wishes in the form of an advanced directive. However see, Alasdair MacLean, ‘Advance Directives and the Rocky Waters of Anticipatory Decision Making’ (2008) 16(1) Medical Law Review 1–22. MacLean highlights the problematic nature of advance directives; in particularly, the author critiques the authority, autonomy and implementation of advice directives.

40 Ian Kerridge, Michael Lowe and Cameron Stewart, Ethics and Law for Health Professions (Federation Press, 4th ed, 2013) 582. The role, influence and impact of parents, doctors and judges on end-of-life decision making for neonates are discussed in Chapter Four of this thesis.

41 These stakeholders are primarily the treating doctors, parents and judges. Chapter Four of this thesis explores the role and impact of stakeholders in end-of-life decision making in greater detail.

Paediatric medicine concerns the care and treatment of sick children. Neonatology exists as a branch of paediatrics specific to the treatment of newborns. Specialisation in neonatology includes the treatment of neonates with symptoms such as low birth weight, prematurity and congenital malformation.

The impetus to provide medical intervention for premature neonates; that is, those born before full-term pregnancy, did not commence out of benevolence or a duty to protect. ⁴³ Serious attempts to save very young lives began as a drive to rebuild and regenerate a destroyed population after the Franco-Prussian war during 1870–1871 in Paris. ⁴⁴ Neonatology as a medical science also began to develop in England. ⁴⁵

In western society, it is generally considered that providing medical treatment is motivated by preserving or improving quality of life. However, neonatology as a science was formed from practical considerations arising out of the geopolitical patchwork of nineteenth century Europe, where famines, war and poverty contributed to population loss that required a solution, including the preservation of the existing population. It is generally considered that the first infant incubator was developed by

---

⁴³ Today, a full-term pregnancy is calculated at 37–42 weeks’ gestation.
Tarnier, a French obstetrician in 1880 at the Paris maternity hospital. By the turn of the twentieth century, another French physician, Pierre-Constant Budin, had concluded that the use of the infant incubator was an integral piece of equipment to improve the chances of survival of premature neonates.

Over the past half-century, western medicine has witnessed both a widespread increase in public awareness and a corresponding increase in efforts to develop new technologies to improve pre-term neonatal survival and health outcomes. However, despite these efforts, of those neonates that are treated and survive, many are still being left with a handicap or disability.

Decisions to withdraw or withhold life-sustaining treatment from premature and critically ill neonates have an emotional and financial impact on many individuals and groups. Those most affected by decisions to either continue or withdraw or withhold treatment are parents. However, end-of-life decisions concerning neonates also

---


49 This thesis finds that although advancements in science and technology have improved the survival rates of neonates born extremely premature (23 weeks), the likelihood of severe and long-term disability has largely remained unchanged. See, eg, Saroj Saigal and Lex W Doyle, ‘An Overview of Mortality and Sequelae of Preterm Birth from Infancy to Adulthood’ (2008) 371(9608) The Lancet 261–269. This is discussed in greater detail in Chapter Five of this thesis.

50 This is considered in detail in Chapter Five of this thesis.
profoundly affect medical practitioners and the wider society. There is a need to guide the discussion in this area with greater transparency and objectivity. It is this need that this thesis proposes to facilitate.

VI: Thesis purpose

The primary contention of this thesis is that current practices in decision making to withdraw or withhold life-sustaining treatment from premature, critically ill neonates, predominantly in the UK and more recently in Australia, are nebulous and unsatisfactory. This thesis argues that end-of-life decisions for neonates born extremely prematurely should be driven by an objective, transparent and tangible approach.

This thesis advances the existing debate and learning in this area. The key points that it attempts to establish are:

(i) The law regarding treatment decisions about critically ill neonates is obscure and incapable of providing meaningful guidance to relevant stakeholders, including doctors, parents and courts;
(ii) Resource allocation and corresponding quality of life should be important considerations regarding the treatment of neonates;
(iii) Ostensibly, resource allocation does not drive decisions in this area;
(iv) In fact resource allocation and quality of life decisions seem to cohere with the outcome of medical and judicial decisions in this area; and

51 The most recent case in Australia that has required legal intervention is TS & TD v Sydney Children’s Hospital (‘Mohammed’s case’) [2012] NSWSC 1609. This case is discussed in detail in Chapter Two of this thesis.
Resource allocation should be a cardinal consideration regarding the treatment of neonates. This would explain and justify existing practices and lead to more sound policies and decisions.

While recognising the existing academic work in this area to date, this thesis contests existing practices and traditional thinking and provides recommendations for achieving more consistent and objective outcomes in decision making for extremely premature and critically ill neonates.

Although religion, culture and morality predominantly drive decisions and debate in end-of-life decision making, this thesis argues that, although important, they should not overwhelm the debate and that objective medical, social and economic factors should be more weighty. The latter chapters of this thesis consider how such objectivity can be established.

**VII: Research methodology**

The method of research used in this thesis is interdisciplinary, involving an analysis of legal case judgments, peer-reviewed scholarly articles and grey literature across the fields of law, medicine and ethics. This will facilitate an understanding of the key factors relevant to determining end-of-life decisions from the, often competing, perspectives of each of the respective key stakeholders (that is, parents, doctors, judges) and the wider society.
This chapter provides an introduction to the relationship between law, medicine and technology, and the public awareness and engaging debate about death and dying among a growing number of individuals in western society. This chapter has offered a brief reflection on the historical development of neonatal care and treatment in modern medicine. In addition, Chapter One establishes the research position and scope, the thesis’ structure and the research methodology applied throughout this work.

Chapter Two provides a detailed critical analysis of selective case judgments involving end-of-life decisions concerning critically ill neonates. It examines the complex nature and relevance of the sanctity of life principle—*that all human life is sacred and requires the utmost care and protection*—in decision making for neonates. The chapter also assesses subjectivity and the arbitrary nature of decision making for incapacitated neonates by evaluating the application and effectiveness of the best-interests principle applied by the courts and medical practitioners to allow the withdrawal or withholding of life-sustaining treatment from critically ill neonates.

Additionally, Chapter Two critically evaluates medico-legal concepts of futility, quality of life and intolerability, developed and discussed at length by judges in determining neonatal end-of-life decisions. A key part of the thesis is examining the current stream of judicial reasoning in this area, establishing a baseline from which the current orthodoxy can be evaluated and critiqued.52

52 Based primarily on the application of the concepts of best interests, futile treatment and quality of life.
Chapter Three progresses to critique the efficacy and arbitrary nature of various frameworks applied in hospitals in the UK and Australia. This chapter also critically examines the impact and effectiveness of other initiatives and the much-publicised Nuffield Council on Bioethics report: Critical Care Decisions in Foetal and Neonatal Medicine: Ethical Issues 2006.53

Chapter Four examines the subjective role and influence of the key stakeholders (that is, parents, doctors, judges) and the wider society in the decision-making process to withdraw or withhold life-sustaining treatment from critically ill neonates. It explores the competing interests of each stakeholder group, and how these are evaluated and weighed.

In Chapter Five, the discussion turns to the limited financial resources available to treat critically ill neonates, particularly those suffering severe disability. It examines the objective and transparent nature and role that resource allocation should have in informing medical decisions relating to severely premature neonates. This chapter also provides other recommendations and alternative considerations for neonatal end-of-life decision making. Relevant to this discussion are the profound short and long-term impacts of decisions to keep critically ill neonates alive, particularly as this decision relates to life after hospital discharge and the effect it may have on the neonate, wider family circle and the wider community.

Chapter Six concludes this thesis, drawing the thesis together by re-visiting the research aims and summarising its overall findings before proposing recommendations and a way forward.

IX: Conclusion

Death is an inevitable event. This thesis focuses on one of the most vulnerable groups of society. However, decisions concerning whether critically ill neonates live or die should not be circumvented due to their vulnerability. On the contrary, given the long-term ramifications for many individuals involved in such decision making, it is necessary to base such discussion on more objective and pragmatic grounds. The following chapter begins by examining the effectiveness of the best-interests principle in end-of-life decision making for incapacitated neonates.
CHAPTER TWO: DOES THE BEST INTEREST PRINCIPLE FUNCTION EFFECTIVELY?

I: Summary

The previous chapter provided an overview of the purpose and outline of this thesis. It included a brief insight into the historical impetus to save pre-term neonates, which would in time lead to the development of the NICU. Chapter One also discussed the advancement of science and medical technology, and the corresponding need for development of the law in matters of life and death.

II: Introduction

Chapter Two examines the best-interests principle as applied by the courts in determining whether to withdraw or withhold treatment from critically ill neonates. The focus of this chapter is an analysis of the relevant case law and the application of the best-interests test. This leads to a critical evaluation of the function and effectiveness of the best-interests principle as it applies to end-of-life decisions for incapacitated neonates and young infants. This chapter illustrates the first of several speculative, subjective, nebulous and arbitrary factors that are currently applied to decisions to withdraw or withhold life-sustaining treatment from incapacitated neonates.¹ It thus supports the contention of this thesis: that there is a need for a more

¹ Chapter Three explores the subjectivity and lack of uniformity of clinical guidelines in the hospital setting. Chapter Four examines the subjectivity of decision making of parents, doctors and the courts. This leads to Chapter Five, which argues the need for greater objectivity and transparency in end-of-life decision making for neonates born at 23 weeks by focusing on resource allocation as an objective factor in decisions to withdraw or withhold life-sustaining treatment.
objective, transparent and tangible approach to decision making for premature and severely imperilled neonates, and that this approach should primarily be based on resource allocation.

Before examining the best-interests principle and its application in relevant case law from the UK and Australia, this chapter begins by considering the historical and religious orthodoxy underpinning modern-day societal approaches to life and death. The principle of sanctity of life is informed by this view, and an understanding of its genesis is necessary to illustrate its gradual attrition over time, and the prevailing notion of the principle of best interests in relation to decisions to withdraw or withhold life-sustaining treatment from incapacitated neonates.

III: Sanctity of life perspectives

(A) Judeo-Christian tradition

Distilled, the sanctity of life principle is that human life is a gift from God and is sacred. The doctrine of sanctity of life is most widely associated with the Judeo-Christian tradition asserting that life is precious and valuable. According to the book of Genesis, God created man in his own image and, as it is gifted, only God may take life. Further,

---


3 Book of Genesis: 1:26 and 1:27. Robert L Barry suggests that it is immoral for an individual to take the life of another, as it ‘deprived God of a possession which is rightly His’. See further, Robert L Barry, The Sanctity of Human Life and its Protection
Keown, a leading advocate for the sanctity of life principle highlights that those in favour of this school of thought believe ‘human life is … therefore, possessed of an intrinsic dignity which entitles it to protection from unjust attack’. 4

In his book, *History of European Morals*, Lecky provides what some commentators have referred to as a ‘classical account’ of the sanctity of human life:

> Considered as immortal beings, destined for the extremes of happiness or of misery, and united to one another by a special community of redemption, the first and most manifest duty of the Christian man was to look upon his fellowmen as sacred beings and from this notion grew up the eminently Christian idea of sanctity of human life … it was one of the most important services of Christianity that besides quickening greatly our benevolent affections it definitely and dogmatically asserted the sinfulness of all destruction of human life as a matter of amusement, or of simple convenience, and thereby formed a new standard higher than any which then existed in the world. 5

More recently, Amarasekara and Bagaric have discussed the sanctity of life as being one of the highest moral orders over human law stating, ‘…a belief in eternal life allied to sanctity of human life, and a metaphysical value attached to pain and suffering. Underpinning these is an assertion of the primacy of Divine, Eternal or Natural Law over human law’. 6 The idea of living by virtue of ‘guiding principles’ or an ‘acceptable moral system’ 7 can be found in many biblical texts, in particular the Book of Exodus.

---

and the Ten Commandments. Perhaps the most acknowledged commandment in society today and the most relevant to this thesis is from the King James Bible: Exodus: 20:13—‘Thou Shalt Not Kill’.

The ideal that human life is sacrosanct and of the greatest importance is ‘emotionally appealing’ and, intuitively, probably the easiest approach to take in matters of life and death. In this regard, Brazier asserts ‘to most people who are not philosophers the answer is simple. There is a deep and embedded instinct that taking human life is wrong. Life is a most precious possession. All other possessions, all potential joys, depend upon its continued existence’.

The primacy of this principle has diluted over time in line with evolving social and political thought, and is enforced today with less rigidity than previously. In a western modern secular society, the rigid application of these principles distilled from religious philosophies and traditions is limited, and it is arguable that it does not have the same support that it may once have enjoyed. Churches, Synagogues and other places of worship remain of importance and retain symbolic value when people marry or are buried or cremated. At death, however, the attachment to a particular creed or practice is more limited.

For many, to live a life in accordance with this most fundamental principle of the sanctity of life is both honourable and practical. This is reflected in the laws governing our societies. Even if most individuals do not conform to the biblical moral code for

---

10 Ibid.
reasons of virtue or belief, they will still adhere to the legal code for reasons of community and identity. In addition to the religious philosophies regarding the sanctity of life, some of the longest standing and most influential philosophies of Greek Medicine derive from Hippocrates.

(B) Greco-Roman principles and the Hippocratic Oath

Ancient Greek philosophers and texts played an important role in the birth of medical ethics. Both Aristotle and Plato placed importance on the principle of life, believing that body and soul was one unit, with the soul ultimately being the ‘life principle’ of the body.11

The Hippocratic Oath is the most well-known Greek medical text, and is thought to have established the principles of medical ethics, obligations and responsibilities bestowed on medical practitioners. It was written by the Greek physician Hippocrates of Kos, an archetypal figure of western civilisation, circa fourth and fifth century BCE.12 Many believe Hippocrates to be the father of medicine; he rejected notions of superstition, legend and myths, laying the foundations of medicine as a science guided by ethics and professionalism.13 However, in his book Pilgrims in Medicine, Faunce, sceptical of the way Hippocrates is often revered, asserted:

11 Jesus Christ Saviour, Traditional Principles of Medical Ethics <http://www.jesuschristsavior.net/Ethics.html>. See generally, Steven H Miles, The Hippocratic Oath and the Ethics of Medicine (Oxford University Press, 2004). Jesus Christ Saviour, Traditional Principles of Medical Ethics <http://www.jesuschristsavior.net/Ethics.html>. For selected works by Aristotle, see generally, Aristotle (English translation by A L Peck), On the Generation of Animals (W Heinmann, 1943) and Aristotle (Translated by Richard Cresswell), On the History of Animals (Henry G Bohn, 1862).
The Hippocratic Oath is often portrayed as a course of culture-neutral professional virtues and foundational ethical principles. Its espousal of medical duties not to do harm (non-maleficence), to enter houses only for the good of patients (beneficence), to practise within the bounds of competence and to respect a patient’s confidences, even after they are dead, show an egalitarian respect for human dignity remarkable, though not necessarily unique for its time.  

A translated version of the Oath from the National Library of Medicine reads: 

I swear by Apollo the physician, and Asclepius, and Hygieia and Panacea and all the gods and goddesses as my witnesses, that, according to my ability and judgement, I will keep this Oath and this contract:

To hold him who taught me this art equally dear to me as my parents, to be a partner in life with him, and to fulfil his needs when required; to look upon his offspring as equals to my own siblings, and to teach them this art, if they shall wish to learn it, without fee or contract; and that by the set rules, lectures, and every other mode of instruction, I will impart a knowledge of the art to my own sons, and those of my teachers, and to students bound by this contract and having sworn this Oath to the law of medicine, but to no others.

I will use those dietary regimens which will benefit my patients according to my greatest ability and judgement, and I will do no harm or injustice to them.

I will not give a lethal drug to anyone if I am asked, nor will I advise such a plan; and similarly I will not give a woman a pessary to cause an abortion.

In purity and according to divine law will I carry out my life and my art.

14 Alured Faunce, above n 12, 121.
I will not use the knife, even upon those suffering from stones, but I will leave this to those who are trained in this craft.

Into whatever homes I go, I will enter them for the benefit of the sick, avoiding any voluntary act of impropriety or corruption, including the seduction of women or men, whether they are free men or slaves.

Whatever I see or hear in the lives of my patients, whether in connection with my professional practice or not, which ought not to be spoken of outside, I will keep secret, as considering all such things to be private.

So long as I maintain this Oath faithfully and without corruption, may it be granted to me to partake of life fully and the practice of my art, gaining the respect of all men for all time. However, should I transgress this Oath and violate it, may the opposite be my fate.

Although the Hippocratic Oath may be considered as an aspirational body of principles, it has evolved significantly from its founding principles to the current medical declaration taken by practitioners. Brazier’s translation of some parts of the Oath is of interest. She notes:

…a doctor’s loyalty to his teachers is the main premise, followed secondly by his obligations to exercise skill for the benefit of his patient’s health and well-being. Doctors were not allowed to take payment for teaching others, the practice of patient confidentiality was imposed; abortion and euthanasia were prohibited, as were improper sexual relations with patients.¹⁶

While the principle of patient confidentiality remains as rigid today as when the Oath was first written, other elements are now outdated, reflecting society’s current mores.

¹⁶ Brazier, above n 9, 36.
For example, in Australia and the UK, the practice of abortion is no longer prohibited, doctors pay for their tuition at medical school and, although prohibited in law, euthanasia is widely supported.\footnote{For further discussion about the evolution of the Hippocratic Oath, in particular from a postmodern and feminist perspective focusing on the changing values of the patient and the treatment and care of the pregnant patient, see, eg, Ben A Rich, ‘Postmodern Medicine: Deconstructing the Hippocratic Oath’ (1993) 65(1) University of Colorado Law Review 77–136. See also, G Iacovelli, ‘The Evolution of the Hippocratic Oath’ (1989) 1(1) Medicina nei Secoli 39–48.}

The current day declaration made by medical practitioners has evolved to incorporate contemporary values and changes in societal attitude. Central features of this renewed oath focus on the principles of respect for human life, honour, nobility and dignity. These principles do not necessarily translate to the absolute preservation of human life. The modern-day declaration taken by many medical practitioners is considered below.

(C) Declaration of Geneva

The explicit prohibition of euthanasia and abortion in the Hippocratic Oath is not found in the Declaration. The most recently amended version of the Declaration was adopted in the 173rd WMA Council Session, Divonne-les-Bains, France, May 2006.\textsuperscript{20} It is taken at the time of being admitted as a member of the medical profession, and states:

I solemnly pledge to consecrate my life to the service of humanity;

I will give to my teachers the respect and gratitude that is their due;

I will practise my profession with conscience and dignity;

The health of my patient will be my first consideration;

I will respect the secrets that are confided in me, even after the patient has died;

I will maintain, by all the means in my power, the honour and the noble traditions of the medical profession;

My colleagues will be my sisters and brothers;

I will not permit considerations of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, social standing or any other factor to intervene between my duty and my patient;

I will maintain the utmost respect for human life;

I will not use my medical knowledge to violate human rights and civil liberties, even under threat;

\textsuperscript{20} World Medical Association, \textit{WMA Declaration of Geneva} \texttt{<http://www.wma.net/en/30publications/10policies/g1/>}. 
I make these promises solemnly, freely and upon my honour.

Today, modified versions of the Declaration of Geneva are used by many medical schools for students to declare their professional and ethical commitment to the practice of medicine.\(^{21}\)

This chapter began by examining the genesis and historical, philosophical and theological foundations of the sanctity of life principle—that all human life is sacred.\(^{22}\) In addition, thus far, it has been noted that the Hippocratic Oath taken by medical practitioners has undergone modification, and the most current declaration taken by medical practitioners focuses on a respect for human life, which does not impose an absolute obligation to preserve human life at all costs. The gradual erosion of the sanctity of life principle and its staunch application in law is illustrated in the case law examined later in this chapter.

This shift away from the sanctity of life principle in law has been noted by eminent academics. Keown asserts that ‘the western world is undergoing a legal revolution’ and ‘respect for life’s inviolability has been eroded increasingly by efforts to promote largely unbridled individual autonomy and the notion that some human lives, those

\(^{21}\) A study conducted across several university medical faculties in Australia and New Zealand between 2000 and 2001 found that varying versions of the Hippocratic Oath and the Declaration of Geneva were used at graduating and declaration ceremonies. See further, Paul M McNeill and Bruce S Dowton, ‘Declarations Made By Graduating Medical Students in Australia and New Zealand’ (2002) 176(3) Medical Journal of Australia 123–127.

\(^{22}\) John Keown has highlighted three competing interests that the law should consider when making end-of-life decisions. These are ‘vitalism, sanctity of life and quality of life’. Keown argues that the sanctity of life principle is a ‘middle way’ between two extremes. These extremes being a vitalist approach—‘that regardless of pain, suffering, or expense that life-prolonging treatment entails, it must be administered because human life must be preserved at all costs’—and a quality of life approach—‘accepting that certain lives are of no benefit and may lawfully be terminated by omission’. See, especially, John Keown, ‘The Incompetent Patient: Sanctity of Life, Quality Of Life and Vitalism’ in Michael Parker and Donna Dickenson (eds), The Cambridge Medical Ethics Workbook (Cambridge University Press, 2001) 27–32.
which pass a certain “Quality” threshold, merit protection’.23 In contrast, Huxtable asserts a more progressive view about the erosion of the sanctity of life principle, referring to its ‘survival’ and application in English case law,24 stating:

English law therefore continues to promote the sanctity of life in the face of competent requests to have life ended. Quite how long that final barrier will stand remains to be seen, since the logic if autonomy and quality of life might ultimately necessitate dismantling’.25

The ‘dismantling’ of the sanctity of life principle is demonstrated by the development and application of the best-interests principle in law. Decisions to lawfully withdraw or withhold life-sustaining treatment from incapacitated patients illustrate that end-of-life decision making does not always equate to a preservation of life. This chapter focuses on the first of several factors that are currently of central importance when making decisions to withdraw or withhold life-sustaining treatment from premature, critically ill neonates; that is, the effectiveness of the best-interests principle. First, the foundations of the best-interests principle will be considered.

IV: What is the best-interests principle?

As noted in Chapter One of this thesis, unlike competent adult patients, neonates cannot express their wishes or choices in relation to medical treatment, articulate their

24 Huxtable, above n 23, 60.
25 Ibid 79.
individual autonomy or consent to or against treatment. Therefore, all decisions for neonates and young infants are (at least at first instance) made by their parents.

As Skene notes, parents of neonates or very young infants are ‘legally entitled (and responsible) to decide what medical treatment their child will—or will not—have, provided that they act in the child’s best interests’.26 Under the protection of the law in Australia, under section 61B of the *Family Law Act 1975*, parental responsibility includes, ‘…all duties, powers, responsibilities and authority which, by law, parents have in relation to children’.27

Under English jurisdiction, parental responsibility is defined under section 3 (1) of the *Children’s Act 1989* as, ‘…all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property’.28

However, where parents disagree with either the discontinuation or continuation of medical treatment recommended by medical practitioners, the court has inherent power and *parens patriae* jurisdiction to make orders and determinations with the child’s welfare as its paramount consideration.29 As the ‘parent of the nation’, it is settled law that the courts’ ‘prime and paramount consideration must be the best interests of the child’.30

---

28 S 3(1) *Childrens Act 1989*.
29 For further discussion on the origins of *Parens Patriae* see, J Seymour, ‘Parens Patriae and Wardship Powers: Their Nature and Origins’ (1994) 14(2) *Oxford Journal of Legal Studies* 159–188. The paramount consideration of the child’s welfare is governed under s.1 of the *Children’s Act 1989* in the UK. The *Parens Patriae* is also an inherent jurisdiction of Australian Supreme Courts.
In both English and Australian legislation, there is no further explanation or definition of ‘best interests’. Such interests are merely to be the prime and paramount ‘consideration’ of the courts in making decisions for children.31 This assertion is supported by Eekelaar:

…”the heavily subjective nature of the power granted to the judges means that, so long as he or she does not claim to be applying it as a conclusive rule of law, a judge can consider almost any factor which could possibly have a bearing on a child’s welfare and assign to it any weight he or she chooses.32

However, even with the lack of any normative basis upon which the best-interests principle can be established, it remains the benchmark for deciding life and death decisions for incapacitated neonates and young infants.33 The best-interests principle is so powerful that it can, at times, overwhelm competing principles such as patient autonomy and even the right to life.34 Despite its important status and the high number of decisions in which it has been applied, the criteria by which it is informed remain surprisingly unclear.

---

31 Archard extends this point further, arguing that the use of the indefinite and definite articles ‘a’ and ‘the’, in addition to the use of prime and paramount, allows for several interpretations of the best-interests principle. Further, the use of consideration allows for other factors to be considered, as opposed to a definite and authoritative assertion as to the child’s best interests. See especially, D W Archard, ‘Children’s Rights’ in E N Zalta et al (eds), The Stanford Encyclopaedia of Philosophy (Winter 2002) <http://plato.stanford.edu/archives/win2002/entries/rights-children/>.


33 The best-interests principle is also applied to cases of incapacitated and incompetent adult and adolescent patients. The seminal case of F v West Berkshire Health Authority [1989] All ER 545 considered the lawful sterilisation of an incompetent patient. It was decided by the court that it was in the best interests of a mentally retarded but sexually active woman to be sterilised.

34 This point is illustrated throughout this chapter in cases that have required legal intervention, where parents consider that life-sustaining treatment should be continued, contrary to medical opinion. However, it has been noted that given the infinite range of typically tragic medical conditions that can afflict individuals, it is understandable that the best-interests test can never be expressed with absolute rigidity to form a precise rule. For a discussion of the distinction between rules and principle see, Ronald Dworkin, Taking Rights Seriously (Harvard University Press, 4th ed, 1977) 22–28, 76–77.
Case law from the UK and Australia has explored factors that should be considered in
deciding what is in a patients best interests, and some of these cases will be discussed later in this chapter.

V: The undefinable concept of futility

In addition to the nebulous best-interest principle, the courts invariably apply the concept of futility in lawfully allowing for the discontinuation of life-sustaining treatment. In doing so, the courts, with the endorsement of medical opinion, prescribe that further treatment will provide no benefit or improvement to the patient’s health status or prognosis. The concept of futile is as inexplicit and ambiguous as the best-interests principle. Given that both concepts are overwhelming co-dependant, there is a compelling need to improve the clarity and objectivity of these concepts.

In light of this, Stewart correctly asserts that there have been several failed attempts to define and elucidate the concept of futility by an objective standard. Qualitative and quantitative measures have been considered as methods of defining when treatment is futile. However, the application of the term remains a central contention in end-of-life decisions.

37 Chapter Three of this thesis considers the application and interpretation of the best-interests principle and the concept of futility in clinical guidelines.
This thesis contends that perhaps, although not publically expressed, the courts and medical practitioners implicitly place emphasis on the utilisation of limited health resources, particularly when making end-of-life decisions for extremely premature and severely impaired neonate and young infants. This consideration should be discussed with greater transparency to achieve a more objective decision-making model.38

The best-interests test has been endorsed and applied in both English and Australian jurisdictions, although most cases requiring legal intervention have taken place in the UK. The number of decisions from the UK as compared to Australia is disproportionate, even allowing for its sizeable population advantage. The reason for this is unclear. Nevertheless, the analysis commences with a consideration of the jurisprudence from the UK.

VI: Early case law involving neonates: Inconsistency in case decisions

During the early 1980s, the issue of withholding or withdrawing treatment from severely disabled neonates began to gain the awareness of the courts and the public in the UK. The British cases of Baby John Pearson and Baby Alexandra led to greater public awareness of the medical dilemmas concerning neonates. Doctors also became more cautious and aware of their actions being subject to scrutiny.

The case of R v Arthur concerned a reported criminal prosecution in relation to a Doctor withholding care from a neonate.39 John Pearson was born with Down

---

38 This argument is supported by John Lantos, see further, J Lantos, ‘When Parents Request Seemingly Futile Treatment for Their Children’ (2006) 73(3) The Mount Sinai Journal of Medicine 587–589.

syndrome in June 1980 to Molly Pearson in Derby General Hospital in the UK. His parents did not want him to survive. Baby Pearson’s mother is reported to have told nurses ‘I don’t want it, Duck’. The treating physician, Dr Arthur, instructed the nurses to give ‘nursing care only’, which included a strong painkiller called dyhydrocodeine (DF 188) in four-hourly intervals as required.

However, although Baby Pearson was born with many of the common known features of Down syndrome—slanting eyes, a flattened nose, a large tongue and a broad head—he did not have any of the other more severe abnormalities that can afflict people with the chromosomal defect, such as heart defects or intestinal blockages. He was capable of taking nourishment, by means of food and water. However, he was taken into a separate room and given only water and the drug DF 188. By the first evening of ‘letting nature take its course’, John was ‘going grey’. He died three days later.

Dr Arthur had provided ‘nursing care only’ and had previously allowed other unwanted newborns to die with only hospital staff and their parents’ awareness. However, in this case, one of the hospital staff informed an anti-abortion organisation called Life, who then reported the case to the police. He was later arrested and charged with murder, owing to having given Baby Pearson unnecessary and inappropriate drugs, in addition to allowing him to be starved to death. This was not a case of withdrawing or withholding medical treatment, but basic nourishment.

---

40 Helga Kuhse and Peter Singer, Should the Baby Live? (Oxford University Press, 1985) 1.
41 Ibid 2. Duck is a term of endearment used in some parts of the UK.
42 Ibid.
43 Peter Singer, Rethinking Life and Death (Text Publishing, 1994) 121.
The case was heard before Justice Farquharson and a jury at Leicester Crown Court in November 1981. The prosecution relied on evidence of the pathologist, Dr Usher, who alleged that the cause of death was lung poisoning by the DF 118 prescribed by Dr Arthur. In addition, Dr Usher claimed that, in an ‘uncomplicated’ case of Down syndrome such as that of Baby Pearson, the use of DF 118 was unnecessary.

However, doubt was later cast on Dr Usher’s reasoning and evidence by the defence. Professor Emery stated that Baby Pearson had been suffering other defects before birth that may have caused his death. Moreover, several other medical physicians and colleagues considered Dr Arthur’s course of action as being ‘normal medical practice’.45

The evidence put forward by the defence led to the charge of murder being reduced to attempted murder, in a trial in which neither Dr Arthur nor Baby Pearson’s parents gave evidence. During his interview with the police, Dr Arthur claimed his main intention in prescribing DF 118 was to alleviate any ‘suffering’ the neonate may have endured.46 After a mere two hours of deliberation, the jury returned to the dock, acquitting Dr Arthur. Justice Farquharson stated to the jury:

---

45 Kuhse and Singer, above n 40, 123.

46 This is contrary to the view that providing excessive medication or withdrawing or withholding life-sustaining treatment that intentionally causes the death of a neonate amounts to murder. Considering the decision in R v Arthur, Kuhse argues that there are instances and distinctions that should be drawn between killing and letting die. The author asserts that there may be cases in which it is morally permissible to intentionally allowing a neonate to die, such as when the neonate is suffering excessive pain. See especially, Helga Kuhse, ‘A Modern Myth. That Letting Die is Not the Intentional Causation of Death: Some Reflections on the Trial and Acquittal of Dr Leonard Arthur’ (1984) 1(1) Journal of Applied Philosophy 21–38. This thesis extends this argument further based on limited financial resources. This is discussed in greater detail in Chapter Five of this thesis.
The case really revolves round the question of what is the duty of the doctor when prescribing treatment for a severely handicapped child suffering from a handicap of an irrevocable nature where parents do not wish the child to survive.47

Kennedy interpreted Justice Farquharson’s words as establishing a criteria justifying ending the life of a neonate in the instance ‘where the child is irreversibly disabled and … rejected by its parents’.48

Arguably, the decision in R v Arthur was flawed. The courts are not bound by the decisions or choices of either parents or medical practitioners. The judge placed heavy emphasis on the medical opinion presented by several expert witnesses. In his summing up before the jury, the judge stated ‘I imagine you will think long and hard before concluding that doctors, of the eminence we have heard … have evolved standards that amount to committing a crime’.49 In subsequent decisions made by the courts, discussed later in the thesis, judges vehemently declare that the wishes of parents and medical opinion, although given consideration, are not determinative in decision making.

Considering in this decision a neonate was allowed to die because of the circumstances of his uncomplicated Down syndrome, it would be understandable to assume that another case that same year, heard before the same judicial system, would lead to a similar result. However, in Re B (a minor) (wardship: medical treatment),50 the court

---

48 Ian Kennedy, Treat Me Right (Oxford University Press, 1988) 155.
50 Re B (a minor) (wardship: medical treatment) [1990] 3 All ER (CA) 927.
was asked to decide on surgical treatment for an infant suffering an intestinal obstruction and who had Down syndrome.

Known as ‘Baby Alexandra’, her parents refused to authorise the surgery on the grounds that it was for either God or nature to decide the fate of their daughter. The Court of Appeal declared that the best interests of the neonate were served by allowing treatment. In a brief judgment of three pages, it was concluded that life, in this case, trumped death, medical and public opinion at the time.51

Templeman LJ stated:

It devolves on this court in this particular instance to decide 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 … Faced with that choice, I have no doubt that it is the duty of this court to decide that the child must live.52

However, it is apparent further in the judgment that his lordship allowed for contrary applications of the principle of best interests in the future by stating, ‘there may be cases … of severe proved damage where the future is so certain and where the life of the child is so bound of pain and suffering that the court might be driven to a different conclusion’.53

52 Re B (A Minor) (wardship: medical treatment) [1990] 3 All ER (CA) 927, 929.
53 Ibid.
Unlike in the case of Baby Alexandra, John Pearson’s withdrawal of treatment and subsequent death was judged to be in his best interests, as Justice Farquharson deemed an irreversible disability and parental rejection as a permissible reason to end his life. The inconsistency in the decisions made by the courts in these early cases, both of which involved infants afflicted by Down syndrome, is stark. The decision in *R v Arthur*, in which the court determined to allow an infant with uncomplicated Down syndrome rejected by his parents to die, is illustrative of the non-application of the erosion of the sanctity of life principle. However in *Re B* (on appeal), Justice Templeman found no evidence that, even with an intestinal blockage, Baby Alexandra’s ‘quality of life’ would be hindered or would be any worse than any other child with Down syndrome. As Gunn and Smith succinctly state:

> On the facts as they appeared to Dr Arthur at the time of his decision and, indeed, up to the time of the child’s death, John Pearson’s circumstances were, if anything, better than Baby B’s. If those responsible for Baby B owed a duty to keep her alive, there must have been at least an equal duty on those responsible for John Pearson.54

In *Re B*, the attitude of David Plank, Director of Social Services, was very different to that of the doctors: ‘we decided that clearly it was right that the baby should have the operation because the baby was an independent person and had a right to life … she was a child first and had Down syndrome second’.55

Robertson considered the need for a uniform, authoritative decision-making process in end-of-life decisions in 1981, soon after the Pearson case, stating:

---

55 Read and Clements, above n 50, 501.
The criteria cannot be whatever doctors and families decide … rather they should be developed by an authoritative body that is representative of the community as a whole, such as legislature, a national commission or some publicly constituted body that reflects a wide range of societal views.56

The assertion above reinforces the contention of this thesis: that there is a need for a more objective and tangible approach to decisions to withdraw or withhold life-sustaining treatment from incapacitated neonates. Three decades after the incongruous decisions in the cases discussed above, the arbitrary nature with which end-of-life decisions are made remains an issue in need of reform, as illustrated in later case decisions.

Robertson’s suggestion of a ‘community caucus’ is commendable, although deserving of some caution. As already noted in this chapter, societal views, values and perceptions continually evolve, as demonstrated by the widespread public acceptance of both the parental and medical decisions taken in the Pearson case in 1981. At the time of Dr Arthur’s acquittal, a contemporary British newspaper reported that women rejoiced ‘Thank God’. This societal attitude was further evidenced in a separate poll conducted by the BBC of 2000 adults, which reflected widespread support for Dr Arthur, with 86 per cent of British citizens stating that a doctor should not be found guilty of murder if, with the agreement of the parents, a severely handicapped baby dies.57

---


57 Kuhse and Singer, above n 40, 10. For further reading of the newspaper article reported women rejoicing see, ‘Women Cry ‘Thank God’ as Dr Arthur is Cleared’, *The Times* (UK), 6 November 1981.
In contrast, most cases concerning critically ill neonates heard by the courts in more recent times have involved parental objections to life-sustaining treatment being withdrawn or withheld. As will be considered later in this chapter, more recent case decisions are far removed from that of Baby John Pearson, in which the treatment decision was based on his condition and parental rejection. It is very likely that a case such as that of Baby Pearson would be decided differently today.58

Post R v Arthur and Re B, end-of-life decision making by means of withdrawal or withholding life-sustaining treatment was subject to significant legal consideration and scrutiny in the seminal English case, Airedale National Health Service Trust v Bland,59 which concerned the withdrawal and withholding of life-sustaining treatment from an incapacitated adult.

This thesis focuses on decisions to withdraw or withhold life-sustaining treatment from incapacitated neonates; however, to facilitate the discussion of the best-interests principle in cases involving neonates and young infants, it is illuminating to examine its application in Bland. Chiefly, the case provided an important legal platform compelling the courts to explore the legal and ethical role of the best-interests principle

---

58 A study conducted in Canada in the early 1990s found a significant change in medical practitioner attitudes towards the withdrawal or withholding of treatment for neonates born with Down syndrome. Compared to a similar study conducted in 1975, the study found ‘Positive changes in physicians’ attitudes during the past 15 years have been influenced by parent advocacy groups, court decisions, and studies showing that the ultimate intellectual and social skills of Down syndrome children are greater than was previously believed. The most prominent variable associated with attitudes was the physician’s age: the older the physician, the more likely he or she would be non-supportive of active treatment on behalf of the Down syndrome individual’. See especially, Robert H A Haslam and Ruth Milner, ‘The Physician and Down Syndrome: Are Attitudes Changing?’ (1992) 7(3) Journal of Child Neurology, 304–331. A similar societal shift in attitude has been evidenced in the UK, see, eg, Polly Curtis, ‘Down’s Syndrome Changing Attitudes’, The Guardian (Online) 1 September 2007 <http://www.theguardian.com/stage/2007/sep/01/theatre3>.

and its employment in decisions to allow for the lawful withdrawal or withholding of life-sustaining treatment.

**VII: The legal and ethical challenges: Airedale NHS Trust v Bland**

The concept of best interests was considered at length in the case of *Airedale National Health Service Trust v Bland.* The legal judgments focused on whether it was in the best interests of a patient in a permanent vegetative state to die. Anthony Bland was a victim of the Hillsborough football disaster on 15 April 1989 in the UK. From this, he was left with motor reflexes, but had no indication of significant cognitive function and was being kept alive via artificial life-sustaining machinery. After he had remained in the same mental and physical state for three and a half years, his family and the medical professionals responsible for his care sought a declaration that no civil or criminal liability would result in discontinuing life-sustaining treatment.

*Bland* was the first case in which the English courts were required to consider the lawful discontinuation of life-sustaining treatment concerning an adult patient. In *Bland*, the court decided in favour of discontinuing artificial hydration and nutrition. However, reaching this decision was not an easy or comfortable decision for their honours to make. Both the Court of Appeal and the House of Lords were confronted with what Miola refers to as ‘a blank canvass and recognition that the questions put to them were intrinsically moral and ethical’.

---

60 Ibid.
61 The origins of the term PVS are discussed by Sir Stephen Brown in *Airedale NHS Trust v Bland* [1993] AC 789, 797. The term ‘permanent vegetative state’ was devised by Professor Bryan Jennet of Glasgow and Professor Plum of New York. For a discussion about the terminology and understanding of the term PVS, see, eg, C J Borthwick and R Crossley, ‘Permanent Vegetative State: Usefulness and Limits of a Prognostic Definition’ (2004) 19(4) *Journal of Neuro Rehabilitation* 381–389.
Sir Bingham’s description at the Court of Appeal of Anthony Bland’s physical condition provides a useful starting point for this discussion:

Mr. Bland lies in bed in the Airedale General Hospital, his eyes open, his mind vacant, his limbs crooked and taut. He cannot swallow, and so cannot be spoon-fed without a high risk that food will be inhaled into the lung. He is fed by means of a tube, threaded through the nose and down into the stomach, through which liquefied food is mechanically pumped. His bowels are evacuated by enema. His bladder is drained by catheter.63

One of the grounds on which Airedale NHS Trust sought a declaration to discontinue medical treatment in Bland lawfully was ‘for the sole purpose of enabling Mr Bland to end his life and die peacefully with the greatest dignity and the least of pain, suffering and distress’.64

The issue that confronted each of the judges in Bland was how to reach their concurring conclusions. Their honours sought to argue that it was lawful to discontinue treatment, but without explicitly advocating that inevitable death was in his best interests. Each of the judges took their own novel route to come to the same conclusions. The judgments by their honours in Bland are illustrative of the legal and ethical challenge between the sanctity of life principle and the competing concept of patient autonomy.

64 Ibid 807–808.
(A) Sanctity of life

Judges at the Court of Appeal and the House of Lords discussed the sanctity of life principle at some length. McGee has described the decision in *Bland* to allow treatment to be withheld as ‘inexorably leading towards the deterioration of the sanctity of life principle’. 65

Hoffman LJ’s judgment in the Court of Appeal began by discussing the importance of the sanctity of life principle and the intrinsic value of human life:

our belief in the sanctity of life explains why we think it is almost always wrong to cause the death of another human being, even one who is terminally ill or so disabled that we think that if we were in his position we would rather be dead.66

However, his honour swiftly progressed to highlight the contrast between the sanctity of life principle and the competing doctrine of patient autonomy, stating:

Take, for example, the sanctity of life and the right to self-determination. We all believe in them and yet we cannot always have them both. The patient who refuses medical treatment which is necessary to save his life is exercising his right to self-determination. But allowing him, in effect, to choose to die, is something which many people will believe offends the principle of the sanctity of life.67


67 Ibid 826-827.
Only a few paragraphs later, in his judgment, Hoffman LJ asserted that between the two conflicting principles there might be a requirement for a ‘painful compromise to be made’.68 Lord Keith in the House of Lords was more robust in his approach, stating:

The principle [of sanctity of life] is not an absolute one. It does not compel a medical practitioner on pain of criminal sanctions to treat a patient, who will die if he does not, contrary to the express wishes of the patient. It does not authorise forcible feeding of prisoners on hunger strike. It does not compel the temporary keeping alive of patients who are terminally ill where to do so would merely prolong their suffering.69

68 Ibid 827.
69 Ibid 859.
The substituted judgment test often applied under American jurisdiction focuses on the treatment options that the incapacitated patient would have opted for based on the values or views or lifestyle choices of the patient while still having capacity.\(^70\)

Theirhonoursconsidered the test in *Bland* and the court assessed that further treatment would simply prolong Anthony Bland’s ‘futile’ existence. As such, his existence was measured against his prior life as a youthful and energetic adolescent. This was illustrated by Lord Browne-Wilkinson, who stated, ‘the withdrawal of food and Anthony Bland’s subsequent death would be for his benefit, and attach importance to impalpable factors such as personal dignity and the way Anthony Bland would wish to be remembered’.\(^71\) As his father succinctly stated, ‘he certainly wouldn’t want to be left like that’.\(^72\) Lord Goff considered the substituted judgment test, stating:

*I wish however to refer at this stage to the approach adopted in most American courts under which this courts seeks, in a case in which the patient is incapacitated from expressing any view on the question whether life-prolonging treatment should be withheld in the relevant circumstance, to determine what decision the patient himself would have made had he been able to do so. This is*

---

\(^70\) McQueen and Walsh argue that the substituted judgement test is flawed as it ‘focuses disproportionately on the person’s statements rather than on the person’s overall best interests’. See especially, Moira M McQueen and James L Walsh, ‘The House of Lords and the Discontinuation of Artificial Nutrition and Hydration: An Ethical Analysis of the Tony Bland Case’ (1991–1994) 35 Catholic Lawyer 363, 368. The substituted judgement test is a contrast to the best-interests test, which takes a more paternalistic role in deciding what is ‘best’ for the patient. The origins of the substituted judgement test can be found in the nineteenth century ‘Lunacy Law’, whereby ‘Lord Eldon crafted the legal fiction of doing that which it is probable the lunatic himself would have done’. See especially, Louise Harmon, ‘Falling Off the Vine: Legal Fictions and the Doctrine of the Substituted Judgement Test’ (Oct 1990) 100(1) Yale Law Journal 1, 1.


\(^72\) Ibid 807.
called the substituted judgement test, and it generally involves a detailed inquiry into the patient’s views and preferences.\(^{73}\)

While ultimately rejected as an applicable test for decision making in *Bland*, at the Court of Appeal, Lord Hoffman affirmed a view similar to the substituted judgment test, stating, ‘we should try our honest best to do what we think he would have chosen’.\(^{74}\) However, unlike in cases involving incapacitated adults, best interests when applied to neonates is not distracted by comparisons of the life and capacities that the patient enjoyed prior to the illness or injury that now afflicts them.

The court in *Bland* favoured and applied the best-interests principle as the cornerstone in deciding to withdraw or withhold life-sustaining treatment. Although not as clearly subjective as the substituted judgment test, the application of the best-interests principle in decisions to withdraw or withhold life-sustaining treatment raises others concerns, which are discussed below and considered later in this chapter.

\[\text{(C) Reliance on the medical profession}\]

Lord Keith reached his conclusion by applying the test laid down in *Bolam v Friern Hospital Management Committee*,\(^{75}\) which states that a doctor has a duty to act in the best interests of patients as understood by a ‘responsible body’ of medical opinion. In relying on this test, Lord Keith abjured himself of any moral responsibility to reach a decision in *Bland*: ‘…a medical practitioner is under no duty to continue to treat such

---

\(^{73}\) Ibid 871.

\(^{74}\) Ibid 829–830.

\(^{75}\) *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.
a patient where a large body of informed and responsible medical opinion is to the
effect that no benefit at all would be conferred by continuance’.  

Lord Goff was more forthright about the role of doctors. He also relied on the Bolam test and the ethics committee of the British Medical Association (BMA) in stating, ‘he [the doctor] will be acting with the benefit of guidance from a responsible and competent body of relevant professional opinion’.  Like Lord Keith, Lord Goff was unwilling to commit to a more independent position on the matter of lawful withdrawal of treatment:

> The truth is that, in the course of their work, doctors frequently have to make decisions which may affect the continued survival of their patients, and are in reality far more experienced in matters of this kind than judges. It is nevertheless the function of the judges to state the legal principles upon which the lawfulness of the actions of doctors depend; but in the end the decisions to be made in individual cases must rest with the doctors themselves.  

In effect, Lord Goff considered that it was the role of doctors to make end-of-life decisions, and that the courts and judges were required to endorse the conduct of medical practitioners.

That two of the presiding judges arrived at their conclusions for best interests via the application of the Bolam test demonstrates its limitations. As a test, it has not been formulated and hypothesised in a wholly independent and informed manner.  

---

77 Ibid 871.
78 Ibid.
79 Right Honourable Lord Woolf argues that the courts should not interfere with medical decision making unless the courts are justified in doing so. Lord Woolf refers to the court’s role being that of a ‘regulatory body’ rather than a decision-making body.
reinforces this view, arguing that the *Bolam* test ‘places the assessment of best interests solely within the sphere of medical competence’.80 Stone, in the New Law Journal, raised similar arguments:

The reliance on the *Bolam* test of medical negligence to determine whether it is in the patient’s best interests to be allowed to die is scarcely an ideal approach where it is the continued existence of the patient rather than the conduct of the doctor which is to be assessed. ‘Best interests’ is a nebulous concept at the best of times.81

Lord Browne-Wilkinson did not show the same deference to the medical profession, highlighting that there might be instances in which a doctor, in deciding to withdraw life-prolonging treatment, ‘may well be influenced by his own attitude to the sanctity of human life.82 However, Lord Goff considered that, for this potential offence and the attendant consequences, a ‘change of medical practitioner’ would provide the necessary resolution.83

Although, the courts have the jurisdiction to override medical practitioners, judges rarely do so. Lord Browne-Wilkinson’s wording conveys the impression that the courts feel inconvenienced in having to make decisions regarding areas in which, ‘in the past,

---

82 Airedale NHS Trust v Bland [1993] AC 789, 884. Empirical research has found that medical practitioners are influenced in end-of-life decision making based by their personal values and beliefs. The role and impact of key stakeholders in decision making is examined in detail in Chapter Four of this thesis.
83 Ibid 874.
doctors exercised their own discretion in accordance with medical ethics’.84 In the area of prolonging life, doctors ‘took the responsibility of deciding whether the perpetuation of life was pointless’.85

It is clear that Lord Browne-Wilkinson’s preference in Bland was for doctors to make life and death decisions and for the courts not to be troubled or confronted by such. Previously, doctors were given wide latitude to make difficult decisions behind closed doors; they assumed control and sole responsibility, and were seldom challenged. While not overtly criticising this shift away from the infallibility of doctors, Lord Browne-Wilkinson acknowledged the reason behind the increasing incidence of intervention by the courts:

…there are now present amongst the medical and nursing staff of hospitals those who genuinely believe in the sanctity of human life, no matter what the quality of that life, and report doctors who take such decisions to the authorities with a view to prosecution for a criminal offence.86

Arguably, reliance on the medical profession to make end-of-life decisions allows for less discomfort, debate or discussion by the courts, and does not force the courts to have to consider end-of-life decision making with the need to formulate any unified principles in this area.

Any association between the discontinuation of treatment and euthanasia was explicitly denied by Lord Lowry: ‘I reject the idea, which is implicit in the appellant’s
argument, that informed medical opinion is these respects is merely a disguise for a philosophy which, if accepted, would legalise euthanasia’. Lord Browne-Wilkinson was also vigorous in attempting to prevent the terms death and best interests being coined together, by asserting:

…the critical decision to be made is whether it is in the best interests of Anthony Bland to continue the invasive medical care involved in artificial feeding. That question is not the same as, ‘Is it in Anthony Bland’s best interests that he should die?’

Ensuring that the onus for ‘responsibility and accountability’ remained with the medical profession, and perhaps revealing some of the discomfort discussed above, Lord Browne-Wilkinson commented:

…it follows that the legal question in this case is not whether the court thinks it is in the best interests of Anthony Bland to continue to receive intrusive medical care but whether the responsible doctor has reached a reasonable and bona fide belief that it is not.

Lord Mustill seemed to believe that Anthony Bland had no best interests at all, stating, ‘the distressing truth which must not be shirked is that the proposed conduct is not in the best interests of Anthony Bland, for he has no best interests of any kind’. While a bold statement, it was not helpful in responding to the immediate matter at hand; that is, whether it was in his best interests to have life-sustaining treatment withdrawn or withheld.

87 Ibid 876.  
88 Ibid 884.  
89 Ibid.  
90 Ibid 897.
Unlike his learned friend Lord Browne-Wilkinson, Lord Mustill did not show the same blind confidence in the medical profession in determining life and death decisions. Lord Mustill considered the role of the courts and the law in decision making with caution, and acknowledged the difficulties facing judges in determining the best interests of the patient:

But when the intellectual part of the task is complete and the decision maker has to choose the factors which he will take into account, attach relevant weights to them and then strike a balance the judge is no better equipped, though no worse, than anyone else.  

In line with the contention of this thesis, Lord Mustill did not consider doctors to be those ‘best equipped’ to make such decisions—a welcome change to the general tenor of the judgment.  

(D) Acts and omissions

The courts in *Bland* were required to differentiate between the ‘act’ of withdrawing life-prolonging treatment or merely ‘omitting’ to provide it. The distinction between the two was of significant importance to the court because, without resort to this distinction, the court would have effectively legalised euthanasia. As discussed earlier in this chapter, in the 1980s judgment in *R v Arthur*, the courts underlined the importance of distinguishing between ‘letting die’ by means of omission or ‘killing’ by an act. This issue continued to confront the courts over a decade later in *Bland*.

---

91 Ibid 887.

92 The role, impact and function that the medical profession should have in end-of-life decision making is discussed in greater detail in Chapter Four of this thesis.
Lord Goff addressed this complexity:

so to act is to cross the Rubicon which runs between on the one hand the care of the living patient and on the other hand euthanasia- actively causing his death to avoid or to end his suffering. Euthanasia is not lawful at common law.93

Subsequent comments reflected an appreciation of the complexities of the distinction between acts and omissions:

It is true that the drawing of this distinction may lead to a charge of hypocrisy; because it can be asked why, if the doctor, by discontinuing treatment is entitled in consequence to let his patient die, it should not be lawful to put him of out his misery straight away, in a more humane manner, by lethal injection, rather than let him linger on in pain until he dies. But the law does not feel able to authorise euthanasia, even in circumstances such as these.94

His honour was concerned about the possible repercussions and the potential for unintended consequences, as ‘…once euthanasia is recognised as lawful in these circumstances, it is difficult to see any logical basis for excluding it in others’.95

In the Court of Appeal, Lord Hoffman also considered the infamous ‘lethal injection’ scenario. In opposition to the judges in the House of Lords who thought the use of an injection would be ‘more humane’ than any suffering caused by the withdrawal of nutrition and hydration for an extended period of time, he asserted, ‘I must start by considering why most of us would be appalled if he was given a lethal injection. It is,

94 Ibid.
95 Ibid.
I think, connected with our view that the sanctity of life entails its inviolability by an outsider’.\(^96\) However, he went on to say ‘on the other hand, we recognise that, one way or another, life must come to an end’.\(^97\)

Lord Hoffman’s view is aptly defined by Kuhse’s novel term, ‘qualified sanctity of life’, which affirms:

> It is absolutely prohibited either intentionally to kill a patient or intentionally to let a patient die, and to base decisions relating to the prolongation or shortening of human life on considerations of its quality or kind; it is, however, sometimes permissible to refrain from preventing death.\(^98\)

Lord Browne-Wilkinson considered that the objective of lawfully allowing the patient to die would alleviate the family’s suffering,\(^99\) while still acknowledging the difficulties in reconciling the difference between a positive act to end Anthony Bland’s life and a mere omission to preserve it:

> …the conclusion I have reached will appear to some as almost irrational. How can it be lawful to allow a patient to die slowly though painlessly, over a period of weeks from lack of food but unlawful to produce his immediate death by a lethal injection, thereby saving his family from yet another ordeal to add to the tragedy that has already struck them?\(^100\)

\(^96\) Ibid 831.
\(^97\) Ibid.
\(^99\) In Bland, Lord Browne-Wilkinson considered that allowing treatment to be withdrawn from Anthony Bland would perhaps ease some of the distress his family experienced with his prolonged PVS state. However, Amarasekara and Bagaric promote that in cases of active euthanasia, a slow dying process allows for ‘a last minute change of mind … [that is not possible] in the case of active euthanasia and we can be more certain of the patient’s commitment to the decision to die’. See, Amarasekara and Bagaric, above n 6, 98.
\(^100\) Airedale NHS Trust v Bland [1993] AC 789, 885.
Lord Mustill concurred:

Unlike the conscious patient he [Bland] does not know what is happening to his body, and cannot be affronted by it; he does not know of his family’s continuing sorrow. By ending his life the doctors will not relieve him of a burden become intolerable, for others carry the burden and he has none.  

In dealing with the distinction between acts and omissions, the judges were required to consider the manner in which Anthony Bland’s life could be brought to an end. The issue raised some discomfort, as it did not concern the withdrawal of medical treatment but the withdrawal of hydration and nutrition.  

(E) Does withdrawal of nutrition and hydration amount to starving to death?

Lord Keith began by considering that artificial feeding amounted to medical treatment and care. He considered nourishment to be a form of ‘medical technique’ because of the way it was administered.  

Lord Goff extended the point, addressing the concept of futility of treatment: ‘when such treatment has no therapeutic purpose of any kind, as where it is futile because the
patient is unconscious and there is no prospect of any improvement in his condition’. 104

Further, ‘in a case such as the present, it is the futility of the treatment which justifies its termination’; 105 it is ‘no longer in his best interests’ 106 for such treatment to continue. He concluded that, to ‘terminate’ such futile treatment, continuation of artificial feeding would have to cease. He did not understate the ethical and highly emotive nature of the discontinuation, stating:

…it can be said that the patient will as a result starve to death; and this may bring before our eyes the vision of an ordinary person slowly dying of hunger, and suffering all the pain and distress associated with such a death. But here it is clear from the evidence that no such pain or distress will be suffered by Anthony, who can feel nothing at all. 107

The medical perspective on the withdrawal or withholding of artificial feeding was discussed in the international medical journal The Lancet in the early 1990s, where Ahronheim and Gasner commented:

The use of the word ‘starvation’ is especially provocative when applied to clinical consequences of withholding or withdrawing artificial feeding … such images disturb our well-fed society but … are irrelevant to discussions of feeding patients who are hopelessly ill. 108

104 Ibid 869.
105 Ibid.
106 Ibid 867.
107 Ibid 870.
108 Judith C Ahronheim and M Rose Gasner, ‘The Sloganism of Starvation’ (1990) 335(8684) The Lancet 278, 278. Similar terminology was inaccurately applied in the case of Maria Korp in Victoria, Australia in 2005. Maria Korp was reported missing in February 2005 and found alive but in a state of post-coma unresponsiveness four days after her disappearance. Victorian public advocate Julian Gardner authorised the withdrawal of artificial hydration and nutrition and for palliative care to be implemented. The case aroused much controversy and publicity, and the withdrawal of tube feeding was sensationalised by the press media as ‘starving her to death’. See especially, Julian Gardner, ‘Dilemmas in End-of-life Care: The Maria Korp Case’ in Simon Barraclough and Heather Garner (eds), Analysing Health Policy: A Problem Orientated Approach (Elsevier, 2008) 166–176.
Not surprisingly, as the majority of judges in Bland relied heavily on medical opinion to justify their decisions to allow Anthony Bland to die, Lord Hoffman made reference to the American coined terms ‘sloganism and emotional symbolism’:

I do not think one should make light of these deeply intuitive feelings, which derive, as I have said, from a principle of kindness which is a badge of our humanity. But like the principle of the sanctity of life, they cease to provide true guidance in the extreme case.109

A recent Victorian pilot study found that the provision of proper palliative care facilitates a natural body response, reporting ‘terminal dehydration is seen as part of the homeostatic process involving an adaptive physiological response when the dying body goes into multi-system failure’.110 Arguably, responsible doctors would contend that they are simply facilitating this adaptive physiological response and allowing nature to take its course while managing the pain. They may dispute they are hastening the process, and it is likely they would have the support of the courts in this regard.

The judges in Bland wrestled with semantics to allow doctors to withdraw nutrition and hydration lawfully, renaming it as the withdrawal of medical treatment that no longer served Anthony Bland’s best interests, and was thus futile. Arguably, one of the issues of contention in Bland was the application of the doctrine of causation. All parties concerned with Bland’s care (including the Catholic priest) agreed that continuation of treatment was not in his best interests. The central issue was whether discontinuation amounted to an act or an omission and the court considered this to be an omission rather than an act.

Given the time, energy and painstaking efforts spent wrestling with the phraseology of what essentially amounted to euthanasia, the courts would have been better served by dealing directly with the life and death issues that confronted them. This reluctance to be seen as sanctioning any form of euthanasia has compelled recent judgments to invoke obscure and sometimes indefensible principles, standards and criteria, which are explored and illustrated in the case judgments discussed below. The next section of this chapter considers the relevant case law and manner in which judges apply the imprecise best-interests test to cases of incapacitated neonates and young infants in a way that is arguably a smoke screen for what would otherwise be considered as passive euthanasia.

VIII: Seminal English decisions involving neonates and young infants: The Re: J and Re: C cases

The case law considered in this section is critiqued sequentially for ease of understanding of the evolution and development of judicial thought regarding the best-interests principle and its application in end-of-life decisions concerning incapacitated neonates or young infants.

The following cases from the 1990s examine the court’s application of the best-interests principle to allow the lawful withdrawal or withholding of life-sustaining treatment. The cases also highlight the recurring reluctance of the courts to oppose medical opinion in making end-of-life decisions.
In the case of *Re C (a minor) (wardship: medical treatment)*,\(^{111}\) a neonate suffered a congenital hydrocephalus, a blockage of cerebral spinal fluid to the brain and brain malformation. The neonate was diagnosed as severely and irreversibly brain damaged.\(^{112}\) The local authority sought a declaration from the court to determine ‘what treatment should be given in the best interests of C if, as sooner or later was inevitable, she suffered some infection or illness over and above the handicaps from which she was already suffering’.\(^{113}\)

The medical practitioner responsible for the care of the neonate recommended that the objective of treatment should be to ease her suffering and pain rather than to prolong her life. For such an objective to be met, medical practitioners stated it was unnecessary to provide antibiotics, intravenous infusions or nasogastric feeding mechanisms.

Interestingly, in the Court of Appeal judgment, Lord Donaldson MR was required to clarify what he referred to as a ‘misleading phrase’ in Justice Ward’s initial judgment. In the first instance, in concluding that the hospital authority could lawfully withhold further treatment, Justice Ward had stated, ‘I direct that leave be given to the hospital authorities to treat the ward to die, to die with the greatest dignity and the least of pain, suffering and distress’.\(^{114}\)

\(^{111}\) *Re C (a minor) (wardship: medical treatment)* [1989] 2 ALL ER 782.

\(^{112}\) Ibid 783.

\(^{113}\) Ibid 784.

\(^{114}\) Ibid 787.
Referring to Justice Ward’s initial ‘failure to express himself with his usual felicity’, Lord Donaldson MR was quick to ‘revise’ the sentence in the judgment to: ‘I direct that leave be given to the hospital authorities to treat the ward in such a way that she may end her life and die peacefully with the greatest dignity and the least of pain, suffering and distress’. This illustrates a rare occasion in which the court was originally overly frank in its judgment. However, the higher court was quick to turn the statement in question away from anything bordering the controversial.

As noted already in this chapter, judges do make decisions to allow the lawful withdrawing or withholding of life-sustaining treatment leading to inevitable death. While this is arguably euthanasia by another name, it is masked in terms such as best interests or futile treatment. This highlights the contention of this thesis: that there is a need for an objective, transparent and tangible approach to end-of-life decision making for incapacitated neonates. As will be further evidenced below, given that decisions to allow life-sustaining treatment to be lawfully withdrawn or withheld have such absolute consequences, the best-interests test should be informed by clear criteria, rather than continuing the arbitrary manner in which decisions are currently made.

One of the leading cases of the early 1990s was *Re J (a minor) (wardship: medical treatment)*. This case illustrates the preparedness of courts to equate best interests with probable death. In this case, Baby J was born prematurely at 27 weeks’ gestation, and due to a shortage of oxygen and impaired blood supply, received severe brain damage. The neonate subsequently suffered recurring convulsions and periods during

---

115 Ibid.
116 Ibid.
117 *Re J (a minor) (wardship: medical treatment)* [1990] 3 All ER 930.
which he stopped breathing, and on various occasions, the neonate was placed on ventilation. However, the neonate was diagnosed as neither dying nor near the point of death; although the prognosis was made that the neonate would develop spastic quadriplegia.

The medical practitioners sought the approval of the court to pursue the course of action that, in the event the neonate suffered another collapse and stopped breathing, a mechanical ventilator should not aid him. Again, the courts agreed with the doctors declaring that it would be lawful for doctors not to provide mechanical ventilation that was ‘intrusive and painful and palliative care could be offered.\textsuperscript{118} The decision in \textit{Re J} is important and influential to later decisions in that, although \textit{Baby J} would never lead a ‘normal’ life in the sense of seeing and hearing, the baby was neither dying nor likely to die if given the appropriate medical treatment and support.

In the Court of Appeal, Lord Donaldson MR discussed the likely prognosis:

\begin{quote}
…It is debatable whether he will ever be able to sit up or to hold his head upright. J appears to be blind, although there is a possibility that some degree of sight may return. He is likely to be deaf. He may be able to make sounds which reflect his mood, but he is unlikely ever to be able to speak, even to the extent of saying ‘Mum’ or ‘Dad.’ It is highly unlikely that he will develop even limited intellectual abilities. Most unfortunately of all, there is a likelihood that he will be able to feel pain to the same extent as a normal baby, because pain is a very basic response. It is possible that he may achieve the ability to smile and to cry.\textsuperscript{119}
\end{quote}

\textsuperscript{118} Skene, above n 26, 351.

\textsuperscript{119} \textit{Re J (a minor) (wardship: medical treatment)} [1990] 3 All ER 930, 933.
Balcombe LJ explained the medical procedures that the neonate would be subjected to:

He would have to be fed by a nasogastric tube or intravenously; the latter method would probably be the safer. Drips have to be re-sited from time to time. Constant blood sampling is necessary to ensure that the oxygen levels are neither too high nor too low. External cardiac massage may be necessary with the injection of drugs directly into the heart. There are no half measures to intensive support and the evidence was that there is a risk that these procedures may cause significant distress to J. who is thought to feel pinpricks and other forms of pain. 120

The fact that the neonate was not dying but that he would be subject to invasive medical treatments and, more importantly, would suffer pain, created a greater dilemma for the judges in the appeal court. The prognosis and decision by the court to allow the lawful withdrawal of future ventilation provides a clear illustration of the dilution of the sanctity of life principle. Although the judges were reluctant to declare overtly that the principle was redundant, this was evident in the significant contradictions by their honours in the case.

Lord Donaldson MR referred to an established point of law when he stated, ‘we know that the instinct and desire for survival is very strong. We all believe in and assert the sanctity of human life’. 121 Taylor LJ also acknowledged the doctrine of the sanctity of life: ‘the court’s high respect for the sanctity of human life imposes a strong presumption in favour of taking all steps capable of preserving it, save in exceptional circumstances’. 122 Further:

120 Ibid 940.
121 Ibid 938.
122 Ibid at 943.
As a corollary to the second principle, it cannot be too strongly emphasised that the court never sanctions steps to terminate life. That would be unlawful. There is no question of approving, even in a case of the most horrendous disability, a course aimed at terminating life or accelerating death.\textsuperscript{123}

It would appear that Taylor LJ had firmly accepted the fundamental stance of the law concerning life and death issues, and may have opposed the decision to allow the child to die in any future instances of breathing difficulties. However, he then progressed, ‘the court is concerned only with the circumstances in which steps should not be taken to prolong life’.\textsuperscript{124}

This is a considerable \textit{volte-face} from his previous acknowledgment of the doctrine of the sanctity of life, made within the same paragraph of his judgment. That such a cardinal principle or ideal can be defeated based on such a fine distinction as the difference between accelerating death and not prolonging life demonstrates a lack of real commitment to it in the first place.\textsuperscript{125}

It is apparent from the judgments in \textit{Re J} that each of the judges in turn attempted to justify the prevention of further ventilation based on the child’s future quality of life. The judges in \textit{Re J} adopted a patently paternalistic approach, by providing that the prevention of further treatment would provide some form of ‘salvation’ for the child.

\begin{footnotesize}
\textsuperscript{123} Ibid.
\textsuperscript{124} Ibid.
\end{footnotesize}
from a life that the judges and medical practitioners considered ‘intolerable’. The courts found it necessary to employ such benevolent terms to mask the reality that best interests overwhelmingly equates to death. Where the withdrawal or withholding of life-sustaining treatment is in the best interests of a critically ill neonate or young infant, such discussion should be guided by greater transparency and based on clearer criteria.

Taylor LJ’s statement is illustrative of this benevolence:

Despite the court’s inability to compare a life afflicted by the most severe disability with death, the unknown, I am of the view that there must be extreme cases in which the court is entitled to say: The life which this treatment would prolong would be so cruel as to be intolerable. 126

In Re J, the courts seemingly applied a deemed autonomy role that if Baby J were able to express his own free will and patient autonomy, he would have reached the same decision as the judges and medical practitioners.

Further, Taylor LJ asserted:

At what point in the scale of disability and suffering ought the court to hold that the best interests of the child do not require further endurance to be imposed by positive treatment to prolong its life? I consider the correct approach is for the court to judge the quality of life the child would have to endure if given the treatment and decide whether in all the circumstances such a life would be so afflicted as to be intolerable to that child. I say ‘to that child’ because the test should not be

126 Re J (a minor) (wardship: medical treatment) [1990] 3 All ER 930, 944.
whether the life would be tolerable to the decider. The test must be whether the child in question, if capable of exercising sound judgement, would consider the life tolerable.\textsuperscript{127}

The Court of Appeal judgment illustrates a position of deemed autonomy taken by the judges:

…where a ward of court suffered from physical disabilities so grave that from his point of view be so intolerable if he were to continue living that he would choose to die if he were in a position to make a sound judgement, the court could direct that treatment without which death would ensue from natural causes need not be given to the ward to prolong his life, even though he was neither on the point nor dying.\textsuperscript{128}

Thus, the judges in the appeal court rejected the outright primacy of sanctity of life in favour of appreciating the ‘quality’ of life that the incapacitated neonate would be subject to, to establish what would be in his best interests.

However, there is no reference within the judgments in \textit{Re J} of how the ‘quality’ of a handicapped neonate’s life is to be measured. There is a strong presumption in favour of withdrawing treatment when the patient’s life will be ‘intolerable’ or considerably ‘awful’; but a clear lack of precision is evident in defining what should be considered as a life that lacks substantial ‘quality’.

This provides another example of the ineffectiveness of the best-interests principle and the additional concepts that have been introduced by the courts to allow the lawful withdrawal or withholding of life-sustaining treatment. This thesis does not contend

\footnotesize{\textsuperscript{127} Ibid 945. \\
\textsuperscript{128} Ibid 931.}
that life must be preserved at all costs; however, life and death decisions should be made with greater objectivity, transparency and tangibility, rather than continuing to be based on subjective and undefined concepts.

The imprecision and ambiguity evident in the judgments regarding the ‘quality of life’ argument is considered by Gostin:

It is difficult to argue with the premise underlying the ‘quality of life’ position, for there must come a point for most of us where life is so devoid of meaning and contentment that it is not worth living. As a philosophic position, its weakness is that the factors that would justify forsaking continued life are seldom, if ever, specified. If one accepts that continued life is not in the infant’s interests, then those who make this decision must be clear about the criteria adopted. Yet the basis for identifying and measuring those interests under a ‘quality of life’ standard is unclear. 129

Two years later, another case, also named Re J (a minor) (wardship: medical treatment),130 went before the courts. The second Re J case concerned a 16-month-old infant who, because of a fall, had sustained severe brain damage and was left mentally and physically handicapped. He suffered severe cerebral palsy, epilepsy (43 epileptic attacks lasting between 10 minutes to 2.5 hours)131 and had to be predominantly fed through a nasogastric tube. His life expectancy was considered short and uncertain. In light of this, the treating doctor was of the medical opinion that ‘it would not be medically appropriate to intervene with intensive therapeutic measures such as artificial ventilation if [J] were to suffer a life threatening event’.132

131 Ibid 617.
132 Ibid 615.
Lord Donaldson MR reaffirmed his position in the earlier *Re J* case of 1990, stating that ‘no one can dictate the treatment to be given to the child, neither courts, parents nor doctors. There are checks and balances’.\(^{133}\) This stands in contrast to Justice Balcombe’s statement in the same judgment, which unquestioningly accepted the right of the medical fraternity to make such decisions:

…I can conceive of no situation where it would be a proper exercise of the jurisdiction to make such an order as was made in the present case: that is to order a doctor, whether directly or indirectly, to treat a child in a manner contrary to his or her clinical judgement.\(^ {134}\)

Finally, Leggatt LJ concluded his judgment by stating that ‘the court has not given to doctors any right that they did not previously have: it merely declined to deprive them of a power which it is for them alone to exercise’.\(^ {135}\) This contradicts the view of Lord Donaldson MR, and many individuals may have grave concerns that, according to Leggatt LJ, it is a doctor’s ‘right’ and ‘power’ to make life and death decisions.

As a final important note from this judgment, Balcombe LJ openly emphasised the importance of resource allocation,\(^ {136}\) which is rarely discussed by judges. Lord Balcombe stated:

I would also stress the absolute undesirability of the court making an order which may have the effect of compelling a doctor or health authority to make available scarce resources (both human

---

\(^{133}\) Ibid 623.

\(^{134}\) Ibid 625.

\(^{135}\) Ibid 626.

\(^{136}\) Discussed in greater detail in Chapter Five of this thesis.
and material) to a particular child, without knowing whether or not there are other patients to whom those resources might more advantageously be devoted.  

The statement above supports the contention of this thesis: that there is a need for a greater objectivity and transparency in decision making for incapacitated neonates and young infants. This can be facilitated by the allocation of limited health resources as the cardinal factor in decisions to withdraw or withhold life-sustaining treatment from extremely premature and severely impaired neonates. 

The final case examined in this section is *Re C (a minor)*, which concerned a 16-month-old infant suffering from spinal muscular atrophy and placed on ventilation to support her breathing. Her doctor concluded that it would not be in her best interests to continue indefinite ventilation, and that, as it was highly probable that the infant would suffer a further respiratory relapse, it would not be in her best interests to be re-ventilated. The hospital sought a declaration to withdraw ventilation. The infant’s parents were prepared to allow the withdrawal of ventilation to see whether their infant could breathe independently. However, they wished the ventilation to be reinstated in the event of further breathing difficulties. The declaration was granted. Sir Stephen Brown concluded:

I believe that in this case I should assent to the course, which is proposed by the Hospital Trust. I do so with a feeling of grave solemnity because I realise that the parents themselves will be greatly disappointed. It is a sad feature of this matter that there is, in fact, no hope for C, and what has to

---


138 This thesis argues that limited health resources are a factor in decision making in healthcare, but should be discussed more openly. This issue is taken up in greater detail in Chapter Five of this thesis.

139 *Re C (a minor)* [1997] 40 BMLR 31 (Fam Div).
be considered is her best interests to prevent her from suffering as would be inevitable if this course were not to be taken.140

From the case law examined so far, it can be concluded that the courts consider the withdrawal or withholding of life-sustaining treatment to be in the best interests of premature, imperilled neonates or young infants. In the second Re J case and Re C, the courts determined that medical practitioners could not be compelled to treat a neonate or young infant, whether by the court in the exercise of its wardship jurisdiction, or by the parents. Further, the decision as to whether to provide medical treatment is dependent on the judgment of medical practitioners in accordance with their profession.141

The decisions in both Re J and Re C established the strong judicial belief in medical practitioners’ autonomy to decide the best interests of an incapacitated neonate. Montgomery correctly asserts that ‘important moral judgements are being clothed with the mystique of professional expertise and appropriated by medicine from their proper place as social and political problems’.142 Seemingly, end-of-life decisions that equate to certain death founded on the best-interests principle are not publicly expressed as such, and should instead be understood as judicial reasoning cloaked by clinical opinion.

140 Ibid 38.
The next section of this chapter continues the critique of case law and its application of the best-interests principle and the introduction of further concepts applied by the courts to allow for the lawful withdrawal or withholding of life-sustaining treatment from incapacitated neonates or young infants. The cases examined below once again illustrate that the outcomes of legal decisions are nearly always consistent with the opinion of medical practitioners.

IX: The turn of the millennium: *Re A (Conjoined Twins)*

At the turn of the millennium, the case of *Re A (children) (conjoined twins: surgical separation)* made news around the world. It concerned conjoined twins, Mary and Jodie, joined at the lower abdomen. It was predicted that Jodie’s circulatory system would collapse within a matter of weeks under the strain of supporting herself and Mary.

In light of medical testimony, the High Court ordered the twins to be separated against the wishes of their devout Catholic parents and the Archbishop of Westminster, Cormac Murphy-O’Connor. Mary and Jodie’s parents believed that the twins were a gift from God, and that their fate and best interests should remain in God’s hands. However, religion or morals were given no consideration when the matter went before Ward LJ, who stated that ‘this court is a court of law, not of morals, and our task has been to find, and our duty is then to apply, the relevant principles of law to the situation before us, a situation which is quite unique’.  

144 Ibid 969.
Bound under *Section 1 (1) Children’s Act 1989*, which provides that the ‘welfare of the child shall be the court’s paramount consideration’, in addition to the competing best interests of the twins, the court’s task was undoubtedly complex.

The court acknowledged that, if it acted in the best interests of Mary, then Jodie would also die after an estimated six months. If the court acted in the best interests of Jodie, then Mary would die immediately. After much deliberation and legal debate the Court of Appeal authorised the separation of the twins. Ward LJ discussed the competing interests of the twins stating:

> The reality here—harsh as it is to state it, and unnatural as it is that it should be happening—is that Mary is killing Jodie. That is the effect of the incontrovertible medical evidence and it is common ground in the case. Mary uses Jodie’s heart and lungs to receive and use Jodie’s oxygenated blood. This will cause Jodie’s heart to fail and cause Jodie’s death as surely as a slow drip of poison. How can it be just that Jodie should be required to tolerate that state of affairs? 145

Referring to Keown’s assertion about the sanctity of life, Ward LJ emphasised that ‘human life is created in the image of God and therefore possessed of an intrinsic dignity, which entitled it to be protected from unjust attack’. 146 However, he then concluded:

> Mary may have a right to life, but she has little right to be alive. She is alive because and only because, to put it bluntly, but nonetheless accurately, she sucks the lifeblood of Jodie and she sucks the lifeblood out of Jodie. She will survive only so long as Jodie survives. Jodie will not survive

145 Ibid 1016.
146 Ibid 999.
long because constitutionally she will not be able to cope. Mary’s parasitic living will be the cause of Jodie’s ceasing to live.\textsuperscript{147}

Ward LJ considered that ‘the sanctity of life doctrine does, however acknowledge that it may be proper to withdraw or withhold treatment … the question is whether treatment is worthwhile not the patient’s life’.\textsuperscript{148} Here, the judge attempted the impossible, to marry the sanctity of life principle and the concept of futile treatment. As discussed earlier in this chapter, the religious and philosophical underpinnings of the sanctity of life principle are that all life is sacred; decisions to withdraw or withhold futile treatment, even when a neonate is not dying, do not protect or save all life.

Ward LJ continued by applying the ‘substituted judgement’ approach that was rejected in \textit{Bland}: ‘if Jodie could speak, she would surely protest, “Stop it, Mary, you’re killing me”. Mary would have no answer to that’.\textsuperscript{149}

The Court of Appeal concluded that it would be in the best interests of the twins to give Jodie a chance of survival, even at the cost of another life. Ward LJ attempted to justify the separation as a form of self-defence: ‘the reality here, harsh as it is to state it and unnatural as it is that it should be happening, is that Mary is killing Jodie.’\textsuperscript{150}

Justice Ward also made reference to the American term ‘unjust aggressor’, in which he drew an analogy to a six-year-old boy on a shooting spree in a school playground. Although in law that six-year-old is innocent, it is lawful to kill that child in self-

\textsuperscript{147} Ibid 1010.
\textsuperscript{148} Ibid 1000.
\textsuperscript{149} Ibid.
\textsuperscript{150} Ibid 1016.
defence.\textsuperscript{151} However, in arguing that the same situation applied in this case, Justice Ward was incorrect. Mary was not deliberately trying to harm Jodie, and the harm that Jodie suffered was through no choice of Mary’s. Both twins were ‘harmed’ by genetic malformation, a sad state that neither of them had chosen.

In this case, the Court of Appeal again demonstrated reverence to the medical profession, and Ward LJ appeared to confer a quasi-judicial role upon them:

Faced as they are with an apparently irreconcilable conflict, the doctors should be in no different position from that in which the court itself was placed in the performance of its duty to give paramount consideration to the welfare of each child. The doctors must be given the same freedom of choice as the court has given itself and the doctors must make the choice along the same lines as the court has done.\textsuperscript{152}

Their lordships referred to texts including Aristotle and Cicero,\textsuperscript{153} to justify in law killing one twin to allow the other to live. However, these texts did not supply the answer; instead, the judgment in \textit{Bland} was used, in which the House of Lords found the doctor’s withholding or withdrawing of treatment lawful in cases of certain death.

As considered earlier in this chapter, a person who omits to act is said to let the patient die of a pre-existing illness or injury, whereas a person who acts is deemed to have killed the patient. In \textit{Bland}, life-sustaining treatment in the form of artificial nutrition and hydration was withdrawn, and the doctor’s conduct was held to be an omission. The judgments by Lord Browne-Wilkinson and Lord Mustill highlighted that both

\textsuperscript{151} Ibid 1017.
\textsuperscript{152} Ibid 1016.
\textsuperscript{153} Ibid 1041.
judges doubted the morally and intellectually dubious distinction between acts and omissions. The decision in \textit{Bland} was significant as far as accepting as lawful conduct with an aim or objective resulting in death. In so doing, the House of Lords shifted the boundary between what is and what is not murder.

By contrast, the Court of Appeal in \textit{Re A (children) (conjoined twins: surgical separation)} cannot be accused of hiding behind the act or omission, killing or letting die dichotomy. The judges acknowledged that any procedure to separate the twins would be a positive act, leaving the judges in a quandary as to how the treating doctors would not be guilty of a charge of murder. Thus, in addition to the terms futility, quality of life, intolerability and best interests, the judges introduced legal terms applied in criminal and family law to justify killing Mary to keep Jodie alive.

Ward LJ preferred to base his decision on a balancing exercise between Mary’s right to life and the breach of duty to save Jodie’s life. Justice Walker sought to distinguish Mary’s death as a foreseen consequence as opposed to an intended killing. Further, the court resurrected the much-debated doctrine of necessity, to justify the separation in law.

Justice Brooke based the justification of the lawfulness of the separation on the doctrine of necessity, which has been inapplicable in previous murder cases, and is not available as a defence to homicide.\textsuperscript{154} A striking aspect of this judgment was his reference to a quote by Sir James Stephen, who acted as one of the commissioners on the \textit{Criminal Code Bill 1897}, stating:

\begin{quote}
\end{quote}
Compulsion by necessity is one of the curiosities of the law, and so far as I am aware is a subject on which the law of England is so vague that, if cases raising the question should ever occur the Judges would practically be able to lay down any rule which they considered expedient.\textsuperscript{155}

Primarily, the application of the common law defence of necessity relates to tortious or criminal charges, and in extreme situations. In particular where the necessity to kill another is the only way to save a life. In this instance, it was applied to the lawful separation of conjoined twins that would result in the death of one of them. The next section of this chapter considers recent judicial reasoning and case law from the UK.

X: Recent decisions—Scoreboard of benefits and burdens

The case of \textit{An NHS Trust v OT} \textsuperscript{156} went before the courts in 2009. \textit{Baby OT} had a rare metabolic disorder and suffered brain damage and respiratory problems. His parents went to the High Court to prevent doctors from stopping treatment. When this proved unsuccessful, the parents appealed against the decision of the doctors and the High Court that it was in \textit{OT}’s best interests for treatment to be stopped. However, Justice Ward and Justice Wilson did not overturn the decision. \textit{OT}’s parents noted:

\textsuperscript{155} \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 ALL ER 961, 1036. Some commentators suggest that the principle of necessity is a tenable consideration in end of life decision making. Magnusson supports the application of the defence of necessity and the principle of double jeopardy in \textit{Re A (children) (conjoined twins: surgical separation)} and in general palliative care. See especially, Roger S Magnusson, ‘The Devil’s Choice: Re-Thinking Law, Ethics, and Symptom Relief in Palliative Care’ (2006) 34 (4) Journal of Law, Medicine and Ethics 559-569. See also, Glenys Williams, \textit{Intention and Causation in Medical Non-Killing: The Impact of Criminal Law Concepts on Euthanasia and Assisted Suicide} (Routledge-Cavendish, 2006). However there are other factors that require consideration when applying the doctrine of necessity to end of life decision making for impaired neonates. Such factors include community consideration and the allocation limited financial resources and poor health prognosis. This is considered in greater detail in \textit{R v Cambridge Health Authority; ex p B} [1995] 1 WLR 898 – see chapter five.

\textsuperscript{156} \textit{An NHS Trust v OT} [2009] EWCA Civ 409 (14 May 2009).
That was the real argument between us and the doctors—they think his life is intolerable and that his disability is such that his life has little purpose; but we, along with some of the nurses, believed that he experiences pleasure and that he has long periods where he was relaxed and pain free.\textsuperscript{157}

The tensions that arise between medical teams and parents are discussed further in Chapter Four of this thesis. However, this case again illustrates the reliance placed on medical opinion by the courts.

Also in 2009, Justice McFarlane in the Royal Courts of Justice was required to consider the case of \textit{Re: Baby RB (A Child)}.\textsuperscript{158} Born on 10 October 2008, RB suffered from a rare genetic disorder, congenital myasthenic syndrome. Justice McFarlane described RB as:

\begin{quote}
\ldots profoundly disabled by a defect which prevents the effective transmission of messages from his brain and nerves to his muscles. It affects every aspect of his physical life. Apart from being able to make small movements of his lower arms and hands, he has little control over his limbs. His face is incapable of expression and his eyelids hang low and are not often open. A tube through which air passes to his lungs passes through one nostril and a feeding tube in the other nostril. His need for breathe \textsuperscript{[sic]} is now such that, unless the machine delivers air one every three seconds, his body will go into crisis and decline.\textsuperscript{159}
\end{quote}

By the age of 13 months, medical practitioners were of the opinion that ventilation should be stopped and that RB should be allowed to die. A doctor caring for Baby RB, referred to as Doctor F, stated that Baby RB was ‘living on a knife edge’.\textsuperscript{160}

\begin{itemize}
\item \textsuperscript{158} \textit{Re: Baby RB (A Child)} [2009] EWHC 3269 (Fam) (10 November 2009).
\item \textsuperscript{159} Ibid [2].
\item \textsuperscript{160} Elizabeth Day, ‘Baby RB: Heartbreak in Court 50 as Life of a One-year-old Hangs in the Balance’, \textit{The Guardian} (Online), 8 November 2009 <\texttt{http://www.guardian.co.uk/society/2009/nov/08/baby-rb-court-case}>.
\end{itemize}
The infant’s parents could not agree as to what was in the child’s best interests. RB’s mother agreed with medical opinion and supported the application to withdraw ventilation from RB. However, the baby’s father believed strongly that a surgical procedure should be performed to create space in his airway for him to breathe without ventilation and he should be allowed to be cared for at home. The views of Baby RB’s father were supported by Professor Kirkham, a neurologist at Southampton Hospital, who considered that ‘a cure’ for Baby RB’s medical condition could possibly be found in the ‘foreseeable future’, thus allowing him to operate a mechanical wheelchair in later years.161

At the beginning of the hearing, Baby RB’s father set out his extensive knowledge of his son’s condition and needs, and had recorded a video showing Baby RB playing with a rattle and banging a drum; activities that practitioners had stated RB would not be able to enjoy.162

Throughout the hearing, evidence was provided by leading experts regarding RB’s condition, future development and treatment options. Justice McFarlane was satisfied with the majority medical evidence provided, stating he had ‘total confidence’ that both parents and the medical team ‘had done all that they possibly could have to make RB’s life as viable, comfortable and enjoyable as it could be’.163 Arguably, the judge had already decided it was in RB’s best interests that ventilation be stopped.

161 Ibid.
162 Ibid.
163 Re: Baby RB (A Child) [2009] EWHC 3269 (Fam) (10 November 2009) [8].
Presumably, with some relief to the court, within a week of the hearing commencing, RB’s father returned having changed his mind, and agreed that ventilation should be discontinued in his son’s best interests.\textsuperscript{164} Justice McFarlane stated, ‘I suspect that the father and I have travelled a similar path down the evidential road and have now reached the same conclusion’.\textsuperscript{165}

Again, demonstrating the courts deference to medical opinion, with particular gratitude for Professor B’s opinion, and referring to Professor B as an ‘independent voice’ discussing the ‘burdens and benefits’ of RB’s life in the future,\textsuperscript{166} the court adopted a scoreboard approach, measuring RB’s life in terms of burdens, benefits, futility and worthwhileness.

Thus far, it has been illustrated that, in addition to the nebulous concept of best interests, the courts have, over time introduced other subjective and indefinable concepts to allow the lawful discontinuation of life-sustaining treatment. Terms such as worthwhileness, futility and burdens and benefits of treatment are subjective and each stakeholder may measure their importance differently.\textsuperscript{167}

\textsuperscript{165} Re: Baby RB (A Child) [2009] EWHC 3269 (Fam) (10 November 2009) [9].
\textsuperscript{166} Ibid.
\textsuperscript{167} By way of example, John Keown suggests that the central issue is not whether the patient’s life is ‘worthwhile’, but rather whether treatment would be ‘worthwhile’. See especially, John Keown, ‘Restoring Moral and Intellectual Shape to the Law after Bland’ (1997) 113(3) Law Quarterly Review 481, 481. Further, both Harris and Freeman separately state that the most important factor is a ‘worthwhile’ life, and the secondary factor must be whether ‘treatment is worthwhile’ to allow the patient to enjoy a particular quality of life. See especially, Michael Freeman, ‘Whose Life is it Anyway?’ (2001) 9 Medical Law Review 259 and John Harris, ‘Human Beings, Persons and Conjoined Twins: An Ethical Analysis of the Judgements in Re A ’ (2001) 9(3) Medical Law Review 221, 225.
The deficiencies of this approach are further illustrated in the 2004 case of *Portsmouth Hospital NHS Trust v Wyatt*,\(^{168}\) which made global headlines. The case concerned Charlotte Wyatt, and was the first to consider withdrawal or withholding of treatment from a minor in an open court, without the anonymity of the parties’ names.\(^{169}\) This approach was taken at the request of her parents, who believed that transparency in the decision-making process was important.

Although the transparency was welcomed from a societal and community point of view; from a legal viewpoint, the court’s decision to allow doctors to discontinue treatment lawfully was not revolutionary. Predictably, the courts placed considerable weight and reliance on medical opinion.

Charlotte was born prematurely and suffered considerable disabilities, including poor kidney function, difficulty breathing and brain damage. At the time the case went before the law, Charlotte was 11 months of age and her chances of survival for another 12 months were estimated at 5 per cent. The medical opinion of those caring for her was that, in the event of respiratory failure, it was not in her best interests to continue to survive on mechanical ventilation.

However, Charlotte’s parents strongly maintained that it was their duty to preserve her life and that it was not her time to die. Considering medical opinion and evidence that Charlotte experienced pain and possibly little or no pleasure, Justice Hedley concluded

---

\(^{168}\) *Portsmouth Hospital NHS Trust v Wyatt* [2004] EWCA 2247 (Fam) (7 October 2004).

\(^{169}\) In *Re C (a minor) (wardship: medical treatment)* [1989] 2 ALL ER 782, 783. In this case, Lord Donaldson MR addressed the issue of an injunction to protect the parents as well as local and health authorities from harassment because of the sensitive nature of the case.
that, in the event that Charlotte needed ‘invasive treatment’ that would be ‘intolerable’, the medical team could withhold the use of mechanical ventilation.

This declaration was made for a six-month period. However, after six months, Charlotte’s parents returned to the court, contending that she was no longer considered terminally ill and that the declaration should be removed. Justice Hedley did not remove the declaration and continued to rely on the medical opinion that Charlotte’s health had not improved. Justice Hedley boldly began his judgment in the High Court stating, ‘on the basis of the unanimous medical evidence in this case, the issue in all probability is not whether this baby should live or die but how and when she should die’.170

Similar to in *Re A (Conjoined Twins)*, in which Ward LJ began his judgment that ‘this court is a court of law, not of morals’,171 Justice Hedley began:

> What is the role of the court in all this? Any civilised society must have the means by which intractable disputes, whether between the state and the citizen or between citizens themselves are to be resolved. That is the purpose of the courts and the system of civil and family justice in this country. This kind of dispute is to be resolved by a Judge of the Family Division and whilst the judge will be more aware than anyone of his own limitations in deciding as profound an issue as this, decision there simply has to be. It may well be that an external decision is in the end a better solution than the stark alternatives of medical or parental veto.172

---

170 Portsmouth Hospital NHS Trust v Wyatt [2004] EWCA 2247 (Fam) (7 October 2004) [1].
172 Portsmouth Hospital NHS Trust v Wyatt [2004] EWCA 2247 (Fam) (7 October 2004) [4].
However, such profound statements about the authority and impartiality of the courts could be deemed redundant, given that judges habitually defer to medical opinion to reach their final decisions.

The judge considered the burdens and benefits of treatment, and concluded that three things would benefit Charlotte and presumably be in her best interests: comfort and little pain, as much time as possible in the presence of her parents, and that she meets her end surrounded by the love and affection of those around her.\textsuperscript{173} After ‘deriving considerable assistance’\textsuperscript{174} from the judgment of Lord Donaldson MR in the first \textit{Re J} case of the 1990s, Justice Hedley found:

\begin{quote}
Helpful though these passages are, it is in my view essential that the concept of ‘intolerable to that child’ should not be seen as a gloss on, much less a supplementary test to, best interests. It is a valuable guide in the search for best interests in this kind of case.\textsuperscript{175}
\end{quote}

Although Justice Hedley found passages from the judgment of \textit{Re J} to be of some benefit, it was not the most relevant authority on the matter of best interests. Instead, the judgment of Thorpe LJ in \textit{Re A (Male Sterilisation)}\textsuperscript{176} concerning an adult male patient lacking capacity, was preferred:

\begin{quote}
There can be no doubt in my mind that the evaluation of best interests is akin to a welfare appraisal. … Pending the enactment of a checklist or other statutory direction it seems to me that the first
\end{quote}

\begin{footnotes}
\item[173] Ibid [38].
\item[174] Ibid [24].
\item[175] Ibid.
\item[176] Re A (Male Sterilisation) [2000] 1 FLR 549.
\end{footnotes}
instance judge with the responsibility to make an evaluation of the best interests of a claimant lacking capacity should draw up a balance sheet. 177

Interestingly, the ‘balance sheet’ to weigh up the benefits and burdens of treatment considered by Thorpe LJ in Re A was endorsed and applied by the Court of Appeal in Wyatt. Justice Wall’s concluding comments on the best-interests test are particularly pertinent:

In our judgment, the intellectual milestones for the judge in a case such as the present are, therefore, simple, although the ultimate decision will frequently be extremely difficult. The judge must decide what is in the child's best interests. 178

The ‘intellectual milestones’ referred to by Justice Wall are by no means revolutionary. They are simply an amalgam of key statements made by judges in previous decisions to withdraw or withhold life-sustaining treatment. Milestones were considered at paragraph 87 of the judgment:

In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the patient (Re J). There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable (Re J). The term ‘best interests’ encompasses medical, emotional, and all other welfare issues (Re A). The court must conduct a balancing exercise in which all the relevant factors are weighed (Re J) and a helpful way of undertaking this exercise is to draw up a balance sheet (Re A). 179

---

177 Portsmouth Hospital NHS Trust v Wyatt [2004] EWCA 2247 (Fam) (7 October 2004) [26].
178 Ibid [87].
179 Ibid.
Justice Wall failed to provide any detail or elaboration of the ‘milestones’ in Wyatt. Arguably, this was a lost opportunity to clarify the vague nature of the best-interests test and end-of-life decision making for critically ill patients. By expanding on these milestones, the best-interests test could have been injected with further structure and precision.

The *Wyatt* case was followed by *Re L (Medical Treatment: Benefit)*,\(^1\) which concerned Baby Luke, who was born with Edwards Syndrome, a chromosome abnormality that has an average two-month life expectancy. Luke suffered serious cardiac problems and had experienced several cardiac arrests that required resuscitation. While the doctors caring for Luke believed it to be in his best interests not to resuscitate him in the event of another cardiac arrest, his mother disagreed and wanted treatment continued. Dame Butler-Sloss ruled in favour of the medical team, and Luke died soon after the case was concluded in the High Court. Dame Butler-Sloss followed previous authority, stating that the preservation of life is most favourable, ‘but not where treatment would be futile’\(^2\).

Based on the case law considered thus far, it is noted that, in the UK, decisions to withhold or withdraw treatment from seriously ill neonates and young infants are often based on the court’s deference to medical opinion.

As has been evinced, it is uncommon for a judge to rule against medical opinion. However, in the case of *An NHS Trust v MB*,\(^3\) Justice Holman held that the

---

discontinuation of medical treatment was not in the infant’s best interests. Born on 25 August 2004, Baby M appeared ‘normal’. However, at seven weeks, he was diagnosed with type 1 spinal muscular atrophy (the most severe) and had since remained hospitalised. At the time of the judgment, M was 18 months old. Justice Holman described M’s condition as:

…degenerative and progressive, i.e. it can only get worse. It may in some sufferers reach a plateau, but it cannot get better. It affects the voluntary muscles (but not the involuntary muscles such as those of the heart) which become progressively weaker and may ultimately cease to work at all.183

In addition, M suffered epilepsy, could not breath unassisted and was fed via a gastrostomy tube. The medical opinion of his treating doctors was:

…quality of life for M is now so low and that the burdens of living are now so great that it is unethical (the word ‘cruel’ has been used) to continue artificially to keep him alive, and that his endo-tracheal tube should be withdrawn. By the use of sedatives, he could have a peaceful, pain free and dignified death, but he would die almost immediately, probably within a few minutes.184

His parents disagreed and sought support from the courts. His mother asserted that he showed marked cognitive function:

M does indeed show pain or distress by frowns and by tears. She says that he similarly displays pleasure to her by his eyebrows going up slightly rather than going down, and she can see the merest movement upwards of the side of his lips as if he is trying to smile. She says that his eyes fix on her and will follow her until, because he cannot move his head, he cannot see her any more.

183 Ibid [5].
184 Ibid [10].
She says that when his brother and sister are there, which they very frequently are, he shows recognition of them and his eyebrows and corner of his mouth will move slightly upwards. If she touches his thumb it will move. She is convinced that he sees, hears and takes in certain TV and DVD programmes and music on CDs.185

Justice Holman considered the concepts of ‘quality of life’ and ‘burdens and benefits’ that have become regular legal discourse. After considering the medical evidence, Justice Holman decided that M should continue on ventilation, as he demonstrated cognitive function and was able to interact and bond with his family.

His Honour disagreed with the treating doctor’s opinion that Baby M’s quality of life was ‘so low that the burdens of living are now so great that it is unethical to keep him alive’.186 The judge applied a linear approach based on his cognitive abilities:

…M is not unconscious, still less in a permanent vegetative state. He is conscious. He is awake most or all of the day, and then sleeps at night. It is probable, and must certainly be assumed, that he continues to see and to hear and to feel touch; to have an awareness of his surroundings and in particular of the people who are most close to him, his family; and to have the normal thoughts and thought processes of a small child of 18 months … But people talk to him and stories are read to him; he is shown TV and DVDs and music is played to him on CDs; and it must be assumed that he processes all these sights and sounds in his mind like any other child of his age and gains pleasure from them.187

The decision in this case represented an important change in tenor to previous judgments. However, as illustrated in the case law examined thus far, Justice Hoffman

---

185 Ibid [43].
186 Ibid [10].
187 Ibid.
failed to critique or examine the effectiveness or efficiency of the best-interests principle, stating that ‘the law around this topic is now well established and tolerably clear.’ Justice Holman ambitiously created ‘ten propositions’, which he believed did not require the ‘need for copious reference to authority’. These ‘propositions’ were largely based on the ‘intellectual milestones’ in *Wyatt*, which, as noted above, were a montage of parts of previous judgments. This case provided the court with another opportunity to consider a normative basis upon which the best-interests principle could have been established but failed to do so.

Although stating that the law in relation to end-of-life decisions for critically ill neonate or young infants was ‘well established and tolerably clear’, Justice Holman proceeded to create and discuss additional propositions. The propositions laid down by Justice Holman were in no way novel, and merely re-stated legal principles and referred to other judgments.

Nevertheless, some of the propositions merit consideration: proposition four stated that withdrawal or withholding of life-sustaining treatment decisions ‘must be decided by the application of an objective approach or test’. However, this objectivity was contradicted by proposition five:

Best interests are used in the widest sense and include every kind of consideration capable of impacting on the decision. These include, non-exhaustively, medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations.

---

188 Ibid [16].
189 Ibid.
190 See proposition 6–8 at [16].
191 Ibid.
192 Ibid.
Proposition five is simply a re-phrased version of part of Justice Wall’s vague intellectual milestone of ‘medical, emotional, and all other welfare issues’ from the Wyatt case.

In conclusion, Justice Holman decided that although not immediately, in the event that Baby M required invasive treatment, the doctors did not have to provide resuscitation and that Baby M would, therefore, die naturally. It would appear that the judge in this case did not allow himself to become embroiled in medical opinion and academic debate regarding quality of life issues, as is evident in his closing paragraph:

Every day some parents somewhere, in consultation with doctors, have to make agonising decisions about the best interests of children with severe SMA or similar disorders. I hope that this judgment and decision will neither deter doctors from commencing ventilation when they consider it should be tried; nor lead any parent who has taken or may take, on the advice of doctors, the agonising decision not to start, or to discontinue, ventilation, to feel that their decision was mistaken.193

The final case to be examined in this section is that of NHS Trust v Baby X and others.194 Baby X was born a healthy child in 2011, but later suffered an accident at home that led to irreversible brain damage. The treating consultant described Baby X’s condition as being comatose, showing no interaction with his parents or carers. He did not recognise touch, voice or his surroundings. Both the treating physicians and other hospital staff concluded that artificial ventilation was no longer in Baby X’s best interests. Further, continuing treatment with no signs of improvement was futile.

193 Ibid [109].
194 NHS Trust v Baby X and others [2012] EWHC 2188 (Fam) (30 July 2012).
The case for withdrawal of treatment was heard before Justice Hedley. Both parents opposed the medical opinion with which they were presented. They believed that their son should be given every possible chance of improvement, and their faith prevented them from giving consent to withdraw treatment that would inevitably lead to Baby X’s death.

Justice Hedley’s judgment was brief at eight pages. In a forthright fashion, he stated, ‘the question in this case is whether a baby known as X should be removed from a ventilator and made the subject only of palliative care’.195

In the judgment, the ‘scoreboard’ approach of burdens and benefits was again highlighted. However, this was not considered worthy of any real discussion: ‘given the enormity and chronicity of the brain damage suffered in this case, the conventional list of burdens and benefits is not very extensive’.196

Justice Hedley suggested that caring and nurturing for their infant was in itself a burden upon Baby X’s parents, given that ‘they come from a faith tradition in which the obligations of parenthood are clear: they are to give lifelong care to X whatever in fact the burden upon them doing so may be’.197

Untypically, the minority medical opinion of Professor Vloeberghs was that greater weight should be given to the views and opinions of the parents.198 This was a

195 Ibid [1].
196 Ibid [20].
197 Ibid [16].
198 Ibid [21].
considerable change from previous cases considering that, as previously argued, most decisions concerning neonatal withdrawal of treatment are substantially guided and influenced by medical opinion. The role of medical practitioners and their relationship with parents and the judiciary in decision making will be considered in greater detail in Chapter Four of this thesis.

However, while Justice Hedley concluded that it would be lawful for the medical team to withdraw ventilation and provide palliative care for Baby X, as in previous judgments considered above, his honour also stated that ‘in those circumstances issues surrounding death must be faced now in a way that otherwise would be quite unwarranted’.199 This ensures the decision is not considered euthanasia, which the English courts fervently avoid.

In concluding this section, the trend of judicial decisions demonstrates that the courts place great weight on medical opinion, and justify decisions to allow the lawful withdrawal or withholding of life-sustaining treatment by applying nebulous terms such as intolerability, futility and a scoreboard of benefits and burdens. The courts decide that inevitable death equates with best interests, even in cases in which the neonate or young infant is not dying but is severely handicapped due to physical and/or mental trauma. This thesis argues that, where such decisions are made, there is a need for greater transparency and objectivity; decisions should not continue to be made under the guise of a sense of benevolence by applying the ill-defined best-interests principle. The case law that has been examined thus far has derived from the UK. Comparatively few cases have required legal or coronial intervention in Australia.

199 Ibid [26].
**XI: Australian case law concerning incapacitated neonates or young infants**

The Australian approach to the withdrawal or withholding of treatment from patients is similar to that of the UK and often follows decisions from English cases. However, in the first case to be considered, Justice Vincent in the Victorian Supreme Court affected a radical departure from the line of English legal thought in his dismissal of the concept of ‘quality of life’.

*Re F: F v F* 200 concerned a neonate suffering spina bifida. The father sought an application from the court, alleging that the neonate was being deprived of food for it to starve to death. An order was made that the neonate be fed until a thorough examination of the case could take place. Unlike in a majority of cases, no medical evidence was brought before the court, nor did the hospital attend the hearing. The issue before Justice Vincent was the application from the child’s father that the child was being denied ‘sustenance’. The judge simply ordered that the ‘hospital take reasonable and necessary steps to pursue good medical practice’.* 201

The order made by Justice Vincent in this case was vague and ambiguous in light of there being no medical evidence about the neonate’s prognosis and only the allegation that the neonate was being ‘starved’. His honour was extremely cautious not to make a decision that could have compounding consequences for any future cases. As such, Justice Vincent ‘sat on the fence’ somewhat in this case:

---

200 *Re F: F v F* (Unreported, Supreme Court of Victoria, Vincent J, 2 July 1986).
201 Ibid 20.
…no parent, no doctor, no court, has any power to determine that the life of any child, however
disabled that child may be, will be deliberately taken away from it … [the law] does not permit
decisions to be made concerning the quality of life, nor does it enable any assessment to be made
as to the value of any human being.  

Justice Vincent’s decision and judgment in this case is strikingly different from that of
his colleagues in the UK some five years earlier. For example, in *Re B*, Lord Templeman found:

…at the end of the day it devolves on this court in this particular instance to decide whether the
life of the 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.

Returning to Justice Vincent’s statement, it is questionable as to who has the ‘power’
to make such decisions, if not the law, parents or doctors. Ultimately, his honour
ordered the medical team to ‘take necessary and reasonable steps’ and to ‘pursue good
medical practice’, which could include ensuring that a patient does not suffer pain or
discomfort, by means of withdrawal or withholding of treatment.

Some years later, the case of *Baby M* in Victoria was considered in a coronial
inquest. In this example, the medical team worked in conjunction with the parents
of a severely ill neonate. Some of the facts of this case, and the situation in which the

---


203 *Re B (a minor) (wardship: medical treatment)* [1990] 3 All ER 927.

204 Ibid 929.

205 *Baby M* (Victorian State Coroner’s Office, Record of Investigation into Death, Case No 3149/89, 29 October 1991) VIC.
doctors and the parents of Baby M found themselves, mirror the 1981 English case of
*R v Arthur*. In the case of Baby M, recently identified as being named Allison,\(^{206}\) the
neonate was born on 14 July 1989 with serious abnormalities, including wasting of the
muscles, inability to walk, incontinence and no sexual function.\(^{207}\)

Allison’s parents were devout Catholics who sought regular advice from Roman
Catholic spiritual advisors. However, they agreed with the opinion of the medical team
that invasive treatment or surgery should not be administered. *Baby M* was given pain
relief and an open crib, dying some 12 days after the decision was made. *Baby M’s*
great aunt informed a right to life organisation of this matter, who then informed the
police. It was alleged that the doctors, in conjunction with *Baby M’s* parents, had
decided to allow her to die due to her quality of life being considered so poor that it
was not worthy of preservation.\(^{208}\)

The central issue considered by the doctors and the coroner in this case surrounded
*Baby M’s* quality of life. Where the pattern in English case law has insisted upon giving
the utmost regard and preference to medical opinion, it would seem that in this case,
the coroner, Wendy Wilmoth, took on the role of an impartial adjudicator. Albeit in
contradiction to Lord Donaldson’s judgment in the first *Re J* case and, it would seem,
outside the remit of her duties as coroner, she stated:

\(^{206}\) Kate Hagan, ‘Doctors Tread Ethical Minefield, 21 Years On’, *The Age* (Victoria), 14 August 2010, 4.
\(^{208}\) Ibid 235.
This gives recognition to the role of quality of life considerations, and recognises the lack of absolutes in life, whilst still upholding principle … that no parent or court can judge the quality of a person’s life to be so low as not to be deserving of continuance.209

The two treating doctors in this case, Drs Loughman and McDougall, discussed their decision to withdraw treatment publicly in a newspaper article in 2010.210 Dr McDougall reported having ‘wrestled with the decision for years’ and remained concerned about the ‘impact on Allison’s family’. However, he felt he had ‘closure at last’ after her parents sought a reunion with the doctors in 2008.211

At the time of the coronial report, the treating doctors were provided with considerable support and solace by virtue of the final coroner’s report that stated that the decisions made by the parties involved were ‘reasonable and appropriate’.212 The coroner found:

The decisions made by Baby M’s doctors and parents, and the careful steps taken to ensure these decisions were legally, ethically and morally sound, have been tested and found entirely reasonable and appropriate. The community’s interest is best served by … leaving the decision-making with doctors and their respective advisers, conscientiously determining the best course for their child.213

Until 2011, no other cases in Australia concerning withdrawal or withholding of treatment from critically infants have required legal or coronial intervention. However,

209 Ibid 242.
210 Hagan, above n 206, 4.
211 Ibid.
212 Skene, above n 26, 353.
213 Hagan, above n 206, 4.
this is not to say that such decisions have not been, and do not continue to be, considered daily in Australian hospitals.214

Although a significantly smaller number of cases have gone before Australian courts as compared to in the UK, there is healthy academic debate and an exceptional body of literature in the field of end-of-life decision making for incapacitated patients in Australia. This is supported by Faunce and Stewart, who correctly assert that ‘the discussion about what Australian courts would do has been largely confined to legal academia’.215 Willmott, White and Cooper also acknowledge that ‘traditionally, decisions in Australia to withhold or withdraw life-sustaining medical treatment have not been brought before the courts’.216

There have been a small number of cases since the millennium involving the withdrawal or withholding of treatment deemed futile concerning incapacitated adults.217 An examination of two seminal adult patient cases highlights the application of the best-interests principle in Australia.

In 2000, in Northridge v Central Sydney Area Health Authority,218 the New South Wales Supreme Court was required to consider whether life-sustaining treatment should be withdrawn or withheld from an adult patient. In this case, the patient had

---

214 A possible explanation for this may be the smaller population of individuals in Australia compared to in the UK.


216 Lindy Willmott, Ben White and Donna Cooper, ‘Interveners or Interferers: Intervention in Decisions to Withhold and Withdraw Life-Sustaining Medical Treatment’ (2005) 27(4) Sydney Law Review 597, 621. The authors note that there has been a ‘small but steady stream’ of cases involving incapacitated adult patients.


218 Northridge v Central Sydney Area Health Authority (2000) 50 NSWLR 549.
suffered brain damage as a result of a cardiac arrest after a heroin overdose. Less than a week after his hospital admission, the treating medical team were of the opinion that medication and artificial nutrition should be stopped and, in the event of another cardiac arrest, that the patient should not be resuscitated. However, the court held that the hospital had been ‘premature’ in their decision to withdraw life-sustaining treatment. This contrast to the English court’s reverence of medical opinion is illustrated in the judgment of Justice O’Keefe:

What constitutes appropriate medical treatment in a given case is a medical matter in the first instance. However, where there is doubt or serious dispute in this regard the court has the power to act to protect he life and welfare of the unconscious patient.

Some years later, in 2004, the case of *Messiha v South East Health* provided another opportunity for an informative Australian discussion on futile treatment issues. The New South Wales Supreme Court was required to decide whether treatment could lawfully be withdrawn from Mr Messiha, as his medical practitioners were of the opinion that it was no longer in his best interests.

Mr Messiha, aged 75, suffered a cardiac arrest at his home and was deprived of oxygen for some 25 minutes while waiting for the ambulance services to arrive. As a result, he fell into a deep coma, resulting in him becoming brain damaged and needing to be fed via a nasogastric tube and requiring mechanical ventilation. The medical opinion was that a ‘do not resuscitate’ order should be applied in the event of another cardiac

---

219 Ibid 569.
220 Ibid 554.
221 Messiha v South East Health [2004] NSWSC 1061.
arrest. However, his family rejected this opinion and ‘believed that the patient had spontaneously opened his eyes to voice and demanded that everything possible be done’.222

Unlike in Northridge, in this case, Justice Howie concluded that continuation of treatment for Mr Messiha, who was in a comatose state, would be burdensome on him. The judge held that where expert medical practitioners deemed further treatment to be futile, with very little prospect of improvement and a poor quality of life, it would be in the patient’s best interests to withdraw treatment.

Returning to treatment decisions concerning neonates and young infants in Australia, within a space of two years following a 20-year hiatus, two cases have reached the Australian courts. These recent cases may herald a change in the Australian legal landscape, with future cases potentially requiring judicial intervention or sanction. Although it is too early to predict what decisions and reasoning the Australian courts will make in future cases, an examination of the application of the best-interests principle in Australian cases involving neonates or young infants continues below.

In 2011, the Australian courts were required to consider the case of Baby D (No 2),223 a twin born at 27 weeks in Melbourne. Neither twin was born suffering physical or intellectual abnormalities. However, Baby D was the weaker of the two, with her sibling making a strong and full recovery and no longer requiring ventilation.

---

222 Faunce and Stewart, above n 215, 261.
223 Baby D (No 2) [2011] Fam CA 176. See also, Ian Kerridge, Michael Lowe and Cameron Stewart, Ethics and Law for Health Professions (Federation Press, 4th ed, 2013) 602.
Baby D continued to have breathing difficulties and, due to the insertion of breathing equipment, began to suffer with airway inflammation. Her treating doctors, with the use of steroids, removed the tubes, assisting her to breathe. However, her respiratory problems remained. Due to a lack of oxygen for a period of 35 minutes during an emergency resuscitation, Baby D suffered brain damage. Her brain stem, which controls basic function, was undamaged, and she could respond to touch and feel; however, she also felt pain and distress. Although the tube remained in place to ensure her airways were open, she breathed independently and did not require such intensive care. After five months in this state, both her doctors and her parents began to consider removal of the tube. However, they were uncertain as to the best course of action should Baby D suffer similar distress in the future.

With such uncertainty, the medical team referred to the hospital ethics committee to consider whether palliative care, in the form of pain relief and sedation, would be more appropriate if Baby D suffered respiratory distress in the future. The committee believed that the question required legal resolution, and as such directed Baby D’s parents to seek advice from the courts. Stewart highlighted that the key issue requiring consideration by the courts was whether the parents could consent to the removal of the tube and whether such removal and palliative care were in Baby D’s best interests.224

Under the Family Court’s jurisdiction, Justice Young considered this issue. He referred to the Australian case of Department of Health v J.W.B and S.M.B (Marion’s Case),225

224 Stewart, above n 164, 227, 228.
225 Department of Health v J.W.B and S.M.B (1992) 66 ALJR 300. In Marion’s case the High court were required to consider at length the scope of parental responsibilities and the rights of the child. Following the case at the High Court, in the case of Re...
which concerned the lawfulness of the non-therapeutic sterilisation of an intellectually
disabled girl. Here, the High Court considered the role of her parents in making such
decisions and concluded, ‘parental rights do not extend to permitting a substantial
operation that is unnecessary for the clinical treatment of an illness or condition’.226

Regarding Baby D, Justice Young determined that the decision to extubate fell within
the remit of parental responsibility and that her parents could lawfully consent to the
procedure. Unfortunately, Baby D had since died.

Seemingly, the Australian approach to end-of-life decision making for critically
impaired neonates and young infants remains as unclear as in the UK. This is evinced
in Justice Young’s judgment in the case of Baby D, which carried a similar sentiment
to that expressed by the UK courts concerning best interests:

The consensus amongst all of the very experienced and qualified medical practitioners … is that
any future life for Baby D must, with certainty, be seen to be one that is, at the least, very
burdensome and futile with no expectation of any enjoyment of life and without sight and any
meaningful brain capacity.227

---

226 Michael Williams, John Chesterman and Philip Grano, ‘Challenging Australia’s “Closed” Model of Neonatal Care: The Need

The final case examined in this section is the recent case of *TS & TD v Sydney Children’s Hospital (‘Mohammed’s case’)*. 228 Notwithstanding the case of *Baby D (No 2)*, *Mohammed’s case* was the first in which the Australian courts had to consider the withdrawal or withholding of life-sustaining treatment with a similar gravity to that with which the English courts have been tasked over the past three decades.

Mohammed’s parents sought a court order to compel the hospital to ‘mechanically ventilate Mohammed and not to leave him breathing either naturally, or else only with oxygen being delivered to him, as at present, by the non-invasive method of CPAP’. 229

Mohammed was born in March 2012 with mosaic trisomy 21, commonly known as Down syndrome. Shortly after birth, he was also diagnosed with a cardiac defect, medically known as Patent Ductus Arteriosus (PDA). At two and a half months of age, he was admitted to hospital and, ‘with the exception of two day visits home, and one overnight visit’, had not left the hospital since. 230 The prognosis for sufferers of PDA, which chiefly involves the collection of lactic acid in the body, includes:

…nausea, vomiting, severe breathing problems, and an abnormal heartbeat. The neurological problems which are a feature of PDD include delayed intellectual development and delayed development of motor skills, such as sitting and walking. Other neurological problems can include intellectual disability, seizures, weak muscle tone or hypotonia, poor coordination, and difficulty walking. 231

---

228 *TS & TD v Sydney Children’s Hospital (‘Mohammed’s case’) [2012] NSWSC 1609 [11].*
229 See further, Kerridge, Lowe and Stewart, above n 223, 602.
230 *TS & TD v Sydney Children’s Hospital (‘Mohammed’s case’) [2012] NSWSC 1609 [25].*
231 Ibid [28].
Mohammed suffered with profound developmental delay, seizures, blindness, deafness and cardiac failure, requiring continuous positive airway pressure. In addition, he was unable to move, as he had no control over his muscles, and did not respond to touch, other than pain.232 Doctors advised against further invasive treatment on the basis that the condition was incurable and mechanical ventilation was not in his best interests. 233

Justice Garling ruled in favour of the doctors that mechanical ventilation would cause pain and discomfort, would provide only temporary benefit and would not alleviate his condition. Rather, his best interests were to receive pain relief and palliative care.234 The judge was careful to consider Mohammed’s parents’ views that their son was ‘a fighter’.235 His honour went on to say, ‘I entirely accept the genuineness and sincerity of the submissions of Mohammed’s parents. I accept that it is their view that Mohammed’s best interests are that he be placed on a ventilator’.236

Due to the lack of cases for neonatal end-of-life treatment decisions in Australia, Justice Garling sought guidance from the English case of Re C (a minor) (wardship: medical treatment) and the first Re J case discussed earlier in this chapter.

Arguably, as the first Australian case of its kind, it provided a timely opportunity for the court to explore and critically analyse the effectiveness and arbitrary nature of the best-interests principle, seemingly driven by the sentiments of the medical team and

---

232 Ibid [33–34].
233 Ibid [76].
235 TS & TD v Sydney Children’s Hospital (‘Mohammed’s case’) [2012] NSWSC [73].
236 Ibid [74].
endorsed by the courts. However, Justice Garling took a conservative stance and followed the judicial reasoning of the English courts, stating:

Mohammed’s life is to be measured in the short term. He should not be subjected to pain and discomfort for the remainder of his life by being placed on mechanical ventilation from which he will not be weaned. It is for these reasons that I agree with the expert opinions of Mohammed’s doctors that it would be better for him to be treated by pain relief and palliative care than by the invasive procedure of mechanical ventilation. That is what is in his best interests. This conclusion is sufficient to warrant a rejection of the parents’ application.\footnote{237}

Justice Garling, followed the direction of the English courts and relying heavily on medical opinion, stated:

…it is not the role of the court to interfere in such a professional relationship and to compel action by an unwilling participant which would have the consequence of placing that individual in the position, in good conscience, of choosing between compliance with a court order and compliance with their professional obligations.\footnote{238}

Further, Justice Garling’s reluctance to make a decision contrary to medical advice was concerning. As he said, ‘regardless of my opinion, I would not have been prepared as a matter of discretion to order them to do something with which they did not agree’.\footnote{239} In concluding, Justice Garling stated:

\footnotesize\textsuperscript{237} Ibid [90–91]
\footnotesize\textsuperscript{238} Ibid [93].
\footnotesize\textsuperscript{239} Ibid [94].
…the court’s responsibility is to assess what is in Mohammed’s best interests and not to allow its judgment to be swayed by sympathy, and the attractive ease of requiring the medical practitioners to provide mechanical ventilation for Mohammed.240

Arguably, it was less confronting for the court to agree with medical opinion, and in doing so conform to English precedent, rather than enter into any robust and explorative debate concerning the nature and effectiveness of the best-interests principle. In doing so, the courts again implicitly endorsed that, in principle, best interests equates to certain death. This thesis contends that end-of-life decisions for extremely premature or very young infants afflicted by severe impairment should be discussed with greater transparency, rather than under the guise of best interests, and that the efficient allocation of finite resource should be a prime consideration in such cases.

XII: The effectiveness of the best-interests principle

This chapter has examined case law from the UK and Australia in which the central determinant for discontinuation of life-sustaining treatment has been the application of the best-interests principle. In addition to the indeterminate best-interests concept, the courts have introduced additional nebulous terms such as ‘futility’ and ‘a scoreboard of benefit or burdens of treatment’, without expressly stating that in such cases the best interests of the neonate or young infant nearly always equates to death.

In the case of incapacitated premature or critically ill neonates, who are unable to express their treatment choices, the courts are asked to act and apply the best-interests

240 Ibid [96].
principle—that the courts ‘prime and paramount consideration must be the best interests of the child’.

What is truly in the best interests of the neonate? Any answer to this question would be too speculative. Courts seemingly use the term ‘best interests’ to cloak decisions that will result in death for the patient. Arguably, the courts apply best interests to convey a sense of benevolence and to transform into an honourable act what is essentially state-sanctioned taking of a life.

This chapter has highlighted that the best-interests test is not sufficiently definable and is ineffective as the central determinant for decisions to withdraw or withhold life-sustaining treatment from neonates or young infants. The only clarity that applies in this area is not doctrinal; rather, it is in the outcome of cases. With an inconsequential number of exceptions, the outcome of the best-interests tests is that judges make decisions consistent with the weight of medical advice, with this advice being consistent with that choice that will end life most rapidly of the available options.

There are no clear answers to the circumstances in which neonates should be permitted to die. Analysis of the case law has demonstrated that many important, often competing, interests are at stake, with no clear reference point against which these should be evaluated. This has resulted in the current situation in which determinations are clouded in obscure and vague principles.

Judges appear to pay lip service to doctrines such as sanctity of life and parental opinion. The emphasis and importance placed on medical advice and opinion allows judges to abdicate themselves of any real responsibility for making life and death
decisions by simply legitimising medical practitioner’s conduct. The legal judgments considered in this chapter highlight the court’s reluctance to enter into informed and robust discussion about the withdrawal or withholding of life-sustaining treatment from critically ill neonates or young infants.

XIII: Conclusion

This chapter has highlighted the first of several current subjective and speculative practices that are currently central features in decision making for critically premature and critically impaired neonates.

The reason that discussion in this area is often so emotive and controversial is that it relates to paramount human interests, and the consequences of the decisions are both considerable and absolute. The role of moral or legal luck or happenstance in relation to outcomes that define the destiny of human beings and the values that underpin a society must be limited.241 The unpredictable nature of human experience must accommodate for some degree of flexibility. However, even allowing for this, the best-interests principle is an uncharacteristically vague legal standard, so much so that it has been described by one commentator as ‘vacuous’.242

This situation is unsatisfactory for a number of reasons that extend beyond the well-known rule of legal virtues that require the law to be knowable and clear.243 This thesis

241 For further examination of the concept of moral luck, see, Thomas Nagel, Mortal Questions (Cambridge University Press, 1979).
contends that matters of significant importance, of which life and death is of the highest importance, should be governed with a greater degree of objectivity, transparency and tangibility. If the best-interests test is to be preserved, it should be informed by clearer criteria. A wholesale re-evaluation is required. The criteria, if they are to be established, need to be developed and debated by a body with a popular mandate to do so; that is, Parliament.

The next chapter of this thesis examines the second subjective and speculative factor currently being considered in end-of-life decisions for premature and critically impaired neonates—the role, effectiveness and utilisation of clinical guidelines available to medical practitioners in the hospital setting.244

244 See, James Tibballs ‘The Legal Basis for Ethical Withholding and Withdrawing of Life Sustaining Medical Treatment in Children’ (2006) 14(2) Journal of Law and Medicine 244, 244.
CHAPTER THREE: DO CLINICAL GUIDELINES PROVIDE CONSISTENCY AND UNIFORMITY TO DECISIONS TO END-OF-LIFE DECISION MAKING?

I: Summary

Chapter Two examined the best-interests principle as applied by the English and Australian courts in deciding whether treatment should lawfully be withheld or withdrawn from critically ill neonates or young infants. An analysis of the relevant case law and judicial reasoning over the past three decades was presented, highlighting the imprecision of the best-interests principle and its inherent subjectivity when applied to end-of-life decision making.

Chapter Two highlighted that the courts place excessive weight on medical opinion, often against parents’ wishes. In addition, courts were found to have developed and adopted additional terms to the principle of best interests to allow the lawful withdrawal or withholding of treatment resulting in death. In light of this, the chapter concluded that the current best-interests test is too nebulous and idiosyncratic to constitute a coherent assessment, and that there is thus a need for a fundamental framework based on objective grounds to assess whether to withdraw or withhold life-sustaining treatment.
II: Introduction

This chapter examines some of the key clinical guidelines and frameworks drafted by a range of bodies that have been used to assist practitioners to make end-of-life decisions. The effectiveness and consistency of clinical guidelines as applied in the hospital setting are also considered. This chapter begins by discussing the earliest possible gestational age at which an extremely premature neonate born alive is likely to be resuscitated and provided with life-sustaining treatment. It is important to briefly discuss gestational age, as it is of particular importance and relevance in the application of clinical guidelines.

III: The threshold of viability

Generally, end-of-life treatment decisions are made within the parameters of the hospital setting by doctors in collaboration with parents. As discussed in the previous chapter, cases that require legal intervention in the UK and particularly in Australia are infrequent.¹

It has previously been noted in this thesis that premature birth is not a new phenomenon. Moreover, although technological advancement in medical science has allowed pre-term neonates to survival outside the womb, many of those that do survive do so with severe abnormality or disability.²

¹ Particularly in Australia. See especially, Baby D (No 2) [2011] Fam CA 176 and TS & TD v Sydney Children’s Hospital (‘Mohammed’s case’) [2012] NSWSC 1609. Associate Professor of Neonatal Medicine, Dr Dominic Wilkinson has discussed a threshold framework concerning the withdrawal or withholding of life sustaining treatment. See especially Dominic Wilkinson, Death or Disability? The ‘Carmentis Machine’ and decision making for critically ill children (Oxford University Press, 2013).

² This is discussed in greater detail in Chapters Four and Five of this thesis.
Advancements in healthcare have been unable to decrease the number of pre-term births, and there has even been an increase in premature births in the UK and Australia in the past two decades.\(^3\) Contributing factors to premature births in the UK include high rates of teenage pregnancy (the highest in Europe)\(^4\) and the decision by women to delay pregnancy until later in life. Another significant contributor is in-vitro fertility treatment (IVF), which can often result in multiple pregnancies and pre-term births as a consequence of the implantation of several embryos simultaneously.\(^5\)

The definition of pre-term birth in its crudest form refers to neonates born before a pregnancy has come to full term, between 37–42 weeks. However, the variation in development and likelihood of survival outside the womb differs drastically for those born between 22 weeks and 26 weeks onwards. At these earlier stages, the uncertainty of the chance of any life, or a life with severe disability, is considerably ambiguous for medical practitioners.

In its 2006 report, The Nuffield Council on Bioethics (NCOB) discussed the survival rates and possible treatment outcomes of babies born at varying gestational ages.\(^6\) In


\(^4\) Although the UK has tended to have the highest teenage pregnancy rates in Western Europe, in 2011, the lowest number of teenage pregnancies (under the age of 18) were recorded since 1969. See especially, Office for National Statistics, Teenage Pregnancies at Lowest Levels Since Records Began (2 April 2013) <http://www.ons.gov.uk/ons/rel/vsob1/conception-statistics-england-and-wales/2011/sty-conception-estimates-2011.html>.


particular, the report considered the likely outcomes of babies born at the ‘borderline of viability’—up to and including 25 weeks + 6 days’ gestation.\textsuperscript{7} Babies born at this stage in England account for ‘0.3 per cent of all deliveries, both born alive and stillborn, their survival rate is much less than 50 per cent’.\textsuperscript{8}

The Nuffield report, which is discussed later in this chapter, found that babies born in the UK at up to 22 weeks + 6 days’ gestation are highly unlikely to survive, or even to leave the intensive care unit; thus, resuscitation is usually rejected.\textsuperscript{9} The chances of survival marginally increase when a baby remains in the womb until at least 23 weeks + 6 days. Often, only at this period do doctors begin to consider the possibility of providing life-sustaining treatment to extremely premature neonates. The Nuffield report asserted that ‘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’.\textsuperscript{10}

From 24–26 weeks’ gestation the chances of survival, albeit with some disability, improve. Neonates born during this period are admitted, treated and given medical support following normal neonatal practice in the UK. Neonates born at 23 weeks pose the greatest medical and ethical challenge for doctors, and this situation is emotionally confronting for parents.

The next section of this chapter examines the core clinical guidelines and frameworks that have been published to assist and reassure doctors that the legally and ethically

\textsuperscript{7} Ibid 33 [3.8].  
\textsuperscript{8} Ibid 33[3.8].  
\textsuperscript{9} Ibid 156 [9.16].  
\textsuperscript{10} Ibid 75 [5.16].
charged decisions they make concerning neonates are supported by the medical profession and the law.

**IV: Clinical guidelines: United Kingdom**

In recent years, several sets of clinical guidelines on end-of-life treatment and care have been published in the UK. It is arguable that this high rate of activity in the production and publication of guidelines is positive and encouraging in ensuring that end-of-life decisions are considered in the most appropriate manner. However, on closer analysis, these guidelines are simply a discretionary tool available to medical practitioners to assist them with decisions to begin, withdraw or withholding life-sustaining treatment from critically ill or extremely premature neonates.

The proliferation of guidelines and frameworks is perhaps a symptom of the variance of thought and treatment approaches in the area of neonatal care. This is reflected in the differing measures applied to pregnancy itself. The Confidential Enquiry into Maternal and Child Health (CEMACH), published in 2009 in the UK, studied perinatal periods internationally. In Australia and New Zealand, the perinatal period begins at 20 weeks’ gestation; in Canada, it begins at 22 weeks; and in the UK, data is collected on fetal losses from 20 weeks’ gestation.\(^\text{11}\)

This thesis contends that end-of-life decisions for premature neonates, particularly those born extremely premature, at the edge of viability, should be driven by an objective, transparent and tangible criteria. Seemingly, the greater the number of

---

clinical guidelines, frameworks and policies published in the UK and Australia, the less clarity, impact and authority any of them will possess.

V: Royal College of Paediatrics and Child Health: Withholding or withdrawing life-sustaining treatment in children: A framework for practice

Following a first edition in 1997, in May 2004, the Royal College of Paediatrics and Child Health (RCPCH) published the second edition of their framework in the UK. The preface of the document notes that the title had been changed from ‘life saving treatment to life sustaining treatment to reflect the fact that treatment this is often given is not curative but supportive’.12 This statement perhaps indicates the value placed by the authors on the philosophical tenets that ‘all life is sacred’ and that ‘life must be preserved at all cost’.13

Warrick et al provide a concise summary of the dilemmas faced by doctors when a baby is born with severe congenital abnormality or at less than 25 weeks:

1. To institute life saving measures at the extremes of viability, commencing a prolonged course of intensive care, with the knowledge that most survivors incur severe and/or moderate disability.
2. To provide intensive management for a serious antenatally diagnosed condition, thereby delaying death.
3. To withhold life saving measures from the outset and offer palliative care.

13 As considered in Chapters One and Two of this thesis.
4. To initiate treatment and withdraw later.14

The RCPCH framework states five situations in which it is both legal and ethical to consider termination of life-sustaining treatment:15

1. Brain Dead Child—it is agreed within the profession that treatment in such circumstances is futile and the withdrawal of current medical treatment is appropriate.

2. Permanent Vegetative State—following trauma or hypoxia, is reliant on others for all care and does not react or relate with the outside world. It may be appropriate to withdraw or withhold life sustaining treatment.

3. No Chance—child has severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering: treatment to sustain life is inappropriate.

4. No Purpose—child 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.

5. Unbearable—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 may be of some benefit.

Generally, the first two categories raise little ambiguity.16 However, the final three ‘situations’ documented above are open-ended and as such can be interpreted subjectively and with a significant amount of discretion, as they do not conform to a bright line rule.17 This view is supported by Morris, who noted the overlap between the categories in determining the prognosis of an incapacitated neonate: ‘the blurring

15 Royal College of Paediatrics, above n 12, 10–11.
16 Although the Nuffield Report (2006) does raise the issue of the difficulty of diagnosing brain stem death in neonates.
of “no purpose” and “no chance” raises important questions about the notion of “futility” as it is used in a medical—and also in a judicial—context.  

Tibballs further reinforces this point, asserting the categorisation is ‘somewhat misguided and confused’:

Although both the ‘no purpose’ situation and ‘the unbearable’ situation may be the basis for withholding or withdrawal of treatment, the ‘no purpose’ situation is also described, confusingly, in terms of the child being unreasonably expected to ‘bear the situation.’

Examined in its entirety, the RCPCH framework echoes the voice of the law, and although it is a clinical guideline, the document assumes much of the same language as would a legal judgment. A considerable section of the framework focuses on legal and ethical considerations, including a brief discussion on the unlawfulness of euthanasia.

The burdens and benefits scoreboard discussed in Chapter Two in relation to legal judgments is also evident in the framework: ‘there is substantial evidence that it is common and accepted practice to withdraw life-sustaining care where parents and medical staff believe that the distress incurred by such care outweighs the benefits’.

---


20 Royal College of Paediatrics, above n 12, 15–21.

21 Ibid 13.
The framework also sounds a cautionary tone as to the role and involvement of the courts in treatment disputes between parents and doctors:

If a doctor wishes to continue treatment of a very ill child, but there is room for reasonable doubt about the benefit, the doctor may be in a difficult position if he continues when the parents have withheld or withdrawn consent. A court might say that the doctor did not act in the best child’s interests.22

The RCPCH framework includes some legislation; for example, the Children Act 1989 and the United Nations Convention on the Rights of the Child 1989 (which cannot be applied by the UK courts), and then summarises the key findings of relevant judgments:

1. There is no obligation to give treatment which is futile and burdensome
2. Treatment goals may be changed in the case of children who are dying
3. Feeding and other medical treatment may be withdrawn from patients who are thought to be in a state of PVS
4. Treatment may be withdrawn from patients where continued treatment is not in their best interests.23

This thesis recognises that guidelines must be broad in nature to ensure some discretion for individual circumstances. However, as will be highlighted through this chapter, the guidelines are often vague or incoherent that they allow for arbitrary decision making. Doyal and Larcher support this view, stating ‘such documents can be criticised as

---

22 Ibid 19.
23 Ibid 16–17.
being too general to be useful, stigmatising to some individuals or groups, and striking the wrong balance between law and morality’. 24

The difficulty of non-prescriptive frameworks is illustrated in the RCPCH’s discussion on intolerability. Considered at length in the case of Re J (a minor) (wardship: medical treatment), 25 the concept was merely touched on in the framework in the statement that ‘a severe/intolerable disability is undefinable’. 26 The framework suggests:

1. Intolerable may mean ‘that which cannot be borne’ or ‘that which people should not be asked to bear’.
2. An individual may believe that he/she is an intolerable burden.
3. An impossibly poor existence may not be recognised by the individual, depending on that person’s cognition’. 27

Arguably, the RCPCH framework would have been better served by refraining from defining what had previously been declared undefinable. The first suggestion merely provides a textbook definition of the term intolerable. The second and third suggestions are also unhelpful, as most children, and particularly neonates, cannot express their wishes, desires or self-awareness.

24 L Doyal and V F Larcher ‘Drafting Guidelines for the Withholding or Withdrawing of Life Sustaining Treatment in Critically Ill Children and Neonates’ (2000) 83(1) Archives of Disease in Childhood: Fetal and Neonatal 60, 60.
25 Re J (a minor) (wardship: medical treatment) [1990] 3 All ER 930. See Chapter Two for case details.
26 Royal College of Paediatrics, above n 12, 25.
27 Ibid.
The RCPCH framework and other guidelines are aimed at providing doctors with reassurance that the decisions they make are both lawful and ‘Bolam-ised’; that is, ‘in accordance with a responsible body of medical opinion’.28

The framework is likely to prove reassuring to junior doctors confronting ethically and potentially legally charged decisions. This is reflected in the RCPCH framework, which holds that juniors should ‘administer life sustaining treatment until senior, more experienced doctors take over’.29 McHaffie and Fowlie make the interesting statement that medical practitioners may find comfort and solace in end-of-life decision making by receiving ‘reassurance and peace of mind from other competent consultants with expert knowledge of neonatology similarly concluding that treatment should be withdrawn’.30

The RCPCH framework is only one of many guidelines that have been created and published in the UK. An examination of another set of guidelines follows. As will be evinced below, there is a considerable amount of overlap between the clinical guidelines. That there is a need for several documents to assist medical practitioners in end-of-life decision making is questionable.

VI: British Medical Association: Withholding and withdrawing life-prolonging medical treatment: Guidance for decision making

28 Bolam v Friern Hospital Management Committee [1957] 1 WLR 582. The Bolam test is discussed in Chapter Two of this thesis.
29 Royal College of Paediatrics, above n 12, 1.
30 Hazel E McHaffie and Peter W Fowlie ‘Withdrawing and Withholding Treatment: Comments on New Guidelines’ (1998) 79(1) Archives of Disease in Childhood: Fetal and Neonatal 1, 2.
The BMA amended and published its third edition of its guidelines in 2007, three years after the RCPCH framework. The BMA handbook provides guidance for the withdrawal or withholding or life-prolonging treatment. It states its main focus as ‘decisions to withdraw or withhold life-prolonging treatment from patients who are likely to live for weeks, months or possibly years, if treatment is provided but who, without treatment, will or may die earlier’. The BMA guidance is not exclusive to neonates and focuses on:

…the process through which decisions are made to withdraw or withhold life-prolonging treatment from all types of patients—adults with capacity, adults lacking capacity, young people with capacity and children and young people who lack capacity.

Although the remit of these guidelines is wide, unlike the RCPCH framework, the BMA guidance considers the ‘legal and ethical considerations’ of decision making in some depth, citing case law and legal judgments.

Unsurprisingly, the BMA guidance merely reflects the law with regard to the withholding or withdrawing of medical treatment, making reference to Bland in stating that ‘although psychologically it may be easier to withhold treatment than to withdraw that which has been started, there are no necessary legal or morally relevant differences between the two actions’.

32 Ibid 2.
33 Ibid 19.
Part eight of the guidance considers decision making for children and young people who lack capacity, with an emphasis on the role of parents in the decision-making process. The guidance again echoes the law, in that although treatment decisions must be discussed with parents, parents’ requests for certain treatments do not have to be satisfied.\(^{34}\) The section then proceeds with a discussion of the situations in which there is a conflict regarding the acceptance or refusal of treatment and care that is deemed to be in the child’s best interests.\(^{35}\)

Compared to the RCPCH framework, the BMA guidance is set on more of a legal footing. The familiar concepts of best interests, futility and the burdens and benefits scoreboard introduced in Chapter Two are present in the BMA guidance. The High Court judgment in *Wyatt* is also discussed as a ‘reminder of the difficulty of accurately assessing prognosis in seriously ill young children and the importance of keeping treatment decisions constantly under review’.\(^{36}\) Additionally, it raises the relationship between intolerability and best interests and the balance sheet approach that the courts are increasingly applying in decisions to withdraw or withhold treatment.

The BMA guidance highlighted that, ‘in reaching a judgement about best interests, the courts are increasingly using the “balance sheet” approach and this can be a useful exercise for health professionals to consider in the event of disagreement’.\(^{37}\) This statement suggests that the BMA were considering more than just clinical guidance when authoring their document. Rather, they appear to have been intending to provide

---

\(^{34}\) Ibid 97 [47.5].

\(^{35}\) Ibid 98 [47.6].

\(^{36}\) Ibid 103 [48.1].

\(^{37}\) Ibid 34 [22.2].
doctors with an advance understanding of factors considered by judges when parental–
doctor treatment conflicts end up at the doors of the court.

In taking such pains to ensure that doctors are legally aware, the BMA are simply
reflecting current legal approaches to decision making in life or death matters, where
the courts have actively promoted the legal and ethical transfer of responsibility to the
medical fraternity. The BMA guidance fails to provide any significant contribution to
the area of end-of-life decision making, and seemingly provides a ‘reference point’ for
medical practitioners as to the currency of the law in decisions to withdraw or withhold

The lack of clarity, consistency and the potential for subjective, discretionary decision
making is further illustrated by the narrow guidelines produced by the General Medical
Council (GMG).

VII: General Medical Council: Treatment and care towards the end-of-life: Good
practice in decision making

The GMG guidelines came into effect on 1 July 2010 in the UK. They are very basic,
such that end-of-care decisions concerning neonates and young children are discussed
in only two pages.

The guidelines adopt more regimented language and read more like a set of ‘rules for
doctors’ as opposed to the legal stance of the BMA guidelines. In this set of guidelines,
the issue of ‘quality of life’ is not discussed in any great detail and any discussion of
the ethical or moral quandaries in determining quality of life are avoided. They state,
‘you must be careful not to make judgements based on poorly informed or unfounded assumptions about the impact of a disability on a child or young person’s quality of life’.38

However, the guidelines do define best interests and use the same concepts as the courts: ‘decisions about treatment for children and young people must always be in their best interests. This means weighing the benefits, burdens and risks of treatment for the individual child’.39 Further, medical practitioners are advised that if:

…you conclude that, although providing treatment would be likely to prolong life, it would cause pain, suffering and other burdens that would outweigh any benefits and you reach a consensus with the child’s parents and healthcare team that it would be in the child best interests to withdraw, or not start treatment, you may do so.40

The GMC guidelines fail to provide anything new or robust, and they lack substance.

Due to the vague nature of clinical guidelines, there is room for considerable subjectivity. Although the guidelines examined thus far do not expressly consider the allocation of limited health resources as an important criterion, there is nothing that prevents doctors basing their decisions to discontinue treatment on available healthcare funds. This thesis contends that allocation of finite healthcare funds should be an objective factor in decisions to withdraw or withhold treatment from extremely premature, critically impaired neonates. As such, this should be documented in one

38 General Medical Council, *Treatment and Care Towards the End of Life: Good Practice in Decision Making* (General Medical Council, 2010) 47 [96].
39 Ibid 45 [92].
40 Ibid 50 [106].
‘universal’ set of uniform clinical guidelines that are utilised by all hospitals in the UK.

Before considering the final set of guidelines from the UK, it is appropriate to critique the EPICure studies.

**VIII: EPICure Studies**

Two ‘population based studies of survival and later health status in extremely premature infants’, known as the EPICure studies, have been conducted in the UK. On its website, the team of three neonatal paediatricians describe the aims and scope of their work as, ‘the whole point of EPICure … [is that] it allows us to quantify the outcomes and shows us where we need to target our care’.  

(A) EPICure Study 1: 1995

The initial study, known as EPICure 1 was conducted between March and December 1995. Data were collected from all 276 maternity units in the UK and the Republic of Northern Ireland. The study was exclusively concerned with the births of babies born between 20–25 weeks + 6 days’ gestation, recorded by the respective hospitals. A full record was generated for those that required neonatal admission after birth.

---

42 Ibid.
43 Kamini Yadav and David Field, ‘The Limit of Viability: Should We Lower It?’ (2011) 100(3) *Neonatology* 295.
The study recorded 4004 births up to 25 weeks + 6 days’ gestation. Of those, 811 were admitted to intensive care and 314 survived, to be later discharged to go home. The study identified that ‘survival ranged from 2 babies (9% of admissions) at 22 weeks, 26 babies (20%) at 23 weeks, 100 babies (34%) at 24 weeks, to 186 babies (52%) at 25 weeks’.44

The results indicate that survival of infants born earlier than 24 weeks was rare. Although important, the EPICure team were unable to provide information about end-of-life decisions to ‘provide active care or whether a decision had been made that the risks were too high and the doctors and midwives would simply make the baby comfortable after birth and not intervene’.45 Such information was unlikely to be provided given the very real risk of criminal proceedings against doctors.46 The 1995 study was an ambitious ongoing project, monitoring and recording the health status of those born and those that survived. Local paediatricians reported at one year of age:

…there were continuing medical problems for a proportion of the children at one year of age, 95 (31%) of the children had significant problems in areas such as development, neurology and need for oxygen. 40 children had two or more of these disabilities.47

The follow-up questionnaire was conducted by local paediatricians at two and a half years of age. Of the 314 survivors at birth, six had died after hospital discharge, and several others had moved overseas. Further studies were conducted to assess the progress and development of those born in 1995 when they reached the age of 5.5–7,

45 EPICure, Survival <http://www.epicure.ac.uk/overview/survival/>.
46 R v Arthur (1981) 12 BMLR 1, see Chapter Two for case details.
47 EPICure, EPICure at One Year <http://www.epicure.ac.uk/epicure-1995/epicure-at-one-year/>.
and again at age 11. However, many families and children were untraceable and many more had moved overseas.

The EPICure study was highly publicised as the largest study examining neonates born at less than 26 weeks’ gestation. Its findings were reported in several English newspapers and medical journals, and exclusive access to interviews with the researchers was given to the BBC.48

(B) EPICure Study 2: 2006

The findings of the 1995 EPICure study supported the contention that advancements in medical science and technology have improved standards in neonatal care, resulting in neonates surviving longer. In 2006, a similar study was conducted to determine whether, 10 years on, pre-term neonates were surviving for longer, and whether there had been any improvements in the risk of those born premature, consequently suffering severe disability. The second EPICure study aimed to:

…it tell us how effective advances in Neonatal care have been. It will also tell us more about the lung development of very tiny babies. The professional approach of different baby units will also be considered. This will build on the knowledge gained through the hard work of the EPICure families and study group in the original study.49

49 EPICure, EPICure 2 <http://www.epicure.ac.uk/epicure-2/>.
Data were collected on births throughout England of neonates born between 22 and 26 weeks + 6 days. The second study also considered mothers and their pregnancies, rather than exclusively monitoring the development of neonates born alive and being discharged. In addition, microscopic evidence of cord attached to the placenta in the womb was examined, to look for inflammation and infection prior to birth.\textsuperscript{50} The extension of the study to include pre-natal health of the neonate and mother is supported by this thesis. As will be considered in greater detail in Chapter Five, preventative measures against premature birth, by focusing on the health and wellbeing of mothers, is crucial in reducing extremely premature birth.

The aims and continued focus of the research team are commendable. The task of a co-ordinated national effort in data collection and clinical observation in collaboration with maternity and intensive care units represented a significantly challenging task. This comprehensive view was represented in the results, which reflected the reality of pre-term births—while the survival rate of those born between 22 and 26 + 6 days had improved by 13 per cent (up from 40 per cent in 1995); of the 152 babies born at 22 weeks, only three survived.

The findings, published recently in the British Medical Journal, are invaluable and provide a stark lesson in the limits of medical science, which, while advancing rapidly, often cannot totally defy nature.\textsuperscript{51} As the vice president of the RCPCH, Dr Simon

\textsuperscript{50} Ibid.

Newell, poignantly said, ‘we can only protect so much from the effects of immaturity’.52

This thesis contends that there is a need for greater transparency in end-of-life decision making for neonates. Although the results of the EPIcure studies highlight a pessimistic outlook for those born at the edge of viability, the publication of and intense media attention surrounding the findings is a positive step towards public awareness of the realities that extremely premature neonates and their families face.53

The impact on those surviving with severe disability, for example, is profound, affecting the individual, their families and society through the continued financial demands involved in satisfying the day-to-day requirements of such individuals.54

Professor Marlow asserts that, ‘as the number of children that survive pre-term birth continues to rise, so will the number who experience disability throughout their lives’.55 Professor Marlow also highlights that ‘intensive care for small babies is expensive, and providing care for children with disabilities as they grow up is also expensive, impacting the demand for health, education and social care services.56


53 This is discussed in greater detail in Chapter Four of this thesis.

54 The allocation of finite health resources is examined in Chapter Five of this thesis.

55 Dennis Campbell, ‘Premature Babies Study Shows Survival Rates on Rise’ The Guardian (Online), 5 December 2012 <http://m.guardian.co.uk/society/2012/dec/05/survival-rates-premature-babies-rise>. The cost associated with the upbringing of severely disabled neonates and infants is discussed in detail in Chapter Five of this thesis.

While the allocation of finite health resources is an uncomfortable topic in regard to making life and death decisions, serious discussion in this area is important. It is necessary to break the taboo on putting a ‘price’ on life, to have a pragmatic and honest debate about these decisions.

This thesis argues that end-of-life decisions concerning critically ill neonates should be made in the most efficient manner, by encouraging public discussion and awareness of the rising cost involved in treating those with severe disability due to prematurity.

A final examination of the clinical guidelines utilised in the UK is provided below.

**IX: British Association of Perinatal Medicine: The management of babies born extremely pre-term at less than 26 weeks’ gestation—A framework for clinical practice at the time of birth**

Published in 2008 with the stipulation that it was not ‘a set of instructions, but a framework to highlight the range of evidence and opinion that needs to be considered by staff and parents’, the British Association of Perinatal Medicine (BAPM) began on an encouraging note.

Relying heavily on the statistics following the EPICure studies, the BAPM framework provided the following recommendations to assist doctors on end-of-life decision making for critically ill neonates:

---

1. Babies born with certain gestational age of less than 23 weeks—in the best interests of the baby and standard practice, resuscitation not to be carried out: based on the 1995 EPICure study only two survived, one suffering severe disability. The 2006 study revealed a high occurrence of major morbidity.

2. Babies born with certain gestational age of 23–23 + 6 days—where a fetal heart is heard and a professional experienced in resuscitation should be available. However express parental express wishes not to resuscitate should be honoured: based on the 1995 EPICure study 80% of those born at this gestational age died in hospital. The 2006 study revealed the survival rate had not significantly improved.

3. Babies born with certain gestational age of 24–24 + 6 days—resuscitation should be commenced unless both parents and practitioners consider that the baby will be severely compromised. The critical issue is the baby’s lung and heart response using a mask: based on the 1995 EPICure study of those born at this age, given intensive care 66% died. The 2006 study found survival increased by 12%.

4. Babies born with certain gestational age of 25 weeks or more—survival is greater than of those born in 1995, therefore resuscitation is appropriate: base on the 1995 study 48% died, but 27% survived with no identifiable impairment at the age of six years. The 2006 study revealed an increase of 13% in survival from 54% to 67%.

Considered holistically, the BAPM framework does not advance the existing discussion about end-of-life decision making for critically impaired neonates in any meaningful way. It fails to address concerns that doctors may have in managing the expectations and discussions about end-of-life care with parents and families of pre-term neonates.
The guidelines and frameworks considered thus far can be viewed as often repetitive. By their very nature, these guidelines carry no significant weight or authority. Doctors retain absolute discretion to make decisions without reference to them and, as noted in Chapter Two of this thesis, where withdrawal or withholding of treatment considerations go before a court of law, judges overwhelmingly support this discretion. The next section of this chapter examines some more initiatives and the much-publicised NCOB 2006 report.

**X: Bliss and the National Institute of Clinical Excellence**

The charitable organisation Bliss, which operates throughout England, Wales, Scotland and Northern Ireland, aims to provide families of premature babies with information and support, rather than to provide clinical guidelines for doctors regarding the withdrawal or withholding of treatment.58 The charity works with the key stakeholders, parents and doctors, to provide services to assist with the best possible care for such infants. Bliss produces information booklets and parent packs that address issues from birth through to care after discharge. The booklets include information and recommendations from the BAPM, RCPCH and the 2006 Nuffield report.

The Bliss website contains information on the care standards and frameworks that have been published across the UK. Given the audience, the documents detail the general standards that parents should expect from healthcare providers, rather than the clinical practices of treatment withdrawal. However, since the wealth of material available

through the website is considerable, it does risk further confusing already distressed parents.

The National Health Service and Department of Health jointly published their ‘Toolkit for High Quality Neonatal Services’ in 2009 with assistance from Bliss. This ‘toolkit’ proves eight principles to determine high-quality neonatal care, and aims to provide a standardised practice across neonatal care, including staffing for the care of infants in intensive care, family involvement in the care of pre-term babies and best practice for transferring neonates to other units.59

On its website, Bliss states that the ‘toolkit is the best opportunity in 30 years to make much-needed improvements in neonatal care in England’.60 Arguably, however, the ‘toolkit’ is yet another document that lacks any serious depth or discussion about pressing issues surrounding neonatal care.

The repetition of information is further evinced in the National Institute of Clinical Excellence (NICE) publication, ‘Quality Standards in Neonatal Care’, which is similar to the NHS standard.61 NICE also based its document on nine guiding statements ambitiously aimed at a wide range of stakeholders, including the neonate, parents, clinicians, public health practitioners, commissioners and service providers.62

---


The principles of the quality standard are as widely cast as the target audience, ranging from breastfeeding and encouraging parental involvement in care, to data audit and research. The NICE standards also fail to provide any detailed recommendations to any of the targeted stakeholders, and potentially could leave parents feeling confused and actually less intimately involved in the treatment and care of their newborn.

The final consideration in this section is the 2006 Nuffield report, which also failed to meet the expectations with which it was conceived.

---

63 Other guiding quality statements include: care pathways, annual needs assessment, skilled and multidisciplinary staff, neonatal transfer services, coordinated transition to community care and health outcomes. See further, Department of Health, above n 59.

The NCOB is a multi-disciplinary, independent body in the UK. The council was established by joint funding and co-operation of the Nuffield Foundation, the Wellcome Trust and the Medical Research Council. The council aims to ‘advise policy makers and stimulate debate in bioethics’, and its work has been recognised internationally.

The council consists of several eminent professors from disciplines such as medicine, science, philosophy and law. It has successfully completed several projects on topics of significance to societal development and medico-ethical debate, including an examination of ethical dilemmas in dementia, public health, research involving animals and, most currently, the disclosure of information in relation to donor conception. For the purposes of this thesis, the 2006 report entitled Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues is of most relevance and importance to this thesis.

The report examined ‘ethical, social and legal issues that arise when making critical care decisions’. Although the report is to be commended for reintroducing the issues surrounding end-of-life decision making into the public domain, it has produced little reform since its publication seven years ago. The 2006 report arose out of an

---

64 Hereafter referred to as the NCOB. The Nuffield Foundation is a charity founded by Lord Nuffield in 1943 and William Morris to contribute to and improve issues of societal importance such as education and social wellbeing. Nuffield Foundation, About the Nuffield Foundation <http://www.nuffieldfoundation.org/About-the-foundation>.
66 Nuffield Council on Bioethics, above n. 6, 3 [1.4].
impressive multi-disciplinary working party chaired by Professor Brazier. Other members of the party included eminent professors in medicine, nursing and philosophy, as well as a disability commissioner, an economist and a lawyer.

Although the nine chapter report was primarily ‘targeted at policy makers’, it was written with a broad audience in mind.\textsuperscript{67} The report examined ethical, social and legal issues concerning end-of-life decision making for neonates. The fact that the report and the further exploration of the issues were deemed necessary in 2006 indicates that existing practices and published guidelines are insufficient, ambiguous and need reform. This thesis argues that, seven years on, there has been little development, and the need for clarity, transparency and uniformity in end-of-life decision making for neonates remains.

As the NCOB is an independent body, their 2006 report provided an ideal platform for candid and clear discussion on neonatal end-of-life decision making. The report presented the opportunity to introduce coherent recommendations for legislative reform, and the public interest and media attention attracted by the findings of the report could have been beneficial in discussing the issue of resource allocation. However, the report avoided the robust reforms necessary to inject the clarity required. Instead, the report endorsed the current abundance of clinical guidelines published by national bodies and supported existing key legal concepts such as best interests, futility and intolerability.

\textsuperscript{67} Ibid 5 [1.10].
The report emphasised the need for a continued ‘partnership of care’ between key stakeholders, parents and the healthcare team, as recommended by the RCPCH and the BAPM.\textsuperscript{68} It also strongly endorsed the guidelines and recommendations of the RCPCH and BAPM and the EPICure study findings. The NCOB working party rejected the need for legislation on decision making for neonates born at the edge of viability, despite commenting that ‘clearer guidance would be helpful to both parents and professionals’.\textsuperscript{69}

Further, the NCOB produced another set of guidelines and best practice as to thresholds for resuscitation and withholding or withdrawing of treatment from critically ill neonates based on their gestation age. The report suggested: \textsuperscript{70}

At \textit{25 + weeks}—intensive care should be initiated as babies born at this time have a high survival rate, unless it is known that the infant will be affected by a severe abnormality.

At \textit{24–24 + 6 days}—normal practice should be that the baby will be offered full intensive care and support from, birth unless the parents and clinicians agree that such treatment is not in the baby’s best interests.

At \textit{23–23 + 6 days}—future outcome predictions are difficult and precedence should be given to the wishes of the parents regarding resuscitation and intensive care.

At \textit{22–22 + 6 days}—standard practice should be not to resuscitate, unless it is considered to be in the baby’s best interests.

\textsuperscript{68} Ibid 23 [2.48].
\textsuperscript{69} Ibid 154 [9.14].
\textsuperscript{70} Ibid 155 [9.16].
At below 22 weeks—no baby should be resuscitated unless experimental reasons, and for approved research studies.71

The Nuffield report suggested that intensive care should not be offered at certain gestational periods, but did not present any new recommendations. Morris noted that the gestational periods at which the report recommends that neonates not be resuscitated almost mirror those of the RCPCH framework. The Nuffield report categorises neonates born before 25 weeks’ gestation and affected by abnormality as having ‘no chance’. This is similar to the ‘no purpose’ or ‘unbearable’ categories in the RCPCH framework. In these instances, the neonate is judged to have a quality of life that makes treatment the least best option.72

The report generated a range of responses from national medical bodies highlighting the variance of opinion on guidelines, their effectiveness and requirements. Some members of the BMA considered the proposed guidelines to be ‘too restrictive, undermining of professional judgement’,73 and argued that they set out ‘blanket rules—smothering clinical discretion’.74

In contrast, the Royal College of Obstetricians and Gynaecologists (RCOG) stated that the working party should seriously consider ‘the role of active euthanasia in neonatal critical care’. Where the BMA considered greater subjectivity in approach appropriate,

71 Ibid 156 [9.19].
72 Morris, above n 18, 347, 356.
74 Margaret Brazier and David Archard, ‘Letting Babies Die’ (2007) 33(3) Journal of Medical Ethics 125, 125.
the RCOG may have welcomed a more objective test, similar to that of the Groningen
protocol used in the Netherlands, which allows babies to be euthanised.\textsuperscript{75}

However, the working party ‘unreservedly rejected active ending of neonatal life, even
when such a life would be considered to be intolerable’.\textsuperscript{76} Any discussion on active
euthanasia was avoided by applying the ‘slippery slope’ argument that such would
open the flood gates to adult euthanasia.\textsuperscript{77} In taking this stance, the Nuffield report
echoed the law, stating that there is ‘no reason to distinguish between withdrawing
treatment and decision not to start it, provided the decision is made in the best interests
of the baby’.\textsuperscript{78}

The report continued to endorse the law relating to the concept of ‘double effect’,
concluding that, ‘provided treatment is guided by the best interests of a baby, and had
been agreed in the joint decision making process, potentially life-shortening but pain
relieving treatments are morally acceptable’.\textsuperscript{79}

Although the report acknowledged the ‘frequently cited resource constraints of the
National Health Service’\textsuperscript{80} associated with the treatment of neonates born at 23 weeks,
it avoided any further discussion by disclaiming that such decisions should be made
not on the basis of economic considerations, but on clinical judgments based on the
best interests of the baby.\textsuperscript{81} This thesis argues that, given the repute of the multi-

\textsuperscript{75} This will be considered in Chapter Five.
\textsuperscript{76} Nuffield Council on Bioethics, above n 6, 157 [2.37].
\textsuperscript{77} Brazier and Archard, above n 74, 125, 125.
\textsuperscript{78} Nuffield Council on Bioethics, above n 6, 154 [9.14].
\textsuperscript{79} Ibid 20 [2.38].
\textsuperscript{80} Ibid 84 [5.45].
\textsuperscript{81} Ibid 22 [2.43].
disciplinary working party and the media platform on which the report was presented, an open and thorough discussion about the efficient application of medical resources would have been invaluable.

Overall, the report adopted an inoffensive approach to issues that required, and continue to require, robust discussion. This was likely a strategic decision to avoid any condemnation from the public or from statutory bodies. Brazier and Archard, both members of the working party, ‘felt it right to respect the feelings of those most intimately involved in decisions about premature babies and who may want the opportunity to spend time caring for a dying baby’. 82

In its foreword, the party stated that it ‘embarked on its task with some trepidation’. This was evident throughout the report, which, as a result, failed to discuss the issues surrounding end-of-life decision making concerning neonates or to offer any robust reform or recommendations, thus confirming the status quo.

While Brazier and Archard believed the report attempted to ‘start an honest debate about these issues’, 83 this thesis contends that the report was ineffective in its aim: an honest and open debate, by its very nature, challenges established ideas. In this case, this would have involved discussing matters that were ethically and morally repugnant. As mentioned, this was not the case.

Next, having highlighted the abundance of repetitive and ineffective guidelines being used in the UK, the paucity of guidelines in Australia is discussed.

82 Brazier and Archard, above n 74, 125, 126.
83 Ibid.

To date, no guidelines published by any national body that exclusively consider withdrawal or withholding of treatment in neonates are available in Australia. In its guidelines, the Royal Australasian College of Physicians (RACP) emphasise the role of the family and the shared role of parents and doctors in the decision-making process:

Collaborative decision making is the safest and most robust model, incorporating and balancing the observation, knowledge and insights of both the family/whanau and the members of the treating team. This model allows a variety of responses and can adapt to most circumstances. It also provides an inherent system of ‘checks and balances’ against extremes in decision making, while providing support and validation for the conclusions of the decision making.  

The RACP document establishes the role of the health team as:

…to care for the family/whanau, while facilitating the process of decision making around the child’s care and maintaining a relationship of trust and respect … Health professional have a duty to argue their views concerning management choices but there is also an obligation to respect group decisions and the decisions of the family, regardless of personal beliefs.

The emphasis on ‘collaborative decision making’ with families is evidenced in the RACPs acknowledgment of the best-interests principle:

84 Royal Australasian College of Physicians, Decision Making at the End of Life in Infants, Children and Adolescents (Royal Australasian College of Physicians, 2008) 11.
85 Ibid 8.
Clinicians and guardians, usually parents, have a duty to make all key decisions in the best interests of the child. The treating team must always see itself as the advocate for the interests of the child and be prepared to manage differences with the parents from this perspective.  

Similar to the guidelines from the UK, the RACP guidelines state that there are ‘no legal or morally relevant differences between withholding or withdrawal of treatment’. However, unlike the RCPCH framework, the RACP guidelines describe only three conditions in defining scenarios in which continuing treatment is appropriate:

1. Where death is imminent
2. Treatment would be ineffective making life intolerable because of pain and suffering
3. Life would be shortened regardless of treatment and non-treatment would allow for increased comfort.

These three situations apply the seemingly ‘standardised’ terms of intolerability and relief of pain and suffering as considered in clinical guidelines and used by the courts. The guidelines state, ‘in the circumstances of infants with an extremely small chance of survival it may be appropriate not to offer treatment such as with infants at 22–23 weeks gestation particularly in poor condition’. Further, ‘there is no legal obligation to offer treatment which is not medically indicated or which is futile, although taking

---

86 Ibid 6.
87 Ibid 9.
88 Ibid 9.
89 Ibid 21.
this step in the absence of agreement should be considered only after all avenues have been exhausted’.\textsuperscript{90}

The guidelines fail to explain what the ‘other avenues’ that must be exhausted are. Overall, the RACP guidelines are basic and provide little clinical guidance. Although worthy, the emphasis on parental involvement does not negate the need for more prescriptive guidelines to assist doctors with end-of-life treatment decisions.

In marked contrast to in the UK, with its abundance of information and the repetitive and intersecting guidelines freely accessible to all, in Australia, approaches to end-of-life decision making for premature neonates appear to be specific to individual hospitals. Guidelines within hospitals on withdrawing or withholding life-sustaining treatment are often confidential and internal, and are unavailable to the public. Further, they vary between hospitals, even within the same state. This thesis argues that a more uniform approach is required with regard to clinical guidelines; that is, a universal set of guidelines is needed, for application by all hospitals.

During the course of this thesis, unsuccessful attempts were made by the researcher to access and examine hospital clinical guidelines in Victoria and South Australia. Access was attempted via hospital websites and correspondence with a leading children’s hospital in Victoria. However, in all cases, end-of-life clinical guidelines were restricted to hospital staff only.

\textsuperscript{90} Ibid 21.
This lack of access to examine the documents that guide doctors on end-of-life decisions is arguably symptomatic of the high level of autonomy of hospitals to set their own guidelines. It also highlights the lack of uniformity in clinical treatment for neonates. Moreover, such careful guarding of these policies provides little transparency for parents, who may be seeking information and understanding about decisions that are being made about their child.

The variation between hospital clinical guidelines means that there is a lack of consistency in end-of-life decision making in Australian neonatal care units. This may lead to confusion, ambiguity and a lack of confidence in treatment management on the part of parents, who may consider that a different hospital would treat their neonate more in line with their own views of appropriate treatment.91

Further, the lack of any uniformity in clinical guidelines allows for an inappropriate level of medical discretion and autonomy in end-of-life decision making for neonates. Alongside the insufficiently defined best-interests principle applied by the courts, as discussed in Chapter Two, clinical guideline variation illustrates the potential subjectivity and ambiguity in current decision making to withdraw or withhold life-sustaining treatment from critically impaired neonates.

---

91 Parental and medical opinion, views and the role and impact of key stakeholders is discussed in Chapter Four of this thesis.
Lui et al acknowledged the number of international guidelines on end-of-life treatment decisions for premature neonates, and the associated ‘grey zones’ of uncertainty at which end-of-life decisions are the most complex. The authors considered the need for such guidelines in Australia, with a consensus workshop being held with participants from New South Wales (NSW) and the Australian Capital Territory (ACT). The aims of the workshop were two-fold:

1. To produce consensus statements to supply clinicians and parents dealing with challenging scenarios encountered at the borderlines of viability.
2. To agree on accurate, meaningful and consistent information across NSW and the ACT for clinicians, parents and prospective parents of extremely premature infants.

The workshop was attended by nominated representatives from each of the 10 NICUs across NSW and the ACT, across the disciplines of obstetrics, midwifery, neonatology, neonatal nursing and allied health. In addition, representatives from parents’ groups, medical and nursing colleges and rural and regional practices were invited to participate.

The focus of the discussions in the workshop was based on data gathered between 1998–2000 from 897 births of pre-term babies between 22–25 weeks + 6 days gestation.

---


Ibid 495.
in NSW and ACT. The findings, published in the Medical Journal of Australia, stated that those neonates not admitted to the NICU died, and that as the gestational period increased, the number of babies born with severe disability decreased.

Overall, the findings of the workshop did not differ to those of the EPICure studies, or other work conducted in the UK. The group concluded that ‘at gestational ages between 23–25 weeks + 6 days treatment is discretionary’. Members of the group were divided as to the initiation of treatment at 23–26 weeks + 6 days, and concluded:

1. At 24 weeks + 6 days—option of non-resuscitation offered.
2. At 25 weeks + 6 days—active treatment is offered, although this may be discretionary based on poor prognosis and severe abnormality.
3. At 26+ weeks—High obligation to treat, unless there are exceptional circumstances.

The consensus statement also asserted that, where the family of a pre-term neonate opts for non-intervention at 23–25 weeks’ gestation, the following should be available:

1. All hospitals should have guidelines for communication with parents in situations in which the family had opted for no intervention.
2. Counselling should be done by, or at least in consultation with senior clinical staff.
3. If the birth occurs in a non-tertiary centre, access to senior staff in a tertiary centre for consultation should be available.

---

95 Ibid. The statistics from the consensus highlighted that 72 per cent of participants agreed that at 25–25 weeks + 6 days treatment should not be initiated.
4. Clinical staff should be well versed in preparing parents for palliative care.  

The group were unanimous on the need for a good partnership of care between parents and doctors, and determined that good communication was of key importance. The group discussed the importance of non-directive counselling offered to parents of those born in the ‘grey zone’ (at the borderline of viability). Commendably, the group did candidly discuss the varying attitudes and views of stakeholders: parents, doctors and nurses. The group agreed that ‘consistent, transparent information should be shared between parents and members of the perinatal team’.  

The creation and publication of this consensus is important, particularly given the absence of any national guidelines in Australia. This thesis contends that the workshop was an ideal opportunity for developing consensus statements at a state level, as a base from which national guidelines could have been developed.  

Boneh et al acknowledged that the issue of withdrawing and withholding treatment in newborns ‘remains unclear, due to the lack of cases reaching the courts in Australia, and resulting in the absence of any judicial discussion or authority on such matters’. Given that the first case concerning end-of-life decision making for a critically ill neonate (Baby D) was considered by the court in 2011, this thesis asserts that it is now timely for both medical and legal institutions to consider the development of a national and unified framework.  

97 Lui et al, above n 93, 495, 498.  
98 Darlow, above n 95, 477, 478.  
99 Lui et al, above n 93, 495, 499.  
100 Boneh et al, ‘Clinical, Ethical and Legal Considerations in the Treatment of Newborns with Non-Ketotic Hyperglycaemia’ (2008) 94(2) Molecular Genetics and Metabolism 143, 145.
In this regard, there are lessons to be learned from the UK, where, over the past 30 years, an increasing number of end-of-life decisions have required judicial intervention. In light of this, Australia has the opportunity to create unified practices nationally, to prevent any potential increase in withdrawal or withholding of life-sustaining treatment requiring court intervention.101

XIV: Conclusion

As set out in Chapter Two, the law places great emphasis on medical opinion and has relied on the clinical guidance of medical bodies when making end-of-life decisions. In Bland, Lord Goff relied on the Bolam test—which holds that a doctor will act with the benefit of guidance from a responsible and competent body of relevant professional opinion—and the advice and guidance of the BMA ethics committee to reach his conclusion to withdraw and withhold treatment.102

In addition, in Re C,103 the judicial decision to withdraw treatment from a neonate born with spinal muscular atrophy was made after careful analysis of the RCPCH guidelines. Sir Stephen Brown highlighted the need to make a decision with the child’s best interests as the paramount consideration.104

101 As noted in Chapter Two of this thesis, there have been two cases within the space of 2001–2012 that have required legal intervention in Australia. Although it is too early to establish whether the number of cases requiring legal intervention will increase, national standardised guidelines would create greater clarity and uniformity.
103 Re C (a minor) [1997] 40 BMLR 31 (Fam Div).
Somewhat aberrantly, it appears that judges rely on medical opinion and doctors rely on case law decisions when developing guidelines to assist doctors in decision making. Like the case law and judicial deference to medical opinion considered earlier, guidelines provide yet another non-prescriptive or directional formality to medico-legal dilemmas concerning end-of-life decision making for neonates.

This is a highly charged ethical and moral quandary, fraught with controversy. The reliance demonstrated by both the medical and legal professions on each other in guiding and deciding life and death decisions is an illustration of both professions’ unwillingness to take the lead in any real or meaningful dialogue towards decisions in this area. Medical practitioners and judges both apply ill-defined terms such as best interests, futility and benefits and burdens, and both have demonstrated inconsistent and loose application of such.

The abundance of information and frameworks in the UK is confusing, and one unified guidance document that is applied nationally is required. Both the UK and Australia have either missed or deliberately avoided taking the opportunities to have frank discussions about more robust decision-making reforms.

Several commentators support the contention of this chapter that greater consistency in guidelines is needed. In his paper in the Singapore Medical Journal, Foo highlights that the paediatrician Whitelaw recommends ‘near certainty of death or no meaningful
life’ as the benchmark for decision making. He also states that ‘no meaningful life is a virtual certainty of complete incapacity not just a handicap’. ¹⁰⁵

Other academics have suggested proposals and frameworks to address the ambiguity and low impact of clinical guidelines that have been published. Lamb suggests a more robust approach, employing the term ‘slippery slope’ to describe situations in which a specific course of action that may be seen as ethical, actually leads to other courses of action that are unethical.¹⁰⁶ Pinter agrees with this ‘slippery slope’ concept in relation to guidelines, and noted that without ‘sharp and precise boundaries’, there will be a deterioration of ethical decision-making.¹⁰⁷

Further, Zutlevics proposed a ‘co-operative discursive’ framework with essential features such as ample time (where possible), a diverse and inclusive group of moral decision makers who have an equal opportunity to contribute to the discussion informing decision-making, and rational and principled decision making.¹⁰⁸

In contrast, McHaffie et al assert that there is no need for stringent guidelines to clarify roles and responsibilities, and instead recommend a ‘flexible package of care, tailored to specific need’. ¹⁰⁹ While it cannot be denied that every individual case has its own unique characteristics, this thesis argues that this does not negate the need for a unified

¹⁰⁵ K B Foo ‘Medico-legal and Ethical Problems Associated with Treatment of Children Born with Congenital Malformations’ (1994) 35(2) Singapore Medical Journal 184, 188.
national framework. On the contrary, such a framework would allow the intricacies of each case to be given a thorough examination against a common denominator. This is of key importance to moving forward to a better system of decision making with greater transparency and uniformity.

Premature neonates cannot express their inherent right to autonomy or advocate their treatment wishes. Thus, the roles and relationships between other key stakeholders (that is, chiefly, doctors, parents and the judiciary) in decision making for critically impaired neonates are imperative. This issue is examined in the next chapter of this thesis.
CHAPTER FOUR: THE ROLE, IMPACT AND IMPORTANCE OF KEY STAKEHOLDERS IN DECISIONS TO WITHDRAW OR WITHHOLD LIFE-SUSTAINING TREATMENT

I: Summary

Chapter Three considered the role of clinical guidelines in the context of end-of-life decision making for critically ill neonates. It examined the guidelines and frameworks created and implemented in hospitals in the UK, and their lack in Australia.

In the UK, the guidelines are not exclusive to critically ill neonates, and are general in nature, thus leaving much room for interpretation, with a resulting variance of outcome. In examining these sources of information and the available guidelines, Chapter Three also critiqued the 2006 Nuffield Council of Bioethics Report and its missed opportunity to make any robust recommendations to improve the existing, and repetitive, wealth of guidelines and frameworks in the UK.

Regarding Australia, it was concluded that each hospital exercises an unhealthy degree of autonomy, with life and death decisions made based on internal policies, inaccessible to the wider public.
II: Introduction

This chapter considers the roles and weight afforded to other key stakeholders in the end-of-life decision-making process. Chapter Four begins by examining the tangled dynamic that exists between parents and doctors in decision making. It then considers how the dynamic changes when the decision making is taken out of the hospital setting and transferred into the court.

Discussion in the area of end-of-life decision making for neonates is invariably emotive and controversial due to the final consequences of such decisions. Neonates cannot express their free will and are entirely dependent on others to decide their fate. Stakeholders (that is, doctors, judges and parents) must therefore assume this authority, and they occasionally take actions that detract from the rights and interests of the neonate. In some cases, these actions lean towards the perceived duties and interests of the stakeholder. Dunn acknowledged this, stating:

In defending the patient’s rights, whether it be to have a prenatal diagnosis or to have a caesarean section or to submit to life-saving interventions, we must never lose sight of that most fundamental right of all, the right to choice, and the right not to have what doctors sometimes naively assume our patients will or should want.¹

There is a wealth of material in this area that could comfortably accommodate a PhD in its own right. Many medical journals provide global empirical research in the form of surveys, questionnaires and polls that have been conducted to ascertain medical professionals’ attitudes and perceptions towards end-of-life decision making for

¹ Peter Dunn, ‘Appropriate Care of the Newborn: Ethical Dilemmas’ (1993) 19(2) Journal of Medical Ethics 82, 82.
neonates. Similar studies have also been conducted concerning parents and the wider family.

This thesis contends that the views and opinions of other stakeholders affected by decision making concerning treatment for incapacitated neonates should not be explicitly or implicitly determinative in life and death dilemmas. In seeking to better understand this area, it is first important to identify, in concrete terms, the interests that are affected. Then, the respective weight that should be accorded to each of them can be discussed. This requires an examination of the ideals and values involved, and also a determination of the relevant stakeholders.

Chapter Four examines parents, doctors, the judiciary and the wider community as the stakeholders affected or involved in the decision-making process for critically ill neonates. There are often competing rights, duties and interests at play, which means that this ethical problem will produce different answers depending on who is seeking them. Heimer supports this observation:

> Each group’s claim has a long and distinguished legal history. Parents stake their claim on their right to family autonomy, privacy and freedom of religion and on their ultimate responsibly for the child. It is they who must bear the burden of raising a disabled child, balancing its needs against those of other family members. Physician claims are based on their traditional rights to make

---


treatment decisions on possession of arcane medical knowledge and on experience treating other infants with similar problems. Other members of the medical community make similar claims. And the state, through legislatures, regulatory bodies and courts, argue that its interest in the lives and health of its citizens take precedence over parents right to control their own children. As Parens Patriae it claims to be a disinterested protector of infant citizens.  

Further, Kerridge, Lowe and Stewart highlight that parens patriae powers in Australia ‘is the notion of the sovereign as the “father of the nation”’. As such, ‘the Supreme Courts of the States and Territories have the power to consent to treatments on behalf of incompetent adults and children under their inherent jurisdiction’.

Should certain stakeholders be regarded as functionaries in the process? Is the ad hoc system currently applied in hospitals to make life and death decisions the most effective and efficient? These are some of the key questions addressed in this chapter. The next section considers some of the factors that affect parents, who are primarily ‘one time players’ in decisions to withdraw or withhold life-sustaining treatment from their neonates.

III: Parents: Conflicting interests and views

The parents of neonates born severely premature or with severe abnormality are affected significantly in decisions about the withdrawal or withholding of life-sustaining treatment from their children. The period during which such decisions are

---


6 Ibid.
made is marked by measures of joy and anguish, as parents are asked to consider the loss of a child, and as they grapple with the consequences of their decision in the process. For many adults born in the 1970s–1980s, death or dying may be unfamiliar; this may be their first experience of losing a loved one.7

A study published in the UK by McHaffie in 2001 found that ‘contemplating tragic outcomes, watching a baby die, burying their own child, these are extraordinary experiences for young people to live through’.8 In addition, many young parents ‘lamented their lost youth and innocence … they were now permanently separated from their peers, and could not regain their carefree approach to life’.9

Ostensibly, parents of premature neonates are the victims in the end-of-life decision-making process and are deserving of nothing but the utmost sympathy and pity. However, to rely entirely on such a view would be misguided. Such a one-dimensional assessment does not explain the varying reactions of parents in these situations, and fails to capture the most complete picture of parents, the emotions they experience and the decisions they come to make.

(A) The influence of media, development of medical science and technology

There has been a shift in societal attitudes towards the family structure. This has corresponded to the increased accessibility of contraception, women’s rights and

---

7 For a more in-depth examination of parental experiences after the death of a baby see, Nancy Khoner and Alix Henley, When a Baby Dies: The Experience of Late Miscarriage, Stillbirth and Neonatal Death (Pandora Press, 1991).
9 Ibid.
personal autonomy on matters such as abortion and planned pregnancies.\textsuperscript{10} Twentieth century innovations and developments have allowed neonates to defy nature, and have given parents and doctors considerable capacity to play a significant role in a neonate’s ultimate destiny. Shelp explains the situation prior to these developments:

> Medicine, for all practical purposes, was impotent to effectively intervene to rescue life or transform a sick baby into a healthy one. Parents necessarily received what the natural lottery of human reproduction delivered. Cure and/or habilitation [sic] to a normal life were beyond the control of both parents and medicine.\textsuperscript{11}

Often parents have their dreams, hopes and aspirations tied up in their child. Relationships, career choices and life experiences all contribute to parents having a vested interest in the birth of a child. There are many reasons that people want, need and have children. Nearly all of these are admirable, although others may be regarded selfish. By way of example of the latter, financial reasons, reasons that uphold notions of social status, familial pressures and the internal dynamics of individual relationships may contribute to the drive to reproduce.\textsuperscript{12}


\textsuperscript{11} Earl E Shelp, \textit{Born to Die? Deciding the Fate of Critically Ill Newborns} (The Free Press, 1986) 77.

\textsuperscript{12} There may be societal pressures on couple’s to reproduce, see, eg, Christine Crowe, “‘Women want it’: In-vitro fertilization and women’s motivations for participation’ (1985) 8(6) \textit{Women's Studies International Forum} 547–552. Further, cultural or religious reasons may mean that women are under pressure to reproduce. Susan Martha Kahn asserts that Jewish citizens derive from immigration, conversion to the Jewish faith or by birth. Thus, ‘Israeli Jewish women are left as the primary agents through which the nation can be reproduced as Jewish … Jewish women are under extraordinarily pressure to reproduce, whether they are married or unmarried’. See especially, Susan Martha Kahn, \textit{Reproducing Jews: A Cultural Account of Assisted Conception in Israel} (Duke University Press, 2000) 4.
Prospective parents may regularly speculate on the future goals and dreams they wish to see their child achieve. During the pregnancy, soon to be parents often begin to consider names, the suburbs in which they would like to raise their children, the schools their children might attend, and the activities in which they hope their children will participate. The thought of a difficult or premature pregnancy, or of bearing a child with a severe abnormality, does not sit comfortably alongside the ideals or hopes of prospective parents. As Shelp explains:

There may be an awareness of the potential risks and pitfalls of parenting, but they may not be expressed in a way that materially connects the risk with the current pregnancy. It is frightening for parents to think that this pregnancy might result in the birth of an infant with serious impairment that could effectively shatter all the hopes and dreams they have for this child. 13

Scientific and technological progress has enabled significant advances. However, with these achievements have come greater expectations as to what can be delivered to the patient. Moreover, as technology has advanced, women have been able to embark on pregnancy later in life, and those that may once have been considered infertile now have the opportunity to become mothers.

This raises an important question: just because we ‘can’ save imperilled neonates from death, does this mean we ‘should’ save all imperilled neonates born at extreme prematurity from death or severe disability? Guyer considers the question, stating that ‘some parents push too hard for treatments that are medically inappropriate’. 14 Others

13 Shelp, above n 11, 54.
may rely on ‘reproductive technologies in order to conceive a baby and then expect that other technologies will rescue and maintain their baby’.15

In the quest of a ‘good story’, the media often publishes stories and bold headlines about ‘miracle babies’. Distressed parents often passionately cling to such stories of babies surviving against all odds, believing that their baby can do the same. This sentiment is candidly echoed by Guyer:

Sometimes media hyperbole focuses on a single micropremmie—‘The Size of a Coke Can!’—or on a baby whose radical surgery—‘Infant Heart, the Size of a Walnut, Rebuilt and Running’—stands as testimony to a surgeon’s technical prowess but not to what constitutes an appropriate reaction to nature’s inevitable anatomical mistakes.16

It can be argued that medical professionals may have become victims of their own success. By now being able to save neonates that may have died as little as two decades ago, there is often an unrealistic expectation that doctors will keep these critically ill neonates alive. Dr Andrew Watkins, Director of the NICU at the Mercy Hospital in Melbourne, carries a similar view:

There is no pleasure in the irony that the NICU is a victim of its own success; 20 years ago, 28 weeks was the limit of viability for premature babies. Today, sophisticated advances in biomedical engineering, with cots that light up like cockpits … the result is that younger than ever babies are now surviving … needing beds for longer.17

15 Ibid.
16 Ibid.
A study conducted in New Zealand highlighting the survival rate of neonates born weighing between 501–1500 grams over a 50-year period found marked improvements. Neonates born with a birth weight of 501–1000 grams saw a survival rate increase from less than 10 per cent in 1959 to 80 per cent in 2009.18 This vast improvement in survival rate has not been confined to New Zealand. Both the UK and the University of Washington reported increased survival rates for neonates of this weight for between 1965 and 1975.19

Given the improvements in survival rates, it is understandable that parents today may push for aggressive treatment. This may also be true of situations in which the continuation of treatment is futile, but where parents are hoping that their child will also be a ‘miracle baby’, as read about in tabloid newspapers.

Although very rarely seen, two such ‘Sunday features’ recently in Australia should be commended for attempting to present a more nuanced view of babies born at the edge of viability.20 Additionally, 2011 saw the BBC air a documentary by science writer Adam Wishart in the UK, entitled *The Price of Life*. Wishart spent six months in the NICU of the Birmingham Women’s Hospital, where he was given unrestricted access to interview parents and doctors and, in doing so, document the very different experiences of families and medical staff in making end-of-life decisions for babies born at 23 weeks.

19 Ibid 598.
20 Segments of both articles and the documentary will be discussed throughout this chapter. Tracey McVeigh, ‘I Would Have Wanted Him to Die in My Arms’, *Sunday Herald Sun Magazine, The Herald Sun* (Australia) 17 April 2011; Evans, above n 17; *The Price of Life* (Directed by Adam Wishart, BBC Production, 2011).
These newspaper articles and documentary present an exception to the rule in representing a realistic view of life in, and beyond, the NICU. They will thus be discussed later in this chapter and in Chapter Five. However, generally, the bulk of media reporting fails to discuss the realities that face neonates and their families. Critically, there is often a failure to highlight the real survival rates and discuss the denominator against which survival can be measured.21

As highlighted in Chapters One and Three of this thesis, neonates that survive without any disability against medical odds are unusual rather than the norm. In representing the exception, the media reinforces the contention of this thesis, that there is a need for greater transparency and objectivity in relation to end-of-life decision making for imperilled neonates.

Greater public awareness is required to realistically highlight life for neonates born at 23 weeks’ gestation, removing some of the emotion that is often attached to birth and newborn babies. The significant impact of the internet and the media in decision making is supported by Moro et al’s recent empirical research, which found:

In one case, the mothers experience raising a foster daughter who was born preterm and a television show impacted the way she looked at the loss of her infant since, unlike the woman on the show, she would not have wanted her daughter to live only to die weeks later. For another mother, the information she gathered on the internet impacted her ability to hold out hope that her daughter would survive.22

---


Today, due to the media reporting stories of survival and presenting an unbalanced view, parents are often surprised to discover that they have a premature neonate and that, as a result of its prematurity, it is likely to have severe disabilities. Hammerman et al support this point:

Parents in such situations are emotionally vulnerable, still reeling from the shock of not having the normal, healthy baby they had heretofore envisaged. They must struggle with many conflicting emotions. On the one hand there is the love, concern and hope for their baby’s wellbeing counterbalanced by the grief, disappointment and guilt over the reality of their imperfect infant. 23

(B) Religious and cultural beliefs

Varying religious beliefs affect parental attitudes and views of withdrawal or withholding of treatment and death. Hammerman et al conducted a study on attitudes of pregnant women towards medical decision making for critically ill neonates. The subjects of the study were Israeli-born Muslim and Jewish women in their mid-twenties to thirties.

Based on the level of religious observance of the women, the research found that ‘mothers who described themselves as ultraorthodox/fundamentalist constituted a higher proportion of those selecting maximally aggressive medical intervention (25% v 17% of the total population)’. 24 In comparison, mothers who considered themselves

24 Ibid 165.
more secular and would select minimal intervention accounted for 31% v 20% of the general population.25

The study highlighted that women with more religious and fundamental beliefs considered that the principle of sanctity of life was of utmost importance, regardless of the child’s disability or handicap. One respondent in the Hammerman-led study asserted that ‘even the most severely handicapped child has a soul and all care must be taken to ensure his survival. In fact I have heard that “special” children have the loftiest souls’.26 Women that considered themselves more secular indicated that the key influencing factor in their decision making was the quality of life the neonate would have and his or her inability to enjoy life and all it had to offer.

Religious affiliation and decision making for critically ill neonates thus appear to be commonly linked. Often parents believe that life and death decisions should be left in God’s hands. They are of the belief that God is the ultimate decision maker, not them. Many parents consider doctors to be ‘representatives of God in the healing process’.27 However, this line of thought is fraught with contradiction: if God is the decision maker, how can doctors, medical science and medical equipment, which are ultimately ‘keeping the baby’ alive, all be held in the hands of a higher power, greater than man?

Paris et al agree with this line of thought, stating ‘the child is trapped in technology from which death is the only exit. When the inevitable NICU death does occur, those

25 Ibid.
26 Ibid 168.
27 Ibid.
involved assure themselves “We did everything possible. It was God’s decision, not ours”’. 28

A recent American study published in 2011 indicates a more literal application of God as the ultimate referee. One family in the study led by Moro believed that the decision as to whether the infant survived should be left entirely in God’s hands, and that the only way to allow ‘God to handle it’ was to remove the infant from the ventilator and allow God to decide the child fate. 29 One religious parent, interviewed for a Melbourne newspaper, described having thoughts about the conversations he would have with God in the future: ‘I can’t wait to meet him (God)’. 30

(C) The common denominator: Hope

Human beings often make the most important decisions in their lives based on emotion. Marriage is a key example of this; those who are about to wed probably do not consider divorce statistics or allow information regarding unhappy marriages to deter them. Such life-changing decisions are generally made following one’s desires, rather than based on rational thought processes. Decisions regarding the withdrawal or withholding of life-sustaining treatment from critically impaired neonates are generally founded on parental emotion and an instinctive desire to protect and unconditionally love their newborn. This is illustrated in a case study documented in Wishart’s BBC documentary.

29 Moro et al, above n 22, 52, 56.
30 Evans, above n 17, 38, 43.
In this case study, the parents of baby Simone, the only survivor of triplets, born at 23 weeks, spoke of their hope of taking their child home. The baby’s mother, 23-year-old Kelly stated, ‘It gives you hope seeing her move, she’s a little fighter’.31 She added ‘she looks normal, kicking, moving, wriggling about, crying, it’s weird … she’s come too far to give up now’.32 In the same documentary, another parent, police officer Craig, discussed his fears of setbacks: ‘if you get your hopes up too much you might get knocked down—so it’s best to keep it level and don’t get too excited … and then good news is good news’.33 The importance of ‘framing’ conversations with parents about outcomes in a manner that will be understood rationally has been discussed by Janvier, and will be considered later in this chapter.34

For parents, emotions play a very significant role in decision making. Humans instinctively desire to love and nurture their loved ones, particularly neonates. These instinctive desires are enshrined in cultural mores: the creation of a successful family unit and good parenting are considered to be worthy goals. This is further demonstrated by the abhorrence with which society regards those who harm or kill children.

Many parents of critically ill neonates hold on to hope, even when the prognosis is bleak. Arguably, hope is an intangible entity that no doctor or court of law can take away from parents, and as such it is something parents may not let go of until the very last moment.

31 The Price of Life, above n 20, 00.18.25.
32 Ibid 00.23.54 and 00.24.10.
33 Ibid 00.49.29.
This assertion is supported in one of McHaffie’s 2001 studies, in which it was noted that one couple were staunch believers that their child would survive, and ‘not wanting to jeopardise her chances, they refused to have her out of the incubator to cuddle her until the last few minutes of life’. Further, Moro’s empirical study considered ‘hope’ as a factor in the decision-making process. Two mothers in the study stated:

In one case, hope that the infant would survive fuelled the mother’s determination to make physicians try to save the infant in the delivery room. While this mother thought there was less than 1% chance that her daughter would live, she indicated that she had hope until the last moment. Another mother of triplets reported feeling hopeful even after the first infant died because there were two who survived.

(D) Parental ethnicity

Parental ethnicity and cultural beliefs also play a significant role in decision making. A study conducted in 2004 by Roy et al in the UK found that Jewish and African families were more likely to request aggressive treatment. The study further found that over a period of 45 months found that, of the 1807 babies that were admitted to the NICU, 85 per cent died. Withdrawal of life-sustaining treatment was the cause of death for 58 per cent of those imperilled neonates that died. Discussions were undertaken with parents before treatment was withdrawn, with 72 per cent of cases agreeing with withdrawal:

---

36 Moro et al, above n 22, 52, 55.
White parents, those from the Indian subcontinent and Afro-Caribbean parents (20 of 23) were more likely to agree to withdrawal of LST (life sustaining treatment) than Black African or Jewish (8 of 16) parents. Of the 11 sets of parents who refused the option of withdrawal of LST, three (including two orthodox Jewish families) gave religion as the primary reason.37

The study also found that only 54 per cent of black African parents, as compared to almost all of the white parents, agreed to withdrawal of life-sustaining treatment, giving their religious and personal beliefs as the key deciding factor.38 Boneh et al, acknowledging that parental attitudes are often determinative of the decisions they make, recommend doctors to:

…be aware of the parents’ cultural attitude to decisions regarding end of life. They need to explore the willingness of the family of the newborn to make decisions regarding withholding or withdrawing therapy and to counsel families using appropriate terminology.39

Life experience is also a factor in end-of-life decision making for parents. For many mothers, life experiences and societal attitudes in their maternal country of origin are influential factors in decision making. Hammerman noted that women from former Soviet Russia, where approximately 10 per cent of women have experienced an abortion at least once during child-bearing age, had a less restrictive approach to withdrawal of treatment decisions:


38 Ibid 529.

immigrant mothers in the USSR, were much less aggressive in their approach to treating critically ill, damaged neonates, probably reflecting prevalent attitudes in a country where families are generally limited to one to two children and where abortion is considered an acceptable method of contraception.\textsuperscript{40}

Thus, the considerations so far suggest that, while parents believe they are the chief advocates for their child’s life and its protection, and have the highest authority to decide ‘what is best for their child’, parents’ decisions regarding treatment are often made based wholly on their own subjective interests and beliefs.

This is supported by McHaffie et al’s study, which described one scenario in which parents felt compelled to leave their dying baby alone due to a cultural belief that witnessing their child’s ears turning blue would signify the end of meaningful life.\textsuperscript{41}

Kopelman and Kopelman discussed a case with similar cultural obstacles in America.\textsuperscript{42} The case concerned Baby S, a neonate born at 26 weeks’ gestation to graduate student parents from India. The neonate suffered several conditions due to premature birth and had a 70 per cent chance of survival with the strong possibility of problems (ranging from mild to profound). A week after birth, the parents requested that treatment be withdrawn, an opinion that was not shared by the attending physicians.

\textsuperscript{40} Hammerman et al, above n 23, 164, 168.
\textsuperscript{41} McHaffie et al, above n 8, 104, 108.
While doctors were optimistic about the prognosis, the parents believed that once they returned to India, they would not have financial access to the level of care their son would possibly require. Further, they feared hostility due to a cultural stigma relating to abnormalities.43 Ordinarily, such a conflict of opinion would have been referred to the courts; however, in this case, doctors, social workers and nurses, independent of the courts, concluded that pursuing treatment would not be in the best interests of the neonate.

*Baby S’s* condition deteriorated and he passed away before treatment was revoked. However, the case provides an example of the impact of cultural beliefs in life and death decisions. In most developed countries, laws are not tailored to specific cultures.44 While they are, and should be, respectful of the myriad of cultural beliefs, they are not dictated by them. However, there may be exceptional instances, such as the one discussed above, where too much emphasis could be placed on cultural preferences or personal bias.

Looking at *Baby S’s* case, it is questionable whether the same decision would have been reached had the neonate not been born to parents returning to a developing nation, particularly given the parents’ reliance on arguments for withdrawal of treatment that centred on cultural stigma and limited access to financial resources for further care.

---

43 Handicap, disability or congenital abnormalities are often viewed as punishment for past ‘sins’ committed in Indian culture. See generally, Anita Ghai, ‘Disability in the Indian Context: Post-colonial Perspectives’ in Mairian Corker and Tom Shakespeare (eds), Disability/Postmodernity: Embodying Disability Theory (Continuum, 2002) 88–100. See also, Luanne Linnard-Palmer and Susan Kools, ‘Parents Refusal of Medical Treatment Based on Religious and/or Cultural Beliefs: The Law, Ethical Principles, and Clinical Implications’ (2004) 19(5) *Journal of Pediatric Nursing* 351–356.

Parental bias and judgments may not be physically visible to the outside world, but it can still affect parental decision making. An example of such personal bias has been examined by Shelp, who discussed a case involving a premature neonate born with severe respiratory issues, and who also suffered with a non-functioning micro penis, which could have been removed, allowing the neonate to be raised as female. However, Shelp found:

Rather than cope with a perceived failure of his masculinity, the father, with the consent of the mother, refused treatment of the infant’s respiratory disease. Treatment nevertheless, was undertaken but the baby died anyway … the defect need not be visible to others or affect the brain in order to provoke a judgment that death of the newborn is a desirable end.45

Another factor that plays a role in the decision-making process for parents is the pain and suffering of the child.

(E) Pain and suffering of the child

During their initial consultations with medical teams about prognosis, parents may instinctively have a firm vision and make an immediate determination that their neonate’s life must be preserved at all costs. Moro highlighted that all mothers initially indicated ‘they wanted everything done for their infant in the delivery room’.46

Interestingly, Moro also found that neither parents nor doctors explicitly defined what ‘everything done’ meant.47 This is an important point and further discussion or

45 Shelp, above n 11, 63.
46 Moro et al, above n 22, 52, 55.
research in this area would be valuable. As will be considered later in this chapter, parent and doctor perceptions vary extensively as to what treatments can and should be offered to a critically ill neonate. The term ‘everything done’ is highly subjective, and for a medical team that has assessed the prognosis for the neonate, ‘everything done’ could be interpreted as alleviating pain or suffering and providing the neonate with palliative care and comfort.

Conversely, for parents, ‘everything done’ may mean aggressive treatment, even when there is no positive response by the neonate. Moro found that, ‘despite the mother’s insistence that the physician do everything, she felt that they did not provide appropriate care … “it seemed like when they, took her to the table to try, they put a mask on her and handed her back”’.48 McHaffie similarly found that parents discussed a constant need to ‘beg the staff to do all they could in the face of frequent comments implying treatment was futile’.49

A key turning point for many parents from wanting the medical team to ‘do everything’ to save their neonate to agreeing to the withdrawal of treatment is conversations with the medical team regarding the pain and suffering endured by their neonate. In the Wishart documentary, parents Lucy and Craig expressed their reservations for aggressive treatment for their daughter Matilda, stating ‘she has to have a quality of life, if it comes to it we have to let nature takes its course’.50

48 Ibid 55.
50 The Price of Life, above n 20, 00.28.48.
Both Moro’s study and those conducted by McHaffie highlight the significance of pain as a key factor in end-of-life decision making for parents and doctors. In the McHaffie study, some parents expressed a desire to ‘ameliorate their child’s suffering’, and one mother stated ‘I just wanted the best for my daughter. I didn’t want her to suffer anymore’. 51

Visible deterioration such as skin colour changes, noises of exasperation and ‘clear information’ about prognosis also influenced withdrawal decisions. 52 In another study, McHaffie found that, when neonates were taken off ventilation and began to struggle to breathe independently, parents found this distressing. 53 One mother described withdrawal of life-sustaining treatment from her son:

He was coughing, spluttering, gasping … the minute he (the doctor) was coming over (to check that his heart has stopped) he started again. I was just not looking … My arm was numb. They were saying, ‘Go and have a lie down, this could go on for hours’, but I couldn’t even move. I was just so damned scared. I think it was more his noises that haunt me than the colour of his blue hand. 54

Doctors may attempt to protect parents from the beginning of the dying process when their neonate is removed from ventilation, either due to a sense of paternalism or empathy or out of an awareness of the fragile emotional state of parents at this time. Studies have shown that, as difficult as it may be, parents prefer to be given the facts and told in very certain terms exactly what the dying process entails. In failing to do so, many parents lose trust in the treating physician. This is explained below.

51 McHaffie, Lyon and Hume, above n 50, 339, 341.
52 Ibid 342.
53 McHaffie, Lyon and Fowlie, above n 36, 8, 10.
54 Ibid.
McHaffie, Lyon and Fowlie explored parental perceptions of the dying process between three to 13 months after neonatal or infant death from treatment withdrawal. The study was conducted across three regional units in East Scotland, and its findings were published in 2001. The findings are noteworthy. Sixty-eight per cent of those interviewed were satisfied with the manner in which the ‘dying process’ was handled, while only 8 per cent found the process unsatisfactory. These statistics should provide the medical fraternity with reassurance that, generally, the process is perceived to be handled with emotional sensitivity. However, 22 per cent of parents expressed discomfort about the length of the dying process.55

After grappling with emotionally challenging decisions and accepting that their neonate is too imperilled to survive, some parents wanted the ‘dying process’ to be as quick as possible. In McHaffie’s study, one couple could not ‘face watching their son die’ and simply wanted to be informed if he deteriorated any further.56

Other parents felt the need and duty to be with their neonate or young infant right up to the dying moment. However, these parents then risked being traumatised by the duration of the dying process and the distress and physical changes that occurred to their neonate. As McHaffie explains, one neonate’s parents ‘believed that death would be instantaneous when the ventilator was withdrawn and they were completely

55 Ibid 8.
56 Ibid 9.
unprepared for the 21 hours they had with the living child’. For other parents, the process varied from three to 36 hours.

Although unpleasant for any parent, once their infant had died, 16 per cent of those interviewed wished they had made the decision to withdraw treatment sooner and that the entire process had been shorter. For some couples, the quick or ‘rapid death, reinforced the accuracy of the medical prognosis’. Another couple went even further, stating ‘they wished their child had been “euthanized” early on and they all had been spared the agonising experience they had endured’. Three other couples ‘found it unhelpful when the doctors did not give the child something to end life sooner, to lessen the baby’s suffering and their own distress’.

The neonate’s suffering is not always the foremost consideration. The recent Moro-led study highlighted the case of one mother of triplets, who, having endured the death of two of them, ‘did not want her last infant to only live for a few weeks or months’. She said ‘since I already had to bury the other two … maybe I should let them all go together’. While this may seem a selfish comment for a mother to make, it reflects a necessary form of emotional self-preservation.

This thesis acknowledges that each individual’s life experiences vary. The empirical studies undertaken, largely by McHaffie, explore parent perceptions and individual opinions or beliefs. Some parents began to doubt their decision to withdraw treatment

---

57 Ibid 10.
58 Ibid.
59 Ibid.
60 Ibid 11.
61 Moro et al, above n 22, 52, 55.
when the dying process took longer than anticipated. As discussed earlier in this chapter, parents continued to hold onto hope and the possibility that their baby was going to ‘fight on’ until the very end. Parents’ thoughts revolved around questions like, ‘if the baby was fighting so hard to live should they give him/her every chance? Was he or she trying to tell them that they [sic] wanted to live?’

(G) Perceptions and realities of disability

The area of disability activism is wide reaching and beyond the scope of this thesis. However, it is necessary to discuss briefly how disability affects individuals and families when decisions to continue treatment are made. As has been noted thus far in this thesis, there is a strong likelihood of disability when a neonate born at 23 weeks survives. The uncertainty of initial survival, and then the severity of the disability the neonate is likely to suffer, are just two of the issues that make end-of-life decision making for these neonates so controversial and challenging.

Moral values and interpretations of quality of life vary, and perceptions of disability and its severity are also subjective. Varying levels of cognition, intellect and

---

62 McHaffie, Lyon and Fowlie, above n 36, 8, 10.
64 For further discussion, see also, Saigal et al, ‘Self-perceived Health-related Quality Of Life of Former Extremely Low Birth Weight Infants at Young Adulthood’ (2006) 118(3) Pediatrics 1140–1148. For a discussion on the World Health Organisation’s International Classification of Functioning (ICF) on Disability and Health and its application to children, see, eg, Simeonsson et al, ‘Applying the International Classification of Functioning, Disability and Health (ICF) to Measure Childhood Disability’ (2003) 25(11–12) Disability & Rehabilitation 602–610.
disability may be given more or less weight, dependent on who is assessing such quality of life.\textsuperscript{65}

For example, physical impairment may be less important to an individual than mental impairment. Millions of individuals wear corrective lenses in glasses due to a visual impairment, but would be unlikely to question their ‘quality of life’ or consider themselves limited in choices or lifestyle. In contrast, a lower intelligence quotient (IQ) or learning disability is more likely to affect an individual’s life choices, career and socio-economic outcomes. Saigal and Tyson’s studies indicate that parents and doctors may report a higher level of disability and lower quality of life than the affected person. They assert:

\hspace{1cm} Several studies have shown that proxy respondents tend to report higher morbidity and lower QoL (Quality of life) than the individuals whose perceived health status and QoL is being judged. It also appears that the perceptions of health professionals and caregivers are often at odds with those of patients. Parents’ views on QoL may be negatively influenced by the burden of caregiving, stress, and their own mental, social, and economic status. Children generally report they have fewer problems and a higher QoL than do their parents and clinicians.\textsuperscript{66}

This is supported by Zutlevics, who argues that ‘the impact on families and particular affected individuals from disability is also highly variable’. Disability activists are concerned about a ‘general misapprehension that people with moderate or greater


\textsuperscript{66} Saroj Saigal and Jon Tyson, ‘Measurement of Quality of Life of Survivors of Neonatal Intensive Care: Critique and Implications’ (2008) 32(1) \textit{Seminars in Perinatology} 59, 62. See also, Saroj Saigal, ‘Quality of Life of Former Premature Infants during Adolescence and Beyond’ 2013 89(4) \textit{Early Human Development} 209–213.
physical and intellectual disabilities cannot lead lives of quality’. Further, Zutlevics raises the point that ‘more than disability, more crippling is societal attitudes and inadequate resources to assist such individuals’. This is of particular relevance and importance to this thesis, which contends that the allocation of limited public resources should be an objective factor applied in end-of-life decision making for critically impaired neonates born at 23 weeks. This is discussed in detail in Chapter Five.

Research from the UK in 2010 found that premature neonates were ‘more at risk of lower IQ, poorer cognitive function, learning disabilities and behavioural problems than full term babies’. In the BBC documentary mentioned above, Wishart also highlighted that ‘life-saving’ treatments can often cause more harm than good: ‘tubes can lead to lung diseases, drugs to assist with development can cause cerebral palsy and medication for the heart can cause fragile guts to collapse’.

In the documentary, Wishart also provided an illustrative example of the first-hand experience of an individual born at the edge of viability, at 23 weeks. Twenty-one-year-old Heather candidly discussed her disabilities and her perception of quality of life. Heather could only use her left arm, and unless the ‘carers come to the house she is stuck in bed all day. Heather suffered severe depression, had considered suicide and did not see anything positive in her life. Due to her heavy reliance on her parents, she feared losing them and worried about what life would be like when they died: ‘I

---

68 Ibid.
69 McVeigh, above n 20, 17.
70 The Price of Life, above n 20, 00.30.02.
71 Ibid 00.31.17.
72 Ibid 00.32.08.
am massively scared about when my parents die, so, so, so scared, I rely on them so much … each year I get more scared’. 73

As mentioned, this documentary, which also aired in Australia, is commendable, and provided much-needed transparency and a real portrayal of life for those born as, or caring for, extremely premature and impaired neonates. Heather continues to be directly affected by her parents’ decision to push for aggressive treatment to keep her alive at 23 weeks, and her parents are just as affected by their decision.

The birth of her daughter at 23 weeks served as the impetus for Catherine Rutherford to become a nurse practitioner in the Birmingham NICU. She discussed the difficulty parents face when making such life-changing decisions at the time of birth: ‘at that point in time you have no understanding of what people are telling you, because you have a baby, your child in front of you and you want that child to survive’. 74

While Catherine did not openly discuss any doubts or regrets she may have had about her decision not to withdraw treatment, another mother interviewed in an Australian Sunday magazine did. Alexia Pearce spoke honestly about her decision to keep her premature Nathan alive: ‘if I’d known then what I know now about what extremely premature babies have to go through, I wouldn’t have chosen that for my little boy’. 75 Alexia expressed guilt over her decision: ‘even though it was made with the best

73 Ibid 00.33.22.
74 Ibid 00.33.01.
75 McVeigh, above n 20, 16.
intentions … no mother or father wants to see their child suffer. But because of the choices I made, I feel he’s suffered, and still does’. 76

Gunderman and Engle highlight the varying perceptions individuals have about disability and quality of life:

> Judgements about what constitutes an acceptable quality of life may vary from physician to physician and family to family. One family may judge even relatively mild sensory, cognitive and motor impairments unacceptable, while another may eagerly welcome a child that others would regard as neurologically devastated.77

Eichenwald et al described an opposing view held by some parents, in which doctors may decide contrary to initial discussions to continue treatment when a neonate or young infant is considered to ‘appear healthy’. The authors found that some parents showed anger and frustration that their initial ‘agreement’ to withdraw treatment had now been breached. Parents stated that they could not ‘manage an impaired child’ and that their doctors had a ‘duty to respect their wishes’. 78

However, the competing view is that such selective withdrawal decisions may be inequitable. Wilkinson also agrees with this position, that decisions to withdraw treatment based on potential disability could be argued to be discriminatory or ‘based on a false assessment of the quality of life of those with such disabilities’. 79 Both views

reflect the significant levels of subjectivity in both the withdrawal and continuation of
treatment decisions by parents.

(H) Relationships of trust and confidence with the medical team

The one certainty in end-of-life decision making for critically ill neonates is the
uncertainty of the prognosis and survival. Lantos et al note that ‘prognosis will always
depend on a combination of factors, and will always be somewhat uncertain for any
particular baby’. 80

Critically, at this stage, the lack of certainty of outcomes means that doctors often
cannot give parents certainty even about the dying process. As discussed earlier, the
dying process for infants varies considerably. Doctors attempt to communicate clinical
information in the most sensitive manner to parents. There is a fine line between
parents trusting the treating doctor and having confidence in his or her medical
opinion, and parents losing faith and belief in medical judgment when medical
predictions and probabilities become possibilities.

Due to the uncertain nature of predicting outcomes for premature neonates, parents
often doubt their own decisions and those of the medical team, right up to and after
death. McHaffie highlighted a case in which one family ‘recalled being told three times
that when successive treatments were withdrawn their child would die. When forecasts

71(3) Archives of Disease in Childhood-Fetal and Neonatal Edition 218, 220.
proved wrong the parents lost trust in medical expertise and as a result the child’s eventual death took them by surprise’. 81

There is no clear solution to avoid parental loss of trust in the medical team. Often both stakeholders, parents and doctors, tread very carefully, knowing that the decision-making process will be more harmonious when they work together. However, several studies have highlighted that parents prefer open and honest discussion with doctors, even when it entails the communication of uncomfortable or confronting information.

Moro noted one mother that ‘reported that communication and relationship with providers impacted ... experiences of decision making’. 82 Other mothers have expressed similar views. 83 Further, ‘parents need more than just information’ and ‘relationships between both parties can be forged on trust’. 84 Moro argued that ‘trust can be built by admitting uncertainty’. 85 McHaffie echoed a similar sentiment, giving the example of one parent who stated: ‘if they had just told us that (there was no hope before they resuscitated him on day six), we wouldn’t have had to go through all this agony for the next three weeks until he died’. 86

However, doctors are often not in a position to make such predictions, and ‘parents seem able to tolerate a degree of uncertainty and they demonstrate trust in expertise of

81 McHaffie et al, above n 8, 104, 106.
82 Moro et al, above n 22, 52, 58.
83 Ibid.
84 Ibid.
85 Ibid.
86 McHaffie, Lyon and Fowlie, above n 36, 8, 11.
senior clinicians…one of the main contributing factors to their [parents] insecurity is a lack of concrete evidence of a bleak outcome’. 87

Therein lays the problem. Often there is no concrete evidence, and decisions about prognosis and predictions are based on retrospective data and statistics. This also explains why, when one neonate ‘survives’ and continues to flourish in his or her life, he or she is referred to as a ‘miracle baby’. Parents continue to hold onto hope throughout the entire process. Moro et al found that ‘hope can be very powerful and provide a source of strength for parents even in the most dismal circumstances … [In the end,] parents want their health care providers to be honest yet hopeful’. 88

In the Wishart documentary, Lucy, mother of Matilda, born at 23 weeks, felt ‘we have to trust in what the professionals tell us about how much trauma and pain she will suffer’. 89 However, a counter point to be made is that, when parents and doctors disagree on treatment decisions, there is a likelihood of volatility and distrust of the medical team. 90 Overwhelmingly, the studies suggest that for parents to trust treating doctors, those doctors have to communicate to parents, in a firm and honest manner, the harsh realities of the neonate’s prognosis, the confronting truth of the dying process and what to expect.

87 McHaffie, Lyon and Hume, above n 50, 339, 343.
88 Moro et al, above n 22, 52, 58.
89 The Price of Life, above n 20, 00.26.29.
(I) Do parents carry guilt and the burden of responsibility in decision making?

After being intimately involved in the decision to withdraw or withhold life-sustaining treatment to their neonates, parents may feel guilt or carry a heavy sense of burden and responsibility during the process itself. For many parents, the thought of ‘giving up’ may cause emotional discomfort and does not align with external community ideals. There may also be familial influences at play.91

Bracegirdle agrees with this view, stating that ‘parents feel pressurised by family, friends and the media to allow technology to keep trying, and thus may feel compelled to carry on with treatment when they do not feel that the benefit exceeds the harm’.92 In more extreme situations, there may be no parental emotional attachment to a child, yet there remains a continued push for medically futile treatment.93

Wishart documented the perception of baby Simone’s father that his role as a father was to ‘protect’ his child: ‘I’m supposed to be a dad, supposed to protect her, daddies are supposed to look after their little girls’.94 He went on to explain that he would feel like he was killing her: ‘if she’s suffering, it’s bad not to (withdraw treatment) but I couldn’t do it, I’ve killed my own child, couldn’t live with that’.95

93 Lantos et al, above n 81, 218, 221.
94 The Price of Life, above n 20, 00.18.33.
95 Ibid 00.22.24.
Another couple, Claire and Paul, stated that they had wanted their daughter, Holly, resuscitated after Claire’s waters broke at 23 weeks. Holly died soon after birth and was cradled by her parents, who were given the choice to hold her while she remained attached to tubes and had her heart rate sustained by artificial ventilation, or without tubes. Her father Paul asserted: ‘at least we tried, if things don’t pan out at least we can say we had the choice and we went for it’.  

Returning to empirical research, McHaffie’s study reported that medical teams of doctors and nurses assumed that decisions to withdraw or withhold life-sustaining treatment from infants were ‘too weighty a burden for parents to bear … only three per cent of doctors and six per cent of nurses thought parents should take the ultimate decision’. There is much literature that supports the statistics from McHaffie’s study. For example, Pinter suggests that ‘to prevent unnecessary guilt, we (doctors) should always be careful to avoid giving parents the sense that the decision is completely theirs’. Tripp and McGregor convey a similar sentiment:

Although both parents and professionals have rights, it is usually going to fall to the professional team, to elicit how much of their ‘rights’ parents want to exercise—bearing in mind the responsibility and potential for guilt that comes with a right determination.

Further, a doctor’s ‘willingness’ to take on the responsibility of being the decision maker is an ‘important mechanism to ally parental guilt’; ‘parents may actually

96 Ibid 00.05.06.
97 McHaffie et al, above n 8, 104, 105.
welcome the opportunity to be completely relieved of the decision and turn to the courts’. Arguably, this is an exception to the norm, and most parents do not turn to the courts, or only do so as a last resort. This is particularly true in Australia, given the dearth of material in this area, where only two cases have required judicial intervention in recent times.

Contrary to this opinion, many parents feel that the decision falls within their responsibility as parents. As discussed further below, 56 per cent of parents in the McHaffie study believed that they had made the decision. More recently, Moro et al’s study in 2011 found that only one out of the five mothers interviewed expressed feelings of burden in the decision-making process.

Although the decision carries much emotional strain, many parents felt that the experience, although unpleasant, challenged or changed their previous opinions or beliefs. One parent in the study had previously been a devout pro-life supporter, but after experiencing her newborn’s suffering, acknowledged that such decisions were fraught with uncertainty.

It is noteworthy to consider Paris et al’s summary of parental responsibility in end-of-life decisions for neonates, conceptualised against the backdrop of Dostoevsky’s classic novel The Brothers of Karamazov. In the novel, personal responsibility was not considered an option, as ‘collective’ family decisions were made. Paris et al suggest that a similar approach could be taken by families in decision-making scenarios. This

---

100 Ibid.
102 McHaffie et al, above n 8, 104, 105.
103 Moro et al, above n 22, 52, 58.
is often the case in practice: mothers make treatment decisions, taking into account the opinions of the neonate’s father and members of the wider family.

Making life and death decisions is not easy. The difficulties that parents face in wanting treatment withdrawn, or in accepting responsibility for the decision, are of particular magnitude. The guilt associated with actively requesting that a newborn die is a heavy burden, particularly when that newborn is your own child.104

Paris et al illustrate this point, stating:

for parents that choice is not so easy. They look at the physician and ask, Doctor, do you mean you want our permission to kill our baby? How could parents agree to that? How could they endure the guilt of having given up on their child?105

The authors suggest that life and death decisions for neonates or young infants are best made without putting parents in the position such that they feel considerable guilt or responsibility. They suggest that a more assertive approach on the part of doctors, without much ‘choice’ or ‘active involvement’ for parents, in the decision-making process is better for parents:

Do not ask the parents, ‘If your baby suffers a cardiac arrest, do you want us to try to save him?’ Such a question gives parents false hopes and unrealistic expectations, expectations that inevitably lead to demands for more and more interventions and the risk of further complications.106

104 Paris et al, above n 28, 389.
105 Ibid 390.
106 Ibid.
Interestingly, Shapiro described a darker side to the guilt that parents may carry from deciding to withdraw treatment. The author described parents feeling that wanting or allowing a loved one to die was a ‘dirty secret’ that they carried.\textsuperscript{107} It is uncommon that such feelings would be discussed frankly and openly, and indeed, in the wider community, it is considered taboo for parents to express such sentiments. Instead, Shapiro asserts that in these cases, family members may do the opposite to what they really want, driving out taboo feelings by passionately advocating for treatment to be continued.

Montello and Lantos further suggest that there may be ‘strange communication’, wherein individuals may feel discomfort in expressing their true desires or wishes.\textsuperscript{108} This may be considered an unspoken message: the more vehemently parents advocate for treatment to continue, the more they may want treatment not to continue. However, this is perhaps a dangerous assumption to make, as there is potential for severe miscommunication, through a lack of honest communication. A better view may be to push for doctors to engage in a more open and honest dialogue and provide clinical information, while also maintaining a degree of empathy for parents in making treatment decisions.

Perceptions of ‘making the decision’ or being ‘involved’ in the decision-making process vary between parents. Gillam and Sullivan point out that ‘involvement in

\textsuperscript{107} Martha Montello and John Lantos, ‘The Karamazov Complex: Dostoevsky and DNR Orders’ (2002) 45(2) Perspectives in Biology and Medicine 190, 194.

\textsuperscript{108} Ibid.
decision making could lead to guilt and repentance and yet did not regard not being involved as a way to resolve the potential difficulty’. 109

Parents are thus in a difficult situation: the ‘doctor knows best’ paternalism evident in some of the cases examined in Chapter Two suggests that in the early 1970s and 1980s, decision making was predominantly left to the medical professionals. 110 Today, while some parents may find a lack of involvement in the decision-making process easier, the majority would probably disagree. Studies conducted by Orfali and Gordon involving American and French mothers found:

…on the one hand they want to be involved and became angry if they are not given control over many medical aspects of the baby’s care … but no mother in our sample ever requested more active involvement in life and death decisions. They seemed to want some control over a dreadful situation, but none of them expressed an eagerness to take over the terrible act of deciding. 111

As considered earlier in this chapter, parents take several indicators and factors into account when making end-of-life decisions. Some rely on religious or cultural beliefs, leaving decisions in God’s hands and negating any ‘responsibility’ for making the decision. Others make treatment withdrawal decisions based on their neonate’s visual deterioration, and a desire to end their newborn’s pain and suffering.


110 Pinter, above n 99, 430, 433. See also R v Arthur (1981) 12 BMLR 1.

McHaffie et al found that a majority of parents did not feel guilt or doubt about the decision to withdraw treatment. Only one mother in their study referred to any feeling of guilt, with this being related to her individual feeling, possibly selfishness, in not wanting her newborn to die, ‘when she knew it was in his best interests’. Further, Pignotti asserts that the overwhelming consensus in Europe is that parents play a crucial role in decision making for their children, based on the ‘assumption that, in exercising their authority, they are acting in their child’s best interests’.

Pignotti’s study also indicated that, rather than wanting to be ‘spared’ the trauma of decision making, parents were ‘appalled’ at the idea that decisions about their newborns could be made without their involvement. This leads to a final consideration about the role and impact of parents as key stakeholders in end-of-life decision making for critically impaired neonates.

(j) Are parents the ultimate decision maker or is it an illusion?

Parental autonomy in decision making for their children is important, and the law provides parents with a significant amount of discretion on such matters. However, as Stewart noted, ‘in the case of minors, the rights of parents to consent or to refuse medical treatment are not absolute’. This prevailing legal opinion seems to have long-standing global consensus. This was evinced in an American president’s

---

112 McHaffie, Lyon and Hume, above n 50, 339, 343.
114 Ibid.
commission 30 years ago, when it was stated that ‘parental authority must occasionally be superseded by clinicians when it is determined that the parent’s decisions are at odds with societal consensus about what best serves a child’s interests’.116

From the case law and discussion presented in this chapter, it is clear that parents find it difficult to accept that the best possible therapy is often non-treatment. Many journeys across different terrain are taken for parents and wider family units in arriving at the reality that their neonate will not survive, or that survival will not provide a fruitful life. Nevertheless, a majority of parents perceive that they have been the ones to make the final decision to withdraw treatment.

McHaffie et al reported that 56 per cent of parents felt that the ultimate decision was theirs. The 7 per cent that did not make the ultimate decision wished they had done so.117 Further, parents felt that this decision had to be made by them as part of their responsibility as a parent. However, most parents cannot make an informed and independent decision to withdraw or withhold life-sustaining treatment due to their lack of medical skills, training and information. Gilliam and Sullivan assert that ‘many parents wanted to participate [in decision making], but not decide, citing lack of medical knowledge and the possibility for emotional factors to overwhelm a rational decision’.118

117 McHaffie et al, above n 8, 104, 105.
118 Gillam and Sullivan, above n 110, 594, 596.
Thus, any decisions regarding neonates must be made in collaboration between the parents and the medical team. For this reason, transparent, honest and informative relationships between parents and doctors are crucial.\textsuperscript{119} However, parents are often aware of the inequality that exists between medical staff and parents. McHaffie found that discussions or disagreements between staff about treatment decisions happened ‘behind the scenes’, yet when discussing options with parents, the medical team stage a united front. Often doctors excluded certain information from parents that they deemed ‘irrelevant’ to decision making, to strengthen a particular professional opinion or recommendation about treatment.\textsuperscript{120} This will be discussed in greater detail later in this chapter.

This leads to the question of who is really making the decision. It would seem that doctors ‘stage’ the communication process with parents, making parents believe they are casting the deciding vote. Given that parents are those most affected by decisions to withdraw treatment, both at the time and for many years later, this staging could be seen as allowing parents to draw some closure, solace and comfort in believing themselves to have made the choice, enabling them to bid farewell to their child with a sense of benevolence and duty.

The discussion so far has focused on parental involvement in decision making to withdraw or withhold life-sustaining treatment from critically impaired neonates. It has been noted that the medical team takes into account parental wishes and that parents play an active role in the decision-making process. However, situations arise in which parents oppose the treatment options that doctors deem best for the neonate.

\textsuperscript{119} This point is supported by Bracegirdle, above n 93, 513, 514.
\textsuperscript{120} McHaffie et al, above n 8, 104, 107.
In such instances, doctors must work together with parents to help them understand their options.

It is established in law and medicine that parents cannot seek to demand or refuse life-sustaining treatment for a critically ill neonate. As considered in Chapter Two of this thesis, parental wishes are noted and carefully considered. However, the prevailing interests of the child are given paramount importance. Ahluwalia et al make this point:

…decisions are to be jointly made on the basis of the infant’s best interests, with clinicians and parents entering into what has been described as a ‘partnership of care’. The parents’ wishes, while significant, are not overriding. The treating physician continues to have an independent responsibility towards the newborn’s well-being.121

Nevertheless, while they should not dictate the fate of the neonate, parental wishes must be given considerable weight. Each individual is a complete moral entity, and given legal rights at birth, a neonate’s moral status is not derivative upon others. It is beyond the scope of this thesis to examine the entire area of personhood; however, it is established in English law that once a child is born, they transition from the legal status of a foetus to a person possessing individual rights.122

As one of the key stakeholders in the decision-making process, parents’ decisions and perceptions are influenced by many factors. All these variables are subjective, and no two families reach their conclusions identically or experience their newborn’s death in the same way.

When examined as a group from a macro level, given their subjectivity, parents could be considered unpredictable and confused. This is understandable, given their position as the most immediate and emotionally connected of the relevant stakeholders.

In seeking to navigate the decision-making process, and in looking for clear objective advice, parents will turn to the next most immediate stakeholder, their doctors and medical advisors, who are considered in the next section of this chapter.

IV: Doctors: Subjectivity, conflicting interests and views

The previous section considered the perspective of parents in end-of-life decision making, raising the issue of the emotional conflict they face in making these challenging decisions. By contrast, medical practitioners might be seen as the more able of the two stakeholder groups in taking a clear and dispassionate approach in the decision-making process. However, as detailed below, this is not necessarily the case.

As the examination of case law in Chapter Two highlighted, between the early cases in the 1980s, in particular Dr Arthur’s case, and the more recent case law of the 2000s, there has been a shift in both parent and doctor attitudes and perceptions of the role and duties of the medical profession. A move towards a ‘rights’-driven culture and greater awareness of personal autonomy may have contributed to this change in the doctor–patient dynamic. There is potential for conflict between parents and doctors,

123 This has entailed a shift from withdrawing treatment at a parent’s request such as in the case of Baby John Pearson, to doctors resisting treatment that they consider to be futile, even when parents request treatment continuation.

124 Professor Julian Savulescu has researched and examined the area of medical decision making, rationalism and autonomy in detail, taking into account medical, legal and philosophical theory. See further, Julian Savulescu, ‘Autonomy, the Good Life, and Controversial Choices’ in Rosamond Rhodes, Leslie P Francis and Anita Silvers (eds), The Blackwell Guide to Medical Ethics.
evidenced in the case law wherein treatment withdrawal disputes have turned to the courts for resolution. Moreover, there is clear inequality between the two groups, with one group possessing expert medical knowledge, while the other does not.

This inequality is reinforced by a doctor’s sense of empowerment, driven in part by the development of new technologies and the expansion of neonatology as a field of medicine. Arguably, saving from death those neonates still young enough to die and be considered a miscarriage or even aborted has allowed doctors to feel a sense of authority and benevolence.

Guyer supports this view, asserting that the parent–doctor collaborative decision-making process is often quite to the contrary: ‘…what happened in the NICU was not collaboration but collision. Some doctors were loathed to give up their positions as the primary decision makers, and even today some continue to cling to old paternalism’.  

However, support for the view above is not universal. Truog believes that doctors are losing their ‘professional autonomy’ by being forced to provide treatment they consider futile. He further states that patients’ relatives place heavy and inappropriate demands on doctors, and that the traditional hierarchy of doctor and patient is being eroding. Gampel further asserts that placing such demands of continuation or


125 Guyer, above n 14, 40.

discontinuation of treatment on doctors could be seen as making doctors ‘slaves to whatever patients want’. 127

The traditional view of the medical profession and medical ethics is that it is driven by ideals of paternalism, beneficence and non-maleficence. Further, the belief is that a doctor will always do good for his or her patients and will never harm them. 128 However, this is a simplistic notion. Doctors, like parents or any other human being, are exactly that—human. Like parents, they are the sum of their life’s experiences and at least partially driven by the same emotions and prejudices. The decisions that medical practitioners make in their professional setting are thus also affected by these factors, and are not intangible or exclusively independent.

Further to this, each doctor’s personal beliefs and attitudes will differ, and consequently their ultimate treatment decisions for critically ill neonates may vary considerably. 129 Craig iterates, ‘there are times when two doctors, each with the best interests of the patient at heart, would treat in diametrically opposite ways’. 130 End-of-life decision making for critically impaired neonates is thus influenced by medical practitioner subjectivity, highlighting the contention of this thesis—that there is a need for greater transparency and for decisions to withdraw or withhold treatment from critically ill neonates to be based on objective grounds. A driving force and a significant consideration in this regard should be the allocation of limited resources. 131

---

131 This is considered in Chapter Five of this thesis.
An examination of some of the factors affecting medical stakeholders in end-of-life decision making follows.

(A) Religious beliefs and cross-country attitudes

Having considered the role played by religious beliefs in influencing parents, this section considers whether doctors are also subject to such influences. Cross-country empirical research suggests that end-of-life decision making for neonates varies within Europe, with the secularity of certain countries also a determining factor.

The EPICure studies from the UK, considered in Chapter Three, and a EURONICS study across Europe overwhelmingly indicate that doctors acknowledge that there must be ‘limits’ to the amount of intervention they provide to premature neonates.132 However, this is the only issue on which there is consensus. The studies reveal a surprising range of views as to the gestational age such decisions should be made. Some variability is understandable, given the differing jurisdictions and educational backgrounds.

Warrick notes that the ‘highest rate of physicians in agreement was in the Netherlands, the UK and Sweden’.133 This is perhaps predictable, particularly given the progressive societal attitudes and secular democracies of these countries. The lowest rate of withdrawal of treatment decisions were in Spain and Italy, perhaps reflecting the

---

133 Ibid.
strong Catholic influences operating in these countries. If correct, this supports the view of a religious influence in medical decision making.

Further, Rebagliato et al provide some important data that supports this correlation.\footnote{134} They found that 33 per cent of doctors in Italy believed that all human life is sacred and therefore that all premature neonates should be treated aggressively regardless of severe disability as a consequence. The study also found that greater consideration to ‘quality of life’ was made by female doctors that were either protestant or did not consider religion as an important factor in their lives.\footnote{135}

The resuscitation of premature neonates is mandatory in Italy, and the law strongly advocates a pro-life stance, even in instances of an induced late abortion.\footnote{136} This creates a potential for internal conflict for an Italian doctor, where he or she may believe that withdrawal of treatment is in the best interests of the newborn. In such cases, the doctor’s decision is bound by the dominant faith, prevailing tenet of sanctity of life and the illegality of withdrawal of intensive care treatment in that country.\footnote{137}

Doctors of the Jewish or Muslim faith have also been found to make end-of-life decisions based on their faith, sometimes justifying withdrawal of treatment based on Jewish law rather than considering the lawful authority of the country in which they reside. Warrick et al highlight this point:

\footnote{134} Rebagliato et al, above n 2, 2451.\footnote{135} Ibid 2455.\footnote{136} Ibid 2458.\footnote{137} Pignotti, above n 114, 405.
In the Jewish faith active withdrawal of care, e.g. discontinuation of ventilation is forbidden. In clinically stable infants with a poor prognosis, withholding treatment is unacceptable as one should not judge the quality of another’s life. However, if an infant is likely to die then Jewish law states that ‘one must not impede the natural departure of the dying soul’.138

This decision-making process is challenging. Doctors are seemingly not only being guided subjectively by their religious beliefs, but also by religious laws that may not have any bearing on the laws of the relevant jurisdiction.

This is supported by Morris, who reinforces that subjective factors play a significant role in decision making, and that treatment decisions are often swayed by the social and religious values of the consulting physician. Morris claims that in situations in which the doctor held religion in high regard, the decision to withhold or withdraw treatment was less likely.139

Interestingly, Morris posits that, although doctors in the UK strongly believed that parents should be involved in decision making, they felt that the ultimate treatment decision rests with them (doctors). Significantly, she states that ‘ownership’ of the final decision provides doctors with the opportunity to give greater weight to their own personal non-clinical views.140

A study published in the Journal of Perinatology in 2007, found that American doctors made treatment withdrawal decisions based on their own interpretation of the ‘grey

138 Warrick et al, above n 133, 110.
139 Morris, above n 129, 364.
140 Ibid 365.
zone’ of gestational period. Eighty-five per cent of neonatologists in the study stated that resuscitation should be enforced anywhere between 22 weeks’ gestation to 26 weeks.141 In this study, the disparity of gestational ‘grey zones’ and doctors’ personal fear of litigation were the subjective factors that most determined treatment decisions, while religious beliefs or practices were less significant for this group of doctors. The study found, ‘the litigiousness of parents may result in resuscitation of infants against the physician’s better judgement’.142

By contrast, French neonatologists do not share a similar fear of litigation; on the contrary, they feel empowered to make decisions, often without seeking any parental involvement. French doctors perhaps perceive giving parents rights and choices in decision making as ‘opening the flood gates’ to issues of liability and arbitration.

Orfali supports this view: ‘French neonatologists seem actually reluctant about any legal change that could restrict their action; and their attempts to provide rules for self-regulation are a way of obviating the need for changes in the law’.143 The French medical system widely perceives the American legal system as an ‘anti-model’. Orfali finds:

…opposition to what they consider to be a perversion in the American legal system. Liability issues in the US are highly publicised in France, and are viewed as an anti-model contributing to on-going disputes between patients, parents, families and doctors’.144

142 Ibid 758.
144 Ibid.
(B) Doctors’ perceptions of death, disability and decision making

Of the three stakeholder groups considered in this chapter, medical professionals have the most exposure to death. It is not uncommon for neonatologists and other medical professionals to experience the death of one or several patients in any given ‘working week’. While doctors may be thought to be accustomed to this, particularly considering that decisions to withdraw life-sustaining treatment are common in the NICU, this is often not the case, as explained below.

A study conducted by Neonatologist Dr Peter Barr from NSW, Australia supports the view that there is a correlation between withdrawal or withholding life-sustaining treatment and doctors’ personal fears of death and dying. In the study, doctors were asked to consider forgoing life-sustaining treatment where its goal was to relieve pain and suffering or where further treatment was considered futile and burdensome on the neonate. Given the sensitivity and possible illegality of the issue, the surveys were anonymously completed by both Australian and New Zealand neonatologists registered in units across both countries in 2004.145 Barr avoided any issues of contention:

What I indicted to them was that I was asking them something that was medico-legally illegal.

And so I asked them to put that concern to one side for the purposes of answering the questions.

So it’s a self-report questionnaire, rather than ask them what they do in practice.146

However, Barr’s assertion is not entirely correct: given the findings and purpose of the questionnaire, the findings were not ‘hypothetical’, but were more likely to relate to ‘clinical practice’. Of the 138 surveys distributed, 78 were returned. Ninety-four per cent of neonatologists stated that they would provide adequate medication to control pain and suffering, even if the dosage was too high and caused hastened death.\(^{147}\) Barr found that of the eight facets of ‘fear of death’ listed in the survey:

Doctors with a greater fear of the dying process and greater fear of premature death are more likely to accept hastening a newborn infant’s death when further treatment is non-beneficial or overly burdensome, whereas those with a greater fear of being destroyed are less likely to condone such an action.\(^{148}\)

Further, the survey found that an overwhelming number of doctors were prepared to forgo treatment or provide pain relief with the intention of hastening death. Barr stated: ‘ANZ neonatologists seem to support the moral notion that it is sometimes “better to kill than let die” even though, the former is unlawful and seems not to respect the “sanctity of life”’.\(^{149}\)

Barr demonstrates that it is possible to have an open, honest dialogue outside the closed doors of hospital meeting rooms, allowing non-medical professionals to understand what ‘really happens’.\(^{150}\) However, the information arising out of this dialogue does not sit comfortably with everyone. In his article, Schultz reported that Barr’s study


\(^{148}\) Barr, above n 146, 104, 106.

\(^{149}\) Ibid.

\(^{150}\) Loane Skene, Law and Medical Practice: Rights, Duties, Claims and Defences (Butterworths, 1998) 247.
found that ‘one third of Australian doctors would euthanise sick babies’, causing pro-life activists to condemn the findings and question the rights of doctors to ‘kill another person’.151

Subjectivity is also evident when doctors make decisions to treat premature neonates in the face of severe lifelong disability. While some doctors make decisions to aggressively treat in light of their religious beliefs, others may take quality of life considerations into account. Orfali’s study, for example, found that French neonatologists considered the survival of a neonate with severe disability or impairment to be the ‘worst risk’ of continuing treatment.152

As considered in relation to parents as stakeholders, perceptions of disability and the future prospects of neonates are also factors affecting the decisions of treating doctors. Considering that the doctor will not have to bear the stress and financial burden of raising the disabled child, the doctor’s subjectivity in providing aggressive treatment to neonates that will survive with severe disability can be viewed as egotistical. This treatment choice may be a protection for the doctor’s own moral conscience, with little regard for the financial and emotional costs to the family and society once the child has left the NICU.153

In this regard, the French stance should be contrasted. The Orfali-led study found that ‘the acceptability of disability led to very pessimistic evaluations of the infant’s current

151 Shultz, above n 148.
152 Orfali, above n 144, 2018.
153 This is discussed in Chapter Five of this thesis.
and future condition’.154 One doctor interviewed for the study stated, ‘when one imposes such severe handicap on parents, one has a responsibility towards society’.155 French doctors thus appear to have a radically different approach to disability and premature neonates; that is, they recognise the burden to society once a child has left the NICU, and consider that the preservation of life at all costs is not absolute. This point is supported by Orfali’s findings that, ‘statistically there are more divorces and things like that … the same clinicians operate in the NICU and the follow up clinics gives them a kind of legitimate expertise: they know by experience the consequences of their medical intervention’.156

Another example of this wide-angle approach is that French neonatologists believe that their involvement and medical intervention is directly responsible for any arising repercussions and that it is their ‘professional duty to correct them in the appropriate way’.157 One doctor stated, ‘the professional duty of neonatologists is to give parents a child in good condition. I have always thought we should limit treatment instead of giving (the parents) a handicapped child’.158 The French approach is undoubtedly paternalistic, although markedly different from the other examples of judicial and medical paternalism examined above. French neonatologists distinguish themselves in their confidence and clarity in linking their professional obligations to the infant and its family to those they owe to society.

---

154 Orfali, above n 144, 2018
155 Ibid.
157 Ibid.
158 Ibid.
As considered in Chapter One, France was the birthplace of neonatology, the purpose of which was to help to rebuild France’s decimated population. While it may be expected that its long history with the field would make French medical professionals leaders in advocating for saving imperilled neonates, such a view would ignore that neonatology did not derive from a sense of principle to save individual neonates. Rather, the development of neonatology was driven by considerations of the state; a tradition that modern-day French neonatologists appear to be carrying forward.

(C) Different parents, different treatment—Are parents treated differently by doctors?

At a conference in Geneva in 2012, Chicago-based neonatologist, William Meadow, discussed the socio-economic factors and attendant cultural attitudes of African American mothers such as often presented at his hospital. Many mothers that have neonates born at 23 weeks passionately express their desire for resuscitation at birth. Meadow recalled one woman stating ‘save my baby and treat me seriously as a woman in a bad situation’. However, when doctors are of the medical opinion that any treatment would be futile, they often allow parents to believe that they have ‘done everything they can’ to save their baby. Such ‘sham attempts’ allow parents to believe that everything that could possibly have been done to save their neonate has been done, and they are grateful that the doctors ‘tried’.

---

This again highlights the imbalance of power between doctors and parents. However, in this instance, the play on power and the dispersal of information may actually save parents from heartache and guilt and assist them through the grieving process.

Doctors also make decisions to treat more aggressively based on the likelihood of a mother experiencing pregnancy again. This has become a more relevant issue in recent times with the development of reproductive technologies such as IVF.  

Older parents who have used reproductive technologies may be more willing to accept a child with severe disability, as the pregnancy may be their last chance of having a child. Meadow commented that ‘older mothers may consider wanting the child to survive even at odds of five per cent survival with one hundred per cent disability’. He further noted that this group of parents are more likely to be accepting of technology, given its utilisation to conceive in the first place.

According to Meadow, doctors were more willing to apply aggressive treatment for longer periods if the mother of the neonate was older, or had conceived by IVF treatment after several years of infertility. This attitude towards withdrawal of treatment could be perceived as discriminatory in nature. Moreover, such discrimination is not exclusive to the age or fertility history of the parent, it is also apparent in doctors’ perceptions of pre-term infants as patients.

---


161 Meadow, above n 160.

162 Ibid.
Are pre-term infants treated differently to other patients?

While one might predict that there would be a strong desire on the part of doctors to protect neonates given their fragile, vulnerable status, a study conducted by Canadian neonatologist Annie Janvier found that doctors and medical students did not prioritise treatment for premature neonates above other patients.

The study, which comprised an anonymous questionnaire, posed a scenario with eight critically ill patients ranging from a 24-weeks-premature neonate to an 80-year-old patient suffering dementia and a recent stroke. The patients in between this range included a two-month-old with meningitis, a 14-year-old with leukaemia and a 20 per cent chance of disability, a 35-year-old with brain cancer and a 100 per cent chance of handicap if operated on, and a seven-year-old with cerebral palsy and learning difficulties.163

Janvier noted 842 respondents, including neonatologists, obstetricians and emergency doctors, and students across the disciplines of anthropology, law, medicine and bioethics. She found that of the hypothetical patients, pre-term neonates ranked seventh out of eight, only ahead of the 80-year-old stroke victim.164 The median order ranked the two-month-old with meningitis as the patient that both medical practitioners and students would resuscitate if they could only treat one of the eight patients. Sixty-


164 The order from first to eighth was: 2-month-old with meningitis, 7-year-old with multiple disabilities, 14-year-old with Leukaemia, full-term baby with brain malformation, 50-year-old trauma victim, 35-year-old with brain cancer, 24-week pre-term and 80-year-old stroke victim.
one per cent of respondents ranked the 35-year-old with only a 5 per cent chance of survival and a 100 per cent chance of disability if operated on higher than the 24-week neonate.

This study clearly indicates that premature neonates may be treated differently by medical practitioners. Janvier suggests that one reason for this may be that women are able to abort a pregnancy at a similar gestational age; hence, a premature neonate may not be considered as having the same legal rights or status as other patients, even though born alive.

This aligns with Peter Singer’s view that neonates and young infants lack personhood, autonomy and self-consciousness, and that as such medical professionals and students ‘de-value’ them as members of society. This further reinforces the power that doctors possess in making selective treatment decisions, and reiterates the potential consequences of their subjectivity.

(E) The framing effect

Subjectivity and variability extend to even the manner and type of information that physicians consider important for parents to know and understand. This can vary between doctors in one unit and across different departments, dependant on whether their focus is on withdrawal of treatment and palliative care or intensive care.

---

166 Jox et al, ‘Medical Futility at the End of Life: The Perspectives of Intensive Care and Palliative Care Clinicians’ (2012) 38(9) *Journal of Medical Ethics* 540, 542.
is indicative of a possible internal power struggle between clinicians and departments in having the ‘final influencing role’ in life and death decisions.

McHaffie et al found that doctors gained confidence and authority in decision making through their personal experience. The experience gained then played a pivotal role in influencing recommendations in similar cases. Further, the development of strong communication skills to present a coherent and well-reasoned case directly influenced parents’ perceptions and opinions on treatment decisions. McHaffie et al acknowledged that this is a dangerous path for doctors to take, and referred to ‘recommendations becoming self-fulfilling prophecies’, leading to complacency in making decisions in which results can vary significantly. This view has been supported more recently by Wilkinson, who highlighted that such self-fulfilling prophecies ‘may compromise honest communication with families by causing doctors to mislead families about the patients chance of survival’.

Janvier has discussed the ‘framing effect’: the technique of carefully managing the flow of critical information to parents. Janvier suggested that many parents only remember 25 per cent of the information they receive from the doctor. Accordingly, information and its absorption by parents is dependent on how a doctor ‘frames’ the conversation—thus the ‘framing effect’.

Using this technique, doctors might explain to parents that half of neonates born at 23 weeks die and half survive. From this communication, parents tend to hear only the

---

167 McHaffie et al, above n 8, 104, 106.
168 Wilkinson, above n 91, 401, 407.
169 Janvier, above n 35.
170 Ibid.
latter, positive, part of what is said. Presumably, the selective retention of information on the part of parents is based on hope, as discussed earlier in this chapter.

Janvier found that ‘there were differences in what doctors considered to be ‘important’ information and what the parent perceived as important’. Individuals generally prefer decreasing numbers, and consider what Janvier refers to as the ‘yuck factor’ last. However, the ‘yuck factors’ are what many doctors consider the most important: future prognosis, type of disability, pain and suffering—such information is confronting for many parents.171 The best approach is to present parents with pictures, crosses and ticks rather than charts, graphs and percentages. Instinctively, parents will seek even the slightest improvement or positivity in figures. Catherine Rutherford, interviewed by Wishart, confirms this view: ‘as a parent you hear what you want to hear, you cling onto that five per cent chance’.172

It is evident from the discussion above that doctors hold the ‘trump card’; and like in any transaction in which there is room for negotiation, doctors will cajole, coerce or attempt to influence parents to their way of thinking. This is supported by Moro’s empirical research, in which a nurse stated that ‘she felt that the physician’s presentation of … information [chances of survival] was leading and may have affected decision making [for the parents].173 Further, many parents focused on the information with which they were provided by doctors, and were sensitive to whether information was expressed negatively or positively.174

---

172 The Price of Life, above n 20, 00.34.17.
173 Moro et al, above n 22, 52, 58.
174 Ibid.
This suggests that, although doctors have the medical knowledge and power to dictate and sway parental decision making, often in the midst of emotional turmoil. A better approach may be to empower parents with information that is clear, honest and understandable. In this way, some balance can be injected into the parent–doctor power dynamic.

Kuschel and Kent support this view:

…the relative emphasis of the information provided needs to be gauged against the needs of the family and an assessment of what is appropriate for the infant’s situation. It is critical that clinical staff are as objective as possible when information is provided yet empathetic to the circumstances of the family, as the tone or delivery of the message can have as great an impact as the content.175

The ‘framing effect’ is demonstrated in the findings of a survey of neonatologists conducted by Eichenwald et al. The survey posed a hypothetical scenario concerning further resuscitation decisions for a 23-week neonate. The same prognosis and information was framed as negative—the ‘chance of dying and likelihood of disability’—and positive—‘likelihood of survival with lack of disability’.176 Of those surveyed, 76 per cent chose to resuscitate and 24 per cent chose comfort care.

However, the results from this study were not definitive for all parents and doctors. The reality is often very different: parents are in an unfamiliar, unpleasant environment, being bombarded with distressing information, framed by medical

175 Kuschel and Kent, above n 92, 585, 587.
176 Eichenwald et al, above n 79, 616, 618.
professionals to convey selected information.\textsuperscript{177} This information leads to decisions which have irrevocable consequences, and thus must be balanced between rationality and humanity. It may be the case that such subjectivity in decision making overshadows the ultimate stakeholder—the neonate. It must not be forgotten that such decisions and conversations are to determine whether another human being lives or dies.

With this in mind, Janvier makes a valuable point. She states that it is important to assist parents to understand numbers and data for them to make rational decisions, using both their head and their heart.\textsuperscript{178} Indeed, Janvier can be regarded an appropriate authority on this matter, considering her own experiences of making treatment decisions following the birth of her daughter Violet at 24-weeks’ gestation.\textsuperscript{179}

As she reports, although both she and her husband were neonatologists, their experiences and focuses differed. While she concentrated and relied on clinical statistics, data and her medical knowledge, her husband placed greater emphasis on emotions and any signs of movement or life. Their daughter survived, and the author acknowledges the importance that emotions play in decision making. As previously mentioned in this chapter, some of life’s most precious and influential moments centre on emotion, and although emotions cannot be relied upon solely in cases of making such significant decisions, they should not be disregarded. As Higginson and Janvier

\textsuperscript{177} A better view is held by Dr Ross Haslam, Associate Professor of Neonatal Medicine at the Women’s and Children’s Hospital in Adelaide, Australia, who described re-phrasing withdrawal of care more sensitively to parents as ‘re-directing’ care to palliative care.

\textsuperscript{178} Janvier, above n 35.

state, ‘medical research narrowly focuses on issues that can be measured … [However,] most decisions in life are not based on measurable quantities’.

(F) The roster lottery

In Chapter Three, the examination of clinical guidelines and frameworks concluded that there is no objective unified set of rules that is adhered to by medical professionals when making end-of-life decisions. There are an abundance of non-exclusive guidelines to which to refer; however, the non-binding nature of these reflects that decisions regarding treatment are unaudited and rarely challenged.

Within same states governed and funded by the same health systems, different hospitals exercise their prerogatives based on religious or cultural factors. The scope of subjectivity extends to the doctor treating patients within one unit. Some doctors may treat more aggressively that others, allowing their own beliefs and opinions to override the wishes of parents, and possibly the best interests of the neonate.

Given the number of variables and the amount of subjectivity that doctors apply when making end-of-life decisions, the term ‘roster lottery’ seems appropriately fitting here. In the crudest form, this term highlights the depth of physician subjectivity, where decisions may be based primarily on their own values and belief systems. Which doctor is on call when a 23-week neonate is delivered can potentially be the deciding factor in whether treatment is withdrawn, withheld or continued.

181 Examples of religious affiliated hospitals in Melbourne are The Mercy and St Vincent’s Hospital.
One result of this might be that parents decide to ‘shop around’ for a hospital and particular doctor that they believe is more inclined to treat or not treat in accordance with their own values and beliefs. Such decision making is random, unethical and indefensible, given that decisions are being made about life and death, with the consequences being absolute.

Wilkinson and Troug assert that arbitrary decision making may be particularly prevalent when the patient’s values are unclear.182 This certainly seems to be the case in making decisions for premature neonates. Wilkinson and Troug further acknowledge that varying attitudes can ‘impact on actual decisions’.183 This supports the call of this thesis for developments aimed at reducing subjectivity in decision making regarding withdrawing or withholding treatment for critically ill neonates.

Finally, having considered the extent of doctors’ subjectivity in making end-of-life decisions, it is appropriate to pose the question: Should the role of doctors, and the autonomy that they are given, be reduced?

(G) Should doctors be considered as functionaries?

The beginning of this chapter discussed the shift in societal attitudes from an acceptance of the traditional ‘doctor knows best’ approach towards a more autonomous and rights-driven culture in which patients feel confident in challenging medical opinion. Indeed, as detailed above, the former approach suffers from

---

183 Ibid 1131.
inconsistency and subjectivity on the part of medical practitioners making life and death decisions. Supported by a wealth of academic literature, incumbent in the acceptance of the shift towards the latter rights-driven approach is a consequent requirement to question the medical profession and their essential function.

Certain standard ethical practices are understood by doctors and patients alike as unacceptable. Examples include not having sexual relations with patients, and not disclosing confidential patient information. The question then is why doctors basing their decisions on their own personal and religious beliefs is allowed to slip through the ethical net. One reason would be that this issue is contested. Foster, for example, believes that for medicine to be practiced to its full potential, doctors need to be more holistic and autonomous. He asks, ‘how can they [doctors] be equipped to deal effectively with the complex bundles of contradictions they call their patients?’ 184

However, a more realistic view is held by medical doctor and ethicist Julian Savulescu, who succinctly states:

To be a doctor is to be willing and able to offer appropriate medical interventions that are legal, beneficial, desired by the patient and a part of a just healthcare system. If we do now allow moral values or self interest to corrupt the delivery of the just and legal delivery of such health services, we should not let other values, such as religious values, corrupt them either. 185

Savulescu’s view is persuasive. An objective, fair system of medical treatment is crucial. Taxpayers, who fund public health systems, should be confident that treatment

---


will be dispensed in a fair, just and objective manner, precluding doctors’ subjective values or judgments. As Savulescu points out, ‘public servants must act in the public interest, not their own’.  

The role of doctors should be functional. Savulescu states ‘…a primary goal of a health service is to protect the health of its recipients’. He takes this expression further, arguing that ‘doctors who compromise the delivery of medical services to patients on conscience grounds must be punished through removal of licence to practise and other legal mechanisms’. 

It is important to note that to ‘protect the health of recipients’ is not necessarily the absolute extension of treatment, particularly in the case of premature birth, where survival is unlikely or carries a risk of severe and debilitating disability. It may be that the best way to protect fragile patients is not to prolong their inevitable death or pain and suffering.

Given the significant role that subjective beliefs and values play in decision making, it would be appropriate to reduce doctors’ decision-making powers, placing greater emphasis on clinical and technical factors dictated by an overseeing body or governed by stricter sanctions and protocols to which doctors must adhere. Doyal and Lister support this view, highlighting the need for public policy on treatment decisions, to

---

186 Ibid 297.
187 Ibid 296.
188 Ibid.
overcome the ‘rules of thumb’ that doctors apply to cases, based on their own ‘personal convictions’. 189

Bagaric and Amarasekara assert that, although doctors’ views should be considered, they should by no means be the vehicle that drives decision making in a particular direction:

Quite simply, there is no reason to think that doctors have a higher level of moral insight that the rest of the community. Certainly, their views should not be discounted—the views of any member of the community concerning moral issues cannot be ignored. However, they should not be given any extra weight… 190

As discussed in Chapter Two, the medical profession plays a crucial role in determining and defining the principles of best interests and futility; 191 concepts on which the courts rely when hearing treatment disputes. Doctors define and characterise the very concept of futility, as Stewart eloquently stated: ‘part of the problem with the concept of futility is that it is a subjective notion masquerading as a form of professional, objective and scientific assessment’. 192

---


191 See, further, Lindy Willmott, Ben White and Jocelyn Downie, ‘Withholding and Withdrawal of “Futile” Life-Sustaining Treatment: Unilateral Medical Decision-making in Australia and New Zealand’, (2013) 20(4) Journal of Law and Medicine 907–924. The authors highlight that in multidisciplinary literature, there are a range of definitions used for the concept of futility, including ‘will not work’ to ‘not worth doing’.

Yet, because this concept arises out of the medical profession, often, no other stakeholder, not even a judge, will contest or overrule a doctor’s definition of futility or decision to withdraw or withhold treatment. This display of professional sovereignty is clear, and Stewart correctly asserts:

The medical concept of futility is based on a similar concept of sovereignty: in situations of end of life care, it is the medical profession who control the definition of futility and therefore control what treatments are provided to the exclusion of other claims for control.¹⁹³

Doctors thus have the overwhelming power in making life and death decisions. The gravity of this power has been commented on by Willmott, White and Downie,¹⁹⁴ who provide four compelling observations about the current practice and power that medical practitioners in Australia and New Zealand have in relation to treatment decisions:

1. There is no general duty on doctors to provide treatment that they consider to be futile.
2. Doctors do not need consent from the patient or a substitute decision maker, or authorisation from the courts or elsewhere to withdraw or withhold treatment they consider to be futile.
3. They are the decision makers as to when their duty to treat ends, and for determining when treatment is futile.
4. There is no obligation on the part of the treating doctor to facilitate the resolution of a dispute in this way [by means of a court/tribunal]. The onus rests on the family or other party objecting to the treatment being withheld or withdrawn.

¹⁹⁴ Willmott, White and Downie, above n 192, 914–915.
These observations reinforce the need for clarity in the roles that doctors play. The medical practitioner’s role should be reduced from decision maker to medical enabler in the decision-making process, and their activities, whether undertaken or not, should adhere to certain protocols and be accountable, auditable and subject to rigorous review and penalty.\textsuperscript{195}

The final stakeholder group considered in this chapter is the judiciary.

V: The Judiciary: Over-reliance on medical opinion

The rule of law commands that courts are the ultimate decision-making body in relation to legal disputes, including those relating to neonates. Thus, there is no question that judges have the final say. However, the rule of law also requires that laws are clear, certain, knowable and predictable.

As noted in Chapter Two, the current application of the best-interests principle in decisions to withdraw or withhold life-sustaining treatment is ill-defined, insufficient and too vague to provide guidance in this area. Moreover, the judicial function is relation to this issue is potentially undermined by the deference that judges have to medical opinion.

It is widely accepted in society that the ultimate arbiter, which should be the most independent and objective, is the judiciary. Decisions and justice should be blind to the preferences or subjectivity of others. However, as has been illustrated thus far, end-

\textsuperscript{195} Stewart, above n 194, 155, 157, 162.
of-life decision making concerning critically ill neonates is often determined by a range of subjective factors.

As discussed in Chapter Two, when parents and doctors disagree on whether treatment should be withdrawn or withheld, the courts are required to make a determination. Less common in Australia than in the UK, some of these decisions merely require the sanction of the court, whereas others require active determination.

Where a determination has been required by the courts, overwhelmingly judges have agreed with medical opinion to withdraw treatment, consequently leading to the death of the neonate. This raises questions as to the weight placed on medical opinion by the courts, and in turn raises questions of bias and impartiality. The judiciary seemingly defer to medical opinion, despite the gravity of these life and death decisions. This is evinced in the case of *A National Health Service v D*,¹⁹⁶ in which Justice Cazalet stated, ‘it is well established that there can be no question of the court directing a doctor to provide treatment which he or she is unwilling to give and which is contrary to that doctor’s clinical judgement’.¹⁹⁷

Thus far in this thesis, a number of factors have been considered that support the contention that there is a need for greater transparency and objectivity in decision making for imperilled neonates. The following observations have been highlighted:

1. The imprecise and ill-defined best-interests principle
2. The lack of uniformity or coherence of clinical guidelines

---

¹⁹⁶ *A National Health Service v D* [2000] 2 FLR 677.
¹⁹⁷ Cited in Skene, above n 151, 357.
3. The documented subjectivity of medical practitioners doctors in end-of-life decision making.

Further, the judiciary’s deference to the medical profession and reliance on medical opinion is of concern. Indeed, Coggon asserts that such deference might ‘permit the doctor to do what he wants, unhindered because of the application of the notoriously troublesome Bolam test and an excessively deferential judiciary’. 198

Arguably, parents seeking the continuation of medical treatment against medical opinion are fighting a losing battle on two fronts. Firstly, in the hospital where medical professionals have expertise far beyond that of parents, allowing non-medical and subjective criteria into the decision-making process to withhold or withdraw treatment. Secondly, in the court room, judges’ decisions to withdraw or withhold treatment reflect their heavy reliance on medical opinion. This suggests that the medical profession has a significant amount of power and authority in the decision-making process, both in the hospital setting and in court. 199

The effect of this excessive weight given to medical opinion has been acknowledged and noted by the medical profession, and as such has possibly further empowered them due to their awareness that the highest authority, the law, is unlikely to question their clinical judgment or opinion. Fortin highlights this:


...there seemed little point in parents seeking the courts judicial assessment of situation involving children—since the answer would always be that the doctors were to be guided by their own clinical judgement ... it led doctors and their lawyers to conclude that since a court would never direct them to act against their clinical judgement, they themselves did not need court authority to override parents objections...

Lord Woolf also acknowledged the judiciary’s preference for, or excessive weighting on, medical opinion, and identified the risks this can pose in presiding over treatment disputes in the courts. He rightly cautioned:

...It is unwise to place any profession or other body providing services to the public on a pedestal where their actions cannot be subject to close scrutiny. The greater the power the body has, the more important is this need.

Such an acknowledgment is remarkable for its frankness, and is cautionary for the potential to abuse such power. As Stewart correctly asserts, ‘the power wielded by the courts is open to public scrutiny. The power wielded by doctors in nursing homes and hospitals is not’. In light of this, and with reference to decision making as it affects the withdrawing or withholding of treatment from critically ill neonates, this thesis recommends that doctors be considered functionaries, and that the judiciary should take ultimate responsibility for decisions that have such absolute consequences.

Ongoing research by Willmott et al at the Queensland University of Technology in Australia is of particular importance to this thesis. The authors are currently undertaking a project that encompasses empirical research as to the ‘role of law in medicine’. Although this research is based on withdrawal or withholding of life-sustaining treatment from adults who lack capacity, the research, findings and recommendations will also be of benefit with regard to decisions concerning critically ill neonates, given their similar lack of capacity and autonomy.

In a series of three articles that explore and examine the legal role of doctors in withdrawing or withholding life-sustaining treatment from incapacitated adults across NSW, Queensland and Victoria, the authors emphasise the importance of educating the medical fraternity about the law. This is valuable and should extend to doctors treating and making end-of-life decisions for critically ill neonates, particularly because of the confronting nature of this area of decision making, which, as has been noted in this chapter, also remains highly subjective.

As Willmott et al correctly assert, ‘medicine is no longer an autonomous professional enterprise, but a social endeavor occurring within social, cultural and legal


Given the organic relationship between law and medicine, better education and knowledge of the law should translate to more informed and considered decisions being made by doctors, and should create a platform for more objective end-of-life decision making. Undoubtedly, this much-needed research and its findings will provide for seminal work in the area of the withdrawal or withholding of life-sustaining treatment in the future.

Thus far, it has been considered in this thesis that medical opinion has informed and continues to inform legal opinion and decisions to withdraw or withhold life-sustaining treatment. White et al note that ‘there is no duty [on the part of doctors] to provide futile treatment’ and as such ‘he or she [the doctor] is the legal-decision-maker and may decline to treat’. This has been highlighted in relation to critically ill neonates, with doctors often overriding parental wishes.

For the rule of law to operate more effectively in this area, it is important that the determining factors in end-of-life decision making for critically impaired neonates are clarified. This thesis argues that one determining objective factor that should be given greater emphasis in this area of decision making is the allocation of limited public resources. Chapter Five discusses this recommendation in more detail.

**VI: Conclusion**

---


206 Ibid 787.
In this chapter, stakeholders have been shown to make withdrawal of treatment decisions based on subjective factors. The parent’s role in decision making is complicated by a range of conflicting factors and claims. Further, medical practitioners, the stakeholder group typically credited with basing their decisions on objectivity and clinical expertise, were also found to make unpredictable, subjective treatment decisions. Moreover, considering the heavy reliance the judiciary place on medical opinion, this group of stakeholders also cannot be said to operate objectively in the decision-making process. Such approaches to end-of-life decision making for critically impaired neonates are indefensible, given that life is at stake.

This thesis argues that decision making should be guided by a greater rationality and objectively. Thus, decision making for neonates born extremely prematurely should be informed by consideration of the allocation of finite public resources. This issue is now considered in the following chapter.
CHAPTER FIVE: AN OBJECTIVE APPROACH: RESOURCE
ALLOCATION AND OTHER RECOMMENDATIONS

I: Summary

The previous chapter examined the role of the key stakeholders in making the decision
to withdraw or withhold life-sustaining treatment from critically ill neonates. Chapter
Four considered the various factors that influence decision making for parents, doctors
and the judiciary.

The chapter identified that both parents and doctors are highly subjective in their
decision making. The judiciary was also found not to be objective; instead
demonstrating an over-reliance on medical opinion. It was concluded that a more
objective approach is needed, particularly when making end-of-life decisions for
neonates born at ‘the edge of viability’.

II: Introduction

This penultimate chapter asks some difficult questions about the cost of keeping
premature neonates alive. For example, what is the cost to society and to families of
keeping severely premature neonates alive? Are desirable outcomes being achieved by
keeping them alive, considering especially those cases in which the neonate’s life is
likely to be limited and of poor quality?
Recommendations are also made regarding improving consistency and outcomes in end-of-life decision-making processes. In particular, the allocation of limited healthcare resources is proposed as an objective factor that should be considered in decisions to withdraw or withhold life-sustaining treatment from impaired neonates. Specifically, the question is whether the limited resources available to health institutions could and/or should be invested in neonatal or other patients.

Any discussion of the healthcare required to sustain severely premature neonates would be incomplete without a full discussion of the associated resource costs. Resource allocation might be considered as the true objective standard in this area, the consideration of which would reduce much of the subjectivity and emotion that currently informs decision making, allowing for a more pragmatic approach. This chapter begins by discussing some of the key concepts that underpin current approaches to health economics.

**III: Economic terminology and quality adjusted life years measures**

With increasing demands for, and limited supply of, health resources, it is unsurprising that health economics is a rapidly growing field. Culyer has defined health economics as:

---

…the application of the discipline and tools of economics to the subject matter of health, accordingly encompasses the full range of two-way causal relationships between the health status of individuals and groups and their economic activities—production, distribution and exchange.2

Klein discussed health economics with reference to the National Health Service in the UK as:

As more emphasis is placed on market transactions so the demand for economic analysis will grow … hence the importance of looking critically at the discipline and its claim to use rational techniques of analysis to resolve complex problems of decision making in the NHS.3

Health economics is supported by a wealth of literature, where the main concepts, including methods of measuring the economic value of healthcare, can be distilled to cost-effectiveness and cost utility.4

Commentators have used this methodology in their critical analysis of the cost of resourcing the NICU. By way of example, Zupancic et al found that ‘the incremental direct medical cost of low birth weight in the first year of life in the United States exceeded $4 billion in 1988’.5 Other commentators estimated the direct cost of NICUs in the United States in 2004 to be closer to $21 billion.6 Regarding Australia, Campbell noted:

---

2 Quoted in, Robert Evans, Strained Mercy: The Economics of Canadian Health Care (Butterworths, 1984) 3.
The typical (only initial hospitalisation after birth) costs for early birth weight babies in intensive care units are around $A 1,000 per day, and average hospitalisation costs around $A 50,000–$A 80,000 per baby. The earlier the gestation, the higher the cost. To achieve a survivor at 24 weeks in our region costs around $A 300,000.7

In considering the cost of keeping neonates alive, Campbell indicated that the returns are relatively small given the large sums spent on keeping these babies alive. In light of both dollars and percentile of disability, the author noted:

Care is nowadays offered at 23 weeks’ gestation, when the chances of survival are less than 10%, the chances of serious handicap in survivors around 30% and the cost for each survivor between $300,000–$400,000 … do caregivers really have a mandate from their society to use such large resources when returns are so poor? 8

Over 20 years ago, in a study conducted at Flinders Medical Centre in Adelaide, Australia, Marshall et al highlighted the expense involved in keeping neonates alive. Concluding in September 1984, the study illustrated the specific costs incurred including the largest cost to any hospital, staffing.9 While medical staff represented a significant cost, many other elements also required consideration. These included ‘consumable, recyclable and ancillary services’, such as sterile linen, hospital porters and radiology, all of which are required daily or several times a week.10 In 1984, the

8 Ibid 303.
figure arrived at by Marshall et al was $690 AUD per day, including all services required for a high dependency infant.

It is likely that, to arrive at a present-day estimate, these costs would have to be doubled or tripled, simply to adjust for inflation. This is without any consideration for capital expenditure costs, and the increased costs of modern-day technology, which would far outstrip any technology expenditure in 1984.

This is supported by Bennett, who stated that ‘advances in medical technology have also placed additional burdens on health care resources with the development of more expensive items of medical equipment or forms of medical treatment’.11

An important clarification is that the figures discussed thus far relate only to staffing, accommodation, medicine and equipment costs within the NICU. They do not include the follow-up healthcare and services required post-discharge from the NICU.12 Calculating direct running costs of a NICU provides an overview of the expenditure that hospitals incur. However, this will vary by hospital and country. Further, such calculations are invariably under-estimations, as various other factors and costs cannot be accounted for by a hospital or government balance sheet. These other costs and expenditures will be examined later in this chapter. The next section examines a popular tool used to measure cost utilisation in healthcare—the quality adjusted life years (QALY) measure.

---


12 Staffing is the highest cost, including nurses, doctors, social workers and therapists, see also, Zupancic et al, above n 5, 483–497.
IV: Quality adjusted life years

The QALY is a common measure applied when examining financial resources in healthcare. It attempts to combine economics and philosophy in measuring cost of healthcare against health benefits.\(^\text{13}\)

Several explanations are available in the health economics literature as to how QALY is measured. Williams’ work on QALY is regarded as seminal, with Hope et al giving Williams’ definition of QALY as:

> The essence of a QALY is that it takes a year of healthy life expectancy to be worth 1, but regards a year of unhealthy life expectancy as worth less than 1. Its precise value is lower the worse the quality of life of the unhealthy person (which is what the quality adjusted bit is all about).\(^\text{14}\)

Therefore, the general premise of QALY is that each year that can be lived in good health is of a higher value than each year that is lived in poor health. Adjustments to the measure are made accordingly. In economic terms, the lower the cost of obtaining positive full health years, the more cost-efficient the treatment is and the greater the priority to provide healthcare. The main objective of health economics is to ‘get the

---


\(^{14}\) Hope, Savulescu and Hendrick, above n 13, 202. See also, Allan Williams, ‘The Value of QALYs’ (1985) (3) *Health and Social Service Journal* 3.
best possible value for each dollar spent’.\textsuperscript{15} Lockwood has applied a rational approach to QALYs, asserting that it is essentially about ‘trading off length of life against quality of life’.\textsuperscript{16}

The measure is not without its critics. Some commentators have criticised QALYs as being an unjust measure for calculating welfare and quality of life.\textsuperscript{17} Arguably, combining philosophical and morals tenets about life and its worth with calculated, measured economics does not make for a congruent equation. Using numerical scales to score the value and quality of life in negative or positive sums also raises ethical concerns. As discussed in Chapter Two, attempts to define quality of life and futility of treatment are highly subjective.

Perceptions of disability and quality of life vary between abled and disabled individuals. Bennett suggests that judgments by abled bodied persons about living with a disability are due chiefly to a ‘lack of understanding about the realities involved’.\textsuperscript{18} It would be grossly incorrect to assume that those living with a disability do not and are not capable of leading happy and fruitful lives. This may be because they fundamentally value life in any form, or have never experienced life without disability and therefore cannot draw any type of comparison.\textsuperscript{19} The reverse is also true, and will be explored later in this chapter. The next section, considers the application of QALY to neonates, the subject of this thesis.

\textsuperscript{16} Michael Lockwood, ‘Quality of Life and Resource Allocation’ in Helga Kuhse and Peter Singer (eds), Bioethics: An Anthology (Blackwell Publishing, 2nd ed, 2006) 451, 453.
\textsuperscript{17} Hope, Savulescu and Hendrick, above n 13, 203.
\textsuperscript{18} Bennett, above n 11, 88.
V: Quality adjusted life years and neonates

At both ends of the human life cycle, QALYs and their application are subject to increased scrutiny and controversy. In measuring cost utility for premature neonates, particularly those born at 23 weeks, QALYs become difficult. Neonates born at the edge of viability have a significantly higher likelihood of suffering severe disability or retardation. Therefore, overwhelmingly, extremely premature neonates never start life with a QALY value of 1 and are unlikely to ever reach that value. Neonates born at 23 weeks are likely to have a poor quality of life, both physically and economically.

Academics Kuhse and Singer apply the QALY and cost benefit analysis in a crude but rational manner. They highlight that, where the chances of handicap to a premature infant are low, the benefit should outweigh the cost. However, where the risk of severe handicap is high and there is the chance of a second pregnancy producing a healthy and abled child, then the high cost of NICU to save the premature neonate ‘produces a loss rather than a gain’. 20

The authors note that society tends to assume that ‘it is better to save the lives of the young than the old, and the younger those saved are, the better it is’. 21 However, it may be that those that advocate for scarce resources to be used to save the young rather than the old apply the notion that the young have their entire lives ahead of them, that they are the future and should have the opportunity to experience life and all it has to offer.

20 Kuhse and Singer, above n 15, 112.
21 Ibid 102.
Kuhse and Singer argue against this idea that saving the very young is better than saving an adult:

The lives of people can be seen as journeys on which they have embarked. Although people know that the final destination must be death, there are goals along the way that they are hoping to achieve before the trip is over. Adding life-years extends the journey.\(^{22}\)

In contrast, Kuhse and Singer argue that foetuses and newborn infants are yet to gain the capacity to embark on life’s journey:

There is no sharp, morally significant boundary between the foetus and newborn infant. If the foetus lacks the capacity to itself as being with a future, so presumably does the newborn infant … being capable of seeing itself as a traveller, and capable of wanting to reach some goal, however simple that goal might be, then the journey does not begin at birth.\(^{23}\)

Further to this, severely premature neonates are unlikely to ever gain the capacity required to independently travel life’s journey or to see many goals or aspirations come to fruition. The authors suggest that, when having to decide whether scarce resources should be given to a newborn in NICU or to an adult, they should go to the adult, as any improvement in health could allow that person a few more years on the long-travelled journey they have already embarked upon. This outcome is not as assured in the case of a baby in NICU. The argument put forward by Kuhse and Singer is supported by a study conducted in Melbourne, Australia by Nord et al, and published in the Social Science and Medicine Journal in 1995.

\(^{22}\) Ibid 106.

\(^{23}\) Ibid 107.
In this study, a questionnaire was distributed to individuals from varying socio-economic groups, asking respondents to consider the prioritisation of treatment and patients, taking into account factors such as age, lifestyle and dependents. The third scenario posed in the questionnaire is of interest to this thesis.

When asked to consider which patient should receive one available organ transplant, 44.2 per cent of respondents stated the organ should be given to ‘the young child’ as opposed to the ‘newborn infant’. The authors of the study noted that ‘the common reason for opting for the young child was that the respondent’s assumed that the young child had a better chance of successful operation’. In addition, ‘the loss of a young child was thought to be more acutely felt by parents and others than that of the newborn who has not had the opportunity to touch as many lives’.

This thesis contends that it is becoming increasingly necessary to exercise a greater level of scrutiny and to engage in a public, open and honest dialogue regarding to whom limited financial resources should be allocated.

While parents of critically ill neonates do not consider the cost of treatment for their children, often demanding futile treatments based on hope, it is important for all stakeholders to recognise and discuss these costs. Treatment for incapacitated persons, whether adults, children or neonates, is costly, and the issue of resource management cannot be ignored.

---

24 Erik Nord et al, above n 4, 1433.
25 Ibid 1434.
26 Ibid.
Any form of medical interaction, intervention or treatment, however minor, incurs a cost. The cost of different types of treatment varies, and other factors must also be considered; for instance, length of hospital stay, medication, surgery and rehabilitation. Each patient also differs, including in age, gender, ethnicity, access to healthcare and socio-economic status. No country or government has unlimited funds available for healthcare. Savings in healthcare mean that finite resources can be distributed to other social needs, such as education and housing.

In most societies, it is generally taboo to put a monetary value on life, especially on the life of a baby. McKie et al acknowledge that discussions about cost of care may be distasteful. They illustrate the possible public opinion on issues about life and death when considered on the same platform as expenditure:

27 In an Australian report in June 2009, it was estimated that the costs associated with acute coronary syndrome, including hospitalisation, in Australia would be approximately $15.5 billion AUD. See especially, Access Economics, ‘The Economic Costs of Heart Attack and Chest Pain’ (Acute Coronary Syndrome) (Report, June 2009) 5. The cost of treating influenza in Australia, including time away from employment, in 2007 was between $828 and 884 million AUD per year. See especially, Anthony T Newall, Paul A Scuffham and Brent Hodgkinson, ‘Economic Report onto the Cost of Influenza to the Australian Health System’ (Report, Research and Practice Development Centre, University of Queensland and Blue Care, March 2007) 6. Another example of healthcare costs is the rising cost of treatment for mental illness. In Australia, treatment for mental illness was recently reported at in the region of $190 billion per year. See, Matt Wade, ‘Income Up, But Mental Illness Costing $190b a Year’ Sydney Morning Herald (Online) 8 June 2013 <http://www.smh.com.au/data-point/income-up-but-mental-illness-costing-190b-a-year-20130607-2nvjy.html>.

28 In 2007, in the UK, it was found that ethnic minority patients generally have poorer health outcomes than do white Caucasian patients. See especially, Parliamentary Office of Science and Technology, ‘Ethnicity and Health’ (Postnote, No 276, January 2007) 1–4. See also, Memon et al, ‘Health Issues in Ethnic Minorities: Awareness and Action’ (2002) 95(6) Journal of the Royal Society of Medicine 293–925.

29 Lockwood, above n 16, 451.
How could we possibly arrive at any figure that would represent the value of human life? And even if we could, would that not be a crass attempt to convert to money values something that is, quite literally, beyond any price?\textsuperscript{30}

However, with an ageing population, increasing costs and limited budgets, clinical decisions have to be made regarding how and to whom health resources are allocated.\textsuperscript{31} Questions need to be asked about the cost of keeping severely premature neonates alive. Further, what health benefits will be gained by investing scarce fiscal resources into NICUs? Over 20 years ago, Lyon made this observation:

In the end, the issue of whether to let defective babies die may be solved, not by the elegant arguments of ethicists or by rhetoric in a court of law, but by the grim realities of the marketplace. The rising cost of medical treatment is placing a tremendous burden on society … since treating birth defects is a particularly expensive form of medicine, it is almost certain to come under scrutiny in the years ahead.\textsuperscript{32}

The issue remains as topical today as it did in 1985. Importantly, Lyon’s assertion about the allocation and cost of healthcare is beginning to be discussed more openly. However, as highlighted later in this chapter, discussion about the allocation of limited resources is still not as candid as it should be. Having explored some of the ways in which the cost of healthcare and the benefits it confers are measured and accounted for, the next section considers cost efficiency in the NICU.

\textsuperscript{31} Bennett, above n 11, 77.
VI: Health economics in the neonatal intensive care unit—An American and Australian perspective

There is an abundance of literature and academic discussion on resource allocation and health economics from the United States. This is unsurprising given the limited government healthcare funding and the role played by the private sector in the provision of health services in that country.

Buchh et al documented the length of stay and survival of infants in a Chicago NICU between 1978 and 2003. They found that, although there had been a significant rise in the number of admissions and bed-days in the NICU, the NICU was a ‘very cost-efficient mode of ICU care’. This is in comparison to adult intensive care units, where ‘over 50 per cent of [adult intensive care unit] bed-days are devoted to non-survivors as opposed to patients who will be discharged’. The authors noted that the NICU was ‘impressively efficient’.

The authors placed emphasis on health dollars spent on surviving neonates:

---

33 This rise was four-fold, from 25 to 100 per year and ten-fold for bed-days from 700 to 7000 per year.
36 Ibid.
Even when we were not very good at saving ELBW (Extremely Low Birth Weight) babies lives, neonatology was still remarkably efficient in directing NICU bed-days/dollars/resources toward surviving infants as opposed to their doomed confreres.37

Further, the authors reported that, ‘in 1978, when 82% of our ELBW babies died, only 24% of our ELBW dollars were devoted to these non-survivors’. In addition, since 1978, birth weight specific (450–750 grams) mortality rates have decreased, with a higher number of survivors. This is encouraging; however, two issues require further consideration.

Firstly, compared to 30 years ago, recent technological advancements mean that neonates born severely premature can now be saved. Secondly, where Buchh et al discuss the cost efficiency of the NICU based on fewer health dollars being devoted to ‘non survivors’, this could be attributed to weaker, smaller ‘non-survivors’ dying sooner, requiring little or no medical treatment or bed-days.

This is supported by research conducted by Meadow et al. The authors noted changes in mortality rates and low-birth-weight infants during the 1990s. They found that some 20 years ago, neonates born pre-term with little chance of survival died quicker. As a consequence, parents were able to determine the ‘life or death’ outcome of their child sooner. ‘[I]f parents could “hold their breaths” for a few days, the outcome for their infants was much clearer’.38 In its crudest form, NICU beds were occupied for the shortest period of time, making a NICU a financially viable and economical unit to manage.

37 Ibid.
With improvements in neonatal medicine and care, by the 1990s, Meadow and his colleagues illustrated that, although non-surviving neonates still tended to die, they took longer to do so. Therefore, to have a better understanding of prognosis, parents had to ‘hold their breath’ for much longer, sometimes a ‘week and a half’.\(^3\) One consequence of this ‘prolongation’ of death is that NICU beds are occupied for longer, even as expensive treatments continue to result in the inevitable death of neonates.

However, the authors did not consider the devotion of NICU beds for ‘doomed’ neonates as economically unviable. They stipulate that, for the weakest, smallest neonates, the ‘median day of death is 3 days’.\(^4\) Therefore, those that survive to see day four are likely to have a ‘more than 50% chance’ to survive.\(^5\) Of those born at less than 25 weeks, Meadow et al assert:

> Of every 100 such infants, 75 will die, but half will be dead in 3 days. The 25 survivors, by contrast, will remain in the NICU for an average of 100 days. Consequently, even for a majority of NICU bed-days (< 90% in our NICU) will be devoted to survivors. … NICU dollars are remarkably well targeted to survivors as opposed to non survivors, independently of the absolute risk of death.\(^6\)

Lantos, Mokalla and Meadow advocate that scarce resources are better spent in the NICU than in intensive care for the elderly, which involves ‘a far greater proportional

---

\(^3\) Ibid 1226.
\(^5\) Ibid.
\(^6\) Ibid.
expenditure of money towards those who will not survive’.\textsuperscript{43} Buchh et al support the view that, ‘ICU dollars spent on patients who will die before leaving the hospital seem less well directed than ICU dollars spent on patients who will survive to be discharged’.\textsuperscript{44}

Taking a similar view to their colleagues, Lantos et al argue that premature neonates present with serious medical complications early in life (often the first few days after birth). This makes the NICU a cost-efficient area of medicine because pre-term neonates ‘declare themselves’ by means of either early rapid decline, or surviving medical complications early in life.\textsuperscript{45} All three authors emphasise NICUs as cost-efficient hospital departments that produce ‘survivors’.

It is necessary to consider whether the economic value of NICUs in producing ‘survivors’ is isolated to the United States or whether other global studies or literature illustrate a similar trend. Professor Lex Doyle in Victoria, Australia has provided seminal work that contributes to the discussion of economics and resource allocation in the NICU.

\textbf{VII: Australian neonatal intensive care units}

\begin{footnotesize}

\textsuperscript{44} Buchh et al, above n 34, 659.

\textsuperscript{45} Lantos, Mokalla and Meadow, above n 43, 188.
\end{footnotesize}
Doyle conducted long-term studies over four epochs (1979–1980, 1985–1987, 1991–1992 and 1997) to evaluate the effectiveness of NICUs for neonates born premature, weighing between 500 and 999 grams. The studies followed the neonate’s survival and development up to at least two years of age. The author placed emphasis on effectiveness and efficiency as factors of importance when evaluating the NICU.

Comparably, the NICUs in Victoria, Australia are also producing more ‘survivors’. Survival rates increased from 25.4 per cent in 1979–1980 to 73 per cent in 1997. Doyle found that ‘survival rate has increased three-fold from 1 in 4 in the late 1970s to 3 in 4 by the late 1990s’.

The studies conducted by Doyle are commendable. The author explicitly states that ‘neonatal intensive care is expensive, especially in developed countries’. He also provides a balanced view of the realities of the NICU and low-birth-weight neonates. Although the statistics highlight an increase in survivors of low birth weight in the NICU, the studies also recognise that, although mortality has decreased, the degree of morbidity for premature neonates remains unchanged. Further, a recent study conducted over a six year period in one Australian hospital found that neonates born


earlier than 24 weeks and weighing less than 500g did not survive without disability. The study is commendable, it has highlighted that neonates born extremely premature do not survive without disability. Discussing the reality of mortality and morbidity on a platform is a leading discussion in this area in the right direction – or more open and transparent dialogue. However this thesis argues that the findings from this study could be an opportunity to extend this discussion further, and to begin to consider the significant amount of financial resources that are utilised to save neonates from death, but not from a life with severe disability. Tudehope highlights this point further, asserting that ‘it is generally accepted that investment in neonatal intensive care reduces mortality but the costs of services are high especially if morbidity is not reduced’.  

Neonates born at extremely low birth weight (500–999 grams) continue to suffer severe disability and poor life outcomes. The studies found that even over a 20-year period, the decrease in cerebral palsy was marginal, from 13.5 per cent in 1979 to 10.7 per cent in 1997. In addition, ‘deafness, developmental delay, and overall neurosensory disability rates were not significantly different over time in survivors in our cohorts’. Overall, Doyle highlighted that the NICUs in Victoria, Australia are both efficient and effective at improving survival rates. However, he qualified his statement as follows:

---


The dramatically improving survival and quality-adjusted survival rates for ELBW infants in Victoria over two decades argue strongly the case for an increasing need for neonatal services in the state. Moreover, such care can be provided relatively efficiently. Neonatal intensive care is approaching 100% availability for ELBW infants in Victoria. As most ELBW infants now survive, the remaining major challenge is to improve the quality of their survival.53

Severe disability and/or long-term health problems associated with premature birth, especially neonates born at 23 weeks, remain as challenging today as 30 years ago. This is reflected by the findings of the UK EPICure studies, which were considered in Chapter Three. In these studies, it was found that, although the survival rates of severely premature neonates have increased, the pattern of major neonatal morbidity, and the proportion of survivors affected, are unchanged. These observations reflect an ‘important increase in the number of preterm survivors at risk of later health problems’.54

Understandably, many neonatologists are optimistic advocates of the NICU. To most neonatologists (and to pro-life activists), any development or progress in saving neonates from death is likely to be considered positive. This also sits comfortably with the principle of sanctity of life, as discussed in Chapter Two. However, as noted earlier in this thesis, this principle is not necessarily the most important, and other factors must also be considered in making treatment decisions.

A critical view may suggest that the drive for the allocation of limited resources to the NICU has less than benevolent intentions. The NICU may be considered a ‘safe

53 Doyle, above n 50, 144.
haven’, with regular financial growth and profit for hospitals, where fiscal cuts are made in other departments. This point is illustrated in an article published in the Bloomberg magazine, which stated that ‘when you add up the million-dollar imagining machines, the incubators, the expensive drugs, diagnostics, nutritional products, and physician services, neonatology is a multibillion-dollar market’.55

American paediatrician and ethicist John Lantos candidly discussed the ‘profitability’ of the NICU: ‘over the past three years, the NICU has had the highest revenue-to-expense ratio of any unit in the entire hospital including both adult and paediatric units’.56 Further, ‘like most new children’s hospitals, will have more NICU beds than the current one but will not have room left over for a new emergency department, new outpatient clinics, or an auditorium for public gatherings’.57

As noted earlier, the largely private American healthcare system is structured differently to that of Australia or the UK, making the issue of limited allocation of public healthcare funds particularly important. Public sector hospitals are essentially ‘not for profit’ organisations, are are, to a greater degree, controlled by government funding and allocations.

In Australia, the government is primarily responsible for deciding the amount of public funds that will be distributed to public hospitals. To achieve this, various methodologies are applied, including ‘activity-based funding’; ‘diagnostic-related

57 Ibid.
groups’ (DRG Codes)\textsuperscript{58} to classify hospital services; and ‘weighted inlier equivalent separation’, based on specific allocations made to hospitals, reflecting historical workloads and population changes.\textsuperscript{59} The systems that are applied are complex in nature and often do not reflect the ‘true cost’ of healthcare or particular treatments.

There is no universal approach to healthcare systems or government funding models. The Nordic welfare model of healthcare, for example, places an emphasis on delivering premium health services to the maximum number of individuals. This model extends to Finland, Norway, Denmark, Iceland and Sweden and has the fundamental goal of ‘equal access to social and health services, education and culture’.\textsuperscript{60} However, such equality and universal access to welfare and healthcare for all members of society, regardless of socio-economic background or privilege, comes at a price. The Nordic model of welfare places high demands on the taxpayer, with these countries having some of the highest taxation rates in the world.\textsuperscript{61}

Studies and literature on the costs, efficiency, effectiveness and efficacy of NICUs are limited. This is probably because only a small proportion of extremely premature neonates’ lives are spent inside the NICU. The relative cost of preventing impaired neonates from dying discussed thus far does not take into account the long-term cost


\textsuperscript{61} In 2012, Sweden ranked second highest in the world for tax rates at 56.6 per cent; the highest taxation rate was 59 per cent in Aruba. See Global Finance, \textit{Personal Income Tax Rates} <http://www.gfmag.com/tools/global-database/economic-data/12151-personal-income-tax-rates.html\textasciitilde axzz2Te01WXqW>. 240
incurred by society and the families of extremely premature neonates. These costs reach far beyond the NICU.

As Chapter One highlighted, significant development has been seen, and is ongoing, in technological advancement and medical science. Neonates, among other groups, have tested the limits of technology. As little as 20 to 30 years ago, premature neonates, particularly those born at 23 weeks, would have died. Today, these neonates, born at the very edge of viability, survive. Every day in the developed world, technology and cutting-edge innovation save some of society’s most vulnerable citizens from death.62

Many individuals applaud the thriving research in medical science, engineering and other industries that have made it possible for humans to increasingly defy nature. The media praise technological progression, highlighting stories of ‘miracle babies’ who, with the assistance of an army of medical professionals and aggressive and revolutionary technologies in the form of incubators and ventilators, combat death. 63

However, as noted in previous chapters, these miracle babies rarely live happily ever after. Although neonates born at 23-weeks’ gestation may survive, they often fail to thrive, and their long-term health prognoses remain bleak.

Most spend several months in the NICU, where medical teams attempt to stabilise them until, with the aid of machinery and medicine, their vital organs have adequately developed. However, even with round-the-clock care and supervision, many die after

days or even months of intensive care. Others may survive, but they are typically left with severe disabilities, affecting both them and their families for the rest of their lives.64

Health economists apply a micro-view when considering costs and benefits incurred through a health industry lens. While this is important, it is also necessary to consider the broader costs involved for the family and society. The following section of this chapter considers these other significant costs, using a social work lens. These are the costs incurred post-NICU, with some being short-term direct financial costs, while others are longer-term and likely to be excluded from consideration by health economists.

VIII: Health economics beyond the neonatal intensive care unit

Extremely premature neonates often spend months in the NICU being mechanically supported and cared for in a controlled environment with constant supervision. The aim is to allow their organs and bodies to fully develop before they are discharged.

Time in the NICU may come as a shock to families that just want to take their newborns home.65 However, they must quickly adapt to the reality before them: they may have to spend months in the NICU. In the NICU, the other parents, the doctors and nurses may often become an extension of the family unit.

65 Evans, above n 63, 42.
Eventually, medical teams of doctors and nurses cease caring for impaired neonates and reassure new parents that ‘they will be fine’ looking after their newborn in an uncontrolled, non-clinical environment. Once discharged, the constant support comes to an abrupt end, and parents find themselves at home with their infant, who will often be severely disabled.66

Evans points out that, often doctors’ ‘…egos push boundaries to produce “miracle babies” which are not going to be raised by super-parents, only ordinary ones with limited resources’.67 Indeed, Evan’s comment does not extend far enough: the needs of a survivor of the NICU will typically stretch far beyond those of a non-severely premature child.

As considered in Chapter Two, ‘quality of life’ arguments tend to focus on physical conditions. However, such considerations should extend to the ‘mass of side-effects both on those closely involved and on the wider society’.68 These include socio-economic factors that affect the quality of life of the neonate and the family.69 Severely disabled individuals require significantly more care, time and financial resources.

Society and medical practitioners consider saving neonates from the brink of death to be both an ethical and a legal duty.70 Thus far, it has been noted that, from a health economics perspective, it is generally considered to be both cost-efficient and effective

---


67 Evans, above n 63, 42.


to use finite resources to save neonates from death. However, Johnson provides a differing view:

When considering the benefits of such care, it is not enough to measure these in terms of survival, without considering the later health status of the surviving children and the impact of their survival of their families, and ultimately on society. It is clear that extremely preterm survivors are at higher risk of later motor sensory or cognitive disorders than neonates born at a later gestational age and the costs of their care are likely to be greater.\(^{71}\)

Global empirical studies highlight that, although medical advancements have reduced mortality rates for extremely low-birth-weight neonates, morbidity in survivors remains prevalent. This point was highlighted again recently by Evans, who stated:

Fifty per cent of babies born at his age [Joshua born at 24 weeks and 5 days] get to go home, though up to 20 per cent [sic] will be severely disabled; the rest will be either fine or affected by conditions such as milder forms of intellectual delay and cerebral palsy.\(^{72}\)

Moster, Lie and Markestad detail the types of disabilities suffered by neonates born at 23 weeks. The authors stipulate that such neonates have a greater likelihood of ‘major disabilities such as blindness or low vision, hearing loss and epilepsy’.\(^{73}\)

Most neonates born at 23 weeks require several follow-up consultations. In addition to later surgeries and post-operative care, some neonates may need medical equipment

---

\(^{71}\) Johnson, above n 62, 272.

\(^{72}\) Evans, above n 63, 38.

such as assisted ventilation at home. Auxiliary services, such as physiotherapy and rehabilitation, may also be required. Lantos and Meadow found:

…former premmies have five times the rate of hospitalisation of full-term babies during the first year of life. Many former premmies require ongoing outpatient care from a variety of specialists. Some require complex home health care.\(^{74}\)

The points above briefly illustrate some of the ongoing health conditions that affect extremely low-birth-weight neonates. Caring for a healthy, normal newborn is challenging and intense, and the care and attention required by a severely premature neonate suffering significant disabilities is far greater.

The cost of post-NICU care far exceeds that of the NICU in terms of money, time and emotion. Some examples of the costs that begin to accumulate are, the cost of travelling to and from hospital appointments, and lost earnings due to one or both parents requiring time off work.

This point is supported by empirical research conducted by Zupancic et al, which found that, while still in the NICU, of 109 low-birth-weight babies in Great Britain, ‘36% of mothers travelled more than 21 miles to the NICU and 88% of families visited daily’.\(^{75}\) The resulting financial strain, constant time pressures and burdens of caring for a severely disabled neonate often affect the wider family circle.\(^{76}\)

\(^{74}\) Lantos and Meadow, above n 6, 123.

\(^{75}\) Zupancic et al, above n 5, 486.

IX: Impact on the wider family

Caring for a severely disabled neonate brings significant challenges for new parents and the wider family. It may affect the existing family dynamic, and partners and other children may be adversely affected by the continuous needs of, and attention required by, the disabled neonate. Further, overall costs within the household have been noted to be ‘ten times higher for parents with low-birth-weight babies when compared with those with term infants’.77

Wilkinson supports this view, highlighting that the ‘burden of care for severely paired infants overwhelmingly falls upon immediate family, often involving physical, financial and emotional burdens’.78 This is very rarely spoken about or documented by the media, who prefer to portray the idyllic, resilient family.

An example of the media portrayal of the idyllic family unit comes from the UK, where a newspaper interviewed four families about their experiences of caring for their premature neonates.79 Predictably, all of the families discussed their ‘miracle’ neonates and the joy that each of them brought to their lives. Of course, regardless of

---

disability, parents talk about their children with great passion, pride and unconditional love. However, the article failed to highlight the realities of the financial hardship and family tensions that often arise when caring for a severely disabled neonate or young infant.

Recently, one mother did openly discuss the pressure of raising a premature neonate suffering severe disability. This mother had also made the decision to place her child in care, for the greater good of the rest of the family.

In the article, Jane spoke about her son James, born at 25 weeks and consequently suffering with quadriplegia, severe autism and epilepsy. Jane spoke about the challenges of caring for him while also raising two older, healthy children, to whom she could no longer provide adequate attention. Regarding the constant physical and mental strain placed on her and her husband, she stated, ‘looking after him [James] was a round-the-clock job, and we became zombies. I would muddle through my day in a fog of exhaustion while my husband, Andrew struggled through his working week on minimal sleep’.81

She also commented on the detrimental effects on her other children: ‘as a family we had no social life, and Andrew and I had no time for our other two children. We knew this was having a devastating effect on them, but there was nothing we could do’. 82

81 Ibid.
82 Ibid.
addition, ‘my doctor prescribed me antidepressants and my marriage to Andrew limped along. What had become of us?’

It is this type of story that the media should publicise, to allow for much-needed discussion about some of the long-term and far-reaching effects of saving neonates at 23 weeks.

The long-term impacts of caring for extremely premature, severely disabled neonates are profound, including broken marriages, financial hardship and, as considered above, have detrimental impacts on the other children within the family. The long-term impact on a family may be far greater when the severely disabled neonate is the couple’s first child, potentially costing them the opportunity of having a healthy child in the future. This is considered next.

X: Opportunity cost

Individuals invest significant time, money, effort and emotion in raising children; this investment is all the greater, and the sacrifices more magnified, when caring for infants born at 23-weeks’ gestation.

Where a neonate is born extremely prematurely, and as a result suffers severe disability, the likelihood of parents having another child is reduced. This could be due to the time or financial constraints associated with the care of the disabled child, or the

---

83 Ibid.
concern that a second pregnancy may also result in a premature birth. Kuhse and Singer support this view:

> It seems reasonable to suppose that families are more likely to have subsequent child if a premature infant dies than if the infant lives; many couples have an idea of how many children they would like to have, and will ‘replace’ an infant who dies in order to reach that number. This assumption is also consistent with data that show that a family with a disabled child is less likely than other families to have further children.\(^8^5\)

In this regard, the NICU enables premature neonates to survive, but also potentially prevents couples from having other healthy children in the future.

Taking Kuhse and Singer’s argument further, the opportunity cost of raising a severely disabled neonate could mean that families never reach their economic potential due to having to give up careers or promotions, which then has a detrimental effect on all children within the family. These children may be deprived of better clothing, social outings or holidays, or even lose access to better education and subsequent career opportunities and experiences. This argument is particularly broad and may not affect all families. However, it is worth noting.

More broadly, there is also a concomitant lost opportunity for society when parents have severely premature and disabled children. Unlike a healthy child born at full term, a severely disabled neonate is unlikely to be able to contribute to the economic workforce later in life. This view is supported by Brock, who noted that, ‘… not just by a desire to prevent or reduce the harms of suffering, disability, and the loss of life to

\(^8^5\) Kuhse and Singer, above n 15, 109.
patients from illness and disease, the direct benefits of health care, but also by a desire to strengthen the state by creating a healthier workforce’. 86

This does not mean that the disabled neonate that survives into adult years will not contribute to and be an integral part of society in other ways. However, he or she is unlikely to be able to contribute economically.

It is both necessary and timely for developed nations such as the UK and Australia to revisit the methodology and reasons for saving neonates at 23 weeks. New advanced technologies are used to save neonates. However, this often yields poor outcomes and leaves these neonates with severe disabilities, consequently affecting the nation’s productivity and future. 87

From an economic perspective, the question becomes whether society is doing itself a disservice by reducing the chances of families having a healthy child later in life. Several commentators have reflected on this question. For example, Lyon considered the billions of dollars that are required to care for severely impaired children by institutions paid for by the taxpayer:

None of these figures appear to make note of the loss to society of the child’s productivity as a potential wage earner. Nor do they tabulate the associated costs that the government must bear, including the provisions of special education, disability payments and public accommodations for the handicapped. 88

87 Lockwood, above n 16, 457.
88 Lyon, above n 32, 285–286. Also see Wilkinson, above n 78, 24.
Any discussion about opportunity cost in this regard would be incomplete without considering the loss of opportunity and life experiences that may affect the severely disabled neonate throughout his or her life.

Moster, Lie and Markestad have explored this issue and state that those born extremely premature with disabilities begin, and continue, life with poor outcomes. Their study of pre-term neonates born between 1967–1983 conducted in Norway found that ‘a lower gestational age at birth was associated with a reduced likelihood of completing high school, of receiving a bachelor’s degree, or receiving a post graduate degree and of having a high income’. The findings also indicate that those born with medical disabilities are less likely to be able to fulfil personal goals such as ‘finding a life partner or having children’.

Further, a study conducted by Pharoah et al in Liverpool, UK supports the view that low-birth-weight neonates have lower educational success. During 1979–1981, the authors examined low-birth-weight neonates (less than 150 grams). They classified disability into a four-point scale measure, from 1 (no disability) to 4 (severe disability), including conditions such as blindness, quadriplegia and epilepsy. The surviving neonates were followed through to the age of four, and a projection was made that those neonates that fell within scale 4 of the measure (severe disability) were ‘assumed to require special education from the age of 4 to 19 years and institutional care from the age of 19 until death’.

---

89 Moster, Terje Lie and Markestad, above n 73, 266.
90 Ibid.
91 Pharoah et al, above n 64, 716.
Zupancic et al contribute to this discussion, asserting the ‘need for special education for children suffering disability as a result of pre-term birth in the United States was approximately $360 million dollars per year’. With increasing survival rates and no significant changes in morbidity, there is also a ‘greater burden on early intervention and educational institutions’.  

The allocation of limited public health resources generally remains an ‘unspoken issue’, but cannot be neglected any longer. The limited resources available to healthcare are increasingly under scrutiny, and it is timely to discuss and seriously consider the allocation of such resources as an objective standard when making end-of-life decisions for critically impaired neonates.

Gunderman and Engle provide some insight, asserting that often decisions to withdraw or withhold life-sustaining treatment focus on the best interests of the child, the likelihood of that child having a poor quality of life, and whether treatment is futile. The authors also suggest that some commentators may find it appropriate to:

…argue that the community as a whole cannot afford to spend hundreds of thousands of dollars saving the life of a premature neonate whose subsequent disabilities will only impose additional hundreds of thousands of dollars in medical costs of a lifetime’.  

---

92 Zupancic et al, above n 5, 493.


In addition, empirical studies show that carers are the least happy group in the wider community, with the highest rate of depression. Although these studies are not sensitive enough to be broken down into the type of people being cared for, there is no reason to suggest that the experiences of carers for impaired neonates are any different to those of carers in general.95

Morris asserts that ‘paying lip service to the value of every life while failing to give adequate support to children and their careers is hypocritical’.96 Thus, the question can be asked: Is society fulfilling its social contract by keeping severely disabled neonates alive, considering that they are not then provided with the care, facilities and support they need for the rest of their lives?97 To explore this issue, it is necessary to consider government spending and budgets in relation to healthcare.


Governments, particularly in developed countries, allocate a substantial portion of their fiscal budget to healthcare, education and welfare. Projected government spending and the annual budget announcement is becoming one of the much

---


96 Morris, above n 129, 376.

anticipated events of the year. This is understandable, given that it impacts all members of society in some way.

Public funds are not infinite, and expenditure in the area of healthcare is increasing as a result of a growing ageing population. This is particularly evident in Australia.98 A recent report by the Grattan Institute entitled *Budget Pressures on Australian Governments* revealed that 19 per cent of the 2012–2013 budget was allocated to healthcare.99 It was noted that, in real terms over the past 10 years, government expenditure in healthcare has risen by 75 per cent.100 The report found that ‘the ageing and aged care services are the highest, and the fastest growing spending category’.101 Further, ‘the expense that did most to increase government spending above GDP [Gross domestic product] was hospital spending’.102

The most recent Australian budget for 2013–2014 proposed two significant fiscal reforms: an investment in education of ‘$9.8 billion over six years, to enhance Australia’s future productivity and wellbeing’,103 and ‘$19.3 billion over seven years to disability care’.104 This latter proposal represents the most significant reform in social policy in Australia since the introduction of public funded healthcare.

---


99 The Grattan Institute is an independent body in Australia that aims to examine, critique and present unbiased reportage and ‘practical solutions to some of the country’s most pressing problems’. See Grattan Institute, *About Us* <http://grattan.edu.au/about-us>.

100 John Daley, *Budget Pressures on Australian Governments* (Grattan Institute, 2013) 16.

101 Ibid 14.

102 Ibid 15.


104 Ibid.
The new *National Disability Insurance Scheme* (NDIS), now governed under legislation, is admirable. Some of the core values of the NDIS are based on providing independence and opportunities to those with significant disability. In addition, the scheme aims to provide care and support to their families and carers, assisting the disabled to have greater access to facilities and to reach their full potential.

*Section 22 (1) of the National Disability Insurance Scheme Act 2013* stipulates that the age requirement for eligibility to the scheme:

A person meets the age requirements if:

(a) the person was aged under 65 when the access request in relation to the person was made; and

(b) if the National Disability Insurance Scheme rules for the purposes of this paragraph prescribe that on a prescribed date or a date in a prescribed period the person must be a prescribed age—the person is that age on that date.

*Section 23* states that persons wishing to participate in the scheme must be a citizen of Australia or hold permanent residency. Eligibility to the scheme based on disability is defined under *section 24*:

(a) the person has a disability that is attributable to one or more Intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition; and

(b) the impairment or impairments are, or are likely to be, permanent; and

---


107 National Disability Insurance Scheme Act 2013 (No 20) (Cth) s 22(1).
(c) the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial Functioning in undertaking, one or more of the following activities:

(i) communication;

(ii) social interaction;

(iii) learning;

(iv) mobility;

(v) self-care;

(vi) self-management; and

(d) the impairment or impairments affect the person’s capacity for social and economic participation; and

(e) the person is likely to require support under the National Disability Insurance Scheme for the person’s lifetime.

(2) For the purposes of subsection (1), an impairment or impairments that vary in intensity may be permanent, and the person is likely to require support under the National Disability Insurance Scheme for the person’s lifetime, despite the variation. 108  

The scheme, due to be gradually rolled out beginning in Tasmania, South Australia and areas of Victoria and NSW, aims to ‘recognise that disability is for a lifetime, and so it will take a lifelong approach to providing care and support. This means that assessment will look beyond the immediate need, and across the course of the person’s life’. 109 In addition, it provides that:

Individual support will also be given to people for whom there is good evidence that early intervention would substantially improve functioning (for example, autism, acquired brain injury,


cerebral palsy or sensory impairments), and those for whom early intervention will delay or lessen a decline in functioning (for example, multiple sclerosis and Parkinson’s disease).\footnote{National Disability Insurance Scheme, FAQs <http://www.ndis.gov.au/about-an-ndis/frequently-asked-questions/#eligible>}

The financial support provided to those suffering disability will no longer be subject to fluctuating budget allocations, but come from a funding pool on a needs-assessment basis. In light of this recent reform, it is appropriate to consider its merits in relation to the subject matter of this chapter and the overall thesis.

The intent of the scheme is noble, and the impact it will have on the lives of those living with disability and/or carers will be profound. It is accepted that dialogue about life and death, disability and the costs associated with such are uncomfortable for many. However, to have an objective and rational discussion about resource allocation, it is necessary to look beyond the benevolence of the NDIS and consider the longer term impacts on society and public spending.

Although remarkable in theory, the far-reaching ramifications of the scheme on the public purse are likely to be significant. Funded by increasing the compulsory Medicare levy by half a per cent, there will be a section of society that is resistant of any additional taxation and who may thus consider that schemes or models for disability care should be provided for out of the existing fiscal budget.

As noted earlier, the cost of allowing neonates to survive at 23 weeks, often with profound disabilities, is significant both in the NICU and beyond. Indeed, scarce
resources may be better spent on saving the lives of neonates born even a few weeks later in the gestation period, as they are less likely to suffer disability.

One of the unintended consequences of the NDIS may be to encourage a culture that is reliant on government financial assistance. Where parents may once have considered financial and personal support as factors in deciding to opt for palliative care rather than aggressive treatment, they may now be swayed towards deciding to raise a profoundly disabled child due to the safety net and the added financial security that the scheme provides.

The burden on the Australian tax payer is thus now two-fold. First, there are compulsory tax contributions to the general healthcare budget, allowing neonates to be saved in the NICU. Second, the increase in the Medicare levy will fund the NDIS, to provide lifelong care post-NICU.

The introduction of the NDIS scheme in Australia, funded by public tax revenue, calls for a critical re-think on the correlation of resources and patient outcomes. Despite projections made by the treasury, the $19.8 billion investment over seven years runs at a risk. It is ultimately dependent on continued population growth or, at the very least, on a stable number of working taxpayers, able to pay the required levy to fund the scheme.

Macro factors may also pose a risk to the funds available to the NDIS. For example, if the economy contracts and unemployment rises, the available pool of tax payers available to pay the levy would shrink. Moreover, if the real cost of living declines and wages fall, the amount of tax the government collects would also diminish. An
example of drastically fluctuating fiscal environments can be found in the current economic status of Europe.

If any of the above risks are realised, there may simply not be enough in the public purse to satisfy need, potentially leaving all scheme participants with insufficient funding. Public funds and the resulting benefits (healthcare, education and welfare) to members of society all depend on a healthy and productive workforce, employed and paying taxes. To maintain a balance between economically productive members of society and those that need to be supported, there needs to be serious parliamentary consideration for a framework or model to determine the minimum gestational age at which medical assistance and treatment should be provided for those born extremely premature.

In light of this, some ethical theories support the premise that the allocation of limited public resources should be guided by those that will benefit the most from treatment, and consequently cost less for society. Utilitarian and consequentialist theories, based largely on the notion of ‘the greatest good for the greatest number’, suggest that focusing limited resources on neonates born even a few weeks later in the gestational calendar would be for the greater good of society and the public purse.

Gibson and Harrison support this view, noting that if treatment and care were not provided to neonates unless born at 25 weeks or above, this would ‘reduce costs from £2.945 billion GBP to £2.903 billion GBP’. This is because those starting life on a

---

112 Pharoah et al, above n 64, 718, See also, John McKie et al, above n 30, 536.
113 Gibson and Harrison, above n 77, 172.
reasonably healthy footing, with no significant disabilities, are less likely to be frequent users of the limited public health dollar over the course of their lives.

Several consequential benefits flow from targeting limited resources to those most likely to make a substantial or full health recovery. For example, such recipients are more likely to be able to pay back the investment via a meaningful contribution to the economy and taxation base; although of course, this is not guaranteed.\textsuperscript{114}

If choices have to be made regarding priority, it is reasonable for public money to be spent in a way that maximises public good.\textsuperscript{115}

It is too soon to measure the success of the recent enactment of the \textit{National Disability Scheme Act 2013} in Australia, given that it is still in the early stages of its implementation. Further, the NDIS is not relevant to all healthcare allocations; thus, the issue of limited healthcare resources remains contentious.

Having considers the role of health economics and the social implications of the allocation of limited health resources, the next section of this chapter illustrates the paradoxical relationship between saving a neonate born at 23-weeks’ gestation and aborting a foetus at the same gestational age.

\textbf{XII: The paradox: Abortion or life-sustaining treatment: Both at 23 weeks}

\textsuperscript{114} There will always be a portion of society that may later acquire chronic disease, commit crimes or suffer harmful addictions.

\textsuperscript{115} Hope, Savulescu and Hendrick, above n 13, 210.
As briefly considered in Chapter Two, in Victoria, under the *Abortion Law Reform Act 2008*, a registered medical practitioner can perform a legal abortion on a pregnant woman after 24 weeks of pregnancy, under the circumstance that it is deemed ‘appropriate, and with consultation of at least one other medical practitioner’. The practitioner is to take into account ‘all relevant medical circumstances and the woman’s current and future physical, psychological and social circumstances’.

This means that within one hospital, while extensive efforts and healthcare dollars are being invested in sophisticated medicine and technology to save a neonate born at 23 weeks, despite the risk of that neonate receiving a poor health prognosis and requiring lifelong care far beyond the NICU, another woman, advised and guided by her medical practitioner can lawfully have a pregnancy terminated at the same gestational period, 23 weeks.

This demonstrates the competing interests at stake in treating neonates of this gestational age. A pregnant woman has the legal right to express her wishes to terminate a pregnancy, with her doctor’s advice and guidance, even when it is likely to result in a healthy child. Thus, in the case of lawful abortion, the expectant mother’s decision prevails. By contrast, when a neonate is born at 23 weeks, considerations other than the parents’ overwhelmingly prevail.

---

117 Ibid s 5 (1) (a)–(b).
118 Ibid s 5 (2) (a)–(b).
This leads to the questions of whether it is just and appropriate that the wishes of parents to have life-sustaining treatment continued for their critically ill neonate should prevail and have greater claim over community resources.

Another key difference between the decision to save or abort a neonate at 23 weeks is seen in the effect on healthcare resources. This thesis argues that there is a need for an open public debate as whether wider society is truly willing and prepared to expend limited public health funds to keep severely premature neonates alive. Considerations such as the cost to society at large ought to feature prominently in such debates.

The relationship between sophisticated medical technology and disability is paradoxical: high tech equipment now allows medical teams to save the lives of neonates that, as little as 20 years ago, would probably have died. Some individuals may consider this to an enormous achievement for mankind, defeating nature and pushing the limits of human biology. However, others question whether saving critically impaired neonates born at 23 weeks is appropriate and the best use of public funds. The next section explores this question.

**XIII: Medical technology: Doing more harm than good?**

There is a need for a critical revaluation of the inter-sect between what health outcomes *can* be achieved using advanced medical technology and what outcomes *should* be achieved.

---

Western societies are seemingly fixated with the preservation of life. This is reflected in attitudes towards suicide, the unlawfulness of euthanasia and the disregard by some medical practitioners of advance directive end-of-life wishes.120

A recent opinion piece by an anonymous Victorian physician in Melbourne takes this idea further, asserting that doctors are not only ‘trained to treat’ in almost all circumstances, but also find it difficult to let patients, particularly the elderly, die of ‘natural causes’. The author stated:

As a GP with 25 years’ experience, I am increasingly disturbed by this trend in modern medical care. It is ironic that we are debating euthanasia when we can currently be denied the opportunity to die of natural causes at a point when it would be appropriate and the kindest thing for the individual.121

This preference to save all lives disregards the principles of personal autonomy and dignity, particularly at the end of life, and fails to consider the increasing expense of hospital care. Australian intensive care specialist, Dr Peter Saul, comments:

The simple solution is to be guided more by what people want, particularly at the end of their lives. What we know is that default setting in acute care is that people receive an enormous amount of,

---
120 See further L Willmott, Ben White and Michelle Howard, ‘Overriding Advance Refusals of Life-Sustaining Treatment’ (2006) 25(4) Medicine and Law 647–661. The authors argue that the current legislation in Queensland under the Powers of Attorney Act 1998 (Qld) s 103, whereby a doctor may override a patient’s refusal of treatment under an advance directive based on ‘good medical practice’, should be repealed.

probably not in the end life saving treatment which carries a huge burden financially and in other ways.122

Although Dr Saul’s assertions above are in relation to decision making for the aged, his comments are persuasive. Similar arguments can be made about treatment decisions for extremely premature neonates. Expensive treatments in the NICU for neonates at 23 weeks generally result in either prolonging an inevitable death or sustaining life with subsequent severe disabilities.

Of course, when the patient is a neonate, it is not possible to ascertain their treatment wishes. This is further exacerbated by parents pushing for expensive life-sustaining treatment, and doctors overwhelmingly taking the standpoint of the need to ‘save life at all costs’, whether these costs be to the neonate, the family or to society.

Protecting and saving the lives of the very sick, the very young and the vulnerable are perhaps considered to be some of the core values and moral obligations placed on western developed societies.123 Severely impaired neonates meet all of these criteria, making their treatment morally fraught. Some commentators have referred to the over usage of technology and medicine to treat extremely premature neonates as a ‘form of extremism’. The phrase seems relevant here.124

122 Eleanor Hall, ‘To Cut Hospital Costs, Talk to the Patients’, The World Today, 29 April 2013 (Dr Peter Saul) <http://www.abc.net.au/worldtoday/content/2013/3747260.htm>.
Thus far, it has been argued in this thesis that NICUs are expensive to manage, and that even with cutting-edge technology, those born at 23 weeks rarely escape severe lifelong disability. Even in an austerity-driven environment in which the cost of treatment and care far outweighs the benefits to the individual and society, governments continue to provide significant resources to NICUs.

Where governments allocate large portions of the healthcare budget to save impaired neonates in the NICU, the argument can be made that there is a corresponding moral duty to extend this to a commitment to allocate monies to provide all necessary support to these individuals for the rest of their lives. Therein lays the problem: public funds do not, and cannot, stretch to this extent. Several other competing claims can be made for the same pool of resources.125

Kuhse and Singer argue that:

There is a limit to the burden of dependence which any community can carry. If we attempt to keep all handicapped infants alive, irrespective of their future prospects, we will have to give up other things which we may well regard as at least equally important.126

There are two schools of thought on disability: that life is valuable and any existence is better than none, or that a life lived under the constraints of a severe disability is no life at all. An example of this latter point can be found in popular support for euthanasia among a wide section of society, who champion the right to die with respect and dignity.

In a recent report entitled, *The Right to Choose an Assisted Death: Time for Legislation?*, which followed a roundtable discussion comprising a multidisciplinary cohort of Australia’s most eminent and influential advocates in the area of health law and end-of-life decision making, a powerful indication was made of the acceptance of euthanasia. This report went beyond moral and ethical opinion as to whether euthanasia should be approved or sanctioned, to actually discuss what a legislative model should look like.

A further illustration of the view of a life of mere existence being no real life at all is provided by Henner and Kluge. The authors stipulate that severely disabled neonates may in some cases be ‘better off dead’:

...the very fact of living constitutes a continuous injury to the newborn who is being kept alive. To keep the newborn alive is to impose on the child a life that most other persons would not want to live and which, given the chance, they would want to leave.

This statement clearly relates to those who are extremely disabled at birth. Many people living with disability are a valuable part of society. Further, individuals living with a disability are distinct from those who merely exist or survive with disability. It is the latter group that Henner and Kluge are referring to above. Unfortunately, due to limited resources, premium care cannot be provided to all that require it.

---


129 For a discussion about the cost of care for disabled individuals in the UK, see Smith et al, *Disabled People’s Costs of Living: More Than You Think* (Joseph Rowntree Foundation, 2004).
The previous chapter introduced Heather, who, in the BBC documentary, candidly spoke about her life, her struggles with depression and her fears of losing her parents. The first-hand experiences and thoughts of 21-year-old Heather, born extremely premature and living with severe disabilities, are valuable here.

Born at 26 weeks, her parents and doctors made the decision to keep her alive. However, she is provided with little to no financial support from the government. Heather advocated the need for lifelong care and financial support for services stating, ‘it’s very selfish to keep a baby alive, we’ve done our bit for society (hospital/government) it’s not true or right, the baby thinks I’m alive, but what do I do now?’\footnote{The Price of Life (Directed by Adam Wishart, BBC Production, 2011) 00.40.30–00.40.35.} She went on to say:

> What’s my purpose now—we kept you alive (hospital/government) but now you cost us too much money, so we are not going to bother … if you are willing to support someone at the beginning of life, you should be willing to support them to the end.\footnote{Ibid 00.40.41–00.40.48.}

Heather’s position is understandable given that it is her life that is constrained by lack of public funds, affecting her quality of life. Moreover, her position is supported by some doctors, who also find the high levels of government funding to the NICU spurious.

Dr Anne Orkit, a paediatrician consultant from Birmingham, UK, discussed the lack of public funds allocated to post-NICU care:

\footnote{130 The Price of Life (Directed by Adam Wishart, BBC Production, 2011) 00.40.30–00.40.35.}
Money from the NHS (National Health Service) has gone into NICU, but not much into community care or disabled care. As a society we don’t look at lower profile things—saving a miracle baby grabs the public and NHS commissioner’s imagination. The need for physio for a cerebral palsy kid does not sound sexy, and you don’t get money in the same way.132

Some Australian doctors offer similar sentiments. For example, neonatologist, Dr Andrew Watkins, stated ‘Australia has a poor track record in providing good-quality care for people with disabilities. Is it ethical to bring children into a world that offers so little in terms of support?’133

Governments in the UK and Australia are in a difficult position, being the source of both the problem and the solution. A rational solution could be to allocate finite resources to saving neonates born at a later gestational age, or focusing on prevention of prematurity to encourage the birth of healthy, abled and productive future members of the economic workforce. However, this does not align with the current situation of large portions of the healthcare budget being absorbed by saving neonates that are so premature they could legally be aborted. Dr Orkit advocates a critical re-evaluation of healthcare funds and their prioritisation:

We should change in terms of looking at what we do at the very early twenty-three week gestation period and have a hard look at the outcomes from that group and make a decision on that. Just as the same way we’ve made hard decisions around things like cancer drugs and seeing the outcome are not good enough to use, therefore we won’t spend that money. With the financial situation as it is, we simply can’t go on giving people what they want.134

132 Ibid 00.38.51–00.39.30.
133 Evans, above n 63, 42.
134 The Price of Life, above n 130, 00.53.35.
Daphne Austin, from the West Midlands NHS specialised commissioning department, also supports a more cautious use of public funds: ‘I can’t think of very many interventions that have such poor outcomes as resuscitating 23 week babies, we’re spending an awful lot of money on treatment with very margin benefit’. She goes on to state, ‘…if I came out and said I’m going to stop resuscitating babies at below twenty four weeks there would be a witch hunt’. 

Discussions about the allocation of finite public funds in regards to life and death decisions for severely premature neonates are uncomfortable for many individuals, due in large part to their taboo nature. However, despite not being openly discussed, placing a financial value on life is an active practice, as discussed in the next section.

**XIV: Placing value and price on life: A common practice**

Many facets of everyday life have an impact, both positive and negative, on health and life outcomes. The consequential effect of some of these practices is reflected in public expenditure.

Taxpayer monies are often spent on items or developments from which not all individuals may receive a specific benefit. For example, taxation revenue is often used for the maintenance or construction of new buildings or roads that will not be accessed or used by all tax payers. This is also true of healthcare funds, which may be utilised for specific initiatives or programmes that an individual may never participate in or

---

135 Ibid 00.57.28.
136 Ibid 00.57.32.
benefit from. As Savulescu et al note, the contrary is also true, with some public
initiatives and regulations such as speed limits contributing to all individuals’ health
and wellbeing.\textsuperscript{137} The following sub-sections outline some of the current practices in
which a value is placed on life and where the utilisation of public funds is of significant
consideration.

(A) Road death tolls

Enforcing speed limits to protect drivers and pedestrians does not provide absolute
protection from danger. Road death tolls provide an indication of the number of lives
that could be saved if cars were banned from certain areas, or particularly drivers were
stopped from driving.

Statistics from the Transport Accident Commission (TAC) highlight that in 2011–
2012, there were 276 fatalities on Victorian roads, across Melbourne and rural areas.
Of those, 200 were male and 121 were the driver of the vehicle. Further, the age groups
most affected were between 30–39 and over 70 years of age.\textsuperscript{138} The figures from the
TAC website also indicate that drivers and motorcyclists killed in drink driving
accidents accounted for 25 per cent of all road deaths; of those, 79 per cent were
male.\textsuperscript{139}

If all life was measured equally valuable it could be argued that the most effective way
of ‘saving’ 276 or more lives this year would be to ban from driving those drivers most

\textsuperscript{137} Hope, Savulescu and Hendrick, above n 13, 211.

\textsuperscript{138} Transport Accident Commission, \textit{Rolling 12 Month Road Toll} <http://reporting.tacsafety.com.au/s/search.html?collection=tac-

likely to cause or be involved in road traffic accidents. However, despite the indication that banning men from driving would statistically considerably reduce the road toll, such a move would be absurd. Extending this argument further, in its strictest form, if all life is to be considered sacred and worthy of preservation at all costs, perhaps it would be appropriate to ban all vehicles from the road.

(B) Triage/Emergency room categories

Triage facilities within emergency departments of hospitals are a clear instance in which the value of life and healthcare is separated and rationed. If an equal value were placed on all life, there would not be a system of prioritisation of treatment for patients based on the urgency or severity of their needs.140

Historically, deriving from the French verb ‘to sort’, triage was a practice developed by the military services over a century ago. ‘[T]he military were looking at cost effective medicine, and were selecting those patients for whom the medical services could offer something useful’.141 The same principle applies in public hospitals today, to target ‘limited resources to the patients with the best chance of survival’.142

Rationing healthcare and targeting emergency treatment based on need is neatly ranked and categorised from 1–5: resuscitation, emergency, urgent, semi-urgent and non-urgent. Based on these categories, assessments are made by medical teams as to

142 Lantos, Mokalla and Meadow, above n 43, 187.
the approximate time frame within which they see each patient, ranging from immediately to within 120 minutes. Many patients will be treated effectively and discharged, while others will require a hospital stay, and some will be referred to their general practitioners for follow-up treatment.

When patients being treated by their general practitioners require elective surgeries, they are placed on ‘waiting lists’ for treatment. In Victoria, the number people waiting for treatment is set to increase to over 55,000 patients, with limited public healthcare resources making it critical to ration treatment by need and chance of improvement.

By the time a patient reaches the top of the waiting list, there is the possibility that, during the course of the wait, they may have died, or their condition may have increased in severity, requiring the deployment of even greater healthcare resources to restore them to full health.

(C) Pharmaceutical Benefits Scheme

In Australia, the pharmaceutical benefit scheme provides another example of the value of life being accounted for by dollars. If all life were measured with the same worth, all medicine and treatments would be covered under the scheme to save or control as many diseases as possible. Yet medicines that are considered too expensive to be funded under public health are not covered under the scheme.

---


The schemes and practices highlighted above reveal that western society does place a monetary value on life, albeit indirectly. Difficult decisions in the current tough financial climate are made daily as to which patients should receive an allocation of the finite public resources.

Gampel’s coining of the term ‘noble lies’ for the subtle practice of rationing healthcare provides a unique interpretation. His first application of the ‘lie’ is in situations in which medical practitioners consider palliative care to be the best option, as further treatment would be futile. This ‘noble lie’ is advantageous in two ways: it allows doctors to avoid being seen as emotionless, and preserves parents from the guilt of expressing their wishes for treatment to be discontinued.145

Perhaps Gampel’s most acute observation of the application of the ‘noble lie’ is that it is simply ‘necessary in order that health care providers perform the function of rationing in a society which is not facing up to the task’. 146 He further asserts:

For family are less likely to take such actions when they are told the treatments were futile, than if told the treatments are ‘potentially effective’, but that the odds of providing a meaningful improvement were too low given the financial costs involved. 147

While some individuals may contend that this is immoral, unjust or deceitful, as noted above, decisions about healthcare rationing are often ‘cloaked’ in other ways. A final illustration of this is provided below.

146 Ibid 103.
147 Ibid.
(D) The judiciary

Chapter Two considered the role of the judiciary in end-of-life decisions for incapacitated neonates, where futility of treatment, the best-interests principle and quality of life are key considerations of the court.

These decisions, which are of paramount human interest, are not taken lightly. It is appropriate and necessary that Parliament and its legislative powers provide societal reforms based on the changing attitudes and social mores of the day. This is reflected in present-day activism in the UK and Australia for the legalisation of gay marriage and voluntary euthanasia.

However, judges have the freedom to guide law making outside the democratic process; a freedom that an elected Parliament does not have. Although judges are inherently conservative, they do possess the autonomy to be robust, which can influence Parliament.

The courts can suggest and influence the creation of law, but changes to law remain the prerogative of Parliament. Courts have been influential as activists and instigators for change, reflected in pivotal moments in Australian and English legislative history, with changes later confirmed in statute. An example of this can be found in the landmark case of Mabo in Australia, which recognised native title. Mabo and Another v Queensland (No 2) [1992] HCA 23.
the withdrawal or withholding of life-sustaining treatment, the courts have been guarded in their response, avoiding the core issues.

Heywood contends that members of the legal fraternity ‘tread carefully around this issue, but it is undoubtedly considered even if not overtly, by the courts in their decision making’. Indeed, it appears that, under the guise of benevolence and with no uncertain degree of paternalism, judges do make decisions based on limited resource allocation, couched in the least offensive language as possible. For example, as considered in Chapter Two of this thesis, judges apply nebulous terms such as futility, best interests and quality of life when treatment is unlikely to yield any improvement or significant results.

The English Court of Appeal, were required to consider the very question of resource allocation in the case of *R v Cambridge Health Authority; ex p B*. The case concerned a 10 year old girl suffering with Non-Hodgkins lymphoma. After initial success with treatment and remission, the disease relapsed, and medical opinion suggested that she had between six-eight weeks to live.

A second medical opinion, sought by her father, suggested that a second bone marrow transplant was possible, but unavailable under the National Health Service (NHS). The proposed cost of the treatment (in two stages) provided privately was approximately £75,000 with a 10-20 percent chance of success.

---

149 Heywood, above n 93, 31.


151 *R v Cambridge Health Authority; ex p B* [1995] [1995] 1 WLR 898.
The health authority concluded that limited public funds for treatment, which they considered to be ‘experimental’ in nature would be inappropriate. B’s father then sought legal intervention and judicial review of the health authority’s decision. The judge found that the health authority had,

…failed to take account of B.’s and her father's wishes, had misdescribed the proposed treatment as experimental, had not, given the threat to B.’s life, adequately explained the authority's funding priorities and had wrongly treated the total sum as that required whereas the initial requirement was limited to £15,000.152

The judge quashed the decision, but did not order the health authority to provide the treatment, rather, requested a reconsideration. On appeal, Sir Bingham was forthright in stating the realities of limited health funds stating:

I have no doubt that in a perfect world any treatment which a patient, or a patient's family, sought would be provided if doctors were willing to give it, no matter how much it cost, particularly when a life was potentially at stake. It would however, in my view, be shutting one's eyes to the real world if the court were to proceed on the basis that we do live in such a world. It is common knowledge that health authorities of all kinds are constantly pressed to make ends meet. They cannot pay their nurses as much as they would like; they cannot provide all the treatments they would like; they cannot purchase all the extremely expensive medical equipment they would like; they cannot carry out all the research they would like; they cannot build all the hospitals and specialist units they would like. Difficult and agonising judgments have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients. That is not a judgment which the court can make.153

152 Ibid 898.
153 Ibid 906.
However, Sir Bingham did not consider the issue of allocation of limited public funds to be one within the courts remit.

Further, in *Re J (a minor) (wardship: medical treatment)*, Lord Donaldson touched on limited resources, before quickly moving on, being careful to avoid commencing any real dialogue about allocation as it applies to healthcare and neonates. He stated:

In an imperfect world resources will always be limited and on occasion agonising choices will have to be made in allocating those resources to particular patients. It is outwith the scope of this judgment to give any guidance as to the considerations which should determine such an allocation, save to say that the fact that the child is or not a ward of court is a total irrelevance.154

The seminal English case *Airedale NHS Trust v Bland*, considered previously, also illustrates the court’s discomfort in discussing resource allocation. Hoffman LJ betrayed the political sensitivity surrounding this issue with a carefully worded judgment, avoiding any suggestion of better resource allocation:

The resources of the National Health Service are not limitless and choices have to be made. This qualification on the moral duty to provide care did not enter into the argument in this case at all. The Airedale N.H.S. Trust invited us to decide the case on the assumption that its resources were unlimited and we have done so. But one is bound to observe that the cost of keeping a patient like Anthony Bland alive is very considerable and that in another case the health authority might conclude that its resources were better devoted to other patients. We do not have to consider such a case, but in principle the allocation of resources between patients is a matter for the health authority and not for the courts.155

154 *Re J (a minor) (wardship: medical treatment)* [1990] 3 ALL ER 930, 934
Lord Browne-Wilkinson also raised questions about resource allocation, but failed to provide any guidance or direction about future discussion on this. He asserted:

In addition to these ethical questions, the new technology raises practical problems. Given that there are limited resources available for medical care, is it right to devote money to sustaining the lives of those who are, and always will be, unaware of their own existence rather than to treating those who, in a real sense, can be benefited, e.g. those deprived of dialysis for want of resources.156

As discussed in Chapter Two, while resource allocation is not an overtly important consideration in neonate treatment cases, the trend of cases and judicial decisions indicates that, in reality, it is probably a forceful driving consideration.

The final section of this chapter considers other recommendations, other than placing an emphasis on the allocation of limited health resources in making end-of-life decisions for critically impaired neonates. The proposed approaches can be considered in a holistic or in a piecemeal fashion.

XV: Other Recommendations

(A) An insight from the Netherlands: Groningen protocol—Permissible neonatal euthanasia

The Netherlands is well known for its progressive ideologies relating to health and personal autonomy at the end-of-life. For example, adult euthanasia has been

156 Ibid 879.
legalised\textsuperscript{157} and individuals over the age of 12 with a ‘limited life expectancy and [who] experience severe and persistent suffering’ are permitted to die. \textsuperscript{158}

The Groningen protocol, formulated by a number of medical practitioners based at the University Medical Centre in Groningen, Netherlands provides criteria to guide doctors in end-of-life decision making concerning critically ill neonates. The protocol and its objectives have been the subject of public debate and controversy.

Jotkowitz et al strongly oppose the protocol, stating ‘any effort to actively euthanize infants is morally unacceptable and violates the traditional ethical codes of physicians and the moral values of the overwhelming majority of citizens of the world’.\textsuperscript{159} However, such criticism reflects the degree of misunderstanding surrounding the protocol.

The above authors’ emphasis on the violation of ‘ethical and moral codes’ fails to consider that one of the core motivations of the protocol is to alleviate ‘hopeless and unbearable suffering’, which to many is considered a moral responsibility. This is particularly so for very young individuals who are unlikely to be able to tolerate the same amount of pain or suffering as an adult, and who, unlike adults, have no comprehension of the reason for their pain and suffering.


One of the chief contributors to the protocol, eminent physician Dr Eduard Verhagen, points out that end-of-life decisions for infants generally fall within three categories:

(1) there is no chance of survival;
(2) the child has a very poor prognosis and is dependent on intensive care and their future condition is grim; and
(3) those with a hopeless prognosis who experience what parents and medical experts deem to be unbearable suffering; their quality of life will be very poor and for whom there is no hope of improvement. 160

As noted in Chapters Two and Three of this thesis, English and Australian courts are conceivably already applying the above, permitting the withdrawal or withholding of treatment when doctors and parents are in agreement. However, the judgments that record these decisions are careful only to apply time-honoured legal principles of quality of life, futility and best interests. 161 Thus, where the Dutch have succeeded, English and Australian jurisdictions have not been able to codify the approach identified above. Nor have they called on Parliament for such.

Another contentious issue considered throughout this thesis, over-reliance on medical technology that yields poor results, is also addressed by Verhagen and Sauer, who state that ‘where even modern technology cannot produce adequate solutions as regards treatment or adequate relief of the suffering caused by disease’. 162 This is a primary focus of the protocol, whereby unbearable pain and suffering to a newborn is alleviated by active euthanasia.


The Groningen protocol expressly stipulates conditions that must be met ‘before’ and ‘after’ any active steps are taken to end the life of a severely impaired infant. These conditions are:

(1) certainty of the diagnosis/prognosis
(2) there must be hopeless and unbearable suffering
(3) the hopeless and unbearable suffering must be confirmed by at least one independent doctor
(4) both parents must give informed consent.¹⁶³

Further, post infant death, the decision is subject to review by an ‘outside legal body’ to determine whether ‘all necessary procedures have been followed’.¹⁶⁴ This requirement reflects the checks and balances inherent in the protocol. Decisions must be weighed and justified, and doctors are not immune from prosecution. The authors sensibly assert that ‘all cases must be reported if the country is to prevent uncontrolled and unjustified euthanasia and if we are to discuss the issue publicly and thus further develop norms regarding euthanasia in newborns’.¹⁶⁵

Taking the idea of the Groningen protocol further, the Belgian Federal Parliament is likely to extend legal euthanasia to critically ill children in the immediate future, making it the first country to provide euthanasia legislation for neonates.¹⁶⁶

¹⁶⁵ Verhagen and Sauer, above n 741, 960.
¹⁶⁴ Ibid.
¹⁶³ Ibid.
Given the discomfort surrounding legal voluntary assisted euthanasia for competent and freely consenting adults in the UK and Australia, it is unlikely that a counterpart to the Groningen protocol or Belgian position will be undertaken in either of these countries in the near future. Nevertheless, the objectivity and transparency of the Groningen protocol should be championed by the UK and Australia. 167

The Groningen protocol offers doctors a comprehensive framework to ‘responsibly end the lives of severely impaired newborns’.168 Verhagen and Sauer describe the protocol as a codified process under which it is acceptable to deliver death as a means of alleviating unbearable pain and suffering in the most exceptional cases of severe impairment in neonates.

(B) Prevention rather than cure

The undercurrent to this discussion is whether it is appropriate to keep extremely premature neonates, born at 23 weeks, alive. While the significant financial resources that have been injected into new technologies and medicines have pushed the boundaries of medical science, this has not proven to be entirely successful.

The prioritisation of healthcare funds for extremely premature neonates needs to be re-visited, and prevention of premature birth rather than cure should be of central importance. Dr Imogen Morgan, clinical director of neonatology at Birmingham

Children’s Hospital in the UK, champions this approach, stating ‘that’s where we put our money in preventing premature birth if we possibly can’. Bennett also advocates that, ‘there is no doubt that funding of prenatal care must always be a priority in the funding of health care’. Emphasis needs to be placed on initiatives and resources to reduce the number of premature births.

As considered earlier, the role of the media and government allocation of health funds reflect a priority to save extremely premature neonates from death, perhaps more so than investing monies into prevention of premature birth. This is considered more appealing than dealing with long-term difficulties and poor health prognoses in any great detail. Musaskas and Parsi support this view:

> In many ways the world of neonatology is a microcosm of our health care system which greatly rewards rescuing our most vulnerable patients through a panoply of technological interventions but downplays the role of prevention.

To prioritise prevention of premature births requires an assessment of the causes of such births.

(C) Increases in educational awareness and reduction of poverty

Rather than injecting finite resources into the NICU to treat 23 week neonates, a better use may be to re-direct some of those funds to improve the overall health and wellbeing

---

169 The Price of Life, above n 130, 00.46.47.
170 Bennett, above n 11, 84.
of those groups in society most likely to produce premature neonates. As Weightman et al argue, government policies and priorities need to focus on ‘tackling social determinants, which … includes health, education, and child poverty’.172

Poverty and social disadvantage are significant factors associated with premature birth and poor healthcare outcomes.173 Dr Orkit contends that the ‘problem is outside the hospital, you are more likely to give birth to a child with extreme prematurity if you live in poverty’.174 In the UK, teenage pregnancy rates are the highest in Western Europe and ‘teenage mothers and their babies are at increased risk of poor health outcomes’. 175

Public funds should be provided for educational initiatives targeting teenagers and school age children that highlight the increased chance of premature birth and the subsequent likelihood of neonatal death or survival with severe disability. Suburbs with the highest rates of teenage pregnancy, and social disadvantage could be targeted under such a scheme. Behaviours are more likely to be mimicked in suburbs with high numbers of school leavers and teenage pregnancies. Thus, targeting these areas would have a good chance of success.

174 The Price of Life, above n 130, 00.45.41–00.46.09.
Paranjothy et al found that, in a randomised controlled study, there was a reduction in the ‘pre-term rate among females under 18 years’, stipulating the need for ‘comprehensive social and medical care using antenatal clinics specific for teenagers’.

It is encouraging that, in the UK, the compulsory legal age requirement for attendance of an educational institution will be raised from 16 to 17 in 2013. High teenage pregnancy rates are on impetus for this change in law. Researcher Tanya Wilson indicates that ‘incarcerating’ teenagers in the schooling system until they are 17 could potentially lead to ‘postponement of motherhood by one year’. This educational reform is commendable, but results will have to be weighed for their efficacy once available.

(D) Pre-natal advance directive

As discussed in Chapter Four, there is a significant amount of subjectivity within each stakeholder group when making end-of-life decisions for impaired neonates. Parents of premature neonates are the group most affected.

As part of the pre-natal care process, parents are informed of fetal development, and advanced technologies now allow parents to not only see their unborn child via ultrasound but also to take sophisticated three-dimensional images of their unborn child. Given the wealth of information that is being imparted to parents regarding the

176 Paranjothy, above n 175, 242.
177 Ibid.
development of their neonate, there is an opportunity for open and frank discussions with parents about the possibilities of and risks involved in premature birth.

The preparation of pre-natal advance directives; that is, a ‘pre-negotiated treatment plan for an imperilled newborn’, should be considered.\(^{179}\) Arguably, arranging such directives would be less confronting for parents than to experience a pre-term birth and the discussions that must follow.

Catlin supports this view, stating that ‘much of the education women receive about preterm delivery occurs at the bedside when preterm labour is occurring, or during or immediately after a preterm birth. At these critical periods, they are often asked to make to serious decisions’.\(^ {180}\) For expectant parents to be able to make a truly informed decision, it is important that they understand all the information provided to them and have time to make rational choices based on that information. The optimum time for this to occur is before the birth, when prospective parents can take away information and discuss it. Catlin again reinforces this point:

> For women to be able to make coherent choices about their own care and the care of their prematurely born foetuses, they must appropriately understand the actual meaning of prematurity and the possible short- and long-term consequences.\(^ {181}\)


Competent adults often prepare advance care directives about their health and wellbeing; thus, ‘competent parents’ should be afforded the same liberty as regards potential life-changing circumstances that will affect them.

Of course, the thought of a premature disabled neonate and the reality are markedly different. Understandably, parents’ attitudes may change radically after birth. However, a pre-natal advanced directive is a powerful tool, creating a platform for an honest and open discussion about the realities of premature birth and possible associated disability or even death.

Finally, this chapter examines Parliamentary intervention: the most effective method of societal and policy change with regard to end-of-life decision making for impaired neonates.

(E) Parliamentary intervention

Chapter Two of this thesis discussed the development of case law with regard to decisions to withdraw or withhold life-sustaining treatment from critically ill neonates. Three decades on from the case of Baby Pearson in 1980 in the UK, treatment decisions for incapacitated neonates remain fraught with subjectivity. It must be questioned whether the courts should be presiding over cases concerning whether impaired neonates live or die when this is unsupported by statute. A host of considerations, moral, legal and constitutional, support the view that Parliament as a
democratically elected institution is the correct home for such a determination, and that the courts should not play the role of moral arbiter.\textsuperscript{182}

A policy-based approach to end-of-life decision making for neonates born at the edge of viability at 23 weeks is the best means of development of a legislative framework. Such a framework could stipulate a minimum threshold at which those born premature and suffering pain and ongoing debilitation should not be resuscitated.

As noted earlier in this chapter, such a debate is unlikely to occur in the current climate of either the UK or Australia. That Parliament adopts an inherently conservative approach to legislative and ethical change is evident in the ongoing debate surrounding voluntary active euthanasia for competent adults, despite 85 per cent of Australians supporting this initiative.\textsuperscript{183} However, academic and community interest in the issue could, through the democratic process, force this issue onto the parliamentary agenda.


288
XVI: Conclusion

This chapter discussed in detail the contentious issue of balancing treatment decisions with finite resource allocation, recommending this as one means by which decision making in this area can be imbued with some objectivity. Additional recommendations were also made towards greater coherence in and a better understanding of end-of-life decisions for extremely premature neonates.

In western societies, there is rarely any detailed consideration about the true fiscal cost involved in preserving life. Advances in technology and medical science have further entrenched the expectation that ‘everything that can be done, should be done’ to save lives. Resource realities are a controversial but real consideration, relating to the question of which individuals are cheaper to keep alive and the likely benefits to society of doing so. On both of these criteria, impaired neonates rank low.

However, placing more importance on resource allocation in decision making would ensure the process is informed by objectivity and rationality, as opposed to subjectivity as is currently the case. Substantial public funds are consumed in keeping 23 week neonates alive, with the typical outcome being that they live with severe disability or endure a painful and prolonged death. This calls into question whether as a society we are doing the right thing by keeping these neonates alive? Are we actually causing them and society more harm by keeping them alive?

The final chapter of this thesis draws together the central themes of each chapter and presents the final conclusions of this thesis.
CHAPTER SIX: CONCLUSION

Just over three decades ago, discussion concerning withdrawing or withholding life-sustaining treatment from critically ill neonates began to receive serious public, political and legal attention in the UK and Australia. Today the area remains fraught with ethical, moral and legal issues and remains unresolved.

The aim of this thesis was two-fold: to identify the deficiencies in the manner in which these decisions are currently being made, and to make pragmatic recommendations to inform the design of an objective, consistent and transparent model.

To meet the objectives of this thesis, it was necessary to critically examine the key factors currently affecting life and death decision making in regards to critically imperilled neonates, to identify the most problematic and contentious issues hindering objectivity, transparency and uniformity.

This thesis has confirmed that the manner in which decisions are made to withdraw or withhold life-sustaining treatment from critically ill neonates is inconsistent, not transparent and heavily influenced by the subjective opinions, beliefs and emotions of all relevant stakeholders.

The development of sophisticated technologies means that extremely premature and critically impaired neonates, that 20–30 years ago would have died, now live. This includes neonates born at the edge of viability at 23-weeks’ gestation (a stage of development at which abortion is still legal).
Although neonates can be saved from death at 23 weeks, the current state of technology and medical science means that these babies continue to be at risk of severe disability. As one commentator candidly asserted, ‘science is moving fast, but until we invent an amniotic sac, there’s a big cost to these babies, and nature is against their survival’.  

This thesis focused on decision making in the UK and Australia. While Australia only has a handful of cases on record that have required coronial or legal intervention, English case law has an abundance of cases in which medical practitioners and parents have disagreed on the withdrawal or withholding of life-sustaining treatment from premature neonates.

Chapter Two critically examined case judgments, highlighting the lack of consistency in the courts in attempting to reconcile the sanctity of life principle, a long-standing tenet of society, with making decisions that uphold dignity and serve a patient’s best interests. Judges often apply nebulous and ill-defined principles such as futile treatment and poor quality of life, and weigh up the burdens of treatment against the benefits it will confer in a scoreboard-like fashion, to cloak decisions that ultimately amount to the lawful withdrawal or withholding of life-sustaining treatment.

The over-reliance on medical opinion by the courts further underscores the reluctance of the courts to drive any meaningful reform of the law in this area. This has given rise to the current situation in which determinations are unpredictable, often almost arbitrary and seemingly driven by the idiosyncratic sentiments of the decision maker.

---

In Chapter Three, a critical evaluation of the most current clinical guidelines in the UK and Australia found that they too are interspersed with inconsistencies and lack any codification or uniformity. While the 2006 Nuffield Report on Bioethics was commended for attempting to provide further guidance and certainty, it was ultimately yet another missed opportunity to generate any robust reforms. The inter-relationship between the courts and doctors also came to the fore in the discussion of these guidelines, which advocate a holistic approach encompassing ethical, legal and clinical factors in decision making. It appears that judges rely on medical opinion and doctors rely on case decisions when developing guidelines to assist in decision making.

Overall, the one aspect of uniformity that exists between these guidelines is their variability. In a particularly stark example, guidelines within the same country, and even within the same state, all provide different gestational ages at which resuscitation is ‘best practice’.

Chapter Four examined the roles and influence of the key stakeholders, parents, doctors and the judiciary, as an integral part of the decision-making process. Stakeholder inconsistency and subjectivity in decision marking was strongly evident.

The brief discussion of the key points of each chapter above serve to highlight the present inconsistent and highly subjective state of decision making as regards the withdrawing or withholding of life-sustaining treatment for critically imperilled neonates. This thesis argues that a formalised process is required at a national level, formulated on objective and pragmatic principles, as discussed in Chapter Five. This could be achieved with reference to the following conditions:
1. An immediate focus on resource allocation, where decisions to save and preserve damaged lives are made in consideration of the immediate costs of medical treatment, the costs of disability for the family, requirements for long-term care, and the benefits and associated costs of life, not only to the patient, but also to society.

2. An immediate discussion of this topic by Parliament, with the eventual aim of a legislated, mandatory and national framework for decision making.

The conservative social and political climate of Australia, and to a lesser extent in the UK, explains why the discussion continues around the issue of end-of-life decision making for impaired neonates three decades on from the cases of the 1980s. It is unlikely that, in the near future, any proposals made by this thesis will be given the serious consideration they deserve.

Despite this, this thesis has attempted to raise general consciousness of the issue, particularly against the present-day backdrop of improving medical technologies and declining healthcare dollars. With improvements in technology, there will be a greater number of neonates surviving at 23 weeks and below, despite the future prospects of these neonates remaining bleak. In light of this, this thesis proposes the adoption of less confronting approaches (as compared to the basing of life and death decisions on resource allocation) that can be actioned now, such as a focus on prevention.

Finally, while critically impaired and extremely premature neonates can be kept alive, in most instances they probably should not be. This thesis recognises and acknowledges that decisions to withdraw or withhold life-sustaining treatment leading
to inevitable death should not be taken lightly. Moreover, this thesis does not take the position that a life with disability is a worthless life.

However, despite medical practitioners’ best efforts and the deployment of substantial public funds to keep premature neonates alive, they are often left with lifelong debilitating disabilities. If such efforts are to continue, then there is a compelling moral obligation to also provide lifelong care and support for these neonates.

That we are unable to provide such support, which has far greater resource implications than the act of saving them in the first instance, is a moral failing in its own right. As a society, in making the choice to actively save impaired neonates and force them into lives of pain and disability, we are failing in not providing requisite standards of care post-NICU support. Until medical technology advances to the point that saving extremely premature neonates does more good than harm, doing so remains detrimental to the neonate, family and society.

However, the aim of this thesis was not to argue for better investment in disability care. It was instead to question the rationale behind decisions to save and preserve lives of extremely premature and impaired neonates. In choosing to preserve such lives, are we making decisions that are best for the infants, best for the parents, or best for our collective moral conscience as a society?

As noted throughout this thesis, the value of human life is measured continually under the guise of concepts or guidelines that indicate at what point further treatment is considered either futile or not in the best interests of the patient or futile.
This thesis proposes a need for greater transparency in end-of-life decision making, already happening in hospitals on a daily basis. When addressed objectively, the stakeholder groups should find considerable common ground. The suggestion made here that the allocation of finite healthcare resources should drive medical choices relating to premature neonates is not novel. Further, in the past, such arguments have not been influential. However, a key contribution of this thesis to the research and thinking in this area is in showing that, in reality, resource allocation already heavily influences medical decisions.

Moral, cultural and religious values and norms continue to render discussing human life in dollar terms taboo. However, in the end, (near) impossible choices appear to be driven by the thinking that finite resources should not be devoted to saving and extending life.

Framing life-saving and -sustaining decisions relating to premature neonates in these terms would therefore be in line with that which informs most life-defining medical decisions. Moreover, doing so transparently would improve the soundness of decisions and the outcomes for all stakeholders in the life or death of critically imperilled neonates.
ARTICLES/BOOKS/REPORTS


April, Carolyn and Michael Parker, ‘End of life decision- making in neonatal care’ (2007) 33 (3) Journal of Medical Ethics 126


Aristotle (English translation by A L Peck), *On the Generation of Animals* (W Heinmann, 1943)

Aristotle (Translated by Richard Cresswell), *On the History of Animals* (Henry G Bohn, 1862)


Bagaric, Mirko and Kumar Amarasekara, *Euthanasia: Why It Doesn't Matter (Much) What the Doctor Thinks and Why There is No Suggestion that Doctors Should Have a Duty to Kill '* (2002) 10 (2) *Journal of Law and Medicine* 221


Barr, Peter, ‘Relationships of Neonatologists: end-of-life decisions to their personal fear of death’ (2007) 92(2) *Archives of Disease Child Fetal, Neonatal Edition* 104


Boneh, A, S Allan, D Mendelson, M Spriggs, L H Gillam and S H Korman, ‘Clinical, Ethical and Legal Considerations in the Treatment of Newborns with Non-Ketotic Hyperglycinaemia’ (2008) 94 (2) *Molecular Genetics and Metabolism* 143


Boyle, R J, R Salter and M W Arnander, ‘Ethics of refusing parental requests to withhold or withdraw treatment from their premature baby’ (2004) 30(4) Journal of Medical Ethics 402


Brazier, Margaret and David Archard, ‘Letting babies die’ (2007) 33 (3) Journal of Medical Ethics 125


Brierley, Joe, Jim Linthicum and Andy A Petros, ‘Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?’ (30 March 2012) Journal of Medical Ethics 100


Buchh, Basharat, Neil Graham, Barbara Harris, Sherrol Sims, Maria Corpuz, John Lantos and William Meadow ‘Neonatology has always been a bargain - even when we weren't very good at it!’ (2007) 96 (5) Acta Paediatrica 659


Campbell, Deborah E and Alan R Fleischman, ‘Limits of viability: Dilemmas, decisions, and decision makers’ 2001 18 (3) American Journal of Perinatology 117

Campbell, Neil, ‘When care cannot cure: Medical problems in seriously ill babies’ in Helga Kuhse and Peter Singer (eds), Bioethics: An Anthology (Blackwell Publishing, 2nd ed, 2006) 303


Clarke, Steve, ‘When they believe in miracles’ (2013) 39 (9) *Journal of Medical Ethics* 582

Cone, Thomas E, *History of the care and feeding of the premature infant* (Little Brown and Company, 1985)


Cook, Deborah and Mita Giacomini, ‘The sound of silence: rationing resources for critically ill patients’ (1999) 3(1) *Critical Care* 1


Craig, Gillian M, ‘On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far?’ (1994) 20(3) *Journal of Medical Ethics* 139

Crowe, Christine, ‘“Women want it”: In-vitro fertilization and women's motivations for participation’ (1985) 8 (6) *Women's Studies International Forum* 547

Cuttini, Marina, Michela Nadai, Monique Kaminski, Gesine Hansen, R De Leeuw, Sylvie Lenoir, Jan Persson, Marisa Rebagliato, Margaret Reid and Umberto de

Daley, John, Budget pressures on Australian governments (Grattan Institute, 2013)


Douglas, Bob, Lindy Willmott and Ben White, ‘The right to choose an assisted death: Time for legislation?’ (Report, Queensland University of Technology, Health Law Research Centre, April 2013)

Doyal, L and D Wilsher, ‘Towards Guidelines for the Withholding and Withdrawal of Life Prolonging Treatment in Neonatal Medicine’ (1994) 70 (1) Archives in Disease in Childhood 66

Doyal, L and V F Larcher ‘Drafting guidelines for the withholding or withdrawing of life sustaining treatment in critically ill children and neonates’ (2000) 83 (1) Archives of Disease in Childhood: Fetal and Neonatal 60
Doyal, Len, ‘Dignity in dying should include the legalization of non-voluntary euthanasia’ (2006) 1 (2) *Journal of Clinical Ethics* 65


Dunn, Peter, ‘Appropriate care of the newborn: ethical dilemmas’ (1993) 19(2)
Journal of Medical Ethics 82

Duxbury, Mitzi and Lawrence R Adams, ‘Nursing research contributions to improve
NICU care’ (1992) 92-2786 National Institute of Health Bethesda, Maryland

Dwivedi, O P, ‘Satyagraha for conservation: Awakening the spirit of Hinduism’ in J
Ronald Engel and Joan Gibb Engel (eds), Ethics of Environment and Development:


Eekelaar, J, Regulating Divorce (Clarendon Press, 1991)

Eichenwald, Eric C, Frank A Chervenak and Laurence B McCullogh, ‘Physician and
parental decision making in newborn resuscitation’ (2008) 10(6) Virtual Mentor 616

Elliston, Sarah, The Best Interests of the Child in Healthcare (Routledge Cavendish,
2007)

Engle, William A, ‘A recommendation for the definition of “late preterm” (near-term)
and the birth weight–gestational age classification system’ (2006) 30 (1) Seminars in
Perinatology 2

Evans, Robert, Strained Mercy: The Economics of Canadian Health Care
(Butterworths, 1984)

Faunce, Thomas Alured, Pilgrims in Medicine: Conscience, Legalism and Human Rights (Koninklijke Brill NV, 2005)


Finnis, Joel, Natural Law and Natural Rights (Oxford University Press, 1980)


Fleischman, Alan R, Motoko Oinuma and Steven L Clark, ‘Rethinking the definition of “term pregnancy”’ (2010) 116 (1) Obstetrics & Genecology 136


General Medical Council, *Treatment and care towards the end of life: good practice in decision making* (General Medical Council, 2010)


Glover, Jonathan, Causing Death and Saving Lives (Pelican Books, 1977)


Hammerman, Cathy, Eti Kornbluth, Ofer Lavie, Pnina Zadka, Yeshayahu Aboulafia, and Arthur I Eidelman, ‘Decision-making in the critically ill neonate: cultural background v individual life experiences’ (1997) 23 (3) Journal of Medical Ethics 164

Harmon, Louise, ‘Falling off the Vine: Legal Fictions and the Doctrine of the Substituted Judgement Test’ (Oct 1990) 100 (1) Yale Law Journal 1


Harris, John, ‘Human Beings, Persons and Conjoined Twins: An Ethical Analysis of the Judgements in Re A’ (2001) 9 (3) Medical Law Review 221

Harrison, Helen, ‘The offer they can't refuse: parents and perinatal treatment decisions’, (2008) 13 (5) Seminars in Fetal and Neonatal Medicine 329


Huibers, Alex K, ‘Beyond the Threshold of Life: Treating and Non-Treating of Critically Ill Newborns in the Netherlands’ (1995) 16(2) *Journal of Legal Medicine* 227


Jox, Ralf, Andreas Schaider, Georg Marckmann and Gian Domenico Borasio, ‘Medical futility at the end of life: the perspectives of intensive care and palliative care clinicians’ (2012) 38(9) *Journal of Medical Ethics* 540


Kennedy, Ian, *Treat Me Right* (Oxford University Press, 1988)

Kennedy, Ian *Treat Me Right: Essays in Medical Law and Ethics* (Oxford University Press, 1991)


Keown, John, ‘The incompetent patient: sanctity of life, quality of life and vitalism’ in Michael Parker and Donna Dickenson (eds), The Cambridge Medical Ethics Workbook (Cambridge University Press, 2001) 27


Kerridge, Ian, Michael Lowe and Cameron Stewart, Ethics and Law for Health Professions (Federation Press, 4th ed, 2013)

Khoner, Nancy and Alix Henley, When a baby dies: The experience of late miscarriage, stillbirth and neonatal death (Pandora Press, 1991)


Kuhse, Helga, ‘Debate: extraordinary means and the sanctity of life’ (1981) 7(2) *Journal of Medical Ethics* 74


Kuhse, Helga and Peter Singer, *Should the baby live?* (Oxford University Press, 1985)


Kuschel, Carl A and Alison Kent, ‘Improved neonatal survival and outcomes at borderline viability brings increasing ethical dilemmas’ (2011) 47 (9) *Journal of Paediatric and Child Health* 585

Lamb, David, *Down the Slippery Slope: Arguing in Applied Ethics* (Routledge, 1988)

Lantos, John D, Jon E Tyson, Alexander Allen, Joel Frader, Maureen Hack, S Korones, G Merenstein, N Paneth, R L Poland and S Saigal, ‘Withholding and
withdrawing life sustaining treatment in neonatal intensive care: issues for the 1990s’
(1994) 71(3) Archives of Disease in Childhood-Fetal and Neonatal Edition 218

Lantos, John D, Mani Mokalla and William Meadow, ‘Resource Allocation in Neonatal and Medical ICUs Epidemiology and Rationing at the Extremes of Life’
(1997) 156(1) American Journal of Respiratory and Critical Care Medicine 185

Lantos, John D, ‘Hooked on neonatology’ (2001) 20(5) Health Affairs 233


Lockwood, Michael ‘Quality of Life and Resource Allocation’ in Helga Kuhse and Peter Singer (eds), Bioethics: An Anthology (Blackwell Publishing, 2nd ed, 2006) 451

Lui, Kei, Barbara Bajuk, Kirsty Foster, Arnolda Gaston, Alison Kent, John Sinn, Kaye Spence, Wendy Fischer and David Henderson-Smart, ‘Perinatal care at the borderlines of viability: a consensus statement based on a NSW and ACT consensus workshop’ (2006) 185 (9) Medical Journal of Australia 495


Lyon, Jeff, Playing God in the Nursery (W W Norton and Company, 1985)


Margaret Cooper, ‘The Australian disability rights movement lives’ (1999) 14 (2) *Disability & Society* 217


McHaffie, Hazel E and Peter W Fowlie, ‘Withdrawing and withholding treatment: comments on new guidelines’ (1998) 79 (1) *Archives of Disease in Childhood: Fetal and Neonatal* 1


McHaffie, Hazel E, Ian A Laing, Michael Parker and John McMillan, ‘Deciding for Imperilled Newborns: Medical Authority or Parental Autonomy?’ (2001) 27 (2) Journal of Medical Ethics 104


McKie, John, Jeff Richardson, Peter Singer and Helga Kuhse, The Allocation of Health Resources: An ethical evaluation of the 'QALY' approach (Dartmouth Publishing Company Limited, 1998)

McLean, Sheila, Old Law, New Medicine: Medical Ethics and Human Rights (Pandora, 1999)


Michalowski, Sabine, ‘Reversal of fortune- Re A (Conjoined Twins) and beyond: Who should make treatment decisions on behalf of young children?’ (2001) 9 Health Law Journal, 149

Miles, Steven H, The Hippocratic Oath and the Ethics of Medicine (Oxford University Press, 2004)

Miola, Jose, Medical Ethics and Medical Law: A Symbiotic Relationship (Hart Publishing, 2007)
Montello, Martha and John Lantos, ‘The Karamazov Complex: Dostoevsky and DNR orders’ (2002) 45(2) Perspectives in Biology and Medicine 190


Moro, Teresa T, Karen Kavanaugh, Teresa A Savage, Maria R Reyes, Robert E Kimura and Rama Bhat, ‘Parent decision making for life support decisions for extremely premature infants: From the prenatal through to end-of-life period’ (2011) 25 (1) Journal of Perinatal and Neonatal Nursing 52

Morris, Anne E and Michael A Jones (eds) Blackstone’s Statutes on Medical Law (Oxford University, 7th ed, 2011)

Morris, Anne, ‘Selective Treatment of Irreversibly Impaired Infants: Decision Making at the Threshold’ 2009 17 (3) Medical Law Review 347


Nagel, Thomas, Mortal Questions (Cambridge University Press, 1979)

Newall, Anthony T, Paul A Scuffham and Brent Hodgkinson, ‘Economic report onto the cost of influenza to the Australian health system,’ (Report, Research and Practice Development centre, University of Queensland and Blue Care, March 2007)
Nord, Erik, Jeff Richardson, Andrew Street, Helga Kuhse and Peter Singer, ‘Maximizing health benefits vs egalitarianism: an Australian survey of health issues’ (1995) 41(10) Social Science & Medicine 1429


Our Emergency Departments The state of our public hospital June 2008 Report (Part 4) Australian Government

Paranjothy, Shantini, H Broughton, Roshan Adappa and David Fone, ‘Teenage pregnancy: who suffers?’ (2009) 94(3) Archives of Disease in Childhood 239

Parliamentary Office of Science and Technology, ‘Ethnicity and Health’ (Postnote, No 276, January 2007) 1


Pharoah, P O, R C Stevenson, R W Cooke and B Sandhu, ‘Costs and benefits of neonatal intensive care’ (1988) 63 (7) *Archives of Disease in Childhood* 715


Porta, Nicolas and Joel Frader, ‘Withholding hydration and nutrition in newborns’ (2007) 28(5) *Theoretical Medicine and Bioethics* 443


Royal Australasian College of Physicians, Decision making at the end of life in infants, children and adolescents (Royal Australasian College of Physicians, 2008)

Royal College of Paediatrics and Child Health, Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice (RCPCH, 2nd ed, 2004)

Saigal, Saroj, Barbara Stoskopf, Janet Pinelli, David Streiner, Lorraine Hoult, Nigel Paneth and John Goddeeris, ‘Self-perceived health-related quality of life of former extremely low birth weight infants at young adulthood’ (2006) 118 (3) Pediatrics 1140

Saigal, Saroj and Jon Tyson, ‘Measurement of Quality of Life of Survivors of Neonatal Intensive Care: Critique and Implications’ (2008) 32 (1) Seminars in Perinatology 59


Saroj Saigal, ‘Quality of life of former premature infants during adolescence and beyond’ (2013) 89 (4) Early Human Development 209


Savulescu, Julian, ‘Liberal Rationalism and Medical Decision-making’ (1997) 11 (2) Bioethics 115
Savulescu, Julian, 'Consequentialism, reasons, value and justice' (1998) 12(3) Bioethics 212

Savulescu, Julian, ‘Conscientious objection in medicine' (2006) 332 British Medical Journal 294


Savulescu, Julian and Judith Hendrick, Medical Ethics and Law: The Core Curriculum (Churchill Livingstone Elsevier 2nd ed, 2008)

Savulescu, Julian, ‘Abortion, infanticide and allowing babies to die, 40 years on’ (2013) 39(5) Journal of Medical Ethics 257


Shelp, Earl E, Born to die? Deciding the fate of critically ill newborns (The Free Press, 1986)


Simeonsson, Rune J, Mathilde Leonardi, Don Lollar, E Bjorck-Akesson, Judith Hollenweger and Andrea Martinuzzi, ‘Applying the International Classification of
Functioning, Disability and Health (ICF) to measure childhood disability’ (2003) 25 (11-12) Disability & Rehabilitation 602

Singer, Peter, Practical Ethics (Cambridge University Press, 2nd ed, 1993)

Singer, Peter, Rethinking Life and Death (Text Publishing, 1994)


Skene, Loane, Law and Medical Practice: Rights, Duties, Claims and Defences (Butterworths, 1998)

Skene, Loane, Law and Medical Practice: Rights, Duties, Claims and Defences (Lexis Nexis Butterworths, 3rd ed, 2008)


Smith, Noel, Sue Middleton, Kate Ashton-Brooks, Lynne Cox, Barbara Dobson and Lorna Reith, Disabled people’s costs of living: More than you think (Joseph Rowntree Foundation, 2004)


Stewart, Cameron, ‘Futility determination as a process: Problems with medical sovereignty, legal issues and the strengths and weakness of the procedural approach’ (2011) 8(2) Journal of Bioethical Inquiry 155

324

Stewart, Cameron, ‘The sanctity of life in law: Comparisons between Jewish, Catholic, Islamic and common law approaches’ in Peter Radan, Denise Meyerson, Rosalind F Croucher (eds), *Law and Religion: God, the State and the Common Law* (Routledge Studies in Religion, Volume 9 2004) 249


Stewart, Cameron, ‘Withdrawal of Treatment from a Newborn with Congenital Myasthenic Syndrome’ (2010) 7 (1) *Journal of Bioethical Inquiry* 3

Stewart, Cameron, ‘Withdrawal of treatment from newborns in Australia: Baby D (No 2) [2011] Fam CA 176’ (2011) 8 (3) *Bioethical Inquiry* 227


Thomasma, David, ‘The vulnerability of the sick’ (2000) 16 (2) *Bioethics Forum* 5

Thoren, Emelie Maria, Boris Metze, Christoph Bührer and Lars Garten,’Online support for parents of preterm infants: a qualitative and content analysis of Facebook ‘preemie’ groups’ (June 2013) (Online) *Archives of Disease in Childhood - Fetal and Neonatal Edition* 1


326

Vavasseur, C, A Foran and J FA Murphy. ‘Consensus statements on the borderlands of neonatal viability: from uncertainty to grey zones’ (2007) 100 (8) Irish Medical Journal 561


Viner, Russell and Janet Golden, ‘Children’s experiences of illness’ in Roger Cooter and John Pickstone (eds), Companion to Medicine in the Twentieth Century (Routledge, 2003) 575


Weightman, Alison L, Helen E Morgan, Michael A Shepherd, Hilary Kitcher, Chris Roberts and Frank D Dunstan, ‘Social inequality and infant health in the UK: systematic review and meta-analyses’ (2012) 2(3) BMJ open 1


White, B, L Willmott, M Parker, C Cartwright and G Williams, ‘Should law have a role in end- of- life care?’ (2012) 42 (9) Internal Medicine Journal 966


328


Wilkinson, Dominic, Death or Disability? The ‘Carmentis Machine’ and decision making for critically ill children (Oxford University Press, 2013)

Williams, Allan, ‘The value of QALY’s’ (1985) (3) Health and Social Service Journal 3


Woolf, Right Honourable Lord, ‘Are the courts excessively deferential to the medical profession?’ (2001) 9 (1) *Medical Law Review* 1

Yadav, Kamini and David Field, ‘The limit of viability: Should we lower it? (2011) 100 (3) *Neonatology* 295


Zinn, Christopher, ‘Court rules food and hydration are treatment’ (2003) 326 (7401) *British Medical Journal* 1233


Zutlevics, Tamara, ‘Pursuing the golden mean - moral decision making for precarious newborn’ (2009) 27(1) *Australian Journal of Advanced Nursing* 75
CASES

*A National Health Service v D* [2000] 2 FLR 677

*Airedale NHS Trust v Bland* [1993] 1 ALL ER 789

*An NHS Trust v MB* [2006] EWHC 507 (Fam) (15 March 2006)


*Auckland Area Health Board v Attorney General* [1993] NZLR 235

*Baby D (No 2)* [2011] Fam CA 176

*Baby M* (Victorian State Coroner’s Office, Record of Investigation into Death, Case No 3149/89, 29 October 1991) VIC

*Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582

*Department of Health v J.W.B and S.M.B (Re Marion)* (1992) 66 ALJR 300

*Dudley v Stephens* (1884) 14 Q.B.D. 273

*F v West Berkshire Health Authority* [1989] All ER 545

*Gardner; re BMV* [2003] VSC 173

*Mabo and Another v Queensland (No 2)* [1992] HCA 23

*Messiha v South East Health* [2004] NSWSC 1061

*NHS Trust v Baby X and others* [2012] EWHC 2188 (Fam) (30 July 2012)

*Northridge v Central Sydney Area Health Authority* (2000) 50 NSWLR 549

*Portsmouth Hospital NHS Trust v Wyatt* [2004] EWCA 2247 (Fam) (7 October 2004)

*R v Arthur* (1981) 12 BMLR 1
R v Bournewood Community and Mental Health NHS Trust Ex Parte: L [1998] 3 ALL ER 289

R v Cambridge Health Authority; ex p B [1995] [1995] 1 WLR 898

R v Howe [1987] 1 AC 417

Re A (children) (conjoined twins: surgical separation) [2000] 4 ALL ER 961

Re A (Male Sterilisation) [2000] 1 FLR 549

Re B (a minor) (wardship: medical treatment) [1990] 3 All ER (CA) 927


Re C (a minor) (wardship: medical treatment) [1989] 2 ALL ER 782, 783

Re C (a minor) (1997) 40 BMLR 31 (Fam Div).


Re J (a minor) (wardship: medical treatment) [1990] 3 ALL ER 930

Re J (a minor) (medical treatment) [1992] 2 FCR 753

Re J (a minor) (wardship: medical treatment) [1992] 4 ALL ER 614

Re J (a minor) (wardship: medical treatment) [1992] 4 ALL ER 625

Re L (Medical Treatment: Benefit) [2004] EWHC 2713 (Fam)

Re Marion (No 2) (1992) 17 Fam LR 336

Re R (a minor) (wardship: medical treatment) [1991] 4 ALL ER 177 CA 183

Re: Baby RB (A Child) [2009] EWHC 3269 (Fam) (10 November 2009)

Schloendorff v New York Hospital (1914) 211 NY 125
Slaveski v Austin Health [2010] VSC 493

TS & TD v Sydney Children’s Hospital (“Mohammed’s case”) [2012] NSWSC 1609

LEGISLATION

Abortion Law Reform Act 2008 (Vic) (No 58)

Charter of Human Rights and Responsibilities Act 2006 (Vic)

Childrens Act 1989 (UK)

European Convention on Human Rights 1950

Family Law Act 1975 (Cth)

National Disability Insurance Scheme Act (No 20) 2013 (Cth)

Powers of Attorney Act 1998 (Qld)

The Human Rights Act 1998 (UK)

Victorian Medical Treatment Act 1988 (Vic) (No 41)

OTHER SOURCES

Printed/Electronic Newspapers

Anonymous, ‘Why is it so hard to grant the wish to die in peace?’, The Age (Online), 16 May 2013 <http://www.theage.com.au/comment/why-is-it-so-hard-to-grant-the-wish-to-die-in-peace-20130515-2jmnt.html>

Brick, Samantha, ‘Born at the very brink of life: Over half of babies now survive at 24 weeks, the legal abortion limit…but at what cost to their health and families? Four mothers tell us their stories’, The Daily Mail (Online), 2 January 2013
Campbell, Dennis, ‘Premature babies study shows survival rates on rise’ The Guardian (Online), 5 December 2012

Curtis, Polly, ‘Down’s Syndrome changing attitudes’, The Guardian (Online), Saturday 1 September 2007,

Day, Elizabeth, ‘Baby RB: heartbreak in Court 50 as life of a one-year-old hangs in the balance’, The Guardian (Online), 8 November 2009

Doward, Jamie, ‘Rise in school leaving age is predicted to cut number of teenage pregnancies’, The Guardian (Online), Sunday 7 April 2013


Hagan, Kate, ‘Doctors tread ethical minefield, 21 years on’ The Age (Victoria), 14 August 2010, 4

McVeigh, Tracey, ‘I would have wanted him to die in my arms’, *Sunday Herald Sun Magazine, The Herald Sun* (Australia) April 17 2011, 16


Raca, Jane, ‘Would you give up your disabled son to allow your other children a chance of happiness? Despite agonies of guilt, Jane says it’s the best decision she ever made’ *The Daily Mail* (Online), 14 March 2013 <http://www.dailymail.co.uk/femail/article-2293579/Would-disabled-son-allow-children-chance-happiness.html>
Smith, Rebecca, ‘Women finding access to contraception difficult’, *The Telegraph* (Online), 11 May 2012,

<http://www.telegraph.co.uk/health/healthnews/9257070/Women-finding-access-to-contraception-difficult.html>

The Week, ‘Waiting for a miracle: Is it inhumane for religious parents to prolong treatment of sick kids?’, *The Week* (Online), 17 August 2012,

<http://theweek.com/article/index/232122/waiting-for-a-miracle-is-it-inhumane-for-religious-parents-to-prolong-treatment-of-sick-kids#>

Wade, Matt, ‘Income up, but mental illness costing $190b a year’ *Sydney Morning Herald* (Online), 8 June 2013 <http://www.smh.com.au/data-point/income-up-but-mental-illness-costing-190b-a-year-20130607-2nvjy.html>

Watson, Callie, ‘With technological advances, most premature babies survive against the odds’, *The Australian* (Online), 4 November 2012,


White, Anna, ‘Premature babies: The pregnant elephant in the room is stress’, *The Telegraph* (Online), 17 December 2012


‘Women Cry ‘Thank God’ as Dr Arthur is Cleared’, The Times (UK), 6 November 1981

Films and Audio-visual Recordings

The price for life (Directed by Adam Wishart, BBC Production, 2011)

Television and Radio Transcripts

Hall, Eleanor, ‘To cut hospital costs, talk to the patients’, The World Today, 29 April 2013 (Dr Peter Saul)

<http://www.abc.net.au/worldtoday/content/2013/s3747260.htm>

Miller, Barbara, ‘1 in 3 doctors would break the law to euthanase disabled babies: survey’, AM, 7 February 2007 (Peter Barr)

<http://www.abc.net.au/am/content/2007/s1842041.htm>

Internet Materials

Australian Government, Key Initiatives of the 2013-14 Budget

<http://www.budget.gov.au/201314/content/overview/html/overview_key_initiatives.htm>

Australian Institute of Family Services, Half of Australia’s carers are depressed - making a hard job even harder Australian Government

Australian Institute of Health and Welfare, *Australian refined diagnosis-related groups (AR-DRG) data cubes* Australian Government

BBC News, *Couple’s distress at baby ruling* (21 March 2009)
<http://news.bbc.co.uk/2/hi/uk_news/7956450.stm>

BBC One, *Miracle baby grows up* (17 September 2004)
<http://news.bbc.co.uk/2/hi/programmes/panorama/3655050.stm>


Bliss, *NICE quality standard for specialist neonatal care*


Bloomberg Business Week Magazine, *Million Dollar Babies*

Collins, *Definition of neonate* Collins English Dictionary
<http://www.collinsdictionary.com/dictionary/english/neonate>


Department of Health and Ageing, *Why is it important* Australian Government
Department of Health, Toolkit for high quality neonatal services NHS


Department of Health, Victoria, Australia, Activity Based Funding


EPICure, Population based studies of survival and later health status in extremely premature infants
<http://www.epicure.ac.uk/>

EPICure, Population based studies of survival and later health status in extremely premature infants
<http://www.epicure.ac.uk/epicure-1995/>  

EPICure, Population based studies of survival and later health status in extremely premature infants
<http://www.epicure.ac.uk/overview/survival/>  

EPICure, Population based studies of survival and later health status in extremely premature infants
<http://www.epicure.ac.uk/epicure-at-one-year/>  

EPICure, Population based studies of survival and later health status in extremely premature infants
<http://www.epicure.ac.uk/epicure-2/>  

Gallagher, James, Severely premature babies: More survive being born early (5 December 2012) BBC
<http://www.bbc.co.uk/news/health-20583678>

Global Finance, Personal Income Tax Rates

Grattan Institute, About Us
<http://grattan.edu.au/about-us>

History of Medicine Division, *Greek Medicine* National Library of Medicine


Jesus Christ Saviour, *Traditional Principles of Medical Ethics*

<http://www.jesuschristsavior.net/Ethics.html>

Madison Park, *Death at 25: Blogging the end of life* (27 April 2010) CNN


Miracle Babies <www.miraclebabies.org.au>


National Health and Medical Research Council, New research tackles depression among older Australian and their carers Australian Government


NICE, Specialist neonatal care quality standard


Nuffield Council on Bioethics About <http://www.nuffieldbioethics.org/about>

Nuffield Council on Bioethics, Background: extremely premature babies

Nuffield Foundation, About the Nuffield Foundation
<http://www.nuffieldfoundation.org/About-the-foundation>


Shultz, Gudrun, *One-Third of Australian doctors would euthanize sick babies, survey finds* (8 February 2007) LifeSite news


**Speeches**


Power point presentation at Treuman Katz Center for paediatric bioethics, Seattle 2007 Conference <http://www.seattlechildrens.org/research/initiatives/bioethics/>