

DECIDING FOR OTHERS:
INCOMPETENCE,
BEST INTERESTS
AND
END-OF-LIFE CASES

Kathryn M^cAuley

A Thesis Submitted for the Degree of Doctor of Philosophy
at Te Whare Wānanga o Otāgo, University of Otago,
Aotearoa, New Zealand, 2016

Abstract

The ideal way through life for each of us is a journey, where we can control our own lives and make our own decisions. For some this is not possible, and for these people decisions need to be made on their behalf. Healthcare decisions are of fundamental importance, and of these, the most acute are about life and death. This thesis discusses the tragedy of the incompetent patient, for whom such a life or death decision must be made. The difficulty of these sorts of decisions has necessitated decision-making on behalf of these incompetent patients by the judiciary. The case may have gone to court because of differences of opinion between the medical profession and the families, or it may be because it is unclear whether the proposed action is even legal. Regardless of how it came within the court's domain, the judges then become the decision-makers for the incompetent patient.

To make these difficult decisions the judge uses the best interests of the patient as the decision-making principle. Best interests is a complicated term, as it necessitates the involvement of other values, which are compared and evaluated. To understand how well judges are using this principle, this thesis analyses cases from four Commonwealth jurisdictions, concluding that the best interests test has been applied in a way that is less consistent than can be expected from a common law jurisdiction focused on predictability. Specifically, there is little agreement on the definition of best interests, nor is there a common formula for the weighting and balancing of the various interests which are inevitably at stake. What counts as interests, and which interests a permanently incompetent person is attributed with also varies. Additionally, the focus on the individual, which is fixed in its centrality to the best interests test, has become its primary goal, to the detriment of recognising a wider interpretation of interests that the patient may have, including the interest that he or she may have for others, such as their family. This thesis discusses all of these issues, and concludes with a list of recommendations for the consideration of the best interests test when applied to the permanently incompetent person.

For Elizabeth and Laura

Table of Contents

Abstract	ii
Dedication	iii
Table of Contents	iv
List of Tables	viii
List of Appendices	ix
List of Abbreviations	x
CHAPTER ONE: INTRODUCTION	1
Thesis Overview	2
Prospective, End-of-Life Cases with an Incompetent Patient	5
End-of-life	6
Permanently, Terminally Incompetent and Unconscious	8
Best Interests	9
The Role of Autonomy in Decision-Making for the Incompetent Patient	10
Prospective Decisions	12
Common Law Jurisdiction	13
Some Further Considerations	14
CHAPTER TWO: BEST INTERESTS	16
An Introduction to Best Interests	17
Five Themes in Prospective, End-of-Life Cases	20
Complex Relationship Between Law and Ethics	21
Acknowledgement of Ethical Issues	23
Best Interests as a Multi-Faceted Concept	25
Value-laden and Inconsistent Use of Language	25
Differences in Outcome With the Same Reasoning	29
Ancillary Guidance	31
Inadequacy of Existing Law	35
Parens Patriae Jurisdiction	37
Guidance Principles: Best Interests and Substituted Judgment	38
Best Interests in Law	41
Summary of Chapter Two	50
CHAPTER THREE: EXPLORATION AND CATEGORISATION OF INTERESTS	52
Part One: Exploration of Interests	55
Dworkin	55
Experiential Interests	55
Critical Interests	56

Feinberg	61
Welfare and Ulterior Interests	61
Want-Regarding and Ideal-Regarding Interpretations of Interests	63
Interests of Others	64
Surviving Interests	65
Sperling	66
Life Interests	66
After-Life Interests	67
Far-Lifelong Interests	69
Summary of Part One	70
Part Two: A Framework for the Interests of Incompetent Patients	71
A Proposal for Categorising Interests	71
Self-Regarding Interests	72
The Self, Not Selfish	72
Experiential interests	73
Non-Experiential Interests	73
Other-Regarding Interests	76
Whānau	78
Community	84
An Overlap of Interests	88
Way Family Remember You	88
Family's Views Respected	89
Taxonomy of Interests	92
Summary of Chapter Three	93
CHAPTER FOUR: DISTINGUISHING BETWEEN DIFFERENT INCOMPETENT PATIENTS	95
Part One: The Concepts of Competence and Incompetence	96
Informed Consent	97
Competence and Capacity	98
Components Needed for Competence	100
Capacity to Understand, Reason and Communicate a Decision	102
Possession of a Set of Values	104
Summary of Part One	106
Part Two: Interests and the Relationship with Prior Competence	107
Permanently Incompetent Patients	107
Previously Competent	108
Never Competent	117
Summary of Chapter Four	118

CHAPTER FIVE: PRIOR VIEWS OF THE PERMANENTLY INCOMPETENT ADULT	120
Part One: The Importance and Veracity of Prior Views	121
The Significance Problem	122
Respect for Autonomy	122
The Individual Patient	125
Statutory Guidance	126
The Conflict Problem	127
The Patient with Current Views	127
The Epistemic Problem	128
Expectations Regarding Prior Views	130
Ascertaining Authenticity of Prior Views	132
Summary of Part One	139
Part Two: Case Analyses	140
Cases With No Clearly Expressed Prior View	141
Inferred-General Cases	144
Inferred-Specific Cases	148
The Previous Self in End-of-Life Cases	150
Cases With Explicitly Expressed Prior Views	152
Explicit-General Cases	152
Explicit-Specific Cases	158
Summary of Chapter Five	165
CHAPTER SIX: NARROW APPLICATIONS OF BEST INTERESTS	168
Possible Interpretations of Best Interests	169
Application One: Only Experiential Interests Matter	170
What Does it Mean to be a Person?	172
Definitions of Personhood	174
The Opposition of the Mind and Body	176
Application Two: Deferment to a Medicalised View	181
<i>Bolamising</i> Best Interests	182
Medicalising Best Interests	184
Application Three: Objective and Subjective Test	185
Best Interests as an Objective Test	187
The 'Reasonable Person'	188
Best Interests as a Qualified-Objective Test	190
Summary of Chapter Six	191

CHAPTER SEVEN: CONFLICTING AND CONFLUENT INTERESTS	193
Conflicting Interests	195
Sanctity of Life and Quality of Life	196
Experiencing a Quality Life	200
Twin vs Twin	202
Jodie's Best Interests	204
Mary's Best Interests	207
Parental Views and Child's Interests	210
Prior Views and Other Interests	215
Experiential	216
Non-Experiential	222
Other-Regarding Interests	226
Other-Regarding Interests of the Previously Competent	226
Other-Regarding Interests of the Not Previously Competent	228
Summary of Chapter Seven	230
CHAPTER EIGHT: CONCLUSIONS AND RECOMMENDATIONS	233
Proposal for Weighting of Interests	237
Sensate with a Prior Self	240
Sensate with no Prior Self	241
Non-Sensate with Prior Self	242
Non-Sensate with no Prior Self	242
Deciding in the Best Interests of Incompetent Patients	242
APPENDIX ONE: TABLE OF CASES	244
APPENDIX TWO: CHART OUTLINING REASONING	260
APPENDIX THREE: PRÉCIS OF CASES	263
New Zealand Case Law	263
Australia Case Law	265
Canada Case Law	267
England and Wales Case Law	275
ACKNOWLEDGMENTS	286
BIBLIOGRAPHY	288

List of Tables

Table 1: Four Categories of Views	136
Table 2 Proposal for Weighting of Interests	238

List of Appendices

Appendix One: Table of Cases	244
Appendix Two: Chart Outlining Reasoning	260
Appendix Three: Précis of Cases	263

List of Abbreviations

ANH	Artificial Nutrition and Hydration
ACT	Australian Capital Territory
CPR	Cardiopulmonary Resuscitation
CCB	Consent and Capacity Board, Ontario
CRPD	Convention on the Rights of Persons with Disabilities
GAA (Qld)	Guardianship and Administration Act 2000, Queensland
The Code of Patient Rights	The Health and Disability Commissioner Code of Health and Disability Services Consumers' Rights Regulation 1996
HCCA	Health Care Consent Act 1996, Ontario
MCA	Mental Capacity Act, 2005, England and Wales
MCS	Minimally Conscious State
NHS	National Health Service, United Kingdom
NSW	New South Wales
PEG tube	Percutaneous Endoscopic Gastrostomy tube
PVS	Persistent Vegetative State
PPPR	The Protection of Personal and Property Rights Act 1988, New Zealand

CHAPTER ONE: INTRODUCTION

“The time has come to redirect the focus of bioethics toward the problem of the incompetent patient.”¹

Anne Blythe was 58 years old when she suffered a devastating medical event that changed her life irrevocably. She had lived what she considered to be a good life, had a husband and three children to whom she was close. Whilst the doctors saved her life after the initial trauma, afterwards she showed no signs of comprehension or deliberate movement. She was then put on various life supports, including ventilation and artificial nutrition and hydration (ANH) to keep her alive. Eventually she was able to breathe unassisted. Her loving family were convinced that she was improving, that they could see her respond to their voices and their touch. But her medical carers told them no, she is not able to respond to anything, it is just spontaneous movement. They gently told the Blythe family that Anne was effectively ‘gone’ and that, to give her a dignified death, ANH should be removed, or if that was not acceptable to the family then if Anne got an infection she should not be treated with antibiotics. Anne’s family refused to consent to this treatment plan. They said “Anne would not give up at this stage and neither are we”. Anne had left no document behind that had set out her wishes should something like this happen to her. There were many family conferences, many medical opinions sought, much attempt at persuasion by the doctors, who did not want to prolong Anne’s life needlessly. The doctors were convinced that it was in Anne’s best interests for treatment to be withdrawn or withheld, just as Anne’s family were convinced it was in her best interests to continue treatment. They had reached an impasse, and eventually the only way forward was to seek an answer from the only institution who could provide a declaration as to which treatment options were in Anne’s best interests – the courts.

This is a hypothetical case, setting out some of the many issues to be explored in the subsequent chapters.² The patient has been diagnosed as being in a permanently incompetent state. Treatment decisions need to be made for her, and everyone wants the right decision to be made. It would seem that identifying her best interests will reveal the right thing to do, but there may be disagreement about what those best interests are. The body with the authority to resolve this disagreement is the court, and so it must make the decision.

This thesis analyses cases from four common law jurisdictions in which a person is unable to make a decision for themselves, and a decision is required about treatment which may mean

¹ Allen E Buchanan and Dan W Brock *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge University Press, 1990) at 3.

² All hypothetical cases in this thesis are indicated by italics.

continuation of life, or imminent death. The decision the judge would need to make about Anne Blythe would determine her future treatment; treatment that would determine (to a reasonable degree of likelihood) whether she lives or dies in the near future. To reach a decision the judge has to make a determination as to whether continuation of treatment is in Anne's best interests. How does the judge do this? What value does the judge place on the family's assertion that Anne would want to have treatment continued? More problematically, what value should be placed on the family's own views? How does this balance with advice from the medical profession that treatment should be withdrawn, with the inevitable consequence that this would hasten her death? This thesis is an endeavour to understand how judges are making these end-of-life decisions concerning incompetent patients, and contends that best interests, used as a decision-making tool by multiple jurisdictions, is not being applied as consistently and transparently as expected in a common law tradition relying on precedent. All of the data is drawn from judgments from four common law countries. Each case involved judges making decisions on behalf of incompetent patients, and this thesis shows that there is no general agreement regarding: (1) a definition of best interests; (2) a list of what counts as an interest; and (3) a formula for the weighting and balancing of the various interests that inevitably are at stake. Judges are using the test of best interests inconsistently, and while it is concluded that it is, of course, necessary for there to be some level of discretion, the lack of transparency and consistency that sometimes occurs can, and should, be modified.

Thesis Overview

Thousands of articles have been written concerning the cases that are examined in this thesis. Many of these discussions focus on the merits of the outcome of the cases, however fewer commentators have taken a step back from considering whether the judge reached the right decision, and discussed the *way* in which the judge reached the decision. Firstly, how do judges make decisions for incompetent patients in end-of-life cases? The answer to this, at least ostensibly, is that they focus on that individual's interests. In most of the jurisdictions discussed in this thesis, a best interests test is the primary decision-making tool for substitute decision-making.³ However, all judges accommodate, to differing degrees, the prior views of

³ *Substitute decision-making* or *substitute decision-maker* should not be confused with the concept of *substituted judgment*, more on this distinction in Chapter Two: "Value-laden and Inconsistent Use of Language".

the patient if they were previously competent. How does prior competency affect the way in which the decision was reached? In this thesis it is shown that the focus on the individual can take two forms: (1) the epistemic question of how can it be known what a person's interests are, when they cannot tell us themselves; and (2) the substantive question of what interests the courts actually take into account. The thesis then broadens this question to include all incompetent patients, asking what interests *should* be taken into account by the courts.

In order to properly evaluate the epistemic and substantive questions, the legal and ethical framework for substituted decision-making needs to be understood. Chapter Two examines the concept of best interests – what does this term mean? As presented in the hypothetical case of Anne Blythe, best interests can be used by doctors to justify withdrawing treatment, and it is also used as a legal test by the courts. It also has some roots in bioethical literature. How can the approaches of these disparate disciplines best be appraised? The analysis of the cases reveal certain themes in end-of-life cases, themes which are then utilised to explore the complexities of the concept of best interests. These themes persuasively display three major contentions: (1) that end-of-life decision-making is difficult because of the complex relationship between law and ethics; (2) best interests is a multi-layered and complex term; and (3) that the legal framework is inadequate, or inadequately applied.

Before the question of what interests *should* be taken into account can be addressed, the question of what interests are, and what interests *could* be taken into account is discussed in Chapter Three. This topic is explored by discussing accounts from Dworkin, Sperling and Feinberg, arriving at the conclusion that two broad categories of interests, self-regarding and other-regarding, can be used to enhance the understanding of interests by judges.⁴ Self-regarding interests are defined as consideration for one's own interests; these can be either experiential or non-experiential. Other-regarding interests are defined as consideration for others' interests; the 'others' of this definition has two categories, those closest to the patient, namely family and friends, and society as a whole, usually the community that the patient is living in. The exploration and recognition of other-regarding interests could benefit the

⁴ Ronald Dworkin *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (First Vintage Books, New York, 1993); Joel Feinberg *Harm to Others* (Oxford University Press, New York, 1984); Daniel Sperling *Posthumous Interests: Legal and Ethical Perspectives* (Cambridge University Press, Cambridge, 2008).

patient in end-of-life cases, and ignoring them could mean failing to adequately apply the best interests test.

An individual's views, their beliefs, and even their personality prior to becoming incompetent are at the very least discussed, and often prioritised, by the courts (and legislation). This is one way of answering the epistemic question: "what are an incompetent adult's interests?" Prior views and beliefs immediately denotes that the individual was able to formulate and demonstrate an identity with cohesiveness, and this often excludes minors and adults with severe cognitive impairment. Chapter Four explores the concept of incompetence, discussing the specific terms *competence* and *capacity* and subsequently arriving at the position that they are interchangeable. To further the understanding of what it means for a patient to be incompetent, the focus of the chapter is a categorisation of incompetent patients and whether they have been previously competent or not. Subsequent chapters show that this is a crucial distinction, as is the further distinction made within previously competent patients; those who expressed a view, when competent, on possible future choices should they become incompetent, and those who did not do so.

Chapter Five comprises a discussion of the prior views of the patient, using the distinction between previously competent patients established in Chapter Four. In this chapter it is argued that, if the question is framed only in relation to what the patient would want themselves, there can be no definitive answer to the epistemic question of "what is an incompetent patient's best interests?" Chapter Five also identifies that the way in which the prior views of the individual are being utilised by judges is problematic; this utilisation is not satisfying the most important question in relation to these views: are we sure that they are valid? Validity is linked to the extent that the views can be safely relied on as the patient's own view. A proposal is set out to determine the veracity of the prior views which are taken into account in making a best interests determination, and analyse specific cases employing this proposal.

The substantive question, regarding the range of interests that the courts take into account when focusing on the individual, can be discussed in terms of a range of particular applications of best interests. There are three main narrow approaches identified in the judgments investigated in Chapter Six: (1) a person has no interests if they cannot experience anything; (2) medicalisation of best interests, which posits that only the medical condition matters; and (3) an objective approach that includes what a reasonable person would want in

the circumstances. There are a range of reasons why the courts focus on these narrow aspects of the best interests test, and these are explored, before the conclusion is drawn that a *qualified-objective* approach is the one most commonly utilised, and this also optimises the application of the best interests test. This approach takes into account the patient's prior views, but also evaluates a wide range of interests, including objective interests.

An alternative to the narrow applications of best interests considered in Chapter Six, is a wider method which includes all possible interests that a substitute decision-maker could attribute to another person. Such interests may be discussed in terms of whether they are self- or other-regarding, and include such interests as the patient's family having an interest in how the patient is treated, or an interest in being remembered (or even well remembered) after death. In Chapter Seven the broader approach to best interests is discussed, necessitating that an evaluation of the weighting of all the possible interests is made on some level. Many times the cases demonstrate conflicting interests, and sometimes confluent interests, and in Chapter Seven these are addressed. The focus is on common manifestations of these conflicts: (1) sanctity and quality of life; (2) parental views and child's interests; and (3) prior views and other interests. From this discussion a question as to the importance of other-regarding interests emerges, and this informs the last chapter.

In the concluding chapter, Chapter Eight, guidelines are proposed for the weighting of interests; these provide a transparent hierarchy of interests from which it can be determined that consistent decision-making is possible. These are based on four categories: sensate and non-sensate with a prior self, and sensate and non-sensate with no prior self. This is the denouement of all previous discussions.

Prospective, End-of-Life Cases with an Incompetent Patient

“This case presents us with a tragic yet increasingly common conflict. A patient is unconscious. He is on life support — support that may keep him alive for a very long time, given the resources of modern medicine. His physicians, who see no prospect of recovery and only a long progression of complications as his body deteriorates,

wish to withdraw life support. His wife, believing that he would wish to be kept alive, opposes withdrawal of life support. How should the impasse be resolved?”⁵

The concept of best interests is invoked by judges in a range of situations (for example, when making decisions for minors in custody disputes). Court cases dealing with best interests in a medical setting are often where the patient is incompetent, the decision has life or death consequences, and the decision is being made prospectively. Identifying these cases from four common law countries has provided a rich resource for a number of observations. These observations have provided a base on which to establish a number of general contentions regarding the way in which these courts have made decisions for incompetent patients. Unsurprisingly, these observations lead to a conclusion that substitute decision-making for the incompetent patient is a difficult, complicated and challenging process. More specifically, I advance a thesis in response to these difficulties which argue that the test for best interests has been applied inconsistently; different (and sometimes opposite) interests have been attributed to the same patient, both narrow and wider approaches as to what counts as interests have been used, and at other times the emphasis on the individual has manifested in disingenuous ways. The following sections outline the parameters of this thesis; a discussion is provided about how the cases were chosen and their country of origin, and guidance is provided on how certain terms, such as *incompetent* and *patient* are to be used throughout the thesis.

End-of-life

“It is a platitude that we live our whole lives in the shadow of death; it is also true that we die in the shadow of our whole lives. Death’s central horror is oblivion – the terrifying, absolute dying of the light. But oblivion is not all there is to death; if it were, people would not worry so much about whether their technical, biological lives continue after they have become unconscious and the void has begun, after the light is already dead forever. Death has dominion because it is not only the start of nothing but the end of everything, and how we think and talk about dying – the emphasis we put on dying with ‘dignity’ – shows how important it is that life ends *appropriately*, that death keeps faith with the way we want to have lived.”⁶

In the context of this thesis *end-of-life* denotes that a judge has to make a decision which is literally a choice about the patient’s life or death. For example, in the hypothetical Anne Blythe case, the court would need to decide whether to either withdraw treatment or withhold

⁵ *Cuthbertson v Rasouli* [2013] 3 SCR 341 at [1] per McLachlin CJ.

⁶ Ronald Dworkin *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (First Vintage Books, New York, 1993) at 199. Emphasis in original.

future treatment, either of which would result in the patient's death, or to continue those treatments and potentially prolong her life. In all of the cases analysed in this thesis, the person was in a hospital (or under medical care). Therefore, the term *patient* is often used to signify the person at the centre of the court case. In many of the cases the patient was in a persistent vegetative state (PVS). The New Zealand Medical Association accepts a definition of PVS which relates to lack of responsiveness to any stimulation:

“A state of unconsciousness (i.e. loss of self awareness) where the body cyclically awakes and sleeps but expresses no behavioural or cerebral metabolic evidence of possessing cognitive function or of being able to respond in a learned manner to external events or “stimuli”, and where such a state persists for more than a few weeks.”⁷

It is also important to note that a clinical diagnosis of PVS takes place several weeks, and usually months, after the initial incident:

“The common feature of all definitions is that there should be no clinical evidence of cortical activity. PVS may arise from cerebral anoxia, from ischaemia, or from damage due to trauma, or rarely due to disease. Before beginning to consider the discontinuation of treatment of PVS the diagnosis must be sure, and this takes time. Some recovery from PVS has been recorded after a period of several months. During the period of initial assessment it is appropriate to provide aggressive medical treatment. ... The longer the period of PVS, the more likely it is that the condition will be permanent.”⁸

By comparison, a patient may be in a minimally conscious state (MCS), the difference being that the patient displays some form of awareness:

“The minimally conscious state (MCS) is a recently defined clinical condition; it differs from the persistent vegetative state (PVS) by the presence of inconsistent, but clearly discernible, behavioral evidence of consciousness.”⁹

There are a wide range of patients within both of these categories, as evidenced by extensive clinical and academic dialogue regarding the various permutations of what each means.

⁷ New Zealand Medical Association *Position Statement: Persistent Vegetative State* (August 2004). See also: Australian Government National Health and Medical Research Council *Post-Coma Unresponsiveness (Vegetative State): A Clinical Framework for Diagnosis* (18 December 2003) where the term post-coma unresponsiveness is used as synonymous with “vegetative state” but without the time-restrictive terms of “permanent” or “persistent”. Discussion of the use of PVS is provided in “Value-laden and Inconsistent Use of Language” in Chapter Two.

⁸ New Zealand Medical Association *Position Statement: Persistent Vegetative State* (August 2004).

⁹ Mélanie Boly and others "Auditory Processing in Severely Brain Injured Patients: Differences Between the Minimally Conscious State and the Persistent Vegetative State" (2004) 61 (2) JAMA 233.

Permanently, Terminally Incompetent and Unconscious

In end-of-life cases there is a distinction that can be made between cases as to whether the patient is competent or incompetent. Where the patient is competent the issues are, of course, entirely different, as the individual can speak for themselves. There are three distinctions that can be made: (1) cases involving competent patients;¹⁰ (2) cases about determining competence;¹¹ and (3) cases involving incompetent patients. The first two categories of cases offer some peripheral background to decision-making for incompetent patients but do little more than this. The focus of this thesis is on the third distinction, the incompetent patient, which is an area worthy of further critique (justified in subsequent sections).

The many issues concerning competence and incompetence are discussed in Chapter Three, but first clarification should be provided regarding the use of the term *permanent* in this thesis, and how it manifests in the two main groups of patients. *Permanently incompetent*, as used in this thesis, denotes either: (1) an adult with a severe cognitive impairment (which will prevent achieving competence at any stage from that point forward); or (2) a young child who may or may not have an underlying cognitive impairment. Incompetence in minors is firstly due to their age and lack of developmental maturity, and may or may not also be contributed to by some condition which damages cognitive abilities. The description of permanently incompetent, however, is still applicable to minors in these cases because, (in almost every case, except those of conjoined twins) it is anticipated that they will not be able to live long enough to reach competence.¹²

The term permanently incompetent has been chosen carefully to describe the patients at the centre of all the cases. In most cases they could also be described as unconscious, but some are in a MCS which is why the term permanently unconscious (used by some commentators) is not used in this thesis.¹³ Additionally, some of the minors are not unconscious. In this

¹⁰ Often involving the right to assisted suicide: in England application not granted: *R (Pretty) v Director of Public Prosecutions (Secretary of State for the Home Department Intervening)* [2002] 1 AC 800; *Pretty v United Kingdom* (2002) 35 EHRR 1. Canada: *Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 521. Application not granted but overturned 22 years later by *Carter v Canada (Attorney General)* [2015] 1 SCR 331. New Zealand: *Seales v Attorney-General* [2015] NZHC 1239; application not granted.

¹¹ For example: *Re B* [2002] 2 All ER 449. This is an often-quoted case where the patient refused life-prolonging treatment. Ms B was a tetraplegic who successfully sought the right to refuse treatment; her ventilator support was removed.

¹² This may represent an anomaly amongst the cases chosen, however it is representative of this selection. Normally pre-competent unimpaired children are not classified as permanently incompetent.

¹³ Buchanan and Brock (1990).

thesis the term permanent denotes a minute chance of any recovery (as predicted by doctors) in the patient's condition (or circumstances), and therefore the consideration of gaining, or regaining, competence at a future time is not at any stage part of the decision-making process.¹⁴ Furthermore, *incompetent* in these cases signifies a more severe and global incompetence than a legal finding of incompetence. For example, a person with a mild cognitive impairment, such as someone with Down syndrome, could be deemed incompetent for some decision-making, but the patients in the cases in this thesis are severely cognitively impaired (or minors) and are completely unable to make any of their own healthcare decisions. This is reflected in the end-of-life aspect which signifies that the decisions to be made can be anticipated to have life and death consequences. The patients will *never* be able to participate in *any* treatment decisions and decisions *must* be made for them. The patient is always incompetent, and permanently so, and there is no prospect of deferring the decision until they are competent. Therefore, they are unable to make the decision for themselves as to what treatment plan they would choose.¹⁵

Best Interests

“As judges, we are often required to make difficult decisions which have a profound effect on the lives of others... The decisions do not get any easier, no matter how often a judge must deal with the issues. This is one of the most difficult cases that I have had to deal with, as it may not only change lives, but it may have the effect of ending a life. I can assure you that the last week has been most difficult for me as I have wrestled with the competing issues that have been raised.”¹⁶

In all of the end-of-life cases that I canvassed, three major ethical issues came to the fore: best interests, autonomy and sanctity of life. Sanctity of life, whilst often mentioned in the cases, it is with little discussion or definition, despite the decision that is subsequently made resulting in the death of the patient.¹⁷ The apparent contradiction, of giving priority to the notion of sanctity of life, but also maintaining that it can be overruled, is a result of the complex relationship between judges having to make decisions, and the way they justify these decisions. Upon further scrutiny the presumption in favour of life was at times found to be outweighed by other factors and to be part of the consideration of best interests.

¹⁴ This effectively excludes cases about blood transfusion or transient mental incapacity or illness.

¹⁵ They may have an advanced directive, more detail on this in Chapter Four, but even if they do have such a document they are still not able to give their *current* views.

¹⁶ *Sawatzky v Riverview Health Centre Inc* (1998) 167 DLR (4th) 359 at 362.

¹⁷ *Airedale NHS Trust v Bland* [1993] AC 789. *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147. See Chapter Seven: “Sanctity of Life and Quality of Life” for extensive discussion.

Legal issues around the incompetent patient have emerged as an area of contemporary significance in New Zealand. For example, in 2014, barrister Alison Douglass was awarded the New Zealand Law Foundation's "premier legal research award", the International Research Fellowship. Her topic is titled "Mental Capacity: Updating New Zealand's Law and Practice". On receiving the award she noted:

"In New Zealand, there is no specific guidance for medical or legal practitioners and others in this field, yet incapacity permeates all aspects of law and healthcare practice".¹⁸

There is also an increasing awareness of the importance of decision-making for incompetent adults in a manner that includes the incompetent patient in the process, as exemplified by the recent Victoria Law Report on "supported decision-making" and "co-decision making".¹⁹ Furthering this point, there has been debate regarding the concepts of capacity and best interests applying in New Zealand and Australia, and that these tests may become obsolete as a result of ratifying the International Convention on the Rights of Persons with Disabilities (CRPD) in 2008 which requires shared decision-making.²⁰ However, this is seen as supplementing the existing common law and legislative regimes that allow for substitute decision-making where the patient cannot participate.²¹

The Role of Autonomy in Decision-Making for the Incompetent Patient

The principle of autonomy will be referred to frequently throughout this thesis. Although it may not seem to be relevant to the incompetent patient (they currently have no way of engaging currently with autonomous decision-making), if they had previously been competent questions can be raised about any previous wishes they may have had.²² Autonomy is not usually understood as just one more interest in the mix, it is a different

¹⁸ The Law Foundation "International Research Fellowship" www.lawfoundation.org.nz/2014. See www.alisondouglass.co.nz/ for the final report.

¹⁹ Victorian Law Reform Commission *Guardianship: Final Report* (2012). Neither of these concepts need to be dealt with where the patient is permanently incompetent.

²⁰ United Nations Convention on the Rights of Persons with Disabilities www.un.org/disabilities/convention/conventionfull.shtml

²¹ Australia made a declaration on ratifying the CRPD that it would co-exist with existing substituted judgement policies, see: Shih-Ning Then "Evolution and Innovation in Guardianship Laws: Assisted Decision-making" (2013) 35 Sydney L Rev 133 at 135. In the first report to the United Nations regarding the CRPD the implications were discussed as to The Protection of Personal and Property Rights Act 1988 and the existing powers of substitute decision-making were not deemed incompatible: New Zealand Government *First New Zealand Report on Implementing the United Nations Convention on the Rights of Persons with Disabilities* (March 2011).

²² With regards to the competent patient and judicial discussion of autonomy see Kenneth Veitch *The Jurisdiction of Medical Law* (Ashgate Publishing Limited, Cornwall, 2007). This book is an invaluable insight into the judicial duplicity of the way that autonomy is utilised.

principle altogether, and one that often takes priority over best interests. This is predicated on the right that every competent person has to refuse any medical treatment and thereby assert their autonomy.

“The courts have effected a process of change over the past 30 years which has fundamentally altered the focus of the law from being based on the duties of the doctor (as defined by doctors themselves) to emphasis on and prioritisation of the patient’s right to autonomy.”²³

The obvious point is that incompetent patients do not have such a right; there is no way of ascertaining their current autonomous wishes. But in keeping with the individualistic nature of autonomy, the focus on the individual is the one agreed criterion for the best interests test. This has often taken the form of focus on autonomous principles, which is argued in this thesis can lead to a more convoluted expression of the interests that the incompetent patient may have.

The primary context for autonomy is in the consideration for prior views that a previously competent patient may have had on their future treatment. The significance of *any* prior views is reflected in the two approaches to substituted decision-making: substituted judgment and best interests. Substituted judgment *prioritises* the autonomy of the patient, and any prior views they may have had as the most important factor. This is a view of autonomy which prioritises a person’s precedent autonomy. By comparison, the best interests approach *includes* prior views as one of the factors that should be considered in the decision-making process. Whilst the main focus in this thesis is on best interests, this must be done with reference to substituted judgment for two reasons: (1) substitute judgment is the decision-making tool used for incompetent patients in some Australian and Canadian states; and (2) it is necessary to understand both, as their close relationship has resulted in a blurred distinction between them. The prior views of an incompetent patient (which necessarily involves discussion of autonomy) are examined extensively in this thesis: Chapter Two outlines the legislative framework, Chapter Four discusses the significance of including an approach which recognises precedent autonomy, and Chapter Five outlines a proposal for ascertaining the veracity of prior views, and also analyses cases in detail in reference to this proposal.

²³ Charles Foster and José Miola "Who's in Charge? The Relationship Between Medical Law, Medical Ethics, and Medical Morality?" (2015) 23 (4) MLR 505 at 508. This will be discussed in more detail in Chapter Six, "Application Two: Deferment to a Medicalised View".

Prospective Decisions

The next criterion applicable to this thesis is that only prospective cases are analysed. Often some kind of catastrophic medical situation has arisen, and the court is being asked to clarify what should happen next. Sometimes this decision will need to be made urgently, sometimes there will be more time for the courts to consider it. Often it will be about withdrawal of treatment such as in the hypothetical case of Anne Blythe. The proposed action could be a specific procedure, for example an operation to separate conjoined twins where one will definitely die if the operation takes place. Whoever is taking the case to court is asking – can we do this? What should we do? Occasionally everyone will be in agreement, but it is not clear if the proposed action is even legal. At other times it will be a dispute between different parties, for example the family and the medical profession, and the judge will then have to decide between opposing views.

The cases require prospective decisions (on behalf of incompetent individuals) and this requirement leads to the reliance on an anticipatory tool being used. Best interests in this context is an anticipatory tool which is used to make substitute decisions in advance of possible future events. The prospective nature of the decisions made by the courts in this thesis represents a shift in their function. Until relatively recently, courts were rarely entreated to make decisions regarding future events. In the last twenty five years this has changed;²⁴ courts are now being called upon to make prospective decisions, and are not only seemingly content to do so, but some judgments actually encourage the practice.²⁵ The reasons for this change are not entirely clear, and there are many contributing factors. It may be the result of more litigation, or more cases being reported, or perhaps courts were simply not approached previously. With regard to end-of-life cases, the advancement of medical technology has undeniably played a significant role. Courts are being asked to answer questions that were quite simply unimaginable fifty years ago. Complex ethical and legal questions regarding whether a patient should be kept alive artificially were the subject of science fiction, not court cases.

²⁴ PDG Skegg and Ron Paterson *Medical Law in New Zealand* (Thomson Brookers, 2006) at 534. “Until the 1990s most reported New Zealand cases (involving omissions to prolong life) concerned the conduct of laypeople, who had failed to provide essentials for people for whom they had special responsibility... However, during the 1990s there were several cases which dealt in advance with the responsibilities (and potential criminal liability) of individuals and organisations providing health care.”

²⁵ *Airedale NHS Trust v Bland* [1993] AC 789.

“It may be helpful if I were to describe at the outset what I consider to be the function of the court in a case of this kind. It belongs to a group of cases which have been recurring with increasing frequency in recent years where the courts are being asked to give their authority to actions to be taken by medical practitioners which raise acute questions of moral or ethical principle. Medical science has now advanced to such a degree that many techniques are now possible which only a generation ago would have been unthinkable.”²⁶

Additionally, there does appear to be a rise in prospective cases coinciding with an increasing lack of confidence in the medical profession. This perception may be due to a Western society that is increasingly aware of its personal autonomy and various rights that it wants to negotiate. Kennedy attributes it in part to an increasing awareness that decisions that the medical profession make are ethical, and not just clinical.²⁷

Common Law Jurisdiction

Under the parameters identified so far – incompetent, end-of-life and prospective – five cases from the New Zealand jurisdiction were identified.²⁸ Using the cases from New Zealand there were numerous citations of cases from England and Wales.²⁹ From all of these cases two other jurisdictions were often cited: Australia and Canada. Using these guidelines, and to ensure a wide range of documentation, cases were gathered from New Zealand, Australia, the United Kingdom and Canada. All of these countries are common law jurisdictions, and although the legislation differs in each country, the similarities are sufficient from which to draw useful conclusions.³⁰ The only other common law country which is often referred to, the United States of America, has been excluded for two reasons. The first is that, due to the size of the country, its inclusion would increase the number of cases disproportionately, and the second, main reason is that it differs in regards to best interests, favouring a substituted

²⁶ *Law Hospital NHS Trust v Lord Advocate* (1996) Scot CS CSIH 2; [1996] 2 FLR 407 at 852 per Lord President Hope.

²⁷ Ian Kennedy *Treat Me Right: Essays in Medical Law and Ethics* (Clarendon Press, Oxford, 1991).

²⁸ *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235; *Re G* [1997] 2 NZLR 201; *Auckland Healthcare Services Ltd v L* [1998] NZFLR 998; *Shortland v Northland Health Ltd* [1998] 1 NZLR 433; *Hutt District Health Board v B* [2011] NZFLR 873.

²⁹ For example *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33 was cited in *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235. In *Re G* [1997] 2 NZLR 201: *Airedale NHS Trust v Bland* [1993] AC 789 and *Frenchay Healthcare NHS Trust v S* [1994] 2 All ER 403 were cited. In *Shortland v Northland Health Ltd* [1998] 1 NZLR 433: *Airedale NHS Trust v Bland* [1993] AC 789 and *R v Cambridge District Health Authority Ex Parte B* [1995] EWCA Civ 49 were cited.

³⁰ It must be noted however that Canada is bijural: it has both the common law and civil law traditions. This is due to the Quebec Act 1774 which confers civil law as the legal tradition that will be followed in Quebec: Government of Canada Department of Justice "Where Our Legal System Comes From" www.justice.gc.ca/eng/csj-sjc/just/03.html 30 April 2013. As no cases arise from Quebec the cases from Canada that I do analyse are all from a common law tradition so this does not pose any complications.

judgment approach.³¹ Whilst the cases from within New Zealand, the United Kingdom, Australia and Canada have all been discussed, and often cited with approval by each of the other jurisdictions, this does not apply to the American jurisdiction. Instead, occasionally dissenting judgments have been referred to with approval from the jurisdictions that this thesis is focused on.³²

Using these criteria 68 cases have been gathered which form the basis of the analysis in this thesis. In each, an application was made to the court regarding a decision which had major consequences concerning whether the patient would live or die.

Some Further Considerations

“These are hard cases for the patient, they are hard cases for the family and they are hard cases for those that have to treat the patient.”³³

Other than the patient, there are three main groups of people – judges, the medical profession, and families – that are the most involved in, and most affected by the kinds of cases that are the subject of this thesis. I want to acknowledge their contribution before embarking on the process of evaluating these cases from a privileged position which is very different from the reality that these groups faced.

I am aware that I have spent many months reflecting upon judgments that judges have had to make in a considerably shorter time frame – in some instances mere hours. Additionally I have not had to make tough decisions about life and death. While respectful of the need to be heedful of this, it is maintained that it is also not possible to be constantly excusing a particular decision based on time constraints. This thesis claims decisions for incompetent patients should be more robust, and more consistent, and does this by shining a spotlight on the decision-making process. However, the following caution elucidated by an American judge is acknowledged:

“Whatever judges may say or even believe, there is little reason to doubt that they exercise considerable discretion and frequently must and do decide indeterminate cases.”³⁴

³¹ This will be discussed in more detail in Chapter Two.

³² For example, *Cruzan v Director, Missouri Department of Health* (1990) 497 US 261. Substituted judgment does however form part of the statutory requirements in certain jurisdictions in Canada and Australia; these are discussed in Chapters Two and Five.

³³ *NHS Trust v A* [2005] EWCA Civ 1145; [2006] Lloyd's Rep Med 29 at [86] per Waller LJ.

³⁴ Richard A Posner "The Jurisprudence of Skepticism" (1988) Mich L Rev 827 at 872.

The doctors and nurses who care for incompetent patients do a remarkable job, and thereby serve their communities, when caring for some of the most vulnerable patients in our society. Some of the cases are brought about by disputes between the medical profession and family, but only a tiny minority of medical carers could have the allegation directed at them that they do not have the patient's best interests as their motivation. It is a testament to the medical profession that despite the impression given in this thesis – that courts commonly need to make decisions for incompetent patients – it is actually a rarity.

From the outset I also want to be mindful that in all of the cases that are analysed, there is a person at the centre of that case. All of these patients had many people who cared about them. Therein lies the devastating sadness associated with these cases; there has been a traumatic event or events that has left a much-loved person in a permanently incompetent state. All of this has occurred before the case gets to court, and sometimes the families have lived for years with the uncertainty of not knowing what will happen. There is no doubt that there has been much sadness and grief for these families who have had to endure the unbearable. I have endeavoured at all times to be respectful of this.

Throughout this thesis there is little comment on the correctness of the outcome of the judgments, except in relation to how those outcomes were reached. For example, no statements are made regarding whether ANH should or should not be withdrawn from a person in a PVS, or in any particular case involving a patient in PVS. The focus is on making extensive observations concerning the manner by which the judges have reached their decisions. Effectively a step has been taken back from a lot of what has been written on these difficult cases, much of which is framed around “should the judges have decided that?”³⁵ Instead, this thesis examines *how* they decided what they did. The answer to this lies in the next section which shows how the close analysis of the cases produced a discernible pattern. Having established this to be the central proposition of the thesis, the next logical question to ask is *how well* are the judges making the decisions? Chapters Five, Six and Seven address this question.

³⁵ For example: John M Finnis "Bland: Crossing the Rubicon?" (1993) 109 Law Q Rev 329; John Keown "Courting Euthanasia?: Tony Bland and the Law Lords" (1993) 9 (3) Ethics Med 34; Suzanne Uniacke "Was Mary's Death Murder?" (2001) 9 (Autumn) MLR 208; Gemma McGrath and Noella Kreleger "The Killing of Mary: Have We Crossed the Rubicon?" (2001) 8 JLM 322.

CHAPTER TWO: BEST INTERESTS

“The common characteristic to all these cases is that Judges have been asked to determine complex legal issues, sometimes urgently, in a context in which philosophical, moral, ethical and clinical viewpoints are deeply divided.”³⁶

This chapter aims to establish a broad understanding of the complexity regarding the concept of best interests. To achieve this goal fundamental preliminaries are addressed, providing the basis for the detailed analysis in subsequent chapters. When someone is unable to make healthcare decisions for themselves a decision must be made for them, effectively requiring a substitute decision. Two questions then arise: *who* should make the decision for the person and *how* should they make it? Often the ‘who’ part of the question is easily answered (especially by the time it gets to court), but how the decision is made, or should be made, is the difficult part.³⁷ All four of the Commonwealth jurisdictions focused on in this thesis use best interests as a mechanism for decision-making on behalf of those who cannot decide for themselves. Best interests is prevalent in cases regarding end-of-life issues for those who are permanently incompetent, and even a cursory examination into cases dealing with end-of-life reveals how frequently it is employed. In this chapter possible definitions of the best interests test are addressed, as are some of the complexities involved with the use of the term, the legal framework for the best interests test, and then preliminary observations will be made regarding the difficulties judges are faced with in applying a best interests test. The Appendices, which provide comprehensive overviews of the end-of-life cases, are also outlined.

Although the focus in this chapter is on providing an overall summation of best interests, as used in end-of-life cases, the outcome of this inquiry is less than ideal. All of the countries attach great importance to best interests, but a clear description of its meaning is not able to be provided. Therefore, the analysis in this chapter reveals that further investigation into the concept of best interests is required. The first part of this analysis is provided in Chapter

³⁶ *Seales v Attorney-General* [2015] NZHC 1239 at [17] per Collins J.

³⁷ Further exploration of this will be provided in the specific legal sections, and in Chapter Four, when discussing a competent adult making advance decisions.

Three, which isolates the term *interests* and discusses what is meant by interests; this affirms how important an understanding of interests is to the concept of best interests.

In the comprehensive analysis of prospective end-of-life cases in the Commonwealth undertaken in this thesis, five main themes were revealed: (1) a complicated relationship between law and ethics; (2) a notable use of language; (3) unanimous decisions, despite individual judges employing different reasoning; (4) use of ancillary guidance; and (5) the legal framework that the courts are working within in each jurisdiction is inadequate, or inadequately applied. These themes have been used to structure the enquiry into the concept of best interests, and how it relates to end-of-life issues both legally and ethically.

An Introduction to Best Interests

There is no simple or single definition of best interests. This lack of cohesion stems in part from its multi-faceted nature as a guiding principle, used in all three fields of practice on which this thesis focuses – legal, ethical and medical. Not only is it discussed in all of these different professions, but there are diverse ways that it is employed, and therefore numerous definitions have been applied in the various fields of practice that it is used in.

In the legal and medical professions the term best interests is most commonly used in areas not dealing with end-of-life issues. In law, best interests is often invoked when dealing with custody disputes over children. Medically, it is discussed in relation to patients, but this is not necessarily dependent on the patient being incompetent. All healthcare decisions have to be made in the best interests of the patient, with two notable exceptions: treatment refusals by competent patients have to be honoured, whether or not they are in the patient's best interests, and rationing decisions have to balance the interests of different patients. When a patient is competent they can choose whether to have treatment, irrespective of others' views of their best interests.³⁸ This thesis discusses best interests in a specific situation; a patient is in an end-of-life situation, and treatment decisions are linked to whether it is in their best interests to receive the proposed treatment plan or not. Therefore, best interests is essentially a tool that those in a professional capacity often use when making decisions for those who cannot decide for themselves. However, it is not just professionals who get to make decisions based

³⁸ See Chapter Four: "Informed Consent".

on someone's best interests, there are provisions in legislation to designate a person with substitute decision-making capabilities for another person, such as appointing an enduring power of attorney. These provisions and how they work are looked at more closely in Chapter Four, but it is worth noting at this introductory stage that there are three groups of decision-makers – doctors, judges, and friends or family – who are the principal sources for deciding what someone's best interests are.

The considerations deliberated on by these substitute decision-makers are effectively ethical. Often the central question being asked can be reduced to this maxim: “will this decision to treat/continue treatment/withdraw treatment be of benefit or harm to the person?” In considering this, the decision-maker will evaluate the patient's best interests. This means that best interests acts as an umbrella term or gateway to other ethical principles, because, when considering what is in a patient's best interests, other concepts will be invoked. For example, in considering whether or not to withdraw treatment from a patient in a PVS, the principle of sanctity of life (expressed as the presumption in favour of life or an interest in continued life) is seen as intrinsically valuable, and therefore always considered as an interest that the incompetent person has. This is balanced against their perceived interest in being “alive but not living”.³⁹

Best interests is therefore not a term that can be considered in isolation. Whilst it may seem that the basic tenet of the principle is that a person has interests, this is not necessarily accurate, as shown in Chapter Six.⁴⁰ The usual way we live our lives is that we are able to decide what is in our own best interests. Generally speaking, the ability to make an autonomous and valid decision about your own life overrules someone else's perception of your best interests. Best interests as a concept is very broad, and just what constitutes a particular person's best interests is not always easy to discern. This is because best interests is a gateway term to assessing other principles, and the interests that it aims to assess are value-laden. A competent person decides what they value and then balances these values, and this may relate to undertaking a particular action or not. For example, they may weigh up the pros and cons of a medical procedure. The same approach may be taken when making

³⁹ As discussed in Chapter One, the sanctity of life principle can be distinguished as independent from a person's interests, but will also be considered under the guise of best interests. See Chapter Seven “Sanctity of Life and Quality of Life” for extensive discussion of this principle.

⁴⁰ This is actually one of the questions that the courts ask – does a person have interests? This initial overview assumes that everyone does, which is consistent with the conclusions in Chapters Three and Six that the permanently incompetent person does have interests.

the decision for someone else – what did the particular person consider important? What interests would they have likely valued given this situation? There are often competing values to consider, such as an interest in living versus an interest in the manner of death. For example, on contemplation of a MCS, a person who had ardent religious views on continuation of treatment regardless of futility, would probably have very different views to someone who was intensely private, who could not think of anything worse than being subjected to such dependence. The weight that is placed on each of the possible values can also be difficult to determine and this is examined more closely in Chapter Seven.

In their book “Deciding for Others” Buchanan and Brock outline an ethical framework, which serves as a theory of substitute decision-making, which comprises of a:

“coherent set of principles related to one another in a systematic way, and with sufficient power to resolve a wide range of important issues.”⁴¹

Their framework provides a very valuable insight into the complexities of best interests, and why it poses so many difficulties in interpretation. Essentially they distinguish between the different elements that comprise patient-centred principles for deciding for others: (1) underlying ethical values – primarily related to the individual, although they acknowledge that others may be relevant; (2) guidance principles – “principles that provide substantive direction as to how decisions are to be made”,⁴² including the specific concepts of advance directive, substituted judgment, and best interests (which is defined as “acting so as to promote maximally the good of the individual”);⁴³ (3) authority principles – those relating to who should make the decision; and (4) intervention principles – the principles specifying when those in institutional roles may intervene, such as physicians, courts, and government protective agencies. Using their framework, this thesis evaluates a guidance principle, best interests, when intervention principles by the courts are invoked. However, as the authors identify, these principles do not exist in isolation from each other, and distinguishing them as they do makes it easier to see how easily they can be conflated.⁴⁴ By using the five themes identified from the end-of-life cases – and looking at best interests from different aspects according to these themes – an attempt is made to avoid this possibility of conflation.

⁴¹ Buchanan and Brock (1990) at 87.

⁴² Ibid at 88.

⁴³ Ibid.

⁴⁴ This is examined in more detail in Chapter Seven.

Five Themes in Prospective, End-of-Life Cases

This thesis focuses on a clearly defined set of prospective, end-of-life cases, from the four jurisdictions of New Zealand, Australia, Canada and the United Kingdom. Initial critique showed that there were a number of ways these cases could be categorised. Appendix One is a table of the majority of cases that could be identified as fitting within the criteria outlined in Chapter One, listed in numerical order by the year of the judgment. These cases are further sorted into three basic divisions, on the basis that the decision at the centre of the cases was about a proposed or disputed treatment action which could be described as either: future provision of life-prolonging treatment, withdrawal of treatment, or an operation. This action was then ruled on by the court. Further to the dispute in each case was consideration of whether the action was recommended by the medical profession, and whether the family were in agreement with this recommendation.

From this extensive canvassing a clear pattern emerged, which can be applied to a large number of the cases.⁴⁵ Essentially inconsistencies across the cases were observed, resulting in five specific themes being developed from this analysis. The identification of these themes initially justified further evaluation of how well the judges applied the best interests test, and can also be utilised to demonstrate both the definable aspects of the principle and the difficulties that best interests presents. Three overall conclusions are presented by (a), (b) and (c), with the specific themes (1) – (5) organised under each heading.

- (a) End-of-life decision-making is problematic, and illustrative of:
 - (1) a complex relationship between law and ethics.

- (b) Best interests is a complex and multi-layered concept, as demonstrated by:
 - (2) value-laden and inconsistent use of language;
 - (3) the same conclusions being reached in cases, despite differences in individual judges' reasoning; and
 - (4) frequent discussion of, and reliance upon, ancillary guidance such as academic commentary.

- (c) The legal framework within each jurisdiction is inadequate, or inadequately applied as illustrated by:
 - (5) convoluted use of legal principles.

⁴⁵ In fact, cases that had not yet been decided when the criteria were being developed met all five: for example, *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65; *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

The first two themes are primarily a descriptive exercise, so, rather than providing an account of numerous quotations from the wide range of available data, two influential end-of-life cases, *Airedale NHS Trust v Bland (Bland)* and *In Re A (Children) (Re A)*, have been relied on to illustrate these themes.⁴⁶ Each theme is discussed separately, and the last theme will incorporate a summary of the overall legal framework in order to demonstrate the inadequacy.

Complex Relationship Between Law and Ethics

“The issue of end of life decisions remains a thorny one.”⁴⁷

End-of-life cases raise a myriad of ethical issues. There is, in all likelihood, an overlap in these difficult cases which make decisions about life and death, between what might be considered ethical reasoning and what might be considered legal reasoning. Any extended exposition to identify what exactly constitutes ‘ethical’ and what is ‘legal’ is not necessary, except as a means of highlighting the difficult task that judges face. In a large number of the cases, judges acknowledge the ethical component of the case, noting that it is the complexities brought about by the ethical issues that make it so difficult. Part of this difficulty lies in the nature of the relationship between law and ethics. This has always been an intensely contested area with a large amount of work already dedicated to this very question, and therefore it can only be addressed with a narrow scope for the purposes of this thesis. A brief overview, which provides the main features of what constitutes *law* and what constitutes *moral*, is, however, useful for the overall discussion.

In his book, *Responsibility in Law and Morality*, Cane establishes two normative domains – law and morality.⁴⁸ The jurisprudence on what constitutes a ‘law’ is formidable, so trying to

⁴⁶ *Airedale NHS Trust v Bland* [1993] AC 789. This was the first case in the United Kingdom to consider whether ANH (which was deemed medical treatment) could be withdrawn from a person in a PVS. All three courts that adjudicated on it – the High Court, the Court of Appeal and the House of Lords – decided that treatment could be withdrawn.

In Re A (Children) [2000] EWCA Civ 254; [2001] Fam 147. An application was made to separate infant conjoined twins. One ‘stronger’ twin (Jodie) was sustaining the life of the other ‘weaker’ twin (Mary), and although separation would definitely result in the death of the ‘weaker’ twin the evidence from their medical practitioners was that this was the only way to possibly save the life of Jodie, instead of them both dying. The twins’ parents were against the operation. A detailed summary, and justification for their usage here, is provided in Appendix Three. Furthermore, *Airedale NHS Trust v Bland* [1993] AC 789 is discussed extensively in Chapter Five in the section titled “Inferred-General Cases”, and *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 is discussed in Chapter Seven in the section “Twin vs Twin”.

⁴⁷ *Children’s Aid Society of Ottawa-Carleton v MC* CanLII 49154 (ON SC); (2008) 301 DLR (4th) 194 at 27 per Métivier J.

marry this, with what is ‘moral’ is part of the difficulty when trying to define a concept, best interests, that is used in both domains. A relatively simplistic interpretation would be to say that because the judges are ruling on these cases, then what they are doing is ‘law-making’, ergo it is law. But with further elaboration of what it actually means to be law, the complexity of the issue emerges. Because something is law that does not necessarily make it right or morally correct.⁴⁹ For the purposes of this thesis the rightness or moral authority of the law in these cases is not at issue. The law can be described as being law by legislation and law by adjudication.⁵⁰ The decision-makers in these latter cases are judges; their judgments are documented, and are able to be read and analysed as representative of their jurisdictions. This is because law is institutionalised, for example by parliament, the judiciary and police. By comparison, much within the moral domain is not.⁵¹

Trying to define morality is therefore even more problematic as it does not have comparable formal institutions to fall back on. With a specific concept such as best interests to refer to though, it is possible to state that evaluating what interests matter, and questions as to how they should be balanced, and what interests should be prioritised, unquestionably invokes ethics because evaluating and weighing up interests invokes ethical values.⁵² If the person was previously competent it also invokes the possibility that the substitute decision-maker should respect their autonomy, and this necessitates deciphering how this should happen.⁵³ The usual practice is that if the patient had stated their wishes prior to becoming incompetent on what they would want to happen to them, these are followed. But this possibility raises many more questions, discussed in Chapters Four and Five, about how these prior views are utilised in a way that does respect the individual.

⁴⁸ Peter Cane *Responsibility in Law and Morality* (Hart, Oxford, 2002) at 3. Cane notes that this term is not optimal in footnote 16: “The word ‘domain’ is not ideal for describing the relationship between law and morality because it carries a general suggestion of separation and differentiation. It is important to note, therefore, that I use it only to bring out the significance of institutions. I certainly do not want to suggest that in terms of their subject matter, law and morality inhabit different domains.”

⁴⁹ A classic example being many of Germany’s policies under Adolf Hitler – should people have obeyed the law or not? See Ingo Muller *Hitler’s Justice – The Courts of the Third Reich* (Harvard University Press, 1992). On a lesser scale there has been the recent case in the United Kingdom of charging those found guilty with court costs, resulting in an innocent plea being penalised, highlighted on the London Review of Books blog by Frederick Wilmot-Smith “Unjust and Expensive” www.lrb.co.uk/blog/2015/10/15/frederick-wilmot-smith/unjust-and-expensive/

⁵⁰ Cane (2002) at 7.

⁵¹ Ibid at 28.

⁵² This is shown in the extensive discussion of interests in Chapter Three, and the balancing of interests discussed in Chapter Seven.

⁵³ This is examined in detail in Chapter Four: “Precedent Autonomy” and Chapter Five: “Respect for Autonomy”.

Some commentators call the intersection of these difficult legal cases with ethical issues an opportunity for judges to comment on difficult moral issues. Lee and Morgan argue that judges *should* use this opportunity to make moral issues clearer, in what they call “stigmata cases”. Criteria for stigmata cases include that they be ethically challenging, and they also require the courts to develop a moral vision; therefore it is a term which could also apply to the end-of-life cases in this thesis.⁵⁴ Veitch does not necessarily disagree with the view that judges should comment on moral issues, but points out that judges have been reluctant to use this so-called opportunity.⁵⁵

It is at this extreme end of difficulty with judicial decision-making that a tension inherent in these kinds of cases comes to the fore. There is a tension between a requirement of predictability as a measure of success in a common law system, whilst still maintaining suitable flexibility. One of the manifestations of this tension is provided by the acknowledgement of the existence of ethical issues. This is the most elementary of the five themes identified in this thesis. If the judges themselves acknowledge this struggle then it is an important starting point for looking at cases that use ethical principles. The impartiality of judges is one way that consistency of decision-making manifests, and it is one of the core principles of the legal system which Henaghan alluded to in his inaugural professorial address:

“I am sure you would want the judge to be as impartial as humanly possible and listen fairly to both sides of the case and treat them with equal respect. You would want to know that the result you received would have been the same no matter who the judge was. You would want to know the result of your case was consistent with other cases similar to yours.”⁵⁶

Acknowledgement of Ethical Issues

A common way that the complexity of the relationship between law and ethics surfaces in end-of-life cases is not only in the acknowledgement of the co-relation between the two

⁵⁴ Robert G Lee and Derek Morgan "Regulating Risk Society: Stigmata Cases, Scientific Citizenship & Biomedical Diplomacy" (2001) 23 Sydney L Rev 297 at 297. “Stigmata cases” are: “1. are relatively novel and ethically controversial; 2. raise the balance of personal interests and public interest; 3. force us to ask of the very basis of medical practice not how, but why; goals, rather than methods, being their primary concern; 4. offer an opportunity to take stock, to re-examine the existing boundaries between the anomalous and the routine; between the normal and the pathological; 5. require courts to develop a social, even a moral vision with which to respond to the dilemmas created by the social and cultural revolution of contemporary medicine.”

⁵⁵ Veitch (2007) at 126.

⁵⁶ Mark Henaghan "Can You Feel the Law Tonight? Family Law in Action" (2001-2004) 10 Otago L Rev 289 at 289.

domains, but also in the existence of ethical issues. In *Bland* most of the judges discussed this in some way or another:

“This appeal obviously raises acute problems of ethics, but this should not obscure the fact that it is also exceptionally difficult in point of law”.⁵⁷

“This case clearly raises serious moral, medical and ethical issues.”⁵⁸

“The present appeal raises moral, legal and ethical questions of a profound and fundamental nature, questions literally of life and death.”⁵⁹

Likewise, in *Re A* the judges also acknowledged the legal and ethical challenges:

“I freely confess to having found it exceptionally difficult to decide – difficult because of the scale of the tragedy for the parents and the twins, difficult for the seemingly irreconcilable conflicts of moral and ethical values and difficult because the search for settled legal principle has been especially arduous and conducted under real pressure of time.”⁶⁰

Whether judges should strive to align their judgments with moral considerations is a contested jurisprudential issue. Some argue that no difference should exist between what is right and what is legal:

“I think it would be not only lawful but right to let Anthony Bland die... This is not an area which any difference can be allowed to exist between what is legal and what is morally right.”⁶¹

Not all judges recognised the potential conflict between ethical and legal issues however, and in a case where the issue was continuation of treatment for an infant, Holman J stated that his job was to apply the law without concerning himself about the ethical issues:

“I wish to stress and make clear, however, that I myself am not concerned with any ethical issues which may surround this case. My task, difficult enough in itself, is to decide, and only to decide, where the objective balance of the best interests of M lies. If I decide that it is not in his overall best interests to continue with a given form of treatment, in particular with continuous pressure ventilation, then I must say so; and it will follow as a matter of law (and I will declare) that it is lawful to withdraw or withhold that form of treatment. The ethical decision whether actually to withdraw or withhold it must be made by the doctors concerned. Judges are neither qualified to make, nor required, nor entitled to make ethical judgments or decisions.”⁶²

⁵⁷ *Airedale NHS Trust v Bland* [1993] AC 789 at 886 per Lord Mustill.

⁵⁸ *Ibid* at 797 per Sir Stephen Brown P.

⁵⁹ *Ibid* at 808 per Sir Thomas Bingham MR.

⁶⁰ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 155 per Ward LJ. See also *Burke v General Medical Council (Official Solicitor Intervening)* [2004] EWHC 1879; [2005] QB 424 at 2 per Munby J: “The case plainly raises issues of great importance. Central to those issues are fundamentally important questions of medical law and ethics.”

⁶¹ *Airedale NHS Trust v Bland* [1993] AC 789 at 825 per Hoffmann LJ.

⁶² *An NHS Trust v MB* [2006] EWHC 507 (Fam) at [24] per Holman J. The abrogation of responsibility to the medical profession as demonstrated here will be discussed in Chapter Six: “Deferment to a Medicalised View.”

Therefore, as well as the acknowledgment of ethical issues, there is a tension between judges who think no difference should be discerned between law and ethics (as per Hoffmann LJ) and judges who think that law and morality are, at the end of the day, separate things (as per Holman J).

The complex relationship between law and ethics is undoubtedly an important factor in the decision-making process in these end-of-life cases, and it is a factor which is integral to the difficulties that these cases present. The next section expands on this, concluding that there are three themes related to substitute decision-making which demonstrate that best interests is a complicated term: (1) value-laden and inconsistent use of language; (2) differences in outcome with the same reasoning; and (3) ancillary guidance.

Best Interests as a Multi-Faceted Concept

Value-laden and Inconsistent Use of Language

Expanding on Wittgenstein's view that "Philosophy is the battle against the bewitchment of our intelligence by means of language", Crouch and Elliott discuss the relationship of language to philosophical thought:

"Language bewitches our intelligence by suggesting to us certain ways of thinking about philosophical matters. The manner in which we ask and answer questions, use metaphors, and offer descriptions all subtly influence the way in which we think about the world. Because we do not have a clear overview of our language, we can easily be led into philosophical confusion."⁶³

One way that this bewitchment is noticeable in end-of-life judgments is in the notable use of language. During the course of this thesis various terminology is used, but care has been taken to describe what is meant by these terms.⁶⁴ The following examples illustrate: (1) that different terms can be used for the same concept, or be mistaken for a similar concept; and (2) language, by its very nature, is value-laden and the words chosen and the way they are used reflect and influence the perceptions of individuals. The first example of the complexity which language provokes is found with the use of the terms *competence* and *capacity*. In Chapter Four it is shown that these are often used to indicate the same meanings, but what is important is not which term is used but that the person using it is clear about how they are

⁶³ Robert A Crouch and Carl Elliott "Moral Agency and the Family: The Case of Living Related Organ Transplantation" (1999) 8 (3) Camb Q Healthc Ethics 275 at 275.

⁶⁴ For example, the use of *permanently incompetent*.

using it, and what meanings they are applying to it. As another example, the term *substitute decision-making* can be confused with the principles required for *substituted judgment*: both require a substitute decision-maker, however substitute decision-making can refer to any proxy decision-maker, including those evaluating best interests and those making a substituted judgment for an incompetent person.⁶⁵

An example of language being value-laden is provided in the phrase *persistent vegetative state*; it has been criticised for being erroneous and misleading, which may be justified.⁶⁶ Perhaps the difficulty with PVS is because although it may seem that it is descriptive, it may also be evaluative of a patient's state. The use of the words "vegetative state" may influence the perceptions, and subsequently lead to assumptions, regarding the value of the life of that person in a PVS, namely that they are of little value. It could also convey a confidence (perhaps falsely) in the certainty of the prognosis. Nevertheless this term is used extensively in this thesis, because it is the predominant terminology referred to in judgments. It is not always important which particular word or phrase is used. Instead, the significance could lie in recognition of the range of other possible interpretations, and the fact that any word or phrase should be questioned as to its neutrality.

Language is something that is very personal, and judges are not immune to this. The personal nature of language does not, however, invalidate the following observations that can be made. Expanding on the idea that all language can be perceived in different ways with different connotations, and that it is not possible to avoid this, it has to be recognised that it is also possible to use it in a detrimental way. In a number of the cases an abundance of value-laden terminology was found: words, phrases and metaphors that seemed to exist outside the scope of what would be expected in legal judgments. If emotive language being used this seems at odds with the impartiality expected of the legal profession. Is the language 'value-laden'? Are the judges using language which implies a moral judgment? For example, Lords Browne-Wilkinson and Keith use the imagery of Anthony Bland in a state of "living death".⁶⁷

⁶⁵ Substituted judgment is discussed in this chapter in the section "Guidance Principles: Best Interests and Substituted Judgment".

⁶⁶ Bryan Jennett "A Quarter Century of the Vegetative State: An International Perspective" (1997) 12 (4) JHTR 1. Another example is "Clinically Assisted Nutrition and Hydration" (CANH) instead of "Artificial Nutrition and Hydration" (ANH): Simon Halliday, Adam Formby and Richard Cookson "An Assessment of the Court's Role in the Withdrawal of Clinical Assisted Nutrition and Hydration from Patients in the Permanent Vegetative State" (2015) 23 (4) MLR 556 at 557.

⁶⁷ *Airedale NHS Trust v Bland* [1993] AC 789 at 879 per Lord Browne. See also: *Rasouli v Sunnybrook Health Sciences Centre* [2011] ONCA 482 (CanLII) at [44]. "Ms. Salasel points out that while the appellants may

This could be described as language which attempts to convey some emotional reaction (perhaps ‘horror’ to the idea of ‘living death’). At other times it may be an attempt to convey the comprehension of the judge, for example the description of Anthony Bland as “alive but has no life at all”.⁶⁸ Other times judges make personal statements, often to convey to the patient’s family their personal sympathies.

“It may be no great comfort to them to know that in fact my heart bleeds for them.”⁶⁹

Bolstering the viewpoint that there is a need for awareness of language, some of the judges recognised the possible difficulties, exemplified by Butler-Sloss LJ:

“we have to rid ourselves of emotional overtones and emotive language which do not assist in elucidating the profound questions which require to be answered.”⁷⁰

This was also discussed in *Re A* by the three appellate judges who all indicated (in various ways) that they were not comfortable with the phrase “monstrous births” to describe conjoined twins.⁷¹ Brooke LJ quoted Williams:

“There is, indeed some kind of legal argument that a ‘monster’ is not protected even under the existing law. This argument depends upon the very old legal writers, because the matter has not been considered in any modern work or in any court judgment.”⁷²

But why does there need to be any mention of ‘monsters’ in reference to the conjoined twins? There would probably, and quite rightly, be outrage today if there was a case about a child with Down syndrome, and the judge stated the use of mongol is not acceptable. Any reference to this word would be seen as prejudicial. An appeal court judge, in the earliest prospective end-of-life case identified, did refer to a child with Down syndrome as a mongol:

consider her husband’s condition to be a “living death”, in the eyes of the law, he remains a human being. As such, he is entitled to remain alive, with the assistance of life support measures, until such time as she feels there is no further hope for his recovery.”

⁶⁸ *Airedale NHS Trust v Bland* [1993] AC 789 at 829 per Hoffmann LJ. The use of these phrases in regards to personhood is also discussed in Chapter Six: “Application One: Only Experiential Interests Matter”. A further note: I will follow the lead of judgments when referring to patients from the cases, hence the use of “Anthony Bland” not Mr Bland.

⁶⁹ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 196 per Ward LJ.

⁷⁰ *Airedale NHS Trust v Bland* [1993] AC 789 at 816.

⁷¹ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 212 per Brooke LJ. For a reference to “monsters” see Ward LJ at 186, Brooke LJ at 212, and Robert Walker LJ at 242. See Cameron Stewart “Legal Constructions of Life and Death in the Common Law” (2002) 2 OJCLJ 67 at 70 for a discussion on the notion that traditionally murder could only be committed against “reasonable creatures”, which excluded those who were born “monsters”.

⁷² *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 213. See also: at 212 per Brook LJ: “Is Mary a reasonable creature? ... she has for all practical purposes a useless brain, a useless heart and useless lungs”; and at 182 per Ward LJ: “I would not wish to leave this topic without saying firmly that the notions expressed in earlier times that Siamese twins were ‘monsters’ is totally unacceptable, indeed repugnant and offensive to the dignity of these children in the light of current medical knowledge and social sensibility. I deprecate any idea of ‘monstrous birth’.”

“The shock to caring parents finding that they have given birth to a child who is a mongol is very great indeed, and therefore while great weight ought to be given to the views of the parents they are not views which necessarily must prevail.”⁷³

The interpretation of value-laden or emotive language should of course include an element of relativity. In 1981 it seems plausible that mongol was a commonly used term. However, closer inspection shows that there had been controversy over the word since the 1960s and it had been increasingly out of use since then.⁷⁴ Therefore, mongol may simply have been used as an archaic diagnostic term, or it may be that Templeman J’s choice of language was indicative of values on his part.

The claim here is that awareness of value-laden language must be present for full transparency in judgments, not that it is possible to discuss this type of case avoiding any emotive overtones. There will always be judges who have more colourful expressions than others:

“Certainly, there could always be hope but for Mrs. Holland it was sadly scant. Mrs. Holland was inexorably approaching death’s cold door and already within reach of knocking on it.”⁷⁵

As well as the initial distancing from ‘monsters’ in *Re A*, on even a cursory reading the language and metaphors used can be described as evocative. Ward LJ compared the case to that of one where parents starved their child to death, questioning whether the principle in either case was different.⁷⁶ He also used a metaphor of parents at a concentration camp choosing which child to save:

“In my judgment, parents who are placed on the horns of such a terrible dilemma simply have to choose the lesser of their inevitable loss. If a family at the gates of a concentration camp were told they might free one of their children but if no choice were made both would die, compassionate parents with equal love for their twins would elect to save the stronger and see the weak one destined for death pass through the gates.”⁷⁷

⁷³ *Re B* (1982) 3 FLR 117 at 121 per Templeman LJ.

⁷⁴ Norman Howard-Jones "On the Diagnostic Term "Down's Disease"" (1979) 23 (01) Med Hist 102.

⁷⁵ *Scardoni v Hawryluck* (2004) 69 OR (3d) 700 at [82]. This type of language has also been noted by other commentators: Grant Gillett, Lowell Goddard and Michael Webb "The Case of Mr L: A Legal and Ethical Response to the Court-sanctioned Withdrawal of Life-support" (1995) 3 JLM 49 at 50. "As the judge waxed lyrically, "[t]he doctors are surely entitled to exchange the threat of the sword of Damocles for the protection of the sword forever proffered in the outstretched hand of justice". From the judgment of Thomas J in *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235 at 242.

⁷⁶ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 199.

⁷⁷ *Ibid* at 196.

The first problem with this is the unfortunate imagery of a concentration camp and reference to a situation which has no relevance whatsoever to the case. Secondly, he makes several leaps of logic and presumptions about moral issues: that the parents would make a choice, that they would save the stronger child, that the weaker child is destined for death, and that to make this choice is morally acceptable or correct because it means they are compassionate parents with equal love for their children.⁷⁸

It may be unfair to infer so much from an analogy. It is possible to isolate and compare certain features of cases without claiming that they are similar in all respects; the doctrine of precedent necessitates this (albeit that it was not being used in the above example). Ward LJ's moral conclusions in the previous example may not owe much to the language he used, so much as the analogy he drew and assumptions he relied on. A better example may be in the following excerpt, where Ward LJ might be argued to have used evocative imagery, as well as a questionable analogy, to support his conclusion:

“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?”⁷⁹

The use of language – words, phrases, terms, metaphors – is important to the overall consideration of dissecting ‘best interests’. Why is it such a complicated term? Part of the reason is that it is imbued with different values, different interpretations, and different analyses. As language plays a significant part in this, it needs to be understood from the outset that the impact of decisions regarding language is an important consideration.

Differences in Outcome With the Same Reasoning

The third theme that emerged from closer inspection of the end-of-life cases is crucial; it is the observation that, although judges are reaching the same conclusion, they are basing this decision on very different reasoning.⁸⁰ Whilst discrepancy is not unusual in such difficult

⁷⁸ Further elaboration on parental views is provided in Chapter Seven: “Parental Views and Child’s Interests”.

⁷⁹ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 203. Similarly to the use of “monster” in the next sentence he states: “One does not need to label Mary with the American terminology which would paint her to be “an unjust aggressor”, which I feel is wholly inappropriate language for the sad and helpless position in which Mary finds herself.”

⁸⁰ For example: in *Airedale NHS Trust v Bland* [1993] AC 789. The best interests of the patient posed the central question as articulated by Lord Browne-Wilkinson at 884: “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.” All of the judges used the best interests test in their decision-making, however there was no uniformity about

cases, the degree of differences, coupled with how widespread these differences are, highlights the justification for further examination of best interests. The differences in reasoning are not confined to consideration of the best interests test, but overwhelmingly this is where the most confused, complex and inconsistent reasoning occurred. Other issues, such as examination of the sanctity of life principle, also demonstrated different reasoning, however it is often discussed more shallowly and sparingly.⁸¹ Appendix Two provides a flow-chart documenting in detail the justification for this claim, and how the various permutations of this theme emerge.

This is not an original observation, and other commentators have remarked on the lack of cohesive reasoning in these difficult end-of-life cases.⁸² This thesis, however, furthers these investigations by identifying it as a trend across a large number of prospective, end-of-life cases. The acknowledgment that judges use different reasoning, to reach the same conclusion, essentially acts as a conduit for recognising a very important point: best interests is a concept that is applied and interpreted in many different ways. This may be due to the fact that judges have rarely engaged explicitly with the notion of interests, which is a lot more complex than they may perceive. It is this underlying, contestable utilisation by the courts of best interests which forms the basis for this thesis. After a taxonomy of interests is established in the next chapter, Chapters Five, Six and Seven employ these distinctions to explore very specific differences of reasoning regarding best interests: *how* best interests is applied, *who* the concept applies to and how it *should* be applied, *which* interests matter and which do not.

The recognition of different reasoning in the judgments links into the last two themes identified. Miola noted that two aspects stood out in the *Bland* judgment: (1) there was a

how it was used. Lord Mustill (and perhaps Lord Keith) found that Anthony Bland had no interests and therefore his best interests in being kept alive no longer existed. This narrow approach will be discussed in Chapter Six. Lord Goff found that Anthony Bland did still have interests but that could be discontinued as prolongation of treatment was no longer in his interests. Lords Lowry and Browne-Wilkinson seemed to agree with this approach.

⁸¹ For example in *Airedale NHS Trust v Bland* [1993] AC 789: The assertion by Sir Thomas Bingham in the Court of Appeal that “profound respect for the sanctity of human life is embedded in our law and our moral philosophy” is echoed in the other judgments. Eight of the nine judges did refer to sanctity of life, and they all acknowledged its importance and supported the view that it can be overridden by other factors. However, the differences outnumbered this similarity. For example, there was no one place that is pointed to that it is derived from. Hoffmann LJ said it was intuitive; Lord Goff said legislation; Lords Keith and Mustill said the State.

⁸² For example: Jose Miola *Medical Ethics and Medical Law* (Hart Publishing, Oxford; Portland, 2007); Rebecca Dresser "Missing Persons: Legal Perceptions of Incompetent Patients" (1994) 46 Rutgers L Rev 609; Lee and Morgan (2001) 23 Sydney L Rev 297.

wide range of approaches regarding the amount of ethical guidance the judges cited; and (2) there was variation in how much law creation the judges were engaged in, and how they reached their conclusion.⁸³ Both of these aspects are variants on the next two themes discussed: the appeal to sources outside legal sources and the corresponding paucity of legal precedent or legislation that is relied on.

Ancillary Guidance

“Where old law must be adapted to new circumstances, and where new law must be developed, ethical guidance is essential.”⁸⁴

It is not uncommon, unusual or even unconventional for judges to refer to supplementary texts, such as those written by academic lawyers. It is, however, indicative of complex issues, and therefore it is one component to revealing the difficulty of a case.

Some commentators on medico-legal writing argue for greater use of non-legal materials:

“If it were more generally recognized that the main significance of precedents is information rather than authority, judges and lawyers might make greater use than they do of nonlegal and comparative materials – important sources of information but not of authority.”⁸⁵

In *Bland* Hoffmann LJ acknowledged the assistance he received from Professor Bernard Williams, and also quoted Isaiah Berlin’s *Two Concepts of Liberty*, an excerpt which in turn referred to Kant. Hoffmann LJ attributed some of his thinking to the manuscript of Dworkin’s *Life’s Dominion*, and (in a rather circular manoeuvre) in the published version of the book Dworkin referred to the *Bland* case:

“Lord Justice Hoffmann, in a strikingly philosophical opinion said ... that even though respect for the sanctity of life might argue in favor of keeping him alive, respect for the competing principle of self-determination justified the law permitting him to die.”⁸⁶

In *Aintree University Hospitals NHS Foundation Trust v James (James)* the use of extraneous texts is noteworthy. Sir Alan Ward discussed Keown and Finnis and the vitalist view, in order to decide whether the treatment was futile.⁸⁷ Keown is also discussed in relation to vitalism in *Re A*: (life is absolute and cannot shorten it or fail to lengthen it) and the right to

⁸³ Miola (2007) at 163.

⁸⁴ Buchanan and Brock (1990) at 5.

⁸⁵ Posner (1988) Mich L Rev 827 at 848.

⁸⁶ Dworkin (1993) at 188.

⁸⁷ *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65 at [35].

life is defined with reference to Keown.⁸⁸ This statement stands alone and is not followed up in any way, and seems very much at odds with the surrounding text. It is interesting how often Keown has been quoted in legal judgments, especially as he is seen as on the conservative end of the scale in many academic fields.⁸⁹

The use of the additional non-legal sources is therefore common. But is there anything wrong with it? Foster and Miola argue that the use of such guidance is self-serving, given that it is possible to find arguments for any decision:

“Professional medical ethics, if used at all, has been as often as not used as a tool to help the court come to a decision at which (perhaps on other grounds) it has already decided to arrive.”⁹⁰

With the knowledge that judges are referring to extraneous texts, and that these texts are from medical ethical discourse, in the following section there is discussion about some of the questions raised by these cases to show why judges may be referring to other sources. There is also discussion about two particular changes in our society which have necessitated different responses in relation to the assessment of best interests; the advance of medical technology and the increased respect for a person’s autonomy.

Best Interests in Relation to Ethical Principles

“The best interests standard has been widely used both in and beyond health care.”⁹¹

As stated in the introduction, an incompetent patient’s best interests cannot be considered in isolation. To assess best interests it is necessary to ascertain what the person’s interests are, and evaluate what would then be in their best interests. The notion of best interests is predicated on the idea that as a society we should do good, or at the very least not cause harm, to individuals, and it is therefore based in beneficence, or the principle by which we want to ‘do good’ by the patient.⁹² The emphasis is not only what is generally good, but what

⁸⁸ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 186 per Ward LJ.

⁸⁹ This is discussed in more detail in Chapter Seven.

⁹⁰ Foster and Miola (2015) 23 (4) MLR 505 at 513. As evidence of this they cite the following end-of-life cases: *Airedale NHS Trust v Bland* [1993] AC 789 and *Burke v General Medical Council (Official Solicitor and Others Intervening)* [2005] EWCA Civ 100.

⁹¹ Tom L. Beauchamp and James F. Childress *Principles of Biomedical Ethics* (5 ed, Oxford University Press, New York, 2001) at 102.

⁹² Perhaps the principle of non-maleficence would fit too, as there is undoubtedly the concurrent obligation to ‘do no harm’. I contend that the assessment and weighing up of interests for the *best* of the patient excludes this. The notion of society’s obligation to do good is explored in Chapter Three’s discussion of interests.

is good for the individual patient. There is little doubt that some form of value system is necessary for the evaluation of best interests:

Any assessment of an individual's best interests must be based on an underlying value system, a conception of what constitutes 'the good', both for that person and generally."⁹³

Sometimes it is not easy to decipher what the harms and benefits are in a particular case, especially in the end-of-life cases which are the focus of this thesis. Do we want to act with beneficence or is non-maleficence a high enough standard? For example, where is the harm in letting a patient die? How do we measure quality of life? Consequently the link between ethics and best interests comes when looking at its application, and for the purposes of this thesis its application in legal cases. What constitutes interests? Are they physical, emotional or spiritual? Do they include interests after death? What kinds of things are considered to be interests of a permanently insensate patient or a minor? Why should we care what is considered? Is there another way of looking at the best interests of a patient? What principles are at work here? Do you have to have personhood to have interests? If so what constitutes personhood? Who gets to be the decision-maker? Is it the doctors, the family or the courts? Once the interests are identified, what weight should they be given? Should there be a hierarchy? All of these questions invoke an evaluation and reference to some sort of values, usually ethical values, in order to be answered. Furthermore, many can be answered by consideration of what an interest is, who has them and identifying where they come from, all of which are discussed in the next chapter. Although decisions have been made on behalf of the incompetent for centuries, the emphasis on their best interests and what those interests entail have necessarily changed dramatically due to: (1) advances in medical science (the prospective end-of-life cases have only been possible due to advances such as ventilators and ANH),⁹⁴ and (2) the increased respect for a patient's autonomy.

Advances in medical science have effectively created this prospective nature of law-making whereby treatment decisions about whether to keep patients 'alive but not living' need to be made. It has created the dichotomy between 'what we can do' and 'what we ought to do'.⁹⁵

"Death, for some, is an end; death, for others, is a beginning; death, for all, is the unavoidable outcome of birth, the natural completion of life. Medical treatment and

⁹³ Jocelyn Grant Downie, Timothy A Caulfield and Colleen M Flood *Canadian Health Law and Policy* (Butterworths, 2011) at 397. The idea that there can be a 'general good' is explored in Chapter Three.

⁹⁴ Buchanan and Brock (1990) at 3.

⁹⁵ "Scientists were so preoccupied with whether they could, they didn't stop to think whether they should." Jurassic Park 1993.

technology can remedy some illnesses one encounters along life's path, but medical treatment cannot alter the inevitability of death. The past half century has seen, however, significant developments in the ability of medical technology to prolong existence, delay death, and create conditions where the final phases of life risk becoming overly medicalized. Consequently, as a person advances closer towards death, issues arise about what medical assistance should be administered."⁹⁶

Just because doctors *can* keep a person alive in a PVS indefinitely, *should* they? What treatment burdens should a patient be subjected to? How should their quality of life be assessed? All of these are ethical questions that are inherent in any weighing up of best interests. It must also be noted that there is a complex relationship between these difficult cases and the duty of care as predicated on a reasonable medical opinion. Oftentimes the recommended provision of treatment, or withdrawal, or withholding, is done based on the medical profession's duty to life sustaining care, and their corresponding duty to not burden the patient where there is no hope of recovery.

The second shift is the accumulative respect for a patient's autonomy, which has, at times, been touted as the weightiest of considerations in the last few decades (although there has more recently been some resistance to this).⁹⁷ When looking at the best interests of incompetent persons, autonomy may not be an obvious competing factor. How can a person exercise their autonomy when they cannot communicate any of their views? As discussed in Chapter Five, the pervasiveness and influence of autonomy is so strong that it appears judges are trying to adhere to it when it is technically impossible to do so. This is because it is considered to be upheld within the concept of best interests when deciding that a patient's prior, competent views should be given weight.⁹⁸ It is also a way to keep the focus on the individual. There are other considerations, those of other-regarding interests, that can, and perhaps should, be made and this idea is explored in Chapters Three and Seven.

The last theme discussed explains to some extent why the courts have appealed to sources other than legal precedent or statutes; namely that there is a scarcity of these resources.

⁹⁶ *Barbulov v Cirone* [2009] CanLII 15889 (ON SC) at [1].

⁹⁷ Angus Dawson "There's So Much More to Life: Socially-Embedded Concepts as the Foundation for Public Health Ethics" (Paper presented at the Working with Diversity: Bioethics and Health Law Conference, Wellington, New Zealand, 25-28 June 2015).

⁹⁸ This is discussed in depth in Chapters Three and Five.

Inadequacy of Existing Law

“We do not ask for work but we have a duty to decide what parties with a proper interest ask us to decide... Deciding disputed matters of life and death is surely and pre-eminently a matter for a court of law to judge. That is what courts are here for.”⁹⁹

This section sets out the theme identified in relation to the law governing best interests. Following that the general legal principle of *parens patriae* is discussed, which is informed by an exploration of the differences between the two predominant ways to make decision about an incompetent person in common law jurisdictions: the best interests and substituted judgment tests. The substituted judgment test is one that is crucial to the understanding of best interests as it relates to the formerly competent patient’s expressed wishes, therefore the particular focus is on how prior views are factored into legislation. Finally, each country’s specific case law and legislation is examined – within certain parameters – and how the best interests test has been utilised is discussed.

The cases examined can all be similarly classified as indeterminate. Whilst all cases that go before the courts are indeterminate to some extent, the lack of certainty associated with the cases in this thesis may be more exaggerated where there is no established legal precedent or settled reasoning process upon which to base the decision-making. It is also presumed that an increased predictability of the outcome corresponds with a decreased likelihood in reaching the courts.¹⁰⁰ To reach a decision, judges use legal reasoning, which at a very basic level means that statutory interpretation and the use of precedent are employed.¹⁰¹ Where there is no legislation or precedent for the judge to determine from, it is suggested that there are three possible approaches: (1) arguing from analogy – using binding precedent from cases with similar facts that established broad enough principles; (2) following persuasive precedent from similar jurisdictions; and (3) considering public policy and dispensing justice as befitting the society they are in.¹⁰² Some of these characteristics are lacking in the group of cases analysed, which leads to the conclusion that there may be something besides legal reasoning being utilised; perhaps something closer to ethical reasoning. The difficulty is, of course, in defining what is meant by ethical or legal reasoning. A working definition of these

⁹⁹ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 174 per Ward LJ.

¹⁰⁰ Posner (1988) Mich L Rev 827 at 840. “A sample of cases litigated to judgment will be biased in favor of uncertainty, because if the outcome is clear the parties will usually settle the case before trial.”

¹⁰¹ Janine F McIlwraith and William J Madden *Health Care and the Law* (5th ed, Thomson Reuters (Professional) Australia, Prymont, NSW, 2010) at 41.

¹⁰² *Ibid* at 46.

terms could be advanced, for example the way that permanently incompetent was defined in Chapter One. But the legitimacy in doing this lies with how nothing in particular hangs on how the terms are defined. Since this thesis contends that transparency with terms is an issue, it would then be hypocritical to confuse the issues with personal suggestions regarding what is relevant. Instead, an attempt is made to show *how* the terms are analysed by the courts. It is therefore problematic to outline an extensive exposition on the definitions of legal and ethical reasoning since these cover such a vast array of philosophies that there can be no definitive answer. Instead, the subject matter is discussed irrespective of the type of reasoning someone may assign to it. Some may call what the judges are doing legal reasoning, some may call it ethical reasoning – it is actually irrelevant to this thesis, but it is important to acknowledge that some commentators would describe the reasoning utilised in these difficult cases as resembling something closer to ethical reasoning than legal reasoning.

A fundamental question emerged from the cases: to what extent are the judges referring to precedent or statutes as the basis for their reasoning? The contention, regarding inadequacy of law, arises from an observation that in some cases there is very little discussion of statute law, or precedent, that the judges rely upon to reach decisions. This was particularly true, as might be expected, in earlier cases in which some of these end-of-life issues were still being negotiated. Often this was acknowledged by judges who stated their reluctance for court involvement, and that the matter should be legislated by parliament.¹⁰³ If they are not relying on precedent or statute then what are they using to reach their conclusions? This led to the deduction that often judges relied on very different doctrines or interpretations of the same concept, which was often best interests. They also at times did not even agree on how to apply best interests, and *Re A* is a good example of this as the judges disagreed as to whether the operation was in both twins' best interests. It is also a good example of judges relying on a variety of legal doctrines (bodily integrity, doctrine of necessity, self-defence) to justify separating the conjoined twins.¹⁰⁴ This also ties into the above theme regarding different reasoning to get to the same conclusion.

¹⁰³ For example: *Airedale NHS Trust v Bland* [1993] AC 789 at 890 and 896 per Lord Mustill; at 878-79 per Lord Browne-Wilkinson. *Law Hospital NHS Trust v Lord Advocate* (1996) Scot CS CSIH 2; [1996] 2 FLR 407 at 866 per Lord Milligan.

¹⁰⁴ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147. This was complicated by the difficulty of having to decide whether the operation was actually lawful. Best interests was used to justify the operation in civil law terms, but other doctrines were needed to show that it was lawful.

The following sections set out the general law regarding end-of-life so that the gaps can be identified. Discussion of the legislation and case law is presented as it applies to incompetent patients needing end-of-life care, and this does not negate the general theme outlined, but rather bolsters the observation. First, there will be a discussion of *parens patriae*, which is the historical jurisdiction for protecting an incompetent person, followed by an illustration of the main difference between best interests and the other main guidance principle, substituted judgment. From here the importance of a person's prior competent view emerges as an essential consideration for Chapter Five. Finally, there is a brief overview of the law in each of the four jurisdictions focused upon in this thesis.

Parens Patriae Jurisdiction

Parens patriae jurisdiction is an instrument of the court that enables it to make decisions on behalf of any person who is deemed to be incompetent. Specifically, it places the court under a duty to protect those who are unable to protect themselves. It is an ancient power of the courts, dating back as far as the thirteenth century.¹⁰⁵ It originated from the upper class' duty towards those in need of protection; these were typically aristocracy with obligations to serfs on their land:

“Under it the Crown as *parens patriae* had both the power and the duty to protect the persons and property of those unable to do so for themselves”.¹⁰⁶

Parens patriae jurisdiction is an instrument that is still used by the courts today. In New Zealand, Australia and Canada it can apply either to children or to adults who are incompetent. However, in England and Wales it applies solely to children.¹⁰⁷ There is also some doubt whether *parens patriae* is a substitute for parental powers or derived from the State's duty to protect their citizens.¹⁰⁸

When considering the application of *parens patriae* powers it appears that the courts are required to use the incompetent person's best interests as their main consideration. They are making a decision because the person is unable to do so themselves, and they do so using that

¹⁰⁵ Dworkin (1993).

¹⁰⁶ *Posthumous Interests: Legal and Ethical Perspectives* (Cambridge University Press, Cambridge, 2008) at 551. For a more detailed historical overview see: Antal Szerletics *Best Interests Decision-making Under the Mental Capacity Act* (University of Essex: Essex Autonomy Project Green Paper Report, 2011).

¹⁰⁷ The section titled “Best Interests in Law: United Kingdom” in this chapter provides a detailed explanation.

¹⁰⁸ John Seymour "Parens Patriae and Wardship Powers: Their Nature and Origins" (1994) 14 (2) OJLS 159 at 160. In an Australian case the majority held that *parens patriae* jurisdiction was wider than parental rights: *Secretary, Department of Health and Community Services v JWB* (1992) 106 ALR 385.

person's best interests as the guiding principle. However, *parens patriae* provides little guidance in determining what those best interests are, except as it provides a historical jurisdiction to the judiciary who are able to invoke it to protect those who are unable to protect themselves.

Guidance Principles: Best Interests and Substituted Judgment

There are two approaches to how decision-making for incompetent adults is discussed in common law jurisdictions: whether to make the decision based on a person's best interests or whether this decision is made using substituted judgment. Chapters Four and Five demonstrate that this distinction is an important one, and it is referred to extensively in this thesis. Substituted judgment is the test for incapacitated adults most widely used in the United States,¹⁰⁹ while New Zealand, England and Wales, Scotland, Australia and Canada all adopt the best interests approach (with some variances in some of the different states in Australia and Canada).¹¹⁰

Similar to best interests, substituted judgment does not have a clear definition. The usual interpretation of substituted judgment is that the substitute decision-maker makes the decision based on what the patient themselves would have wanted when they were capable.¹¹¹ This is distinguished from substituting the decision-maker's judgment for that of the individual's.

“Substituted judgment is an approach that requires the decision maker to attempt, as far possible, to make the decision the represented person would have made if they did not have impaired capacity.”¹¹²

Therefore, the ethical foundations for substitute judgment are mostly linked to autonomy, as articulated in a report from the Victoria Law Reform Committee:

“Jeremy Moore, President of the South Australian Guardianship Board, has argued that a substituted judgment approach ‘ensures the greatest respect is given to the autonomy of the represented person’, and allows the person to ‘live the life they would have lived, but for the incapacity’.”¹¹³

¹⁰⁹ *In the Matter of Karen Quinlan* (1976) 355 A 2d 647.

¹¹⁰ The specific States are discussed in the subsequent section. Additionally, in the United Kingdom, prior to the MCA, the substituted judgment standard was used for substitute decision-making for property matters for incompetent adults under the Mental Health Act 1983. The best interests test is now used for both property and welfare considerations under the MCA.

¹¹¹ Dresser 46 Rutgers L Rev 609 at 620.

¹¹² Victoria Law Reform Commission (2012) at [17.67].

¹¹³ *Ibid* at [17.71].

This differs from the emphasis of best interests whereby the substitute decision-maker takes into account all the patient's interests. This is why best interests was shown to be linked to the ethical value of beneficence (rather than to autonomy) in the previous discussion of the theme relating to ancillary guidance. It could be argued that under a best interests test the substitute decision-maker takes a more objective view of the patient's condition in weighing up best interests. However, sometimes there is little difference between the two in practice; this theme is explored extensively in Chapter Five. At the very least it can be said that current common law principles, and some legislation, such as the Mental Capacity Act 2005, (MCA) include a person's views in a consideration of their best interests, whereas this is the main priority in a substituted judgment test.¹¹⁴ Chapter Six outlines the various interpretations of best interests and concludes that the best interests test is most often interpreted as a qualified-objective test, whereby objective and subjective elements are taken into account, and this is especially true if the person was previously competent. Because previously expressed competent views are a crucial part of understanding what a person's best interests may be, the following section expands on where, and how, prior views are considered in the various jurisdictions.

Prior Views

Since 1991 there has been judicial recognition that somebody's prior views and values can be informative for an assessment of their current best interests, as advanced by the English case *Re J*.¹¹⁵ There have been legislative changes in the area of incompetent patients over the last couple of decades, and these laws require substitute decision-makers to make their decision under guidance as to what the incompetent person's previous wishes were. There are two main approaches to incorporating previous wishes. The first is that these prior views are considered alongside other factors, and this is currently the law in the England and Wales and in New Zealand. In England and Wales the MCA s 4 (6) (c) requires consideration of "the other factors that he *would be likely to consider* if he were able to do so".¹¹⁶ Under New Zealand's Health and Disability Commissioner Code of Health and Disability Services Consumers' Rights Regulation 1996 (Code of Patient Rights), Right 7 provides that the decision should be made: "consistent with the informed choice the consumer *would make* if

¹¹⁴ Mental Capacity Act 2005.

¹¹⁵ *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33.

¹¹⁶ Emphasis added.

he or she were competent”.¹¹⁷ The best interests of the patient is the core guiding principle for decisions made by substitute decision-makers in most Australian jurisdictions. Currently in Victoria the wishes of the patient and the family members must be taken into account, along with considerations about the actual treatment.¹¹⁸ In New South Wales (NSW) the general principles laid out in the Guardianship Act 1987 require the views of the patient to be taken into consideration.¹¹⁹ The second approach was alluded to earlier – a test that is effectively substitute judgment; this is currently in place in South Australia, the Australian Capital Territory (ACT) and Queensland. In South Australia, under the Guardianship and Administration Act 1993, (GAA Qld) s 5 (a) “consideration (and this will be the paramount consideration) must be given to what *would*, in the opinion of the decision maker, *be the wishes* of the person in the matter”.¹²⁰ However, there must be “reasonably ascertainable evidence” upon which to base the decision. The ACT adopts an approach that prioritises a person’s “wishes” over their “interests”, but not if doing so will adversely affect their interests.¹²¹ In Queensland, the general principles of guardianship are “maximum participation, minimal limitations and substituted judgment”:

(4) Also, the principle of substituted judgment must be used so that if, from the adult’s previous actions, it is reasonably practicable to work out what the adult’s views and wishes would be, a person or other entity in performing a function or exercising a power under this Act must take into account what the person or other entity considers would be the adult’s views and wishes (6) Views and wishes may be expressed orally, in writing or in another way, including, for example, by conduct.¹²²

In Ontario, Canada, there is a two-tier system which prioritises the person’s expressed wishes, but also requires consideration of any other beliefs under the Health Care Consent Act 1996 (HCCA) s 21 (2) (a): “the values and beliefs that the person knows the incapable person held when capable and believes *he or she would still act on* if capable”.¹²³ In s 28 (4) of the Manitoba Mental Health Act, a patient’s wishes are prioritised; if there is no

¹¹⁷ Health and Disability Commissioner Code of Health and Disability Services Consumers' Rights Regulation 1996 (NZ). Emphasis added.

¹¹⁸ The Victorian Law Reform Commission released a report in 2012: Guardianship: Final Report (2012).

¹¹⁹ Guardianship Act 1987 (NSW), s 4 (d).

¹²⁰ Guardianship and Administration Act 1993 (Qld). Emphasis added.

¹²¹ Guardianship and Management of Property Act 1991, s 4(2): (a) the protected person’s wishes, as far as they can be worked out, must be given effect to, unless making the decision in accordance with the wishes is likely to significantly adversely affect the protected person’s interests; (b) if giving effect to the protected person’s wishes is likely to significantly adversely affect the person’s interests—the decision-maker must give effect to the protected person’s wishes as far as possible without significantly adversely affecting the protected person’s interests; (c) if the protected person’s wishes cannot be given effect to at all—the interests of the protected person must be promoted.

¹²² Office of the Public Guardian "The General Principles" 2015.

¹²³ Health Care and Consent Act 1996 (Ont). Emphasis added.

knowledge of any prior wishes, then the proxy decision-maker must make the decision guided by the patient's best interests.¹²⁴

All of these provisions are relevant for discussion of prior views in Chapter Five. Under the MCA, prior views have to be considered but there are no clear guidelines as to the weight given to these views (this has led to some confusion which is explored in this later chapter). South Australia's Act is an example of a substituted judgment test as it clearly makes the patient's prior wishes paramount. New Zealand has very little guidance with only the Code of Patient Rights to reference. Canada, similar to Australia, has various approaches in different states, Ontario's is highlighted as it is pertinent to later discussion.

Best Interests in Law

“But neither law nor legal scholarship has provided an adequate theory of decision making for incompetents or a satisfactory analysis of competence.”¹²⁵

It is difficult to discuss the law on best interests at this introductory stage because the case law forms the basis of the analysis in subsequent chapters, and therefore the legal background is problematic to convey without duplicating information. This is mainly because the data – the end-of-life cases examined – have two main purposes in this thesis: (1) they inform and are an important part of the common law, and are therefore an integral part of this chapter which looks at the concept of best interests; and (2) this same group of cases are subsequently used to analyse how well the judges are using best interests. Consequently, the end-of-life judgments are part of the common law and require to be discussed as such, but these cases also form the data used to analyse how well the best interests test is being applied. Two approaches have been used to disentangle the potential difficulty that this overlap between data and analysis might present.

Firstly, Appendix Three has provided a précis of 31 cases from the different jurisdictions. Listed by country, each case's facts have been summarised, with a particular focus on how best interests is utilised.¹²⁶ Due to the volume of cases from the United Kingdom and Canada, cases from these countries were chosen based on their contribution to the

¹²⁴ Manitoba Mental Health Act.

¹²⁵ Buchanan and Brock (1990) at 4.

¹²⁶ In subsequent chapters, when critiquing particular aspects of the cases, and discussing them in more depth, they are introduced with a brief summary for the ease of readership. Additionally, Appendix Three is not intended to be an independent document. The details it provides is in addition to the information contained within the thesis chapters to avoid repetition of the same material.

understanding of the best interests test, but the lower number identified from New Zealand and Australia resulted in nearly all of those being featured in Appendix Three. Appendix One is a comprehensive list of the cases which informed this thesis. It should be referred to for the following information: case name, year, court, country, condition, if the patient is a minor, the disputed action, what the decision was, whether the family agreed with the prospective action, whether the disputed or proposed action was recommended by doctors, and who the court instigator was. The decisions that the courts faced were about a proposed or disputed action to treat (or not treat) the patient in some way with medical treatment. Those actions were further categorised into the type of end of life decision that was discussed: (1) an operation (for example to separate conjoined twins); (2) a device needing to be re-inserted (often a shunt or similar device); (3) future provision of life-prolonging treatment (often regarding administration of antibiotics, cardiopulmonary resuscitation (CPR) and use of a ventilator); and (4) withdrawal of life-prolonging treatment (often ANH or a ventilator).

Secondly, this section focuses on the legislation dealing with best interests rather than the common law. This fits in with the fifth theme identified, that there is a dearth of law from which judges can refer to inform decisions in these cases. Obviously, precedent from the common law forms part of this picture, but the intention with these themes is to provide enough information to show that they are present, rather than a detailed exposition on every possible case that they apply to; this can be done without compromising the aim of this section which is a broad overview of the law as it relates specifically to best interests.

This thesis deals with multiple jurisdictions, all of which have common law and legislative redress to the courts regarding the best interests of incompetent patients, both minors and adults. With these complexities in mind this section has been set out as simply as possible for clarity. A comprehensive account of the law is not the objective; consequently this section is descriptive, and highlights particular instances of best interests in cases, with the intention that the amount of detail given is sufficient to inform the remainder of the thesis. A wide-ranging discussion of all relevant legislation is also not beneficial here. But what is needed is to point to the key legislation so that the indicators regarding use or lack of use of statutes can be more readily identified. There is additional complexity for this when considering the legislation of Australia and Canada as they both have federal legal systems, whereby each state has its own legislature. Consequently the cases are used as the point of origin – what

states are they from and therefore which legislation does (or can) apply to the issues that the cases address.

There are a number of ways that the prospective cases come to court. For example, the family might disagree with a medical opinion,¹²⁷ the family members may disagree with each other,¹²⁸ or all parties involved might be unanimous in their views but are unsure if the proposed plan regarding treatment is legal or not.¹²⁹ As well as these possibilities, there is a further complication regarding whether the patient is a minor or an adult lacking capacity.¹³⁰ If the patient is an adult, there are generally guardianship laws in each jurisdiction which apply.

“The vast majority of Western societies have legal regimes that provide decision-making mechanisms for adults with some kind of impaired capacity.”¹³¹

Each jurisdiction has its own specific legislation, but they all provide in some way for those who are incapacitated. Most allow for a competent person to make advance decisions, (such as an advance directive) and appointment of a substitute decision-maker in the case that they became incompetent. If they have not done so then other powers, such as *parens patriae*, can be invoked by the court.

In all cases it must be noted that best interests as a *legal* test has a different starting point from that of an *ethical* framework. This is because the decisions are being made against the established precedent that consent is needed for treatment, and everybody has the right to refuse treatment. Where there is no consent (as the person is unable), the test can be interpreted in two ways, but both involve clearing a threshold where the benefits outweigh the harms. The first interpretation is that of a cross roads where the two possibilities are to treat, or not treat, and the ‘best’ path is chosen. The second is justificatory, where there is a barrier that must be overcome.¹³²

¹²⁷ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

¹²⁸ *Janzen v Janzen* [2002] OJ No 450 44 ETR (2d) 217 (Ont SCJ).

¹²⁹ *Airedale NHS Trust v Bland* [1993] AC 789; *Queensland v Alyssa Grace Nolan (an Infant, by her Litigation Guardian Shaun Nolan) and Bethany Rose Nolan (an Infant, by her Litigation Guardian Shaun Nolan)* (2001) QSC 174; [2001] 122 ACR 517.

¹³⁰ This is examined in Chapters Three and Seven.

¹³¹ Shih-Ning Then "Evolution and Innovation in Guardianship Laws: Assisted Decision-making" (2013) 35 Sydney L Rev 133 at 133.

¹³² *Airedale NHS Trust v Bland* [1993] AC 789. The Court of Appeal exhibited the ‘cross roads’ approach, and the House of Lords the ‘barrier’ approach. These are discussed in further detail in Chapter Six.

There have been few cases in New Zealand which fit within the criteria for this thesis, and in those few cases although there is clearly *parens patriae* jurisdiction it has been used rarely, declarations and orders under specific legislation being more frequent. *Parens patriae* jurisdiction is vested in the High Court by s 17 of the Judicature Act 1908.¹³³ By exercising this power, courts can make prospective decisions on behalf of all incompetent adults. Peart and Gillett argue that the method of resolving such issues by declaratory powers instead of *parens patriae* is not ideal. This is because the focus in declaratory powers is on the potential liability of the doctors rather than the best interests of the patient.¹³⁴

In *Auckland Area Health Board v Attorney-General*, Thomas J considered the submission regarding *parens patriae* powers, but he found that, while this jurisdiction existed in New Zealand, it was not necessary in this case to consider whether it should be invoked.¹³⁵ The reasons for this conclusion were not entirely clear. In *Re G* the judge decided to use the best interests test rather than substituted judgment, but also gave weight to Mr G's prior views.¹³⁶

Specific legislation regarding decision-making for incompetent patients has not been addressed by the New Zealand Parliament for over twenty years. Under existing legislation there are clear authority principles under which substitute decision-makers can be appointed. There are two formal means of appointing decision-makers: welfare guardians and enduring powers of attorney. The Protection of Personal and Property Rights Act 1988 (PPPR Act) gives powers to welfare guardians for incompetent adults:

18 (3) In exercising those powers, the first and paramount consideration of a welfare guardian shall be the promotion and protection of the welfare and best interests of the person for whom the welfare guardian is acting, while seeking at all times to encourage that person to develop and exercise such capacity as that person has to understand the nature and foresee the consequences of decisions relating to the personal care and welfare of that person, and to communicate such decisions.¹³⁷

¹³³ Judicature Act 1908. "The court shall also have within New Zealand all the jurisdiction and control over the persons and estates of mentally disordered persons, and persons of unsound mind, and over the managers of such persons and estates respectively".

¹³⁴ Nicola Peart and Grant Gillett "Re G: A Life Worth Living?" (1998) 5 JLM 239 at 240. Professor Peart was chairperson of the Southern Regional Health Ethics Committee that approved withdrawal of treatment for Mr G and Professor Gillett testified as a neurosurgeon in *Re G* [1997] 2 NZLR 201.

¹³⁵ *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235 at 242. This case is discussed in detail in Chapter Six: "The Opposition of the Mind and Body".

¹³⁶ *Re G* [1997] 2 NZLR 201. This case is discussed in detail in Chapter Five.

¹³⁷ Protection of Personal and Property Rights Act 1988.

Under s 93A, the PPPR Act also enables a competent person to “grant to another person an enduring power of attorney to act in relation to the donor's personal care and welfare if the donor becomes mentally incapable”. The same requirement to prioritise a person’s best interests applies to an individual with enduring powers of attorney under s 98A. This is a relatively recent amendment, in 2008.

The Code of Patient Rights is delegated legislation from the Health and Disability Commissioner Act 1994. It gives ten rights to all New Zealand consumers in all health care services, and places obligations on all providers of those services to enable consumers to exercise those rights. Right 7 is the right to give informed consent and make an informed choice. It also provides guidance for when the patient is not competent:

- Right 7 (4) Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where –
- (a) it is in the best interests of the consumer;
 - and
 - (b) reasonable steps have been taken to ascertain the views of the consumer.

The qualification under Right 7(4) that “no person entitled to consent on behalf of the consumer is available” means that it would apply to minors only when their parents were unavailable, (s 4 of New Zealand’s Care of the Children Act 2004 states that the child’s best interests are the paramount consideration in any decisions made under the Act)¹³⁸ and incompetent adults where they had not appointed an enduring power of attorney or had a welfare guardian appointed for them. Right 7 (4) (c) goes on to state that the provider must also have regard to the consumer’s views if they have been ascertained and make a decision that is “consistent with the informed choice the consumer would make”. But if they are not known the provider may “take into account the views of other suitable persons who are interested in the welfare of the consumer”. Section 7(4) therefore requires the decision-maker to consider both the incompetent person’s best interests and take reasonable steps to ascertain their views, which is consistent with other jurisdictions. It is important to note that the Code of Patient Rights applies to all providers of services – so it is the provider who is the decision-maker that is being referred to.

¹³⁸ Care of the Children Act 2004 (NZ). This Act replaced The Guardianship Act 1968.

“To date there has been no analysis of how patients’ rights under the Code of Patient Rights fits within the adult guardianship law under the Protection of Personal and Property Rights Act 1988.”¹³⁹

Australia

In Australia the *parens patriae* jurisdiction exists, but the use of guardianship orders and other legislation governing decision-making for those who are incompetent is more common. Every Australian State and Territory possesses legislation that governs substitute decision-making for those who are incompetent.¹⁴⁰ Unlike in New Zealand, in all of the Australian states a spouse can consent to some treatments.¹⁴¹ In Australia all jurisdictions’ legislation governing substitute decision-making includes consideration for the person’s prior wishes. However the ACT and South Australia give the person’s wishes priority over other considerations.¹⁴²

In *Re Marion* the Australian Family Court considered the application regarding sterilisation for a teenaged girl, and it provides a starting point for the consideration of best interests test for minors in Australia.¹⁴³ Nicholson CJ dissented in his judgment that all applications for sterilisation should go through the court, but this view was eventually upheld by the High Court.¹⁴⁴ Furthermore, the best interests test for medical procedures on minors that Nicholson CJ put forward, when the case was referred back to the Family Court in *Re Marion (No 2)*, was essentially codified by the Family Law Rules.¹⁴⁵ Section 4.09 of the Family Law Rules sets out a list of considerations, including (2) “(c) the likely long-term physical, social and psychological effects on the child” and “(f) that the procedure is necessary for the welfare of the child”. The other sections are concerned with the necessity of the procedure, the child’s ability to consent, and if the parent or caregiver agrees. However, in *Re Baby D (No 2)* there was no discussion of these Family Law Rules in the context of withholding life-

¹³⁹ The Law Foundation "International Research Fellowship" (2014) www.lawfoundation.org.nz/wp-content/uploads/2014/12/2014-article-about-International-Research-Fellow-Winner-Alison-Douglass.pdf

¹⁴⁰ Ben White, Fiona J McDonald and Lindy Willmott *Health Law in Australia* (Thomson Reuters Australia, 2010) at 150.

¹⁴¹ McIlwraith and Madden (2010) at 127.

¹⁴² White, McDonald and Willmott (2010) at 162. Guardianship and Management of Property Act 1991 (ACT) s 4(2)(a). Guardianship and Administration Act 1993 (Qld) s 5(a).

¹⁴³ *Re Marion* (1990) 14 Fam LR 427, (1991) FLC 92-193.

¹⁴⁴ *Secretary, Department of Health and Community Services v JWB* (1992) 106 ALR 385.

¹⁴⁵ *Re Marion (No 2)* 17 Fam LR 336. Family Law Rules 2004, s 4.09 (1) “... evidence must be given to satisfy the court that the proposed medical procedure is in the best interests of the child”.

prolonging treatment to Baby D which indicates that these rules may not apply to withholding treatment.¹⁴⁶

The *parens patriae* jurisdiction has not often been used in Australia to allow withholding or withdrawing of treatment, but instead has been used positively to order that treatment be continued. *Northridge v Central Sydney Service (Northridge)* used the *parens patriae* jurisdiction to protect the patient and order his treatment.¹⁴⁷ *Re BWV; Ex Parte Gardner* differed from *Northridge* because it was decided on the basis of the Medical Treatment Act 1988, not *parens patriae* jurisdiction.¹⁴⁸ The issue before Morris J was to determine which instrument (if either) was appropriate to use for the withdrawal of the Percutaneous Endoscopic Gastrostomy (PEG) feeding tube. He found that the statutory provisions laid out in the Medical Treatment Act were meant to be used by Parliament for such a decision. He even stated that there was no place for the use of *parens patriae* powers in Victoria where they have extensive legislation dealing with guardianship matters, namely the Guardian Administration Act 1986. The powers given to the Public Advocate under this Act were akin to those that the court could wield under the use of *parens patriae*.¹⁴⁹

Canada

At the federal level little legislation exists, but the provinces and territories have been more active and enacted legislation governing substitute decision-making.¹⁵⁰

In Ontario the HCCA establishes a Consent and Capacity Board (CCB) which governs all disputes that arise when health practitioners disagree with substitute decision-makers over treatment.¹⁵¹ Under s 21, the substitute decision-maker can consent to or refuse treatment based on the incapacitated person's expressed preferences, where known, and their best interests. In Manitoba the Mental Health Act provides for proxy decision-makers, and if the person has not appointed a proxy then a relative may make decisions for the incompetent

¹⁴⁶ *Re Baby D (No 2)* [2011] FamCA 176.

¹⁴⁷ *Northridge v Central Sydney Service* [2000] NSWSC 1241.

¹⁴⁸ *Re BWV; Ex Parte Gardner* [2003] 7 VR 487. Medical Treatment Act 1988 (Vic).

¹⁴⁹ Guardian Administration Act 1986, Victoria. *Re BWV; Ex Parte Gardner* [2003] 7 VR 487 at 510. Victoria's laws are currently under review, see: The Victorian Law Reform Commission (2012).

¹⁵⁰ Jocelyn Downie and Michael Hadskis "In Defence of Consent and Capacity Boards for End-of-Life Care" (2014) 61 (10) Can J Anaesth 899 at 386.

¹⁵¹ Health Care and Consent Act 1996 (Ont).

person. However, s 28 (3) (a) requires that the relative must have been in contact with the incompetent person within the last twelve months in order to qualify.

United Kingdom

Firstly, a note about the court structure in the United Kingdom. The United Kingdom refers to the countries of England, Scotland, Wales and Northern Ireland. This is complicated by those countries having separate parliamentary and court structures. There are two parliaments: United Kingdom and Scotland, and two assemblies: Wales and Northern Ireland. Legislation which is enacted by the Parliament of the United Kingdom may apply to the whole of the United Kingdom (in the case of ‘reserved’ matters), or only to certain constituent parts. The MCA only applies to England and Wales. The treatment of incompetent adults in Scotland is governed by the Adults with Incapacity (Scotland) Act 2000. While Scotland and Northern Ireland have their own court system, the Supreme Court is the final court of appeal in civil matters for all of the United Kingdom (replacing the House of Lords in 2009). Where necessary, it is indicated in this thesis if, for example, the case is from the Scottish courts and they have a different finding from the English and Welsh jurisdictions.

The *parens patriae* jurisdiction in relation to incompetent adults ceased to exist in England and Wales, seemingly unintentionally by statute.¹⁵² As a result, there was a void in the law governing how the courts could protect adults who lacked capacity.¹⁵³ Many of the cases in England and Wales were decided before there was legislation governing the decision-making. The MCA rectified this, and s 4 of the MCA 2005 effectively codifies the best interests test. Paragraph 28 of the Explanatory Notes to the MCA states:

“It is a key principle of the Act that all steps and decisions taken for someone who lacks capacity must be taken in the person’s best interests. The best interests principle is an essential aspect of the Act and builds on the common law while offering further guidance.”

¹⁵² *Airedale NHS Trust v Bland* [1993] AC 789 at 552. “The effect of s 1 of the 1959 Act, together with the warrant of revocation ... was to sweep away the previous statutory and prerogative jurisdiction in lunacy, leaving the law relating to persons of unsound mind to be governed solely, so far as statutory enactments are concerned, by the provisions of that Act.”

¹⁵³ This was one of the many issues dealt with in *Airedale NHS Trust v Bland* [1993] AC 789.

In Scotland, *Law Hospital NHS Trust v Lord Advocate* discussed best interests as to whether the proposed action was lawful or not, and also found that the *parens patriae* jurisdiction (referred to as *pater patriae*) applies in Scotland:

“What is required from the court is [a decision as to] whether the proposed operation is in the best interests of the patient and therefore lawful, or not in the patient’s best interests and therefore unlawful.”¹⁵⁴

Baker J in the 2011 case of *W v M* summarised the legal position in England regarding best interests:

“Any decision made under the Mental Capacity Act for a person who lacks capacity must be made in her best interests. The law requires the court to identify those factors which are relevant to the person’s best interests and carry out a balancing exercise weighing up the factors on each side of the issue. This approach is well established in cases involving medical treatment.”¹⁵⁵

Prior to the enactment of the MCA, *Bland* was the leading legal authority regarding decision-making for incompetent patients in end-of-life circumstances. *James* was the first Supreme Court case to consider end-of-life issues for an incompetent patient under the MCA.¹⁵⁶ *Bland* was discussed extensively in *James* and the Supreme Court interpreted a major aspect on best interests, upholding the threshold approach taken by the House of Lords in *Bland*:

“Hence [following from *Bland*] the focus is on whether it is in the patient’s best interests to give the treatment, rather than on whether it is in his best interests to withhold or withdraw it.”¹⁵⁷

Therefore, best interests is the guiding principle for those lacking capacity in England and Wales, under ss 2 and 4 of the MCA:

Section 2: People who lack capacity:

(1) For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.

(2) It does not matter whether the impairment or disturbance is permanent or temporary.

¹⁵⁴ *Law Hospital NHS Trust v Lord Advocate* (1996) Scot CS CSIH 2; [1996] 2 FLR 407 at 858 per Lord President Hope. Janet Johnston had been in a PVS for four years. Law Hospital NHS Trust applied for a declaration, with the support of her medical staff and family, that all treatment and feeding could lawfully cease. Withdrawal of treatment was allowed by the Scottish Court of Session. The Law Lords decided that future cases should be by petition for the exercise of *parens patriae* jurisdiction and not declaratory powers as in England. However, this may be revisited as it was decided prior to the Adults with Incapacity (Scotland) Act 2000.

¹⁵⁵ *W v M* [2011] EW COP 2443 (Fam) at [4].

¹⁵⁶ *An NHS Trust v DJ* [2012] EWHC 3524 (COP); *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65; *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

¹⁵⁷ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 at [22] per Lady Hale.

Section 4: Best interests:

(5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.

(6) He must consider, so far as is reasonably ascertainable —

(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),

(b) the beliefs and values that would be likely to influence his decision if he had capacity, and

(c) the other factors that he would be likely to consider if he were able to do so.

7) He must take into account, if it is practicable and appropriate to consult them, the views of —

(b) anyone engaged in caring for the person or interested in his welfare ... as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

The MCA *Code of Practice* was published in 2007, and discusses how to approach assessing best interests, stating that a decision in the person's best interests may lead to their death (for example withdrawing treatment), that any prior statements the person made should be considered, and that there is no obligation to continue treatment.¹⁵⁸

Summary of Chapter Two

This chapter has provided the background information needed to examine the thesis question: how are judges making decisions for incompetent patients, and how well are they applying the principles of the best interests test in end-of-life cases? The answer to this question is in the analysis of cases from four Commonwealth jurisdictions: New Zealand, Australia, the United Kingdom and Australia. From a starting point of no agreed definition of what best interests is, the analysis has provided five themes grouped around three conclusions. (1) End-of-life decision-making is difficult, which is exemplified in the complex relationship between law and ethics. (2) Best interests is a complex concept, with no clear rules on how it is applied. This is shown in the cases by the same term being used to express different concepts, and the observation that language is inherently value-laden. Confusion over the terminology is therefore not easily avoided when coupled with a complicated concept such as best interests. Differences in judges' reasoning, despite reaching the same conclusion, forms the main investigation into how judges are reaching the decisions regarding incompetent

¹⁵⁸ *Mental Capacity Act Code of Practice* (2007), ss 5.31-33.

patients, and this is examined in the remainder of the thesis, especially Chapters Five, Six and Seven. The use of ancillary texts was highlighted to discuss the impact on the way that best interests relates to other ethical principles, and the dichotomy that has arisen between what society ‘can do’ to keep people alive indefinitely regardless of their medical condition, and what they ‘should do’. The principle of autonomy was also discussed as it is an influential factor in decision-making for incompetent patients who were previously competent. (3) The inadequate legal framework from the four countries has resulted in convoluted law-making. In the exploration of this theme 68 cases that fit the thesis parameters are charted in Appendix One, and a précis of 31 of these cases is given in Appendix Three. A tension between predictability and flexibility appears necessary for judicial decision-making, and the application of the best interests test could be considered to epitomise this tension.

The discussion in this chapter has presented various ways that the best interests standard has been utilised. In doing so, there was no clearly agreed definition of best interests, and furthermore no indication that judges explicitly engaged with the notion of interests. In the next chapter some philosophical accounts of interests are investigated. Part of the process of understanding how judges are making their decisions about what is in a patient’s best interests, lies with gaining an understanding of what is meant by the term interests.

CHAPTER THREE: EXPLORATION AND CATEGORISATION OF INTERESTS

“In order to know what is in the patient’s best interests one has to inquire about the nature of these interests in the first place.”¹⁵⁹

It is essential to understand what interests actually are before exploring how they are discussed in the test of *best* interests. This chapter therefore addresses fundamental questions, starting with – what are interests? What are judges actually incorporating into the balancing of interests? Are they utilising commonly understood interests? What kinds of interests are being attributed to incompetent patients? What sort of things count as interests? Does the term ‘best interests’ refer only to a person’s interests in his or her own life, or does the term encompass that person’s interests for others? Do the interests that we have for ourselves outweigh the interests we have for others? What, if any, is the difference between an interest, and a want or desire?

In this chapter three different accounts of interests are explored; Feinberg, Dworkin and Sperling all make significant distinctions amongst interests. These include, for example, the distinction between interests in pleasant experiences, and interests in things we may not or could not experience; and the distinction between interests which we have while alive, and those we have after we are dead. In addition to these distinctions, and others discussed by these commentators, a further and particularly important distinction emerges between two further broad categories of interests: self-regarding and other-regarding. Self-regarding interests are interests about ourselves that we can experience (for example an interest in music) and those that we cannot (for example the interest we have in being well remembered). Other-regarding interests are the interests that we have for others – usually someone we care about – enough to consider others’ interests as much as (or sometimes more than) our own interests. These definitions are used throughout the thesis, and especially in Chapters Five and Seven.

¹⁵⁹ Sperling (2008) at 2.

There are numerous texts on the subject of interests and what they are, or may be. Sperling asserts that at a fundamental level:

“An interest is a kind of stake in the well-being of an object or state.”¹⁶⁰

Feinberg also discusses interests as related to having a stake in something:

“If I have an interest ... I have a kind of *stake* in its well-being. All interests are in this way types of risks: the word ‘stake’ has its primary or literal use to refer to ‘the amount risked by a party to a wager, or match, or gamble, a thing whose existence, or safety, or ownership depends on some issue’ ... In general, a person has a stake in X ... when he stands to gain or lose depending on the nature or condition of X.”¹⁶¹

Having a stake in something means caring about something. We might care because we will be affected by a particular state or decision, or we might care, not because it affects us personally, but because we attribute some value to that state or decision. For example parents have many interests in regard to their children, both for the child’s sake and their own.

This chapter examines the predominant themes that appear in any discussion of interests, with particular reference to three influential books in this area: Joel Feinberg’s *Harm to Others*, Ronald Dworkin’s *Life’s Dominion* and Daniel Sperling’s *Posthumous Interests*.¹⁶² With a concept as ubiquitous as ‘interests’ there are innumerable ways that they could be described, categorised and analysed. Feinberg identifies many interests in *Harm to Others*; welfare, ulterior, other-regarding and surviving. In *Life’s Dominion* Dworkin identifies two types of interests, experiential and critical.¹⁶³ In *Posthumous Interests* Sperling identifies four (possible) categories of interest: (1) pre-birth; (2) life interests; (3) after-life interests; and (4) far-lifelong interests.¹⁶⁴ The first of Sperling’s categories is not relevant to this discussion as it focuses on interests that arise pre-birth and are contingent on the person coming into existence, however, the other three of his categories are applicable here. Both Feinberg and Sperling discuss what could be called specific categories of interests, whereas Dworkin’s discussion of interests is more expansive, linking his notion of interests to an assertion that interests can explain *why* people live their lives in certain ways, and why they *should* live their life in certain ways. Feinberg and Sperling discuss interests in a narrower context; they use multiple categories to argue that there are certain types of interests that people have, or

¹⁶⁰ Sperling (2008) at 9.

¹⁶¹ Feinberg (1984) at 33. Emphasis in original.

¹⁶² Feinberg (1984); Dworkin (1993); Sperling (2008).

¹⁶³ Dworkin (1993) at 200. Dworkin is also quoted in legal judgments which makes his notion of interests particularly important to canvass.

¹⁶⁴ Sperling (2008) at 14.

can have. These categories reflect the specific work that they are embarking upon. Feinberg discusses interests in relation to harm (defining harm as a setback to an interest) and Sperling discusses interests in relation to life and death. Dworkin discusses interests on a much broader scale, saying that all interests are one of two types, focusing on their properties or qualities. In this thesis Dworkin's lead is followed in the proposition that interests can be discussed broadly, as well as in the proposition that it is possible to discuss all categories of interests under two headings. However, the terms chosen to define the categories, self-regarding and other-regarding, are similar to those used by Feinberg and Sperling. It is not suggested that all interests can be described by these terms, but rather that for the purposes of a discussion of the interests for the permanently incompetent individual these distinctions can provide a valuable insight. This is because other-regarding interests have been undervalued by courts in end-of-life cases, and this has led to missed opportunities to truly engage with the patient's interests. In regard to the concept of best interests, where the discussion is focused on the individual (and in many cases the individual's family), then referring to interests in a way that relates to that person, *and* relates to interests they have for others, is not merely justifiable, it also contributes to the understanding of best interests.

All three of these books were published within the last three decades, starting with Feinberg in the 1980s, Dworkin in the 1990s and then Sperling in the 2000s. Therefore, they provide a spectrum of contributions to the discussion of interests which is necessary for the purpose of this exercise. The objective of this chapter is to show the way that interests have been discussed, and the range of interests which can be identified, which will then inform the understanding of interests as related to best interests. Subsequently, the engagement with the material is on this descriptive level and intentionally so; discussion deliberately refrains from engaging with the particular intricacies of the definitions of interests. Instead, common themes in all of these theories of interests are identified as an area of agreement from which a taxonomy of interests can be extrapolated. These themes are then drawn on in order to advance a new framework for the consideration of self- and other-regarding interests.

Part One: Exploration of Interests

Dworkin

In Dworkin's account there are two kinds of interests that people have, or could have. Experiential interests are relatively easily defined as the things that we want to experience, and things that we do not. Critical interests are the interests that reflect, represent, or are determined by the type of person we are or want to be; essentially the 'character' of the person you are or want to be.

Experiential Interests

Dworkin describes the things that we do just because we like the experience of doing them, as *experiential interests*.¹⁶⁵ Experiential interests exist because of, and in relation to, something we can actually experience. Therefore, to have experiential interests a person must be sensate, but does not need to be able to convey what interests they have in relation to what they are actually experiencing. A baby has experiential interests in being fed, being warm, and getting enough sleep. But they also have interests in not experiencing pain or suffering. For example, I have experiential interests in reading vampire fiction (much better than non-fiction), watching the BBC version of *Pride and Prejudice* for the eleventh time, or spending time with loved ones.¹⁶⁶ The interest in, and value of, these experiences lies with the person who is experiencing them – obviously it would be some people's worst nightmare to read novels about vampires or to watch *Pride and Prejudice* umpteen times, but because I enjoy these things they can be considered to be in my experiential interests to pursue. Although I may think that others are missing out on pleasure by not sharing my interests I cannot sincerely hold that they are wrong in their views.¹⁶⁷ Some of these interests as described by Dworkin can be distinguished from Feinberg's account of interests, which would term some experiential interests as passing desires. For Feinberg, interests are more closely linked to the stake one has in them.

¹⁶⁵ Dworkin (1993) at 201.

¹⁶⁶ This may be a critical interest also.

¹⁶⁷ I really do think that they are. How can Mr Darcy emerging from Pemberley's lake not be enjoyed? Likewise Book 4 of *True Blood*?

Dworkin further explains that some experiences are not pleasurable, and uses pain as one such example. He claims that the transient nature of pain shows how ‘time sensitive’ our experiential interests are – once our time is done in the dentist’s chair we are indifferent to the suffering we endured while in it.¹⁶⁸ If Dworkin is referring to the memory of pain then it could be argued that people are not indifferent to the memory of pain, but instead a painful experience contributes to an ongoing interest in avoiding similar experiences and perhaps causes ongoing distress. If it is particularly painful or distressing it can provide a watershed experience which then informs our subsequent approaches to similar events. There is often a narrative based on previous experiences as to whatever those may be, positive or negative. And if the experience is particularly painful or upsetting then understandably this will inform, and probably affect, subsequent experiences. The discussion of pain becomes relevant when discussing the suffering or ‘intolerability’ that patients are perceived to be enduring, and hence their past experiences could reasonably be construed as informing any views that they made regarding future suffering.

Critical Interests

Not all interests are experiential, they can be aspirational or future-orientated (in the sense of one’s life-long purposes, not just things we may want to experience in the future) or character-orientated. Dworkin calls this group of other interests *critical interests* and states that these are harder to grasp than experiential interests, but people have:

“interests that it does make their life genuinely better to satisfy, interests they would be mistaken, and genuinely worse off, if they did not recognize.”¹⁶⁹

He uses the following to illustrate his point:

“They represent critical judgments rather than just experiential preferences... I do think my life would have been worse had I never understood the importance of being close to my children, for example, if I had not suffered pain at estrangements from them. Having a close relationship with my children is not important just because I happen to want the experience; on the contrary, I believe a life without wanting it would be a much worse one.”¹⁷⁰

Dworkin states that critical interests are not necessarily more important than experiential interests:

¹⁶⁸ Dworkin (1993) at 201.

¹⁶⁹ Ibid.

¹⁷⁰ Ibid at 202.

“I do not mean that experiential interests are characteristically frivolous or critical interests inevitably profound ... Nor am I trying to contrast supposedly elite, reflective, philosophical lives with more ordinary or mundane ones. I mean to identify what is elite, in the sense of aspirational, within most lives. Nor am I saying that people who do not consciously reflect on how their lives are going as a whole, who just get on with living, taking things as they come, are defective or not living well ... I do believe, however, that even people whose lives feel unplanned are nevertheless often guided by a sense of the general style of life they think appropriate, of what choices strike them as not only good at the moment but in character for them.”¹⁷¹

In Dworkin’s account of interests, the distinction between experiential and critical takes on an almost deontological versus consequentialist tone, as he uses it to explain why people should or should not be treated in certain ways. This is a critical point, as Dworkin proposes that people should *want* to live a good life and this is an interest that they have regardless of whether or not they know it. The next section further discusses this notion of what life you *should* lead, described by Feinberg as an *ideal-regarding* concept. Dworkin not only uses this to argue that people should lead their lives in certain ways, but to state that critical interests show why there is disquiet sometimes with the way that people are treated:

“We need the distinction between experiential and critical interests to understand many of our convictions about how people should be treated. We need it, for example, to explain why we think that mind-changing drugs or other forms of brainwashing that produce long-lasting pleasure and contentment are not in their victims’ interests: we mean they are not in their critical interests. Understanding the difference between experiential and critical interests is also essential to understanding a certain kind of tragedy, in life as well as in fiction.”¹⁷²

There are numerous examples of this distinction in books and movies; it seemingly fascinates us that people can have positive experiences whilst living a life that does not fit within their view of their critical interests.¹⁷³ Dworkin argues that interests are not necessarily restricted to what people think their interests are, or what their pleasurable experiences may be. This needs to be discussed in relation to the evaluation of best interests, because this thesis adopts an approach that comes close to this reasoning when it proposes that an incompetent patient may have non-experiential, and other-regarding interests. Although judges have discussed

¹⁷¹ Ibid. Feinberg also holds that the instrumentality of an interest is not necessarily related to its importance: Feinberg (1984) at 59.

¹⁷² Dworkin (1993) at 202.

¹⁷³ For example: movies – *Total Recall* [1990]; *The Truman Show* [1998]; *The Matrix* [1999]; *The Island* [2005]; *Repo Men* [2010]: “Why should your loved one pass on just because of a little brain damage? That’s barbaric. That’s just bad science. With the M5-neuralnet yesterday’s dreams are today’s reality. Imagine your loved ones living out the rest of their natural lives in a world where they are always happy, always content, and always taken care of.” Books – *The Wool Series* by Hugh Howey; *The Uglies Series* by Scott Westerfield.

these kinds of interests (for example, an interest in being well remembered) it is important to explore Dworkin's ideas more thoroughly to show why we care about things that we may never have knowledge of.

In order to achieve this, critical and experiential interests are explored using the premise of the movie *The Truman Show*, which centres around a man who has been filmed for his entire life, all day, every day, as part of a reality television programme. He does not know that all of his family and friends are actually paid actors, and that his life – and even the village he lives in – is fictional. At the start of the movie Truman is happy, and if he lived out his whole life remaining ignorant of his true situation, could we say that his life had been negatively affected due to the deception? Most people would recognise that there is something intrinsically wrong with the scenario even though Truman is unaware that he is being deceived, but what – if anything – are we objecting to? Any objection would be based on a sense that Truman is being denied something, and that something is a life lived with honesty and sincerity. This could be what Dworkin is clarifying with his concept of integrity:

“Recognizing the independent importance of integrity helps us to understand much that would otherwise be puzzling in the idea of critical interests.”¹⁷⁴

Dworkin explains the concept of integrity as being linked to a steady, self-defining commitment to a vision of character or achievement.¹⁷⁵ Presumably Truman could still have such a commitment whilst unaware that his life was a television show, but Dworkin would argue that his integrity was being harmed. Within the duration of the movie, Truman develops awareness of the sort of critical interests which, Dworkin says, are objectively good for him (for example wanting to have authentic relationships with people). What does the fact that these critical interests are exercised in a context in which they cannot be achieved (because actually he has no family to want to be with) mean? It is not that Truman is making a mistake – he is not mistaken about what the ‘right’ interests are. This is in contrast to Tolstoy's Ivan Illich who Dworkin uses as an example of a man who realised he had mistakenly had the wrong critical interests all his life and this is his torment – because, in part, he is the author of his own failure. The tragedy of Ivan Illich is that he was also given a false sense of what was actually good; this is different from Truman who has the ‘right’ interests. The problem for Truman is that these right interests are based on deception: he

¹⁷⁴ Dworkin (1993) at 206.

¹⁷⁵ Ibid at 205. This is reflected in some assessments of competence discussed in Chapter Four. It is a view that I endorse, that competence includes a requirement that a person should have a set of values and consistent adherence to these.

cares about his best friend, and thinks this is a mutual bond, without realising that his friend is an actor following a defined script to maintain his false life. Truman's problem is a bit like the problem of those in the movie *The Matrix* as they are divorced from a certain truth about their situation.¹⁷⁶ What we might note, however, is that within both *The Matrix* and *The Truman Show* some of the same critical interests might be developed as those that are found in 'the real world'. However the nature of the deception practiced by the actors around Truman, and the fictional world created by computers in *The Matrix*, seems to automatically exclude any notion we could hold about what 'integrity' means in any real sense. This way of forming the discussion links integrity to reality, but is integrity predicated on truth? Not necessarily, it requires knowledge of one's self and its true values, but also the truth about one's relation to the world. If taking this viewpoint, then it may be possible to have critical interests which are predicated on a deception about whether those interests are being authentically satisfied (although this would be invalidated in Dworkin's account as he presents critical interests as being linked to a 'good' life). It would seem that those around him inform, and therefore preclude, any attempt Truman would make to live his 'good' life.

It is helpful at this point to canvass the three main approaches from normative ethics as they all contribute to ideas of what Dworkin is driving at with his discussion of a good life. One form of Utilitarianism might state that the only considerations for ethical importance are the consequences, and the most benefit for the most people, which means that as long as Truman was happy, and he was entertaining thousands of people around the world which increased their happiness, it is irrelevant that any possible critical interests are being harmed. This could be countered by devising a rule that the greatest good was only met if it was not predicated on sacrificing one person's true self for the happiness of others, justified by its overall contribution to happiness.¹⁷⁷ Another understanding could be derived from deontology; a person's life should not be based on any deception. Virtue ethics contributes by asking whether Truman himself, while he could still be a virtuous person, could truly have the attribute of *phronesis* (practical wisdom) or *eudaimonia* (the sense of living a life well). This may be what Dworkin is alluding to when he discusses the notion of a good life:

¹⁷⁶ The premise of *The Matrix* is that machines have taken over the world and are harvesting humans for their energy. In order to produce maximum benefit the humans are 'programmed' into *The Matrix* – a computer-generated world where people live out their lives believing that the world around them is real.

¹⁷⁷ Ursula K Le Guin "The Ones Who Walk Away from Omelas" in *The Wind's Twelve Quarters* (Harper & Row, 1975). This short story is about a utopian society where all enjoy wealth, education and happiness. However their happiness is predicated on the suffering and misery of a child living in a cellar, who is completely neglected and covered in filth.

“We have the abstract ambition to lead a *good* life, and we worry, some of us all our lives, about what that is.”¹⁷⁸

In his account, the finding (the experiencing) of the life as good is as important as the life being good:

“it is important both that we find a life *good* and that we *find* it good”¹⁷⁹

Therefore it could be said that Truman would prefer to discover the truth, even though his life may be a good one, because he is not able to *find* this good himself since he is not free to do so. As Feinberg points out, one of the major philosophical problems that Socrates and Plato discussed was the separation of interests from the person’s character.¹⁸⁰ So, can a person with no goal of having lived a ‘good’ life be harmed? In opposition to Plato’s position Feinberg suggests that they are not.¹⁸¹ It is a reasonable supposition in major ethical theories that any life based on deception is not a good one.¹⁸² However, even within the virtual environment, characters in *The Matrix* could still have an authentic sense of what matters, and could choose to make ethical decisions and display personal priorities. They were not necessarily deceived about where their critical interests lay (or their experiential interests, for that matter). The integrity that is lacking lies in the deliberate deception, not just because there is an ideal that full disclosure of information enables true autonomy over our lives. But it does not necessarily follow that all of Truman’s other critical interests are frustrated by the deception. Much would depend on what we thought those interests actually were and whether Truman was able to find his life good.

From Dworkin therefore a full picture can be derived of two kinds of interests – experiential and critical, from which a number of things can be deduced: (1) there are interests we have that can be both experiential and non-experiential; (2) there are some interests we have that are not dependent on us knowing them, but nevertheless are important to our sense of self; and (3) there are some interests that we *ought* to have. Feinberg challenges this this last idea, and it is his account of interests which is discussed in the next section, before addressing Sperling’s account of interests.

¹⁷⁸ Dworkin (1993) at 205. Emphasis in original.

¹⁷⁹ Ibid at 206. Emphasis in original.

¹⁸⁰ Feinberg (1984) at 66.

¹⁸¹ Ibid at 67.

¹⁸² There is, of course, the argument that we practice self-deception daily. Tali Sharot "The Optimism Bias" (2011) 21 (23) *Curr Biol* R941. However, this is able to be distinguished from deliberate deception from others as a deliberate act rather than the unconscious self deception that may happen.

Feinberg

Feinberg discusses interests in relation to harm in his seminal text “Harm to Others”.¹⁸³ He discusses a complex system of interests as related to different ways that interests can arise, and what form they may take. The complexity of his description provides both a challenge and a rich resource in this attempt to summarise the kinds of interests that people may have. At first there will be discussion of his general framework of identified interests, before then canvassing those which relate to end-of-life issues, namely interests of others and surviving interests.

Welfare and Ulterior Interests

Firstly, Feinberg suggests that two standards can show the importance of an interest to the well-being of the person.¹⁸⁴ *Welfare interests* are extensive, and include:

“the interests in the continuance for a foreseeable interval of one’s life, and the interests in one’s own physical health and vigor, the integrity and normal functioning of one’s body, the absence of absorbing pain and suffering or grotesque disfigurement, minimal intellectual acuity, emotional stability, the absence of groundless anxieties and resentments, the capacity to engage normally in social intercourse and to enjoy and maintain friendships, at least minimal income and financial security, a tolerable social and physical environment, and a certain amount of freedom from interference and coercion.”¹⁸⁵

Welfare interests are termed “minimal but nonultimate” and can be contrasted by *ulterior interests* which are closer to Dworkin’s concept of critical interests and can be seen as “a person’s more ultimate goals and aspirations” such as:

“producing good novels or works of art, solving a crucial scientific problem, achieving high political office, successfully raising a family, achieving leisure for handicraft or sport, building a dream house, advancing a social cause, ameliorating human suffering, achieving spiritual grace.”¹⁸⁶

Feinberg’s description provides an informative discussion of the difference between *interests* and *wants*. He acknowledges that there must be a close connection between a person’s

¹⁸³ One of the senses of harm that Feinberg defines is “the thwarting, setting back, or defeating of an interest”. Feinberg (1984) at 33.

¹⁸⁴ Feinberg (1984) at 37.

¹⁸⁵ Ibid.

¹⁸⁶ Ibid.

interests and his or her wants,¹⁸⁷ and although wants are necessary for interests, they can be distinguished:

“it does not seem likely that wants, even strong wants, are sufficient to create interests.”¹⁸⁸

Therefore there must be something more to raise a *want* into an *interest*:

“... some degree of ulteriority, stability, and permanence is necessary to the very existence of an interest. A mere ‘passing desire,’ however genuine or intense, does not establish an interest. A sudden craving for an ice cream cone on a hot summer day, when plenty of cold water is available, does not itself make it true that ice cream is ‘in one’s interest’ at that time. To say that something would be ‘in my interest’ is to say that it would increase my ability or opportunity to satisfy those of my ulterior wants that are themselves the bases of interests, those goals in whose advancement I have a stake.”¹⁸⁹

According to Feinberg there are three categories of wants that create interests: *instrumental wants*, *welfare interests* and *focal aims*. The terminology does not help with clarity here as in Feinberg’s account an *instrumental want* is actually an interest by virtue of being a want that is linked to ulteriority. For example, consider a young athlete. A *passing want* would be to eat ice cream, an *instrumental want* is to forgo dessert, a *welfare interest* is in their general physical health and the *focal aim* is winning an Olympic medal.

Declining dessert, or working late, involve our interests insofar as they advance our “more general, stable and permanent goals like health and financial sufficiency”; he calls these interests *instrumental wants*.¹⁹⁰ *Welfare interests* as already discussed are typically instrumental interests, although they can be “goals as ultimate as any that one has.”¹⁹¹ *Focal aims* are related to ulterior goals:

“Common to all of [interests], however, is their character, at least in part, as ends in themselves. These aims are as ‘ulterior’ as our dominant ends can be, and their value cannot be entirely instrumental. Still, for the most part, their value is not entirely intrinsic either, since their advancement or fulfilment invariably produces benefits of a great many kinds throughout the whole network of personal wants and interest.”¹⁹²

¹⁸⁷ Feinberg (1984) at 38.

¹⁸⁸ Ibid at 42.

¹⁸⁹ Ibid at 55.

¹⁹⁰ Ibid at 57.

¹⁹¹ Ibid at 59.

¹⁹² Ibid at 60.

Want-Regarding and Ideal-Regarding Interpretations of Interests

What Feinberg's analysis brings out clearly is the interrelatedness and complexity of interests, something that is somewhat lost in Dworkin and Sperling's accounts.¹⁹³ One of the ways he achieves this is by pointing out the different concepts behind the notions of interests that we have, such as 'wants' and 'ideals':

“A concept is want-regarding if it can be analyzed entirely in terms of the ‘wants which people happen to have,’ whereas it is ideal-regarding if reference must also be made to what would be ideal, or best for people, their wants notwithstanding, or to the wants they ought to have whether they have them or not.”¹⁹⁴

Feinberg employs a want-regarding view of interests in his analysis of harms. He maintains that what a person wants or strives for is the most important (or only) factor to consider. However, the ideal-regarding view suggests that there is something lacking if consideration is given only to the wants a person may have, and that the ultimate good is not merely to have the things we want, but to be a good person, and to have a good character, regardless of what we want.¹⁹⁵ Dworkin's concept of the good life is therefore an ideal-regarding view of interests, where he argues that there are interests people ought to have regardless of whether they are aware of them or not. Therefore, on this critical point Dworkin and Feinberg disagree. This ideal-regarding view of interests is one that will be revisited in the context of other-regarding interests that incompetent patients may have, and this thesis will put forward the position that an ideal-regarding view can be separated from the question of whether or not there are objective interests. Objective interests are interests that everyone *has*, regardless of whether or not they want them. Ideal-regarding interests are interests that everyone *should* have. For example, dignity is often ascribed by the courts to the permanently incompetent patient in a way that aligns it with an objective interest that everyone has.¹⁹⁶ Possibly this is because it is something that someone *should* have, but even if it could be shown that the person did not have an interest in their own dignity (that they did not care what happened to them if they were unaware of it), it is unlikely that they would then be treated without respect. Some notions of dignity are objective, in that they involve the belief that everyone has an interest in being treated with dignity, whether or not they are aware of, or have ever been aware of it. Such accounts – including from some judges – do not necessarily involve

¹⁹³ Ibid at 61.

¹⁹⁴ Ibid at 67. Utilising terms from: Brian Barry *Political Argument: A Reissue with New Introduction* (Univ of California Press, 1965) at 183.

¹⁹⁵ Feinberg (1984) at 67.

¹⁹⁶ *Airedale NHS Trust v Bland* [1993] AC 789.

the claim that patients should have an interest in dignity, but rather, that they do in fact already have such an interest.

Therefore, whether interests are held to be want-regarding or ideal-regarding is significant as it relates to whether there is an objective application of interests that everyone has, which is different from finding that there are interests that a person ought to have. Are there some interests – such as altruistic tendencies towards resource allocation – that a person ought to have? This thesis contends that it is sufficient to have a framework of interests that take into account objective interests, and it is not necessary to argue the more difficult position of ideal-regarding interests. This is predicated on the position proposed in the summary of Part One, that there are interests we can have that we are unaware of. If this is true then it is also true that there are objective interests.

Interests of Others

It is not just our own interests that matter according to Feinberg, and in his analysis there are two ways that a person can have an interest in another person's wellbeing. The first is when *A* is dependent on *B* for the advancement of *A*'s interests. The second is where *C* is so invested in *D* that *D*'s wellbeing becomes a personal stake for *C* also.¹⁹⁷ It is this second proposition that used in this thesis's proposal for interests. However, as Feinberg points out, rarely in life is the distinction so neatly exemplified. Often, the interest in another's wellbeing has links to our own interests, and he uses the example of a parent. Harm to their child violates the other-regarding interest that the parent has, but it could also affect their instrumental self-regarding interests of emotional and financial stability, and be a burden on their time.

“Loving interests are so commonly intertwined with, and reinforced by, instrumental, essentially self-regarding interests, that many observers are led to discount the former, or even deny altogether their existence in given cases.”¹⁹⁸

This egoist way of interpreting all of our actions – that ultimately we benefit – is one that Feinberg dismisses, and he makes a compelling argument for why there are other-regarding interests that are separate from self-regarding interests that we may have, dismissing arguments against their existence by the following exposition.¹⁹⁹ Self-regarding and other-

¹⁹⁷ Feinberg (1984) at 71.

¹⁹⁸ Ibid.

¹⁹⁹ Ibid at 72.

regarding acts can both be self-interested, and this is how other theories which argue against other-regarding interests have been misled, Feinberg surmises, as there is a linguistic difficulty in having other-regarding interests that are related to the person, for example using your last dollar to pay for a doctor for your children, and so such acts can be described as acting out of conscience or principle.²⁰⁰ In his account there are acts which can be self-interested (acts that promote the person's own interests) and not self-interested (acts not done in order to promote the person's own interests).²⁰¹ One example he uses is when there is pooled interest in a common goal, or sharing of a common lot. Taylor-Sands uses this idea in a way that proposes saviour siblings have familial interests because they have a stake in the future family.²⁰² Using Feinberg's account, Crouch and Elliott also accept and add to the concept of other-regarding interests:

“Other-regarding interests involve the desires that an agent has for the well-being of another person. Here, the agent may act to bring about the increased well-being of another person, and may in fact serve this other person's own interests at least partly as an end in itself. Thus an agent who acts in the service of other-regarding interests may do so partly for instrumental reasons (some of her own interests are served through the action) and partly because the end that I promoted (the well-being of another person) is important to the other person.”²⁰³

The interests of others are integral to the understanding of the best interests; this position is argued in the second part of this chapter.

Surviving Interests

In Feinberg's account, interests can be posthumous; he calls these *surviving interests*. Surviving interests can be ascribed to the ante-mortem person; that is the person who, although now dead, is described as they were in life.²⁰⁴

“The interests of a person that can be said to have ‘survived’ his death are those ulterior interests that can still be thwarted or promoted by subsequent events. These

²⁰⁰ This fits within the theme identified in Chapter Two: “Value-laden and Inconsistent Use of Language” which identifies the difficulty that language presents to philosophical discourse: “Language bewitches our intelligence by suggesting to us certain ways of thinking about philosophical matters” Crouch and Elliott (1999) 8 (3) *Camb Q Healthc Ethics* 275 at 275.

²⁰¹ Feinberg (1984) at 74.

²⁰² Michelle Taylor-Sands *Saviour Siblings: A Relational Approach to the Welfare of the Child in Selective Reproduction* (Taylor and Francis, Hoboken, 2013). Saviour siblings are selected pre-birth to save the life of an existing sibling.

²⁰³ Crouch and Elliott (1999) 8 (3) *Camb Q Healthc Ethics* 275 at 280.

²⁰⁴ Feinberg (1984) at 90. As opposed to the post-mortem person as they are in death.

include his publicly oriented and other-regarding interests, and also his ‘self-centred’ interests in being thought of in certain ways by others.”²⁰⁵

Feinberg argues that what interests we can have, and do have, for ourselves and others are dependent on the degree of investment (as stated from the outset of this chapter, with quotations from both Feinberg and Sperling claiming that interests are something that we have to have a stake in). His account differs from that of Dworkin in that he maintains interests are something that we need to have more than a passing desire for. He also provides an account that is sceptical of the notion that interests are ideal-regarding, effectively rejecting the idea that there are interests that people ought to have, which also differs from Dworkin. Rather the interests are predicated on the person themselves and their wants and desires. Both Dworkin and Feinberg’s explorations of interests have accepted the idea that a person can have interests that persist beyond death, and this is something that accords with Sperling’s detailed account of posthumous interests, as discussed in the next section.

Sperling

Sperling’s discussion of interests is intimately related to the state of the person, and whether that person is alive or dead, as might be expected from a book titled *Posthumous Interests*. As noted in the introduction, he proposes four categories of interests relating to life; those relevant to this thesis are *life interests*, *after-life interests* and *far-lifelong interests*.

Life Interests

The category of *life interests* is derived from experiences, and consequently overlaps with Dworkin’s experiential interests. Both are therefore recognising interests that we have just by virtue of being cognitively aware *or* merely sensate. Obviously, there is a significant difference between cognitive awareness, which has implications for notions of personhood, and only being capable of experiencing bodily responses to pain or warmth. This is examined further in Chapter Six, but it should be noted here that all three accounts of interests allow for both.

²⁰⁵ Feinberg (1984) at 93. Unfortunately Feinberg does not expand on what he means by distinguishing publicly orientated and other-regarding interests. Harris also accepts that there are surviving interests (he calls them ‘persisting interests’); but argues that they weaker than some other interests: John Harris "Organ Procurement: Dead Interests, Living Needs" (2003) 29 (3) J Med Ethics 130. This is discussed in more detail when Sperling’s account is examined.

Life interests also overlap with critical interests, as highlighted by Sperling, who considers the interest in survival and financial security to also be within this category.

“The importance of most interests included in this category derives from the experience or awareness of their fulfilment and is dependent upon the existence of the person, whose interests they are, and the mere fact that this person is a living person.”²⁰⁶

This congruence makes sense in light of the many ways that interests can be divided, and it also furthers the assessment that Dworkin is discussing interests on a broader scale which is interwoven through Feinberg and Sperling’s categorisations.

After-Life Interests

After-life interests are different from life interests in that they are posthumous interests, and although in existence when a person is alive, they are only realised after death. They refer to such things as views regarding what happens to your body and your estate, and anything else that happens after your death, including:

“being remembered after death as a human being with specific characteristics”.²⁰⁷

This overlaps with Feinberg’s description of *surviving interests*, and in Sperling’s account these interests can be both self-regarding (using the example of being well remembered after death) or other-regarding (for example the desire that one’s loved ones flourish).²⁰⁸ The will of actor Robin Williams exemplifies this interest in a very twenty first century way. In it he restricted the use of his image for 25 years after his death.²⁰⁹ In an age where someone’s digital likeness can be replicated to the extent that they can appear in movies after their death, and be credited – somewhat chillingly – as appearing ‘post-production’ this restriction by Robin Williams was a strong assertion of an after-life interest.²¹⁰ Many individuals want to be remembered as a good or caring or loving person after death.²¹¹ This desire to be well remembered may partly explain why people leave money to charity in their wills, as they want to extend their ‘good’ selves past their death. It also explains the phrase ‘they died

²⁰⁶ Sperling (2008) at 14.

²⁰⁷ Ibid.

²⁰⁸ Feinberg (1984) at 86.

²⁰⁹ "Robin Williams Trust" www.scribd.com/doc/260402133/Robin-Williams-Trust. The Robin Williams Trust, Article 4.3.1.1.(a): “All ownership interest in the right of the Settlor’s name, voice, signature, photograph, likeness and right of privacy/publicity” was gifted to the Windfall Foundation “subject to the restriction that such right of publicity shall not be exploited for a twenty-five (25) year period commencing on the date of the Settlor’s death”.

²¹⁰ For example, Philip Seymour Hoffman appeared, posthumously, as ‘Plutarch Heavensbee’ in *The Hunger Games: Mockingjay – Part 2: “Philip Seymour Hoffman”*.

²¹¹ Obviously whether they actually *will* be is an entirely different matter.

doing what they loved' which is often depicted as a comfort to the loved ones the person has left behind. Buchanan and Brock agree with Sperling and Feinberg that people can have interests that survive their death:

“The additional fact is that the interests of persons can survive not only incompetence and the loss of personhood, but death itself.”²¹²

Dworkin also accepts the notion of interests that survive beyond what the person has knowledge of, using critical interests to show this.²¹³ Therefore, in all three accounts there is consensus that interests are not dependent on an individual's awareness that they actually have any interests at all, something that is explored further in Part Two of this chapter.

All of the interests that Sperling calls *after-life interests* are interests that nobody can personally experience. Thus, while it is an interest that is predicated on being present whilst alive, the actual interest can only be realised when the person is dead. Some interests, such as our will being recognised, are examples of what we want to happen after our death and these are (usually) legally upheld. Other interests are not legally binding, but most people feel a strong duty to uphold them regardless. For example, my Grandfather was a true 'Southern Man' – born and raised in Dunedin, New Zealand where his parents had also lived all of their lives. Although in his adult life he lived in various places, New Zealand was his home. He died in Adelaide, Australia while visiting with his oldest child, and my mother travelled from New Zealand for his funeral. It was a scorching hot day, about 40°C, and as they lowered Grandad's casket into the ground Mum could see ants scurrying across the red earth, in stark contrast to the cooler green grass of his home. Her overwhelming impression was that it was wrong for him to be there, so far away from any family (as no family members now live in Adelaide) and that he should have been cremated and brought to Dunedin. As is often the case in families, it was not until many years later that Mum was told that Grandad had been adamant about his views after his death – he had wanted to be buried. This knowledge was not just of great comfort to Mum; it made the difference between her feeling contentment about Grandad's resting place rather than regret. This was because she knew it was his view, it was an interest that he had expressed, and so the fulfilment of that wish was enough to appease any lingering doubt.

²¹² Buchanan and Brock (1990) at 162.

²¹³ Dworkin (1993) at 209.

Some commentators, such as Harris, rank after-life interests as secondary to other interests. Using the term *persisting interests* to describe those that can survive death, Harris states:

“I believe that although there are such things as persisting interests they are, of necessity, less significant than person affecting interests.”²¹⁴

Person-affecting interests are not dependent on the person experiencing them “in the sense of being aware of them”, but are dependent on the person being alive, not dead. Harris uses the example of malicious gossip whereby it can affect the person even if he or she is not aware of it because it can impact on the interests that you are aware of, such as not getting the job you wanted or losing friends. Therefore, if my Grandfather’s wishes had been ignored, who would have been harmed, and how would the harm occur? According to Harris, Grandad’s persisting interests (in being buried) would have been harmed but this was not a person-affecting interest. Therefore the greater harm was to my mother’s interests (in ‘doing right’ by her father) as she was still living. Person-affecting interests of the living, in Harris’ account, should always outweigh persisting interests of the dead.²¹⁵ This view can also help inform the concept of other-regarding interests if it is accepted that a person-affecting position is sustainable.

Whatever term is used – ‘surviving’, ‘after-life’ or ‘persisting’ – the consensus is that there are interests that a person can have after their death. Harris qualifies this by saying that although they exist they are weaker than the interests of the living.

Far-Lifelong Interests

Sperling’s last applicable category, *far-lifelong interests*, can apply in life or death. These include:

“being the object of an affection or esteem of others, the interests that one’s promises not be broken, the interest that one’s loved ones flourish within and beyond one’s life, the interest in the integrity on one’s body and the interest in respecting one’s privacy and good reputation.”

How does an interest in having your reputation protected, as discussed as a far-lifelong interest, differ from a life interest in the same thing? Sperling refers to Steven Luper’s categories of personally and impersonally defined projects.²¹⁶ The personal projects are things that we want to do ourselves; personal achievements such as aiming to obtain a PhD or

²¹⁴ Harris (2003) 29 (3) J Med Ethics 130.

²¹⁵ Ibid.

²¹⁶ Sperling (2008) at 15.

run a marathon. The impersonal are those things that if we do not undertake to fulfil the interest ourselves we want others to fulfil for us.²¹⁷ For example, a dedicated environmentalist who wants a particular species of bird saved from extinction would want the bird species to continue to exist regardless of whether or not they are alive. Sperling goes on to construct what he calls the “Human Subject’ who is:

“construed as one whose existence persists over time and extends over the life of the person whose interests they are.”²¹⁸

From his analysis, the Human Subject is someone who holds all four categories that Sperling identified. Their existence is not just defined by their life and death however, they have pre-birth interests and after-life interests that extend beyond these boundaries. The existence of the Human Subject never ceases, but time can limit the effect of their interests.²¹⁹ This is helpful for the discussion of the interests of the incompetent person because it shows that interests are not dependent on experiences, and it perhaps offers a reason as to why courts often say that an incompetent person has an interest in being well remembered.²²⁰

Summary of Part One

Any taxonomy of interests will need to provide an account which describes all of the different categories and qualities of interests that Feinberg, Sperling and Dworkin have outlined. The overview of interests presented in this thesis endeavours to provide a summary which, in particular, does not claim any metaphysical truth beyond acknowledging that there are interests. The focus has been directed at discussing a set of complex, interrelated, but not entirely congruent views into the form of a single synthesis.

Where possible the common denominator has been extracted; this forms the approach outlined in the next section which is aimed at: (1) identifying what interests are applicable to the incompetent person; and for subsequent chapters (2) deciphering what the *best* interests are. Based on this synthesis it is possible to state that there are many interests that we probably all have – interests that we can experience and those that we cannot, interests that we have a stake in personally and interests that we can have for others. There are also

²¹⁷ Steven Luper "Posthumous Harm" (2004) 41 (1) Am Philos Q 63 at 69.

²¹⁸ Sperling (2008) at 48.

²¹⁹ Ibid at 36.

²²⁰ The Human Subject is also relevant when discussing requirements for competence in Chapter Four, something alluded to earlier, in stating that a ‘set of values’ is a necessary component.

interests that we can have that survive our death. Part Two of this chapter utilises these ubiquitous ideas by formulating a framework for categorising interests.

Part Two: A Framework for the Interests of Incompetent Patients

A Proposal for Categorising Interests

It is proposed that all of these various ideas of what interests are, can be accrued under two headings, self-regarding and other-regarding.

1. *Self-Regarding Interests* – Consideration for one’s own interests.

These can be:

- (a) experiential, or;
- (b) non-experiential.

2. *Other-Regarding Interests* – Consideration for others’ interests.

The ‘others’ of this definition has two categories:

- (a) those closest to the patient, namely family and friends, who I will collectively call the whānau, and;
- (b) society as a whole, usually the community that the patient is living in.

The following section outlines these, and the remainder of this chapter will present a discussion of each of them in detail, with reference to specific examples in selected cases. Part of the overall picture derived from the discussion of interests in Part One is that they are intimately related to the work they are intended to do. For Feinberg therefore, his discussion of interests related to harm. Conversely, Sperling used terms for his categorisation of interests that relate to life and death. Dworkin used his discussion to show why some things ought to be cared about. Therefore it is legitimate to propose a framework for interests which is formulated from the subject of discussion. In this thesis this has been done by using the terms self-regarding and other-regarding. Firstly, the range of interests that judges described in the end-of-life cases is identified, and then is widened to interests that they perhaps should have considered. Therefore, this proposal for interests advanced in this thesis is not intended to be the definitive answer to defining all possible interests, but instead a way of referring to two broad possibilities of interests that a permanently incompetent patient may have.²²¹ By

²²¹ It was after constructing these terms that the following authors were canvassed, although of course this thesis benefits hugely from their discussion of interests, especially other-regarding interests: Feinberg (1984); Crouch and Elliott (1999) 8 (3) *Camb Q Healthc Ethics* 275.

using these terms, a different lens can be used to focus on a permanently incompetent person's interests. This focus is on the acknowledgement of other-regarding interests, which is at times either lacking in judgments, or warped into something resembling a self-regarding interest. This does a disservice to the incompetent patient, and therefore it is proposed that using these terms demonstrates how the best interests of a permanently incompetent patient may be better explored.

Self-Regarding Interests

Experiential interests, and having negative or positive experiences, can only be self-regarding; although we can seek out the company of others, and empathise with them to an extent, it is still our own experience that we have intimate knowledge of. It is not necessarily true, though, that we have to directly experience all self-regarding interests, as Feinberg's ulterior interests and focal aims, Dworkin's critical interests, and Sperling's life interests show us. Therefore, a picture of interests emerges, about the self, that are directly experienced (experiential) and also not directly experienced (non-experiential). Into this picture it is possible to plot the various terms that are used in the three accounts, but what matters is that there is agreement from all three authors about this. This group of interests can be labelled *self-regarding*, as the individual is the subject of the interests. The definition is qualified by adding that these can be experiential or non-experiential interests.

The Self, Not Selfish

It is irrefutable that individuals have interests related to themselves. Indeed, the majority of our interests are about ourselves, and what we want or need or require to pursue those interests. Much of what was discussed in Part One of this chapter highlights interests that are focused on individual pursuits and personal preferences, the values that individuals have, and the value that they place on the interests that they pursue. This does not mean that the interests are selfish, it means that the subject of the interests is the person themselves, not someone else. In considering an archetypal selfless person, such as Mother Theresa, it seems unequivocal that even she also had interests that were about herself. She surely had a self-regarding interest in living a long and healthy life, and this is separate from the reason that she may have had to do so, which was to help others. Conversely we could take an archetypal selfish person, for example Kanye West, whose self-regarding interest in having a

long and healthy life is separate from the reason that he may have, which is bestow us all with his ‘genius’.

Experiential Interests

There are a whole range of interests that arise when a person can experience *anything* – whether that is any degree of pain or suffering or merely sensations – and having such interests triggers a certain response for any appraisal of best interests. In Chapter Eight the recommendation is advanced that experiential interests should be a primary consideration for any substitute decision-maker in appraising best interests for the permanently incompetent patient. In the current proposal self-regarding, experiential interests are dependent on the person being sensate, and that sensation is usually physical, but can include the person having cognitive awareness.²²² Essentially, some form of awareness is central to the notion of experiential interests. Some interpretations of best interests hold that these are the only interests that matter, and if a person cannot experience anything this means that they have no interests.²²³ Another interpretation is that medical best interests should prevail, which may be referencing an interest in having a certain state of wellbeing, or the possible futility of the treatment that the permanently incompetent patient is experiencing. These are thoroughly explored in Chapter Six, and criticised for being too narrow an approach.

Non-Experiential Interests

A permanently incompetent patient can also have non-experiential interests, and it is important to note that these interests also overlap with those that a sensate person can have; they are self-regarding interests that they can experience (or not): an interest in having their dignity maintained, an interest in not being subjected to invasive treatment and humiliations, an interest in the manner of their dying, and an interest in having their views on their treatment considered.

If a patient is non-sensate, for example in a PVS, then they may still have interests that are self-regarding. In fact, all of the interests considered to be non-experiential interests can be ascribed to any of the patients in end-of-life cases analysed in this thesis. Non-experiential

²²²An example of an experience which only someone sensate can be aware of is an interest in not suffering or experiencing pain. An example of cognitive awareness (but perhaps no bodily sensation) is an extreme form of Guillain-Barré syndrome which means that the person is ‘locked’ into their body, unable to move.

²²³This is discussed – and dismissed – in Chapter Six.

interests are an interesting subsection of interests, as they are more difficult to quantify, and appear to be more nebulous than experiential interests. What do concepts such as *dignity* and *manner of dying* even mean? Where do those interests come from? Do they depend on things that the patient used to care about? Are they objective interests?

In the landmark case of *Bland*, Hoffmann LJ recognised the idea that someone in a PVS does have interests other than those they experience, dismissing the argument that suggests people only interests in what they can experience:

“I think that the fallacy in this argument is that it assumes that we have no interests except in those things of which we have conscious experience. But this does not accord with most people’s intuitive feelings about their lives and deaths. ... Most people would like an honourable and dignified death and we think it wrong to dishonour their deaths, even when they are unconscious that this is happening. We pay respect to their dead bodies and to their memory because we think it an offence against the dead themselves if we do not. Once again I am not concerned to analyse the rationality of these feelings. It is enough that they are deeply rooted in our ways of thinking and that the law cannot possibly ignore them.”²²⁴

These remarks from Hoffmann LJ demonstrate one salient difference between an academic discussion of interests and the manner by which judges make their decisions. Hoffmann LJ acknowledges that the “rationality” of respecting dead bodies is something that can be challenged, but this is immaterial as this respect is indisputably part of the society in which we live. This may be different from stating that it is an interest of the PVS patient themselves. Some commentators suggest that the principle of dignity (which underlies the interest that someone has in it) is the only principle needed in any ethical theory.²²⁵ This debate is not evaluated here, but instead a summary is presented showing that the courts have endorsed the notion that there is such a principle, and it is a principle that applies to a permanently incompetent patient. Butler-Sloss LJ in *Bland* stated:

“A mentally incompetent patient has interests to be considered and protected, the basic one being the right to be properly cared for by others... He has the right to be respected. Consequently he has a right to avoid unnecessary humiliation and degrading invasion of his body for no good purpose.”²²⁶

²²⁴ *Airedale NHS Trust v Bland* [1993] AC 789 at 829.

²²⁵ Charles Foster *Human Dignity in Bioethics and Law* (Hart Publishing, Oxford, 2011).

²²⁶ *Airedale NHS Trust v Bland* [1993] AC 789 at 822. And see also *NHS Trust v I* [2003] EWHC 2243 (Fam) at [25]. “It is in the patient’s interest to be given such treatment and nursing care, either at hospital or elsewhere, under medical supervision as may be appropriate to ensure that she retains the greatest dignity until such time as her life comes to an end.” It is worth noting the change in language from a ‘right’ to an ‘interest’; an interest being something altogether easier to proffer.

However, in *NHS Trust A v M; NHS Trust B v H*, Butler-Sloss LJ discussed the principles of *Bland* which needed to be reconsidered in the light of the implementation of the European Convention for the Protection of Human Rights and Fundamental Freedoms 1953²²⁷ and appears to contradict her earlier endorsements with regards to the concept of dignity as non-experiential:

“... article 3 requires the victim to be aware of the inhuman and degrading treatment which he or she is experiencing or at least to be in a state of physical or mental suffering. An insensate patient suffering from permanent vegetative state has no feelings and no comprehension of the treatment accorded to him or her.”²²⁸

These different approaches, from one judge, epitomises one of the difficulties inherent in concept of dignity. Is dignity dependent on awareness or not? This is discussed further in Chapter Seven, which concludes that awareness is not a necessary requirement. This position is bolstered by the judicial application of dignity; for example, most of the judges in *Bland* recognised dignity as non-experiential, and Hoffmann LJ placed a lot of importance on this.²²⁹

“It is demeaning to the human spirit to say that, being unconscious, he can have no interest in his personal privacy and dignity, in how he lives and dies.”²³⁰

Lord Goff also recognised that Anthony Bland had self-regarding, non-experiential interests, including the invasiveness of the treatment and the indignity he suffered.²³¹

The Amicus Curiae who appeared in the High Court in the *Bland* case was quoted by Sir Stephen Brown P in his judgment, seemingly with approval, putting forward the view that Anthony Bland had interests in the way his family remembered him and his manner of dying.

“The best interests of the patient in my judgment embrace ... a dignified death.”²³²

²²⁷ European Convention for the Protection of Human Rights and Fundamental Freedoms 1953: Article 3: “No one shall be subjected to torture or to inhuman or degrading treatment or punishment.” This Convention entered into the domestic law by virtue of the Human Rights Act 1998.

²²⁸ *NHS Trust A v M; NHS Trust B v H* [2001] Fam 348 at 363. This change in position fits within the theme identified in Chapter Two regarding different reasoning.

²²⁹ Sir Thomas Bingham MR, Butler-Sloss and Hoffmann LJ all agreed in *Bland* that a patient in a PVS (so someone who ostensibly has no experiential interests) nevertheless has non-experiential interests in the way their family remembers them, the manner of their dying, and an interest in not being subjected to constant medical invasions and humiliations. Both Butler-Sloss and Hoffmann LJ linked their views to the dissenting opinion in *Cruzan v Director, Missouri Department of Health* (1990) 497 US 261. Hoffmann LJ also cited *In Re Conroy* (1985) 98 NJ 321. Nancy Cruzan was in a PVS and her parents wanted treatment withdrawn. The majority opinion of the United States Supreme Court upheld the Missouri Supreme Court’s finding that treatment could only be withdrawn if there was clear evidence she would have wished it – family statements to this effect were not sufficient.

²³⁰ *Airedale NHS Trust v Bland* [1993] AC 789 at 829 per Hoffmann LJ.

²³¹ *Ibid* at 869.

²³² *Ibid* at 833.

But what does a dignified, or good death mean? Hedley J in *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam) (*Wyatt*) gave the following definition:

“Given that death is the one experience (other than birth) that all humanity must share, no view of life that does not include a contemplation of the place of death, even in a child, can be complete. As a society we fight shy of pondering on death yet inherent in each of us is a deep desire both for oneself and for those we love for a “good” death. It seems to me therefore that in any consideration of best interests in a person at risk of imminent death is that of securing a “good” death. It would be absurd to try to describe that concept more fully beyond saying that everyone in this case knows what it means – not under anaesthetic, not in the course of painful and futile treatment, but peacefully in the arms of those who love her most.”²³³

Wyatt centred on the best interests of a child, Charlotte, and yet the concept of a ‘good’ death still arose. Hedley J considered this an interest that Charlotte, although a minor, would have regardless of her awareness of what a good death was, and irrespective of not being able to form any preferences she may have had regarding it.

Other-Regarding Interests

“Adding intimacy concerns expressly brings another player to the table: we have not only a potential clash of individual concerns (this, indeed, is arguably the case in any medical intervention, given the present climate of fiscal scarcity), but also a clash between the interests of individuals and the interests they share as members of a family.”²³⁴

In the discussion of interests presented in Part One there was acceptance that people can have interests regarding others. In Dworkin’s discussion of critical interests he determines this when he refers to his children. Although he is not specifically talking about the children’s interests, it is implied that he has a critical interest in their well-being.²³⁵ Sperling also acknowledges the interest that we have in our loved ones flourishing, which he categorises as a far-lifelong interest.²³⁶ Feinberg’s engagement with the interests of others is more direct, and provides a clear account whereby considering others’ interests alongside our own is a

²³³ *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam) at [28] per Hedley J.

²³⁴ James Lindemann Nelson "Taking Families Seriously" (1992) 22 (4) Hastings Cent Rep 6 at 10.

²³⁵ Dworkin (1993) at 202.

²³⁶ Sperling also refers to Glannon’s two categories: (1) the person-affecting (personal interests) – whereby the person has an interest in what happens to him or her, and (2) the non-person-affecting (impersonal interests) where the content of the interest is not restricted to the experience or even existence of the person who has the interest. This is really another way of saying that we have interests in things that we experience, and interests in things that we do not. Sperling (2008) at 13. See also above discussion in the section on “After-life Interests” from Harris (2003) 29 (3) J Med Ethics 130.

rational conclusion.²³⁷ It is therefore credible that there is a second group of interests that we all have, the corollary to self-regarding interests, which is *other-regarding interests*.

The concept that individuals may have interests that are not about themselves needs more investigation than the notion of self-regarding interests. There are three reasons for this: (1) although Feinberg directly referred to other-regarding interests, Dworkin and Spierling did not explicitly engage with the notion, and therefore the justification should be further explored; (2) this thesis defines other-regarding interests in relation to the concept of best interests; and (3) this thesis contends that other-regarding interests have been undervalued and often overlooked in the best interests test. The following section discusses different relationships with people that individuals could possibly have interests in, demonstrating that the conclusion that individuals do have other-regarding interests is a legitimate claim.

The question now becomes: if we can have interests in something other than just ourselves, what are those other interests in? It is logical that we care about, and have interests in, our own family and friends, but what about other things? What about interests that are not people-centred at all? The care for pets and their wellbeing is a common interest people have.²³⁸ Many also care about animals in a wider context – some people are vegetarian or vegan, citing the treatment of animals and the rights of animals as their reason. Many care about endangered species of animals that will never personally be seen. Environmental ethics shows us that non-anthropocentric views, and interests in things other than human beings are genuine and widespread, and that people can have interests in things other than ourselves. We care about the state of our planet, and on a daily basis may show this by using recycling bins. This could be because of a belief in the protection of the earth and its environment for its own sake, or because of other-regarding interests in protecting future generations. Regardless of the underlying values this viewpoint highlights that individuals can have a wider view of interests, and although an extensive discussion regarding these kinds of interests is outside the scope of this thesis, they are discussed briefly to show that there is a wide scope of interests that people have.

²³⁷ Feinberg (1984) at 71. He also makes reference to definitions of ‘love’ which are defined solely by having a ‘purely’ other-regarding interest in another person.

²³⁸ See Hoffmann LJ’s remarks on this in the section “Non-experiential Interests” which supposes that it is not necessarily rational but everyone has interests in things we cannot experience. This conviction can also be used to show care for others, and other things such as pets.

Whānau

The other-regarding interests that are most common, and best understood, are those that we have for the people that we care about. We care about our family and their well-being to varying degrees (often depending on the closeness of the relationship rather than its status), and have regard for their interests. Often, the nature of a person's interests can depend on what is going on in their lives (parents quickly learn the truth of the old saying that 'you are only as happy as your least happy child'). These interests are other-regarding because it is an interest that one individual has for another person's interests. Parents want their children to be happy and healthy, for the child's sake, completely unrelated to their own interests.²³⁹ I agree with Feinberg; people have other-regarding interests for those closest to them in a way that is not reliant on themselves benefitting, regardless of how inextricably our self-regarding interests are tied up with theirs.

The development of other-regarding interests is a deliberate approach to the test of best interests, whereby an individual can only be understood by reference to others around them:

“the picture of the independent and self-interested agent is inappropriate in the context of the family.”²⁴⁰

It makes sense that people care for others in their lives, that they care for the people who have been good to them or who they feel connected to on some level. However, infants (and some severely cognitively impaired adults), are not capable of recognising, or deliberately caring about, other people. An important distinction needs to be made here. Does a person need to be aware of others in order to have other-regarding interests? For example, can an infant have other-regarding interests? This thesis takes the (arguably) controversial position that they can. If a person can have non-experiential interests, it seems to follow that infants can have interests which they are not aware of (if it is accepted that non-experiential interests do not derive from ever having awareness). Infants do have interests tied up with certain people; for example statutory requirements that parents should, if they are able, provide their children with basic necessities for continued survival. This legal protection can be traced to moral imperatives and social mores in every society in existence; all communities place a high value on protecting the children born into it. Taylor-Sands argues that, because of the future

²³⁹ See section on Feinberg for arguments which dismiss the premise that all actions can be interpreted as benefitting the self-regarding interests, although as he points out there are self-regarding reasons as well.

²⁴⁰ Crouch and Elliott (1999) 8 (3) *Camb Q Healthc Ethics* 275 at 284.

stake that an infant has in their family, there are shared interests. Using feminist and communitarian theories, she argues that a child's interests are inextricably linked to those of their families and that there are "collective interests" that any child shares with their family.²⁴¹ Therefore, a child in her argument has an interest in the well-being of the parent, whether or not they are aware of such an interest.

The issue with an infant having other-regarding interests may be intrinsic to the question of whether other-regarding interests should be linked to things people *actually* develop an interest in, rather than interests they *might* have gone on to develop. In this thesis it is advocated that, whilst the incompetent patient is an individual, they are also something more: they are also someone who has not descended on the courts as an individual entity without ties to other people. This is exemplified by the fact that many of the cases are actually brought to the courts by families who disagree with the treatment plans of the medical professionals.²⁴² This is an important conceptual difference in the way that the best interests test can be interpreted. Because it is the best interests of an individual that needs to be assessed the courts have interpreted this with all interests needing to be focused on *self*-regarding interests rather than acknowledging the *other*-regarding interests that the person may have. The view expressed here is not that the courts fail to acknowledge the families of the patients in the cases, but rather that their role can be elevated; as expanded upon in Chapters Five and Seven.

In Aoteroa New Zealand, the Te Reo Māori concept of *whānau* is one that forms an integral part of society. It is used in this thesis to reference the other-regarding interests individuals have for those closest to them; their family and friends.²⁴³ Whānau is not used in any

²⁴¹ Taylor-Sands (2013) in Chapter Four.

²⁴² For example: *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67; *Portsmouth Hospitals NHS Trust v Wyatt* [2005] 1 WLR 3995; *Northridge v Central Sydney Service* [2000] NSWSC 1241; *Sawatzky v Riverview Health Centre Inc* (1998) 167 DLR (4th) 359; *Isaac Messiha (by his Tutor Magby Messiha) v South East Health* [2004] NSWSC 1061; *Jin (Next Friend of) v Calgary Health Region* [2007] ABQB 593 (CanLII); [2008] 2 WWR 723; *Rotaru v Vancouver General Hospital Intensive Care Unit* [2008] BCSC 318; *Barbulov v Cirone* [2009] CanLII 15889 (ON SC); *Maraachli v Dr Fraser* [2011] ONSC 124; [2011] OJ No. 2168. Of the 68 cases listed in Appendix One, 25 were instigated by the families.

²⁴³ There are many ways *family* can be described, for example Taylor-Sands (2013) at 72 uses the term "intimate family" which she defines as "a diverse range of family structures in which members are closely connected". *Whānau* is used for the reasons given, and because it is a concept special to New Zealand, expressed in the indigenous language of Aotearoa: Te Reo Māori. It is a term used by all New Zealanders, both Māori and Pakeha (non-Māori).

judgments, and therefore this thesis will also often refer to *family*, especially when discussing the end-of-life cases.²⁴⁴

“Whānau is often translated as ‘family’, but its meaning is more complex. Whānau ake describes an individual and their immediate whānau. This can refer to a large group as it may also include friends. Whānau can mean immediate family or much wider family.”²⁴⁵

There are two other reasons that the term whānau has been chosen in this context, both of which correlate to the ideas to be advanced in relation to other-regarding interests. The first is inherent in the concept of whānau, it is the sense that an individual is interconnected with those around them.

“Whānau begins with the individual. The relationship between the individual and the whānau is subtle and complex. Individuals have rights of their own, but they exist because of the whānau and have responsibilities to the whānau. People are expected to express their individuality within the context of the whānau framework and whānau do not set out to create clones. Respected Ngāti Porou elder Merekaraka Ngarimu explained the significance of the individual using performance of the haka ‘Ruamoko’ as an example. The individuals in the haka party will perform the haka differently according to their own natures and styles. In doing so they contribute to, support and strengthen the whole. The aim of their teacher was not to standardise the performance but to allow the uniqueness of each individual to emerge. This pepeha (saying) encapsulates the essence of the individual within the whānau:

Ehara taku toa i te toa takitahi engari he toa takitini taku toa.

My strength does not come from my individuality, my strength comes from many.”²⁴⁶

Whānau describes the intimate relationships that people actually have. Some do not feel a sense of kinship with their traditional family, but instead form these relationships with others, and the whānau concept acknowledges this. Secondly, it also provides a framework of inclusion whereby there are associated duties, so if someone is not performing those duties their position in the whānau would reflect this. For example, if an immediate family member is treating another member badly this could indicate that the courts should rely less on that

²⁴⁴ Rarely are friends’ views referenced in judgments, which supports the position advocated here that the courts take a narrow approach to the other-regarding interests of the permanently incompetent patient. “Affidavits from family and friends” is one of the rare examples of a wider audience canvassed: *Re G* [1997] 2 NZLR 201 at 212 per Fraser J.

²⁴⁵ Tai Walker " 'Whānau – Māori and Family - Description of Whānau' (Te Ara - the Encyclopedia of New Zealand)" www.TeAra.govt.nz/en/whanau-maori-and-family/page-2 2014.

²⁴⁶ Ibid. This was also supported by the paper: Ben Gray "Pacific Forum" (Paper presented at the Working With Diversity: Bioethics and Health Law Conference, Wellington, New Zealand, 25-28 June 2015). “Individual values come from connectedness to the whole community”. This was distinguished from the idea that everyone has individual values and need to find a way to make them all work in society.

relationship.²⁴⁷ Any account that allows for whānau and their wishes to factor into the decision-making for an incompetent patient must consider that not all family situations are the same, and understand that, while no one is from the quintessential ‘perfect’ family, some families are very far from this ideal.²⁴⁸ There should also be recognition that not everyone has strong familial ties.

“The fact that most of us feel a strong sense of obligation towards our family members, then, cannot in itself form the basis of a moral duty incumbent on those who do not, or cannot, have similar feelings.”²⁴⁹

However, in most of the end-of-life cases, families are very present, and have often actually instigated the proceedings because they feel strongly about a certain outcome. In those cases, there is no reason to question the incompetent person as a connected member of a familial community. Of course, the courts do recognise the role that families play, and in some cases prioritise certain family members’ views. In the Canadian case *Janzen v Janzen*, Mr Janzen had suffered severe brain damage and the prognosis was that he would live in a vegetative state for the rest of his life.²⁵⁰ His siblings sought guardianship of their brother, as they wanted treatment for him to be continued, but his wife was refusing treatment for him. The judge commented on the nature of their relationship and prioritised the wife’s view of what the patient would want over the siblings’:

“I note that Maria Janzen and Edward Janzen have been married for over 12 years. They have two children. They have operated as an intimate family unit for many years. There is no evidence whatsoever to suggest that Maria Janzen would not know

²⁴⁷ This is reflected in the Manitoba the Mental Health Act which provides for proxy decision-makers, and s 28 (3) (a) requires that the relative must have been in contact with the incompetent person within the last twelve months in order to qualify.

²⁴⁸ A particularly sad example of this is an American case described by Fleming where motivation to not withdraw treatment could be attributed to the parent not wanting to face a murder charge: Miriam S Fleming "A Case Study of Child Abuse and a Parent's Refusal to Withdraw Life-Sustaining Treatment" (1999) 26 (2) Human Rights 12. Interestingly in the Republic of Ireland the ‘family’ is given constitutional importance: Constitution of Ireland Bunreacht na hÉireann 1937. “The family is the basic unit group of society, its special position in our community is recognised by the Constitution. Article 41, s. 1 states:- 1. The State recognises the Family as the natural primary and fundamental unit group of Society, and as a moral institution possessing inalienable and imprescriptible rights, antecedent and superior to all positive law. 2. The State, therefore, guarantees to protect the Family in its constitution and authority, as the necessary basis of social order and as indispensable to the welfare of the Nation and the State. See also: *In the Matter of A Ward of Court* [1995] IESC 1; [1996] 2 IR 73 at [353]. “This case concerns a ward of court and so the jurisdiction to make the decision in this situation lies with the court and not the family. The mother of the ward is the committee of the ward and her view is shared by the entire family. The family’s view as to the care and welfare of its members carries a special weight. A court should be slow to disagree with a family decision as to the care of one of its number if that decision has been reached bona fides after medical, legal and theological advice and careful consideration.” *In the Matter of A Ward of Court* [1995] IESC 1; [1996] 2 IR 73 at [355].

²⁴⁹ Colin Gavaghan "Saviour Siblings: No Avoiding the Hard Questions" (2015) 41 (12) J Med Ethics 931 at 931.

²⁵⁰ *Janzen v Janzen* [2002] OJ No 450 44 ETR (2d) 217 (Ont SCJ).

her husband's wishes in these circumstances and that she would not have his best interest at heart. I consider it instructive that under s. 20(1) of the Health Care Consent Act, 1996, supra, in the absence of a court order, the spouse of an incapable person is considered to have a higher right than a sibling to give or refuse consent to medical treatment on behalf of the incapable person. I believe this reflects that in the normal course, a spouse will have been more intimately involved than a sibling in the recent life of the incapable person."²⁵¹

This is an entirely reasonable approach to any consideration of best interests, but is, arguably, implicitly based on Mr Janzen's other-regarding interests. Who is he most likely to have the most other-regarding interests for? His wife, and therefore her view should be prioritised over the views of his siblings.

The individual interests of the patient are considered the focus of the best interests test, and any consideration to the interests of the family secondary, which is appropriate. However, this is done by applying a broad stroke which does not consider that the patient can have interests which actually align with the 'family's best interests'. In the following case Ms D may have had other-regarding interests in her family's hope for a miracle; she may have prioritised their hopes over her interest in a dignified death. The point here is not how likely this view is (the veracity of views is discussed in Chapter Five) but the lack of consideration for these interests.

"From the family's point of view, of course, every extra day is worth fighting for and, given what they have had to face in the past few years, no one can have anything but the profoundest sympathy for them in their hope for the arrival of a miracle. But my focus must be on the patient's best interests and not on the family best interests. In my judgment Ms D's best interests demand that she should not be subjected to more than the minimum necessary to allow her to die peacefully and with dignity."²⁵²

Often too the family's interests are seen as 'emotional', and therefore not objective enough to impact upon a legal decision:

"That understandable concern of the members of his immediate family adds its own dimension of sadness to the overall situation with which the Court is called upon to deal, and makes it particularly important that in coming to grips with the issues on the present application, the Court take care not to be inappropriately distracted by feelings of sympathy, entirely proper and logical feelings of sympathy, for the plight of the members of Mr Krommydas's family. They are entitled to express their views as they have done through their solicitor. They are entitled to have those views given every proper and respectful consideration by the Court. But in the end the way in which the present application falls to be considered depends not upon consideration of that kind,

²⁵¹ *Janzen v Janzen* [2002] OJ No 450 44 ETR (2d) 217 (Ont SCJ) at [42].

²⁵² *The NHS Trust v Ms D* [2005] EWHC 2439 (Fam) at [45] per Coleridge J.

but upon cut and dried considerations of law, and cut and dried findings of fact based not upon supposition or hope, but upon concrete evidence.”²⁵³

Whilst the judge recognised in *Krommydas* that the family views should be considered, the overall tenor of this passage shows that they are in actuality held in relatively low regard. Of course, there is no suggestion here that other-regarding interests should be applied without discretion, and Chapter Seven discusses the difficulties involved with prioritising interests. However, a framework for the consideration of best interests is presented in this thesis which does not simply dismiss other-regarding interests either. This is, perhaps, an even more persuasive point when the child is a minor (the following case dealt with twins who had the same degenerative disorder):

“The father also made the point that withdrawal of life support and the consequent deaths of the children would not affect just him and his wife and their elder surviving son, but also the whole family, most of whom remain in Iraq. I completely understand and deeply sympathise with that point. However, as is clear from the propositions of law quoted above, my decision must be governed solely by the best interests of each of these children themselves. I cannot ultimately be influenced by the obvious impact upon, or sympathy for, the families.”²⁵⁴

Holman J has overlooked that the impact upon the family might actually be an other-regarding interest of the children in this case. A parent is almost always the person who is closest to the child, and spent the most time with them as recognised by Holman J in a different case, *NHS Trust v MB*.²⁵⁵

Chapter Seven discusses the implications of other-regarding interests with regard to the parental role. However, for the purposes of this chapter it is sufficient to note that, although judges are understandably aware of the impact on families in these cases, mostly this is not manifested as an interest that the patient can have.

²⁵³ *Krommydas v Sydney West Area Health Service* [2006] NSWSC 901 at 4. See also the comment from Dixon J in *Slaveski & Others v Austin Health* [2010] VSC 493 at [3] “I was unable to discern any relevant material facts from the somewhat hysterical and theatrical performance of Mr Slaveski in the course of the hearing that evening.”

²⁵⁴ *Central Manchester University Hospitals NHS Foundation Trust v A* [2015] EWHC 2828 (Fam) at [20].

²⁵⁵ *An NHS Trust v MB* [2006] EWHC 507 (Fam) at [42] per Holman J. “I have to caution myself that she cannot, because of her relationship, be objective; but it is the fact that no one other person has spent so much time with M and been as intimate in their contact with him. I do consider that she is, in various respects, very understandably and humanly, deluding herself. But I considered her to be entirely honest in her evidence; and even if not wholly objectively reliable, considerable weight has to be attached to her account as a source of evidence.”

Community

The focus on the individual, which is unchallenged in its centrality to the best interests test, means that consideration for other-regarding interests is difficult to advance in a way that recognises these interests. Nelson refers to this individualist tradition as one that has consequences for the end-of-life cases.

“[Medical ethics] and medicine’s own ethical tradition are ruggedly individualist: the interests of the individual patient, in splendid isolation from her social context, are to a considerable extent privileged. To be sure, there are powerful reasons for this focus, rooted in our concern about defending the vulnerability and privacy of patients. Yet there is increasing reason to believe that this intensity of focus on patient interests – considered as the interests of splendidly isolated individuals – reflects a kind of moral obtuseness, and that we would do better to design a system of medical decisionmaking sensitive to a broader range of values.”²⁵⁶

Whilst interests relating to families that the courts do recognise are discussed, other-regarding interests that go beyond their friends and family are even more difficult to assert. It does, however, seem plausible to care about people other than those closest to us. For example, people often care about those seen on the news who may be suffering, or starving, or who have lost loved ones. The *solidarity principle* proposes to explain this, but is itself a difficult concept to define.²⁵⁷ Gillett has contributed to this discussion with the following syllogism:

“The solidarity syllogism.

- (1) A human being is a relational and dependent entity, the well-being of whom rests partly on that relatedness and, therefore, on other human beings.
- (2) It is rational and good to enhance the lives of those whose lives contribute to one's own well-being.
- (3) Any human being has a (rational, endorsable) interest in enhancing the lives of other human beings with whom she is in contact. (Call this The Solidarity Principle.)

The solidarity principle is, like any other principle, defeasible and not over-riding in the light of a person's other interests, but it serves as a sound default position from which to begin in reasoning about the dues we owe to others. If it is true then, in principle, we have some interest—a solidarity interest—in contributing to the lives of others when we can do so at no or minimal cost to ourselves. Thus, it posits an

²⁵⁶ Nelson (1992) 22 (4) Hastings Cent Rep 6 at 7.

²⁵⁷ Barbara Prainsack and Alena Buyx "Solidarity in Contemporary Bioethics - Towards a New Approach" (2012) 26 (7) Bioethics 343 at 344.

interest even where the benefits (of solidarity) that underpin it no longer apply to oneself.”²⁵⁸

The last sentence is particularly significant to this thesis, where Gillett refers to an interest in the good of others which does not benefit oneself. Gillett uses the solidarity principle to argue for elective ventilation where the patient has not yet been declared dead and consequently the ventilation is solely for the purpose of facilitating organ donation. This solidarity interest endorses the view that other-regarding interests exist, but also elevates it to a positive principle that we actually owe others a duty to enhance their lives where it does not negatively affect our own interests. Gillett also posits that this principle is defeasible, but states that there is a presumptive case for donating, whether or not the person involved expressed a preference to do so. Where the person involved had a strong subjective interest in not donating, then:

“It would also be instructive to see whether such a subjective antisolidarity interest was reasonable (in some intuitive sense).”²⁵⁹

This seems to be a claim that people *ought* to have such interests, not necessarily that they actually *do* have them. Or maybe that we should *assume* the existence of such interests? The inclusion of reasonableness into the standard may be requiring too high a level of beneficent action. It also assumes that being ventilated for the sole purpose of organ donation does not negatively affect that individual’s interests – which could be disputed. This is especially true if we extrapolate from the current model of autonomous decision-making in healthcare, which allows for refusal of consent for any reason for any procedure whereby it is explicitly stated that reasonableness or rationality is not necessary.²⁶⁰ The standard may also escalate too quickly from wanting to enhance the lives of those who have contributed to our well-being, to enhancing the lives of any others with whom we are in contact.

However, Gillett’s solidarity principle asserts that it is possible to have interests about others beyond any awareness an individual might have, and that this interest is one that is vested in the community of others around us:

²⁵⁸ Grant Gillett "Honouring the Donor: in Death and in Life" (2013) 39 (3) J Med Ethics 149 at 150. The contribution that the solidarity concept can make was also emphasised in a Keynote presentation by Dawson (Paper presented at the Working with Diversity: Bioethics and Health Law Conference, Wellington, New Zealand, 25-28 June 2015). Professor Dawson argued for solidarity as a way to explain why we care about others and why we are socially embedded.

²⁵⁹ Gillett (2013) 39 (3) J Med Ethics 149 at 150.

²⁶⁰ See Chapter Four for an extensive discussion on competence.

“... to act consistently with the solidarity principle we can all be deemed to have, we should support measures that enhance the likelihood that it will be served by decisions made about us when we can no longer be part of them and are beyond any adverse consequences they might cause.”²⁶¹

But does this necessarily mean that we have other-regarding interests not just to those closest to us, but also other-regarding interests in our community? This is also expressed in the notion that our identities are only understood in a wider context of our communities. Sperling addresses this idea when he discusses the concept of the ‘social self’:

“The idea is that the self originates in a social context and becomes aware of itself only after communication with another is enabled.”²⁶²

The view that an individual can only be explained in relation to a community is important in many cultures:

“individuality is not found in ‘textbook’ cases but in the social and cultural aspects of the people involved in the situation; individuals are created and discovered in relation to others – that is, to communities.”²⁶³

If the idea of solidarity is accepted, where does that fit with a notion of altruism? In some accounts they share characteristics, but altruism is described as a general principle compared to the practice of solidarity:

“Solidarity might also share features with the concept of altruism, but again, there are important differences. Altruism is a more general attitude towards (all) others, whereas solidarity comprises concrete practices within a community of people who are sharing certain things in common. The outcome may well be the same, but the motivations differ: I may help someone because I am motivated by a sense of altruism, and thus generally think that it is important to help others without thinking of my own benefit, or I might help someone because I recognize sameness in a relevant sense with her and I am thus enacting solidarity.”²⁶⁴

There have been few cases in the end-of-life context which have discussed the notion of altruism. This is possibly because it seems inextricably linked to resources, and any consideration of resources gives the impression of going against the patient’s best interests:

“I have considerable difficulty with application of such a test in the circumstances of a proposed withdrawal of treatment case such as the present. However, I do accept that such a test can properly be applied in a case such as the present if the matter be viewed negatively, namely that it is not in the best interests of the patient to be kept alive by artificial means, where the court is satisfied that the diagnosis is so clear and

²⁶¹ Gillett (2013) 39 (3) J Med Ethics 149 at 150.

²⁶² Sperling (2008) at 43.

²⁶³ D Micah Hester *Community as Healing: Pragmatist Ethics in Medical Encounters* (Rowman & Littlefield, Maryland, 2001) at 6.

²⁶⁴ Prainsack and Buyx (2012) 26 (7) Bioethics 343 at 348.

the prognosis so futile that the ward truly has no interest in being kept alive. Parliament will no doubt require to grapple in due course with the thorny problems of implication of altruistic sentiments and the relevance, if any at all, of interests other than those of the patient.”²⁶⁵

Sir Thomas Bingham MR was the lone judge in *Bland* to consider the possibility that the patient could have an interest in altruism:

“[An] account [of the individual’s best interests] may be taken of wider, less tangible considerations ... even, perhaps, if altruism still lives, to a belief that finite resources are better devoted to enhancing life than simply averting death.”²⁶⁶

It is interesting that he was the only judge to address this directly; however he had little to say beyond this as the National Health Service (NHS) had invited the court to consider the issue as if resources were unlimited. This in itself is indicative that the medical profession (and by association the judiciary) are very careful to avoid the perception that decisions are made based on where limited resources could best be used. This is undoubtedly divorced from the reality of all healthcare situations, which is of course that money, medical practitioners and hospital beds are all finite, and resource decisions must be made daily on both a micro and macro level.

In the New Zealand case of *Shortland*, resources were more transparently the issue, as the treatment decision was about kidney dialysis and the judge found that the basis for the decision-making was unclear:

“It is not clear to me whether the decision to cease dialysis was made on the basis of a judgment that it was not in Mr Williams’ best interests or whether it was based on an assessment of where scarce resources should best be used.”²⁶⁷

In England and Wales the best interests standard under the MCA 2005 can apply to property, and in *The Matter of G (TJ)* the judge recognised that the patient had altruistic interests:

“These various references to gifts, lifetime and testamentary, and settlements for the benefit of others, suggest to me that the word “interests” in the phrase “best interests” is not confined to matters of self interest or, putting it another way, a court could conclude in an appropriate case that it is in the interests of P for P to act altruistically.”²⁶⁸

²⁶⁵ *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235 at 866 per Thomas J. See also *Rasouli v Sunnybrook Health Sciences Centre* [2011] ONCA 482 (CanLII) at [33]; *R v Cambridge District Health Authority Ex Parte B* [1995] EWCA Civ 49; [1995] 1 WLR 898.

²⁶⁶ *Airedale NHS Trust v Bland* [1993] AC 789 at 813.

²⁶⁷ *Shortland v Northland Health Ltd (Unreported)* M75/97 NZHC 732 at 13 per Salmon J.

²⁶⁸ *In The Matter Of G (TJ)* [2010] EWCOP 3005 at [35].

Property and life or death matters are, however, very different. A patient could, however, have altruistic interests of their own; altruism does not necessarily have to be an objective interest that everyone should have. That we can have altruistic interests of our own seems a far less controversial claim than that we have objective interests in the welfare of others.

An Overlap of Interests

Ways of Being Remembered by Family

There are also other-regarding interests that a permanently incompetent person can have, some of which can be categorised as self-regarding. Whilst at first this seems counter-intuitive, the following example demonstrates how it can work.

Mark Darcy has a secret. He met his wife Elinor after she had run away from her abusive husband, bringing their one year old daughter Marianne into hiding with her. Mark raised Marianne as his own daughter, and Marianne thought that Mark and Elinor were her biological parents. When Mark was diagnosed with terminal cancer he thought about telling Marianne the truth, but decided that he wanted her to remember him as her Dad for not only his sake, but also for hers. He did not want to diminish any of the memories that she had of him and did not want to add to her suffering.

In this scenario, Mark has a self-regarding, surviving interest in the way that he is remembered after death as Marianne's Dad. However, there is another aspect to consider here, and that is the other-regarding interest Mark has in how Marianne remembers him for her *own sake*. This other-regarding interest arises because people care for their loved ones and the memories they have of them with consideration of their loved ones' interests, not just their own. A non-experiential interest in being remembered a certain way after death is not always both self-regarding and other-regarding, but it may be and it should be considered as a possibility. The right to be well regarded is one that is protected by the law, as stated by Sperling:

“In addition to these legal cases, there are some legal areas in which one can find support for the idea of the interest in the recognition of one's symbolic existence. With regard to the living, and in some jurisdictions also to the dead, defamation law and the law of privacy protect a person's interest in maintaining her good name”.²⁶⁹

Therefore, a person can have an interest in how they are remembered after they are dead; this interest can be a self-regarding, non-experiential interest that they had while competent (expressed as an after-life interest by Sperling and a surviving interest by Feinberg). This is

²⁶⁹ Sperling (2008) at 46.

an interest that is fairly common. Most people if asked would probably express a desire to be remembered after death in a particular way that resonated with the person that they were during life. For example, a mountain climber may want to be remembered as someone who loved the outdoors and a challenge. In this thesis however the idea is taken further by suggesting that an interest in how a person is remembered can also be other-regarding; it does not necessarily need to be predicated on how the particular person wants to be remembered, it can also be based on consideration for others' interests.

Butler-Sloss LJ in the Court of Appeal identified this distinction in the *Bland* case:

“He retains in my view the right to be well regarded by others, and to be well remembered by his family. That right is separate from that of his family to remember him and to have the opportunity to grieve for him when he is dead.”²⁷⁰

Although, again, she discussed this in terms of ‘rights’ (which could require too high a threshold) she nevertheless recognises that there are different interests, and that these are self- and other-regarding.

Family’s Views Respected

“S described how he and other family members had concluded that what M would have wanted was to ‘put an end to her suffering’. He stressed that he was not seeking to alleviate his own distress. ‘It’s not about us. We’re irrelevant. I could only speak up for her, knowing her views and opinions. We’re her voice’.”²⁷¹

There is also a self-regarding, non-experiential interest in wanting your whānau to have their views considered. This is probably more significant than an interest in how the patient is remembered because it has implications for the patient’s current care. As a competent person I can say that if I became incompetent I would want my whānau’s views on what should happen to me to be considered, as they know me the best, and it is for *my* benefit that their views are known. This is separate from the other-regarding interest I have, in wanting them to have their views considered for their own sake.

Harriet Jones is pregnant. She says to her husband – “if anything happens to me over the next few months please keep me alive on a ventilator if it means that the baby might live. I want my baby to have a chance at life. And I don’t want you to lose me and the baby.”

²⁷⁰ *Airedale NHS Trust v Bland* [1993] AC 789 at 822.

²⁷¹ *W v M* [2011] EWCOP 2443 (Fam) at [121].

If something happens to Harriet, leaving her in a permanently incompetent state, it could be said that she had an interest in being kept alive artificially while pregnant, an interest that was expressed previously to her husband. This is a self-regarding, surviving interest which is separate from the interest she has for the baby to live, and the interests that her husband has for himself.

A person's interest in their whānau having their views respected regarding treatment decisions is a self-regarding interest. One reason that a person may want their whānau's views taken into consideration is because the whānau are the most likely to know what, if any, views the permanently incompetent person may have held on possible treatment considerations.²⁷² This is linked to a respect for the patient's autonomy, and is something that is discussed extensively in Chapter Five. However, it is important to note here that there is a distinction that can be made in relation to these views, a way of interpreting them that means that the family's views are taken into consideration as an other-regarding interest. A person can want their family's views respected in end-of-life treatment decisions because they want whānau to have influence on the decision-making, which perhaps is a way of recognising that their loved ones are more affected in some situations than themselves.²⁷³ The views of family for those who have not been previously competent will be examined in more detail when discussing parental views.²⁷⁴ There is, therefore, an other-regarding interest that a person may have regarding their family's views being respected, not just because of the possible benefit to the person, but because the close relationship reflects that they do have a valid view on any treatment decisions and these treatment decisions should not be made in isolation from this.

In clinical practice the family's view is an important one, and it is one that the medical profession does take seriously. For example, in New Zealand the family does not have a legal right to veto an organ donation from somebody who has indicated that they would like to donate organs. In practice, however, the medical profession are reluctant to override a

²⁷² Obviously this could only apply to those who were previously competent. Competence is discussed in the next chapter, and then Chapter Five presents a discussion of prior views.

²⁷³ In some cases a person has appointed their own substitute decision-maker from their friends or family through legally recognised channels, such as an Enduring Power of Attorney under the PPPR Act in New Zealand.

²⁷⁴ This is discussed in Chapter Seven.

family's strong objection to donation.²⁷⁵ There are various reasons for this, namely not upsetting families when they are already going through an extremely difficult time, and not wanting to erode doctor-patient relationships with either that particular family or the wider public. Not only is this an example of the medical profession giving credence to family's views, it is also an example of a no-longer competent person's autonomy being overridden for reasons that are not based on the person themselves, but others close to them. This is a potentially meaningful example for later chapters as it demonstrates the importance of family, and it is also an example of what Harris argued, that a person-affecting interest is more important than a surviving interest.²⁷⁶

In many cases, it is the family who are the instigators in bringing the case to court, as they disagree with the approach that the medical practitioners have taken. *Northridge* is one of the most extreme examples of a breakdown between family and the medical profession, and an aberration in the cases canvassed.²⁷⁷ This Australian case was characterised by extremely poor communication between physicians and family; at one stage it is alleged (and the doctor accused of doing so did not deny it) that, in response to requests for the resumption of antibiotics for the patient, he pointed to the patient Mr Thompson and said "What's the point?".²⁷⁸

Lord Goff discussed the distinction between the actual indignity, and the perception of the indignity:

"It is reasonable also that account should be taken of the invasiveness of the treatment and of the indignity to which, as the present case shows, a person has to be subjected if his life is prolonged by artificial means, which must cause considerable distress to his family – a distress which reflects not only their own feelings but their perception of the situation of their relative who is being kept alive."²⁷⁹

This introduces some quite subtle and ramified ideas. First, there is the actual indignity of the patient, and there is also the distress the family feels in experiencing the artificial prolongation of their loved one's life. Additionally, there is the *perception* of the indignity

²⁷⁵ Martin Wilkinson "Individual and Family Decisions about Organ Donation" (2007) 24 (1) J Applied Phil 26. at note 5: "It is widely known that in the UK, the USA, New Zealand, and elsewhere, families do have the power to veto individual wishes to donate. However, this power is a medical rather than a legal creation."

²⁷⁶ Harris (2003) 29 (3) J Med Ethics 130.

²⁷⁷ *Northridge v Central Sydney Service* [2000] NSWSC 1241. There appeared to be more goodwill on behalf of the medical profession in the breakdown demonstrated in *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam).

²⁷⁸ *Northridge v Central Sydney Service* [2000] NSWSC 1241 at 555.

²⁷⁹ *Airedale NHS Trust v Bland* [1993] AC 789 at 869.

which is being visited upon that loved one, which raises an interesting question as to whether this is really just another reference to the indignity of the patient, or whether the perception of an indignity is an additional concern. Regardless, it does exemplify the point that there are interests which can be separated into self-regarding, non-experiential (Mr Thompson and Anthony Bland suffering indignity) and the other-regarding view of the patient's family seeing him being subjected to the indignity.

Taxonomy of Interests

Using this extensive discussion it is possible to summarise and categorise all the various interests discussed in this chapter.

1. *Welfare Interests*
Self-Regarding interest
Not valuable for themselves, but instrumentally valuable for the satisfaction of other interests. For example, a basic standard of health.
2. *Future-Orientated Interests*
Self- or Other-Regarding interest
Critical interest
Surviving interest
Interests that do not correspond to anything a person values or cares about now, but which relate to things that they are likely to value later.
3. *Awareness-Dependent Interests*
Self-Regarding interest
Experiential interest
Interests that do not survive death or total loss of physical or cognitive awareness. For example, an interest in avoiding pain. In some accounts (not the one proposed in this thesis) an interest in dignity belongs in this group.
4. *Value-Dependent Interests*
Self- or Other-Regarding interest
Precedent interest
Only applicable to those who have – or have had – relevant values. Can potentially survive death.
5. *Collective Interests*
Interests that are shared interests, for example infants having an interest in their family's wellbeing. The family unit is seen as being more than just an 'other', but something of which the individual is a part. Collective interests can be described as straddling the self-regarding and other-regarding categories, and can be objectively applied based on future-orientated interests. Collective interests not based on future-orientated interests are more controversial, as they more closely resemble an ideal interest.

6. *Ideally Motivated Interests*

Self- or Other-Regarding interest

Critical interest

Interests that are linked to a sense of good. For example, an interest in doing the right thing, or being the right sort of person. Possibly the most controversial of all interests if applied as an other-regarding interest as it then risks conflating interests and duties.

7. *Objective Interests*

Self- or Other-Regarding interest

Critical interest

Interests that everyone has regardless of either being aware of having any interests, (unlike category 3) or having been capable of valuing anything (unlike category 4). This is a crucial category as any recognition of objective interests is essentially recognising that a human being has interests merely by virtue of this status. If there are objective interests then they are not dependent on a person's state of awareness. Two self-regarding interests could also be called objective: an interest in dignity and an interest in avoiding prolonged suffering. An interest in not suffering is an experiential interest, the person must be sensate. However, dignity is an interest that is more disputed. Does a person need to be aware of their own dignity to have an interest in it? Although in one case this was ruled necessary, mostly it has been recognised as independent from awareness by the courts.²⁸⁰ It is contentious to have objective, other-regarding interests.

Summary of Chapter Three

This chapter has discussed the various kinds of interests that people can have. This thesis places a particular emphasis on the distinction between self-regarding and other-regarding interests, a distinction that I have suggested has been under-discussed in the literature to date. Essentially people may care about other people: (1) for the sake of those other people; (2) because the well-being of those other people is related to their own well-being or life plans; or (3) out of some more general sense of altruism. (1) and (3) are genuinely other-regarding, whereas (2) could be instrumentally and indirectly self-regarding. Where there are other-regarding interests, these could form the basis of a presumption about what most people actually have, or – more controversially – a prescriptive statement about what people ought to care about, as advocated by Dworkin. A prescriptive application of best interests would take the test in a very new direction, as it would be including the notion of ideal-regarding interests and ascribing to the incompetent patient interests that they ought to have.

²⁸⁰ See section on “Non-Experiential Interests” for discussion on Butler-Sloss LJ’s positions covering both approaches.

Sometimes the interests a person has, or has had, may depend on what they are currently experiencing, or not experiencing. Feinberg, Dworkin and Sperling all accept that interests are not necessarily dependent on a person's direct experience of them, and that everyone has interests that go beyond those that are directly experienced. There is also agreement that there is a link between how someone lived their life and what interests they may have. What this means is that what the person is, or is not, experiencing, and what they have, or have not experienced in their lives is important in assessing any interests that they may have. In order to do this whether or not they had a previous self becomes a crucial distinction. If someone has been previously competent they will have experienced a life and this should inform and help decision makers decide what the best interests of the incompetent are.²⁸¹ As I discussed in Chapter Two, the prior wishes of an incompetent person are a component of any best interests consideration, and therefore the establishment of categories regarding incompetency are necessary to properly reflect whether or not a person has even been able to previously express any wishes.

In this chapter there has been a discussion of what kinds of interests people may have, and issues relating to competence have been raised: is prior competence equated with more interests? Are the interests that are ascribed to someone who is permanently incompetent different to those ascribed to someone currently competent? The following chapter provides a detailed exploration of incompetence, and provides distinctions regarding the different states of competence.

²⁸¹ The term 'should' is used deliberately here, as this is consistent with the position taken in Chapter Five when discussing the prior views of incompetent patients.

CHAPTER FOUR: DISTINGUISHING BETWEEN DIFFERENT INCOMPETENT PATIENTS

"[A]n analysis of competence determination is one central part of the ethical and legal analysis in a theory of decision making for incompetents."²⁸²

Best interests, as shown in Chapter Two, becomes a decision-making tool in the courts once someone is incompetent and can no longer exercise their own self-determination. Therefore, a person's incompetence is a prerequisite for the use of the best interests test. If a person is not incompetent, then there is no need to make decisions on their behalf. Of course, a person's competence is not a simple determination. There are various accounts of what competence entails, and similar to the use of best interests, there are various ways that competence can be utilised. Is it a legal or medical term? How is it used in end-of-life cases? It is important to understand the concepts of competence and incompetence, because individuals who are incompetent are not all identical in ways which are relevant to determining their best interests; for example, some may be able to experience pain, while others may not. Additionally, and critically, some incompetent patients will have been previously competent and some will not. The example of a patient with dementia, and precedent autonomy, is used to show the difference between previously held interests and current interests; this is further developed in Chapter Five to sometimes be conflated in end-of-life judgments.

It is commonly accepted that there are three states relating to competence that a person can be in: (1) currently competent and able to make their own decisions; (2) transiently incompetent at the time decision-making is required; and (3) permanently incompetent. As described in Chapter One this thesis provides a consideration of permanently incompetent patients within the context of end-of-life decision-making, and this group of incompetent patients is further categorised these into three different groups: (1) permanently incompetent and made prior expressions of their views when competent; (2) permanently incompetent and made no prior expressions of their views when competent, despite having the capacity to do so; and (3)

²⁸² Buchanan and Brock (1990) at 17.

permanently incompetent and made no prior expressions of their views, because they never achieved competence. The differences between these three groups of patients is significant; these categorisations are used in Chapters Five, Six and Seven to indicate that judges have made crucial distinctions about the possible interests that a permanently incompetent person may have based on what group they fall within. In trying to assess best interests of someone who cannot now say what they want (or communicate what they believe their own best interests to be) there is the presumption that what they once would have wanted will be relevant. This focus on previous views (which necessitates that the patient had prior competence) is a legislative requirement, and is further justified by the interpretation that such a focus respects the patient's autonomy. This is problematic, as the question of 'what the patient wanted when they were competent' could be viewed as an attempt to preserve and act upon current autonomy when that autonomy has in fact been lost, as the patient no longer has any ability for autonomous decision-making. It is therefore necessary to examine the important ideas that emerge from a discussion of competence to illustrate the basis for some of the attitudes towards interests and prior views.

Part One: The Concepts of Competence and Incompetence

Difficulties exist regarding the context, the terminology, and the definitions applied, in any discussion of competence. The contextual difficulty relates to a broader debate regarding competence and when a person is, or is not, competent, and when a person can, or cannot, participate in the informed consent process. This is not of particular relevance to this thesis, except insofar as this broader debate has established that the concept of competence can be more deeply understood as being pertinent to decision-making for specific tasks and specific decisions. The following section outlines the importance of informed consent in order to provide a background for the discussion of competence in the healthcare setting.

The issues around terminology primarily concern the words *competence* and *capacity* when discussing a person's ability to make their own decisions. Do competence and capacity apply to the same concept or do they have different meanings? In this thesis the position is taken that they are interchangeable, but that the separate components of the concept – whichever term is used to label it – need to be understood in order to understand the concept as a whole.

Relating to the fact that competence has requisite components, there has been some debate over what these should include. The components which are universally agreed upon are the ability to communicate, to understand information, and to reason and deliberate. It is not always accepted that there should be a requirement that a person has a set of values, or sense of good, included in the requirements for competence. A framework is proposed in this chapter which accepts values as a component of competence, arguing that it is not only necessary, but also important for any determination of a person's best interests. This may seem like an exaggerated claim at this point, but it is proposed to show how this is linked to what we understand of a person, and their views, and how this can subsequently be used to assess their best interests when they are incompetent.

These difficulties are discussed in Part One, with a focus on acknowledging the complications and utilising the discussion as it relates to the permanently incompetent patient.

Informed Consent

In the health care setting, the accepted ethical practice from a medico-legal point of view is that every patient has the right to make decisions about their own body and health care treatments. This means anyone has the right to consent to, or refuse, treatment. This is a right that is enshrined in all four of the legal systems considered in this thesis, as summarised by the following maxim:²⁸³

“every human being of adult years and sound mind has a right to determine what shall be done with his own body”.²⁸⁴

In end-of-life cases, substitute decision-makers are therefore appropriating this basic right accorded to everyone, and this partly explains why it is such an onerous duty. This basic right is not, however, applied indiscriminately, and is dependent on the person actually being able to give or withhold informed consent to any health care treatment or investigation. In order to be able to consent the person must give *informed* consent. Informed consent is a process in which both the individual and the medical practitioner participate, and it is considered to be the foundation for respecting the autonomy of the patient. It is generally

²⁸³ Jeanne Snelling, Lynley Anderson and Andre Van Rij "Incidental Findings" During Surgery: A Surgical Dilemma or the Price Paid for Autonomy? " (2013) 13 (1) Otago L Rev 81 at 83. "The fundamental maxim eloquently quoted by Cardozo J is one of those most commonly reiterated in medical law texts".

²⁸⁴ *Schloendorff v Society of New York Hospital* (1914) 211 NYR 125 at 129.

accepted that the informed consent process has three elements: that the individual has (1) been informed of all necessary information; (2) has given consent voluntarily; and (3) is competent to make the particular decision where competence includes components of: (a) communication and understanding; (b) reasoning and deliberation; and (c) (in some interpretations) a set of values or concept of the good.²⁸⁵ A person who is determined to have met the threshold of competence required for the particular decision in the informed consent process, is then in a position to be able to make their own decisions.

“Participation in decision-making provides the opportunity to exercise choice according to one’s own values and beliefs rather than receiving treatment through paternalistic imposition of another’s treatment decisions.”²⁸⁶

The permanently incompetent patient therefore cannot participate in the informed consent process because they lack any ability to participate in the three elements comprising the process. While a deeper discussion on precisely how the informed consent process is approached by health professionals is not merited in a thesis focusing on permanently incompetent patients, it is appropriate to note that there is little controversy over the central role of informed consent in the health care setting. The next section of this chapter focuses on the components required for competence and what it means to find that someone is, or is not competent, before Part Two discusses the categorisation of incompetent patients.

Competence and Capacity

Until now the terms competent and incompetent have been principally used in this thesis, but the term *capacity* is widely referred to in this area. Competence and capacity have the shared meaning of “the ability to perform a task”.²⁸⁷ Both of these terms are used when considering if an individual has decision-making abilities, and both are used when discussing the ability for autonomous decision-making. Since there is a lack of clarity regarding these two terms, including if indeed there actually is any difference between them, some possible interpretations are briefly examined here. This section concludes that there is little difference in the way that the terms are used, both medically and legally, and that little rests on what

²⁸⁵ Some discussion focuses on four elements; see Beauchamp and Childress (2001).

²⁸⁶ Patricia Peppen "Informed Consent" in Jocelyn Downie, Timothy Caulfield and Colleen M Flood (eds) *Canadian Health Law and Policy* (LexisNexis Canada, Markham, Ontario, 2011) at 153.

²⁸⁷ Tom L Beauchamp and James F Childress *Principles of Biomedical Ethics* (7th ed, Oxford University Press, New York, 2013) at 115. The authors use this to describe competence only but the meaning is extended to capacity here based on its common usage.

term is used – the important part is to identify what it means for a person to be competent, or to have capacity – and therefore the terms are interchangeable.

In some discussions regarding a lack of ability to consent, the distinction has been made that competence is a legal term which is assessed by the courts, and that a person either is, or is not, competent. In those discussions, capacity is discussed as a term that is used for decision-making as assessed by health professionals. This position is outlined by Grisso, who surmises that there is little practical difference:

“Most authors distinguish between assessments of *decision-making capacity*, which health care professionals can conduct, and *determinations of competence*, which are legal judgments left to the courts. Although technically correct this distinction seems to break down in practice. When clinicians determine that a patient lacks decision-making capacity, the practical consequences may be the same as those attending a legal determination of incompetence.”²⁸⁸

In legal and bioethical commentary there are also different viewpoints presented. In *Health Law in Australia*, one of the earliest books to comprehensively discuss Australian medical law, the authors note that there are divergent views as to whether there is a distinction between capacity and competence, observing that the courts seem to suggest an important distinction.²⁸⁹ The Australian text itself does not distinguish between the terms. In *Medical Law in New Zealand* the authors state that the same legal concept is at issue with both competence and capacity, and disagree with the conclusion in *Health Law Australia*, stating that neither case nor statute law reflect any distinction.²⁹⁰

As a result of the ambiguity in the application of competence and capacity this thesis follows the New Zealand approach that the terms can be used interchangeably. This is also how the terms are used in legislation: Right 7 (Right to Make an Informed Choice and Give Informed Consent) in The Code of Patient Rights refers to competence; however the PPPR Act uses both competence and capacity to denote the same legal concept.²⁹¹

²⁸⁸ Thomas Grisso and Paul S Appelbaum *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals* (Oxford University Press, 1998) at 11. Emphasis in original.

²⁸⁹ White, McDonald and Willmott (2010) at 151. “There is also judicial authority which suggests that there is an important distinction between the terms, namely that an individual is ‘competent’ when he or she has ‘capacity’ to make a decision, *and* the ability to communicate that decision”. Emphasis in original. The authors cited as the judicial authority for this statement: *Burke v General Medical Council (Official Solicitor and Others Intervening)* [2005] EWCA Civ 100.

²⁹⁰ Skegg and Paterson (2006) at 172.

²⁹¹ Protection of Personal and Property Rights Act 1988. See the section in this chapter titled: “Capacity to Understand, Reason and Communicate a Decision” which sets out s 93B in full; it refers to both competence and capacity.

In the following section, the specific components that are required for competence are explored, and the need for a set of values included in this requirement is further discussed.

Components Needed for Competence

The usual state of being for most of us is that we are competent and are able to make our own decisions, not only about our own healthcare but also about all aspects of our life. We can choose to live our lives doing what we perceive to be in our own best interests, or, crucially, what is not in our best interests. As mentioned previously, competence is one of the three elements of informed consent and it has requisite elements. Buchanan and Brock discuss three components necessary for a person to competently decide about their health care: “capacity for understanding and communication”, the “capacity for reasoning and deliberation”, and the possession of “a set of values or conception of the good.”²⁹² The authors therefore advocate an approach which acknowledges several components or elements required for competent decision-making. This multi-faceted approach is usual; however the reference to a set of values is not always present. For example, Beauchamp and Childress’ standards of competence omit this condition; their three kinds of abilities required for competence focus on the ability to formulate a preference, the ability to understand information and appreciate one’s situation, and the ability to reason through a consequential life decision.²⁹³

It is often assumed that people make decisions in line with their best interests. But this is not necessarily true and it is not necessarily as simple as that would suggest. Sometimes people do things that are not obviously or entirely in their best interests, for example prioritising short-term gain (dessert) over long-term gain (weight loss).²⁹⁴ Further, some people may choose to place someone else’s interests above their own. In the last chapter, the conclusion that was advocated was that there are other-regrading interests, a standard example being a mother experiencing difficulties during labour, whose choices are made for the safety of the baby, not herself. Competence denotes only that autonomous beings are capable of making their own decisions, leaving it possible that these decisions are irrational, nonsensical, or contrary to what might be perceived by others to be in that person’s best interests. For

²⁹² Buchanan and Brock (1990) at 23.

²⁹³ Beauchamp and Childress (2013) at 118.

²⁹⁴ Feinberg might describe the dessert as a “want” not an “interest”; however Dworkin would probably describe it as an “experiential interest”. It could also be described as competing interests, however the *best* modifier to best interests suggests that healthy eating or necessary weight loss is preferable to dessert.

example, if someone wants to go swimming in a river beside a large sign saying ‘warning hungry crocodiles’ it may be a competent decision, despite the questionable rationale (the person may relish risky activities). However, while it is accepted that people who are competent are permitted to make any foolish decisions, if they are not competent then there are protections in place. One form of this protection is for others who are competent to make decisions for them; in the Commonwealth jurisdictions this means to decide in someone’s best interests. As explained in Chapter Two, this can be traced back to the *parens patriae* jurisdiction of the courts.

Sometimes the capacity to make decisions may fluctuate. Any or all of the components of understanding, reasoning or communication may vary depending on the underlying cause of the impaired capacity. There are four main types of conditions that adults can have which may cause a lack of capacity: organic brain disorders (such as dementia), intellectual disability, acquired brain injury and mental illness.²⁹⁵ It is important to note that, if a person has any of these conditions, it does not automatically render them incompetent. In fact, often the person will be able to exercise their ability to consent, or refuse consent, to health care procedures. This is because the components necessary for informed consent are not binary – either present or absent – but instead present to varying degrees. We all understand, reason, and deliberate to differing degrees, with differing levels of skill and mastery.

Competence is also task-specific. Buchanan and Brock discuss competence as *decision-relative*; where a person’s competence is related to making a specific decision.

“A competence determination, then, is a determination of a particular person’s capacity to perform a particular decision-making task at a particular time and under specified conditions.”²⁹⁶

What this means is that a person may be competent to make one sort of treatment decision but not competent to make another sort of treatment decision. Additionally, a person may be competent to make a treatment decision one day, but the next day they may not be.

Beauchamp and Childress describe competence judgments as serving a ‘gatekeeping role’ for the decisions that patients may make. When a person meets the required threshold of competence, then the gate is opened to the patient being able to determine his or her own health care. This imposes an obligation of the health professional to honour that person’s

²⁹⁵ White, McDonald and Willmott (2010) at 151.

²⁹⁶ Buchanan and Brock (1990) at 18.

choice. However if the person is assessed as incompetent to make the decision because they have failed to reach the threshold of required competence, there is then no such obligation and the health professionals may choose to ignore or override the person's choice. The gate to choice is closed to that person and others must make the decision on behalf of that person. This means that decisions made by an individual should be accepted – or not – depending on the individual's level of capacity to understand and decide their own health care issues. If the individual is incompetent it is permissible for the health professionals to override the decision and to move to other mechanisms for decision-making (dependent on the jurisdiction), such as using surrogate decision-makers or approaching the courts for assistance.²⁹⁷

Capacity to Understand, Reason and Communicate a Decision

The first component that Brock and Buchanan discuss as a requirement for competence is the requirement for both capacity *and* the ability to communicate this capacity. This dual requisite is central to understanding the components needed for competence. Decision-making *capacity* is different from the *ability* to communicate that decision. Decision-making competence is therefore constituted by a set of capacities and possessions, where a person can have capacity for understanding and reasoning and deliberation – but if they cannot demonstrate their ability to do so then it is not possible for them to be considered competent. One of the end-of-life cases from New Zealand provides an example of the importance of communication; the patient had Guillain-Barré syndrome and may have been cognitively aware (and potentially may also have had capacity for understanding and reasoning and deliberation) but had no ability to communicate anything at all. The patient was therefore necessarily deemed incompetent.²⁹⁸ Conversely, somebody with advanced Alzheimer's disease or severe intellectual disability could have the opposite problem – they would probably lack capacity to understand, appreciate and reason, but may still retain the capacity to communicate. Consequently, they might be deemed incompetent on the grounds that the communication does not represent a decision made with sufficient cognitive capacity.²⁹⁹

²⁹⁷ Beauchamp and Childress (2001) at 69.

²⁹⁸ *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235. There was no discussion of the implications of the patient being (possibly) cognitively aware. This is discussed in more depth in Chapter Six. For a competent refusal of treatment see *Re AK* [2001] 1 FLR 129. The patient in this case had locked-in syndrome, but through an infinitesimal movement in one eye could convey his wishes for withdrawal of treatment.

²⁹⁹ There have been many advocates for interpreting 'basic' levels of communication from those lacking capacity to mean an expression of views, for example, repeated removal of feeding tube or refusal to eat

The MCA and PPPR Act both require that a person has the ability to understand information, and use that information, for decision-making competence. As explained in Chapter Two, the preeminent legislation in the England and Wales dealing with incompetent adults is the MCA which, as the title denotes, discusses capacity, and describes a person lacking capacity when they are unable to understand, retain, use or weigh that information or communicate their decision.³⁰⁰ In New Zealand under the PPPR Act a person is presumed, until it is shown otherwise, to be: (1) competent to manage their own affairs; and (2) have the capacity to understand information relating to their situation, foresee consequences and communicate decisions about those matters.³⁰¹ This also fits within the “gold standard of capacity assessment”³⁰² the ‘MacCat T’ test which outlines four components: the ability to express a choice, that the person understood the information, that the person appreciates the significance of the information and the person is able to reason.³⁰³

Impairment in any one of the components does not necessarily make the person incompetent to make any and every decision. This is because impairment may be a matter of degree, and a component may be only mildly impaired. Significant impairment, however, in any of the components can result in that person being deemed incompetent. This is particularly true of the capacity to communicate because communication is essential for two reasons: (1) in order to determine the person’s ability to understand, reason and deliberate; and (2) so that the person can communicate their choice.

meaning that they wish to die. For one example, see Muriel R Gillick "Rethinking the Role of Tube Feeding in Patients with Advanced Dementia" (2000) 342 (3) N Engl J Med 206.

³⁰⁰ Section 2 – People who lack capacity: (1) For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain. Section 3 – Inability to make decisions: (1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable – (a) to understand the information relevant to the decision, (b) to retain that information, (c) to use or weigh that information as part of the process of making the decision, or (d) to communicate his decision (whether by talking, using sign language or any other means).

³⁰¹ Section 93B (1) For the purposes of this Part, every person is presumed, until the contrary is shown, – (a) to be competent to manage his or her own affairs in relation to his or her property; (b) to have the capacity – (i) to understand the nature of decisions about matters relating to his or her personal care and welfare; and (ii) to foresee the consequences of decisions about matters relating to his or her personal care and welfare or of any failure to make such decisions; and (iii) to communicate decisions about those matters.

³⁰² Greg Young, Alison Douglass and John McMillan "Capacity Assessments: A Burden to Doctors or a Benefit to Patients?" (Paper presented at the Bioethics Seminar Series, Bioethics Centre, Dunedin, 23 March 2015).

³⁰³ Grisso and Appelbaum (1998).

Possession of a Set of Values

The notion that a person must possess a set of values, or a sense of ‘good’ as part of the criteria needed for competence is a contested issue. The position in this thesis is that it might not be explicitly included in some accounts but that it has to be implicitly present. How can a person reason and deliberate about consequences, and make choices based on these deliberations, if not by considering what would be a good outcome or a bad outcome? Any balancing of a ‘good’ or ‘bad’ outcome has to be informed by their own values. For example, when a person is considering an outcome that is continued life at any cost – whether this is a ‘good’ or ‘bad’ outcome is wholly dependent on that person’s own viewpoint.

The ability to reason and deliberate is predicated on an ability to understand the information and circumstances, whilst the possession of a set of values, or a conception of what is good, informs the deliberation process to the extent that the decision-maker is able to make decisions consistent with his or her own concept of what a good or bad outcome would be, and what matters most. This set of values must be:

“at least minimally consistent, stable and affirmed as his or her own ... Competence does not require a fully consistent set of goals, much less a detailed ‘lifeplan’ to cover all contingencies. However, sufficient internal consistency and stability over time in the values relative to a particular decision are needed to yield and enable pursuit of a decision outcome.”³⁰⁴

The requirement to possess a set of values is absent from the MacCat T test. It has been included, not only for the reasons already demonstrated, relating it to a logical extension of the balancing of outcomes, but also because, as discussed in Chapter Five, decision-making on behalf of an incompetent person involves an attempt to determine what is in their best interests, and this necessarily requires consideration of their prior interests, values and character when competent. Therefore, it seems artificial to state that, when a person’s competence is assessed, a set of values is not similarly a required factor. This position is bolstered by s 4, para 6 (b) in the MCA where the substitute decision-maker must consider “the beliefs and values that would be likely to influence his decision if he had capacity” in determining the incompetent person’s best interests.

The requirement for a set of values is difficult because it can involve making judgment calls on others’ beliefs. An example of how it could be used in practice is a patient refusing blood

³⁰⁴ Buchanan and Brock (1990) at 25.

products. If this person was of the Jehovah's Witness faith then this could be interpreted as an expression of their value system. If, however, they had no such prior beliefs and the context was such that blood products were potentially life-saving then this decision would warrant further inquiry. It might suggest the person was inadequately informed or had failed to understand the information and circumstances or it might raise serious questions about the person's competence. Using a previous analogy, in the case of the swimmer who ignores the warning about swimming in the crocodile-infested waters, this may accord with their previous dare-devil approach to life, reflecting the value they place on risk and excitement. But otherwise, we may wonder if he was informed (for example, has he seen and fully understood the warning sign), or if his decision-making capacity is undermined, for example he may be drunk. Appropriately, when a person makes an apparently poor decision (not in their own best interests or not consistent with their usual values) this leads to assessment or re-assessment of their competence.

“Discerning whether current decisions are autonomous may depend, in part, on whether they are in character or out of character.”³⁰⁵

A decision not consistent with a person's character is therefore a flag that there might be a problem with competence. Or it might just be a poor decision, or even more simply a decision which we do not understand or agree with. It is often the case that when we judge someone to be competent we are less inclined to think critically about their decisions – but when we think they have impaired competence we tend to judge their decisions more carefully. And when the decision does appear to be a poor one the person's competence should be re-examined whilst remembering that competence varies in degrees. This recognition of the varying abilities of individuals to make decisions and give consent not only respects a person's autonomy, it is also often legally required. New Zealand's Code of Patient Rights is one example of this:

Right 7 (3) Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence.

An added difficulty in incorporating consideration of the person's values into judgments of their competence is that values can, and (debatably) should, change as a person's circumstances change – or at least the values become more informed, or informed from a different perspective even if they do not change. However, we have to allow people to

³⁰⁵ Beauchamp and Childress (2013) at 114.

change what they think is good and bad in relation to themselves, and the outcomes of their choices. What then can be said of a set of values as a component of competence? Choices, by necessity, will be referenced to some sense of good and bad, and what a person values. Judgments on a person's beliefs, whether they are right or wrong, or reasonable or unreasonable, the same as ours or different, is not the goal, and care needs to be taken to ensure that a person's competence is not determined on this basis. The possession of a set of beliefs and the relationship of those beliefs to the decision can be helpful in understanding the decisions people make and should be used to inform any assessment of competence. The *content* of the decision is not the issue, rather the question is whether this content reflects a personal set of *values*, or at least is consistent with the espoused values and beliefs of the person.

Summary of Part One

A person needs to be competent, to the extent necessary, to participate in the informed consent process. Informed consent reflects a fundamental aspect of healthcare; respecting the patient, and their right to make autonomous choices about their own health decisions. An important duty of health care practitioners is to ensure that any decision that a person makes is autonomous, and an important aspect of ensuring this is determining that the person possesses the necessary competence, even if impaired. The terms capacity and competence are used interchangeably in this thesis, to be consistent with New Zealand's usage. Although there is no singular definition for competence it is generally agreed that at least three components are necessary: the ability to understand, to communicate and to reason. This chapter argues that a set of values is also necessary, proposing that any decision that a person makes, and especially healthcare ones, are related in some way to what the person perceives as a good or bad outcome. This also has some value for the healthcare practitioner in determining competence. In Chapter Three various accounts of interests were considered and how these too are linked to a sense of character, a sense of self. This notion of congruence with character is one that is examined in more detail in Chapter Five, as it is integral to many concepts in decision-making processes.

Part One has provided a discussion of how and where competence fits within the wider healthcare picture. Part Two contains a discussion of what this means in relation to the conclusions regarding interests presented in Chapter Three – does incompetence affect the

interests a person has? The answer to this question is a significant determination; incompetence does not negate a person's attributable interests, and prior competence increases the number of possible interests.

Part Two: Interests and the Relationship with Prior Competence

Decision-making, and any assessment of competence, is a difficult process. Decision-making for others also involves complex considerations which need to be understood before discussing end-of-life cases in detail. The last chapter proposed that all competent people have interests that are both self-regarding and other-regarding, but the more pertinent questions for this thesis are: once a person becomes incompetent does this affect the interests that they may have? Which of these possible interests depend on whether they have been previously competent?

The role of precedent autonomy over current interests is one that has implications for the permanently incompetent patient. Part Two of this chapter discusses transient incompetence to provide a point of reference to those who are permanently incompetent. When someone is transiently incompetent the question is: 'what action would the person want the substitute decision-maker to take?'. Furthermore, is this a decision that has to be made now, or could it be deferred until the patient regains competence? This is a very different question to 'what is it in the person's best interests to do', however Chapter Five demonstrates that these questions have, at times, become conflated. The interests that may be attributed to those in a permanently incompetent state depend on whether the patient has been previously competent, because if they have been, then their prior values, views and character can factor into the decision-making process.

Permanently Incompetent Patients

In the end-of-life cases compiled for this thesis, the patient is incompetent with no dispute over this diagnosis, and whether this status is medically or legally decided is irrelevant. In all of the cases the patient is either a significantly cognitively impaired adult or a minor, and they are at the extreme end of the competency – incompetency continuum, with no

controversy over this categorisation. From this group of permanently incompetent patients three possible states relating to their prior competency have been identified:

- (1) Patients who have been previously competent and have expressed views which might be able to guide future decisions in the event of incompetence (*incompetent patients with an explicit prior view*);
- (2) Patients who been previously competent, but whose views are not discoverable (*incompetent patients with a previous self*);
- (3) Patients who have never been able to express views due to their age or lack of cognitive ability (*never able to express views*).

There are three reasons for grouping incompetent patients according to their previous competency. The first is that prior competency generates more possible interests because the patient's life will provide, for example, more possibilities for other-regarding interests, as discussed in the previous chapter. Secondly, there is a legislative difference in many jurisdictions between those who held a prior view and those who did not. Thirdly, the acknowledgment of previous competency and prior views aligns with a perception of respecting the incompetent patient's autonomy. Whilst it is appropriate for prior views to be taken into any account of best interests, proper diligence needs to be shown as to how they are considered, and it is this aspect which forms the discussion in Chapter Five.

Previously Competent

In many of the end-of-life cases the involved patient was a previously competent adult. Prior to becoming incompetent they had lived enough of a life for those closest to them to know something of their interests, values and personality.³⁰⁶ Essentially, they have 'had a life', in the way we understand living a day-to-day life, making their own autonomous decisions.³⁰⁷ This is what is referred to by use of the terminology *previously able to express views*. They had lived enough of a previously competent life such that they had made many decisions for themselves based (at least presumptively) on their own value systems and beliefs. Being previously competent with regards to the best interest test means: (1) this person is often presumed to have made decisions (largely) in line with their own best interests and values – thus their prior decisions provide evidence for what their best interests might be; (2) this

³⁰⁶ Although none of the cases deal with this issue in particular, some older children would also fit into this category.

³⁰⁷ In relation to resource allocation some commentators have placed importance on the 'complete lives system', for example: Govind Persad, Alan Wertheimer and Ezekiel J Emanuel "Principles for Allocation of Scarce Medical Interventions" (2009) 373 (9661) *Lancet* 423.

person may possibly have interests they are not necessarily cognisant of, but which they have developed for various reasons; and (3) this person has possibly developed other-regarding interests through the sorts of things they have engaged with in their lives.

One justification or argument in support of deciding that the permanently incompetent patient does have interests is the finding that individuals have interests developed when alive that survive death. Surviving interests are discussed (and accepted) by Feinberg, and after-life interests are discussed (and accepted) by Sperling.³⁰⁸ In the taxonomy of interests, set out in Chapter Three, it was recognised that surviving interests should form part of the interests that should be taken into account. What does this mean for the previously competent adult who is permanently unable to express any interests? It would seem absurd to say there is a hiatus in terms of interests such that they had interests when they were competent, and have interests that survive their death, but while they are permanently incompetent they have no interests. Therefore, extrapolating from the accounts which assign interests after an even more permanent event – death, it becomes possible to argue that a permanently incompetent patient does have interests. This is qualified by the following points: (1) the interests they have when permanently incompetent are not necessarily the same as those post death (for example an interest in their will being upheld); and (2) the interests they have when incompetent may not be the same as those they had when competent, so that there is a question as to how the interests they had when they were competent relate to the interests they have when permanently incompetent. Chapter Five explores the prior views in depth, providing an extensive proposal for ascertaining the veracity of prior views and beliefs, which shows that these interests are important but that they need to be assessed robustly. To do this the system of grouping these need to be outlined, and this is what is undertaken in Part Two of this chapter.

If a person is permanently incompetent what kinds of interests can they have? If such a person is sensate, they can have self-regarding interests that are experiential; for example, a self-regarding interest in not experiencing pain or in having the best quality of life. There are also self-regarding interests that a person may have regardless of whether or not they can actually experience them. Examples of these are an interest in having dignity maintained, an interest in not being subjected to invasions or humiliations, the manner of dying and (specifically with regards to the previously competent patient) having your previous views

³⁰⁸ Feinberg (1984) at 87. Sperling (2008) at 84. Feinberg and Sperling both use interests in maintaining your good reputation, and having your will executed as you set out, as examples of surviving interests.

considered as to what you would want to happen to you in an incompetent state. All of these interests that have been defined as self-regarding are derived from the three accounts of interests canvassed in Chapter Three. These all acknowledged that there are interests that people have that are ulterior, or critical, or far-lifelong interests; interests that everyone has and, although which apply may depend on the different circumstances, are nevertheless in some measure intertwined with living a life with values, as the person has a stake, an interest in certain things.

Precedent Autonomy

“But I’ll still be me won’t I?”³⁰⁹

It is a common occurrence that competent people submit to being rendered temporarily incompetent when they agree to undergo surgery involving general anaesthesia.³¹⁰ This can pose particular dilemmas if an unanticipated decision is required during the procedure. Consider the surgeon, who upon operating, discovers something unexpected from the initial diagnosis, known as an incidental finding. The dilemma for the surgeon is: should I act on this finding now, especially if by doing so it would mean the patient would not have to undergo another procedure later, or do I not do anything now and work out with the patient what they want to do when they have woken up?³¹¹ Essentially the surgeon, as a substitute decision-maker, is asking the questions: ‘which option would this *particular patient* want me take’, or ‘what is it in their *best interests* to do?’ These are two distinct, albeit related, questions – and the important thing is to be sure which one is the one that is being asked – and how they relate to each other. Whilst the patient’s best interests would be a major component in the factors considered, if the surgeon knew for some reason that the person would not want the option that was in their best interests it seems unlikely that they would carry out the procedure. This is because the person is going to regain competence, and in that

³⁰⁹ Private conversation May 2014. A grandmother expresses her fears on being given a diagnosis of Alzheimer’s disease.

³¹⁰ The medical condition, and subsequent determination of incapacity by physicians, is relied upon for a finding of incompetency by the courts, and therefore carries a significant amount of weight. Often, there is very little discussion about medical condition and the permanence or not of incompetence. Although this may be expected in cases where a patient is in a permanently incompetent state, such as a PVS, a patient in one case did recover to some extent, see *Northridge v Central Sydney Service* [2000] NSWSC 1241. Remarkably, there was little discussion of the possibility in the judgment. The possibility of regaining competence is considered under some legislative regimes, for example Ontario’s HCCA, s 21(2).

³¹¹ Snelling, Anderson and Van Rij (2013) 13 (1) Otago L Rev 81 at 105. “Addressing an incidental finding is a complex issue because it is not foreseeable with any certainty what a patient would wish.”

case it seems reasonable to consider foremost what they would want to happen, and therefore their autonomy trumps any objective view of their best interests.

Conversely, when a person is not going to regain competence, such as the permanently incompetent patients in the end-of-life cases, the question asked is, ‘what is in this person’s best interests?’ This is very different to ‘what would the patient have wanted if they were competent?’ The difference between these two questions lies in the fact that one is a test of best interests, whereas the other is a test of substituted judgment. Chapter Five proposes that these two questions are often conflated, with the answer to their best interests becoming analogous to the patient’s previously held views.

When a person is only transiently incompetent the decision needs only to be made for that point in time, in anticipation of the patient regaining competence and being able to participate again and make their own decisions, and therefore only a short term decision is required. However, if a person demonstrates different degrees of cognitive change, should their previously held views be binding on their future self? An often used example that describes this is a patient with dementia, as illustrated in the case study below.

A person is living a fully autonomous life (P1) – Person 1, (T1) – Time 1.³¹² They then develop symptoms of dementia, notably exhibiting short-term memory loss, and signs of frustration which deteriorates into an inability to live independently. But they still do many things that are consistent with their character such as caring about their appearance and enjoying music, are able to do many things for themselves such as dressing and eating, are able to fully participate in conversations, remember the past, and recognise family and friends (P1 and sometimes P2, T2). At this point they could often consent to many routine healthcare procedures but this may depend on the time of the day (they may be more disorientated in the evening for example). Or perhaps they break a hip and are admitted to hospital (being out of their normal environment is a documented cause of increased cognitive impairment in those with dementia). Eventually at T3 they lose any form of independence, no longer recognise family, and have little recognisable traits of the person they started out as P1 and have now become P2 or P3.

This scenario shows the same person having different cognitive abilities over time, due to progressive cognitive decline. P1 has what we might call full cognitive capacity for consent – the ability to form and communicate autonomous views. P2’s ability to consent has been adversely affected compared to P1, but they retain the ability to communicate views. P3 is obviously the most severely cognitively impaired. P2 and P3’s ability to consent could

³¹² ‘P1, P2, P3’ has been used for the same person over time as this most accurately reflects the difference that the progressive cognitive decline causes.

fluctuate daily or hourly, and be dependent on what the decision was (as discussed in Part One, and described as decision-specific competence by Buchanan and Brock). It could be said that, while P2's ability to consent has been compromised, they may not yet be actually incompetent. Furthermore, different conditions could exacerbate decision-making ability. P2 with a broken hip, who then wants to get out of bed, would not be deemed capable of making that choice. These kinds of competence determinations are difficult, and represent the challenges faced by many clinicians. This difficult scenario is complicated considerably if P1's precedent autonomy (what they wanted at T1) is in conflict with P3's current interests. How much influence should the prior, competent P1 have over the future, incompetent P3?

Dworkin engaged in this debate, famously expanding on an article written by a medical student which described Margo – a woman who was living a happy life, but had advanced dementia.³¹³ What should happen if Margo had stated at T1 that as P3 she did not want to be treated with antibiotics for even a minor infection? Dworkin posed the question of whether precedent autonomy (Margo previously stating that she would not want treatment) should overrule current interests (Margo with dementia was living an apparently happy life). It could have been put to Margo at T1 – but what if you will be happy when you have advanced dementia? And you will die a death where you suffer badly if you do not let your future self receive certain medications? Seemingly, it would be in her best interests to reply, that if that was so, then treatment should be administered. In Dworkin's consideration of Margo's Dilemma he opts for upholding her precedent autonomy, appealing to his notion of integrity (discussed in Chapter Three as being integral to a person's critical interests). Not respecting Margo's previously competent wishes violates her precedent autonomy.³¹⁴ Dresser is critical of this conclusion by Dworkin, and suggests the answer to how Margo's previous wishes are treated lie with different criteria of personal identity theory (as it addresses the conditions of a person persisting over time).³¹⁵ If Dworkin is correct that Margo's precedent autonomy applies, then Margo is the same person at P3 as at P1. If he is mistaken, then another model

³¹³ Dworkin (1993) at 266. referring to the article by: Andrew D Firlik "Margo's Logo" (1991) 265 (2) JAMA 201. It is also referred to in the President's Council on Bioethics *Taking Care: Ethical Caregiving in our Aging Society* (Executive Office of the President, 2005) This case study has become known as "Margo's Dilemma".

³¹⁴ Ronald Dworkin "Life Past Reason" in Helga Kuhse and Peter Singer (eds) *Bioethics: An Anthology* (Blackwell Publishing Ltd, United Kingdom, 2006) at 362.

³¹⁵ Rebecca Dresser "Dworkin on Dementia: Elegant Theory, Questionable Policy" in Helga Kuhse and Peter Singer (eds) *Bioethics: An Anthology* (Blackwell Publishing Ltd, United Kingdom, 2006) at 369. See also the section on "Far-Lifelong Interests" in Chapter Three for discussion on Sperling's Human Subject as a person persisting over time.

of personal identity theory perhaps applies, which argues that the major changes between the person at T1 and T3 has the following consequence:

“Margo’s earlier choices lack moral authority to control what happens to Margo the dementia patient.”³¹⁶

What this means for the permanently incompetent patient is that their prior views on their future incompetence (their precedent autonomy) may be upheld, or might not be upheld, depending on which view of personal identity theory is taken. The one qualification to this is that, in Margo’s case, her *current* interests were able to be ascertained to a greater extent. This is much more difficult with the groups of patients in the end-of-life cases. What Margo’s case does highlight, when considering incompetent patients, is that there is a difference between the interests the previously competent person once had and the interests that the incompetent person has currently. Does the patient have significant experiential interests that need to be taken into account, such as suffering? The role that precedent interests have is an important one in the assessment of best interests, and therefore in the next chapter an extensive proposal is developed for ascertaining the validity of these prior views. The currently incompetent patient will, therefore, have precedent interests, one of these being precedent autonomy. It is therefore important to further categorise what these interests may be, by grouping incompetent patients into those who have previously expressed specific views on future treatment, and those who have not. This distinction is discussed in the following sections.

Incompetent Patients with an Explicit Prior View

The first group of permanently incompetent patients to be discussed are those who previously expressed a specific view. When considering the prior views of somebody who is no longer able to express any current views there are two (very broad) possibilities. One is that the person had views on their current situation which are known, the other is that the person did not have any known views. Therefore, I am proposing that there are two ways that prior views can be interpreted. The first is narrowly, whereby a person’s prior view has to relate in some way to their current condition. This would include a range of possible views with varying degrees of relevance to their condition. The other possibility is a wider interpretation, in which somebody’s prior values and beliefs are taken as prior views. This concept is described by the term *previous self* and refers to someone’s values and beliefs,

³¹⁶ Ibid.

how they have lived their life, and generally the kind of person that they were. Essentially, this is the difference between competent patients who have previously been *able* to express views and either have, or have not, done so. This difference leads to the two ways that prior views can be interpreted, either narrowly or widely.

For the purposes of this thesis, the narrow definition of prior views is applied. This is because it provides a more transparent language around the discussion.³¹⁷ In such circumstances, the now-incompetent patient who has expressed a prior view can have this *explicit view* taken into account, and – this is key – their *previous self* also. Where there is no specific view then it is only the incompetent patient’s previous self which is being considered. When referring to any incompetent patient who was previously competent the term *prior self* is used to cover both of these interpretations.

All competent adults face the possibility that they can be rendered permanently incompetent at some stage in their life, and in all four jurisdictions considered in this thesis any competent adult can appoint a substitute decision-maker to make decisions for them if they become incompetent.³¹⁸ For some permanently incompetent patients who have previously expressed views, these are attestable, well evidenced, views. The textbook example is the patient with a progressive illness, who, knowing what is likely to happen, has written an advance directive with extensive advance care planning. This is one way a competent person can try to ensure their views and preferences are respected and honoured if they become incompetent.³¹⁹ In this situation it should be possible to ascertain their probable prior wishes regarding future provision of treatment, or the withholding or withdrawing of treatment. It is a testament to the medical profession and their expertise with this delicate task that very few cases have been brought to the courts where an advanced directive exists.³²⁰ However, Chapter Five’s discussion of prior views does not require these views to be as formal as, for example, an advance directive. To constitute prior views, the previously held ‘wish or view’ can be as simple or unpremeditated as the following: a person saying to a friend “I wouldn’t like to live like that” in reference to a permanently incompetent person. This stance is in line with

³¹⁷ This is explored further in the section of Chapter Five: “A Proposal to Ascertain Authenticity of Prior Views”.

³¹⁸ See Chapter Two for accounts of substitute decision-makers.

³¹⁹ This is, of course, the aim and not necessarily the reality.

³²⁰ One often talked about example is that of Ms B: *Re B* [2002] 2 All ER 449. However this case differed in one major respect – the patient was competent. It may also be because there are fewer numbers of people with advanced directives.

legislation governing previous statements.³²¹ However, critically, there must be *something* relatable to the person's state when they subsequently become incompetent for it to count as a relevant or significant previously held view, however tenuous the connection may be.³²² Obviously, different weightings should be given to this type of casual statement compared with an advance directive, but it is also not as simple as the advance directive outweighing the statement. For example:

Louisa Elliot had written a formal document ten years prior to her incompetence, stating that no extraordinary treatments should be given if she was in a seemingly permanent coma, but she had since experienced major life changes. She said to her family the week before she became permanently incompetent "I would want treatment for as long as possible".

Which previous, competent view should be taken into consideration? The answer to this question lies in the consideration of interests that should be taken into account, something that is discussed in detail in Chapter Seven.

Therefore, for the purposes of this thesis, the incompetent person with an explicit prior view is a person who was previously competent, who lived a life considering their own interests, and who expressed at some point in time, however tenuous, a view or views about what they would like to happen to them if they became incompetent at some time in the future.

Incompetent Patients with a Previous Self

Within the group of previously competent patients the second group are those who did not make any explicit views regarding what they would like to happen if they became incompetent (or at least any views they might have had are not able to be ascertained). It is therefore their *previous self* that is being taken into consideration. There are a range of individuals who fall within these parameters, as the following example shows.

Jane Bingley is eighteen years old when she becomes permanently incompetent, with little life experience or test of her character or values. Eric Northman is 59 when he becomes permanently incompetent. There had been no major life changes or variations of behaviour in his life recently.

Neither Jane nor Eric have explicitly stated views about their future wishes. Jane's whānau can only surmise from what they knew about her, and how she lived her life, what she *may*

³²¹ See Chapter Two's section on prior views for a summary of the legislation.

³²² In *Scardoni v Hawryluck* (2004) 69 OR (3d) 700 the statement that "where there's life, there's hope" was considered to be a previously held view. It is this level of vague connection that is used in this thesis to qualify as a previously held view.

have wanted. Eric's whānau can point to certain traits that Eric possessed, and a steadfastness of character as the basis for their opinion about what he would have wanted. An earlier battle with a life-threatening illness, for example, where he 'never gave up' could point to an attitude of preparedness to deal with suffering. This is in contrast to the case of Jane, who at eighteen may find it more difficult to possess a level of certainty in her character, and it may also be harder for others to extrapolate values from her life. However, there is recognition in both legislation and common law that the person's prior beliefs, personality and character, can be used to ascertain what they may have wanted, including what they believed to be in their best interests. This is what is referred to in this thesis as their previous self. If the starting point for assessing an incompetent person's best interests is their prior views, and there is a low threshold for what these views constitute, then there is an obvious consequence which is to incorporate the patient's character and values into the test for their best interests. This is examined in detail in Chapter Five.

With the group of patients who have no explicit prior views, a vacuum is created whereby their previous life becomes the focus, and the conduit for their *supposed* prior views, beliefs and character. There are fundamental differences between a patient's prior views, and their previous self, which is at times conflated by the judges as is discussed in depth in Chapter Five. The term previous self refers to their personality, how they have lived their life, and generally the kind of person that they were. It is a way of assessing their values and in the MCA is acknowledged under ss 6 (b) and (c) where the "beliefs and values" and "the other factors" the person would be likely to consider must be considered by the substitute decision-maker where those views are "reasonably ascertainable". It may not be quite as obvious where the spectrum for those who were able to express views, and did not do so, lies, but it is demonstrated by two of the most influential cases on decision-making for adult incompetent patients which lie at either end of this scale. The first case is that of *Bland*. Anthony Bland was eighteen, an age where most teenagers about to enter adulthood have not given much thought to ending up in a permanently incompetent state and what this would mean.³²³ His relative youth also meant that, like most teenagers, he had not have as many opportunities to show how he would have responded in different situations to adversity. A man who had had such an opportunity was David James, whose values in *James* were extrapolated from the

³²³ *Airedale NHS Trust v Bland* [1993] AC 789.

way that he had approached a previous life-threatening diagnosis of cancer.³²⁴ In both cases, the family put forward views, purportedly from the patient, that could be said to be safely relied upon.

Never Competent

The third group of incompetent patients to consider are individuals who never had a chance, or the ability, to express any views. Two examples of patients who most commonly fall into this category are very young minors and people with severe cognitive impairment since birth or an early age. One difficulty with the case of the individual who has never been able to express any views is that the substitute decision-maker is forced to try to determine best interests without that particular type of information specific to the individual.³²⁵ In essence, nobody has any idea what the particular individual would want, and any pretext of “let us imagine what they might say if they suddenly became competent” is, at best, a fiction.³²⁶ The lack of prior competence necessitates trying to determine the best interests about the individual without any useful information either directly or indirectly from the individual themselves. The prior wishes of the incompetent patient, where they can be identified, are considered to be an important factor in ascertaining the best interests of the patient. Without any prior views, ostensibly objective interests, as opposed to subjective interests, become the central factor in the decision-making process.³²⁷ While everyone can be said to have objective interests, such as the preservation of self, no one can tell a competent person that they must act upon them, for reasons of autonomy and freedom. For example, where a patient has cancer (with low probability of cure), an objective interest in prolonged life can conflict with their subjective interest in not suffering from the side-effects of chemotherapy side-effects, for whatever time is left. One difficulty with the best interests test (as explored in Chapter Six) is that the person-specific focus has lacked clarity of what is subjective and

³²⁴ *An NHS Trust v DJ* [2012] EWHC 3524 (COP).

³²⁵ Experiential interests, such as avoidance of pain, could be surmised but this is different question from what the individual would choose for themselves.

³²⁶ There is support for this view in *Airedale NHS Trust v Bland* [1993] AC 789 at 895 per Lord Mustill. “To postulate a patient who is in such a condition that he cannot know that there is a choice to be made, or indeed know anything at all, and then ask whether he would have chosen to terminate his life because that condition made it no longer worth living is surely meaningless, as is very clearly shown by the lengths to which the court was driven in *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417. The idea is simply a fiction, which I would not be willing to adopt even if there were in the case of Anthony Bland any materials upon which a surrogate could act, which as far as I can see there are not.”

³²⁷ *Objective* and *subjective* is discussed in Chapter Six.

what is objective, and furthermore, in the case of the never competent patient, there is a gap in what is often considered to be the subjective component.

Essentially, this discussion is focused on answering a particular question, which needs to be addressed with regards to interests and permanently incompetent patients: can a person only have interests if they have been previously competent? If yes, then the group of never competent patients have no interests. But, as discussed in Chapter Three, there are many interests that can be attributed to an individual which arise from sentience. There is agreement that everybody has interests at a rudimentary level in certain common and basic things, such as not experiencing prolonged pain for no purpose. By this account, individuals in a permanently incompetent state do have interests, regardless of whether or not they have previously expressed these. Therefore, the answer, that having interests is not dependent on prior competency, leads to another question regarding how these interests can be determined. If the patient has never had any meaningful engagement with possible interests, if they have never articulated a stake in something, then how do we determine what their interests are? Because of this difficulty, it seems that we may have to use an objective best interests test whereby interests are assigned to a person, completely independent of who that person is, and in a way that reflects our beliefs about the interests that are common and shared by all. Certainly, this appears to be what the courts have done in some cases. As discussed in Chapter Three, objective interests, such as an interest in dignity, are legitimate interests and can be attributed in this way. Objective interests that are other-regarding are more problematic. It is much harder to determine what other regarding interests might be, in never competent individuals, and also to whom and how these other-regarding interests could apply. At this juncture, it is sufficient to point out that patients who have never been previously competent do have interests, and that identifying these is problematic.

Summary of Chapter Four

When considering best interests determinations, and decisions on behalf of incompetent patients, there are two distinct categories of incompetent patients – those who have never had a chance to express previous wishes, and those who have had this opportunity. This is critical to any approach to best interests which attempts to take account of patients' prior views or beliefs. Further categorising those who have been previously competent into those who expressed views, and those who were able to but did not, is imperative for investigating the

veracity of views, as is outlined in Chapter Five, and for assigning certain weighting to any prior wishes, as addressed in Chapters Seven and Eight. Throughout the cases examined there has been a persistent inconsistency in the extent to which previous wishes are adhered to, and confusion over the important distinction between respecting someone's previous views as if they are the sole determinant of best interests, compared with an approach which recognises and interprets prior views as important but as only one of several factors to be considered in deciding what is in someone's best interests.

From the extensive investigation of interests and competency it is possible to conclude that the *best* interests of any permanently incompetent person is not able to be discussed in a way that ignores any interests that they previously had. It is also possible to highlight a particular range of interests that a person may have, interests that are derived from their lives. Many virtue ethicists discuss the importance of a person's narrative and this description embodies what is referred to in this thesis as the *previous self*. This term, although perhaps misleading in the sense that it implies that a person can be two separate entities, is intended to convey the notion that a permanently incompetent person is not someone who has descended upon the courts without their own past, their own personal history, their own narrative. Someone who has a previous self does not necessarily have to have been previously competent either, although that will usually be the case.³²⁸ What it does denote, is that a person has lived enough of a life from which their interests can be derived and discussed. Therefore, a young child could not be discussed in terms of having a previous self, but older children and adults could be. This is made more difficult when there are no prior views to rely on or utilise. This also demonstrates why, even when there are prior views, it should be acknowledged that prior views cannot, and should not, be the only consideration – because even people who have previously expressed views have other interests besides those that they explicitly expressed.

³²⁸ The legal definition of competence and incompetence was discussed in Part One. However, for the purposes of defining the term previous self similarly to the way that permanently competent is defined, it is not confined only to those who have been previously *legally* competent. For example a person who has Down syndrome may not be legally competent but they do still have a previous self.

CHAPTER FIVE: PRIOR VIEWS OF THE PERMANENTLY INCOMPETENT ADULT

“What is it about differently abled people, that we attribute noble characteristics to them? It’s the way everyone thinks blind people are really nice. But they’re not, not always. They’re just like the rest of us.”³²⁹

In this chapter the uncontentious position that an incompetent person’s prior views are an important factor in decision-making for incompetent patients is first established, and then the more challenging question is addressed of how and indeed whether these views can be applied in end-of-life cases. Any prior views of the permanently incompetent patient are at least considered, if not seen to be the most important aspect, in the legislation and common law in assessing their best interests.³³⁰ The significance of the previous wishes that the now incompetent adult expressed is reflected in the legislation that now governs many decisions regarding best interests in the four jurisdictions discussed in this thesis.³³¹ As outlined in Chapter Two, there are differences between countries in their approaches to an incompetent person’s prior views, but all of the common law jurisdictions do acknowledge that the prior views should in some way inform decision-making regarding the person’s best interests. In this chapter the differences between the jurisdictions are discussed in more detail, with reference to specific cases, and the conclusion is reached that the best interests test, where there are strong prior views, can become a substituted judgment test. This is a major shift in the fundamental purpose of the best interests concept, and one that therefore needs to be examined in closer detail.

Given the implications of prior views in assessing best interests, an important question emerges: how certain is the substitute decision-maker that these prior views are *valid*? By

³²⁹ Marian Keyes *The Woman Who Stole My Life* (Michael Joseph, 2014) at 185.

³³⁰ There are two main ways to describe prior views: they are often referred to as either views or wishes. Views may relate to more generic values, whereas wishes may be more specifically related to particular decisions. However, these terms are used interchangeably in this thesis, as there is no discernible difference between them in cases or statutory provisions. Where appropriate, however the terms are used as reflected in the specific legislation referred to. For example, the HCCA, Ontario refers to “wishes”; The Code of Patient Rights, New Zealand, refers to “views”.

³³¹ See Chapter Two, Section on “Prior Views”, for more detail on this.

using the term valid the intent is to convey a query as to how safely the substitute decision-maker can rely on the information regarding the person's prior view or previous self. The aim is to be able to say whether, with a degree of accuracy, the treatment 'is what he or she would most likely have wanted'. This could relate to the reliability of the evidence of the prior views, or it could relate to the prior views themselves; for example, were the views well informed or uttered under duress? Are any *prior* views a true reflection of what the patient would want in their *current* circumstances? What role should the views of whānau play in determining the likely views of incompetent patients? This chapter assesses the prior views of incompetent patients, establishing a framework of how these views can be properly weighted, and then discusses the judiciary's observations against this background. The question of validity is fundamental to ascertaining prior views, and this chapter examines this in-depth; in doing so an outline is proposed to determine how valid the prior views may be. This is a three-part assessment tool which is designed to ascertain how safely the substitute decision-maker can state what the incompetent person's views were. After outlining the proposal in detail it is then discussed in relation to eight cases, each selected for the way demonstrates different aspects of how prior views can work in these difficult end-of-life cases.

Part One: The Importance and Veracity of Prior Views

The first part of this chapter proposes that there are three problems concerning the use of a person's prior views or beliefs in end-of-life decision-making.

- (1) *The significance problem.* Why should the prior views matter at all? If best interests is a weighing-up tool why should what the person wanted in the past matter now?
- (2) *The conflict problem.* The prior views may clash with the patient's current interests.
- (3) *The epistemic problem.* If prior views and beliefs do matter (and the answer to the significance problem tells us that they do) how does the substitute decision-maker know what they are?

The bulk of this chapter deals with the epistemic question, but the first two difficulties are dealt with first to clarify some of the confusion that these problems present.

The Significance Problem

The significance problem asks why a substitute decision-maker should care about the prior views of the incompetent patient. Of what significance have the prior views, or prior self to a best interests assessment? If best interests is an (objective) weighing-up tool why should what the person wants matter?³³² There are three key answers to this: (1) ethically it matters because it is respectful for their autonomy; (2) to ascertain what is in an individual's best interests requires that the person, their values and beliefs are considered; and (3) pragmatically it matters because legislation says that it does. In some jurisdictions the test is substituted judgment at first instance, and then the person's best interests if their views are unknown. Obviously the reason there is legislative provision for prior views is because they are held as important, so it is, then, rather circular to use it as a reason to show why prior views matter. However these three reasons can be used as arguments to show prior views do matter – and that there is both a moral and legal standing for saying that they do.

Respect for Autonomy

The respect for competent patients making fully autonomous, informed choices is now enshrined in many countries, and the four jurisdictions discussed in this thesis are amongst these. The increase of deference to the principle of autonomy is discussed by Veitch. In Chapter Two of his book he discusses four examples which show how legalisation (denotes a civilisation where individual autonomy and self-reliance, rather than dependency and community, are the guiding principles) has displaced medicalisation (a society with a moral community and a holistic vision of welfare). The four examples showing this shift in social organisation are: (1) increasing resort to litigation to seek individual redress; (2) erosion of trust in doctor-patient relationships; (3) willingness to challenge doctors' opinions; and (4) contractualisation of health care services.³³³ The result of this legalisation is that respect for autonomy has become an integral part of medicine and the law. When the two intersect at the extreme edge of decision-making there is still the perceived burden to respect a person's autonomy. This individualistic outlook is one, I argue, that has been manifested (at times inappropriately) in the concept of best interests.

³³² The objective and subjective approaches are discussed under Application Three in Chapter Six.

³³³ Veitch (2007) at 39-40. In reference to Dingwall and Hobson-West.

The concept of informed consent stems from respecting a patient's autonomous right to choose what happens to their own body, as discussed in Chapter Four. An extension of this is an advance directive whereby a person's precedent autonomy can decide for their future incompetent self. This is a similar premise to that of the substituted judgment test whereby the substitute decision-maker makes the decision based on what the person would have wanted when they were competent. Conversely, the best interests test has no such requirement to prioritise the patient's precedent autonomy, except that the patient could have an objective, self-regarding interest in their prior views being taken into account, stemming from their competent self's future-orientated interests in having some say over their future incompetent self. The best interests test asks the question: what is in this patient's best interests? By prioritising the incompetent person's prior views this appears to epitomise respect for *this patient's* autonomy. How should, or even can, the decision be made if the person's individuality is not being considered? And surely, this is accomplished by respecting their prior views? Undoubtedly, prior views should be taken into account, but not to the point where what is happening is a fictionalised version of autonomy. To properly respect an incompetent patient, a robust process should take place, assessing whether the prior views are actually those of the patient, and how safely they can be relied on. The critical question to ask is – how valid are the prior views? This question links directly to how strongly the patient's autonomy is being respected. It is incongruent to purport to be doing so if the reflection on these prior views is not vigorous. The following hypothetical case shows how this distortion arises.

Emily Willoughby is dying. She has a congenital condition with a high likelihood of predictable, inevitable decline resulting in loss of control over her body. Knowing this, while competent, she makes an informed choice and expresses her desire, both verbally and in writing, to receive life-prolonging treatment for as long as possible until 'there was no hope'.³³⁴ Her condition progresses to the point that she is no longer competent, she has a tracheotomy and no bodily control. She then gets an infection which needs to be treated with antibiotics. Her doctors think it is in her best interests to withhold this medication; her family disagrees, citing her previous wishes.

There are two ways that Emily's prior views could be approached in assessing her best interests, and both of these approaches have been utilised by the courts. (1) The views can become a mechanism by which we can ascertain what the person themselves may have

³³⁴ This would be poor advanced care planning in its lack of detail, but have made it deliberately flawed for the purposes of this example.

wanted, and therefore a tool to help determine what the best interests of the person may be.³³⁵ Emily's prior views regarding her future condition could be utilised in a way that aligned her prior views – continued treatment – with what is in her best interests. This is essentially a substituted judgment test, and has been implemented in some jurisdictions' legislative reforms regarding decision-making for the incompetent patient. (2) The best interests of the patient includes a wide variety of interests, (the *best* part of the test necessitates a weighing-up exercise), and prior views are one of those factors that are weighed up. Emily's prior view for treatment would therefore be weighed against her doctors' views of her best interests, her family's views, her experiential interests, and any other considerations. These are very different approaches.

The substituted judgment test is an expression of the importance of autonomy in decision-making for the incompetent patient. The usual interpretation of substituted judgment, as described in Chapter Two, is that the decision-maker makes decisions about treatment for the patient based on what they think the patient would have wanted themselves. One of the criticisms of this model is that often the substitute decision-maker performs poorly at this task in terms of making the decision that the person themselves would have made.³³⁶ This means that the decision becomes based on faulty assumptions and does not actually uphold the patient's autonomy at all. The best interests test purports to circumvent this concern by acknowledging the prior views, but as one part of the equation, not the whole answer. This may mean that substitute decision-making based on best interests makes it a better decision. The difference between the two guidance principles regarding decision-making for the incompetent patient is considerable and, I submit, partly responsible for some of the confusion that has permeated the best interests test.

The permanently incompetent, but previously competent patient has no *current* autonomy in their existing state. But that does not mean that they do not have *any* autonomy. The relevant autonomy that they may have is precedent autonomy, and the relevant interests that they may have are future-orientated interests in their precedent autonomy being upheld. If their precedent autonomy is held to apply to their future self this is applying the view that the previously competent person and the now-incompetent person is the same person. This is of

³³⁵ The validity of this view still needs to be assessed, see section below on the validity of prior views.

³³⁶ Allison B Seckler and others "Substituted Judgment: How Accurate are Proxy Predictions?" (1991) 115 (2) Ann Intern Med 92.

some debate philosophically, as discussed in the last chapter.³³⁷ Essentially the courts have aligned with Dworkin on this issue, whereby a prior competent self can make decisions for the future incompetent self, and thereby that is respecting a person's autonomy.³³⁸

Respect for autonomy can therefore be relied on as a reason for respecting someone's prior views, and later in this chapter the ramifications of this are further explored. These ramifications do in some way indicate that it is not always clearly understood that it is precedent autonomy being upheld rather than current autonomy. A particular point needs further clarification: it is not that prior views should be excluded as a factor in an incompetent person's best interests; on the contrary it is entirely correct where possible. However, any suggestion that a 'patient would want this', should be considered as inaccurate, as there is no way of knowing at *that particular time* what the patient does or does not want – if indeed they are capable of wanting anything – hence the need for a decision to be made on their behalf. This is bestowing the incompetent patient with current wishes that are simply not able to be ascertained. This is due to the adherence to a doctrine that autonomy is one of the, if not the most, important moral principles to respect.

The Individual Patient

The second reason why prior views are important is because these views represent the manifestation of interests that people may have (summarised in Chapter Three) and some of these interests are related to the differentiation between patients who have been previously competent and those who have not (as described in Chapter Four). Reflection about a permanently incompetent patient, who has been previously competent, means discussing someone who has lived a life, with many interests both self-regarding and other-regarding. These can include all categories and qualities of interests explored in Chapter Three, for example critical, future-orientated, life-long, but whatever terminology is used to describe them they are both experiential and non-experiential. Interests in being healthy, being a good person, advancing your career, reading lots of books, caring for your loved ones are all examples of interests that different people may have. The longer the life you have led, the more opportunities you have had to not only express interests, and develop many interests, but also make it clearer to those closest to you what those interests are. A competent person

³³⁷ See section on "Precedent Autonomy", Chapter Four.

³³⁸ Dworkin "Life Past Reason" in Kuhse and Singer (eds) *Bioethics: An Anthology* (Blackwell Publishing Ltd, United Kingdom, 2006) at 359.

is able to express and act on decisions which they perceive to further their own best interests – or not – and these will routinely involve self- and other-regarding interests.

The exploration of interests is another reason to care about the prior self of a patient. To make a decision that is in a patient’s best interests, *all* of their interests need to be canvassed. If only their medical condition mattered, this would be a narrow approach and has been rejected as such.³³⁹ Considering prior views as a factor in the best interests test allows for considerable emphasis on the particular person, as is correct in a test focusing on the individual’s best interests. The difficulty is in maintaining the correct function of these views. There is a strong argument that a permanently incompetent patient has a surviving interest in their prior views being applied.³⁴⁰ However, there is a difference between any views ascertained enabling a better decision to be made on the individual’s behalf, and using those views as one of several interests that could be ascribed to the individual. Prior views, therefore, are possible manifestations of the interests that an incompetent person had when they were competent. They are not a category or type of interest, as expressed in Feinberg, Dworkin or Sperling’s distinctions, they are at best the *expressions* of future-orientated interests. This point is elaborated upon later in this chapter, following the next sections which outline the safety of inference from the prior views. To ascertain a person’s interests then questions about beliefs and values must factor into the decision-making.

Statutory Guidance

The third reason that prior views are important is because, where a person was previously competent, their prior views or previous self is taken into consideration for their best interests in legislation governing substitute decision-making. The legislation was outlined in detail in Chapter Two, so it is sufficient for the purposes of this section to reiterate that consideration of prior views (in some form or another) is present in the legislation of each of the countries examined.³⁴¹ Therefore, any practical approach to considering the best interests of patients

³³⁹ See Application Two in Chapter Six for a discussion of medicalising best interests.

³⁴⁰ See Chapter Three for more discussion of this, in the section “Self-Regarding Interests”, and arguments promoting this statement.

³⁴¹ England and Wales MCA: s 4 (6) (c), s 4 (6) (a) must consider the person’s past and present wishes and feelings”, “the other factors that he would be likely to consider if he were able to do so”; New Zealand’s Code of Patient Rights, Right 7: “consistent with the informed choice the consumer would make if he or she were competent”; South Australia’s GAA, s 5 (a) “consideration (and this will be the paramount consideration) must be given to what would, in the opinion of the decision maker, be the wishes of the person in the matter”; Ontario’s HCCA s 21 (2) (a) “the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable”.

must consider the different legislative approaches. The legislative approach is also based on the respect for precedent autonomy, and as already discussed, is based on an assumption that the patient's identity continues even if they are incompetent.³⁴²

The Conflict Problem

There is more than one potential conflict that arises once a person has been previously competent, and has therefore been able to previously express views. The identification of different interests and how they should fit within the best interests concept has been incomplete in some judgments, and this is something that is examined in some detail in Chapters Six and Seven. Specifically, with reference to prior views, there is a potential conflict between the patient's current interests and previously expressed views.

The Patient with Current Views

“People are not the best judges of what their own best interests would be under circumstances they have never encountered and in which their preferences and desires may drastically have changed.”³⁴³

If a patient has said that they want treatment to be continued for as long as possible, this is a view that they expressed in the past while competent. For example, we could say that they have a non-experiential self-regarding view in their previous wishes being adhered to, but they cannot be said to have a current interest in treatment continuing for as long as possible – as their current interests are something that are unknown. The patient *may* have a current view, but there is no way of ascertaining what this is (and it would have to be treated with caution according to the requirements of informed consent) hence the need for a substitute decision-maker. A previously expressed wish often blends into a current view, as shown by the following example (although the judge was not necessarily condoning this viewpoint):

³⁴² *Burke v General Medical Council (Official Solicitor Intervening)* [2004] EWHC 1879; [2005] QB 424 at [75] per Munby J: “Striking examples of the respect the law shows for the principle of autonomy or self-determination, and examples, moreover, which emphasise its absolute nature, are to be found in such well-known cases as *In re C (Adult: Refusal of Treatment)* [1994] 1 WLR 290, *Secretary of State for the Home Department v Robb* [1995] Fam 127, *Re JT (Adult: Refusal of Medical Treatment)* [1998] 1 FLR 48, *St George's Healthcare NHS Trust v S, R v Collins ex p S* [1999] Fam 26, *Re AK (Medical Treatment: Consent)* [2001] 1 FLR 129 and *Re B (Consent to Treatment: Capacity)* [2002] EWHC 429 (Fam), [2002] 1 FLR 1090.”

³⁴³ Dworkin "Life Past Reason" in Kuhse and Singer (eds) *Bioethics: An Anthology* (Blackwell Publishing Ltd, United Kingdom, 2006) at 361.

“The case put forward on behalf of M’s family is based substantially on what they say were, *and still are*, M’s wishes and feelings.”³⁴⁴

Being permanently incompetent does not of course denote that the patient has *no* current views that they can express. As explained in Chapter Three, incompetence does not preclude a range of possible abilities that the patient may have, including awareness and responsiveness. Where a patient is able to experience anything, they then have self-regarding experiential interests, but may not be able to communicate what those interests are.³⁴⁵ The evaluation of these interests is, of course, very important; hence they are discussed in detail in Chapter Seven. However, for the purposes of the expression of these experiential interests as their current views, it needs to be understood that: (1) a previously held competent view is not their current view; (2) permanently incompetent patients may have a current view, but if they have no way of communicating it, there is no way of knowing what it is; and (3) their self-regarding, experiential interests (for example in not experiencing pain) are not equivalent to their current view. When a clear distinction between current interests and previous wishes is adhered to then the correct question is whether a patient’s precedent autonomy should override current considerations. This is a crucial difference between the two guidance principles of substituted judgment test and best interests, where substituted judgment prioritises precedent autonomous wishes over any other interests.³⁴⁶

The Epistemic Problem

The significance problem asks why prior views matter and the answer to this query gives three reasons: (1) as a substituted judgment test it respects the person’s precedent autonomy; (2) prior views and values are a way of focusing on the particular patient; and (3) the legal embodiment of these first two reasons is the incorporation of prior views into legislation for incompetent patients. Given that these views do matter, and that they can be the determining factor, the veracity of these views becomes critical. The only possible way of ascertaining

³⁴⁴ *W v M* [2011] EWCOP 2443 (Fam) at [6] Emphasis added. Baker J further stated in the same paragraph “whilst I take those statements into account, they are not binding and in all the circumstances I do not consider they carry substantial weight in my decision.” The weighting of prior views is examined in the section in Chapter Seven “Prior Views and Other Interests”.

³⁴⁵ Many incompetent patients may be able to express certain experiential interests, for example “that hurts, this tastes horrible” but be unable to balance those against other of their interests. For example, they may not be able to understand that, without the injection or bad tasting medicine, they will die or endure much worse suffering. As already explained the incompetent patient who is the subject of this thesis is usually unable to even express this level of interaction.

³⁴⁶ See discussion of Margo’s Dilemma in the section “Precedent Autonomy” in Chapter Four.

what a patient most likely would have wanted to happen to them with end-of-life treatment decisions is working out what, if any, prior views they had. It is not, therefore, suggested that prior views should always be considered unsafe or not considered at all, but rather that what is being accepted in some cases as ‘the patient’s view’ is not necessarily a genuine representation.

There is no way of knowing what the incompetent patient actually wants at *this precise moment in time*. Even with the best evidence of an explicit prior view, nobody has any way of actually knowing or verifying if the permanently incompetent person: (1) might hold different interests from when she or he was competent (for example, Margo’s dilemma, as explored in Chapter Four, and the conflict problem as explored above); or (2) changed his or her mind while still competent, but left no record or evidence of that change; or (3) actually holds any views relating to the choice at issue, or – in the case of the permanently unconscious and infants – can hold any views at all. Even if the evidence for the prior views is strong and it is highly unlikely that the patient will change their mind, it is still a possibility, and therefore any indication claiming that ‘the patient would have wanted this’ should be subject to some scepticism. ‘Would have wanted’ indicates that their prior competent self wanted a certain treatment decision for their future incompetent self. This is different to ‘wants’ (a current view that cannot be ascertained) or ‘would want’ (a certain treatment decision if they could communicate).

Is there a problem with courts indicating that decisions are in line with what the patient themselves would have wanted? Using such expressions gives judges a way to show that they are respecting the patient’s autonomy, but they may do so by falsely attributing to the incompetent person views that they no longer hold. There are two ways in which that concern may apply. It may mean that the patient, by virtue of being unconscious or incompetent, no longer holds any view about the treatment decision. In that situation, whether we regard the attribution of the interest as a fiction seems to depend on the view we take about surviving or critical interests. If we agree with Dworkin, Feinberg and Sperling that there exists a form of interests that can survive even death, then it seems that we – and hence, the courts – can meaningfully attribute those interests to the individual even after they have permanently lost awareness of them.

Of course, for those who are sceptical of the notion of surviving interests, such attribution may be problematic, even fanciful. In addition, as noted above, such an approach may

present difficulties when those prior interests seem to conflict with the current, experiential interests of the now-incompetent patient. For judges who make use of such reasoning, though, it may be said that, while they are taking a position on a contested area of philosophy, they are not engaging in an approach that is necessarily problematic. Indeed, in taking such an approach, they would be aligning themselves with some esteemed philosophical company.

The second sense in which courts may be falsely attributing interests would arise if they were basing decisions on views that the now-incompetent patient never possessed, or about which the patient changed their mind. Whatever we think about the notion of surviving interests, it seems essential that the individual at one time harboured those interests.

Consequently, the most important questions that can be asked with regards to prior views are: (1) how can the substitute decision-maker know what the prior views of the incompetent patient were? (2) How safely can the substitute decision-maker rely on those views? These questions are now considered in detail for the remainder of this chapter. The following section will discuss the expectations a reasonable person could have regarding the use of any prior views in providing insight into their current incompetent situation. A detailed proposal is then outlined, based on this critical analysis, which is designed to test the veracity of prior views and beliefs. The second part of this chapter comprises an examination of specific cases using this proposal.

Expectations Regarding Prior Views

The distinction between the two groups of patients identified in the last chapter, those permanently incompetent who were able to previously express a view – and whether or not they did so – is critical. Essentially, these groups signify two possibilities for the permanently incompetent, but previously competent, patient: (1) the patient has expressed a view prior to their incompetence, which relates in some way to their current incompetent state; and (2) the patient made no explicit prior view, but has a previous self: they have lived a life from which their beliefs, their character and their attestable values can be extrapolated in helping to determine where their best interests lie. There is both common law and legislative recognition for the prior views and the previous self that these categories denote. This chapter examines what this actually means in practice, teasing out the differences between these concepts and looking at how they are applied in different cases.

At the beginning of this chapter it was stated that prior views are not interests in themselves, but this position requires further clarification. Whilst they are not interests per se, Chapter Three argued that a person has a future-orientated interest in their prior views being considered. If it is true that a person has an interest in having their prior competent views applied to their current incompetent situation, then there is a subsequent interest in having their prior views accurately determined. Whilst these are clearly connected, they are not the same claim. To legitimise the stance that the veracity of prior views matter, it is helpful to consider the categories of interests discussed in Chapter Three. This type of interest, which matters not for itself, but only for its impact on the fulfilment of our other interests, has precedence in the interests canvassed. For example, the upholding of a prior view could be a far life-long interest as discussed by Sperling or even a critical interest under Dworkin's tuition.

There is obviously not only a wide range of *possible* views that someone could express, there is also a wide range of *ways* that these views could be expressed, as well as variances in the *evidence* for these views. A discussion of the consequences of this observation will be presented when the proposal for veracity is outlined, because it is often the distinction between these points that is conflated in the cases considered in this thesis. For those who have expressed a prior view it is generally accepted that this prior view must in *some way* relate to their current condition as a qualifying condition for being considered.³⁴⁷

There is also a difference in the evidential strength of the views ascertained. *Evidential strength* may be taken in two ways: (1) how strong it is as evidence of best interests in relation to the current condition of the person – in this sense strong evidence would mean prior views which are very specifically related to the current condition; and (2) it may be taken to refer to how well evidenced it is that the person actually held a particular view. Is this direct knowledge of what the person said or thought, or is it second hand, or an inference? In this thesis (2) is used to describe evidential strength, whilst (1) is about how specific the views are in relation to the current condition of the person. In assessing the prior views of patients, the judiciary have at times blended the distinctions that can be made between the specificity of the views that patients have had, and the evidence that was provided for those views. What should happen with these very different starting points? A

³⁴⁷ Discussed in Chapter Four in the section "Incompetent Patients with an Explicit Prior View".

framework is now proposed that clarifies these different views and demonstrates how they can be evaluated.

Drawing on this previous discussion, it is reasonable to make the following observations of what can be expected from a substitute decision-maker when considering prior views in the context of best interests:

- (1) Any prior views should be subject to a robust evaluation in order to determine their validity.
- (2) Where there are documented prior views, the evidential strength of these views should not be conflated with an inference of their validity.
- (3) A patient's previous self should not be interpreted as evidence for prior views, and any move by a substitute decision-maker to construe the patient's previous self into their current situation should be treated with extreme caution.
- (4) There should not be any fiction of respecting current autonomy in a situation where the person, by definition, has none.
- (5) When discussing any prior views the substitute decision-maker should be clear that they are respecting the patient's precedent autonomy.

It is not contended that judges have been unaware of these features, since many of the judges do acknowledge and discuss what the purported views are based on, but rather that there has been little critical analysis of how this should, or should not, impact on the conclusions reached. This is perhaps exacerbated by an implicit – and sometimes explicit – assumption that ‘no one wants to live in a permanently incompetent state’. Rightly or wrongly the undeniable consequence of this supposition is that there is a low threshold for finding in favour of views supporting stopping treatment.³⁴⁸

Ascertaining Authenticity of Prior Views

Earlier investigation in this chapter provided an outline as to three broad problematic areas when considering a permanently incompetent person's prior self: (1) the significance problem; (2) the conflict problem; and (3) the epistemic problem. It was argued that there are epistemic issues which arise from the assessment of prior views; issues which need to be considered carefully given that prior views *will* be considered as part of the best interests test for the previously competent patient.

³⁴⁸ See Chapter Seven for a more detailed discussion on this point.

The application of prior views should therefore be a robust process. This is not always something that has been done particularly well by the judiciary (as discussed in Part Two of this chapter). In order to assess how well the judges are doing at assessing the validity of the prior views it is necessary to develop a scale that this can be measured against. This thesis outlines a proposal to ascertain authenticity of prior views, and develops three broad categories which can be used to show the range of views that may be considered in end-of-life cases. The following examples show the difference between a prior view and a previous self, as relating to the distinctions between current and previous times.

Scenario 1: A person states at T1, at a time when they are in a competent state S1, what their wishes are if they become in a permanently incompetent state (S2 at T2). This statement says that if, at a future time T2, they are in a particular state or situation S2 they have particular goals of the care (Rx, S2) that they would wish to achieve.³⁴⁹ This is an example of a prior view.

Scenario 2: A person is in a permanently incompetent state (S2 at T2). They did not state at T1 – a time when they were in a competent state, S1 – what their particular wishes would be at T2 if they were in S2. This person was developed and competent at T1 and was engaged in a full life. This is an example of a previous self.

This distinction between (S1 at T1) – a competent, *prior* time and (S2 at T2) – the situation referred to at T1, which is now the *current* time, is crucial, and it will be referred to it extensively.

The incompetent person, at T2, is unable to state what their wishes are, so a substitute decision-maker needs to assess what, if any, their previously held competent wishes were. The goal for any substitute decision-maker is to make the best decision possible based on the incompetent person's best interests, and, as already discussed, this will need to take into account their prior views.³⁵⁰ These prior views should not be used by any substitute decision-maker without scrutiny, therefore judges – as proponents of the most rigorous standards – should use them with the highest degree of scrutiny. Initially there are two distinct parts to trying to ascertain what the person may have wanted. The first is identifying the content and source of information, and the second is evaluating that information and applying it to the

³⁴⁹ For the purposes of explaining the proposal a binary 'treatment or no treatment' scenario will be used. This is a false binary choice. Currently in advanced care planning the focus is on goals of care – for example the goal might be comfort and relief of symptoms or the goal might be prolongation of life. One of the problems in this whole area is that treatments can be used with different goals in mind and different likely outcomes – and when preferences are stated simply in terms of treatments without reference to goals or without explanation or justification then the statements can be more difficult to apply or interpret in specific circumstances. This is developed further in the case analysis.

³⁵⁰ See Chapter Two section on "Prior Views".

decision. Once these steps have been followed the third step is to make a judgment on the veracity of any views of the prior self. The following proposal separates all the strands that become entangled when trying at T2 to ascertain a person's prior views or previous self at T1.

Investigation I: Identifying Content and Source of Information

Firstly, it should be acknowledged that the judges often had the benefit of first-hand exposure to the evidence, including the family members' testimonies. Judgments are not the same as transcripts, and therefore the information available for analysis may only be a small summary of what the families said. However, the judgments are the judicial representation of these views and can therefore be evaluated as such. There are two mechanisms for information gathering at T2 regarding the views of a patient at T1.

- (1) *Explicit: the individual's explicit expressions of views.* This is a previously expressed wish or statement at T1 that has some significance for their situation S2 at T2.

There are two sources of explicit information:

- (a) Written or direct records. For example an advance directive.
- (b) Report of witnesses. At T1 someone heard the person say something specific or general about their views on S2.

- (2) *Inferred: inferences about what the patient's views at T1 probably were, using the person's previous self.* Where a person at T1 has, or has not made any expressions regarding what their wishes might be at T2, inferences from their previous self may be made about the person's views. These inferences might be made on the basis of the person's character or on the basis of specific behaviours or beliefs but they have a previous self with a life story or narrative from which we might infer their views and values. It is important to note that the inferences made about a person apply to both groups of previously competent patients – those who did express an explicit view as well as those who did not. The fact that somebody has expressed a previously explicit view does not mean that other information should be ignored.

There are two sources of inferred information that can be gathered for the person at T2:

- (a) Observation of witnesses – friends, family, others. The claim is that the person's character leads to certain inferences; or that they behaved in certain ways; for example "he hated hospitals with a vengeance".
- (b) Factual information – information that can be gathered independently. For example, the person's digital footprint – what have they posted on Facebook or how have they described themselves in blogs?

Investigation I is designed to identify the *content* and the *source* of the information; it does not ascribe any weightings to these. Investigation II *evaluates* the information.

Investigation II: Evaluating the Information

There are four critical judgments to make regarding the information gathered at T2 for the person at T1, which are indicated by (a) – (b) under two headings (1) and (2):

(1) *Regarding the source of the information:*

(a) Reliability of evidence. There are two aspects to this.

(i) How reliable is this information from a purely evidential standpoint? For example: ‘how sure are you that she said that?’

(ii) What was the source of the information? Was it written or verbal? Was it from the person themselves or from observations of them?

(2) *Regarding the views it is believed the person had:*

(b) Strength of view. How ardently did the person hold the view? Was it consistently expressed over time? How long before T2 did the person express the view? Was it expressed to more than one person? If it is an inference of their view, what is the basis for this? This may be about how often or strongly the person said what their view was or the lack of direct evidence from them.

(c) Relevance of view. How closely aligned to the person’s current situation is the view or inferences made? Does the prior expression or view apply to the current situation?

(d) The status of the view or inference. Was any view or inference based on good information and comprehension, consistent with their known values and preferences? How informed was this view or inference? Since T1 have there been any obvious changes that might indicate a change of view? Is it of any importance that at T2 the person is or is not suffering? Was it a view that the person expressed consistently throughout their life or was it a throwaway comment in a moment of high (or low) emotion? In regard to observations: how safe is the inference from these to any views – meaning how well founded in what was observed is the imputed view? It is important to note that these are not necessarily completely distinct categories – rather they are a useful heuristic. For example, if someone had told more than one person, this could be used both to corroborate that she or he actually expressed such views, and as evidence that it was a relatively settled and strongly held view (especially if he or she had told the witnesses on separate occasions). This is evaluating the reliability of the content of the view, unlike the first section, which is evaluating the reliability of the source of the information.

Investigation III: Validity of the Inference

Validity of the inference. By identifying the sources of information in Investigation I, and making critical judgments on this information in Investigation II, the substitute decision-maker is able to state as accurately as possible what the person’s views were at T1 and therefore how safely we can infer from this what their most likely view at T2 would be.

From this three part assessment proposal it is therefore possible to discern four broad categories of views, ranging from explicit to inferred, and specific to general. This provides a useful tool with which safety of the prior view or previous self can be generalised. The following table demonstrates this.

Table 1: Four Categories of Views

	Specific <i>Precisely related to the person's current state</i>	General <i>Generally related to person's current state</i>
Explicit <i>ie Prior Views</i>	Explicit-Specific An explicit comment at T1 relating specifically to their condition at T2 <i>Safety: 'strong'</i>	Explicit-General An explicit comment at T1 relating generally to their condition at T2 <i>Safety: 'medium'</i>
Inferred <i>ie Previous Self</i>	Inferred-Specific A life story at T1 that has some specific relevance to T2 <i>Safety: 'medium'</i>	Inferred-General A life story at T1 with only general relevance to T2 <i>Safety: 'weak'</i>

This table provides a useful heuristic for the case analysis, but the strength of the view still needs to be examined under the details of the proposal. Part Two of this chapter illustrates how these categories can be evaluated within end-of-life cases, and also how an inferred-specific previous self may be as safe (or safer) than an explicit-general prior view. The next section demonstrates how the proposal can be applied to a hypothetical scenario.

Applying a Hypothetical Case

In the following scenario an outline has been designed which incorporates 'easily applied' facts to examine, as the nuances of this approach will subsequently be examined when considering the individual specific cases.

Daisy Sullivan: Repeatedly Daisy said to her family, while competent: “if I ever become in a PVS (S2) please do not continue treating me, please do not prolong my life”. This is what I will call her view at T1 about a treatment at some future time (T2) if in S2. She had made those statements while working as a doctor in intensive care, so she had seen many patients in such a state. Then a catastrophic event happened and she was left in a slightly different state, near PVS but not quite S2. This is a different situation to the one she had advanced her wishes on at T1. How can the substitute decision-makers be sure that her view at T1 should apply to T2?

Lily Sullivan: Lily had lived her life at a frenetic pace. She was a naturopathic healer. She took regular homeopathic remedies, ate reasonably healthily (although was not obsessive about it, and would have the occasional treat) and if she was really sick would seek a medical doctor’s opinion. When she suffered a catastrophic event and became permanently incompetent her family were convinced that she would not want to be like that, pumped full of pharmaceutical drugs – the Lily they knew at T1 would not have wanted treatment continued. How do the substitute decision-makers know what Lily would have wanted at T1, and should this apply at T2?

Investigation I

- (1) The nature of the information for Daisy is an explicit-specific prior view, as she expressed to others – (b) report of witnesses – at T1, the wish to not continue treatment if she was in a situation similar to S1. It has some relevance to her current condition at T2.
- (2) For Lily the information available is an inference that she would not want treatment continued based on her previous self, and largely appears to be from the observation of witnesses under (a).

Investigation II

The first part of evaluating the evidence is to make sure that from an evidentiary standpoint, it can safely be relied on.

(a) *Reliability of evidence:* Regarding (a) (i) the reliability of the evidence, there is no reason to doubt the evidence in either scenario. If the facts showed a different scenario, perhaps if the family members stood to inherit a lot of money, or if they had different religious views from the patient then these could be considered as flags for enquiring into the motivations more clearly. But with regards to Daisy and Lily, there are not different opinions amongst family members as to what she actually said or was likely to have said. The family has said that this was Daisy’s wish, and that Daisy herself expressed it. There is also clear evidence that Lily was a naturopath who only occasionally resorted to conventional medicine. Addressing (a) (ii) the source of the

information, it is common in the cases discussed in this thesis that the family state what the person would want. How this assertion be dealt with? If it is a statement from the person, then it can be deemed to be a prior view, as shown in Daisy's case. However, if the family is saying 'Lily would not have wanted this' then this is not necessarily her view, and should be categorised as the family inference of her wishes based on her way of living. This may make it less reliable in some cases.

(b) *Strength of view*: Daisy's view could be characterised as 'strong', as it was made repeatedly to more than one person. The inference from Lily's previous self could be 'medium' as her life story shows that there are some grounds on which to infer the view that she would not want treatment. However there are also factors in her life that could show that her family's interpretations of her previous self are not necessarily correct. There is evidence that she sought medical care in the past so was not averse to conventional medicine, although it is a further inference to say that she would choose pharmaceutical drugs over continued life as it was. Is it really that she would choose this? Or is it the bias that to many, her existence is not a worthwhile one, that is actually creeping into the equation?

(c) *Relevance of view*: Daisy's situation S2 differed from S1 on which she advanced wishes on at T1. However, her position as a doctor means that she clearly understood the situation at S1 and the fact that S2 does not differ significantly means that it is still highly relevant. Lily's situation is different. Her previous views on medicine and perhaps the busy way she led her life are useful indicators here, but not of particular relevance.

(d) *Status of the view*: there is a clearly expressed prior view from Daisy, who expressed the same view repeatedly, and who had superior understanding of what T2 could mean for a patient. For Lily there is an understanding of her life as someone who was probably uncomfortable to some extent with conventional medicine, but not someone who completely rejected it.

Investigation III

Validity of inference: the substitute decision-maker can then state with confidence that Daisy at T2 would most likely not want treatment to be continued. This is based on a thoughtful and considered critical analysis of the information provided at T1. In regards to Lily, the validity of the inference is weaker, but the substitute decision-

maker can state that, more likely than not, Lily would not have wanted treatment continued. Note that this may also be the family's or friends' view of what Lily would have said at T1 about T2, but the whānau's inferences do not have any special reliability or validity. What they do have, is special access to what Lily was really like – the substitute decision maker relies upon this to make an inference. But the whānau rely upon it also. Here it is important to distinguish the reliability of the evidence on which the inference is based, from the reliability of the inference itself. The first is a matter of evidence (was Lily really a naturopath who relied on homeopathic remedies?), and the second is a matter of the validity of the inference (can it be validly inferred from Lily's actions that she would not want to be treated at T2?) The *validity* of inference should not be confused with the *reliability* of the evidence. The family's inference from what Lily was like to what she might have said at T1 about her condition at T2, is not a piece of evidence.

Summary of Part One

In decision-making for the incompetent patient, their prior self, if they had one, is undoubtedly important. An attempt to untangle the difficulties that arise when evaluating previously competent views is, therefore, a crucial part of any discourse on best interests. To help with this process three main areas of contention have been identified when looking at prior views, and these have been grouped under the following headings: the significance problem, the conflict problem and the epistemic problem.

The significance problem asks why do the prior views matter at all? The answer is that they matter because of the respect that is given to an individual's precedent autonomy and because of this respect, the consideration of prior views and previous selves are – and should be – found in the legislation governing best interests. This should not be confused with the patient having current autonomy.

The conflict problem recognises that the incompetent person, who has been previously competent, has the potential for conflicting interests between their previously competent wishes and any current interests. For example, this conflict could arise between a previously expressed wish for treatment as long as possible and an experiential interest in not experiencing pain.

The epistemic problem acknowledges that there is no way to know with certainty what the incompetent person would want. If the patient has not been previously competent, then this is where that enquiry ends. If, however, they have been competent prior to the event that has left them permanently incompetent, this provides the substitute decision-maker with vital information. The significance problem holds that substitute decision-makers should care about prior views, which leads to the conclusion that we do need to consider what the person said or did in the past. This information is considered to be integral to the process of best interests, because it respects the component of the test that makes it specific to an individual, and it can come in two forms, the person's prior views or their previous self. The consequence of not knowing what an incompetent patient would want, but having a legal system which gives weight to that person's previous views or beliefs, means that the key approach when looking at a person's prior views or previous self is to ascertain the veracity of these prior values.

In order to determine veracity in any meaningful way, any inferences about what a person *may* have wanted should be thoroughly examined, and then the decision can be based on the best information possible. A careful step-by-step analysis, as set out above, has asserted that any incompetent patient who has been previously competent can fall within four broad categories. These are set out in the table which categorises the prior views and previous self under four broad labels: explicit prior views which are either specific (specifically relates to their condition) or general (relates generally to their condition); and a previous self which provides inferred information that is either specific (where their life story is informative) or general (where their life story has no particular relevance). The proposal for veracity set out an intensive investigation into each of these four categories and provides a way of determining how safe the inference from the person's life is. The judicial engagement with the veracity of views is one that has been ineffectual in some cases, and this forms the discussion in Part Two.

Part Two: Case Analyses

The first part of this chapter set out the problems with using prior views of incompetent patients, and provided some ways to navigate these. Using this extensive discussion several end-of-life cases are reviewed in-depth in Part Two, with reference to the template as a way to juxtapose a stringent method of determining validity with the judiciary's approach.

Consideration is first given to three cases where the patient's previous self has been used in the best interests assessment, then five cases are examined in which there were explicit prior views. These have been chosen because they demonstrate a range of views from within the four categories identified in Table 1.

Cases With No Clearly Expressed Prior View

In most end-of-life cases concerning an incompetent adult patient, a reasonably sudden event has occurred, which lessens the chance that the patient has had pre-warning of their condition, and they are consequently less likely to have had extensive discussion about what they would want to happen to them. The legislative changes over the last decades appear to be in favour of acknowledging that, although incompetent patients may not have expressed a clear view prior to their current condition, this does not necessarily preclude any inclusion of their possible views into the test of what is in their best interests. The “values and beliefs” of a person referred to specifically in British and Canadian legislation is an example of this.³⁵¹ The roots of this kind of consideration lie in the common law, where judges considering end-of-life decisions decided that an incompetent patient's ‘personality’ could be taken into account as one of the possible manifestations of a person's values and beliefs. But what does it actually mean to take the personality of the patient into account when considering best interests? In what way could the personality of the patient be relevant? Is a person who enjoys a cup of tea and a good book more likely to want to be in a permanently incompetent state than someone is an outdoors, go-getter type? The language of “values and beliefs” would, presumably, mean a stronger sense of the patient's previous self, however for the jurisdictions that rely on the common law, the notion of personality still persists.

Thea Stilton was an outgoing, exuberant person, described by many as ‘the life and soul of the party’. She would set herself many ambitious goals, and just last year climbed Mount Everest. Geronimo Stilton was a quiet, shy man who preferred his books to parties. He loved his family and enjoyed his work with disadvantaged youth.

These rather stereotypical descriptions are chosen because they are (deliberately) clichéd and yet are typical of the way that incompetent patients are often described.³⁵² Where do such descriptions lead? If a description of a person ‘who lived life to the full’ is followed by the proposition that they ‘would not want to continue living under such conditions’, there is a

³⁵¹ HCCA s 21 (2) (a); MCA s 4 (6) (b).

³⁵² For example: “He is described as being self contained, sensitive, quiet, shy and as having “so much depth of character and love”.” *Re C* [2010] EWHC 3448 (Fam) at [5].

reasonable assumption that their personality is being taken into account. This is not necessarily based on what could be called values, except if further evidence could be provided for a life beyond ‘living it to the full’. The notion that an exuberant outgoing person is less likely to want to be in a PVS than someone who is an introverted homebody may, to some, seem a reasonable presumption, but any careful consideration of it leads to the conclusion that it is merely applying stereotypes. The problem with the application of stereotypes is that they are highly generalised and do not take into account individual differences. It is likely that claims that a patient would, or would not want to live in a certain way based on stereotypes would be difficult to substantiate.

However, does the prospect of permanent incompetence make such inferences seem more problematic than they would look in another scenario? For example, if the decision was whether to amputate the limbs of an unconscious patient in order to save their life, is it wrong to draw inferences from such factors as I described earlier? This was the situation in 2002 for Olivia Giles who contracted meningitis aged 36. Faced with such a decision, her family clearly thought there was a quality of life decision to be made in relation to her predicament:

“One evening the doctors told them they were going to have to amputate all four of my limbs, above the elbows and knees, and asked whether they should do that or switch off the life-support machine and let me go. My family decided I would be so dependent that it wouldn’t be much of a life. But the next day the plastic surgeon who was on duty said he might be able to save my joints – and that was what made all the difference.”³⁵³

In this case, would it be more understandable to talk of mountain climbing versus book reading habits to decide on limb amputation? Perhaps so, but again not necessarily. The ‘go-getter’ type of person could also be easily said to be the type of person who embraced challenges and could therefore be more reasonably expected to adapt to the loss of limbs. The issue here is that there is a myriad of ways that generalised comments can be interpreted, and what should be done in each case is to assess how safely any inference can be made from what is known of a person before any treatment decisions are made. The problem, as is demonstrated in the following sections, is primarily with the validity of the inference.

There are two main problems with somebody’s general personality and how they lived their life being subsumed into the best interests test. Firstly, it can lead to dangerous assumptions,

³⁵³ Patricia Kane "Lawyer Who Got Meningitis at 36 Now Helps People in Africa to Walk Again" www.dailymail.co.uk/femail/article-2905310/I-lost-feet-hands-really-feel-lucky-ve-thrown-double-six-Lawyer-got-meningitis-36-helps-people-Africa-walk-again.html. Quality of life is discussed in Chapter Seven.

something which should be avoided, as set out in the expectations determined in Part One. For example, if the patient is Catholic and in a MCS, it may be assumed that they would want to receive treatment for as long as possible. But the mere fact of their Catholicism does not actually tell us what that particular person would want at all.³⁵⁴ It is an overgeneralisation to say that all Catholics adhere to all the teachings of the Church. This is where evaluating the information under Investigation II of the proposal could help with how much weight should be given to this: (1) going to mass regularly and frequently is evidence that the person is a Catholic; and (2) going to mass regularly and frequently can be evidence for the inference that the person is likely to follow Catholic doctrine.

The second problem with personality being subsumed into the best interests test is that it can create a fiction of respecting autonomy in various guises. This fiction is twofold: (1) of respecting current autonomy in a situation where there is no capacity for autonomous decision-making; but more often though, (2) giving the impression that by incorporating the previous self into the decision-making the courts are upholding the patient's precedent autonomy.

This fits within the significance problem identified earlier, which explains why prior views are important. To say that Anthony Bland would have wanted treatment withdrawn is misleading, as we do not know what he would have actually wanted, and there is no way for us to know this. It implies the existence of an Anthony Bland who previously chose certain treatment decisions. There is not actually any such person. In contrast what 'he would have wanted then' could be a fiction, but not in the same sense, because there actually was an Anthony Bland at that time who could have wanted things. This is not just a theme from the countries discussed in this thesis. Its prevalence in American courts has also been noted, but at least the focus on the best interests test does avoid the lengths that the American judiciary will go to, for example, asking what the incompetent patient would decide if they could be competent for five minutes:

³⁵⁴ As illustrated by the Victorian Civil and Administrative Tribunal case: *Korp (Guardianship)* [2005] VCAT 779 at [36] per Morris P "The difficulty is that even if I accept, as I do, that Mrs Korp is a devout Catholic, it does not necessarily follow that if she were competent and were asked to express a view as to whether particular medical treatment was unwarranted in the light of her present condition, that the answer would be that the continuation of medical treatment was warranted. In other words the hypothetical question posed by section 5B(2)(b) of the Medical Treatment Act is not one that is automatically answered in a particular way because a person holds a particular religious faith."

“Asking what such patients would decide is like asking, as one court put it, ‘[I]f it snowed all summer would it then be winter?’”³⁵⁵

The following section discusses cases where the patient has not clearly expressed a prior view, beginning with two cases where the patient is in the inferred-general category, before evaluating one that is an example of an inferred-applicable view.

Inferred-General Cases

Airedale NHS Trust v Bland – Common Law Precedent for Previous Self

Often there are no particular views from the patient on the matter before the courts, other than what can be presumed from the way they have lived their life and what the family says about them. *Bland* is not only a good example of this, it is instrumental in understanding the principles of best interests.³⁵⁶ It is the most quoted case in the Commonwealth regarding incompetent adult patients, and the judgments in this case have contributed in innumerable ways to not only the common law but also to the legislative meaning of best interests.³⁵⁷ It was decided in 1993, prior to the MCA; it was the first case under common law to sanction the withdrawal of treatment from an incompetent adult in the United Kingdom and, as such, it provided a blueprint (though one that differed somewhat between judges and courts) for the best interests test.³⁵⁸

Anthony Bland, aged 21, had been in a PVS for nearly three years when the Airedale NHS Trust applied to withdraw ANH from him. The trial judge in *Bland* stated that there was no evidence of what Anthony Bland’s prior views might be.

“Of course Anthony Bland is unable to express views of his own and there had been no occasion for him to express any view as to how he might view his situation if some terrible tragedy such as this befell him.”³⁵⁹

Accordingly, this is a case where there have been no prior expressions on the patient’s particular situation. It was, consequently, up to those closest to Anthony Bland to put forward their views on what he may have wanted at T1 – not what he would want at T2, as he

³⁵⁵ Dresser "Missing Persons: Legal Perceptions of Incompetent Patients" 46 Rutgers L Rev 609 at 622. This fiction was routinely practiced in cases concerning property for incompetent adults in the United Kingdom until the MCA: *Re M* [2010] 3 All ER 682.

³⁵⁶ *Airedale NHS Trust v Bland* [1993] AC 789.

³⁵⁷ Based on extensive reading of cases.

³⁵⁸ Chapter Seven discusses the points of agreement – and disagreement – between the judges on what constituted interests and what should count under the best interests test.

³⁵⁹ *Airedale NHS Trust v Bland* [1993] AC 789 at 797.

was not capable of wanting anything – and what kind of a life he had led. His father’s evidence to the Court of Protection describes a ‘normal’ boy:

“He traced for me Anthony’s brief life – explaining how he was a thoroughly normal boy. He described him as not a very clever boy but with a good personality – sensitive and willing. His great interest was football and Liverpool his chosen team. He said that he was not religious but that he had attended Sunday School in the Church of England. His assessment of Anthony Bland’s situation was expressed in these clear terms: ‘He certainly wouldn’t want to be left like he is. I would feel that he should be removed and the family feel the same. I was angry when the advice from the coroner was received. I can see no point whatsoever in continuing treatment.’”³⁶⁰

Therefore, there were no applicable or general prior views on his current condition. There was only evidence of his prior interests, predominantly – and ultimately tragically – football (his condition was caused by severe overcrowding at the Hillsborough Football Stadium in 1989). The only other evidence was what those closest to him assert that he would want to happen in his current condition. But how does it stand as evidence of what Anthony Bland would have wanted at T1? It is not evidence of his views, but is instead an inference from his life, made by his family – and from what else the family know of him. They are inferring from their knowledge of him what he may have wanted at T1. How relevant is the information to establishing what Anthony Bland’s views were, and how strong is the evidence that those were his views? Effectively there is only evidence of his previous self. Is it more than likely that this evidence was accurate and reliable as set out by Investigation II (1) (a)? Balancing up the considerations, it can be claimed that it is, as there was no reason to distrust Anthony Bland’s family and their assertions that they knew their son well (on the evidence available from the judgment). But did what they know of him validate the inference they made as to his views at T1? How relevant to Anthony Bland’s condition is this evidence? The only finding possible is that it is not germane to the situation. An assertion from his family, and nothing from Anthony Bland himself in contemplating his current situation, necessarily provides a conclusion that ranks low on the relevance scale, and therefore the safety of inference that Anthony Bland ‘would not want to live like this’ is not robust. It is not suggested that this could (or should) have had an impact on the findings of the courts, but rather that there should have been reflection on the particular nature of Anthony Bland’s views (or lack thereof) and what this meant. The courts linked the family’s views of what Anthony Bland would have wanted, which have been shown to be uncritically assessed, to his best interests. Such an inference was criticised in the above section

³⁶⁰ Ibid. The role of the family and their views is discussed in Chapter Seven.

discussing reasonable expectations for a substitute decision-maker. In the Court of Appeal, Butler-Sloss LJ weighed up the family's views alongside the patient's personality:

“In assessing the best interests of Anthony Bland, however, his views, personality, how others including his family saw him before his accident will form part of that assessment, although that evidence has a subjective element.”³⁶¹

In the House of Lords Lord Goff cited *Re J* in his support of the idea that the best interests test encompasses the patient's personality:

“Of course, consistent with the best interests test, anything relevant to the application of the test may be taken into account; and if the personality of the patient is relevant to the application of the test (as it may be in cases where the various relevant factors have to be weighed), it may be taken into account, as was done in *In Re J. (A Minor) (Wardship: Medical Treatment)* [1991] Fam. 33.”³⁶²

It is therefore established at common law that a person's previous self should be considered as a way to ascertain their best interests. What is lacking in *Bland* is any way of ascertaining how this should be done. Stereotypes were referred to earlier, and in that context, it is easy to wonder if Anthony Bland had been a quiet reclusive teenager, who would have welcomed the drama of being the focus of his family's continued misery, would that have impacted upon the courts' decisions? I suspect it would not (and quite rightly so, but there probably would have been a lack of transparency about this). Dworkin bolsters the idea that a person's previous life informs their current best interests, although predicates this on them being aware of it:

“When patients remain conscious, their sense of integrity and of the coherence of their lives crucially affects their judgment about whether it is in their best interests to continue to live. Athletes, or others whose physical activity was at the centre of their self-conception, are more likely to find a paraplegic's life intolerable.”³⁶³

The following case deals more directly with a discussion of personality and how it applied to the patient.

³⁶¹ *Airedale NHS Trust v Bland* [1993] AC 789 at 817. The subjective and objective elements are discussed in Application Three in Chapter Six.

³⁶² *Ibid* at 872. Obviously there could be no prior views of the patient in this case as J was a minor. This is an example of the criteria regarding lack of precedent; see Chapter Two “Inadequacy of Existing Law” for more detail.

³⁶³ Dworkin *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (1993) at 210.

Re G – Inferring Views from Personality

A New Zealand case, *Re G*, exhibits a judge using a patient's way of life and their personality to inform end-of-life decision-making.³⁶⁴ Similarly to *Bland*, the issue was whether to withdraw treatment from an incompetent adult patient, and this was decided before any legislation was in place to govern the decision-making process. Mr G was not in a PVS, however "his quality of life [was] no different from a person in that condition".³⁶⁵ Fraser J, after considering both the substituted judgment and best interests test, decided that the:

"proper course for me is to adopt the "best interests" test but to give weight to the likely wishes of the patient and to the views of the patient's family and carers."³⁶⁶

Subsequently he separated the patient's prior views from the patient's best interests (and in so doing avoided one of the criticisms levelled at judgments in Part One). This may be due to canvassing the substituted judgment test alongside the best interests test. However, the judgment did not avoid all possible criticism. The following excerpt shows how Mr G's previous self was used in the judgment:

"Affidavits from family and friends show that Mr G has lived a full and active life professionally, with his family and in his varied social and recreational interests. There are a number of comments from the people who knew him best to the general effect that he was uncomfortable with and found it difficult to cope with frailty, illness and suffering. While he does not appear ever to have expressed any wish as to what might be done in the event of him being in the situation in which he now is, his family and the friends who have made affidavits are unanimously of the view that *if his wishes could be ascertained he would not want to continue in his present state* and would choose not to continue with the life-saving treatment. I agree that this is an entirely reasonable inference from his character and general philosophy of, and approach to, life as described in the affidavits."³⁶⁷

Mr G's whānau sought to infer his wishes from their knowledge of him. It is reasonable to assume that they had good knowledge of him (whatever evidence they have about his previous self is strong) but how relevant are the views for which they had evidence? They knew things about his personality and his character, which was of some relevance to inferences about Mr G's views about how he would have felt about his current state had he said anything about it. It is of more relevance than the evidence in *Bland*, as it related to an aversion to fragility and illness which could be related to a general dislike of dependence,

³⁶⁴ *Re G* [1997] 2 NZLR 201.

³⁶⁵ *Ibid* at 211.

³⁶⁶ *Ibid*. As the first case of its kind in New Zealand both approaches were canvassed. This is also an example a qualified-objective approach which is discussed further in Chapter Six, Application Three.

³⁶⁷ *Ibid* at 212. Emphasis added.

leading to a conclusion that the inference was safer than the one in *Bland*. Fraser J's judgment separated the possible prior views from the best interests test and he canvassed the whānau thoroughly, which produced an in-depth portrait of Mr G. However, his claim that there was "an entirely reasonable inference from his character" made by the whānau that Mr G would not want to live in that condition is not necessarily supported. Mr G's current condition meant that he was not suffering, it could have been this he objected to with illness, and therefore he may have wanted to stay in his current condition. Fraser J also gives credence to the notion that by living "a full and active life professionally, with his family and in his varied social and recreational interests", Mr G would not want to continue treatment. The italicised part of the quotation, that if Mr G's views could be ascertained he would not want to continue treatment, is Fraser J implicitly using the legal fiction of respecting his autonomy. His wishes cannot be ascertained. They are not known, and although his previous self does seem to strongly support withdrawal of treatment, more scrutiny of his previous self may have provided a safer inference of his possible views, or at least a more honest appraisal of them. As it was, there is a leap of inference regarding the strength of evidence from the whānau, which was overwhelming, and its relevance to his current interests. A more transparent statement would have held that at T1 it was more likely than not that at T2 he would want treatment discontinued.

What did the consideration of his previous self achieve? It bolstered the overall perception of it being a reasonable decision to withdraw treatment, because Fraser J linked Mr G's previous self, accepting the whānau's entreaties that he would not want to be kept alive, to his best interests. I am endeavouring to clarify that the impression given of the patient's *current* wishes being upheld in *Re G* is subject to further scrutiny, and offering possible explanations for this. The following case provides an example of a safer inference from the previous self.

Inferred-Specific Cases

Aintree University Hospitals NHS Foundation Trust v James – Best Interests under the MCA

The *James* case was the first to consider future treatment under the MCA, which had been enacted post-*Bland*.³⁶⁸ The family's arguments were formed using Mr James' previous self,

³⁶⁸ *An NHS Trust v DJ* [2012] EWHC 3524 (COP); *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65; *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

arguing that in the MCA under s 6 a person's "past feelings" and "beliefs and values that would be likely to influence his decision if he had capacity" must be considered.

David James was a 68 year old man who was admitted to hospital following complications with his stoma. He had had the stoma fitted while being successfully treated for colon cancer eleven years prior to this event. Whilst in hospital he contracted an infection which resulted in chronic obstructive pulmonary disease, an acute kidney injury, and persistent low blood pressure. He ended up in the critical care unit requiring ventilator support. Between May and December he suffered further setbacks; he had a stroke and also required CPR.³⁶⁹ The NHS Trust petitioned the court to approve declarations that it would be lawful, and in Mr James' best interests, in the event of Mr James clinically deteriorating, to withhold CPR, invasive support for circulatory problems and renal replacement therapy. There was no issue around withdrawing any treatment he was currently receiving, the issue was over future provision of treatment. His family disagreed with doctors over withholding any future treatment regardless of outcome. They maintained that he would want all possible treatment no matter how small a chance of success (the chance of him leaving the critical care unit was put at less than 1%), and pointed to Mr James' tenacious attitude during his cancer diagnosis and subsequent recovery. In this case there was no prior explicit view, instead his family convinced the courts that: (1) his current interactions with them showed that he would want future treatment; and (2) his prior beliefs also pointed to receiving treatment for as long as possible. The judges from the three courts all had different approaches to Mr James' prior beliefs.³⁷⁰ How they were weighed up is discussed in Chapters Six and Seven, but all of the judges declared that they should be factored in some way.

In the Court of Protection, Mr Justice Peter Jackson refused to grant the hospital the required declaration, and found that although Mr James' condition was grim, he was not convinced that there was no chance of recovery.³⁷¹ The Court of Appeal overruled this decision, however the Supreme Court disagreed with the reasoning of the Court of Appeal in their

³⁶⁹ He was considered to be in a MCS, though this was construed as a misleading statement, see Section "Prior Views and Other Interests" in Chapter Seven for more detail.

³⁷⁰ As fitting within the criteria in Chapter Two.

³⁷¹ *An NHS Trust v DJ* [2012] EWHC 3524 (COP) at [84]. There was an unfortunate comment made by one of the attending doctors: "I have collected significant evidence that leaves me with the view that DJ would prefer to be dead rather than be unable to make music...[The judge Mr Peter Jackson responded:] Not surprisingly, DJ's family has been distressed at the use to which Dr Danbury put this snippet of information. In his second report and in his oral evidence he retracted without further comment the observation about making music." at [57-58]. This is also an example of the importance that language can evoke, as in Chapter Two.

judgment and only upheld its decision because Mr James' condition had deteriorated markedly between the two prior hearings.³⁷²

Under Investigation I of the proposal Mr James had made no explicit prior view; the inferences were made from observation of his family about how he had approached cancer previously, and were therefore based on his previous self.

“[Mrs James] felt that his experience of cancer threw light on his values and wishes in the situation in which he found himself. Even though the surgeons had then been pessimistic DJ had never said he had had enough. She and the family believed he would feel the same about his current predicament.”³⁷³

Assessing the evidence in Investigation II, the source of inference was reliable, nothing in the judgment points to disagreement amongst the family; indeed it was the opposite. The strength of view and the relevance are more difficult to ascertain. The marked difference between the two conditions and the difference in predicted outcome (presuming that a recovery from cancer would not involve long-term cognitive impairment compared to any form of recovery from his current condition) means that the relevance of these prior views should be rated as fairly low. But contrast this previous self with Anthony Bland's, and David James' life story is one that is so much more applicable than the *inferred-general* views that were ascertained in the *Bland* case. The strength of the inference is unknowable. It is quite possible that Mr James felt very strongly, but the low relevance to his current condition must be acknowledged. The status of the purported views appear consistent with Mr James' character and his previous battle with cancer. The finding at Investigation III, based on Mr James' previous self, is that it was more likely than not at T1 that Mr James would have wanted treatment continued at T2, and it is therefore likely that his *inferred-specific* view favoured continuation of treatment.

The Previous Self in End-of-Life Cases

Permanently incompetent patients who only have a previous self as a source of information can fall within two broad parameters. The first is *inferred-general* where their life story has no particular relevance to their current condition. The second is *inferred-specific* which denotes a life story that does have some particular relevance to their current condition.

³⁷² David James' condition significantly deteriorated between the hearings of the High Court and the Court of Appeal; and he died ten days after the Court of Appeal hearing. *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 at [14].

³⁷³ *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65 at [17].

Where there have been no explicit views, the courts have sought the views of family, where appropriate. It seems rational that information about a person's prior views or life is most reliable when it comes from that person. With this group of patients it is not possible to ascertain specific views, vis-à-vis the solution to the significance problem which states that there are clearly established reasons why we should care about their previous self. Even if the philosophical reasons can be disputed, the legislative mandate that exists in the common law jurisdictions clearly shows that prior beliefs should be factored into substitute decision-making. Despite the previous self having such a potentially important role there has been little judicial assessment of the reliability of the source of information, which is coupled with an implicit representation of family views as inferior (as shown by the Court of Appeal in *James*, where they were easily overridden). On face value, it makes sense to rely less on views which are less reliable. But this is not what actually happens. What *is* happening in these cases is that the patient's previous self is not being rigorously assessed; instead, their inferred views are shallowly applied, and subsequently used to bolster the impression that the courts are upholding their autonomy. What the judges should be doing is trying to find out what the person might have thought at T1 about their current situation at T2, and then applying this view (with the weight given the view linked to how safe the inference is). Note, for example, that the judges in *Bland* do seem to get it right (at least some of the time), but the judges (in the Court of Appeal) in *James* seem to go awry.

Often, the courts only choice is to infer from what the families maintain would be the patient's wishes, as they remain the only link to any appraisal of the patient's previous self. There is a difference between what the family are saying their loved one would have wanted, and what the patient would have wanted at T1. Making a best guess as to the patient's interests at T1 is a different sort of thing from attributing interests to patients who cannot have them at T2.

The proposal for veracity is one way that this could be more robustly ascertained. This is because the question asked is 'what views, evidenced in the past, might be relevant to his or her current situation' not 'what does he or she want now'.

Realistically, there is no way of knowing for certain what the incompetent person's actual views at T1 were, regardless of what opinions have been gathered. Where there is no explicit view, the substitute decision-maker can look to the person's previous self. There is increasing legislative recognition of the importance that a person's previous values can play

in assessing what their previous view might have been on their current situation and their best interests on the basis of this view. There is a wide range of possible evidence of character – this was shown in the cases regarding a teenage Anthony Bland, and David James in his sixties who had battled cancer – and from there possible values can be extrapolated. It needs to be made clearer that the views described are assumptions, and a more rigorous exploration of the role that these wishes play should be applied by the courts.

Cases With Explicitly Expressed Prior Views

In addition to having a prior self, a previously competent person may have made a more specific statement at T1 that in some way related to their situation at T2. This is supplementary information that should be taken into account, but it is not necessarily a replacement for the information gleaned from their previous self.

Explicit-General Cases

An *explicit-general* remark is a statement from the previously competent person that relates to their current condition, but is broad in its possible application. This is demonstrated in the following Canadian case.

Scardoni v Hawryluck – Two-tier Threshold for Considering Prior Views

Scardoni v Hawryluck (*Scardoni*) is a similar case to *James* in some respects: the instigator in both instances was the family.³⁷⁴ They both disagreed with the medical opinion on withholding future provision of life-prolonging treatment and in both cases the purported views on what the patients would have wanted were upheld by the courts.³⁷⁵

Scardoni illustrates a divergent view from what is considered the majority opinion in cases of those who are permanently incompetent. In this case the patient's previously held and fairly general view – that “where there's life there's hope” and therefore treatment should be provided to her for as long as possible – and how to interpret and apply these views, were at the centre of proceedings. The family and the medical practitioners did not agree on the

³⁷⁴ *Scardoni v Hawryluck* (2004) 69 OR (3d) 700.

³⁷⁵ Additionally, in both cases the patient was not in a PVS, possibly providing a convenient ‘out’ for the judges who did not want to decide on quality of life considerations. This is examined in more depth in Chapter Seven.

proposed treatment plan, and so the matter went to the CCB.³⁷⁶ Ultimately the Ontario Superior Court of Justice agreed with the family that treatment should not be withheld, on the basis of the patient's previously held competent beliefs. Two aspects of the *Scardoni* case make it particularly pertinent for this chapter. One is the way in which Mrs Scardoni's adherence to Catholicism was discussed, and the other aspect is how the relevance of prior views was evaluated. Both of these are discussed in conjunction with the proposal for veracity in the following sections.

Joyce Holland was 81 and suffered from advanced Alzheimer's disease. Her daughters, Patricia Scardoni and Margaret Holland, had been appointed her welfare attorneys before she was diagnosed with the condition. At the time of the court hearing Mrs Holland was incompetent, although the extent of her responsiveness was disputed. All parties agreed that she was conscious, repeatedly got infections which led to painful bedsores, she needed a tracheotomy and was on intermittent ventilation. Mrs Holland's doctors wanted to withhold treatment from her, as the treatment, in Dr Hawryluck's words, took a "terrible toll" on the patient.³⁷⁷ Specifically, they wanted to dispense with treatments undertaken in the intensive care unit and treat all infections locally in the ward, administering pain relief and providing her with as much dignity as possible without using all life-saving measures available. Her daughters refused to consent to this treatment plan, and gave evidence at the Board's hearing that Mrs Holland had expressed the maxim "where there's life there's hope".³⁷⁸

³⁷⁶ Consent and Capacity Board "Consent and Capacity Board" www.ccboard.on.ca/scripts/english/index.asp 2012-15. "An independent provincial tribunal, the Consent and Capacity Board's (CCB) mission is the fair and accessible adjudication of consent and capacity issues, balancing the rights of vulnerable individuals with public safety. The CCB's key areas of activity are the adjudication of matters of capacity, consent, civil committal and substitute decision making." This neutral body is set up under the HCCA, and one of their functions is to facilitate disagreements between substitute decision-makers and health practitioners: see *Scardoni v Hawryluck* (2004) 69 OR (3d) 700 at [36]. "A case will come before the Board only when the health practitioner disagrees with the S.D.M.'s [Substitute Decision-Maker's] application of the best interests test under s. 21(2). The Board will then have before it two parties who disagree about the application of s. 21: the S.D.M., who may have better knowledge than the health practitioner about the incapable person's values, beliefs and non-binding wishes; and the health practitioner, who is the expert on the likely medical outcomes of the proposed treatment. The disagreement between the S.D.M. and the health practitioner potentially creates tension and the Act recognizes this by providing for a neutral expert Board to resolve the disagreement. Indeed, after hearing submissions from all parties, the Board is likely better placed than either the S.D.M. or the health practitioner to decide what is in the incapable person's best interests. Thus, the Board should not be required to accord any deference to the S.D.M.'s decision." Quoting from *In M (A) v Benes* (1999) 46 OR (3d) 271 at 283. This was a case about a substitute decision-maker refusing to consent to electro-convulsive therapy.

³⁷⁷ *Scardoni v Hawryluck* (2004) 69 OR (3d) 700 at 705.

³⁷⁸ *Ibid* at 726.

“. . . they thought they were doing the right thing. They were fighting for their mother’s life and could not be faulted for advancing what they believed were her wishes, values, beliefs and best interests.”³⁷⁹

Following their refusal Dr Hawryluck made an application to the CCB, who directed that the daughters give consent pursuant to s 37 of the HCCA.³⁸⁰ The Board found that Mrs Scardoni and Mrs Holland had not complied with the principles for substitute decision-making set out in s 21. The daughters appealed, and Cullity J allowed the appeal, finding an error of law in how the Board interpreted ss 21 (2) (a) and (b) of the HCCA.³⁸¹

The HCCA directs the substitute decision-maker in s 21 (1), under the heading ‘Principles for Giving or Refusing Consent’, to make the decision based on a prior expressed wish if it is applicable to the circumstances:

21 (1) (1) If the person knows of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, the person shall give or refuse consent in accordance with the wish.

If there is no specific wish, such as in Mrs Holland’s case, then the substitute decision-maker must act in the person’s best interests. The following provision, s 21 (2) which has the heading “Best Interests” therefore applies. This section takes into account the person’s “values and beliefs” and “any wishes”:

21 (2) In deciding what the incapable person’s best interests are, the person who gives or refuses consent on his or her behalf shall take into consideration,

(a) *the values and beliefs* that the person knows the incapable person held when capable and believes he or she should still act on if capable;

(b) *any wishes* expressed by the incapable person with respect to the treatment that are not required to be followed under paragraph 1 of subsection (1).³⁸²

³⁷⁹ Ibid at 713.

³⁸⁰ Ibid at [1]. This is the correct phrasing, surprising as it seems: “In this case, the appellants, Mrs. Patricia Scardoni and Ms. Margaret Holland, refused to consent to a proposal by their mother’s physician that such treatment should be withheld. The Consent and Capacity Board disagreed with their belief that the treatment was in their mother’s best interests *and directed them to consent.*” Emphasis added. This is not an aberration, see also: *Maraachli v Dr Fraser* [2011] ONSC 124; [2011] OJ No. 2168 at [2]. “Further, the Board ordered Mr. Maraachli and Ms. Nader to consent to a withdrawal of the endotracheal tube without replacement and an order not to resuscitate with palliative care for Joseph.” It is not quite worded this way in the HCCA however: s (4) If the Board determines that the substitute decision-maker did not comply with section 21, it may give him or her directions and, in doing so, shall apply section 21.

³⁸¹ The court could only change the Board’s finding if they found that their decision was unreasonable based on findings of fact, or that there was an incorrect interpretation of a question of law. *Scardoni v Hawryluck* (2004) 69 OR (3d) 700 at 715.

³⁸² Emphasis added. Interestingly the other factors to consider under the heading of best interests are all medical under s 21 (2) 1, which details the treatment options as related to the person’s well-being and the likelihood of improvement, or prevention of deterioration.

These two sections effectively create a two-tier threshold, whereby the first hurdle is a substituted judgment test under s 21 (1) (1), and if there is no wish applicable then the decision must be made in accordance with the principles of best interests as set out in s 21 (2). Section 21 (2) (a) refers to the previous self of the now-incompetent person, and s 21 (2) (b) is referring to an explicit-general prior view, as applicable in this case with the phrase “where there’s life there’s hope”. From these two sections it is possible to discern that there was a strong legislative purpose in emphasising the importance of a patient’s autonomy, and this was articulated in the judgment:

“For the purpose of consent to treatment, the interests of a patient’s individual autonomy are reflected in s. 21(1)1. Where the wishes of the patient are not known with sufficient exactness to satisfy the requirements of that provision, they may still be given weight under paras. (a) and (b) of s. 21(2) in determining the patient’s best interests.”³⁸³

The HCCA, therefore, provides a two-tier system, linked to prior wishes, for substitute decision-making. These provisions aim to respect the patient’s autonomy, with best interests (as informed by prior wishes) only factored in if no previously autonomous wishes about the particular decision can be ascertained. This is legislative recognition of the importance of prior competence, and effectively sets out that a person’s previous self and prior views should be taken into account, whilst prioritising an explicit wish over the previous self.

There are two particular aspects of the *Scardoni* case that need to be examined in more detail. The first is the relevance of her wish to her current condition in Investigation II (2) (c) of the proposal, and second is the status of the view in Investigation II (2) (d).

Relevance of View

The evidence given by Mrs Holland’s daughters at the Board’s hearing stated that she believed “where there’s life there’s hope”. Under Investigation I of the proposal this is an explicit wish, though it was a general expression of views as expressed by the phrase *explicit-general* (and in s 21 (2) (b) “any wishes expressed” under the HCCA). The evidence itself can be called reliable, the daughters were in agreement, and both stated that it was their mother’s view regarding hope where there was life. The Board held that this was too general to be considered as a prior capable wish under s 21 (2) (b), but Cullity J found that it would establish too high a standard if the patient needed to have contemplated specific

³⁸³ *Scardoni v Hawryluck* (2004) 69 OR (3d) 700 at [59].

circumstances for this to apply, although the Board was open to find that she had not expressed a wish “applicable to the circumstances” under s 21 (1) (1) on the evidence.³⁸⁴

There was obviously disagreement as to what constituted a “wish” under the HCCA. In trying to decide this question, it was asked: is a very general wish too general to be considered? In regards to s 21 (2) (b), Cullity J found the Board had wrongly interpreted as to what constituted expressed wishes:

“Expressed wishes that, for example, are held to be outside s. 21 (1), because they are insufficiently specific to satisfy the substitute decision-maker – or the Board – that they were in the contemplation of the patient when capable, may still permit an inference with respect to what the patient’s wishes would have been in the changed circumstances. In my opinion, s. 21 (2) (b) directs that they be considered in determining the patient’s best wishes and the Board erred in law in finding to the contrary.”³⁸⁵

In *Scardoni* the two-tier system clearly allows for this general type of wish as Cullity J found. The view that Mrs Holland expressed was undoubtedly vague because the concepts of life and hope are ill-defined. Its relevance was discussed by the judge, who found that Mrs Holland’s explicit view did not apply because she was too close to death (and therefore there was no hope because her life was barely flickering).³⁸⁶

How high should the standard for relevance be set? Under the proposal, because there are a multitude of factors being considered, the extent of the relevance of the prior view can be considered. With Mrs Holland’s case her view, while an explicit one, is also general and must be considered as such. What can help with the veracity of the view in Investigation III is considering the status of the view, which is discussed in the next section.

Status of View

Mrs Holland was Catholic, and both her daughters testified that these religious beliefs were at the root of the view that treatment should be continued. The Board considered whether this belief was justified in light of the Church’s teachings, concluding that while the Church

³⁸⁴ Ibid at 726. The Board even went as far as to ask this question of Mrs Scardoni in relation to the expression of her mother’s beliefs: “Q. Suppose prolonging her life cost the life of one of her children, is that something she would want? A. I can’t answer that.” at [64]. This is also a good example of value-laden language from the themes identified in Chapter Two. Whilst this question was obviously attempting to test the strength of her views it is poorly chosen.

³⁸⁵ *Scardoni v Hawryluck* (2004) 69 OR (3d) 700 at 721.

³⁸⁶ As already quoted in Chapter Two: “Certainly, there could always be hope but for Mrs. Holland it was sadly scant. Mrs. Holland was inexorably approaching death’s cold door and already within reach of knocking on it.” *Scardoni v Hawryluck* (2004) 69 OR (3d) 700 at [82].

maintained an adherence to the sanctity of life ethic, it also promoted the importance of dying with dignity. Cullity J found that s 21 (2) (a) was erroneously interpreted because the Board concluded that Mrs Holland's particular Catholic beliefs were not relevant. The judge said that this ignored the legislative purpose of s 21 (2) (a), that personal beliefs are relevant to the statutory concept of best interests. The *correctness* of the belief is not relevant. The Board did little to evaluate the status of the view; they could have asked such questions as – is the proposed view one that is consistent with all the information garnered of Mrs Holland? Was she a devout Catholic, regularly attending Mass, and 'living' the faith? Or was it something that was in the background for her? Those questions could have helped with the conclusion that she believed in "where there's life there's hope", as her daughters had linked this belief to her Catholicism. The pitfall to avoid was a lack of consideration – regardless of the answer to those questions – of what can be ascertained of Mrs Holland's *own* views? The question is not whether what the Catholic Church teaches is acceptable in this situation, unless it was related to her personal view, for example if she had said, at T1, "if I am ever in a permanently incompetent state please follow the Church's teachings". Or if her statement had seemed to rely on a misunderstanding of the Church's teachings, for example, "as a Catholic, I want to be kept alive as long as possible". But this was not the situation. Instead, Mrs Holland's Catholicism was subjected to a reasonableness test by the Board, and her extrapolation from those beliefs was found to be wrong. Overall, the status of the view appears to be consistent with Mrs Holland's prior beliefs and values, but it is a general view, and as such should be considered as a factor for consideration, not an overriding interest. If Mrs Holland's Catholicism was used as a basis for an inference about how she would have wanted to be treated, then it does make sense to interrogate what her Catholicism meant to her. However, this case shows that there is a danger of inferring that someone's stated religious or philosophical belief corresponds to what the "experts" understand of that belief system.

Scardoni is a case where the views expressed were sufficiently vague as to be open to interpretation; an interpretation found by the court to justify continuing life-prolonging treatment against medical practitioners' advice. Obviously, Mrs Holland's medical condition may be significant here, as she was not in a PVS, which distinguishes her case from *Bland*, *Re G* and *Re Durksen*. But was her explicit-general wish really sufficiently robust to outweigh other interests that she had? It is possible that the overwhelming emphasis on upholding the prior autonomously expressed wishes in the HCCA has led to a reliance on this

wish which does not hold up under scrutiny, as shown when examined in relation to the proposal for authenticity.

The next section discusses *explicit-specific* views to explore the presumption that these are the safest explicit prior view to rely on.

Explicit-Specific Cases

In this section four different cases are analysed, where the prior view can be rated as explicit – they made a specific, and applicable statement at T1 related in a direct way to their situation at T2. The first case is relatively straightforward and upholding the patient’s prior view is readily justified. The discussion then moves to consideration of some more difficult cases.

Re Durksen – Consistently Expressed Prior Wishes Applied

Re Durksen is a relatively straightforward case of an explicit-specific prior view, and (probably) as uncomplicated as possible in terms of the veracity of the prior view.³⁸⁷ Mr Durksen had been a Royal Canadian Mounted Police officer, but was in a PVS after a light plane crash. Regarding the relevance and the strength of view, four of his colleagues testified that he would not want to be in such a state: “Bob said that if he were ever in that situation, he wouldn’t want to be kept alive.”³⁸⁸ His daughter also said he would not want to live that way, and wanted the court to “allow my father to die in peace and [with] integrity.”³⁸⁹ Under Investigation II, regarding strength of view, there were multiple witnesses to a consistently expressed prior view. Additionally, as a police officer, Mr Durksen had been exposed to situations not unlike the one he was now in himself, and the views he expressed to his colleagues appeared to unequivocally show that he had related these prior experiences to his views. So far, it appears that Mr Durksen’s view for withdrawal of treatment was both extremely well evidenced, and highly relevant.

But is this necessarily true? Is the phrase ‘in that situation’ a specific reference to PVS? It seems plausible that it was, or something very like it, and it also seems plausible that a person who has seen people in this situation would not want to be in it himself. How would this view have come across if instead he had wanted to be kept alive in a PVS? Would it have

³⁸⁷ *Re Durksen* (1999) CarswellAlta 1672.

³⁸⁸ *Ibid* at [8].

³⁸⁹ *Ibid* at [12].

been considered less plausible under Investigation III? In that situation it is perhaps understandable that when an expressed view is outside the ‘norm’ or majority view that a higher standard of evidence is needed. This is reflected in other aspects of healthcare, for example when assessing competence the reasonableness of the decision can impact further investigation into whether the patient is competent to make the decision. It is common with patients of Jehovah’s Witness faith to robustly assess their refusal for blood products, as this is outside the standard for most patients.³⁹⁰ In Chapter Four the components for competence were assessed, and it was there argued that the values of a person should be incorporated into the process. Part of the rationale for this was the ability to then have a benchmark against decisions that are at odds with what might be considered the norm. It is not the decision that is being judged (although it may seem like it if requiring a higher standard of evidence) but that the person themselves fervently believed it. In *Re Durksen* there was no information that pointed to any doubt that at T1 Mr Durksen expressed a competent, consistent, informed view to many colleagues that he would not want treatment continued at T2.

So, unlike the previous cases, where the inference could be said to be on the less safe side of the scale, in *Re Durksen* the inference deduced from T1 at T2 is representative of a strong explicit-specific view.

Re C – MCA Underutilised

Re C is an interesting case to examine regarding a patient’s prior views, as there is extensive discussion of these in the judgment.³⁹¹ CW was 16 when he was in a car accident, rendering him in a PVS. When he was 21, his twin brother, parents, sister, and his medical carers petitioned the courts for his treatment to cease, advocating on his behalf, that his prior views were against continued treatment.

The facts in this case are similar to *Bland* with two major differences: CW had specific views about being in a PVS, and the MCA had been enacted. In *Bland*, a very non-specific set of thoughts about his prior views was put forward, but the case was still decided in favour of ceasing treatment. It is, therefore, not surprising that the same conclusion was reached in this

³⁹⁰ *Re T* [1992] EWCA Civ 18; [1993] Fam 95. This was a case about how strongly held the Jehovah’s Witness beliefs were to a young woman who while unconscious needed a blood transplant.

³⁹¹ *Re C* [2010] EWHC 3448 (Fam).

case. What is surprising was the way in which CW's prior views were utilised. The following paragraph sets out the extensive evidence for CW's explicit-specific view:

“While there is no written or oral advance directive in respect of the circumstances in which CW now finds himself his family are clear that he would not have wished to continue living in his current circumstances with no quality of life. He expressed views that he would not like to be kept alive artificially. They are certain that had he been able to he would not have given his consent for the continuation of his life with no physical dignity and no way of communicating.”³⁹² ... “CW's mother, brother and sister believe from their knowledge of him that CW would not want to remain alive in his present state. HW says that CW “feared above all else” being helpless and totally dependent on others and he had stated his wish not to survive in such circumstances several times. AW refers to a conversation he and his brother had a few weeks before the accident when CW said that his worst fear was to be left as he now finds himself. His brother's feelings about being helpless and terminally ill have been well known to his brother, mother and sister for some time. EW says that this is certainly not a life which CW would have wanted and if he had had the option to make the decision himself he would say that he wanted “to pull the plug”.”³⁹³

With such comprehensive discussion of CW's prior views, it is curious that the only references to the MCA are “having regard to sections 1, 2 and 3” and “sections 1 and 4” Ryder J found that CW lacked capacity and that he was given every possible opportunity to improve, and consequently participate, in the decision-making.³⁹⁴ Section 4(6) of the MCA states that the substitute decision-maker must consider the “person's past and present wishes and feelings”. This gives a clear mandate to state that CW, at T1, clearly wanted treatment withdrawn at T2. Instead Ryder J embarks on a summary of the common law, including *Bland* to decide that ANH could be withdrawn. Whilst s 15 MCA “puts those considerations on a statutory footing and gives statutory authority to the procedure for best interest declarations by the court”,³⁹⁵ it is suggestive of omission to not discuss the particular legislation as it relates to CW. Had the judge done so there would have been strong evidence for finding that CW's prior wishes favoured discontinuation of treatment, “his worst fear was to be left as he now finds himself”, and therefore a stronger case that it was in his best interests to do so. Under Investigation II the view was repeatedly expressed, to more than one family member and therefore the view could be safely relied on. However, Ryder J does so by employing the fiction of what CW “would want” if he could say so himself. This is

³⁹² Ibid at [24] per Ryder J.

³⁹³ Ibid at [26] - [27].

³⁹⁴ Ibid at [56] - [57].

³⁹⁵ Ian Wise "Withdrawal and Withholding of Medical Treatment for Patients Lacking Capacity who are in a Critical Condition - Reflections on the Judgment of the Supreme Court in *Aintree University Hospitals NHS Foundation Trust v James*" (2014) 82 (4) Med Leg J 144 at 147.

referenced to the family's assertions, but as already discussed it is actually a finding that most likely CW at T1 would have wanted treatment withdrawn at T2 when he was in S2.

To reference *Bland*, a case that was placed at the opposite end of the spectrum (inferred-general as opposed to explicit-specific), is puzzling. If prior views do not have any weight in the consideration of best interests, then the lack of reference to the view makes sense. However, if they do carry some weight, which is unequivocal under the MCA, then they should have been canvassed and used to bolster the decision.

Burke v General Medical Council – Setting the Limits on Patient's Prior Requests for Treatment

Leslie Burke was competent when he took his case to the High Court.³⁹⁶ He suffered from cerebellar ataxia, a congenital degenerative brain condition that resulted in him being in a wheelchair, but mentally unimpaired. Eventually, those afflicted lose the ability to communicate, although they are likely to retain full cognitive abilities even during the end stage of the disease.³⁹⁷ Mr Burke was concerned that the General Medical Council guidelines on incompetent patients would result in ANH being withdrawn from him – and he did not want this to happen. His case eventually went to the European Court of Human Rights where his appeal was not upheld. Although many view this case as one about a patient trying to compel a doctor to treat, it also provides insights for the place of prior views in the best interests test.³⁹⁸

At the High Court level the *Burke* case was heard by Munby J (who was incidentally the Official Solicitor for the *Bland* case, arguing in favour of not withdrawing treatment from Mr

³⁹⁶ *Burke v General Medical Council (Official Solicitor Intervening)* [2004] EWHC 1879;[2005] QB 424; *Burke v General Medical Council (Official Solicitor and Others Intervening)* [2005] EWCA Civ 100; *Burke v The United Kingdom* (2006) 19807/06. This case is included because it was to clarify what would happen when Leslie Burke was not competent, in effect the court case was a strong indication of his future wishes.

³⁹⁷ *Burke v General Medical Council (Official Solicitor Intervening)* [2004] EWHC 1879;[2005] QB 424 at [4].

³⁹⁸ The difficulty is that the right to refuse treatment is absolute and entrenched in the law, but the right to receive treatment is a lot more ambiguous. The reasons patients cannot demand treatment are briefly summed up as: all medical practitioners are constrained by limited resources, there is no duty to provide treatment if it is futile, patients could be unreasonable in their demands, and it is for the doctor to provide treatment that benefits the patient. Munby's later statement is even more startling in this context: "The personal autonomy protected by Article 8 [of the European Convention on Human Rights] means that in principle it is for the competent patient, and not his doctor, to decide what treatment should or should not be given in order to achieve what the patient believes conduces to his dignity and in order to avoid what the patient would find distressing." *Burke v General Medical Council (Official Solicitor Intervening)* [2004] EWHC 1879;[2005] QB 424 at [178]. See the section on "Sanctity of Life and Quality of Life" in Chapter Seven for extensive discussion on sanctity of life issues.

Bland). Perhaps some of his previous rhetoric seeped through, as his lengthy judgment ruled in Mr Burke's favour.

"The claimant wants to be fed and provided with appropriate hydration until he dies of natural causes. He does not want ANH to be withdrawn. He does not want to die of thirst. He does not want a decision to be taken by doctors that his life is no longer worth living."³⁹⁹

He was critical of the best interests test:

"Best interests may be the legal test but it is on its own a poor signpost to sound decision-making in an area as grave and difficult as this. In this and other areas of medical and non-medical decision-making the quality of the ultimate decision can only be enhanced by the adoption of a rigorously reasoned process of evaluation."⁴⁰⁰

He did not, however, elucidate as to how this differed to the reasoning and weighting exercise inherent in the best interests test, although he applied the test in a way that effectively equated best interests with autonomy:

"If the patient is competent (or, although incompetent, has made an advance directive which is both valid and relevant to the treatment in question) his decision as to where his best interests lie, and as to what life-prolonging treatment he should or should not have, is in principle determinative. Important as the sanctity of life is, it has to take second place to personal autonomy."⁴⁰¹

The alignment of a patient's wishes as the deciding factor in regards to best interests effectively make it a substituted judgment test, where the prior, competently expressed, view overrides all other considerations. In some jurisdictions this is dictated by the legislation, for example the HCCA in Ontario. But no such legislative scheme existed in England and Wales under the MCA. The Court of Appeal did not merely overturn Munby J's decision, they were critical of all aspects of the judgment, especially that he equated best interests with autonomy.

"A theme running through Munby J's judgment is that, provided that there are no resource implications, doctors who have assumed the care of a patient must administer such treatment as is in the patient's best interests and that, where a patient has expressed an informed wish for a particular treatment, receipt of such treatment will be in the patient's best interests. This theme thus equates best interests with the wishes of the competent patient."⁴⁰²

The Court of Appeal decided that the "concept of 'best interests' depends very much on the context in which it is used" and was not relevant to the case as they placed much greater

³⁹⁹ *Burke v General Medical Council (Official Solicitor Intervening)* [2004] EWHC 1879; [2005] QB 424 at [6].

⁴⁰⁰ *Ibid* at [115].

⁴⁰¹ *Ibid* at [116].

⁴⁰² *Burke v General Medical Council (Official Solicitor and Others Intervening)* [2005] EWCA Civ 100 at [27].

weight on the evidence that Mr Burke was likely to be competent until the very final stages of his disease, regardless of his concerns of what would happen after he was not competent.⁴⁰³

“Turning to Mr Burke’s concern that ANH may be withdrawn, contrary to his expressed wishes, so as to cause him to die of hunger and thirst while he is still competent, we have been unable to follow Munby J’s reasoning and fear that he may have lost the wood for the trees.”⁴⁰⁴

The safety of the inference in *Burke* can be said to be the strongest possible. Whilst competent at T1, with full knowledge (as much as is reasonably possible in any medical condition), he stated exactly what he wanted to happen to him. There could be very little doubt at T2, that his view at T1 was what he would want. From this there are two very different judgments: Munby J’s, whereby autonomy is equated with best interests; and the Court of Appeal, whose decision is underscored by the emphasis on a competent patient who is unable to demand treatment, whilst commenting:

“Indeed, it seems to us that for a doctor deliberately to interrupt life-prolonging treatment in the face of a competent patient’s expressed wish to be kept alive, with the intention of thereby terminating the patient’s life, would leave the doctor with no answer to a charge of murder.”⁴⁰⁵

Does this mean that a person can demand at T1 that they would want treatment continued at T2 if in a PVS? Apparently not, as this statement was qualified by the Court of Appeal when they discussed best interests in relation to a person in a PVS:

“While section 26 of that Act requires compliance with a valid advance directive to refuse treatment, section 4 does no more than require this to be taken into consideration when considering what is in the best interests of a patient.”⁴⁰⁶

Therefore a currently competent patient could request continued treatment, but an explicit-specific view at T1 does not have the same weight. This leaves questions for jurisdictions

⁴⁰³ Ibid; *Burke v General Medical Council (Official Solicitor Intervening)* [2004] EWHC 1879; [2005] QB 424. at [4] “The medical evidence indicates that the claimant is likely to retain full cognitive faculties even during the end stage of this disease and that he will retain, almost until the end, insight and awareness of the pain, discomfort and extreme distress that would result from malnutrition and dehydration. (If food and water were to be withheld he would die of dehydration after some two to three weeks.) He is also likely to retain the capacity to experience the fear of choking which could result from attempts at oral feeding. The medical evidence also indicates that the claimant is unlikely to lose his capacity to make decisions for himself and to communicate his wishes until his death is imminent. An eminent consultant in neurology and rehabilitation medicine describes what he calls “the likely scenario during the final days of Mr Burke’s life” as follows:

“he will by then be bed bound and communicating via a computerised device. He would then become unwell with either a chest or urinary tract infection and within a few days would become increasingly obtunded and lose the ability to use his communication aid. If medical treatment for the underlying infection is unsuccessful he would become progressively weaker and semi-comatose and then succumb.””

⁴⁰⁴ *Burke v General Medical Council (Official Solicitor and Others Intervening)* [2005] EWCA Civ 100 at [38].

⁴⁰⁵ Ibid at [34].

⁴⁰⁶ Ibid at [57].

where there is a hierarchy prioritising prior views over best interests; if a patient had said they wanted to be maintained in a PVS would they be? The following case provides some guidance for this in Alberta.

Swiss v Alberta – The Difficulty with Advance Directives

In the Canadian case of *Swiss v Alberta*, the patient had Islamic beliefs which he declared in writing, signing a declaration that he followed all Islamic rules including Sharia law.⁴⁰⁷ He knew he was seriously ill, and wanted to adhere to the teachings regarding removal of life support. Removal of life support systems under Sharia law was only allowed in certain circumstances – which Mr Swiss did not fall within because he retained brain function (however limited) and his heartbeat or breathing had not stopped. The evidence was obviously strong, as is the relevance, and therefore there would a strong basis for adhering to this belief. The Court of Queen’s Bench ruled that it was just one of several factors that had to be taken into account:

“Where possible, the wishes or religious beliefs of the patient should be given considerable weight, subject, however, to the patient’s best interest.”⁴⁰⁸

This is a considerably different approach to that where the starting point is the patient’s own wishes, as in Ontario, where Mrs Holland’s Catholicism was considered in *Scardoni*. However, rather than having a belief which generally reflected a Catholic belief in the sanctity of life, Mr Swiss specifically said at T1 that at T2 any treatment decisions were to be based on the rules of Islamic Sharia Law. In contrast to *Burke* the judge found that an advance directive could direct continued treatment:

“Thus, as the law currently stands, it appears that if a personal directive directs that all possible measures be taken to keep the patient alive, whether or not he is brain dead or no longer breathing on his own, the direction must be followed despite the fact that life support may be required for an indefinite period of time.”⁴⁰⁹

⁴⁰⁷ *Swiss v Alberta Health Services* [2009] ABQB 691 at [3]. Although it did provide a clear indication of his wishes, Ouellette J found that this declaration did not meet the requirements of a personal directive under the Personal Directives Act 2000 (Alberta). However, even if it was a personal directive the legislation did not cover the situation of a person wanting treatment continued.

⁴⁰⁸ *Ibid* at [44].

⁴⁰⁹ *Ibid* at [48].

Summary of Chapter Five

“I can say straightaway that when one examines the law, one finds obviously that the views, if one can interpret them, of what the patient might be and the views of the family are highly material factors. At the end of the day they are not however the governing factors when considering best interests.”⁴¹⁰

At the beginning of this chapter three problems were set out in regards to the prior views of incompetent patients.

(1) *The significance problem: do prior views matter, and if so why?*

Prior views matter, both ethically and legally because:

- (a) respect for autonomy, but this should not be confused with a fiction of respecting an incompetent patient’s current autonomy;
- (b) focus should be on the individual patient, and therefore their prior values, beliefs and interests matter; and
- (c) even without these moral requirements (but because of them) prior views matter because they are provided for in all legislation governing substitute decision-making.

(2) *The conflict problem: how to identify between the patient at T1 and their views at T2.*

The incompetent patient has no current view that is ascertainable. They may also have a previous view that conflicts with their current experiential interests.

(3) *The epistemic problem: since prior views matter, how can the substitute decision-maker know what they are?*

The simple answer is that any substitute decision-maker cannot know what the patient currently wants (which the conflict problem tells us) but it is possible to apply what they previously wanted, or may have wanted, at T1 to their condition at T2.

Having claimed that the logical extension of the significance of prior views is a close investigation into those views; a proposal for the veracity of the incompetent patient’s prior self was advanced. Part of this important step requires the categorisation of previously competent patients into those who have expressed a prior view, and those who have not. Further grouping is required in order to demonstrate differences between patients who had previously expressed wishes, and those who had a previous self that was being used by the courts as evidence for what they would have wanted. These have been categorised into four specific groups of cases, as identified in Table 1 which was generated from Investigation I of the proposal for veracity: inferred-general, inferred-specific, explicit-general and explicit-specific. Once this has been identified, the difficult process of evaluating the information

⁴¹⁰ *NHS Trust v A* [2005] EWCA Civ 1145; [2006] Lloyd’s Rep Med 29 at [59] per Waller LJ.

needs to be performed, and this has been set out under Investigation II of the proposal: (a) the reliability of evidence; (b) strength of the view; (c) relevance of the view and (d) status of the view or inference.

In Part Two of this chapter eight cases have been analysed with reference to the proposal for veracity. The picture that emerges does not fare particularly well against the stringent criteria in the proposal. It may be helpful at this stage to reiterate the expectations regarding prior views set out in Part One, against the analysis of Part Two.

- (1) Any prior views should be subject to a robust evaluation to determine their validity.

The overall analysis of end-of-life cases, coupled with the detailed analysis of the cases in this chapter, point to an indiscriminate pattern of applying the incompetent patient's prior views. Although, generally, they are given weight to (as appropriate, however *Re C* illustrates that this does not always happen) close analysis reveals fundamentally different approaches. These differences are demonstrated by the next three points.

- (2) Where there are documented prior views, the evidential strength of these should not be conflated with an inference of their validity.

James is a case where the strong evidence of his family was perhaps confused with the relevance to his current condition, and therefore his inferred-specific view was taken as valid. *Re Durksen* showed how a strength of view (he repeatedly stated at T1 that he did not want to be in a PVS) can be related to the validity (he had extensive experience in his profession with PVS). *Burke* is also an example of strong, relevant views. However, his views were in favour of treatment continuing. Yet the outcome in cases was different despite both being strong evidentially and relevant.

- (3) A patient's previous self should not be interpreted as evidence for prior views, and any move by a substitute decision-maker to construe the patient's previous self into their current situation should be regarded with extreme caution.

Bland and *James* show the breadth of possibilities that a patient's previous self can occupy. Whilst, in *Bland*, there was no overt statement to the effect that the court considered it to be Anthony Bland's wish for treatment to stop, it was implicitly present in the judgment. How could his personality – in any helpful way – be taken into account? The notion of the introvert versus extrovert personality types can have no bearing in such circumstances. The use of personality was used to bolster the

impression that the decision was in his best interests. By comparison, the family in *James* had a much stronger basis for their assertions that Mr James would have wanted treatment to continue. It is not that there is never any basis for interpreting a previous self as evidence for what the patient may have wanted at T1, it is that courts should be careful when doing so. Mr James' previous self is a good example of the Supreme Court making reasonable inferences from the evidence. There may be a lower threshold for views that accord with the norm (which is perceived as not wanting to live in a PVS or MCS) and therefore Mr James' previous self is subject to increased scrutiny. There is also the danger that a person's previous self, such as Mrs Holland in *Scardoni* can be interpreted in a way that manifests certain assumptions. Mrs Holland was Catholic, and her prior view "where there's life there's hope" was subject to an evaluation which considered the correctness of her belief against Catholic doctrine. The appeal judge appropriately criticised this approach, placing the emphasis on Mrs Holland's own beliefs.

(4) There should not be any fiction of respecting autonomy in a situation where the person, by definition, has no current autonomy.

In *Re G* the judge was satisfied that, if Mr G's wishes could be ascertained, they would favour discontinuation of treatment. The reality of the situation was that Mr G's wishes could not be known, and therefore a more accurate version of this statement is: when previously competent it is likely Mr G would not have wanted treatment to continue for his future, incompetent self.

(5) When discussing any prior self the substitute decision-maker should be clear that they are respecting the patient's precedent autonomy.

It is clear that a person's precedent autonomy is the only form of autonomy that can be upheld in the case of a permanently incompetent person. Despite this, it seems that this is often not clearly articulated in many end-of-life cases.

Assessing the prior self of a previously competent patient is one way to ascertain what a patient's prior interests may be. How else can an individual's interests be assessed if not in relation to themselves, their views and their values? This is reflected in the prioritising of the incompetent patient's previous self in the common law and statutory regimes. The next chapter discusses three narrow applications of the best interests test, and how the focus on the individual has been interpreted differently.

CHAPTER SIX: NARROW APPLICATIONS OF BEST INTERESTS

“It is arguable that, in a field where the law has not developed, where ethical principles remain controversial and where each case turns on its own facts, the law should not pretend to too great a precision.”⁴¹¹

The focus of the best interests test is the individual. On that point there is agreement, regardless of how it is applied; the difficulty lies in interpreting this emphasis. Firstly the person’s interests need to be ascertained, and then they must be evaluated to decide what is the *best* of these interests – should the decision be to treat or not? To operate or not? To withhold treatment or not? How is the focus on the individual best achieved? In the previous chapter a discussion was presented of the prior views that a permanently incompetent person may have had and how these have been interpreted to be (in various ways) part of the best interests consideration. Respect for prior views is not the only factor regarding best interests that may be considered, and if the patient had no prior competent self, then the interests that are possible to be appraised are fewer, but not less important. In Chapter Three several deductions regarding interests were discussed: (1) the sheer range of interests that people may have; (2) the different ways in which things become interests (for example, through experience, through relation to health or well-being); (3) the different types of interests (including subjective and objective, and experiential and non-experiential); and (4) the subject of the interests (the person him or herself, or others). The possibility of tensions between people’s interests was also raised. Simple examples include the common tension between a person’s life style choices and their health. It is important to note that the range of things that can count as interests is not much reduced by the fact that the person in question is incompetent. After all, incompetence is itself a wide-ranging category, including, but not restricted to people who have no experiences.

Against the background conclusion reached in Chapter Three that there are a wide range of interests, three different ways that best interests have been interpreted by the courts will be

⁴¹¹ *Secretary, Department of Health and Community Services v JWB* (1992) 106 ALR 385 at [14].

discussed. What they all have in common is that the judges have applied the test narrowly, and chosen a particular aspect of it to apply.⁴¹² The flexibility of the best interests test, whilst important for the interpretation of best interests for each individual, has also meant that some startling differences emerge. Questions which arise from these differences, and are consequently examined in this chapter, include: (1) does a permanently incompetent patient have any interests? (2) Should best interests be interpreted as best medical interests? (3) Is best interests an objective or subjective test, and, if objective, should it be interpreted as what the reasonable person would want? The answers to these questions reveal narrow approaches that the courts have taken at times, which is at odds with a flexible and malleable concept. The conclusion to these possible interpretations is that a *qualified-objective* approach is best, whereby good evidence of a patient's preferences are considered, as well as other interests.

Possible Interpretations of Best Interests

Judges have struggled to find a consistent voice when describing what kind of test best interests is. In this chapter approaches are demonstrated that limit interpretations of best interests to certain claims: (1) that only experiential interests matter; (2) that only medical interests matter; or (3) that best interests can be defined as objective or subjective and reduced to what the reasonable person would want. In determining what interests should apply to permanently incompetent patients there is likely to be a three step process: (1) identification of all possible interests; (2) deciding which of the full set of possible interests can be identified and specified in the particular case; and (3) making a final decision on which further subset of these will constitute the patient's 'best interests'. In the following sections an analysis is presented of judges ascribing interests in a narrow way to incompetent patients, and then Chapter Seven provides a critique of how interests are measured.

⁴¹² This may stem from the deficiency of guidance in either common law or legislation regarding best interests as per the last theme examined in Chapter Two, "Inadequacy of Existing Law".

Application One: Only Experiential Interests Matter

“Several opinions in the House of Lords decision in the *Bland* case I mentioned simply assumed that only experiential interests can matter, at least legally, and therefore had no difficulty in deciding that it could be neither in *nor* against Anthony Bland’s interests that his life support be discontinued.”⁴¹³

This is a rarely used approach whereby a person’s state – sensate or non-sensate – dictates whether or not they have any interests. Under this category, only experiential interests are of any relevance, and the test could be applied to adults or minors. Because only experiential interests have value, it applies to patients who are not sensate, and from this fact of their medical condition, it is assumed that they do not have any interests at all. Despite few judges finding that only experiential interests are applicable, this approach merits further discussion for three reasons: (1) it demonstrates significant differences between different judges’ application of best interests; (2) it provides a challenge to the conclusion regarding interests that was put forward in Chapter Three – that permanent incompetence does not preclude having interests; and (3) it raises fundamental questions about the relationship between personhood and the permanently incompetent patient.

Lord Mustill in the House of Lords in *Bland* had a firm stance predicated on the patient being sensate, which denied Anthony Bland any interests in his current state:

“Unlike the conscious patient he 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. What other considerations could make it better for him to die now rather than later? None that we can measure, for of death we know nothing. *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.*”⁴¹⁴

Lord Mustill decided that treatment could be withdrawn, but not because it was in Anthony Bland’s best interests for his life to be ended (because he was not capable of any such interest). He based his conclusion on the finding that the initial provision of treatment to Anthony Bland was in his best interests because there was the possibility of recovery, but once the clinical advice overwhelmingly supported the supposition that there was no hope

⁴¹³ Dworkin *Life’s Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (1993) at 208. Emphasis in original.

⁴¹⁴ *Airedale NHS Trust v Bland* [1993] AC 789 at 897. Emphasis added.

regarding recovery then his interest in being kept alive disappeared which justified withdrawal:

“Thus, although the termination of his life is not in the best interests of Anthony Bland, his best interests in being kept alive have also disappeared, taking with them the justification for the non-consensual regime and the co-relative duty to keep it in being.”⁴¹⁵

In effect, Lord Mustill decided that Anthony Bland was receiving treatment without his consent and therefore lawfully it should be removed.⁴¹⁶ This raises an interesting question about Anthony Bland’s possible interests. If it truly was a matter of complete indifference to him whether he lived or died, then why did the law not only allow, but actually require, that treatment be stopped? If the PVS patient himself has no interests tied up in the decision, then why could attention not have been paid to the interests of other parties, such as his family, or the other patients who may benefit from the freeing up of resources? Is it possible that, in requiring treatment that is non-beneficial to be stopped, the law is in fact recognising that Anthony Bland had a (non-experiential) interest, perhaps in bodily integrity or dignity? In adopting a default position of ‘no consent, no treatment’, it is possible that the courts have implicitly recognised an a priori interest in being left alone, an interest that is attributed even to patients who are deemed to be without interests.

Lord Keith also appeared to endorse a position equating interests with the prerequisite that they should be experienced, though not quite as explicitly:

“In the case of a permanently insensate being, who if continuing to live would never experience the slightest actual discomfort, it is difficult, if not impossible, to make any relevant comparison between continued existence and the absence of it. It is, however, perhaps permissible to say that to an individual with no cognitive capacity whatever, and no prospect of ever recovering any such capacity in this world, it must be a matter of complete indifference whether he lives or dies.”⁴¹⁷

Presumably Lord Keith meant that to any individual lacking cognitive capacity, it would be a matter of indifference to that individual whether he or she lives or dies. This would include Anthony Bland, at least on Lord Keith’s account. This was based on Anthony Bland’s current experiential interests. But, on a wider conception of interests that include non-experiential and other-regarding interests, this limitation on what is relevant for existence is

⁴¹⁵ Ibid.

⁴¹⁶ One of the main ratio decidendi in the *Bland* decision is that it is only lawful to treat an unconscious patient who cannot consent to treatment when it is in his or her best interests to do so; if it is no longer in a patient’s best interests to be treated, it is no longer lawful to treat them and it is therefore not unlawful to discontinue. *NHS Trust v A* [2005] EWCA Civ 1145; [2006] Lloyd’s Rep Med 29.

⁴¹⁷ *Airedale NHS Trust v Bland* [1993] AC 789 at 858.

not a legitimate approximation of the kinds of interests that are taken into account. Hoffmann LJ (in the Court of Appeal, decided before Lords Mustill and Keith's judgments) challenged the concept that the only interests that matter are those we experience, giving support to the category of non-experiential, self-regarding interests:

“I think that the fallacy in this argument is that it assumes that we have no interests except in those things of which we have conscious experience. But this does not accord with most people's intuitive feelings about their lives and deaths... Most people would like an honourable and dignified death and we think it wrong to dishonour their deaths, even when they are unconscious that this is happening. We pay respect to their dead bodies and to their memory because we think it an offence against the dead themselves if we do not. Once again I am not concerned to analyse the rationality of these feelings. It is enough that they are deeply rooted in our ways of thinking and that the law cannot possibly ignore them.”⁴¹⁸

In one sense, it would be right to say that a person who has no interests (who does not have the cognitive capacity for any) does not care what happens to them. But, as discussed in Chapter Three, there are a wide range of possible interests, and many of those are not dependent on our knowing about them, and so in this way Lords Mustill and Keith are taking a very narrow approach to the question of interests.

What could explain this very diverse approach to interests? In the next section it is asserted that the interpretation, whereby only experiential interests matter legally, is derived from a perspective which equates being insensate with having no personhood. This notion, of only experiential interests being of importance, has stemmed from a false perception of what it means to be a person, and the difference between a person and personhood which is discussed in the following section.

What Does it Mean to be a Person?

“Perhaps a man really dies when his brain stops, when he loses the power to take in a new idea.”⁴¹⁹

To most people, the question of what it is to be a person may seem ridiculous. It appears easy to define what persons are: they are human beings with recognisable physical characteristics that make them different from other species. The matter begins to look less straightforward, though, when we turn our minds to harder cases. Are foetuses persons?

⁴¹⁸ Ibid at 829. Hoffmann LJ's position was also used to show the difference between a legal position on interests – which has a duty to serve society and society's views – and an academic one.

⁴¹⁹ George Orwell *Coming up for Air* (Numitor Comun Publishing, 1996).

Some, such as Kuhse and Singer, argue that there is not a salient difference between a viable foetus and a newborn baby.⁴²⁰ Further to that and for the purposes of this thesis, what about those who are permanently insensate beings? What is recognisable about them in any way (other than physically) as the person they once were, as they cannot communicate any of their current desires? It is often this upsetting difference between the person that the whānau once knew, compared to the person in the hospital bed, which brings about a willingness and peace in saying goodbye to them. This difficulty, this reality of a medically induced problem which enables people to be kept technically alive long past any sign of continuation of their personality or responsiveness or awareness, has provided new challenges for the notion of personhood.⁴²¹ The distinction between what a person is, and what it means to have attributes of personhood, is one that is implicitly employed in many ways in substitute decision-making. If someone no longer resembles the person that they were and are completely unable to interact on any level, are they still a *person*? Or is someone in a PVS a *human being* which is a separate entity from persons?

If the view that personhood is needed as a prerequisite to be a person is accepted, then all human beings are not necessarily persons, and all persons (in some accounts) are not necessarily human beings.⁴²² There are a range of views expressed by bioethicists, from those who see personhood as a special moral category (defined in various ways) to those who reject this, and hold that being a human being is sufficient to have moral standing. The following section examines these views in sufficient depth to inform the discussion regarding the judicial application of interests. The intent is not a comprehensive exploration of personhood – this is a subject on which there is endless debate and the nuances of these arguments are not relevant for the purposes of this thesis. It is sufficient here to point out the range of views on personhood, show some shared agreement on what it entails, and then to demonstrate how this relates to end-of-life cases.

⁴²⁰ Helga Kuhse and Peter Singer *Should the Baby Live? The Problem of Handicapped Infants* (Oxford University Press, Oxford, 1985).

⁴²¹ Many ideas surrounding the notion of personhood emerged from the Ancient Greek philosophers.

⁴²² Kuhse and Singer (1985); John Harris "The Right to Die Lives! There is No Personhood Paradox" (2005) 13 MLR 386. For example, Koko the gorilla would be accepted as a person under these criteria. Additionally, Argentina and Spain have also granted certain rights of personhood to great apes, see: Martin Roberts "Spanish Parliament to Extend Rights to Apes" (25 June 2008) <www.reuters.com/article/us-spain-apes-idUSL256586320080625>; BBC News "Court in Argentina Grants Basic Rights to Orangutan" (21 December 2014) <www.bbc.com/news/world-latin-america-30571577>.

Definitions of Personhood

Judges have tended to take a particular view regarding personhood without examining the alternatives. For example, some judges have equated attributes of personhood (and being a person) as central to the existence of interests. This is a mistake because even if the patient is a non-person, they may still have interests (though not those we would attribute to a person).

Most accounts of what it means to be a person equate it with personhood:

“A person is a creature who usually has capacity for rationality, is a social being consisting of part of a specific culture, and usually uses a language to communicate with other persons. A person also maintains the ability to experience things and to hold different mental states with regard to their external surroundings as well as their internal state of affairs.”⁴²³

In Sperling’s account, personhood and person have a close conceptual connection, where characteristics of personhood are necessary to be a person. This connection is rather complicated by the distinction outlined earlier in this chapter, that personhood and persons may not necessarily denote the same entity, but they are often described as dependent on each other. There are many conceptualisations of personhood; attributes often include sentience, self-consciousness, the presence of spirit, soul or power.⁴²⁴ Gillett favours an interpretation that defines personhood as the capacity to act intentionally.⁴²⁵ Harris defines persons as:

“beings with the capacity for valuing their own existence. In the case of human beings, they become persons when the capacity to value their own lives develops and will cease to be persons when they have lost that capacity.”⁴²⁶

So, on Harris’ account, infants and younger children are not persons, and neither are those in a permanently incompetent state. Green identifies personhood as a social construct which can be decided by a consensus of “reasonably mature individuals”.⁴²⁷ Doerflinger criticises this view, asserting that it leads to the conclusion that:

“there is nothing inherent in any human being that obliges us to respect that being as a person.”⁴²⁸

⁴²³ Sperling (2008) at 4.

⁴²⁴ "Anthropology and Science: Science and Personhood" 15 December 2014.

⁴²⁵ Grant Gillett "BITC 404 Ethics and Health Care Lecture on Genetics" (Paper presented at Bioethics Centre, Dunedin, 13 October 2004).

⁴²⁶ John Harris *The Value of Life* (Routledge, London, 1985) at 25.

⁴²⁷ Richard M Doerflinger "The Ethics of Funding Embryonic Stem Cell Research: a Catholic Viewpoint" (1999) 9 (2) Kennedy Inst Ethics J 137 at 139.

⁴²⁸ Ibid.

But in some ways Green is correct. Persons might not be able to be defined by consensus, but it does seem that society decides when a human being does, or does not, have certain rights and interests, including the right to life, and that those decisions are linked with some of the features of personhood described above.

Buchanan and Brock describe those who are permanently unconscious as not a person:

“Some of the strongest candidates for being included among the necessary conditions [for being a person] are the following cognitive capacities:

- (a) The ability to be conscious of oneself as existing over time – as having a past and a future, as well as a present.
- (b) The ability to appreciate reasons for or against acting; being (sometimes) able to inhibit impulses or inclinations when one judges that it would be better not to act on them.
- (c) The ability to engage in purposive sequences of actions.

... If any of these three, or anything even roughly similar to any of them, is at least a necessary condition of being a person, then it appears that the permanently and profoundly demented patient ... is not a person”⁴²⁹

It would certainly seem to be the case that a permanently incompetent human being would also fail these tests of personhood. But, since they could also have interests, it seems to follow that Buchanan and Brock do not restrict interests to persons (to entities who have personhood).⁴³⁰

Referring back to the *Bland* case, all of the judges discussed the patient’s characteristics in a way that demonstrated that he lacked any personhood according to any the definitions so far explored. Where they differed was in the conclusions that this observation led to. Lord Mustill (and possibly Lord Keith) concluded that this meant that human beings in a PVS lack interests. For example, Lord Mustill discussed Anthony Bland in relation to personality:

“... I still believe that the proposed conduct is ethically justified, since the continued treatment of Anthony Bland can no longer serve to maintain that combination of manifold characteristics which we call a personality. Some who have written on this subject maintain that this is too narrow a perspective, so I must make it clear that I do not assert that the human condition necessarily consists of nothing except a personality, or deny that it may also comprise a spiritual essence distinct from both body and personality. But of this we can know nothing, and in particular we cannot know whether it perishes with death or transcends it. Absent such knowledge we must measure up what we do know. So doing, I have no doubt that the best interests

⁴²⁹ Buchanan and Brock (1990) at 159; they do however think that if someone had been previously competent they could have future-oriented interests; this is examined in Chapter Seven.

⁴³⁰ Ibid at 129.

of Anthony Bland no longer demand the continuance of his present care and treatment.”⁴³¹

The issue for many regarding personhood is that, if a particular entity is lacking it, for example a foetus or someone in a PVS, this means that different rules may apply.

“Most personhood theorists think that once personhood has disappeared (as in permanent vegetative state) or before it has arisen (as with the fetus and embryo), the life has no value; it is the personhood that is valuable, embodied, in the case of humans, in an organic living body but in the case of other possible forms which persons might take, not necessarily so embodied.”⁴³²

For the discussion in regards to judicial recognition of interests, the question is this: if a permanently incompetent person has no personhood then are different interests ascribable? The consequences of a permanently incompetent individual having no interests at all, taken to its reductio ad absurdum, means that there would be no reason to treat the patient with respect or dignity, or to show any consideration for their prior views. Whilst those proposing this view would probably protest this consequence, when the patient is attributed with no interests this severely undermines the foundation for any reason to treat them with respect, which is surely a minimum requirement for these very vulnerable patients. A lack of personhood should not mean that the permanently incompetent have no interests at all, which many theorists have argued.⁴³³ But what if the permanently incompetent patient fits within some descriptions of personhood, but cannot communicate this ability? The following section examines this dilemma.

The Opposition of the Mind and Body

“I was put in a bed in the intensive care ward; countless tubes ran in and out of my body. I could see and hear and I knew exactly what was happening to me. But, except for being able to blink my eyes, I couldn’t move. I couldn’t swallow, or talk, or wee, or breathe. When the last vestiges of movement left my hands, I had no way of communicating. I was buried alive in my own body. As tragedies go, it’s a good one, no?”⁴³⁴

The year before *Bland* was decided, New Zealand courts considered the question of withdrawal of treatment from an incompetent patient. In *Auckland Area Health Board v Attorney-General*, intensive care doctors at Auckland Hospital, together with the Auckland Area Health Board, applied for a declaration clarifying whether in law they would be guilty

⁴³¹ *Airedale NHS Trust v Bland* [1993] AC 789 at 889.

⁴³² Harris "The Right to Die Lives! There is No Personhood Paradox" (2005) 13 MLR 386 389.

⁴³³ See Chapter Three.

⁴³⁴ Keyes (2014) at 32.

of culpable homicide if they withdrew ventilator support from a 59 year old man, Mr L, suffering from Guillain-Barré syndrome.⁴³⁵

“The disease affected the nervous system of the patient by destroying the conductivity of the nerves between the brain and the body. The result was to leave the brain, though still living, entirely disengaged from the body. The patient survived in a state of “living death”, totally unable to move or communicate and there was no prospect of recovery. However, because the brain, though damaged, was not dead, the patient was not medically brain-stem dead pursuant to the medical definition of “death”. The patient had existed in that condition for 12 months. Eight specialists who had examined the patient and undertaken extensive testing were unanimous that the ventilatory support of the patient could not be medically justified.

In stark terms, Mr L has a living, but impaired, brain which is entirely disengaged from his body. So he cannot move muscle or limb. He lies lifeless and motionless, unable to communicate by even elementary means. His condition is so severe that he has no prospect of recovery.”⁴³⁶

This condition meant he was effectively trapped in his own body. He could not move at all and all methods of communication were permanently shut down. This was described in the judgment by Thomas J in terms that were echoed in *Bland*:

“Whether a body devoid of a mind or, as in the case of Mr L, a brain destitute of a body, does not matter in any sensible way. In their chronic and persistent vegetative condition they lack self-awareness or awareness of the surroundings in any cognitive sense. *They are the ‘living dead’.*”⁴³⁷

It must be noted that he was not in a clinically defined condition of brain death which requires that the brain stem be effectively dead. Nor was he in a PVS or similar state, where the patient has no real awareness or ability to suffer. He was in effect suffering from the opposite condition: he could not move any part of his body meaningfully but his brain was

⁴³⁵ *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235. This case was based on the declaratory jurisdiction that exists in New Zealand rather than *parens patriae*. It is still possible to discuss it here in relation to best interests for three reasons: (1) it demonstrates the theme identified in Chapter Two regarding inadequacy and lack of clarity of law; (2) a best interests consideration did have to be made based on the conclusion that ‘good medical practice’ included a *Bolom* qualification that the treatment withdrawal was in the best interests of the patient (at 237); and (3) it can also be argued that a discussion of best interests would have helped the judge make a more ethically informed ruling: Gillett, Goddard and Webb (1995) 3 JLM 49. Furthermore it was discussed in relation to the best interests test in *Airedale NHS Trust v Bland* [1993] AC 789 at 872 per Lord Goff: “[Y]our Lordships’ House adopted a straightforward test based on the best interests of the patient; and I myself do not see why the same test should not be applied in the case of P.V.S. patients, where the question is whether life-prolonging treatment should be withheld. This was also the opinion of Thomas J. in *Auckland Area Health Board v. Attorney-General* [1993] 1 N.Z.L.R. 235, a case concerned with the discontinuance of life support provided by ventilator to a patient suffering from the last stages of incurable Guillain-Barre syndrome.”

⁴³⁶ *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235 at 238.

⁴³⁷ *Ibid* at 245. Emphasis added. See also: *Airedale NHS Trust v Bland* [1993] AC 789 at 829 per Hoffmann LJ: “But the very concept of having a life has no meaning in relation to Anthony Bland. He is alive but has no life at all.” Lord Keith echoed Hoffmann LJ at 863: “I start with the simple fact that, in law, Anthony is still alive. It is true that his condition is such that it can be described as a living death; but he is nevertheless still alive.”

still operative. There was some discussion in the judgment as to whether Mr L may have suffered some brain damage, but there was no discussion regarding his awareness of what was happening to him, and around him. The Guillain-Barré syndrome had struck Mr L severely and quickly. Most patients recover to various degrees and less than five percent die from the condition. However, Mr L had been in the same state for twelve months and medical experts agreed that there was no hope for his recovery. Thomas J issued a declaration that it would not be culpable homicide if treatment was withdrawn:

“... I do so in the conviction that Mr L deserves the description of ‘living dead’ as much as if he were brain-stem dead.”⁴³⁸

The judges in *Bland* quoted from *Auckland Area Health Board v Attorney-General* with approval. In both cases, the patient is described as being in “living death”. Judges in both cases found that treatment should be discontinued. Also, in both cases there was a disconnect between the mind and the rest of the body – one was working whilst the other was not. This actually represents a major difference, one which does matter “in any sensible way” in comparison to Thomas J’s assertion that it did not. What is this salient difference? In *Bland*, the body functioned, except for the brain, whereas in *Auckland Area Health Board v Attorney-General* the body could not move and the brain may have been functional.

There was no discussion of the difference between a permanently unconscious patient and a patient with Guillain-Barré in *Bland*. Likewise in *Auckland Area Health Board v Attorney-General* there was no discussion of the implications that Mr L possibly had an intact brain but just had no way of communication.⁴³⁹ It is very likely that Mr L overheard discussions regarding his care, was told of the intention to remove his ventilator, heard his family saying goodbye – all without being able to reply.⁴⁴⁰ Thomas J’s statement that he lacked “self-awareness” and “awareness of the surroundings in any cognitive sense” is simply not able to be known.⁴⁴¹ By describing Mr L in these terms, he was effectively removing any possibility of personhood, something that perhaps made the decision easier. Mr L may have possessed

⁴³⁸ *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235 247.

⁴³⁹ This conflation persists, for example in a case heard by the Supreme Court of the Australian Capital Territory Mr L was described as: “in an irreversibly vegetative state.” *Australian Capital Territory v JT* [2009] ACTSC 105 at [31].

⁴⁴⁰ Grant Gillett *Personal Communication* (15 August 2013). (Professor Gillett presented the court with evidence as a neurosurgeon).

⁴⁴¹ There is plenty of anecdotal evidence that this is not true. For example: Kate Allatt "It was Like Being Buried Alive" www.stuff.co.nz/life-style/life/10614408/It-was-like-being-buried-alive 2014. “My experience has taught me that we should always assume that a patient is conscious until we have absolutely proven otherwise.”

many of the characteristics of personhood; he could have had awareness and consciousness and an ability to reason. Mr L could also have possessed all of the components needed for competence examined in Chapter Three; he could have had the capacity to reason, to understand and possess a set of values that he could evaluate these against. The tragedy with Mr L is that he may just not have been able to communicate his personhood, and, as discussed in Chapter Three, the ability to communicate capacity to understand and reason is a necessary component of competence. The implication of this is that it supports a distinction between personhood (or being a person) and competence. Mr L was quite likely to be within the definition of a person (on some of the same criteria) but he was not competent. Therefore personhood may be necessary for competence, but it may not be sufficient.

There is no indication that Thomas J gave any consideration to the fact that Mr L could possibly hear, and understand, the conversations regarding his death. He could have argued that this presented a stronger reason to withdraw treatment – because Mr L would have been aware of being on a ventilator and of all the indignities that his body was being subjected to, and could therefore have a strong experiential interest in treatment being withdrawn. Instead, while acknowledging that Mr L's mind and body were separate and using this as a justification for treatment withdrawal, he did not thoroughly examine the implications of it being the brain that was the living part of the living death. In effect, the judge ignored any experiential interests that Mr L may, and probably did, have.

There was also evidence of an explicit-specific prior view, which, as shown in Chapter Five, can be used to prioritise the patient's prior, competent self where a safe inference can be made: Mr L's wife gave evidence that Mr L had expressed an aversion to being paralysed:

“Jack said to me ‘It would be bloody horrible to be like that [upon seeing someone almost totally paralysed]. I would hate it’.”⁴⁴²

This could have been used as evidence for what Mr L probably wanted *currently*, although he had no means of communicating any preference. Is this any different from applying his previous views at T1 to T2? If this explicit-specific statement was taken as his current wishes, because he had awareness and the ability to formulate a choice, does this compete with upholding a wish expressed prior to incompetence where the patient is not able to formulate any choices? There is no way of knowing in either case if the patient had changed

⁴⁴² Gillett, Goddard and Webb (1995) 3 JLM 49 at 54. Again, there was no discussion of this in the case, but presumably the authors' personal involvement gave them access to Mr L's wife's affidavit to the court.

their mind, and therefore the information in both should be considered similarly. Mr L's dismay at the thought of paraplegia could, however, be used as extra weight for withdrawal of treatment, especially when coupled with the possibility of any awareness that he may have had.

The notion of personhood (though not stated as such) is central to both of these cases, because, if either Anthony Bland or Mr L had demonstrated any of the characteristics of a person – that is acting intentionally, having capacity for self-awareness, and exhibiting sentience – there would have been a debate about the quality of life rather than just accepting that he had “no life at all”, as described by the various judges. Keown describes the personhood debate in terms of dualism; a concept simplistically described as denoting the idea that the mind and body are separate. He points out that the *Bland* judgment endorsed the idea that a human being consists of both a “body” and a “person”, as illustrated by Sir Stephen P:

“To his parents and family he is “dead.” His spirit has left him and all that remains is the shell of his body.”⁴⁴³

This judicial recognition of dualism in the *Bland* case is “both novel and surprising” according to Keown.⁴⁴⁴ The view that this was what the judges were doing was also supported by McEwan:

“Judges at all levels employed language which demonstrates a judicial notion of a metaphysical separation of mind and body”.⁴⁴⁵

Again an extensive debate on the philosophical merits, or lack of, regarding dualism is not needed, except to point out that if Keown is correct, and there is a judicial endorsement of dualism, it has few supporters:

“This sort of dualism, which thinks of the body as if it were some kind of habitation for and instrument of the real person, is defended by few philosophers indeed (religious or otherwise). It renders inexplicable the unity in complexity which one experiences in everything one consciously does.”⁴⁴⁶

It also shows that there is a lack of clarity in thinking – if the mind and body are separate, and we have opposite cases of one working whilst the other does not, how can the conclusion in

⁴⁴³ *Airedale NHS Trust v Bland* [1993] AC 789 at 804.

⁴⁴⁴ John Keown "Restoring Moral and Intellectual Shape to the Law after Bland" (1997) 113 (Jul) *Law Quarterly Review* 482 at 493.

⁴⁴⁵ Jenny McEwan "Murder by Design: The 'Feel-Good Factor' and the Criminal Law" (2001) 9 (3) *MLR* 246 at 252.

⁴⁴⁶ Simon Lee *Uneasy Ethics* (Random House, Kent, 2011) at 35. Quoting Professor John Finnis' discussion of Hoffmann LJ's approach in *Bland*.

both be that the patients are in living death and that treatment can be withdrawn in their best interests? Futility of treatment was used in the *Bland* case – it was not in his best interests to continue to receive life-prolonging treatment. But, in *Auckland Area Health Board v Attorney-General* this argument should have been shifted to wider considerations of Mr L’s self-regarding interests in dignity and the anguish he was possibly suffering of being trapped in his own body with no means of communication. Rather ironically (compared to conclusions drawn elsewhere in this thesis regarding the propensity for applying self-regarding interests)⁴⁴⁷ the lack of evaluation of Mr L’s best interests and his particular circumstances, was, unfortunately, not the primary focus of the argument.

Perhaps if Mr L’s case was being discussed now it would have a different result. Brain scans could probably be used to elicit information from Mr L if he did indeed have capacity, and some form of communication could be used to ascertain – and implement – his current wishes.⁴⁴⁸ But, as it was in 1993, treatment was withdrawn on the basis that he was “irreversibly doomed” – a description that may have been apt, but a description that was unexplored.⁴⁴⁹

The narrow approach, whereby only experiential interests matter, is therefore a difficult one to justify. In the following section the approach which prioritises either a medical view or the patient’s medical condition is discussed as the most important consideration in the best interests test.

Application Two: Deferment to a Medicalised View

In *James*, discussed extensively in Chapter Five, Sir Alan Ward discussed Mr James’ medical interests in relation to his prior wishes:

“But the patient’s wishes are not the deciding factor in working out his best interests and do not determine what treatment he should receive. The patient’s own wishes

⁴⁴⁷ See Chapters Three, Chapter Five and Seven.

⁴⁴⁸ This ability has now extended to those who are seemingly unable to do so: Martin M Monti and others “Willful Modulation of Brain Activity in Disorders of Consciousness” (2010) 362 (7) N Engl J Med 579 at 589. The researchers performed MRI scans on 54 patients with “disorders of consciousness”, finding that five of these were able to wilfully modulate brain activity. “These results show that a small proportion of patients in a vegetative or minimally conscious state have brain activation reflecting some awareness and cognition.”

⁴⁴⁹ *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235 at 245.

have a part to play, as I shall show, in the final question of what is in his best interests but his wishes do not dictate what is in his best *medical* interests.”⁴⁵⁰

What he meant by this is unclear. There are two possible interpretations. The first is that “medical interests” refers to the collective medical opinion of what is in Mr James’ best interests; an opinion that constitutes what the majority of a reasonable body of medical professionals would agree upon (known as the *Bolam* test). The second, and more likely interpretation, is that he was referring to Mr James’ medical condition. Both of these possible interpretations have been utilised in prospective end-of-life judgments, and therefore each warrants the further discussion which is set out in the next two sections.

Bolamising Best Interests

“When McNair J. delivered his direction to the jury in *Bolam v. Friern Hospital Management Committee* just over forty years ago, it can only be a matter of speculation whether he ever appreciated how famous, or infamous, the *Bolam* test would become.”⁴⁵¹

The *Bolam* test, as articulated in the case that it derives its name from, is this:

“A doctor is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular act.”⁴⁵²

The test was formulated in relation to negligence over practices undertaken for electro-convulsive therapy, which appears somewhat incompatible to a guiding principle for medical treatment. The resulting confusion in its application to best interests was demonstrated in *Bland*, and opinions as to how best interests would apply fell into two distinct camps. These approaches are described by Foster and Miola’s generalised typology of medico-ethico-legal decisions: “professional medical ethical decisions” are those that the law decides are best decided by the medical profession.⁴⁵³ A “legal decision” is when the law takes charge and is the final decision-maker on whether a treatment decision is right or wrong.⁴⁵⁴

⁴⁵⁰ *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65 at [36]. Emphasis in original. The third Court of Appeal judge, Laws LJ, agreed with Sir Alan Ward’s orders and the reasons given by him. The tension between these two concepts – prior views and medical interests – is discussed in Chapter Seven in the section “Prior Views and Other Interests”.

⁴⁵¹ Margaret Brazier and José Miola “Bye-bye Bolam: A Medical Litigation Revolution?” (2000) 8 (1) MLR 85 at 85.

⁴⁵² *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582 at 586.

⁴⁵³ Foster and Miola (2015) 23 (4) MLR 505 at 509. The last of their three categories, “moral” decisions are those that the individual makes for him or herself, and is not relevant here.

⁴⁵⁴ *Ibid* at 508.

The first of these approaches held that courts were deciding whether the *medical profession's* assessment of the patient's best interests was legal, and was therefore a *professional medical ethical decision*. This effectively 'Bolamised' best interests. This coined term denotes that the judges were deciding whether the doctors had properly assessed Anthony Bland's best interests.⁴⁵⁵ Was the collective medical opinion, that a "reasonable body of medical professionals" would agree withdrawal of treatment was in Anthony Bland's best interests? If so, then the judges were not independently making the assessment of best interests themselves:

"Different doctors may take different views both on strictly medical issues and the broader ethical issues which the question raises. 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...* Accordingly, on an application to the court for a declaration that the discontinuance of medical care will be lawful, *the courts only concern will be to be satisfied that the doctor's decision to discontinue is in accordance with a respectable body of medical opinion and that it is reasonable.*"⁴⁵⁶

In the second approach, a *legal decision*, the *court* was making a decision about the patient's best interests, independently from the medical profession, where the medical opinion factored in but was not considered to be the overriding factor. Lord Mustill (again) was the outlier in the House of Lords:⁴⁵⁷

"But I venture to feel some reservations about the application of the principle of civil liability in negligence laid down in *Bolam v. Friern Hospital Management Committee* [1957] 1 W.L.R. 582 to decisions on 'best interests' in a field dominated by the criminal law. I accept without difficulty that this principle applies to the ascertainment of the medical raw material such as diagnosis, prognosis and appraisal of the patient's cognitive functions. Beyond this point, however, it may be said that the decision is ethical, not medical, and that there is no reason in logic why on such a decision the opinions of doctors should be decisive."⁴⁵⁸

These two methodologies represent disparate approaches.⁴⁵⁹ The *Bolamisation* in *Bland* was summarised by Miola as "an abrogation of responsibility to the medical profession", which is

⁴⁵⁵ Phrased by: Miola (2007).

⁴⁵⁶ *Airedale NHS Trust v Bland* [1993] AC 789 at 884 per Lord Browne-Wilkinson, emphasis added.

⁴⁵⁷ See the first section in this chapter for his judgment for discussion as to whether Anthony Bland had any interests or not.

⁴⁵⁸ *Airedale NHS Trust v Bland* [1993] AC 789 at 898 per Lord Mustill.

⁴⁵⁹ This fits within the theme identified in Chapter Two regarding difference of reasoning. See also Sir Stephen P at 805, Sir Thomas Bingham MR at 810 and 813, Butler-Sloss LJ at 819, Lord Goff of Chieveley at 874: *Airedale NHS Trust v Bland* [1993] AC 789.

probably a fair assessment of this way of interpreting best interests.⁴⁶⁰ However, these disparate approaches, as to whether best interests is a medical or judicial decision, appears to have been settled. While the courts do rely on the evidence of the medical experts, and give it great weight, it has become clear that it is for the judges and not the doctors to decide what is in the best interests of the patient.⁴⁶¹

“It is, I think, important that there should not be a belief that what the doctor says is the patient’s best interest *is* the patient’s best interest.”⁴⁶²

The determination that it is the courts’ role to evaluate the patient’s best interests appears to have been the result of three factors: (1) the recognition that best interests encompasses a wide range of interests;⁴⁶³ (2) recognition that judges have a role to play in the proceedings beyond ascertaining the doctor’s assessment of best interests;⁴⁶⁴ and (3) the development of legislation which requires the substitute decision-maker to make decisions in the patient’s best interests.

Medicalising Best Interests

“As I see it, this review of s. 21(2) reveals that although a patient’s beliefs and prior expressed wishes are mandatory considerations, there is no doubt that the medical implications of a proposed treatment will bear significant weight in the analysis.”⁴⁶⁵

Another way to view best interests is to interpret it as asking what is in the patient’s best medical interests. This places the greatest emphasis on their current experiential interests, and the possible futility of the treatment that they are receiving.⁴⁶⁶ Whilst these are both

⁴⁶⁰ Miola (2007) at 154.

⁴⁶¹ *NHS Trust v A* [2005] EWCA Civ 1145; [2006] Lloyd’s Rep Med 29.

⁴⁶² *Frenchay Healthcare NHS Trust v S* [1994] 2 All ER 403 at 411 per Sir Thomas Bingham. Emphasis in original.

⁴⁶³ *Airedale NHS Trust v Bland* [1993] AC 789 at 813 per Butler-Sloss LJ.

⁴⁶⁴ “It is important to remember that the *Bolam* test, formulated nearly 50 years ago, was in the context of determining the standard of care to be applied in cases of alleged medical treatment and diagnosis. The standard of care to be applied is of that ‘a respectable body of medical opinion’. In cases such as this, the court is not, of course, applying a standard of care to determine whether past medical treatment has fallen below the standard of reasonable care. In deciding whether future treatment, or the withdrawal of it, is in the patient’s best interests and therefore lawful, the court must, of course, be satisfied that the expert medical evidence in favour of a particular course of action is both responsible and competent. It cannot be in the interests of a patient for the court to act on medical opinion which is not responsible and competent. If the expert medical opinion is responsible and competent, the court is entitled to act on it, even if there is a contrary medical opinion. The court has to evaluate all of the expert evidence. In the case of conflicting evidence, it has to decide which evidence carries greater weight and is to be preferred.” *NHS Trust v A* [2005] EWCA Civ 1145; [2006] Lloyd’s Rep Med 29 at [95] per Mummery LJ.

⁴⁶⁵ *Cuthbertson v Rasouli* [2013] 3 SCR 341 at [96].

⁴⁶⁶ There are some scenarios which counter this, for example: a procedure might be contrary to a patient’s current experiential interests, but still further their *medical* interests. Consider a child having to undergo a

important aspects of their interests to consider (and therefore is discussed in much more detail in relation to quality of life arguments in Chapter Seven), again it is isolating one factor – their medical condition – from a range of possible interests. This position is easier to posit when the patient was not previously competent, because then there is no means of ascertaining the patient’s views and therefore there is no access to any possible interests that may overrule the solely medical considerations. Despite the undoubted importance of a patient’s current experiences, and ascertaining any likelihood of recovery, these are not the only considerations. When taking a wider view of best interests and considering a particular patient who had previous views, there could be a number of possible interests that they may value more, for example an other-regarding interest in their family not seeing them suffer.

However, in support of this view, legislation that lists the considerations that must be taken into account when considering best interests often lists medical factors.⁴⁶⁷ It is difficult to discuss medical interests in isolation beyond this point, and therefore further analysis of this issue is undertaken in Chapter Seven.

Application Three: Objective and Subjective Test

The fundamental basis for a best interests test being interpreted either objectively or subjectively has been the subject of much judicial discussion.⁴⁶⁸ There has been a problem with these terms because the various definitions given to them has created confusion. Much of the confusion stems from the uneasy juxtaposition between respecting patients’ views, and

painful or unpleasant procedure – or even take a bad-tasting medicine – in order to safeguard some aspect of their future health. The courts would probably also take the view that ‘medical interests’ could include future interests; consider the vaccination case of where the court ordered that the teenage girls must have the vaccinations against their own and their mother’s wishes: *F v F* [2013] EWHC 2683 (Fam). This is the third such ruling according to Sanchia Berg "High Court Orders Two Sisters Must Receive MMR Vaccine" www.bbc.com/news/health-24493422 11 October 2013. However for the purposes of this thesis *medical interests* has been interpreted as the current medical interests relating to the patient’s current condition, or likely future condition.

⁴⁶⁷ For example s 38 GAA (Vic) which specifies that the wishes of the patient and then the family must be taken into account, followed by a list of treatment considerations including “(c) the consequences to the patient if the treatment is not carried out”. For a discussion of some of the difficulties of medicalising best interests see: *Secretary, Department of Health and Community Services v JWB* (1992) 106 ALR 385: “The test of therapeutic medical treatment recognizes the importance of personal integrity and of the maintenance and enhancement of natural attributes to the welfare of the child. By comparison, the best interests approach is useful only to the extent of ensuring that the first and paramount consideration is the interests of the child, not the interests of others.”

⁴⁶⁸ This is another example of different reasoning that pervades the discussion of best interests; see Chapter Two for the themes identified.

ascertaining their best interests, which has led to an uneasy alliance – complete with shifting goal posts – between what is considered best interests and what is considered substituted judgment.⁴⁶⁹ In this thesis an attempt is being made to elucidate the use of relevant terms, and this confusion is a prime example of where such clarification is needed. A plain interpretation of the terms may help. ‘Objective’ denotes that a decision is derived from an observation of measurable, evidential factors. ‘Subjective’ denotes that the decision is made from a person’s particular beliefs or views.

McLean offers an explanation for this confusion when describing two main ways in which best interests can be determined. The first is as a strict best interests test, where an attempt is made to balance benefits and drawbacks. The other approach, substituted judgment, is where the courts attempt to identify, as best as possible, what the person would have wanted – and this determines the outcome. McLean says that this is not traditionally described as best interests, but it is just that different interests are taken into account, and it addresses a broader range of values a person may have held, such as previously expressed wishes.⁴⁷⁰ Pollock also discussed this close relationship, and summarised the approaches a major American case, *Re Conroy*, identified in relation to withdrawal of treatment; the following list explains the differences using terms that will be adapted in this section:

- “(1) purely-subjective test substituted judgment; explicit preference of the patient;
- (2) limited-objective test; combined elements of substituted judgment and best interests; combo of some good evidence of patient’s preferences with determination burdens outweighed benefits;
- (3) purely-objective test best interests; no evidence of patient’s preferences so balancing benefits and burdens.”⁴⁷¹

From this description it is possible to plot the current use of the best interests test; predominately it has been used as a *limited-objective* test, where prior views of the patient are known. However, in some jurisdictions a *purely-subjective* test of substituted judgment should be performed if possible, and where there is no evidence of preferences a *purely-objective* test is the only option. Therefore, these categories will be utilised when discussing the best interests test, but with further development by submitting that a *qualified-objective*

⁴⁶⁹ See Chapter Two for a more detailed description of the differences in law in these approaches.

⁴⁷⁰ Sheila McLean *Old Law, New Medicine : Medical Ethics and Human Rights* (Pandora Press, London, 1999) at 147.

⁴⁷¹ Stewart G Pollock "Life and Death Decisions: who Makes Them and by What Standards" (1988) 41 Rutgers L Rev 505 at 525. *In Re Conroy* (1985) 98 NJ 321.

test is optimal. This test firstly assesses what the patient's preferences were (which must contain a reference to their validity), and secondly, takes account of all other interests.

In the next section various accounts are provided of judges stating that the test is objective, followed by a discussion justifying the qualified-objective approach outlined above. Whilst the above scenario provides plausibility for best interests as both an objective and subjective test, neither is consistently applied.

Best Interests as an Objective Test

The Supreme Court of Canada in *Cuthbertson v Rasouli* provided a summary of what it means to interpret the best interests test objectively:

“The substitute decision-maker is not at liberty to ignore any of the factors within the best interests analysis, or substitute her own view as to what is in the best interests of the patient. She must take an objective view of the matter, having regard to all the factors set out, and decide accordingly... The intent of the statute is to obtain a decision that, viewed objectively, is in the best interests of the incapable person.”⁴⁷²

This describes the approach that the substitute decision maker has to take: this person cannot substitute his or her views on the best interests of the patient; instead, the decision-maker has to rely on all the factors which go into a best interests analysis. Therefore, it is supposedly an objective appraisal about whether the decision maker has taken into account all the things that he or she should have.

In *Burke*, the much maligned Munby J's account of best interests was rejected by the Court of Appeal:

“It seems to us that it is best to confine the use of the phrase ‘best interests’ to an objective test, which is of most use when considering the duty owed to a patient who is not competent and is easiest to apply when confined to a situation where the relevant interests are medical.”⁴⁷³

This is a particularly interesting observation in *Burke* in light of the discussion from Chapter Five regarding his strong explicit-specific view (at T1 – a competent, prior time) that he would want treatment continued for as long as possible (at T2 – when incompetent at a future time). Why did the Court of Appeal not place more emphasis on the patient's prior wishes?

⁴⁷² *Cuthbertson v Rasouli* [2013] 3 SCR 341 at [88]. In reference to Health Care and Consent Act 1996 (Ont). It is important to note that an objective best test is different from the *interests* themselves being objective, for example an interest in dignity described as objective in Chapter Three.

⁴⁷³ *Burke v General Medical Council (Official Solicitor and Others Intervening)* [2005] EWCA Civ 100 at [29].

Perhaps it had to do with what the view was – a wish for treatment continuation rather than withholding or withdrawal. This consideration is examined in the following section; an observation that viewing the best interests test objectively at times leads to an implicit ‘reasonableness’ criterion.

The ‘Reasonable Person’

The reasonable person criterion supposes that an *individual* would want a treatment decision to be made according to what a *reasonable person* would want in that individual’s circumstances. An implicit tension with the best interests principle exists here in that the substitute decision-maker for a permanently incompetent patient is required to evaluate what is in the individual’s best interests. Subsequently, there is a difficulty with incorporating what a reasonable person would want in the same circumstances into the evaluation of best interests, because it risks overriding the individual’s preferences regardless of what these are. In Chapter Four there was a discussion of three groups of incompetent patients: those who were previously competent and able to express views, and either did or did not do so, and those who were never previously competent. These groups are important in regards to the reasonable person criterion because of the risk that identified that these prior wishes can be applied shallowly. There are two reasons this is problematic. Firstly, there are statutory regimes which prioritise a patient’s preferences, and secondly, because of the conclusion drawn in Chapter Five, that respect for a person’s precedent autonomy should be factored into the best interests test. The following example demonstrates a prior preference being overridden, despite legislative provision for its inclusion.

Arden LJ, in *James*, stated “that a reasonable individual in the light of current scientific knowledge would reject [treatment]”.⁴⁷⁴ This approach was adopted despite starting with Mr James’ own views, as dictated in section 4 of the MCA. It was argued in Chapter Five that Mr James’ inferred-specific view was quite robust. The Court of Appeal’s adoption of reasonableness was criticised in the Supreme Court:

“Finally, insofar as Sir Alan Ward and Arden LJ were suggesting that the test of the patient’s wishes and feelings was an objective one, what the reasonable patient would think, again I respectfully disagree. The purpose of the best interests test is to consider

⁴⁷⁴ *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65 at [63].

matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail."⁴⁷⁵

I agree with Lady Hale that the purpose of the best interests test is to consider matters from the patient's point of view, and that is in alignment with the MCA. If a reasonableness criterion is then added, it may remove the very essence of what best interests aims to achieve – a decision made in the best interests of *that patient*. Where there is a reasonably strong prior view, there should be no need to infer what the reasonable person would want. There is evidence as to what *that* person would want. Mr James' purported view was contrary to what the reasonable person was proposed to have; this is an example of an implicit judgment on his quality of life.⁴⁷⁶ It may be because of what the decision-maker brings to the decision from their own experiences:

“Our self-concerned habits lead to the easy judgment that what is best for others is merely what we judge to be best for ourselves; at which point, we simply adjudicate according to our own obligations and satisfactions rather than attempt to understand other people's desires and beliefs.”⁴⁷⁷

In *James*, it is relatively easy to criticise the use of the reasonable person criterion since there was good evidence pointing to the patient's views. However, where there is no such evidence, a reasonableness criterion may be useful, or even necessary. With a previously competent patient, their prior self may be able to provide some helpful information as to whether they may or may not agree with what it is perceived most people would want in the circumstances. In a void of information, referring to a reasonable person is sensible. It seems intuitive that most people would not want to be kept alive by artificial means, in a condition such as PVS. Therefore, keeping people alive in such a state, against the majority viewpoint, seems counter-intuitive. No consideration at all of the reasonable person's view is not suggested, but rather that the courts should not be introducing it where there is clear evidence of the individual's view. Where there is a void in information it becomes an easy step to conclude that a reasonable person would not want to continue living in a state such as PVS, and this needs to be a transparently applied observation due to the lack of alternative information, not despite of contrary information.

Therefore, where there is some evidence of prior wishes, but it is not entirely conclusive, it may be legitimate to use a reasonableness test to supplement such evidence. But, as shown in

⁴⁷⁵ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 at [45] per Lady Hale.

⁴⁷⁶ This is examined in more detail in Chapter Seven.

⁴⁷⁷ Hester (2001) at 77.

the Court of Appeal's judgment in *James*, even though there was clear evidence that Mr James would have most likely wanted treatment to continue, the judges decided that his best interests dictated that it should not. This ignored the legislative intent for purpose of the best interests test.

Best Interests as a Qualified-Objective Test

Although substituted judgment is not the predominant test used in the Commonwealth countries considered in this thesis, its importance cannot be ignored.⁴⁷⁸ From the discussion in Chapter Five it is possible to infer that when best interests is the appropriate test, some form of substituted judgment will be factored into it. In some jurisdictions, decision-making for incompetent patients will expressly set out, at the first stage, a substituted judgment test. Some legislation, such as the MCA, allows for the patient's views to be subsumed into the best interests test:

“Further, in most cases the court will be able to determine what decision it is likely that P would have made, if he had capacity. In such a case, in my judgment, P's balance sheet of factors and P's likely decision can be taken into account by the court. This involves an element of substituted judgment being taken into account, together with anything else which is relevant. However, it is absolutely clear that the ultimate test for the court is the test of best interests and not the test of substituted judgment. Nonetheless, the substituted judgment can be relevant and is not excluded from consideration. As Hoffmann LJ said in the *Bland* case, the substituted judgment can be subsumed within the concept of best interests. That appeared to be the view of the Law Commission also.”⁴⁷⁹

In jurisdictions where prior views are a consideration, but not overriding, as Lady Hale sets out in *James*, the test will involve consideration of the views, but it will not be the deciding factor:

“Best interests is not a test of “substituted judgement” (what the person would have wanted), but rather it requires a determination to be made by applying an objective test as to what would be in the person's best interests. All the relevant circumstances, including the factors mentioned in the section must be considered, but none carries any more weight or priority than another. They must all be balanced in order to determine what would be in the best interests of the person concerned.”⁴⁸⁰

⁴⁷⁸ See Chapters Two and Five.

⁴⁷⁹ *In The Matter Of G (TJ)* [2010] EWCOP 3005 at [55].

⁴⁸⁰ *Mental Capacity Act Code of Practice* (2007) [28] of the Explanatory Notes to the MCA 2005. See also New Zealand's Right 7 (4) of the Code of Patient Rights, which requires the patient's views to be taken into consideration, as well as their best interests.

Therefore, a *qualified-objective* approach, which takes into account the patient's views where known, but also makes an evaluation of objectively ascertained interests, is the approach most commonly used in the four Commonwealth countries in substitute decision-making for permanently incompetent patients.

Summary of Chapter Six

The evaluative nature of best interests dictates that it is broad and flexible in order to properly balance the various interests that the incompetent person may have. Incompetent patients do not share all the same interests (though there may be a pool of interests that they could all be entitled to, for example an interest in not being submitted to ongoing indignity). Therefore, any qualifier which confines it to certain values, or narrow interests, results in its misapplication, leading to the conclusion that a qualified-objective approach which provides for this flexibility is the only justifiable interpretation of best interests.

Chapter Three canvassed a range of non-experiential interests that have both judicial and philosophical acceptance in regards to the permanently incompetent person. Subsequently, Lord Mustill's assertion in *Bland* that a patient in a PVS had *no* interests that could be evaluated took a narrow approach by viewing experiential interests as the only possible interests. This chapter proposed that the probable basis for this confusion lies with the interpretation of personhood. The assessment that a person who is permanently incompetent no longer has the characteristics of personhood may be viable, but this does not validate a conclusion that they do not have any interests. Furthermore, experiential interests have been shown to be poorly understood in a case, *Auckland Area Health Board v Attorney-General*, where there was every reason for them to be an influential factor.

A deferment to a medicalised view of interests was discussed as having two possible applications. The first was an interpretation whereby the courts adjudicated on whether the medical profession had properly assessed the patient's best interests, effectively '*Bolamising*' the best interests test, and lessening the judicial involvement. Increasingly, statutory and common law rulings have rendered this version unacceptable by current standards. It is not enough to defer to what the medical profession regards as the patient's best interests, this is an evaluation that the judge needs to undertake for him or herself. The second interpretation

of deferment to medical interests placed the most emphasis on the medical condition of the patient, and this is explored in more detail in Chapter Seven.

An analysis of an objective view of best interests leads to the conclusion that this risks invoking a reasonable person criterion. Whilst appropriate in certain situations, ultimately its focus is not on the individual person. Where there is a void in information it may be justifiable but where there is clear evidence of, for example, an explicit-specific prior view the inclusion of the reasonable person is at odds with best interests as a person-specific test.

This chapter has, somewhat artificially, considered various applications of the best interests test in isolation. Clearly this is not the purpose of an evaluative tool aimed at weighting and comparing various interests that an incompetent person may have. This chapter has been structured in this way to demonstrate some fundamental confusions regarding interpretations of best interests. In the next chapter these confusions are drawn on, as well as the other observations made in previous chapters, in order to consider cases where various interests are in conflict.

CHAPTER SEVEN: CONFLICTING AND CONFLUENT INTERESTS

"I wish I had some clever answers to all these things, but that is not the position. If we did, presumably we would not be here."⁴⁸¹

In this penultimate chapter, the focus is on utilising the foundations laid in this thesis by the previous chapters. Thus far, the principal emphasis has been on the question of how well judges are using the concept of best interests by breaking it down into different components. A test which aims to weigh up the *best* interests of a permanently incompetent individual should first of all seek to identify which interests the individual has. This could be considered as Stage One. Chapter Three discussed various accounts of interests to reach a conclusion that the descriptions *self-regarding* (consideration for one's own interests) and *other-regarding* (consideration for others' interests) could be used as a characterisation of some of the different kinds of interests that people may have. This chapter presents further development of the argument advanced in Chapter Three that the other-regarding interests of the permanently incompetent have been overlooked, and that they are interests which could help the judicial decision-makers.

Stage Two of evaluating interests requires a decision to be made about which interests should prevail; these prevailing interests will outweigh others because they are the interests deemed to be in the patient's *best interests*. There are a number of ways that judges could evaluate interests: (1) the judge could ignore them, and apply a different legal test altogether;⁴⁸² (2) the judge could recognise one kind of interests, or a particular aspect of best interests, as shown in Chapter Six which examined various narrow applications of the best interests test; (3) there could be clear hierarchies of interests set out in either statutory regimes or common law. Often these pertain to prior views, and Chapter Five utilised the discussion from Chapter Four to analyse cases with a range of different previously competent statements, advocating for a proposal to ascertain the veracity of the prior self; (4) interests could be weighed up on

⁴⁸¹ *Re F; F v F* (Unreported, Sup Crt Vic, Vincent J, extract of transcript of proceedings 2 July, 1986).

⁴⁸² For example, in *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235. Thomas J issued a declaration rather than using *parens patriae* jurisdiction.

the basis of each case; and (5) hierarchies could be recognised, while seeking to avoid the consequences of the hierarchy by distinguishing differences at a lower level. In this chapter all of the concepts discussed in the previous chapters are employed to provide consideration of some of the ways that interests fit together, and some of the ways that they do not. This is reflected in the title of this chapter: conflicting and confluent interests.⁴⁸³

Sometimes these interests are conflicting, and sometimes they will be confluent, but they are always difficult to evaluate and weight in a particular order that prioritises one or more over others. And it *should* be difficult to rank them. People may have conflicting interests, for example, in being pain free and dignified, on the one hand and living as long as possible on the other, making it difficult to say what their best interests are. The cases analysed in this thesis concern the determination of life or death. Any person (or judge) who does not appreciate this has missed the point (which they very rarely do).⁴⁸⁴ Some of these cases, such as those of conjoined twins, form the basis for extensive discourse, as in Simon Lee’s book on “Uneasy Cases”:

“This is what I call not just a hard case but an un-easy one because the moral dilemma is so acute that if you do not have some sense of unease, you have not understood the complexities involved.”⁴⁸⁵

The conflicting and confluent nature of the incompetent person’s interests is what the best interests test is at its essence. It is why there is so much difficulty in interpreting the best interests test. In previous chapters these conflicts have been acknowledged but little has been done to engage with them. This chapter addresses the more frequently occurring clashes of interests: sanctity and quality of life, parental views and children’s interests, and prior views and experiential interests; with reference to how this influences stage two of how judges reach their decisions. From this discussion, a bigger question emerges: how does the concept

⁴⁸³ Inspired by Taylor-Sands (2013) at 82. “Compromise is also a natural consequence of living in a shared space where individuals may have conflicting, as well as confluent, interests.”

⁴⁸⁴ One possible exception being *Shortland v Northland Health Ltd* [1998] 1 NZLR 433. Mr Rau Williams applied for an interim order to provide life-saving dialysis, and died the day after this was denied. The Court of Appeal noted at 433 “The issues arising were essentially ones of clinical judgment, not ethics.” However the issue of best interests was flagged by the oral judgment of Salmond J in the High Court *Shortland v Northland Health Ltd (Unreported)* M75/97 NZHC 732. “It is not clear to me whether the decision to cease dialysis was made on the basis of a judgment that it was not in Mr Williams’ best interests or whether it was based on an assessment of where scarce resources should best be used.” He went on to give advice that this should be made very clear, as the doctor in her evidence was ambiguous as to how the decision was made and the basis for it. This was also one of the themes shown in the initial case analysis in Chapter Two, the acknowledgement of ethical issues. This case will be discussed in reference to quality of life considerations.

⁴⁸⁵ Lee (2011) at 5. Referencing *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147. This case is discussed in “Twin vs Twin” later in this chapter.

of other-regarding interests fit into the evaluation of interests, and what emphasis should be placed on them? The conclusion of the thesis outlines broad guidelines that decision-makers should use when they assess the best interests of an incompetent patient. This will be a summation of how it is possible to use the categories of self- and other-regarding interests, as well as evidence of a previous self, to assist in judicial decision-making for the incompetent patient.

Conflicting Interests

“The application throws up the harsh reality that there is no commonality of interest between the sisters in undergoing the operation. It will benefit Alyssa by giving her a chance of a normal life but it will lead to Bethany’s death. It confers no advantage on her. What, then, is in the best interests of the children?”⁴⁸⁶

It is not possible to set out all of the possible permutations of different interests the incompetent patient has, or may have, with all the different emphases of how they clash and how they could potentially clash. Therefore, it is helpful to consider two different ways that they can clash. (1) *Intra-personal*: the various interests an individual has clash with one another. It may be because they are of different kinds (for example experiential vs critical, or future-orientated vs current). Alternatively, they may be of the same kind, but both cannot be realised (for example, someone who has sets of critical interests which are incompatible). The following examples of these will be discussed in this chapter: (a) sanctity of life and quality of life; and (b) prior views and other interests. (2) *Inter-personal*: the clashing of different people’s interests. Seemingly, this question is relatively easily answered if the focus on the *individual’s* best interests is maintained. However, the discussion in the following sections: (a) twin vs twin; and (b) parental views and child’s interests, will argue that inter-personal clashes are not easily avoided.

⁴⁸⁶ *Queensland v Alyssa Grace Nolan (an Infant, by her Litigation Guardian Shaun Nolan) and Bethany Rose Nolan (an Infant, by her Litigation Guardian Shaun Nolan)* (2001) QSC 174; [2001] 122 ACR 517 at [13].

Sanctity of Life and Quality of Life

“Modern medicine is always poised to offer another procedure or therapy for prolonging life, but it often does so without considering the quality of that life. How much suffering is five more weeks worth? Or five days, or five hours?”⁴⁸⁷

The tragic circumstances of conjoined twins where one is sustaining the life of the other gives rise to possibly the most acute ethical dilemma. Essentially, both twins have strong self-regarding interests that are difficult, if not impossible, to reconcile as their most important self-regarding interest is, ostensibly, in continued living. That is not to say that a self-regarding interest only favours continuation of life, but in this case with no evidence of any other suffering it must be a consideration that it was an interest.⁴⁸⁸ One of the difficulties that the judges face is justifying an operation that would leave a child dead. The principle of sanctity of life would therefore need to be addressed by the courts; all of the judges did so and declared that each of the twins had an equal right life.⁴⁸⁹

The sanctity of life principle is an impersonal, deontological one, stating that it is wrong to deliberately kill, even if no-one’s rights or interests would be violated. This is different from the right to life which relates to the individual, and can in theory be waived by that individual, or outweighed by competing considerations. It does not necessarily mean that a particular individual has an interest in having their life prolonged. The distinction between the deontological rule against deliberate killing is not always distinguished by the courts from whether a particular person has an interest in continued life. Exemplifying the sanctity of life ethic, all of the jurisdictions considered in this thesis have prohibitions on any form of voluntary euthanasia or assistance to die, which prevents any deliberate killing, regardless of the person’s consent.⁴⁹⁰

⁴⁸⁷ Shoshana Ungerleider "I'm a Doctor. Preparing You for Death is as Much a Part of my Job as Saving Lives" www.vox.com/2015/10/19/9554583/doctor-good-death.

⁴⁸⁸ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147. Part of the problem was that Mary’s internal mental state was something of a mystery. It was possible that she was suffering, but also possible that she had no awareness at all. If she was completely insensate, should it be assumed that she had a self-regarding interest in continued life? This is discussed in the section “Twin vs Twin”. Contrast this with a case discussed in Chapter Five: *Re Durksen* (1999) CarswellAlta 1672. Mr Durksen’s explicit-specific prior view that he would not want to be kept alive in a PVS could be considered a far life-long, self-regarding interest he held.

⁴⁸⁹ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 211 per Brooke LJ, at 188 per Ward LJ, at 243 per Robert Walker LJ. See also: *Queensland v Alyssa Grace Nolan (an Infant, by her Litigation Guardian Shaun Nolan) and Bethany Rose Nolan (an Infant, by her Litigation Guardian Shaun Nolan)* (2001) QSC 174; [2001] 122 ACR 517 at 14 per Chesterman J.

⁴⁹⁰ Except for Canada: *Carter v Canada (Attorney General)* [2015] 1 SCR 331; *Canada (Attorney General) v EF* [2016] ABCA 155. Canada’s Supreme Court has ruled in that prohibition on euthanasia violates s 7 of the Canadian Charter of Rights and Freedoms in the *The Constitution Act 1982* (Canada). “Everyone has the right

In end-of-life cases the importance of the sanctity of life is often remarked on:

“A profound respect for the sanctity of human life is embedded in our law and our moral philosophy, as it is in that of most civilised societies in the East and the West.”⁴⁹¹

Therefore, the sanctity of life principle is undoubtedly entrenched in the common law, as exemplified by the judges in *Bland* and other leading cases.⁴⁹² However, despite its importance, there are few definitions provided. In *Re A*, Brooke LJ stated that the respect for sanctity of life comes from God and our Christian Western values and the protection of these values is the reason for laws against murder.⁴⁹³ In *Bland*, eight of the nine judges referred to sanctity of life, and they all acknowledged its importance, and also recognised the view that it can be overridden by other factors. One judge, Lord Goff, linked it to legislation, Lords Keith and Mustill linked it to the State, whilst Hoffmann LJ stated that it is intuitive.⁴⁹⁴ Although it is universally acknowledged, the weight attached to it varies somewhat between judges: Lord Goff, for instance, referred to it as “the fundamental principle”, whereas for Thomas Bingham MR it is something to which respect must be paid, but which is not “irrebuttable.”⁴⁹⁵ These differences highlight two further investigations. Firstly, what is the definition, or possible definition of sanctity of life? Secondly, if it can be “rebutted” when does this happen and by what considerations?

to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.” A Bill was enacted upholding this law in June 2016. In 2015, New Zealand had a case challenging the legality of the prohibition on physician assisted suicide before the High Court, which found that there was no right to assisted dying: *Seales v Attorney-General* [2015] NZHC 1239. In England and Wales The Assisted Dying Bill, which would have legalised prescribing terminally ill patients medication they could take to end their lives, was recently voted against: James Gallagher and Philippa Roxby "Assisted Dying Bill: MPs Reject 'Right to Die' Law" www.bbc.com/news/health-34208624 11 September 2015.

⁴⁹¹ *Airedale NHS Trust v Bland* [1993] AC 789 at 808 per Thomas Bingham MR.

⁴⁹² *Aireale NHS Trust v Bland* [1993] AC 789 will be extensively referenced in this section as it addressed questions of withdrawal of treatment leading to death for the first time in the United Kingdom: “Its importance cannot be over-emphasised.” at 819 per Butler-Sloss LJ; “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” at 826 per Hoffmann LJ; “It is on this basis that I turn to the applicable principles of law. Here, the fundamental principle is the principle of the sanctity of human life” at 863 per Lord Goff; “To my mind, these technical developments have raised a wholly new series of ethical and social problems. What is meant now by ‘life’ in the moral precept which requires respect for the sanctity of human life?” at 878 per Lord Browne-Wilkinson. Also at 894 per Lord Mustill; at 859 per Lord Keith; and at 879 and 884 per Lord Lowry. See also: *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 183-187 per Ward LJ; at 240 per Brooke LJ; and at 243 per Robert Walker LJ. And: *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 at [35] per Lady Hale.

⁴⁹³ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 211.

⁴⁹⁴ *Airedale NHS Trust v Bland* [1993] AC 789 at 826 per Hoffmann LJ; at 863 per Lord Goff; at 894 per Lord Mustill; at 859 per Lord Keith.

⁴⁹⁵ *Ibid* at 812 per Thomas Bingham MR and 863 per Lord Goff.

Brooke LJ's account of sanctity of life accords with John Keown's definition, and in fact Keown's definitions are discussed (with approval) in *Re A*, and *James*.⁴⁹⁶ As argued by Keown, the sanctity of life principle holds that one should never intentionally kill an innocent human being. The right to life is essentially a right not to be intentionally killed.⁴⁹⁷

"The sanctity doctrine is not vitalistic. The core of the doctrine is the principle prohibiting intentional killing, not an injunction requiring the preservation of life at all costs. However, although the doctrine denies that human life is an absolute good, the principle that it may never intentionally be taken is an absolute principle, that is, one which has no acceptable exceptions. Although the value of human life is not absolute, the prohibition on taking it is."⁴⁹⁸

There is a certain irony to the utilisation of Keown's definitions in *Re A* and *James* as he is critical of the judicial application of the sanctity of life in *Bland*:

"It appears then, that in *Bland*, as in *Re J* before it, the sanctity of life was not heard; that the choice as presented and perceived was between vitalism and Quality of life, and that the judges, unsurprisingly, opted for Quality of life. Despite the fundamental importance attached to the sanctity of life by the judges who sat in *Bland*, it is by no means clear that any had the benefit of an accurate appreciation of it."⁴⁹⁹

The importance of the *Bland* decision for the sanctity of life ethic was also emphasised by Peter Singer, who was in agreement with the decision:

"On February 4, 1993, in deciding the fate of a young man named Anthony Bland, Britain's highest court threw out many centuries of traditional law and medical ethics regarding the value of human life and the lawfulness of intentionally ending it."⁵⁰⁰

⁴⁹⁶ This fits within the theme of ancillary guidance discussed in Chapter Two. *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 186 per Ward LJ. *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65 at 36. See Keown's description at: John Keown "The Legal Revolution: From Sanctity of Life to Quality of Life and Autonomy" (1997) 14 J Contemp Health Law Policy 253 at 256.

⁴⁹⁷ "The principle of the sanctity of life is often advocated but much less often understood." Keown "Restoring Moral and Intellectual Shape to the Law after Bland" (1997) 113 (Jul) Law Quarterly Review 482 at 482. This article was published in a slightly different form as: Keown "The Legal Revolution: From Sanctity of Life to Quality of Life and Autonomy" (1997) 14 J Contemp Health Law Policy 253. Both are referenced in this thesis.

⁴⁹⁸ Keown "Restoring Moral and Intellectual Shape to the Law after Bland" (1997) 113 (Jul) Law Quarterly Review 482 at 484.

⁴⁹⁹ *Ibid* at 500. "This Article suggests that the doctrine of the sanctity of life was misrepresented, misunderstood, and mistakenly rejected, and argues that the courts should, by reinstating the law's consistent application of that doctrine, restore moral and intellectual consistency, coherence, and clarity to the law." Keown "The Legal Revolution: From Sanctity of Life to Quality of Life and Autonomy" (1997) 14 J Contemp Health Law Policy 253 at 255.

⁵⁰⁰ Peter Singer "Is The Sanctity of Life Ethic Terminally Ill?" in Helga Kuhse and Peter Singer (eds) *Bioethics: An Anthology* (2nd ed, Blackwell Publishing Ltd, Padstow, Cornwall, 2006) at 327. Keown made the following comment on Singer's remarks: "A leading utilitarian bioethicist and advocate of euthanasia, Professor Peter Singer, has even commented that the case marks the collapse of the traditional Western ethic: the principle of the sanctity of human life. There can be little doubt that the Law Lords dealt a blow to that principle, and although Singer's comment may be overstated, the blow may yet prove fatal." Keown "The Legal Revolution: From Sanctity of Life to Quality of Life and Autonomy" (1997) 14 J Contemp Health Law Policy 253 at 255.

The significant aspect of this discussion, for the question of decision-making for the incompetent patient, is the answer to the second investigation to determine when the sanctity of life principle can be rebutted. In some circumstances it can when it conflicts with quality of life considerations.⁵⁰¹ Due to the technological advances that today's medical care can provide, patients can receive ventilator support or ANH for their natural lifespan, creating an increasing tension between sanctity of life and quality of life. The courts state that everyone has a right to life, but that this right can be overridden by competing interests, such as an interest in not being subjected to prolonged suffering for no reason. This is an objective interest that is dependent on the patient's awareness. Consequently, there is no simple equation because the quality of that life may preclude keeping the patient alive. The following account of Anthony Bland's life shows why this is a factor:

“Since 15 April 1989 Anthony Bland has been in persistent vegetative state. He lies in Airedale General Hospital in Keighley, fed liquid food by a pump through a tube passing through his nose and down the back of his throat into the stomach. His bladder is emptied through a catheter inserted through his penis, which from time to time has caused infections requiring dressing and antibiotic treatment. His stiffened joints have caused his limbs to be rigidly contracted so that his arms are tightly flexed across his chest and his legs unnaturally contorted. Reflex movements in the throat cause him to vomit and dribble. Of all this, and the presence of members of his family who take turns to visit him, Anthony Bland has no consciousness at all. The parts of his brain which provided him with consciousness have turned to fluid. The darkness and oblivion which descended at Hillsborough will never depart. His body is alive, but he has no life in the sense that even the most pitifully handicapped but conscious human being has a life. But the advances of modern medicine permit him to be kept in this state for years, even perhaps for decades.”⁵⁰²

From this description of the life of Anthony Bland, all nine of the judges who deliberated as to whether withdrawal of ANH was lawful, decided that it was. Their characterisations of him painted his life as not worth living, arriving at conclusions that equated a lack of personhood with a lack of any meaningful life.⁵⁰³ Again, because Keown is cited in end-of-life cases, it is useful to recount his positions, as he maintained that the courts misconstrue adherence to a sanctity of life principle with vitalism. Vitalism holds that human life is an absolute moral value and that it is wrong either to shorten it or to fail to lengthen it. Regardless of the pain, suffering or expense that life-prolonging treatment entails, it must be

⁵⁰¹ “How did the quality of life argument enter the jurisprudence? As far as I can trace, it seems to have been introduced by *In Re B* [1981]” *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 185 per Ward LJ. *Re B* [1982] 3 FLR 117: a child with Down syndrome whose parents wanted to leave her to die from an easily treatable condition had their decision overruled by the court.

⁵⁰² *Airedale NHS Trust v Bland* [1993] AC 789 at 824.

⁵⁰³ See Chapter Six for discussion around his personhood.

administered: human life is to be preserved at all costs.⁵⁰⁴ Keown offers further guidance for the discussion when he distinguishes between two different interpretations of quality of life: (1) there is an assessment of the patient's condition as the first step to assessing the worthwhileness of a *proposed treatment* and (2) the assessment is of the worthwhileness of the *patient's life*.⁵⁰⁵ The latter is what the courts have striven to avoid, but as the next section discusses, this interpretation has infiltrated end-of-life cases.

Experiencing a Quality Life

There is a frequently occurring intra-personal clash in regards to an incompetent patient's quality of life, and what kind of life they are experiencing, and their interest in continued living. Decision-making for the incompetent patient should consider three possibilities regarding experiential interests, which have arisen from the end-of-life cases: (1) the patient has no sentience or awareness, for example a patient in a PVS; (2) the patient is sensate and can experience pain and other discomforts such as hunger, but is also capable of positive responses such as responding to whānau; (3) the patient may be sensate or they may not be, and there is no way of knowing which, for example, patients with Guillain-Barré syndrome and some minors.

There are very different considerations to make if the patient is in the second group and can feel or experience anything at all. They then have a raft of interests that are applicable by virtue of being able to feel something – whether that is pain, hunger, sorrow, distress, nightmares, helplessness, frustration, happiness, joy, warmth or touch. Once a patient can feel anything it becomes an extremely difficult balancing exercise between what they may be experiencing, which with end-of-life cases is often associated with some form of suffering (quality of life) and their interest in living (sanctity of life). Dresser points out how the courts have used experiential interests to implicitly make judgments on the quality of life of patients:

“It is in the ultimate legal outcomes that we find evidence of judges' views on which kinds of experiential interests give patients a significant claim to life-sustaining treatment and which do not. I submit that in constructing their decisions on life-sustaining treatment, judges have been acting as arbiters of the normative position on

⁵⁰⁴ Keown "Restoring Moral and Intellectual Shape to the Law after Bland" (1997) 113 (Jul) Law Quarterly Review 482 at 482.

⁵⁰⁵ Ibid at 487. Emphasis added. “The doctrine of the Quality of life is not concerned with assessing the worthwhileness of treatment but with the worthwhileness of the patient's life.” Keown "The Legal Revolution: From Sanctity of Life to Quality of Life and Autonomy" (1997) 14 J Contemp Health Law Policy 253 at 260.

quality of life. Their decisions represent the community's current consensus and disagreement on when nontreatment is a reasonable moral judgment."⁵⁰⁶

This theory by Dresser is validated when summarising the outcomes of the cases considered in Chapter Five. In those cases where the family wanted treatment to be discontinued and the courts agreed (*Bland, Re G, Durksen*), the patient was in a PVS. In those cases where the family wanted treatment to be continued, against medical advice, the courts sided with the family (*James, Scardoni Sweiss v Alberta*) the patient was in a MCS (or similar).⁵⁰⁷ The salient point seems to be whether the patient is sensate, and this is further evidenced by three cases from England. In *An NHS Trust v MB*, the medical evidence was that M at 18 months old had the possibility of normal cognitive function for his age, as spinal muscular atrophy does not usually affect the brain, and it was M's body that was shutting down. Holman J found that it was in his best interests that treatment be continued, against advice from the medical profession and M's court appointed guardian.⁵⁰⁸ In *Central Manchester University Hospitals NHS Foundation Trust v A* the same judge declined to issue a similar order in respect to twins who were both suffering a progressive neuro-degenerative disorder. In that judgment he compared the twins' condition to that of M, stating that they were opposite:

"The circumstances of these two boys is the reverse. Their disorder does not relate to their muscles. It relates fundamentally to their brains."⁵⁰⁹

In *W v M* an adult patient's family advocated the withdrawal of treatment from M. Crucially, her diagnosis changed from PVS to MCS whilst the application was in the process of appearing in court, and permission to withdraw treatment was denied.⁵¹⁰ In all three of these English cases, the patient's sentience was the deciding factor. Even when the family is fighting for continuation of treatment for their loved one in a PVS, their capacity for sensation and responsiveness is the issue. In the Canadian case *Maraachli v Dr Fraser*, "baby Joseph", as he became known as in the media, was clinically diagnosed as being in a

⁵⁰⁶ Dresser "Missing Persons: Legal Perceptions of Incompetent Patients" 46 Rutgers L Rev 609 at 647.

⁵⁰⁷ The family's views may also be influential here: see section on "Other-Regarding Interests" in Chapter Three.

⁵⁰⁸ *An NHS Trust v MB* [2006] EWHC 507 (Fam) at [30] per Holman J: "He is not in a persistent vegetative state. He is able to make some very limited voluntary responses to his environment. It is not possible to give an opinion about his cognitive function as this is impossible to assess. It is very difficult to assess how much discomfort or distress M experiences."

⁵⁰⁹ *Central Manchester University Hospitals NHS Foundation Trust v A* [2015] EWHC 2828 (Fam) at [24] per Holman J. See Chapter Six, "The Opposition of the Body and the Mind" for an extended discussion on the differences perceived between the body and mind.

⁵¹⁰ *W v M* [2011] EWCOP 2443 (Fam) at [221] per Baker J: "She is sensate, clinically stable, aware of herself and her environment, able to respond to people, and to music, and also, in a very limited way, to communicate about her needs. In short, she is recognisably alive in a way that a patient in VS [vegetative state] is not."

PVS, but his parents disagreed with this diagnosis.⁵¹¹ The judge upheld the CCB's finding that the parents had not followed the proper procedure for substitute decision-making, but the parents refused to consent as directed, and Joseph was moved to an American facility for continued treatment.⁵¹² It appears, therefore, that courts have been reluctant to allow patients in a MCS to die, but will do so if the patient is in a PVS.⁵¹³ Therefore, in cases where the whānau is fighting for treatment it is because they disagree with the PVS diagnosis, a very different basis for wanting treatment to continue.⁵¹⁴ The salient difference, perhaps, could be in the demonstration of some form of personhood, as the families often state that the patient is showing some form of awareness.

The principle of sanctity of life is therefore one that can be outweighed by the patient's quality of life. If that life has no demonstration of personhood then treatment is able to be withheld, if it is taken that personhood is a quality judgement. But there is a disunion here regarding the medically agreed fact that while a person in a PVS cannot suffer, a person in an MCS presumably can.

Twin vs Twin

“The basis for the decision in the Conjoined Twins case is not legal principles but the Judges' own views of the best outcome. They were a Court of Morals and not a Court of Law.”⁵¹⁵

Whilst in *Bland* the decision to withdraw treatment from a patient in a PVS appears to many as a reasonable one, or at least reasonably understandable, the decision to separate conjoined twins is perhaps more debated.⁵¹⁶ This was even acknowledged by one of the judges in a subsequent interview:

⁵¹¹ *Maraachli v Dr Fraser* [2011] ONSC 124; [2011] OJ No. 2168 at [6] per Rady J.

⁵¹² "Baby Joseph" www.priestsforlife.org/babyjoseph/ 2011.

⁵¹³ The indication in England is that treatment would be withdrawn: *Burke v General Medical Council (Official Solicitor and Others Intervening)* [2005] EWCA Civ 100. As discussed in the section "Explicit-Specific Cases" in Chapter Five, Ouellette J indicated that in Alberta an advance directive may validly keep a patient in a PVS: *Sweiss v Alberta Health Services* [2009] ABQB 691.

⁵¹⁴ See *Cuthbertson v Rasouli* [2013] 3 SCR 341. Additionally the United States of America have had several high profile cases, including Terri Schiavo. "Terri's Fight" www.terrisfight.org/ 2015.

⁵¹⁵ Henaghan (2001-2004) 10 Otago L Rev 289 at 293.

⁵¹⁶ See the following discussions of *Bland*: Andrew McGee "Finding a Way Through the Ethical and Legal Maze: Withdrawal of Medical Treatment and Euthanasia" (2005) 13 (Autumn) MLR 357; Piotr Szawarski and Vivek Kakar "Classic Cases Revisited: Anthony Bland and Withdrawal of Artificial Nutrition and Hydration in the UK" (2012) 13 (2) J Intensive Care 126; John Coggon "Ignoring the Moral and Intellectual Shape of the Law after Bland: the Unintended Side-effect of a Sorry Compromise" (2007) 27 (1) LS 110. Compared with the questioning of the *outcome* of the decision in *Re A: McGrath and Kreleger* (2001) 8 JLM 322; Uniacke (2001) 9 (Autumn) MLR 208; Barbara Hewson "Killing off Mary: Was the Court of Appeal Right?" (2001) 9 (3) MLR

“Fifty per cent of the population will agree with the decision – fifty per cent will think we have gone potty.”⁵¹⁷

Born just nine months apart, two sets of conjoined twins in the Commonwealth led to two legal applications for their lawful separation. In both cases it was contended that if they were not separated both would die, and in both cases it was contended that in order for one twin to live an operation which would save that twin, but mean death for the other twin, was necessary. These cases have been chosen as a common thread for the first two sections, as a way of demonstrating clashes where various interests, including an inter-personal clash, are in direct conflict.

Seeking out medical practitioners experienced with conjoined twins, Rosie and Gracie Attard’s parents travelled from Malta to the United Kingdom for the birth in 2000 of their daughters (the court case used the pseudonyms ‘Jodie’ for Gracie and ‘Mary’ for Rosie which will be used to avoid confusion). Their parents did not want them to be separated and did not consent to the operation. In 2001, Alyssa and Bethany Nolan were born in Australia. Their parents did consent to the operation, and the girls’ medical condition was more precarious than the Attard twins.⁵¹⁸

The judges in *Re A* all took different approaches to reach the same conclusion that the twins could be separated and, of special relevance for the purposes of my thesis, they reached different answers to the question of best interests.⁵¹⁹ Ward LJ set out the two issues requiring a decision. The first stage was to determine whether or not it was in the best interests of the child. Stage two then determined if it was lawful in terms of criminal law.⁵²⁰ The decision can be critiqued for lack of consistency at both stages. At Stage One, the civil question of best interests, Johnston J (in the High Court), and Robert Walker LJ (in the Court of Appeal)

281; Henaghan (2001-2004) 10 Otago L Rev 289; John Harris "Human Beings, Persons and Conjoined Twins: An Ethical Analysis of the Judgment in *Re A*" (2001) 9 (3) MLR 221.

⁵¹⁷ Hewson (2001) 9 (3) MLR 281 at 281. Quotation in Hewson’s paper from Ward LJ, footnoted as taken from an interview, ITN News, 22 September 2000.

⁵¹⁸ The *Re A* decision forms the bulk of the discussion of this section as it is a much lengthier judgment compared to *Queensland v Alyssa Grace Nolan (an Infant, by her Litigation Guardian Shaun Nolan) and Bethany Rose Nolan (an Infant, by her Litigation Guardian Shaun Nolan)* which was heard under urgency and given firstly as an oral verdict. *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147; *Queensland v Alyssa Grace Nolan (an Infant, by her Litigation Guardian Shaun Nolan) and Bethany Rose Nolan (an Infant, by her Litigation Guardian Shaun Nolan)* (2001) QSC 174; [2001] 122 ACR 517.

⁵¹⁹ Demonstrating a theme from Chapter Two outlining different reasoning to reach the same conclusion. At 61,000 words only some of the themes from *Re A* can be discussed – and are relevant – here.

⁵²⁰ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 181. “(1) Is it in Jodie’s best interests she is separated from Mary? (2) Is it in Mary’s best interests she is separated from Jodie? (3) If this presents a conflict how should it be balanced? (4) If it is in their prevailing interest can it be performed lawfully?”

found that it was in *both* twins' best interests to be separated. Ward and Brooke LJ in the Court of Appeal disagreed, and decided that separation was only in Jodie's best interests, and was if anything contrary to Mary's interests.

In determining legality at Stage Two, the judges relied on different legal principles to find that the separation was legal. Because Robert Walker LJ found that it was in both girls' best interests he did not have to distinguish a separate claim for Jodie that would outweigh her sister's. Brooke LJ extended the doctrine of necessity, summarising the law from the past seven centuries.⁵²¹ Ward LJ weighed up each girl's right to life, and although he stated that these were equal, went on to say that Jodie could use a quasi self-defence plea (or, more accurately, that defence of another could be used by the doctors) to show her right was superior on the "scales of fairness and justice between the children".⁵²² He was employing an approach which recognised that there was a clearly dominant interest (determined by the deontological constraint of not deliberating killing) which was the right to life, but since both twins could claim this it could be distinguished at a lower level by advocating that Mary's right to life could be defeated. Why was this? Because there were quality of life arguments made that supposedly justified this conclusion.

Jodie's Best Interests

Putting aside the implications of the judges not only using different reasoning, but using different legal tests, how did the judges reach different conclusions regarding best interests at the first stage? Brooke LJ agreed with Ward LJ's conclusions in finding that the operation was only in Jodie's best interests, and these will be discussed following section.⁵²³ There was little doubt that the operation could be in Jodie's best interests, therefore the following section discusses how this decision was justified in relation to the position that both twins' lives were of equal value.

⁵²¹ Ibid at 218. An argument could be made that the use of the doctrine of necessity in this context was not especially applicable. His judgment starts with Thirteenth Century precedent and he also references academics including Glanville Williams. Ibid at 219. This also aligns with the themes set out in Chapter Two, where the lack of precedent and appeal to other sources can point to difficulties with the case.

⁵²² Ibid at 196.

⁵²³ Ibid at 205 per Brooke LJ. "I am completely satisfied, for the reasons given by Ward LJ, that if what is now proposed is a lawful operation, the best interests of Jodie compel us to authorise that operation."

In *Re A*, the neonatologist said that Mary's quality of life would be so poor that it was appropriate to terminate her life.⁵²⁴ But all of the judges were careful not to state this so bluntly themselves, instead repeatedly stating that the twins' lives were of equal value. But how could the twins' lives be equal in actuality? Stating that he was not wading into the difficult waters of weighing up lives (that is avoiding stating that one twin's life was worth more because they have a greater chance of long-term survival) Ward LJ appealed to Keown's interpretation of sanctity of life and argued that he was weighing up the worthwhileness of the treatment.⁵²⁵ How did Ward LJ weigh up the worthwhileness of the treatment, not the worthwhileness of Mary's life? He did this by finding that the operation would restore to Jodie the "prospects of a normal expectation of relatively normal life" and, although the operation would shorten Mary's life, "she remains doomed for death."⁵²⁶ Therefore he decided that the 'survivable' twin's interests do outweigh the 'non-survivable' twin's, and the following comment exemplifies an intra-personal clash as discussed previously in this chapter:

"The conclusion that the ensuing months of Mary's life are worth nothing brings the dichotomy between quality of life and sanctity of life into critical focus".⁵²⁷

This is an example of the judge conflating the deontological rule with the person's interest. There is certainly a free standing deontological notion of sanctity of life, which is usually taken to mean a rule against intentionally killing or such like. But this seems different from the patient's own interest in continued life. The latter is often presumed by the courts, but like other presumptions, may be rebutted by other evidence. The sanctity of life doctrine, at least as articulated by Keown, (and subsequently used in *Re A*) does not rely on the quality of Mary's life. The deontological rule prohibiting killing would apply even if everyone were to concede that Mary did not have an interest in continued life, which Keown would attribute to her.

In *Re A*, the medical condition of the twins was not as imminently serious as it was in *Nolan*, and the certainty of death for them both if they stayed conjoined, although high, was most

⁵²⁴ Ibid at 169.

⁵²⁵ Ibid at 196. In *Queensland v Alyssa Grace Nolan (an Infant, by her Litigation Guardian Shaun Nolan) and Bethany Rose Nolan (an Infant, by her Litigation Guardian Shaun Nolan)* (2001) QSC 174; [2001] 122 ACR 517 at 14. Chesterman J agreed that both girls' lives right to life were of equal value, but quoted *Re A* in relation to the worthwhileness of each girl's life: "The application is not to be decided by a comparison between the respective worth or value of the two lives. That was the approach of the Court of Appeal [in *Re A*] and I agree with it."

⁵²⁶ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 196.

⁵²⁷ Ibid at 183 per Ward LJ.

likely to happen in between three and six months. The normality of how the girls could live seemed very important in respect to the idea of quality of life. Becoming a single entity was seen as important enough to die for (the idea of bodily integrity is discussed below). But as Dreger points out, this is a misconception. Many conjoined twins cannot envisage life separate from their twin, and it was not until 2003 that Laleh and Ladan Bijani became the first adult conjoined twins to actively seek out, and therefore consent to, separation.⁵²⁸ As regards to the infant conjoined twins however, this perspective would only be a misconception if it relied on assumptions about what conjoined twins generally want and value. It could be that bodily integrity, like the sanctity of life (and possibly dignity), has a value independently of what people actually want. In *Re A* for the first twenty pages it is striking just how often the word ‘normal’ is used to describe what Jodie can become. Not just by Ward LJ, but also in his selection of statements from medical professionals. There is absolutely no contemplation of a life that could be led by both twins still conjoined. Although the medical prognosis was not promising, there have been numerous incidents of similar predictions being wrong. And, putting aside this unlikely miracle, it still remains – was the quality of life (that may have been possible) so bad that Mary should die so Jodie could live ‘normally’? Really the issue was that without the separation, Jodie would not be able to live at all, so any attempts to justify it on grounds that it would restore her to normality should be questioned.

There was a case in the United States of conjoined twins, Amy and Angela Lakeberg, which highlights need for careful assessment. The twins’ parents aggressively sought the separation, against the advice of the medical team that had delivered the babies (and that hospital’s ethics committee which recommended against it).⁵²⁹ Eventually, they found a surgical team who would perform the surgery. Unlike the Commonwealth cases there was no blatantly weaker twin – Angela was chosen to live because her anatomy gave her a *slightly better* chance of survival.

“Just before the operation, nurses painted Angela’s fingernails pink, in an effort to prevent the surgeons from being confused about which “half” was to be salvaged: they were to save the girl with the pink fingernails. Amy’s bare fingernails signalled her fate.”⁵³⁰

⁵²⁸ Alice Domurat Dreger *One of Us: Conjoined Twins and the Future of Normal* (Harvard University Press, Cambridge, 2005) at 7. Sadly neither survived the operation.

⁵²⁹ *Ibid* at Chapter 3. Dreger refers to these cases – where one twin dies to ‘save’ the other – as “sacrifice surgeries”.

⁵³⁰ Dreger (2005) at 88.

The outcome of this case was dire. Angela did survive the operation but remained on ventilator support, and hospitalised, until her death about ten months later. Aside from the apparent futility of the operation and Angela's short, burdened life, another sad aspect of this case is that her parents visited her less than five times post-operation. It was the medical staff who become her surrogate parents. Dworkin has said of this case:

“True respect for human life was sacrificed, in Philadelphia, to bad slogans about sanctity and rescue, and, perhaps, to a dangerous love for heroic medicine for its own sake.”⁵³¹

Perhaps if the courts had been involved in this case a different outcome may have been achieved – on face value it would be hard to argue that the operation was in either twin's best interests.

Mary's Best Interests

Robert Walker LJ decided that separation would be in Mary's interests as it would restore her bodily integrity and dignity, and also used the doctrine of double effect to justify his decision at the second stage of the case.⁵³² Bodily integrity is a concept that is linked to respecting a person's autonomy; it is about a person's right or interest in protecting their own self.

The surgeon, who gave evidence on the operation to separate the twins, stated:

“If you look at it in terms of Mary dying, no, there is not a therapeutic benefit. If you look at it in terms of what Mary's life would be like attached forever to her sister, then it is not a benefit for her to remain attached to her sister: *she will be much happier if she is separate.*”⁵³³

This is an odd statement to make in light of the fact that there was zero chance of Mary surviving the operation. Indeed, as Ward LJ noted, given that the operation would presumably be performed under general anaesthetic, it is hard to see when it would afford Mary the chance to feel anything at all. This argument could have been better made for Jodie (if she needed anything to support her interests) as Mary was likely to have very limited physical abilities, leaving Jodie to have to move her sister around with her. For Mary, if she was not suffering (and part of the complexity of this case was that this was not known), then it is a hard argument to make that she would be happier dead. Effectively what the surgeon is advocating here is bodily integrity for both twins. Robert Walker LJ used this to justify the

⁵³¹ Dworkin *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (1993) at 7.

⁵³² *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 258.

⁵³³ *Ibid* at 169. Emphasis added.

operation, as it gave Mary bodily integrity and the doctrine of double effect meant that her death was not the purpose of operation but its inevitable consequence:

“The surgery would plainly be in Jodie’s best interests, and in my judgment it would be in the best interests of Mary also, since for the twins to remain alive and conjoined in the way they are would be to deprive them of the bodily integrity and human dignity which is the right of each of them... Mary’s death would not be the purpose of the operation, although it would be its inevitable consequence. The operation would give her, even in death, bodily integrity as a human being. She would die, not because she was intentionally killed, but because her own body cannot sustain her life.”⁵³⁴

Brooke LJ’s approach to the doctrine of double effect differed from Robert Walker LJ’s,⁵³⁵ stating that Mary would be killed intentionally:

“because by no stretch of the imagination could it be said that the surgeons would be acting in good faith in Mary’s best interests when they prepared an operation which would benefit Jodie but kill Mary.”⁵³⁶

Robert Walker’s conclusion that the twins had confluent interests was highly significant for his approach to the criminal law question, as it allowed him to rely on the doctrine of double effect. According to most versions of the doctrine, it cannot be used to benefit one person at the expense of another; it could only be used where the intention of the operation was to achieve an outcome which was in Mary’s best interests as well as Jodie’s.⁵³⁷

Ward LJ, in contrast, agreed that the operation would give Mary bodily integrity – but found that this was an illusory goal as she would not be able to enjoy this state.

“The only gain I can see is that the operation would, if successful, give Mary the bodily integrity and dignity which is the natural order for all of us. But this is a wholly illusory goal because she will be dead before she can enjoy her independence and she will die because, when she is independent, she has no capacity for life.”⁵³⁸

This is a crucial difference in approaches. Is bodily integrity an interest that depends on you being aware of it? On one reading, Robert Walker LJ ascribed to Mary an objective interest in bodily integrity; an objective interest that was used to justify the operation being in her best interests. On another reading, Robert Walker LJ’s approach advocated bodily integrity as being valuable insofar as it would make Mary “much happier”, which would seem to locate the bodily integrity interest in the category of experiential interests.

⁵³⁴ Ibid at 258.

⁵³⁵ Ibid at 216.

⁵³⁶ Ibid at 218.

⁵³⁷ Ibid at 251.

⁵³⁸ Ibid at 184. This fits within the theme identified in Chapter Two regarding different reasoning.

The latter reading accords with Ward LJ who found that bodily integrity is an experiential interest which is dependent on a person being aware of it. If you are not aware of your body and what it means to be intact, then an interest in bodily integrity is a wholly illusory concept. In the way that it was discussed by Ward LJ, bodily integrity was only perceived as experiential, and yet one could imagine someone having surviving interests regarding his or her body to be buried intact, or people talking about wanting to die with dignity without tubes and other artificial apparatus going into the body. These critical or far life-long interests could be predicated on a person's previous values and preferences, something which cannot apply to infant such as Mary.

This leaves the question of whether someone in that situation could still be said to have non-experiential objective interests that exist independently of prior views or values. In Chapter Three the taxonomy of interests was explored, and the interest of dignity was discussed. The courts have fairly consistently applied dignity as an objective interest not dependent on awareness (the exception being Butler-Sloss LJ in *NHS Trust A v M; NHS Trust B v H*).⁵³⁹ In *Bland*, Hoffmann LJ describes the principle as an intrinsic value, not dependent on awareness.⁵⁴⁰ If the same could be said for bodily integrity, then perhaps it would make sense to attribute such an interest to someone like Mary.

The reason for dignity being perceived as an objective interest may, however, explain why the two concepts can be distinguished. Dignity is viewed as an interest accorded to everyone because of the importance it has to our community, as it explains many of the attitudes held towards the dying and the dead in our communities. Other evidence for this is the existence of surviving interests, where society has both moral and legal consequences for disrespecting these. Dignity is therefore not only for the incompetent person's benefit, but also for others. Bodily integrity, however cannot be said to have similar implications. It is much harder to claim that bodily integrity benefits everyone, as it is an individualistic concept. Implicit in the concept of bodily integrity for the twins is the idea that 'normal' is not only an aim, but

⁵³⁹ *NHS Trust A v M; NHS Trust B v H* [2001] Fam 348 at [49]. "I am, moreover, satisfied that Article 3 requires the victim to be aware of the inhuman and degrading treatment which he or she is experiencing or at least to be in a state of physical or mental suffering. An insensate patient suffering from permanent vegetative state has no feelings and no comprehension of the treatment accorded to him or her." Butler-Sloss was considering the application for withdrawal of treatment from two patients in light of the European Convention on Human Rights which had entered into domestic law by virtue of the Human Rights Act 1998.

⁵⁴⁰ *Airedale NHS Trust v Bland* [1993] AC 789 826. "The fact that the dignity of an individual is an intrinsic value is shown by the fact that we feel embarrassed and think it wrong when someone behaves in a way which we think demeaning to himself, which does not show sufficient respect for himself as a person."

that it is also an aspirational goal. To introduce this interest as one that Mary would have is therefore based on false premises. While it might be possible to argue that we each have an objective interest in bodily integrity, it seems more problematic to claim that it manifests in an interest in physical separateness. Conventionally, the bodily integrity is seen as a right to, or interest in, non-interference. Robert Walker LJ's treatment of it as an interest in physical separateness seems idiosyncratic. Furthermore, it may not accord with what we know of how older conjoined twins see their own situation. Of course, an objective interest need not accord with anyone's subjective views, but it would nonetheless seem strange to insist that other conjoined twins have an objective interest in being separated, even if they themselves insist that they prefer being conjoined (as in the example given earlier).

That *Re A* is a difficult 'uneasy' case, both morally and legally, is undisputed. The judges disagreed over the best interests of the twins, and also justified the legality of the separation by applying different tests. The decision seems to fall back on an implicit reasonableness test. In utilitarian terms, it seems counter-intuitive to let both girls die rather than taking the option of saving one.⁵⁴¹ The other controversial aspect to the conjoined twins' case was the fact that the judges overrode the parents' wishes. In the following section the extent to which parental views have been, and should be, taken into account in these difficult end-of-life cases is given consideration.

Parental Views and Child's Interests

"The reasons offered in the Court of Appeal were so confused and mutually inconsistent that they fail utterly to justify, either legally or morally, the overruling of the parents' wishes."⁵⁴²

Parents are the de facto decision-makers for everything regarding their child. What they eat, the clothes they wear, who they see, where they go to school, where they live ... the list is endless. Not all decisions that parents make are in the child's best interests. Often decisions will be made on the basis on familial interests. Consider two sisters, Elizabeth and Laura. If Elizabeth is enrolled in art classes, but Laura is not, then it is not in Laura's best interests to be driven across the city to drop off Elizabeth. But those kinds of pragmatic decisions are made daily, and the scale of them can vary. Perhaps when Elizabeth is ready for high school

⁵⁴¹ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 227 per Brooke LJ. "Our revulsion against a deliberate killing is so strong that we are loth to consider utilitarian reasons for it."

⁵⁴² Harris "Human Beings, Persons and Conjoined Twins: An Ethical Analysis of the Judgment in *Re A*" (2001) 9 (3) MLR 221 at 223.

her parents will choose a school that is the best fit for her, and when it is Laura's turn three years later she will be sent to the same school based on the reasoning "that it's easier". It is not necessarily in her best interests, and could have lasting effects on her life, but it is unlikely to cause serious detriment. The State only steps in as arbiter to parental decision-making if: (1) the parents disagree over what decisions should be made (for example they have separated, and both want custody of the children); or (2) the decisions fall outside the scope of what is considered acceptable parental decision-making (for example they can choose what kind of school, but not whether the child receives an education or not). In a medical context, perhaps the parents expose their child to a risk of serious harm, or perhaps they are subjecting the child to continued suffering.⁵⁴³

Did the opposition to separate their daughters by the parents in *Re A* fall outside of this scope? It is not difficult to understand their reasons for doing so, as explained in the following paragraph, as they perceived Mary's death as deliberate, and they were also concerned about their limited resources if Jodie's disabilities were severe:

"We have of course had to give serious consideration to the various options as given to us by our daughters' treating doctors. We cannot begin to accept or contemplate that one of our children should die to enable the other to survive. That is not God's will. Everyone has the right to life so why should we kill one of our daughters to enable the other to survive. That is not what we want and that is what we have told the doctors treating Jodie and Mary. In addition we are also told that if Jodie survives and that is not known at all, then she is going to be left with a serious disability. The life we have ... is remote ... with very few, if any facilities would make it extremely difficult not only for us to cope with a disabled child but for that disabled child to have any sort of life at all."⁵⁴⁴

The judges did not give this view much credence, rather disingenuously it could be argued, since the basis for the operation implicitly invoked quality of life judgments itself.

As discussed in regards to Elizabeth and Laura's best interests, the State largely leaves parents to be sole decision-makers for their own children. The two exceptions identified were when the parents disagree or when the decision falls outside what is considered to be the normal scope of parenting. This is not, however, how the courts have approached parental

⁵⁴³ This has been argued in many cases regarding children and end-of-life decisions; see *Auckland Healthcare Services Ltd v L* [1998] NZFLR 998; *Portsmouth Hospitals NHS Trust v Wyatt* [2005] 1 WLR 3995; *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam).

⁵⁴⁴ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 13 per Ward LJ.

rights in end-of-life cases. In these cases the act of an interested party, engaging the court's jurisdiction for a minor, effectively overrides any parental control.⁵⁴⁵

“As a dispute has arisen between the treating doctors and the parents, and one, and now both, parties have asked the court to make a decision, it is the role and duty of the court to do so and to *exercise its own independent and objective judgment*.”⁵⁴⁶

This is a very important distinction, as the courts are not limited to reversing a decision if it is unreasonable in light of the parental scope of decision-making capacity; instead the court has a further obligation to exercise its own judgment. The decision therefore becomes “what is in the child's best interests”, not “was the parental decision reasonable”. In these two questions are echoes of the *Bolam* critique, where the decision the courts made was an independent one as to the best interests of the patient, not whether the medical opinion of best interests was the correct one. It could therefore be considered a consistent stance of autonomous decision-making, not abrogating the decision to any person or profession. But it may not be this simple. Is it fair to compare a medical opinion of best interests to that of a parent? A parent has a much higher stake in the outcome, in fact in almost all cases the only person with a higher stake is the child themselves. The parent is the next most affected person. Should this transfer into a greater claim in the decision-making process? The courts have answered this firmly in the negative, and a common theme to their rejection of parental influence is the emotional attachment of parents, and the irrelevance this has to the best interests of the child:

“Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship.”⁵⁴⁷

Consideration of this sentiment – that parental wishes are irrelevant to the consideration of best interests – is problematic with regards to the conjoined twins case. The judges could not agree whether the operation was in both twins' best interests, and on what grounds it was

⁵⁴⁵ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147 at 179 per Ward LJ.

⁵⁴⁶ *An NHS Trust v MB* [2006] EWHC 507 (Fam) [16] per Holman J. Emphasis added. Also see for the same passage: *The NHS Trust v A (A Child)* [2007] EWHC 1696 (Fam) at [40]; *Central Manchester University Hospitals NHS Foundation Trust v A* [2015] EWHC 2828 (Fam) [5].

⁵⁴⁷ *Central Manchester University Hospitals NHS Foundation Trust v A* [2015] EWHC 2828 (Fam) at [16] per Holman J.

legal, and therefore overriding the parents' wishes with disagreement over such fundamental points is troubling.

Where the child is experiencing or is going to experience pain, another dimension is added. While the decision in the conjoined twins case may be difficult to reconcile, where it is one child's interests against parental views there may be some cases where this is easier. In the New Zealand case of *Auckland Healthcare Services Ltd v L*, the parental wishes for their daughter's continued treatment were deemed against her best interests:

“We were satisfied, after considering Baby L's right to life, when contrasted with her right to be free from discomfort and pain; when considering her parents' deeply felt wish for her life to be prolonged as long as possible even if, as would be necessary, that be by artificial means which in part add to her discomfort, Baby L's best interests would be promoted by granting the application... Sadly, this was a case in which we had to make the decision, notwithstanding the wishes of the parents. To have abided by their wishes we would have had to require treatment to be given or continued irrespective of the clinical judgment of the doctors involved and, in our view, contrary to the best interests of Baby L.”⁵⁴⁸

Baby L's self-regarding interest in not experiencing prolonged pain was therefore considered more important than her interest in staying alive, and her parents' wishes to keep her alive. Baby L's best interests were in cessation of treatment, and the courts essentially held that her parents had failed to protect these interests properly when they wanted treatment continued. Is this something that could be alleged in the conjoined twins' situation? Ward LJ's observation that there was a parental duty to separate Jodie and Mary was not justified on the basis of their respective best interests in the way he framed them. In comparison, Baby L was sensate, and – most importantly for the purposes of her best interests – was experiencing pain, and therefore this prompted consideration for her experiential interests which were deemed to outweigh parental views.

The experiential interests of a minor were also the main consideration in an English case, *NHS Trust v A*, where the parents refused to consent to a bone marrow transplant for their daughter, citing the “lengthy, painful and distressing” treatment as their reason for refusing.⁵⁴⁹ There was a 50 percent chance that the transplant would succeed with a lasting cure, and Baby A would have a normal life span, a 30 percent chance of her dying from her

⁵⁴⁸ *Auckland Healthcare Services Ltd v L* [1998] NZFLR 998 at 1006.

⁵⁴⁹ *The NHS Trust v A (A Child)* [2007] EWHC 1696 (Fam).

underlying condition, a ten percent chance that she would die from the treatment, and a ten percent prospect of surviving but with significant impairment.⁵⁵⁰

“So the stark and awesome question for me is: should I approve and authorise this very significant invasive treatment which the doctors so strongly recommend; or respect and endorse the well informed and long considered judgment and decision of the loving parents? The issues are truly ones of life and death, but the case also raises profound issues of parental autonomy in our society.”⁵⁵¹

An interesting aspect of this case is that bone marrow transplants require intensive ongoing co-operation.⁵⁵² The judge recognised this from the outset:

“There has been no suggestion whatsoever in this case that the court should positively order the parents to take her to the hospital for a BMT; still less that she should be removed from them for the purpose, under a care or similar order. So the parents do and will have the final control over whether A undergoes a BMT or not. But the parents are deeply law abiding people who clearly respect the authority of this court and, I hope, its objectivity and wisdom. And they have said that if I do grant the declaration which the hospital seek, then they will most probably feel that they should respect it and co-operate in the BMT taking place.”⁵⁵³

The transplant process was horribly painful. The parents had already witnessed their six month old daughter undergo intensely invasive painful treatments, and they had decided that she had had enough. But the judge disagreed, making an independent decision that it was in the child’s best interests. Her one in two chance at survival, regardless of the cost, was considered to outweigh her parents’ wishes that she be left to enjoy her life in the time that she had left. It could be said that A’s self-regarding intra-personal interests clashed; she had both an interest in avoiding extended, invasive painful procedures and an interest in continued life. What makes the judge the final arbiter in such a delicately balanced decision? If other-regarding interests are factored in, A’s parents are the ones with the closest ties to their daughter, and she to them. Should they be able to decide which one of these self-regarding interests (avoidance of pain and continuance of life) is the most important?

Holman J presided on two other cases where parents disagreed with the medical profession. In both of those, *NHS Trust v MB*, and *Central Manchester*, he ordered that treatment should

⁵⁵⁰ Ibid at [1] per Holman J.

⁵⁵¹ Ibid at [3].

⁵⁵² Ibid at [16] per Holman J: “A BMT is a long process, stretching over 2 months or more. First, there must be a process of ‘conditioning’. The child must be kept in very strict isolation for 2 – 3 weeks, although up to three named family members may visit (and one can be resident at all times). During the conditioning period the child is given chemotherapy drugs which suppress the child’s own immune system, thereby creating space for the new bone marrow cells, when transplanted, to grow. This is a very invasive procedure with some inevitable side effects and a high risk of infertility.”

⁵⁵³ Ibid at [3] per Holman J.

be continued. The same conclusion, regarding parental views being irrelevant, has now been articulated in three of Holman J’s judgments:

“In this regard [that withdrawal of treatment goes against parents’ beliefs] I refer to what I said at paragraph 49 of my judgment in MB, and repeated at paragraph 41 of my judgment in *The NHS Trust v A* [2007] EWHC 1696 (Fam): “This case concerns a child who must himself be incapable, by reason of his age, of any religious belief. An objective balancing of his own best interests cannot be affected by whether a parent happens to adhere to one particular belief, or another, or none. I have the utmost respect for the father’s faith and belief, and for the faith of Islam which he practises and professes. But I regard it as irrelevant to the decision which I have to take and I do not take it into account at all”.”⁵⁵⁴

Parental views could be, and I argue should be, considered an other-regarding interest that a child has. This does not necessarily mean that every child has this interest, although it is possible to start from a position that they do, but these are secondary interests. If the case is made that children have shared interests in the collective flourishing of the family unit a further step is required to support the conclusion that they have an interest in parental views being followed. By virtue of being a member in a family all children have interests that are intimately tied into parental wellbeing. Parents may be considered as the custodians of that collective endeavour. Overruling parental decisions in cases where a child’s best interests are extremely difficult to determine (for example *Re A* and *NHS Trust v A*) means ignoring these other-regarding interests. It may be preferable in these more difficult cases for the courts to take a *Bolamised* approach, and make a decision on whether the parental decision is reasonable, rather than imposing the independent view of the court. This is because it is difficult to argue that the decisions taken were unmistakably in the child’s best interests. Where the cause of conflict is continued suffering, such as Baby L, then there is a much clearer case for the decision to withdraw treatment being in her best interests.

Prior Views and Other Interests

Chapter Five identified different kinds of prior views, making a distinction between cases where there was an explicitly expressed prior view: *explicit-general* – a general comment made at T1 as to wishes at T2; and *explicit-specific* – a specific comment at T1 relating to their condition at T2. There were also inferred views from the person’s previous self: *inferred-general* – a life story at T1 with no particular relevance to T2; and *inferred-specific*

⁵⁵⁴ *Central Manchester University Hospitals NHS Foundation Trust v A* [2015] EWHC 2828 (Fam) 342 at [19]. Holman J is referring to: *An NHS Trust v MB* [2006] EWHC 507 (Fam) at [49]; *Central Manchester University Hospitals NHS Foundation Trust v A* [2015] EWHC 2828 (Fam) at [41].

– a life story at T1 that has some relevance to T2.⁵⁵⁵ It was argued that these distinctions should be material to the evaluation of how safely judges could rely on the decision being made in line with the patient’s views. A proposal was then outlined to ascertain veracity and discussed it in reference to cases using the distinctions related to the previously competent patient, and what kind of wishes (if any) they had previously expressed. This was a different enquiry to the one focused on in this chapter: where prior views are to be considered under the umbrella of a best interests test, what weight is, and should be, given to them?⁵⁵⁶

Experiential

The interests of anyone who can experience anything were discussed above in reference to quality of life. While it seems reasonable to suppose that PVS patients, for example, have no experiential interests, the description of Mr James seems to place him on a very different point of the sentience spectrum from patients like Anthony Bland:

“he recognised and was pleased to see his wife and his son when they visited; kissed his wife when she leaned into him; looked at her when she moved round the bed; mouthed what appeared to be words in answer to his wife, Ms Baker and nursing staff; turned the pages of a newspaper, smiling while he did so, although it was not clear to the doctor whether he was actually reading any of the articles or looking at the pictures; put on and took off his glasses while doing so; and appeared to enjoy watching videos on his son’s phone.”⁵⁵⁷

Firstly, the description of Mr James as someone who was responsive, and had apparent enjoyment of visitors, leads to a query regarding the lack of discussion in any of the judgments to ascertain Mr James’ *current* views. Also lacking is a discussion of the form of his incompetence: is it in terms of his cognitive abilities, his ability to communicate, his having values? Obviously, Mr James’ case would have been treated very differently if there were questions over his competence. If he could mouth words, put glasses on, and watch videos, surely some effort should have been made to ask him if he was in pain, or discomfort, did he mind being dependent, or even if he was happy. Perhaps some form of effort was made to ascertain Mr James’ views, but if so, it is not documented. Under s 4 of the MCA it is required so far as it is “reasonably practicable” for the substitute decision-maker to permit and encourage the person to participate in the decision-making process. Perhaps it was not

⁵⁵⁵ See Table One in Chapter Five.

⁵⁵⁶ There are statutory differences when considering the weight of prior wishes and these have been discussed elsewhere. See Chapter Two: “Prior Views” and Chapter Five generally.

⁵⁵⁷ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 at [6]. See Chapter 6, “Application One” for more discussion on experiential interests.

possible with Mr James, but any attempts to do so should have been documented and any information gathered should have been utilised as appropriate.⁵⁵⁸

Mr James' condition did deteriorate between hearings, so the Court of Appeal was considering a patient who was much closer to a MCS label. However, his inferred-specific view for treatment to continue, which Chapter Five discussed as a reasonably safe summation of what he would have wanted at T2 if asked at T1, was found to be subject to other considerations. In the Court of Appeal, Sir Alan Ward separated patients' views from the best medical interests that they may have, and went on to conclude:

“The harsh reality, so harsh that it was understandably impossible for the family to accept it, was that his position was hopeless. His wishes, if they were to be the product of full informed thought, would have to recognise the futility of treatment, that treatment would be extremely burdensome to endure, and that he would never recover enough to go home. All this would be extremely distressing for his family. One is driven to conclude that his wish to survive was unattainable. Miracles may happen but on the facts of this case the probabilities were overwhelming against a miracle happening in this case. We had to act on the real possibilities not those which were fanciful. In the overall assessment, therefore, of where his best interests lie, *I respect his wishes but in my judgment they must give way to what is best in his medical interests.*”⁵⁵⁹

Effectively, Sir Alan Ward found that his wishes would have to include the realisation that further treatment would not mean his recovery, and therefore should give way to his best medical interests. It is, of course, entirely correct that any views of Mr James were part of the assessment of his best interests and not an overriding factor under the MCA. However, Sir Alan Ward presumed that the objective medical situation should be seen as a part of what Mr James would want or should take into account, when trying to frame a view of what his prior views would have considered. Is this a step too far? As evaluated in Chapter Five, his inferred-specific view, based on what his family said, and a previously difficult health battle, favoured continued treatment. Should Sir Alan Ward have imbued this view with a reasonable person's evaluation of the situation? Do prior views include consideration of what the person *should* have considered? This appears contrary to the purpose of any consideration of what the patient's prior views were if they are then subjected to what any

⁵⁵⁸ The counsel for the family, Ian Wise QC was also concerned about this oversight, although the family had agreed that Mr James lacked any capacity before he became involved in the case: Wise (2014) 82 (4) Med Leg J 144 at 152.

⁵⁵⁹ *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65 at [47]. Emphasis added. See Chapter Six, Application Two, for discussion on “Deferment to a Medicalised View”.

reasonable person would conclude. And Sir Alan Ward seems to acknowledge this, as he does accede that the prior views are “giving way” to his medical interests.

Therefore, it could be argued that Sir Alan Ward did not properly apply the prior views when he considered the factors that Mr James would consider if he was able to do so, and in doing so emphasised the “harsh reality” that “his position was hopeless”. He failed to discuss, or give weight to, Mr James’ previously held wishes, beliefs and feelings that all pointed to further provision of treatment. It is also possible that Sir Alan Ward considered sufficient reasons why the previous ‘fight for life’ approach was reasonable, and perhaps why a reasonable person would abandon this fight when it was not for life, as life post cancer was diametrically opposed to that of a life in a MCS. Because Mr James’ two situations were relevantly different this could justify Sir Alan Ward’s approach. According to the proposal advanced in Chapter Five it should not be straightforwardly assumed that the wishes expressed in S1 (prior battle with cancer) should be applied in S2 (current MCS). However, the basis for this should be any information gathered from Mr James. Any reference to what the reasonable person would have wanted, as discussed in Chapter Six, should be treated with caution.

In the same court, Arden LJ stated that her approach to assess best interests started with Mr James’ wishes, as required under the MCA. Arden LJ inferred from Mr James’ current state – that he showed signs of happiness when he saw his family – that his present wishes would favour continuation of treatment.⁵⁶⁰ She also discussed his prior attitude to a distressing diagnosis:

“DJ has approached life-threatening illness before with enormous courage and determination. He has the great advantage of a devoted family and much to live for in that regard. The inference which I draw from the evidence is that he would wish his life to be saved by all reasonable means, and that he would not be concerned by reduced enjoyment of life due to disability or by being in a state of complete dependence on others.”⁵⁶¹

After clearly setting out the starting point under the MCA as Mr James’ prior views, she decided that:

⁵⁶⁰ *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65 at [57].

⁵⁶¹ *Ibid* at [58].

“Acting with humanity, and with respect for DJ’s autonomy, I consider in the light of DJ’s medical condition, his wishes would be unlikely to be to have the treatment of the kind in issue here, and that a reasonable individual in the light of current scientific knowledge would reject it.”⁵⁶²

Arden LJ takes a different approach to her colleague regarding the question of how the prior views should be weighted, and instead of deciding that they can be outweighed by other interests (and aligning with Sir Alan Ward’s judgment) she decided that no reasonable person could have such a view. In her estimation, Mr James’ prior views informed her judgment, but instead of this being in conflict with Mr James’ medical interests, which Sir Alan Ward found, she has inferred it to be what Mr James would want as a reasonable person.

Despite the preponderance of clauses under the MCA which have regard to the patient’s prior wishes, feelings, beliefs and values, the Court of Appeal appears to have disregarded the intent of the legalisation and although they considered the prior wishes, these were not deemed sufficiently reasonable or rational to rule in favour of continued treatment. If this case had stopped with the Court of Appeal, the best interests test outlined under the MCA and applied by the judiciary would have been very murky; reduced by Arden LJ to what the reasonable person would want regardless of their current or previously expressed wishes, and according to Sir Alan Ward reliant on medical interests that may overrule what a particular person may want.

On appeal to the Supreme Court, the Vice President, Lady Hale, handed down the judgment on behalf of all five judges. The judgment was critical of the way that the Court of Appeal used Mr James’ prior views, and said that the best interests test was not to be interpreted objectively as they had done, but instead:

“The purpose of the best interests test is to consider matters from the patient’s point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient’s wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. In this case, the highest it could be put was, as counsel had agreed, that “It was likely that Mr James would want treatment up to the point where it became hopeless”. But insofar as it is possible to ascertain the patient’s wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account

⁵⁶² Ibid at [63].

because they are a component in making the choice which is right for him as an individual human being.”⁵⁶³

Lady Hale’s judgment is a significant one for assessing the best interests of incompetent patients, not only because it was the first Supreme Court case to consider the MCA, but also because it sets the parameters. Her judgment does three very important things: (1) notes that the best interests test is person-specific, but does not signify that their wishes should prevail; (2) acknowledges that prior views may not always be possible to ascertain and even if they are identified they may not apply to the current circumstances (this aligns with the proposal from Chapter Five); (3) emphasises the importance of the person’s previous self, their values and their prior self and other-regarding interests (effectively ss 6 (b) and (c) MCA), which provides a hierarchy for judges to consider when trying to weigh up the patient’s best interests. Despite a clear hierarchy, it does not necessarily follow that the weighting of the prior views and how they fit with other interests is straight-forward.

Although *James* was the first case to be considered under the MCA regarding future provision of treatment, it was not the first case to consider the best interests standard in the Court of Protection. *In the Matter of G (TJ)* was considered in 2010, in reference to property and affairs, which, under the Act, are subject the same standard of best interests under s (1) 5.⁵⁶⁴ Because the same provisions apply, it is useful to consider what other cases have discussed. Morgan J summarised three other cases⁵⁶⁵ that had considered the best interests test under the MCA for various reasons, concluding:

“The best interests test involves identifying a number of relevant factors. The actual wishes of P can be a relevant factor: section 4(6)(a) says so. The beliefs and values which would be likely to influence P’s decision, if he had capacity to make the relevant decision, are a relevant factor: section 4(6)(b) says so. The other factors which P would be likely to consider, if he had the capacity to consider them, are a relevant factor: section 4(6)(c) says so. Accordingly, the balance sheet of factors which P would draw up, if he had capacity to make the decision, is a relevant factor for the court’s decision.”⁵⁶⁶

⁵⁶³ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 at [45]. The difference between objective and subjective was discussed in Chapter Six in Application Three “Qualified-Objective Test”.

⁵⁶⁴ *In The Matter Of G (TJ)* [2010] EWCOP 3005.

⁵⁶⁵ *In Re S (Protected Persons)* (2009) WTLR 315; *In Re P (Statutory Will)* [2010] Ch 33; *Re M* [2010] 3 All ER 682.

⁵⁶⁶ *In The Matter Of G (TJ)* [2010] EWCOP 3005 at [55]. Note this also perpetuates the fiction of “what would the patient be likely to consider if he or she could” as discussed in Chapter Five. For further discussion of the balance sheet approach see: *NHS Trust v Ms D* [2005] EWHC 2439 (Fam) at [42] “it is my task to balance the benefits or disbenefits, advantages or disadvantages to Ms D in the granting of this declaration” per Coleridge J. In *An NHS Trust v MB* [2006] EWHC 507 (Fam) Holman J headed one section of the judgment at [58]

Tellingly for the subject of this thesis, there was disagreement amongst these cases as to the importance that the prior views has in this “balance sheet” approach of the best interests test. In *Re S*, Marshall J gave great weight to the person’s wishes:

“The Act does not of course say that P’s wishes are to be paramount, nor does it lay down any express presumption in favour of implementing them if they can be ascertained. Indeed the paramount objective is that of P’s best interests. However, by giving such prominence to the above matters, the Act does in my judgment recognise that having his views and wishes taken into account and respected is a very significant aspect of P’s best interests. Due regard should therefore be paid ... when doing the weighing exercise of determining what is in P’s best interests in all the circumstances of the case.”⁵⁶⁷

Although Morgan J concluded that Marshall J had “slightly overstated the importance given to P’s wishes”,⁵⁶⁸ he decided that in the particular case before him, Mrs G’s prior wishes would define her best interests:

“I recognise that this consideration is essentially a “substituted judgment” for Mrs G. I am also very aware that the test laid down by the 2005 Act is the test of best interests and not of substituted judgment. However, for the reasons which I have tried to set out earlier, the test of best interests does not exclude respect for what would have been the wishes of Mrs G. A substituted judgment can be subsumed into the consideration of best interests. Accordingly, in this case, respect for what would have been Mrs G’s wishes will define what is in her best interests, in the absence of any countervailing factors. There are no such countervailing factors here.”⁵⁶⁹

It is interesting that, despite referring to many other cases, Lady Hale did not discuss other cases that have dealt specifically with the provision of best interests under the MCA. Does this mean that there is a significant difference in assessing the *current* views of an adult lacking capacity under the MCA, and the *prior* views of a permanently incompetent adult? In *Re M*, Munby J stated that the weight attached to the incapacitated person’s wishes is issue-specific:

“the weight to be attached to P’s wishes and feelings will always be case-specific and fact-specific. In some cases, in some situations, they may carry much, even, on occasions, preponderant, weight. In other cases, in other situations, and even where the circumstances may have some superficial similarity, they may carry very little weight. One cannot, as it were, attribute any particular a priori weight or importance to P’s wishes and feelings; it all depends, it must depend, upon the individual circumstances of the particular case. And even if one is dealing with a particular individual, the weight to be attached to their wishes and feelings must depend upon

“Weighing the Benefits and Burdens”, which included the Guardian’s balance sheet, and labelled another section at [88] “The Balance of Best Interests – My Own View”.

⁵⁶⁷ *In Re S (Protected Persons)* (2009) WTLR 315 at [56].

⁵⁶⁸ *In The Matter Of G (TJ)* [2010] EW COP 3005 at [41].

⁵⁶⁹ *Ibid* at [65].

the particular context; in relation to one topic P's wishes and feelings may carry great weight whilst at the same time carrying much less weight in relation to another topic. Just as the test of incapacity under the 2005 Act is, as under the common law, 'issue specific', so in a similar way the weight to be attached to P's wishes and feelings will likewise be issue specific."⁵⁷⁰

Section 4 of the MCA states that current and prior wishes should be considered. Where possible, current views should be ascertained, so in a case with facts similar to *Re M*, although the person lacks capacity, they may still be able to express some views, unlike David James in *James*. But the MCA does not differentiate between these views; they must all be considered; s 4 (4) encourages as much participation as possible and, under s 4 (6), the substitute decision-maker must consider the person's past wishes and feelings. Therefore, although *James* is seen as the landmark case for best interests under the MCA, the extent to which the permanently incompetent's previous self can be utilised under the Act it is yet to be resolved. Munby J's discussion of P's wishes and feelings indicates that the weighting given to wishes is "case, fact and issue-specific" and is not to be given priority weighting over other considerations for the incapacitated person's best interests. Of course, in *James*, the wishes that should be considered deal with a very serious issue – whether or not future life-prolonging treatment should be provided. This is not the same level of decision-making as deciding what kind of sandwich he would prefer to eat (to give an example used by Lady Hale), but these two extremes are both subjected to the same best interests test under the MCA.⁵⁷¹ There is little doubt that a person's wishes regarding end-of-life treatment should be subjected to considerably more intense scrutiny than their sandwich preferences.

Non-Experiential

In cases involving PVS patients, there are no experiential interests that could contrast with any prior views. In the case of *Bland*, there was also no safe inference as to what his prior views would be. In this instance, if wanting to attribute him with a view, there are two options: presume he would not want treatment continued, or presume that he would.

“Thus it seems to me that we are faced with conflicting ethical principles. On the one hand, Anthony Bland is alive and the principle of the sanctity of life says that we should not deliberately allow him to die. On the other hand, Anthony Bland is an individual human being and the principle of self-determination says he should be allowed to choose for himself and that, if he is unable to express his choice, we should try our honest best to do what we think he would have chosen. We cannot disclaim

⁵⁷⁰ *In Re M* [2010] 3 All ER 682.

⁵⁷¹ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 at [24].

this choice because to go on is as much a choice as to stop. Normally we would unquestioningly assume that anyone would wish to live rather than die. But in the extraordinary case of Anthony Bland, we think it more likely that he would choose to put an end to the humiliation of his being and the distress of his family. Finally, Anthony Bland is a person to whom respect is owed and we think that it would show greater respect to allow him to die and be mourned by his family than to keep him grotesquely alive.”⁵⁷²

This is in contrast to the approach in American courts.

“The essential point here is that in America the courts have so far taken it for granted that life-support must be continued, unless there is evidence indicating that the patient would not have wished to be kept alive in the circumstances in which she now is. In contrast, the British courts were quite untroubled by the absence of any information about what Bland’s wishes might have been.”⁵⁷³

The general observation to be made here is that the starting point for these two positions are diametrically opposite. Where there is an information void, what interests should count?

In Chapter Six consideration was given to various implications of narrowly applying the best interests test. One approach outlined was that of Lord Mustill in *Bland* who appeared to equate a lack of personhood with a lack of *any* interests. Buchanan and Brock give an account which differs from Lords Mustill and Keith in one vital respect: they do not equate a lack of *experiential* interests with a lack of *any* interests:

“It is nevertheless true that the permanently unconscious individual as such, that is, simply by virtue of his present condition of permanent unconsciousness, has no interests. Whether or not a permanently unconscious individual has interests in virtue of having previously been conscious is a different matter and will depend upon what the individual’s values were when he or she was conscious.”⁵⁷⁴

The interests that a permanently incompetent person may have, in their account, depend on those that they had when they were conscious. For example, a person can have future-orientated interests (they use the example of a religious view to have treatment continued for as long as possible).⁵⁷⁵ The contention that prior consciousness transfers into interests, effectively means that no young children could have any interests, since they could not have developed a sense of values yet. They go on to argue that the best interests principle cannot be applied to those in a PVS:

⁵⁷² *Airedale NHS Trust v Bland* [1993] AC 789 at 829.

⁵⁷³ Singer in Kuhse and Singer (eds) *Bioethics: An Anthology* (2nd ed, Blackwell Publishing Ltd, Padstow, Cornwall, 2006) at 339.

⁵⁷⁴ Buchanan and Brock (1990) at 129.

⁵⁷⁵ *Ibid.*

“The best interest principle, however is a principle that expresses a positive obligation, a duty to do what best promotes someone’s interests or is most conducive to his or her good. As such, the best interest principle does not apply to beings who permanently lack the capacity for consciousness and whose good can never matter to them, and this includes human beings who are in a permanent vegetative state.”⁵⁷⁶

However, this is not how the legal test works. As explained in Chapters Two and Four, best interests does not start from a neutral position; the default is that everyone has the right to refuse treatment, or not to be treated without consent. Therefore, in law, best interests is a threshold test, to determine whether treatment can be justified, and according to most of the judges in *Bland*, this threshold was not met.

In the Scottish case of *Law Hospital*, concerning withdrawal of treatment from Mrs Johnson who had been in a PVS for three years, Lord President Hope and Lord Milligan also agreed with the approach taken in *Bland*:

“If it is possible to say that it can be of any benefit to her, then no doubt there is a balancing exercise to be done in order to assess whether it is in her best interests that the treatment should be discontinued. But if it cannot be of any benefit to her – and it is her benefit alone which must be considered in order to decide how the jurisdiction is to be exercised in the light of the medical evidence – then there are no longer any best interests to be served by continuing it. I agree with Lord Milligan that this is to view the question of best interests negatively.”⁵⁷⁷

However, although there can be no medical benefit to Mrs Johnson, does this actually leave a conclusion that there are no interests that can be balanced? Most characterisations of the interests that patients have, even in PVS, acknowledge a wider view:

“... on this there is no dispute – that best interests go wider than medical interests and include religious views, the views of the family and, so far as they can be ascertained, what would be the views of Mr A himself.”⁵⁷⁸

Balanced against all the possible interests that someone in a PVS may have, is the implicitly employed notion that they would not want to live in such a state. This was shown in *Bland*. There has not been a case where someone clearly expressed a prior view to be kept alive in a PVS, but Leslie Burke did strongly express a wish for treatment to continue, knowing that he would be unable to communicate this wish in the future, when his degenerative condition progressed.⁵⁷⁹ In *Burke*, the courts still found that there was no onus to continue such treatment. Perhaps one explanation is that the courts sought to avoid the consequences of the

⁵⁷⁶ Ibid at 128.

⁵⁷⁷ *Law Hospital NHS Trust v Lord Advocate* (1996) Scot CS CSIH 2; [1996] 2 FLR 407 at 859.

⁵⁷⁸ *NHS Trust v A* [2005] EWCA Civ 1145; [2006] Lloyd's Rep Med 29 at [61].

⁵⁷⁹ *Burke v General Medical Council (Official Solicitor Intervening)* [2004] EWHC 1879; [2005] QB 424 at [4].

hierarchy (clear prior views wanting continued treatment) by distinguishing differences at a lower level (not all competent adults can demand treatment).⁵⁸⁰

What does the comparison here portray? To some extent it can be argued that it shows how implicitly the idea of the reasonable view is imbued into the consideration of a patient's prior views. Perhaps there is even an argument that the family's own view on what their loved one would want reflects not the individual's actual thoughts, but instead a wider social norm. In Chapter Five it was suggested that a conflation of the strength of evidence with the relevance of that evidence relating to the person's individual values and beliefs. This raises an important question: even if we know what someone did think individually, should the norms of society still be taken into account? Should the proposal ascertaining veracity of the person's views, as outlined in Chapter Five, be further qualified by linking it to an appraisal of how this view conforms to wider norms? If so, to some extent this speculation would be congruent with Veitch's speculations regarding autonomy, that despite what they say they are doing, courts are much more likely to find a patient to be competent if they are making a choice that seems, to the court, to be reasonable.⁵⁸¹ This may also be true of best interests decisions. The courts may be more willing to accept evidence of prior views, and value those views, where the views seem 'reasonable', but will be much more likely to be sceptical of those that they see as unreasonable. If this thesis has demonstrated this – or even shown that it is possible – then it is a conflation of a subjective "what did this person want?" test, and an objective "what would a reasonable person want?" test. Sometimes this may be appropriate where there is a void of information, as exemplified in the *Bland* case. But the courts did not actually acknowledge that this is what they doing – instead they said it was likely that Anthony Bland would not have wanted treatment continued, and did not link this to reasonableness. By comparison, in *James* there was reasonably good evidence of his prior views, but this contrasted with what was deemed a 'reasonable' view. Therefore, the Court of Appeal (though not the Supreme Court) used reasonableness as a way to justify discontinuation of Mr James' treatment.

⁵⁸⁰ A Canadian case held that where a Personal Directive existed treatment would have to continue: *Swiss v Alberta Health Services* [2009] ABQB 691 at 74.

⁵⁸¹ Veitch (2007) at 87.

Other-Regarding Interests

Chapter Three advanced a position for acknowledging other-regarding interests, and further advocated that these can be attributed to individuals without any prior competence, or values, or awareness. The following section will discuss how other-regarding interests can be applicable in cases of previous competency, and then consideration will be given to the more contentious claim that those without previous competence can also have other-regarding interests.

Other-Regarding Interests of the Previously Competent

As demonstrated in Chapters Five and Six, there were varied opinions in *Bland* as to what interests Anthony Bland had, and not surprisingly the judge who found that Anthony Bland did not have *any* interests could not conceive of any wider conception of interests:

“But it seems to me to be stretching the concept of personal rights beyond breaking point to say that Anthony Bland has an interest in ending these sources of others’ distress. Unlike the conscious patient he 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.”⁵⁸²

Other judges disagreed, and some discussed these other-regarding interests. Thomas Bingham MR, Butler-Sloss and Hoffmann LJ all found that Anthony Bland had interests in the way that his family would remember him. As canvassed in Chapter Three, this can be interpreted in two ways: a self-regarding interest in how you are remembered, for your own sake, or an other-regarding interest in not wanting to be a burden on your whānau, such that they may then remember you in such a dependent state:

“An objective assessment of Mr. Bland’s best interests, viewed through his eyes, would in my opinion give weight to the constant invasions and humiliations to which his inert body is subject; to the desire he would naturally have to be remembered as a cheerful, carefree, gregarious teenager and not an object of pity; to the prolonged ordeal imposed on all members of his family, but particularly on his parents; even, perhaps, if altruism still lives, to a belief that finite resources are better devoted to enhancing life than simply averting death.”⁵⁸³

If a person has interests by virtue of being previously competent, for example the interest in having their prior self’s views robustly assessed, it follows that an integral part of their prior self is an interactive person with connections of numerous kinds with many people. When a

⁵⁸² *Airedale NHS Trust v Bland* [1993] AC 789 at 897 per Lord Mustill.

⁵⁸³ *Ibid* at 813 per Thomas Bingham MR.

loved one is in a condition such as PVS it is undoubtedly the whānau who are suffering more than the patient. If the reasonable patient view is able to inform what the prior view of the patient may have been, surely it can be also used to identify that most patients would view their family's suffering as an interest they cared about. Again, the family is both a source of information and, where the patient has no experiential interests, the most affected by the grievous situation that the patient is in. As such this thesis advocates that any sophisticated account of interests should consider the interests that the patient would have for their whānau. This is also applicable to a parent's view for their child, and this aspect is discussed in the next section.

Another difficulty with the argument that a person in PVS has no interests is the question of why it would therefore matter what happens to them. Does it not follow that they can then be used as a 'sideboard'?⁵⁸⁴ It is doubtful that Lord Mustill would have agreed with this rationale, but why not? It is because society still maintains that patients in a PVS (or similarly vulnerable) should still be respected and that they are deserving of dignity. This illustrates two important points. The first is that there is a wider conception of interests; if society maintains that we should respect those in a PVS it is because we would want the same kind of respect. Therefore an objectively applied interest in dignity and respect is allotted to everyone. The second point is that societal values are implicitly invoked through concepts such as dignity. Why do the judges not discuss such things as communitarian values? If a person in a PVS is attributed with an interest in altruism, this then opens the door to difficult resource allocation discussions. As already discussed in the above section, this is done implicitly when making quality of life judgments.

“Threaded through the technical arguments addressed to the House were the strands of a much wider position, that it is in the best interests of the community at large that Anthony Bland's life should now end. ... In social terms it has great force, and it will have to be faced in the end. But this is not a task which the courts can possibly undertake. A social cost-benefit analysis of this kind, which would have to embrace 'mercy killing' to which exactly the same considerations apply, must be for Parliament alone, and the outcome of it is at present quite impossible to foresee. Until the nettle is grasped, we must struggle on with the existing law, imperfect as it is.”⁵⁸⁵

Consider, also, the problematic use of an objective interest in bodily integrity by Robert Walker LJ in *Re A*. Judges cannot unilaterally decide which notional 'objective interests'

⁵⁸⁴ Using an example from Keown "Restoring Moral and Intellectual Shape to the Law after Bland" (1997) 113 (Jul) Law Quarterly Review 482 at 494.

⁵⁸⁵ *Airedale NHS Trust v Bland* [1993] AC 789 at 896 per Lord Mustill.

should apply; presumably they have to relate objective interests to genuinely commonly shared values and notions.

Other-Regarding Interests of the Not Previously Competent

If the previously competent patient can have other-regarding interests, the next question is whether someone who has never been competent can also have other-regarding interests. Crouch and Elliott's investigation into the interests of siblings is pertinent here. In their article they looked at three American court cases which had allowed kidney transplants between minors (or mentally incompetent) siblings. They found that, in all three cases, the courts based the decision on the "psychological benefits" that the donor sibling would experience, and determined that donating would, therefore, be in their best interests. Yet, as they point out, these nebulous benefits surely cannot be outweighed by other, more serious (and more likely) harms that are associated with kidney transplantation.⁵⁸⁶ An English case, *Re Y (Mental Incapacity: Bone Marrow Transplant)* is another example of using self-regarding interests rather than the other-regarding interests that may have applied. Y (described as severely mentally handicapped) was able to be a bone marrow donor for her sister. The courts justified the decision on the basis that Y's best interests were bound up with the welfare of her mother, who visited her regularly, which in turn was connected to the survival of Y's sister.⁵⁸⁷

One reason for this convoluted reasoning, suggested by Crouch and Elliott is that:

"the courts may have had in mind a picture of moral agency that identifies the agent's interests with self-interests, narrowly construed."⁵⁸⁸

Therefore, because the justification of the operation had to be in the best interests of the donor, and those interests were interpreted narrowly as self-regarding interests, the courts had to find a way that allowed the operation because they implicitly realised that the donor's interests were intimately tied up with the interests of the families.⁵⁸⁹ Crouch and Elliott argue for a more transparent application of the best interests standard, one that recognises that the interests of another family member (or members) benefit more than the donor's own.

⁵⁸⁶ Crouch and Elliott (1999) 8 (3) *Camb Q Healthc Ethics* 275 at 280.

⁵⁸⁷ *Re Y (Mental Incapacity: Bone Marrow Transplant)* [1996] 2 FLR 787; 2 WLR 556.

⁵⁸⁸ Crouch and Elliott (1999) 8 (3) *Camb Q Healthc Ethics* 275 at 280.

⁵⁸⁹ *Ibid.*

“To attempt to cram a formal relation into an intimate context does violence to the morally significant aspects of the family relationship.”⁵⁹⁰

Compare this to Robert Walker LJ’s approach to the best interests standard, when he used it to find that the operation would be in Mary’s best interests (though it would inevitably end in her death). All of the interests that he attributed to her were self-regarding – an interest in continued living, an interest in bodily integrity and an interest in dignity. As already discussed, the basis for these interests was perhaps disingenuous. Would consideration of other-regarding interests similar to that argued by Taylor-Sands, Crouch and Elliott have helped the analysis in *Re A*?

In Chapter Three Taylor-Sands’ argument that a child has “collective interests” by virtue of being part of the family unit was discussed.⁵⁹¹ This stake (as discussed in relation to saviour siblings) was predicated on the benefit for the family unit in the future. Although this was termed a “collective interest”, framed in this way it is essentially a self-regarding interest in their future life as a family member. But, in end-of-life cases there is no self-regarding interest based on a future stake, because these infants are overwhelmingly likely never to grow up to be a stakeholder in the family. Does this then preclude an other-regarding interest in family members? Part of the reasoning from Taylor-Sands for saviour siblings having collective interests, was that merely by being part of a family this meant that you had a stake in it, a stake in something other than yourself. This is an other-regarding interest. The conjoined twins could be said to have such a stake in the family (an interest that could be considered self-regarding or other regarding) and each other (an other-regarding interest). The problematic part of applying her argument is the next step whereby part of the reason for having a stake in your family is that you are going to benefit from it. Assuming that both twins have other-regarding interests, one of which could be deemed a familial duty to their twin that they survive also, should this argument apply? Could it be argued that Mary had an interest in Jodie’s continued survival due to their familial ties? If the medical advice is accepted (that both will die if they are not separated) then perhaps it is possible to say that Mary had an other-regarding interest in giving her sister an increased chance at life. This would be even stronger in the *Nolan* case, as death for both was imminent.

⁵⁹⁰ Ibid at 285.

⁵⁹¹ Taylor-Sands (2013) at 72.

The child, in end-of-life circumstances, does not have a stake in the *future* of the family, but they will always be *part* of that family. If we accept that everyone has an objective interest in such things as dignity, then this is also an interest that should be considered. This is not in spite of their emotional connectedness, but it arises because of the closeness of the relationship. Taylor-Sands' and other accounts of other-regarding interests generally distinguish between the individual's own interests and the interests they may have for others, concluding that the other-regarding interests are a secondary consideration.⁵⁹² These interests exist in addition to self-regarding interests, not instead of them. Does this exclude Mary, as she can only benefit from the family if she is attached to Jodie? If separated, Mary will never experience life in the family and identify with that family. Conversely, the family (parents, Jodie and others) will be able to make Mary and her short life a part of their family story.

Essentially, assessment of the best interests of Mary were tied to views on whether she could continue living, and what quality of life she would have if she did live. Although she may have been attributed with other-regarding interests, such as an interest in letting her twin live, it would be hard to debate that this could outweigh her own interests. But, I argue, it still should have been considered explicitly not implicitly, as the judges were doing in these cases.

Summary of Chapter Seven

The conflicting and confluent nature of interests is why the balancing, weighting, and attribution of interests to an incompetent patient is so difficult. Judges have used various means of evaluating interests, with inconsistent results.

The inter-personal and intra-personal clashes identified in this chapter were discussed in relation to two instances. The first intra-personal conflict that I discussed, between sanctity and quality of life as shown by *Re A*, found that there has been an implicit application of quality of life assessments. Further exploration showed that evidence of sentience was a deciding factor in the continuation of treatment. Cases where this was evident resulted in continued treatment, where the patient was not suffering. Dignity and bodily integrity were distinguished from each other as dignity is an objective interest, something that is harder to argue for bodily integrity.

⁵⁹² Taylor-Sands (2013); Crouch and Elliott (1999) 8 (3) *Camb Q Healthc Ethics* 275.

The second intra-personal clash between prior views and other interests (experiential and non-experiential) demonstrated a range of approaches to incorporating the patient's prior self. One way that this manifested was in the Court of Appeal decision of *James*, where the patient's medical interests and the view of a reasonable person outweighed Mr James' prior view (argued in Chapter Five to be in favour of continued treatment). The Supreme Court were critical of the Court of Appeal's lack of consideration for the individual. However, they left open the issue of whether the best interests test under the MCA can be used as a substituted judgment test as was done in *In the Matter of G (TJ)* in relation to property (but subject to the same test under the Act). If the approach of substituted judgment rather than best interests is used, it effectively changes the guidance principle used to make decisions on behalf of incompetent patients. The respect for, and inclusion of, prior views into the decision-making process should be clearly stated as upholding of precedent autonomy. The reasonable person criterion has also been discussed, and, in an information void, where the legal test is a threshold for continued treatment, was found to be a useful consideration if used cautiously.

Parental views and the child's interests can sometimes represent an inter-personal clash. Two cases, *Re A* and *NHS Trust v A*, have been highlighted since the decision by the courts overruled the parents' view of their children's best interests. This chapter argued that, in such cases the question should be whether the parents were making a decision in their child's best interests, rather than the courts being an independent decision-maker where the parental view is just another factor to be weighed into the best interests test. This is predicated on the position that the parental stake is one that has been undervalued, and that this stake is one that could be an other-regarding interest of the child.

A particularly difficult (but rare) example of an inter-personal conflict is that of conjoined twins. A fundamental question – whether the proposed action is in the best interests of the child – is obviously exacerbated when there are two children, and one is sustaining the life of the other. The judges could not agree on this issue, two finding that separation was in both twins' best interests, and two finding that it was only in the stronger twin's best interests. The reasons for these views varied also, and concepts such as bodily integrity were considered to be both experiential and non-experiential.

Other-regarding interests are an important consideration of the interests of the incompetent patient, and the claim made in previous chapters, that they should be factored into any

account of interests, was developed. Other-regarding interests depend heavily upon whether the patient had the opportunity to develop these. The patient with other-regarding interests, who has had an independent self, with the ability to decide on their own relationships, has been able to engage and develop these interests. For those patients who have never been competent, the notion of objectively attributing them with other-regarding interests is more controversial. Taylor-Sands' and Crouch and Elliott's approaches show that awareness is not necessarily a prerequisite for other-regarding interests. The difficulty lies in the connection between their contentions, which include a future stake in the families that they are attributing with these interests, and the incompetent patients in end-of-life cases who will (probably) never have this future. The view is hereby advanced that other-regarding interests should be attributed to all groups of incompetent patients; however extra care should be taken with the assignment of these types of interests, including the proviso that they are secondary to other considerations, as modelled in Chapter Eight.

CHAPTER EIGHT: CONCLUSIONS AND RECOMMENDATIONS

"[T]he enhanced biological knowledge and technological skill have served to make our dying all the more problematic: harder to predict, more difficult to manage, the source of more moral dilemmas and nasty choices, and spiritually more productive of anguish, ambivalence and uncertainty"⁵⁹³

Deciding the best interests of incompetent patients is an extremely difficult undertaking. But, at various times, these tough decisions are the judges' duty to rule upon. These are decisions which can, and do, have life and death consequences. In the introduction to this thesis it was stated that in no way was the intention to minimise the challenges that all of these judges have faced (and will continue to face). This is one reason why the focus has been on the reasoning of the decisions, not the decisions that were made (although similar to assessments of competence it is difficult to always separate the decision from the reasons it is based on). More importantly, the purpose for this focus has been to contribute to the understanding of how the best interests test is used when making decisions for incompetent patients.

It is commonly agreed that judges making decisions for the best interests of patients do this by focusing on the individual. The best interests test relates an to evaluation of the best interests *of that patient*. Two broad questions were identified relating to how this focus was applied: (1) the substantive question of what interests the courts take into account; and (2) the epistemic question of how the substitute decision-maker can know what is in the patient's best interests. The substantive question was initially canvassed in Chapter Two, where three themes common to the consideration of the best interests of incompetent patients in end-of-cases were identified. The complex relationship between law and ethics, the multi-faceted features of best interests, and the inadequacy of existing law, demonstrated that the decisions in these difficult cases are made using a myriad of concepts, which often results in similar outcomes being based on different reasoning. To answer the question of what interests the courts are taking into account, an exploration of interests from three different authors,

⁵⁹³ Daniel Callahan "Pursuing a Peaceful Death" (1993) 23 (4) Hastings Cent Rep 33 at 33.

Dworkin, Feinberg and Sperling, was undertaken in Chapter Three. From these accounts a framework for the interests of incompetent patients was constructed. By categorising the different interests referred to in the cases that are analysed in this thesis, the conclusion was arrived at that two broad categories of interests, self-regarding and other-regarding, are useful to this thesis. The definition of *self-regarding interests* is consideration for one's own interests, which has two categories (1) experiential and (2) non-experiential. Examples of interests that patients may have and that they can experience include: quality of life and an interest in avoiding suffering and pain. These can apply to both adults and minors. Experiential denotes that the patient is sensate and aware of the interests in some way. There are other self-regarding interests that can be both experiential and non-experiential, depending on whether the incompetent patient is sensate or not, and these include: having their dignity maintained, avoiding medical invasions or humiliations, and the manner of their dying. Lastly, but shown to be of importance in Chapter Five, there is also the self-regarding interest in having your prior views at the very least considered. Self-regarding interests gives us the corollary *other-regarding interests*, which are defined as consideration for others' interests. The others of this definition have two categories: (1) those closest to the patient, namely family and friends who are collectively called whānau; and (2) society as a whole, usually the community that the patient is living in. There are also interests that are both self- and other-regarding; the way that you are remembered and your whānau's views being considered. The other-regarding interests for your whānau are that they are suffering by seeing you suffer or undignified, and the acknowledgement of being a burden and not wanting to be so. The other-regarding societal interests that you may have include not wanting finite resources to be used, and having communitarian interests in contributing to the community that you live in.

Chapter Four explored the relationship between interests and categorised the permanently incompetent patient into two critical groups: those who had been previously competent and those who had not. Patients who had been previously competent were further categorised into two groups. (1) Patients who had expressed a view, prior to their incompetence, on what they wanted to happen to them if they became incompetent in the future; this view was further differentiated in Chapter Five as (a) an explicit-general view or (b) an explicit-specific view. (2) Patients whose previously competent views were not ascertainable were further characterised as having a prior self that could be characterised as either (a) inferred-general or (b) inferred-specific. All of these categorisations were for the purpose of answering the

epistemic question – how can the decision-maker know what is in an individual’s best interests? The only possible way this can be answered, in regards to the previously competent patient, is by considering their prior views, values and beliefs. This was shown in the significance problem that was addressed – why does a prior self matter? The answer provided both moral and legal justifications for the consideration of a patient’s prior self. These justifications noted that there are two guidance principles that a substitute decision-maker can utilise: best interests and substituted judgment. Whilst some jurisdictions clearly provided for a substituted judgment test if prior views were known, most had a best interests test where the prior views were considered to be a factor in the evaluation, not an overriding feature. In England and Wales, under the MCA, the prior views are considered to be part of the consideration for best interests, not taking priority over other considerations, yet there is still some confusion over the application of these views. There is also judicial acceptance that a person’s prior view can be a deciding factor, although this has yet to be determined in relation to a terminally incompetent patient. However, in some of the states in Australia and Canada, the prior wishes do take precedence. In Ontario there is a two-tier system for the consideration of prior wishes. New Zealand has no clear policy as yet. There is the common law precedent of *Re G* which recognises that a person’s prior views can be a part of the consideration for their best interests, and The Code of Patient Rights requires a substitute decision to be made in the patient’s best interests and with regard to their views under Right 7. This distinction was discussed in light of various narrow approaches taken to the best interests test, where an objective or subjective approach is favoured, and the argument has been advanced in Chapter Six that a qualified-objective approach, which includes a previously competent patient’s prior self, where that prior self has been evaluated for the veracity of views, should be the broad approach used in the best interests test.

A proposal to ascertain the veracity of views was outlined in Chapter Five as a three-part process. In Investigation I the content and source of the information is required – does it fit within the explicit or inferred category? Investigation II evaluates four critical judgments: the evidence and its reliability, the strength of the view, the relevance of the view and the status of the view or inference. Investigation III is a statement as to the veracity of the view or inference – how safely can the substitute-maker state what the patient’s view was at their previously competent time? This wording reflects the answer to the epistemic question. There is no way of ascertaining the patient’s current view (hence the need for intervention to make decisions) and therefore the only way to know what they would have most likely have

chosen for themselves is to scrutinise the information that can be gathered from their prior self.

In many of the cases examined in this thesis, the whānau were convinced that their loved one “would not want to be like this” and the courts accepted these views with varying degrees of scrutiny.⁵⁹⁴ This is perhaps understandable, as the views fell into line with what everyone wanted – the medical profession and the whānau. Nevertheless, it is troubling that the evidence of the prior views, or in some cases evidence of previous selves, were not properly assessed for their actual relevance. Is it because the views fall into the category of what is considered to be the ‘normal’ view of what the reasonable person would want – because who would want to be ‘alive but not living’? The proposal for veracity set out in Chapter Five is an attempt to address this problem: how good is the evidence that the person would not want to live like this? This raises two questions: (1) should there be an implicit assumption that the more the prior self reflects the individual’s views and beliefs, the better it is as evidence? (2) Is it the case that, even if we know what someone did think individually, the norms of society should still be taken into account? In assessing what the person wanted (under Investigation D), should the extent to which this fits in with wider norms be assessed? The courts may be more willing to accept evidence of prior views and values if those views and values seem ‘reasonable’, but will be much more likely to be sceptical of those that they see as unreasonable. Therefore, there is a conflation of a subjective “what did this person want?” test, and an objective “what would a reasonable person want?” test. Sometimes that may be inevitable, even appropriate (where the evidence for the former is not very compelling), but is this being done transparently? In Chapter Six there was a discussion of these questions, with a conclusion being that incorporating a reasonableness component is justified, with certain qualifications.

In Chapter Seven four inter- and intra-personal clashes of interests were discussed. The importance of sentience emerged from the analysis of these clashes, and this was linked to the discussion of personhood in Chapter Six, whereby experiential interests were identified as one of the narrow approaches. This focus on experiential interests ignored non-experiential interests, as it seemingly aligned these with personhood. Although it challenged the

⁵⁹⁴ See also: *NHS Trust v I* [2003] EWHC 2243 (Fam) at [8]. “The family, as I said, is extremely supportive. The son and other members of the family are absolutely certain that if the patient was in a state of awareness, she would say that she did not want to continue a life such as that she has, living, as sometimes it is called, in a twilight world.”

conclusion in Chapter Three that there was a consensus view that incompetent patients could have interests, this was argued to be false. Other-regarding interests of the patients, whilst suffering from what Feinberg called a linguistic difficulty, can be attributed to the patient as interests that they legitimately hold.⁵⁹⁵ It is more problematic to claim that these are objective interests that everyone has, regardless of being able to form these relationships themselves, for example in cases with minors. Therefore although it is argued that it can be an objectively applied interest, it must be secondary to any primary self-regarding interests, such as the avoidance of suffering.

By using all the previously outlined categories a proposal is advanced by which all of the interests that an incompetent person may have can be identified and then appraised. It is acknowledged that this task can not be considered easy, or even that the suggestions made here necessarily make the task any easier. The view arrived at as an outcome of this study is that the decision-making process, and how judges reached their decisions, should be more transparent. Hopefully, the table of recommendations in the next section is a step towards achieving this objective.

Proposal for Weighting of Interests

The following recommendations are not intended as an all-encompassing list, but rather as a guideline for the kinds of considerations that are likely to arise for the patients that are incompetent. By categorising the patients in the previous chapters this study has developed a language and deepened the understanding of all the interests that may apply, particularly for the prior self and the other-regarding interests which appear at various times to have been used superficially in judgments.

Not every incompetent person has the same interests, but they may have some of the same possible interests by virtue of their condition. Three conditions relating to sentience have arisen from the end-of-life cases: (1) the patient has no sentience or awareness, for example a patient in a PVS; (2) the patient is sensate and can experience pain and other discomforts such as hunger, but is also capable of positive responses such as responding to whānau; (3) the patient may be sensate or they may not be, and there is no way of knowing which, for

⁵⁹⁵ Feinberg (1984) at 73.

example patients with Guillain-Barré syndrome and some minors. Best interests is a guidance principle for substitute decision-making, and this evaluative property dictates that it is broad and flexible, in order to properly weigh the various interests that the incompetent person may have.

Table 2 Proposal for Weighting of Interests

IDENTIFYING INTERESTS	SELF-REGARDING	OTHER-REGARDING
<p>Sensate, previous self (adults, could also include older children)</p> <p><i>James Scardoni v Hawryluck</i></p>	<ul style="list-style-type: none"> • Experiential interest in not suffering • (Non)-experiential interest in prior self taken into account • (Non)-experiential interest in manner of death, dignity • Non-experiential interest in way that you are remembered • Whānau having their views considered 	<ul style="list-style-type: none"> • Way that you are remembered by whānau • Whānau having their views considered • Whānau’s suffering • Altruistic and communitarian values
<p>Sensate, no previous self (minors, adults with life-long incapacity)</p> <p><i>Re A Nolan Wyatt Auckland Healthcare Services v L</i></p>	<ul style="list-style-type: none"> • Experiential interest in not suffering • Non-experiential interest in manner of death, dignity 	<ul style="list-style-type: none"> • Familial interests, strongest link probably to parents

IDENTIFYING INTERESTS	SELF-REGARDING	OTHER-REGARDING
<p>Non sensate, previous self (adults, could also include older children)</p> <p><i>Bland</i> <i>Re C</i> <i>Re G</i> <i>Re Durksen</i></p>	<ul style="list-style-type: none"> • Non-experiential interest in prior self taken into account • Non-experiential interest in manner of death, dignity • Non-experiential interest in way that you are remembered • Whānau having their views considered 	<ul style="list-style-type: none"> • Whānau’s suffering • Altruistic and communitarian values
<p>Non sensate, no previous self (minors, adults with life-long incapacity)</p>	<ul style="list-style-type: none"> • Non-experiential interest in dignity 	<ul style="list-style-type: none"> • Familial interests, strongest link probably to parents
<p>Not known if the patient is sensate or not, no previous self</p> <p><i>Mary in Re A</i></p>	<ul style="list-style-type: none"> • Consider all possible interests, and in most cases assume that the patient is sensate (as that gives rise to more possible interests) 	
<p>Not known if the patient is sensate or not, previous self</p> <p><i>Auckland Area Health Board v Attorney-General</i></p>	<ul style="list-style-type: none"> • Consider all possible interests, and in most cases assume that the patient is sensate (as that gives rise to more possible interests) 	

Sensate With a Prior Self

Adults, could also include older children.

This group of patients have the most interests to consider, as they have current experiential interests as well as the prior self's interests. They have also developed other-regarding interests by virtue of being part of some kind of whānau.

If someone can experience anything this must be taken into account. In fact it should be the first thing to consider in any account that weighs up interests. The importance of assessing a patient's self-regarding, experiential interests has manifested in judgments in different ways. Examples of this include: the consideration of medical interests, only taking experiential interests into account, and the confusion between a best interests test that is objective or subjective. Complicating the decision is that if they have experiential interests this makes consideration of their quality of life even more problematic. Whilst judges have ostensibly not made quality of life decisions, implicitly they have as discussed with *Bland*, when statements such as "living death" were made.

Current interests in not experiencing pain, or enjoying visits with loved ones, can clash with the incompetent person's prior self. Both a prior view and a previous self can be (and are) used by judges to determine 'what the person would have wanted'. In Chapter Five the importance of the veracity of these views and how this can then inform the decision-making process was discussed. If the strength of view is found to be in a very safe range then this could perhaps override any other interests. The best interests test would then become a substituted judgment test, or as argued in Chapter Six a qualified-objective test where the prior self is taken into account at the first stage.

Because this patient has a prior self, all of the other interests can be referenced to that prior self. However, as previously argued, this should not be done without discrimination, but there will undoubtedly be a wealth of information that is just not available for an infant or adult who has never expressed a previous self. There can be an assessment of the relationships that the person did have, and currently has, with their whānau; the weight placed on these other-regarding interests will depend on these relationships. For example in *Re C*,

CW's prior view was held to be strong, and the relationships with his twin brother and other family members would probably be considered to be so too.⁵⁹⁶

As the scale developed in this thesis demonstrates, the relevance of the patients' particular views, and what evidence that they are based on, is of great importance. It is crucial how closely the prior views expressed are reflected in the person's current circumstances. As indicated in Part Two, this will predominantly occur in cases where the now incompetent patient has a condition that was diagnosed when they were competent. While competent, they made either an advanced directive or had extensive advanced care planning, and their prior wishes pertain to their condition as closely as possible.

Sensate With No Prior Self

Minors, adults with life-long incapacity.

Decisions about children who have self-regarding experiential interests are difficult because they have to be made using assumptions.⁵⁹⁷ Gathering the best clinical data possible regarding exactly what the child is feeling is the first step. This is not an exact science and it is only possible for medical advice to give a clinical assessment which reflects this uncertainty. Whilst the technology is becoming increasingly advanced (for example, being able to use scans to determine deliberate thought) this will not help in regards to infants' making their own choices. It could, however, help with determining the levels of pain, discomfort or happiness that the child is feeling.

With this group of patients it was argued that parental interests should be considered as other-regarding interests that they would have, independent of the non-existent future stake that they have in that family. In this way, relatively greater weight should be given to parents' views the more difficult the decision is. After the child themselves, it is the parents who will be the most affected by the decision. However, the child's self-regarding experiential interests must factor into this and be given the most weight.⁵⁹⁸

⁵⁹⁶ *Re C* [2010] EWHC 3448 (Fam).

⁵⁹⁷ Although children are referred to in this section as all of the identified cases were about children, it is acknowledged in the title that some adults fit into this section.

⁵⁹⁸ *Auckland Healthcare Services Ltd v L* [1998] NZFLR 998.

Some of the cases examined in this thesis dealt with minors who were wards of the Court. What action should be taken in such cases? Is there an overall state interest in protecting the vulnerable? Alternatively should a more controversial model be applied whereby resources should factor into the decision-making? Working from a premise that prioritises any experiential interests, these should be given priority over any other considerations.

Non-Sensate With Prior Self

Adults, could also include older children.

The incompetent patient with a prior self has all the same considerations as a sensate patient, except of course for the fact that there are no current experiential interests to consider. This may make the decision slightly easier in this regard as there is no potential clash of what they may have wanted and what it seems they may want now.

Non-Sensate With No Prior Self

Minors, adults with life-long incapacity.

The child who has no experiential interests and no prior self can obviously only be assumed to have objective interests. These are interests that apply to any vulnerable patient in our society as there are no subjective interests that they can possess. Without a prior self or experiential interests it is hard to argue for an objectively applied interest in the manner of death, however an interest in dignity is less problematic to accept. As already discussed, the interest in dignity can be both for the person themselves and for the importance placed in living in a society that treats its most vulnerable with respect – and an infant with no cognitive awareness or ability to feel surely fits within this description.

Deciding in the Best Interests of Incompetent Patients

Judges deal with extremely difficult end-of-life decisions; decisions that have been demonstrated in this thesis to involve a multitude of complex interactions, terminology, concepts, and implicitly held ideas. The judiciary, as substitute decision-makers for incompetent patients, have not had a consistent voice in the way they have arrived at these

decisions. Added to the complexity (from the perspective of this thesis, not necessarily for the judges) is the fact that different jurisdictions have different interpretations of how to best adhere to the general application of best interests, which is very much a person-centred principle. Confusion has, however, been pervasive despite the single statutory and common law precedent that they are working under. Where the patient's previously competent self is prioritised there are various ways in which this is upheld. Overall, there is little consideration of the other-regarding interests that can be attributed to the patient; interests that in this thesis are held to better inform the best interests test. To make decisions for the permanently incompetent patient is to traverse a complex, multi-faceted, multi-disciplined area which is fraught with the difficulty of ascertaining the *best* interests of the patients and also acknowledging the emotional impact on their whānau. The difficulty that the judiciary have in finding a way through this mire of obstacles is understandable, but can be improved with a best interests test which is transparent in its approach to a wide set of interests.

The final word is appropriately a postscript itself, as this is the tragic reality after the judges' decision in most end-of-life cases:

*“Note added by the judge when approving this transcript: I have been informed that ... the ventilation was withdrawn from both boys, at the hospital, about five days after this judgment. They died and have been buried. May they rest in peace.”*⁵⁹⁹

⁵⁹⁹ *Central Manchester University Hospitals NHS Foundation Trust v A* [2015] EWHC 2828 (Fam) at [26] per Holman J. Emphasis added.

Appendix One: Table of Cases

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
1*	<i>Re B (A minor)</i> (Wardship: Medical Treatment) [1982] 3 FLR 117	1981	High Court <hr/> Court of Appeal	England and Wales	Down syndrome	Future provision of life-prolonging treatment	No <hr/> Yes	Yes Surgeon thought parents' wishes should be respected	No	State	Yes
2*	<i>Re S D</i> [1983] 3 WWR 597	1983	British Columbia Provincial Court	Canada	Severe brain damage	Future provision of life-prolonging treatment	No	Yes	No	State	Yes
	<i>Re S D</i> [1983] 3 WWR 618	1983	British Columbia Supreme Court				Yes				

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
3*	<i>Unreported</i> <i>Re C (A minor)</i> <i>(Wardship: Medical Treatment)</i> [1990] Fam 26	1989	High Court Court of Appeal	England and Wales	Congenital hydrocephalus	Future provision of life-prolonging treatment	May be withheld (specific directions) May be withheld (directions removed)	No	Ward of Court	State	Yes
4	<i>Re KP ; Minister of Social Services v FP and LP</i> (1990) 69 DLR (4th) 134	1990	Saskatchewan Provincial Court	Canada	Biliary atresia	Life-prolonging operation	No	Disagree	No	State	Yes
5*	<i>New Brunswick (Minister of Health & Community Services v B (R))</i> (1990) 70 DLR (4th) 568	1990	New Brunswick Court of Queen's Bench	Canada	Severely handicapped	Future provision of life-prolonging treatment	Yes	Disagree	No	State	Yes
6*	<i>Re J (A minor)</i> <i>(Wardship: Medical Treatment)</i> [1991] Fam 33	1991	Court of Appeal	England and Wales	Perinatal brain damage	Future provision of life-prolonging treatment	No	Withhold treatment	Ward of Court	State	Yes

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
7*	<i>Auckland Area Health Board v Attorney General</i> [1993] 1 NZLR 235	1992	High Court	NZ	Guillain-Barre syndrome	Withdrawal of treatment	Yes	Yes	Yes	Medical profession	No
8*	<i>Airedale NHS Trust v Bland</i> [1993] AC 789	1992	High Court	England and Wales	PVS	Withdrawal of treatment	Yes	Yes	Yes	Medical profession	No
		1992	Court of Appeal								
		1992-93	House of Lords								
9*	<i>Frenchay Healthcare NHS Trust v S</i> [1994] 2 All ER 403	1994	Court of Appeal	England and Wales	PVS	Future provision of life-prolonging treatment	Yes	Yes	Mixed	Medical profession	No
10*	<i>R v Cambridge District Health Authority, Ex Parte B</i> [1995] 1 FLR 1055	1995	High Court	England and Wales	Acute myeloid leukaemia	Future provision of life-prolonging treatment	Should be re-considered	No	Yes	Family	Yes
	Court of Appeal		No				State				

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
11	<i>Law Hospital NHS Trust v Lord Advocate and Others</i> (1996) Scot CS CSIH 2; [1996] SLT 848	1996	Court of Session	Scotland	PVS	Withdrawal of treatment	Yes	Yes	Yes	Medical profession	No
12	<i>Re R (Adult: Medical Treatment)</i> (1996) 31 BMLR 127	1996	High Court	England and Wales	Severe problems	Future provision of life-prolonging treatment	No	No	Yes	Family	No
	<i>Unreported</i>		High Court				Yes				
13	<i>Re T (A Minor) (Wardship: Medical Treatment)</i> [1996] EWCA Civ 805	1996	Court of Appeal	England and Wales	Biliary atresia	Life-prolonging operation	No	Yes	No	Medical profession	Yes
14*	<i>Re G</i> [1997] 2 NZLR 201	1997	High Court	NZ	Like PVS	Withdrawal of treatment	Yes	Yes	Yes	Family	No
15*	<i>Child and Family Services of Manitoba v RL</i> [1997] MJ 568 (QL)	1997	Manitoba Court of Appeal	Canada	PVS	DNR order	Yes	Yes	No	Medical profession	Yes
16	<i>Re D</i> [1997] 1 FLR 411	1997	High Court	England and Wales	Like PVS	Withdrawal of treatment	Yes	Yes	Yes	Medical profession	No
17*	<i>Auckland Healthcare Services Ltd v L</i> [1998] NZFLR 998	1998	High Court	NZ	Severe neurological disorder	Withdrawal of treatment	Yes	Yes	No	Medical profession	Yes

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
18*	<i>London Health Services Centre v K (R) (Litigation Guardian of)</i> (1997) 152 DLR (4th) 724	1997	Ontario Superior Court of Justice	Canada	PVS	Withdrawal of treatment	Yes	Yes	No (initially)	Medical profession	No
19	<i>Shortland v Northland Health Ltd</i> [1998] 1 NZLR 433	1997	Court of Appeal	NZ	Renal failure	Future provision of life-prolonging treatment	No	No	Yes	Family	No
20	<i>Re C (A minor) (Medical Treatment)</i> [1998] Lloyd's Re Med 1	1998	High Court	England and Wales	Spinal muscular atrophy	Future provision of life-prolonging treatment	May be withheld	No	Yes	Medical profession	Yes
21*	<i>Sawatzky v Riverview Health Centre Inc.</i> (1998) 167 DLR (4th) 359	1998	Manitoba Court of Queen's Bench	Canada	Parkinsons (and other problems)	Future provision of life-prolonging treatment	Yes	No	Yes	Family	No
22*	<i>Re Durksen</i> [1999] CarswellAlta 1672	1999	Alberta Surrogate Court	Canada	PVS	Withdrawal of treatment	Yes	Yes	Yes	State	No

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
23	<i>Royal Wolverhampton Hospitals NHS Trust v B</i> [2000] 1 FLR 953	2000	High Court	England and Wales	Premature birth	Future provision of life-prolonging treatment	May be withheld	No	Yes	Medical profession	Yes
24	<i>A National Health Service Trust v D</i> [2000] Lloyd's Rep Med 411	2000	High Court	England and Wales	Irreversible brain damage	Future provision of life-prolonging treatment	Can be withheld	No	Yes	Medical profession	Yes
25	<i>NHS Trust A v M; NHS Trust B v H</i> [2001] Fam 348	2000	High Court	England and Wales	PVS	Withdrawal of treatment	Yes	Yes	Yes	Medical profession	No
26*	<i>In Re A (Children)</i> [2000] EWCA Civ 254; [2001] Fam 147	2000	Court of Appeal	England and Wales	Conjoined twins	Operation	Yes	Yes	No	Medical profession	Yes
27 *	<i>Northridge v Central Sydney Service</i> [2000] NSWSC 1241; (2000) 50 NSWLR 549	2000	Supreme Court of New South Wales	Australia	Irreversible brain damage	Withdrawal of treatment	No	Yes	No	Family	No
28	<i>NHS Trust A v H</i> [2001] 2 FLR 501	2001	High Court	England and Wales	PVS	Withdrawal of treatment	Yes	Yes	Yes	Medical profession	No
29	<i>Re G</i> (Unreported)	2001	High Court	England and Wales	Severe brain damage	Withdrawal of treatment	May be withheld	Yes	Yes	Medical profession	No

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
30*	<i>Queensland v Alyssa Grace Nolan (an Infant, by her Litigation Guardian Shaun Nolan) and Bethany Rose Nolan (an Infant, by her Litigation Guardian Shaun Nolan)</i> (2001) QSC 174; [2001] 122 ACR 517	2001	Supreme Court of Queensland	Australia	Conjoined twins	Operation	Yes	Yes	Yes	State	Yes
31	<i>Janzen v Janzen</i> [2002] OJ No 450 44 ETR (2d) 217 (Ont SCJ)	2002	Ontario Superior Court of Justice	Canada	Severe anoxic encephalopathy	Future provision of life-prolonging treatment	No	Yes	Mixed	Family	No
32	<i>An Hospital NHS Trust v S and Others</i> [2003] EWHC 365 (Fam)	2003	High Court	England and Wales	Renal failure	Future provision of life-prolonging treatment	No	No	Yes	Medical profession	No
33	<i>NHS Trust v I</i> [2003] EWHC 2243 (Fam)	2003	High Court	England and Wales	PVS	Withdrawal of treatment	Yes	Yes	Yes	Medical profession	No
34*	<i>Re BWV; Ex Parte Gardner</i> [2003] 7 VR 487	2003	Supreme Court of Victoria	Australia	Dementia	Withdrawal of treatment	Yes	Yes	Yes	State	No

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
35*	<i>Scardoni v Hawryluck</i> (2004) 69 OR (3d) 700	2004	Superior Court of Justice (HC)	Canada	Alzheimer's	Future provision of life-prolonging treatment	May not be withheld	No	Yes	Family	No
36*	<i>Unreported</i> [2004] EWCA Civ 1324	2004	High Court	England and Wales	Multiple sclerosis	Re-insert device	Yes	Yes	No	Medical profession	No
	<i>W Healthcare NHS Trust v H</i> [2004] EWCA Civ 1324		Court of Appeal							Family	
37	<i>Re L</i> (Medical Treatment: Benefit) [2004] EWHC 2713 (Fam), [2005] 1 FLR 491	2004	High Court	England and Wales	Edward syndrome	Future provision of life-prolonging treatment	May be withheld	No	Yes	Medical profession	Yes
38*	<i>Isaac Messiha (by his tutor Magby Messiha) v South East Health</i> [2004] NSWSC 1061	2004	Supreme Court of New South Wales	Australia	Severe brain damage	Withdrawal of treatment	Yes	Yes	No	Family	No

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
	<i>Portsmouth NHS Trust v Wyatt</i> [2004] EWHC 2247 (Fam) (7 October 2004)	2004	High Court			Future provision of life-prolonging treatment	May be withheld			Medical profession	
	<i>Wyatt v Portsmouth NHS Trust</i> [2005] EWHC 693 (Fam) (21 April 2005)	2005	High Court			Future provision of life-prolonging treatment	May be withheld			Family	
39*	<i>Portsmouth Hospitals NHS Trust v Wyatt</i> [2005] 1 WLR 3995 (12 October 2005)	2005	Court of Appeal	England and Wales	Premature birth	DNR order removed	Ref back to High Court	No	Yes	Family	Yes
	<i>Portsmouth NHS Trust v W</i> [2005] EWHC 2293 (Fam) (21 October 2005)	2005	High Court			Future provision of life-prolonging treatment	May be withheld			N/A	
	<i>Re Wyatt</i> [2006] EWHC 319 (Fam) (23 February 2006)	2006	High Court			Future provision of ventilation	May be withheld			Medical profession	

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
40*	<i>R (Burke) v General Medical Council (Official solicitor intervening)</i> [2004] EWHC 1879 (Admin); [2005] QB 424	2004	High Court				Judicial review can be sought	N/A	N/A	Patient	
	<i>R (Burke) v General Medical Council (Official solicitor intervening)</i> [2005] EWCA Civ 100	2005	Court of Appeal	England and Wales	Congenital degenerative brain condition	GMC Guidelines on ANH	Guidelines lawful	N/A	N/A	Medical profession	No
	<i>Burke v The United Kingdom</i> (2006) 19807/06	2006	European Court of Human Rights							Patient	
41	<i>An NHS Trust v A</i> [2005] EWCA Civ 1145; [2006] Lloyd's Rep Med 29	2005	Court of Appeal	England and Wales	Ventilated and renal support	Withdrawal of treatment	Yes	Yes	No	Medical profession	No
42	<i>The NHS Trust v Ms D</i> [2005] EWHC 2439 (Fam)	2005	High Court	England and Wales	Mitochondrial cytopathy	Future life-saving treatment	No	No	Yes	Medical profession	No

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
43*	<i>Re LIC</i> [2006] ABQB 130	2006	Alberta Court of Queen's Bench (HC)	Canada	PVS	Withdrawal of treatment	Yes	Yes	Yes	State	No
44	<i>Krommydas v Sydney West Area Health Service</i> [2006] NSWSC 901	2006	Supreme Court of New South Wales	Australia	Unknown	Withdrawal of treatment	Yes	Yes	No	Medical profession	No
45	<i>B NHS Trust v J</i> [2006] EWHC 3152 (Fam)	2006	High Court	England and Wales	PVS	Withdrawal of treatment	No	Yes	Yes	Medical profession	No
46*	<i>An NHS Trust v MB</i> [2006] EWHC 507 (Fam)	2006	High Court	England and Wales	Spinal muscular atrophy	Withdrawal of treatment	No	Yes	No	Medical profession	Yes
47	<i>Jin (next friend of) v Calgary Health Region</i> [2007] ABQB 593 (CanLII); [2008] 2 WWR 723	2007	Court of Queen's Bench of Alberta	Canada	Traumatic brain injury	Future provision of life-prolonging treatment	Yes	No	Yes	Family	No
48	<i>Golubchuk v Salvation Army Grace General Hospital</i> [2008] MBQB 49 (CanLII); (2008) 290 DLR (4th) 46	2008	Court of Queen's Bench Alberta	Canada	Ventilated due to severe brain damage	Withdrawal of treatment	No	Yes	No	Medical profession	No

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
49	<i>Rotaru v Vancouver General Hospital Intensive Care Unit</i> [2008] BCSC 318	2008	Supreme Court of British Columbia	Canada	Irreversible vascular disease and renal failure	Future provision of life-prolonging treatment	No	No	Yes	Family	No
50	<i>Children's Aid Society of Ottawa - Carleton v MC</i> (2008) 301 DLR (4th) 194; [2008] CanLII 49154 (ON SC)	2008	Ontario Superior Court of Justice	Canada	Brain haemorrhage	Withdrawal and withholding of treatment	Yes	Yes	Not known	Children's Aid Society	Yes
51	<i>Re IHV</i> [2008] ABQB 250	2008	Court of Queen's Bench Alberta	Canada	Terminal cancer	Future provision of life-prolonging treatment	No	No	Mixed	Family	No
52	<i>Barbulov v Cirone</i> [2009] CanLII 15889 (ON SC)	2009	Ontario Superior Court of Justice	Canada	Hypoxic encephalopathy	Future provision of life-prolonging treatment	No	No	Yes	Family	No
53	<i>Sweiss v Alberta Health Services</i> [2009] ABQB 691	2009	Court of Queen's Bench Alberta	Canada	Severe brain damage	Future provision of life-prolonging treatment	No	No	No	Family	No

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
54	<i>May v Alberta Health Services</i> [2010] ABQB 213	2010	Court of Queen's Bench of Alberta	Canada	Ventilated due to severe brain damage	Withdrawal of treatment	Temporary injunction	Yes	No	Family	Yes
55	<i>Re C</i> [2010] EWHC 3448 (Fam)	2010	Court of Protection	England	PVS	Withdrawal of treatment	Yes	Yes	Yes	Medical profession	No
56 *	<i>Hutt District Health Board v B</i> [2011] NZFLR 873	2011	High Court	NZ	Terminal genetic condition	Re-insert device	No	No	No	Medical profession	Yes
57*	<i>W v M</i> [2011] EWCOP 2443	2011	Court of Protection	England	Viral encephalitis (MCS)	Withdrawal of treatment	No	Mixed	Yes	Family	No
58	<i>Maraachli v Dr Fraser</i> [2011] ONSC 124; [2011] OJ No. 2168	2011	Ontario Superior Court of Justice	Canada	PVS	Future provision of life-prolonging treatment	No	No	Yes	Family	Yes
59	<i>Re Baby D (No 2)</i> [2011] FamCA 176; (2001) 258 FLR 290	2011	Family Court	Australia	Major hypoxic brain injury	Future provision of life-prolonging treatment	Yes	No	Yes	Family	Yes

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
60	<i>Alberta (Child, Youth, and Family Enhancement Act, Director) v DL</i> [2012] ABQB 562	2012	Court of Queen's Bench Alberta	Canada	Between brain death and PVS	Future provision of life-prolonging treatment	Yes	Yes	No	Director	Yes
61	<i>An NHS Trust v Mrs H, Re (Rev 1)</i> [2012] EWHC B18 (Fam)	2012	High Court	England and Wales	Viral encephalitis	Withholding of treatment	Yes	Yes	No	Medical profession	Yes
62	<i>TS & DS v Sydney Children's Hospital Network ("Mohammed's case")</i> [2012] NSWSC 1609	2012	Supreme Court of New South Wales	Australia	Pyruvate Dehydrogenase Deficiency (probably caused by Down syndrome)	Future provision of life-prolonging treatment	No	No	Yes	Family	Yes

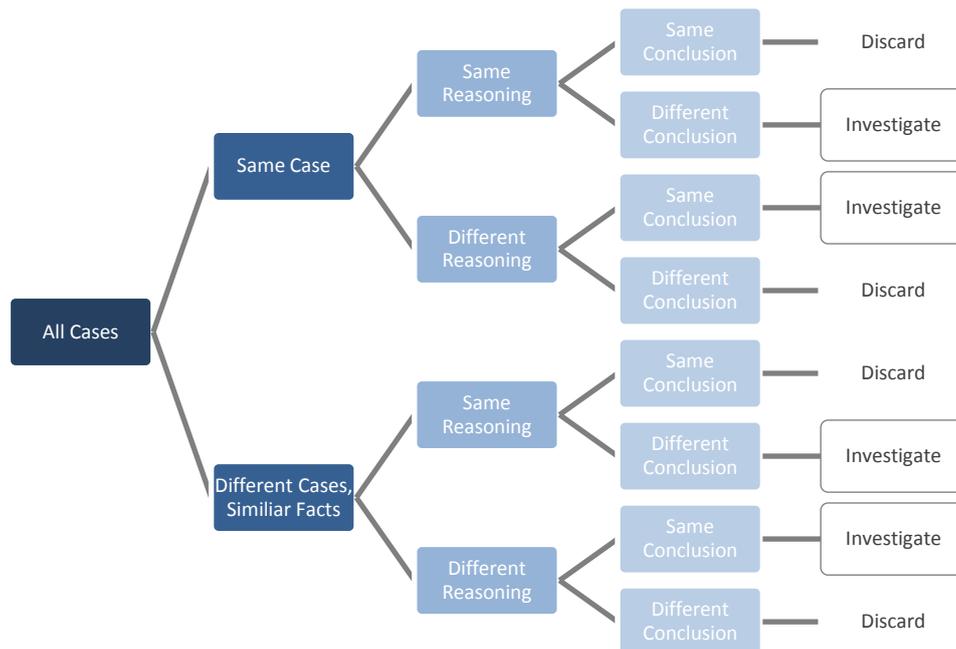
No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
	<i>An NHS Trust v DJ</i> [2012] EWHC 3524 (COP)	2012	High Court				No				
63*	<i>Aintree University Hospitals NHS Foundation Trust v James</i> [2013] EWCA Civ 65	2013	Court of Appeal	England and Wales	Minimally conscious state	Withholding of treatment	Yes	Yes	No	Family	No
	<i>Aintree University Hospitals NHS Foundation Trust v James</i> [2013] UKSC 67		Supreme Court				Yes (but only because change in condition)				
	<i>Rasouli v Sunnybrook Health Sciences Centre</i> [2011] ONSC 1500 (CanLII)	2011	Ontario Superior Court of Justice							Family	
64*	<i>Rasouli v Sunnybrook Health Sciences Centre</i> [2011] ONCA 482 (CanLII)	2011	Court of Appeal for Ontario	Canada	Meningitis	Withdrawal of treatment	Ref case to Consent and Capacity Board	Yes	No	Medical profession	No
	<i>Cuthbertson v Rasouli</i> [2013] 3 SCR 341 (CanLII)	2013	Supreme Court of Canada							Medical profession	

No.	CASE NAME	YEAR	COURT	COUNTRY	MEDICAL CONDITION	PROPOSED OR DISPUTED ACTION	PROPOSED ACTION ALLOWED BY COURT?	PROPOSED ACTION RECOMMENDED BY DOCTORS?	DO FAMILY WANT PROPOSED ACTION?	COURT INSTIGATOR	MINOR?
65	<i>A Health and Social Care Trust v M</i> [2014] NIFam 3	2014	High Court of Northern Ireland	Northern Ireland	Ventilated due to severe brain damage	Withdrawal of treatment	Yes	Yes	No	Medical profession	Yes
66	<i>Ackie v Manocha</i> [2014] ONSC 669	2014	Ontario Superior Court of Justice	Canada	PVS	Withdrawal of treatment	Yes	Yes	No	Medical profession	No
67	<i>Bentley v Maplewood Seniors Care Society</i> [2014] BCSC 165	2014	Supreme Court of British Columbia	Canada	Alzheimer's disease	Withholding of treatment	No	No	Yes	Family	No
68*	<i>Central Manchester University Hospitals NHS Foundation Trust v A</i> [2015] EWHC 2828 (Fam)	2015	England and Wales High Court	England and Wales	Progressive neuro-degenerative disorder	Withdrawal of treatment	Yes	Yes	No	Medical Profession	Yes (twins)

* Indicates that a summary is provided in Appendix Three: Précis of Cases.

Appendix Two: Chart Outlining Reasoning

The following flowchart shows the justification for the inclusion of one of the five themes discussed in Chapter Two. The claim is that best interests, as employed in end-of-life cases, frequently contain the same conclusions reached via different reasoning.



All cases refers to the collected set of data; all the cases that fit into the prospective end-of-life criteria from the four countries that evaluated in this thesis.¹

Same Case. Many cases go to appellate courts and therefore there is more than one judge adjudicating on the same case. Therefore, one case can be looked at as an example in itself by comparing the opinions or rulings of different judges. The judges are discussing the same person’s circumstances, with the same legal question. When analysing these cases the comparison is between different courts of the same jurisdiction, for example judges from the High Court, compared to judges from the Court of Appeal or higher appellate courts. Different judges are also compared from the same court – in the Court of Appeal for instance

¹ In this section italics are used when using a heading from the flowchart.

there could be up to nine judges sitting on the bench. These judgments can be compared and analysed with respect to the reasoning used.

So if within these same cases, the judges have similar or the *same reasoning*, and reach the *same conclusion* this is not worth investigating further. But if there are *different conclusions* with the *same reasoning* this raises questions. If their reasoning is the same, how did they get to different conclusions?

In the remaining cases however, they use *different reasoning*. In this instance judges are deliberating on the *same case*, so there are identical facts, but they identify different issues to base their conclusions on. Alternatively, they have interpreted existing law differently. Judges reaching the same conclusion using different reasoning is obviously not unique to these particular cases, however the frequency of its occurrence amongst the many cases analysed justifies the identification of it as a theme. If judges reach *different conclusions* based on *different reasoning* this is a logical outcome, so these cases can be discarded from further investigation. On the other hand if multiple judges reach the *same conclusion* in the *same case*, but get there via *different reasoning* – this points to an anomaly which is worth investigating further. How can *different reasoning* with the *same conclusion* be justified? *Bland* and *Re A* are examples of this type of case.² Under the *same cases* umbrella this is the far more common occurrence.

On the other side of the flow chart is *different cases, similar facts*. These are cases that are about different individuals and have different proposed or disputed actions, but have enough similarity factually to reasonably be compared. Obviously any difference in the patient's clinical circumstances needs to be separated from any reasoning based on these differences. Examples of factually similar cases are those where the patients are in a PVS, or conjoined twins where an operation is required to separate them. In both instances the legal question is the same. "Can we withdraw treatment from a patient in a PVS which will result in their death"; "can we separate conjoined twins where one will definitely die as a result of the operation?". As with *same cases* the cases worth investigating are those with *same reasoning* and *different conclusions*; as well as cases with *different reasoning* and *same conclusions*. *Re A* illustrates this, where *different reasoning* was used by different appellate court judges to arrive at the *same conclusion*. At this stage only cases that have *different reasoning* to get to

² *Airedale NHS Trust v Bland* [1993] AC 789; *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147.

the *same conclusion* have been identified, so only these are examined, within the *same case* and *different case* scenarios. Even though only this criterion has been fulfilled it is important to note the possibility of the other criteria.

Appendix Three: Précis of Cases

New Zealand Case Law

Adults

Auckland Area Health Board v Attorney-General [1993]³

Doctors at Auckland Hospital, together with the Auckland Area Health Board, applied for a declaration clarifying whether in law they would be guilty of culpable homicide if they withdrew ventilator support from a 59 year old man, Mr L, suffering from Guillain-Barré syndrome.

“The disease affected the nervous system of the patient by destroying the conductivity of the nerves between the brain and the body. The result was to leave the brain, though still living, entirely disengaged from the body. The patient survived in a state of “living death”, totally unable to move or communicate and there was no prospect of recovery. However, because the brain, though damaged, was not dead, the patient was not medically brain-stem dead pursuant to the medical definition of “death”. The patient had existed in that condition for 12 months. Eight specialists who had examined the patient and undertaken extensive testing were unanimous that the ventilatory support of the patient could not be medically justified.”⁴

Thomas J issued a declaration that ss 151 and 164 of the Crimes Act 1961 would not apply if: doctors agreed that there was no reasonable possibility of Mr L recovering; there was no benefit medically or therapeutically for Mr L to remain on a ventilator and to remove it fitted within the medical profession’s exercise of good medical practice; and Mr L’s family agreed with the decision and it received approval from an ethics committee.

Re G [1997]⁵

Mr G was 69 when he was injured in a car accident, and had been in Dunedin Public Hospital for eighteen months when his case came before the Court. His condition was such that he was totally immobile, unable to communicate at all, incontinent, and scans showed severe brain injury. Every effort for rehabilitation had failed. He was being kept alive by ANH. All medical specialists agreed that withdrawal of treatment was in Mr G’s best interests. The issue before the Court was: (a) should the Court use its *parens patriae* powers? And, if so,

³ *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235.

⁴ *Ibid* at 235.

⁵ *Re G* [1997] 2 NZLR 201.

(b) should that consent be by way of substituted judgment or best interests? Fraser J decided that: (a) *parens patriae* powers should be used and (b) the best interests test would be applied but with regard to Mr G's likely wishes and the views of family and friends. Although he also issued declaratory orders to the effect that nobody would be criminally liable for ceasing to treat Mr G, he only did so for the benefit of the medical staff, not because he thought they were needed.

Minors

Auckland Healthcare Services v L [1998]⁶

In 1997 Baby L was born with severe neurological abnormalities and was on a ventilator in intensive care. The muscles of her face were paralysed, she could not swallow, she was deaf and there were signs that she was developing cerebral palsy. There were also indications that her condition was deteriorating. The medical prognosis was that further treatment was futile and causing Baby L pain, and that it was in her best interests that treatment be withdrawn. Auckland Healthcare Services Ltd made an application under section 10B of the Guardianship Act 1968 seeking orders to put Baby L under the guardianship of the Court and appointing Dr Knight of the National Women's Hospital to be the Court's agent in respect of medical decisions. Cartwright and Paterson JJ placed Baby L under the guardianship of the Court and found that it was in her best interests to issue orders to the effect that treatment could be stopped. Therefore *parens patriae* jurisdiction was not used in the *Baby L* case either, the jurisdiction to consent on her behalf being clearer under the Guardianship Act 1968. The judges decided that Baby L's interest in not suffering was enough to outweigh the presumption in favour of preservation of life.

Hutt District Health Board v B [2011]⁷

B was seven years old with a terminal genetic condition (the specifics were redacted from the judgment). He received almost all of his dietary needs from a PEG tube which had become dislodged four days previously. The unanimous clinical view, which was shared by B's mother, was that it should not be re-inserted. An urgent court hearing was then held four days later to seek a declaration that the health professionals, acting on the decision of B's

⁶ *Auckland Healthcare Services Ltd v L* [1998] NZFLR 998.

⁷ *Hutt District Health Board v B* [2011] NZFLR 873.

mother, would have a lawful excuse under ss 151 and 164 of the Crimes Act 1964. Mallon J decided that it would not be in B's best interests for the tube to be re-inserted, and that this would fit within the scope of good medical practice. Although there was some discussion regarding the necessity for declaratory orders, reliance on precedent being put forward as sufficient, it was deemed prudent for a range of reasons. These were: the child's age, that the father's views could not be ascertained, B's death was not going to be immediate (perhaps months) and that there was unanimity amongst all parties.

Australia Case Law

Adults

Northridge v Central Sydney Area Health Board [2000]⁸

Northridge was the first case in Australia to deal with an incompetent patient and withdrawal of ANH. The judgment was written following an emergency application for orders in the Court's *parens patriae* jurisdiction. John Thompson, 37 years old, was admitted to Royal Alfred Hospital in March 2000 following cardiac arrest brought on by an overdose (probably of heroin). Within four days the hospital had labelled him DNR and stopped his nasogastric feeding and ceased administering him antibiotics. This was despite his family's objections to these measures being taken. Ten days after he was admitted Mr Thompson's sister applied to the Supreme Court of New South Wales to get treatment to re-instated. An order was issued by the Court using its *parens patriae* jurisdiction that Mr Thompson should continue to be treated, and any change in his condition should result in an application to the court for new orders regarding treatment.⁹

Re BWV; Ex parte Gardner [2003]¹⁰

BWV was 68 and suffered from severe dementia, probably Pick's disease, and was being kept alive by being fed via a PEG tube. For at least two years her husband had tried to get doctors to withdraw her PEG tube; he finally approached the Public Advocate of Victoria and

⁸ *Northridge v Central Sydney Service* [2000] NSWSC 1241.

⁹ Interestingly it seems that Mr Thompson made an "almost complete recovery" according to this online source: Alex Perrottet "Turning Off to Life Support" www.onlineopinion.com.au/view.asp?article=2751 2004.

¹⁰ *Re BWV; Ex Parte Gardner* [2003] 7 VR 487.

they were appointed BWV's guardian and filed a motion on her behalf. The court ruled that the PEG tube could be removed.¹¹

Isaac Messiha (by his tutor Magdy Messiha) v South East Health [2004] ¹²

Mr Messiha was in a deep coma as a result of an asystolic cardiac arrest which deprived him of oxygen for at least twenty five minutes. His treating doctor wanted to withdraw Mr Messiha from ventilator support and treat him with palliative care as she had concluded that there would be no improvement in his condition. Similar to *Northridge* the family disagreed with the withdrawal of treatment, but unlike that case the judge, Howie J, found that there was no evidence to suggest any prospect of recovery in the condition of Mr Messiha.¹³ The decision was made that the treatment was burdensome and therefore Howie J declined to exercise the court's *parens patriae* jurisdiction to protect Mr Messiha.

Minors

Queensland v Alyssa Grace Nolan (an Infant, by her Litigation Guardian Shaun Nolan) and Bethany Rose Nolan (an Infant, by her Litigation Guardian Shaun Nolan) [2001] ¹⁴

Alyssa and Bethany Nolan were born on 3 May 2001. They were conjoined craniopagus twins (joined at the head). Alyssa only had one kidney whereas Bethany did not have any kidneys or a bladder. Although the medical carers were hopeful of waiting some months before trying to separate them, Bethany's rapid deterioration of health prevented this. Three weeks after they were born the prognosis was that Bethany would die imminently, which would lead to the death of her sister soon after. The only medical option to try to prevent Alyssa's death was an operation to separate the girls; Bethany had a 100% chance of dying from this procedure, whereas Alyssa's chances of death were rated as 60-80%.¹⁵ The State of Queensland applied to the court for an order permitting the urgently required operation that would give Alyssa a chance for life but would result in Bethany's death.¹⁶ The operation was

¹¹ Michael A Ashby and Danuta Mendelson "Gardner; re BWV: Victorian Supreme Court makes Landmark Australian Ruling on Tube Feeding" (2004) 181 (8) MJA 442.

¹² *Isaac Messiha (by his Tutor Magdy Messiha) v South East Health* [2004] NSWSC 1061.

¹³ *Ibid* at 4.

¹⁴ *Queensland v Alyssa Grace Nolan (an Infant, by her Litigation Guardian Shaun Nolan) and Bethany Rose Nolan (an Infant, by her Litigation Guardian Shaun Nolan)* (2001) QSC 174; [2001] 122 ACR 517.

¹⁵ *Ibid* at [8] per Chesterman J.

¹⁶ Interestingly, on a simple Google search (I wanted to see if Alyssa had survived, which she did) little seems to have been said of the controversial aspects of this case in the popular media. In fact it is the opposite – I found articles discussing the separation and the operation that "Bethany sadly didn't survive" – there is no

supported by the girls' parents. Chesterman J heard the application at 11pm on 25 May and gave orders that night declaring that the operation could be lawfully carried out in an attempt to save Alyssa's life; and ordering Alyssa and Bethany be permitted to undergo, and medical practitioners be permitted to perform, surgery that would separate the twins.¹⁷ Chesterman J allowed the operation to go ahead deciding that it was in both of the girls' best interests.

Canada Case Law

Adults

London Health Sciences Centre v K (R) (Litigation Guardian of) [1997]¹⁸

RK was 83 when he was admitted to London Health Care Sciences Centre following a seizure. At first he was conscious and alert but his condition deteriorated and a month later he was diagnosed as being in a PVS. The application to the court was for a declaration to discontinue treatment and withhold life sustaining measures.¹⁹ At first RK's wife, LK, refused to give consent for withdrawal of treatment, but she later changed her mind after the application to the Court had commenced.²⁰ Because LK now consented to the cessation of treatment the application was amended. London Health Care Sciences Centre sought immunity from civil and criminal prosecution if treatment was withheld following a cardiac arrest. This was the first time a Canadian court was being asked to consider this issue.²¹

McDermid J held that immunity from prosecution is the role of the prosecutors, not judges. An order would either interfere with prosecutorial discretion, or be unenforceable which was pointless.²² Furthermore, ventilators were being withdrawn on a daily basis, with no criminal or civil consequences for those withdrawing the treatment which showed the prosecutors were acting in a responsible way.²³ The necessity for proceeding with the application after

acknowledgement of the fact that she was never going to survive: For example: People's Daily Online "Siamese Twin Dies After Surgery in Australia" 28 May 2001: "An emergency operation to separate Siamese twins failed to save the life of the weaker girl, who had heart trouble and other complications, doctors in Australia said Sunday." AAP General News (Australia) 27 May 2001: "After a brave fight, three-and-a-half-week-old Bethany Rose Nolan, died from heart and lung failure 16 hours into the 20-hour operation."

¹⁷ *Queensland v Alyssa Grace Nolan (an Infant, by her Litigation Guardian Shaun Nolan) and Bethany Rose Nolan (an Infant, by her Litigation Guardian Shaun Nolan)* (2001) QSC 174; [2001] 122 ACR 517 at [28].

¹⁸ *London Health Services Centre v K (R) (Litigation Guardian of)* (1997) 152 DLR (4th) 724.

¹⁹ *Ibid* at 726.

²⁰ *Ibid*.

²¹ *Ibid* at 727.

²² *Ibid* at 733.

²³ *Ibid* at 735.

LK consented was questioned, because under s 21 (2) of the HCCA LK could consent on RK's behalf which she had done.²⁴

Interestingly the declaratory judgment in *Auckland Area Health Board v Attorney-General* was discussed.²⁵ The judge concluded that New Zealand was able to declare withdrawal of treatment was not culpable homicide by virtue of the Declaratory Judgments Act 1908 which binds the Crown by the Crown Proceedings Act 1950. No similar legislation exists in Canada for judges to make similar declarations.²⁶

Sawatzky v Riverview Health Centre Inc [1998]²⁷

This case also deals with a DNR order. Mr Sawatzky suffered from Parkinson's disease and other ailments, and had been a resident at the Riverview Health Centre for six months at the time of the hearing. Dr Engel issued a DNR order in respect to Mr Sawatzky which he reversed after the patient's wife, Mrs Sawatzky, objected. The Public Trustee was appointed as Mr Sawatzky's guardian following a later dispute between Mrs Sawatzky and Dr Engel, regarding a procedure for a cuffed tracheotomy tube. The procedure was carried out contrary to Mrs Sawatzky's wishes.

The application was from Mrs Sawatzky wanting an interlocutory injunction for the DNR order to be removed until trial. Beard J granted the application based on the following reasons: (1) treatment at issue was basic resuscitation which may mean the difference between life and death; (2) there was no consent from patient or substitute decision-maker to not treat; (3) the ethical dilemma for the doctors was a serious concern, but Dr Engel did live with it for five months prior to application; (4) disagreement as to appropriateness of DNR is rare; (5) dispute over the exact nature of Mr Sawatzky's condition; (6) Mrs Sawatzky was not given any warning about the DNR order which raises the issue of possibility of unfair treatment; (7) the Public Trustee's refusal to participate was unacceptable.²⁸ "I find her refusal to become involved to protect Mr Sawatzky's interests incomprehensible and inexcusable."²⁹ The Public Trustee's refusal to participate was based on the decision in *Child*

²⁴ Ibid.

²⁵ *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235.

²⁶ *London Health Services Centre v K (R) (Litigation Guardian of)* (1997) 152 DLR (4th) 724 at 736.

²⁷ *Sawatzky v Riverview Health Centre Inc* (1998) 167 DLR (4th) 359.

²⁸ Ibid at 372.

²⁹ Ibid at 373.

and Family Services of Central Manitoba v RL which Beard J stated should not be used to not consider the issue of DNR orders.³⁰

Re Durksen [1999]³¹

Robert Durksen was 47 when injuries suffered in a light plane crash put him in a PVS. The office of the Public Guardian was appointed his guardian and the application was initiated by them to lawfully discontinue Mr Durksen's treatment. Mr Durksen's family were in agreement that withdrawal of treatment was in his best interests. The judge held that the Public Guardian was correct in making application as they had no power to make such a decision without the Court intervening. The Dependent Adults Act RSA 2000, which conferred the power to be Mr Durksen's guardian, did not extend to consenting to withdrawal of treatment.³²

Scardoni v Hawryluck [2004]³³

Joyce Holland had advanced Alzheimer's disease, and opinions differed with regards to the way that she responded to those around her.

“She is unable to communicate verbally. The appellants believe that she recognizes them and is aware of their presence. The physicians and the nursing staff have not observed this and have had no similar experiences. They agree that Mrs. Holland is capable of hearing and that she will open her eyes when her name is called and look at the speaker. While the appellants believe she watches television, Dr. Hawryluck thinks it is not clear whether this is really the case. However, it is agreed that she is conscious and is not in a coma, or vegetative state.”³⁴

Mrs Holland's daughters, Patricia Scardoni and Margaret Holland, had been appointed her personal care attorneys, and they refused to consent to withhold treatment from their mother. All parties did agree that she was conscious, repeatedly got infections which led to painful bedsores, she needed a tracheotomy and was on intermittent ventilation. Mrs Holland's doctors wanted to withhold certain life-prolonging treatments from her as the treatment was not believed to be in her best interests.³⁵ Cullity J overrode the decision made by the CCB ordering Mrs Holland's daughters to consent to the treatment plan outlined by the medical

³⁰ *Child and Family Services of Central Manitoba v RL* [1997] MJ 568 (QL).

³¹ *Re Durksen* (1999) CarswellAlta 1672.

³² *Ibid* at [14].

³³ *Scardoni v Hawryluck* (2004) 69 OR (3d) 700.

³⁴ *Ibid* at [6].

³⁵ *Ibid* at 705.

practitioners, finding that the board had erred in law when applying her specific beliefs under the HCCA.

Re LIC [2006]³⁶

The Public Guardian had been the guardian for the Dependent Adult for 24 years. The Dependent Adult had suffered a brain injury and been a spastic quadriplegic all her life, and at the time of the application was 47 years old and in a PVS. The Public Guardian was applying to the court for directions and advice regarding consent for withdrawal of life-sustaining medical treatment, pursuant to a guardianship order under the Dependent Adults Act RSA 2000.

Although the hearing was in 2004 the written judgment was issued two years later. Acton J held that the Public Guardian could consent to withdrawal of treatment. Under the HCCA:

“10 (3) (sets out potential powers and authority to be given to the guardian, including):

(h) to consent to any health care that is in the best interests of the dependent adult”.

“1 (j) “health care” includes

(iv) any medical, surgical, obstetrical or dental treatment”.

The use of the term “includes” indicates that health care should be interpreted as broadly as possible.³⁷ Additionally, under s 7 (2), guardianship is intended to provide a substantial benefit to the Dependent Adult, as well as be in their best interests. Withdrawal could support this aim, as set out by Lord Goff in *Bland*.³⁸ This case is interesting as it differs from the earlier ruling in *Re Durksen* which held that the Public Guardian did not have the power to consent to withdrawal of treatment.³⁹ In considering *Re Durksen* Acton J stated that there was little analysis in that case to guide the decision, and it was not binding. It was emphasised that although the Public Guardian did have the power to consent to withdrawal of treatment, this should not restrict that office’s ability to seek advice from the court, especially where doctors and family disagreed about proposed treatment. The decision was instead intended to indicate that it was reasonable for the Public Guardian to rely on advice from doctors but where there were conflicts it was appropriate to seek the court’s guidance.⁴⁰

³⁶ *Re LIC* [2006] ABQB 130.

³⁷ *Scardoni v Hawryluck* (2004) 69 OR (3d) 700 at [16].

³⁸ *Airedale NHS Trust v Bland* [1993] AC 789.

³⁹ *Re Durksen* (1999) CarswellAlta 1672.

⁴⁰ *Re LIC* [2006] ABQB 130 at 35-37.

Mr Rasouli had suffered a catastrophic event whilst undergoing surgery for a benign brain tumour. His physicians wanted to withdraw ventilation and ANH but his substitute decision-maker, his wife, Ms Salasel, refused consent, stating their beliefs as Shia Muslims required a person to be kept alive as long as there were any signs of life. The case was appealed to the Supreme Court, with all three judgments ruling that doctors cannot unilaterally withdraw treatment from a patient without consent; where there is disagreement the case needs to go to the CCB.

Rasouli v Sunnybrook Health Sciences Centre (March) [2011]⁴¹

The treating physicians diagnosed Mr Rasouli as being in a PVS, but his family disagreed with the diagnosis, stating he was in a MCS. Ms Salasel had been a physician in Iran before moving to Canada the year before the case came to court, so she would have understood the medical intricacies better than most in her position.

“Counsel for the physicians takes the position that, in accordance with the common law, it is not necessary to take a doctor's proposal to withdraw treatment to the Consent and Capacity Board as the physician is not obliged to offer treatment that will not be of benefit to a patient and where continuing the life-sustaining treatment falls outside the standard of care”⁴²

Himel J found that withdrawing Mr Rasouli from the ventilator constituted treatment; statutory consent under the HCCA applies to the withdrawal of treatment, and therefore the matter should go to the CCB where there was disagreement.

Rasouli v Sunnybrook Health Sciences Centre (June) [2011]⁴³

All three Court of Appeal judges upheld the earlier decision, although their reasons differed somewhat from Himel J. Essentially they decided that palliative care included withdrawal of treatment:

“Interpreting end-of-life palliative care to include the withdrawal of life support measures where those measures are in place and must be terminated before end-of-life palliative care can begin simply means that in cases like the one at hand, treating physicians will have to obtain the substitute decision-maker’s consent to the entire treatment package. Where consent is withheld, and the treating physician is not satisfied that the substitute decision-maker has complied with the requirements of s.

⁴¹ *Rasouli v Sunnybrook Health Sciences Centre* [2011] ONSC 1500 (Can LII).

⁴² *Ibid* at [12].

⁴³ *Rasouli v Sunnybrook Health Sciences Centre* [2011] ONCA 482 (CanLII).

21 of the Act, then he or she may resort to s. 37 of the Act and refer the matter to the Board for determination.”⁴⁴

Cuthbertson v Rasouli [2013]⁴⁵

The Supreme Court decision was a 5-2 majority opinion dismissing the appeal. The judgment nuanced the approach regarding the Court of Appeal’s “palliative treatment package”, and stated:

“The simple fact is that appropriate medical care at the end of life, including palliative care, is closely tied to the withdrawal of life support.”⁴⁶

Where there is disagreement between the appointed substitute decision-maker and the medical care providers, the following six-step approach was set out by the Supreme Court:

- “1. The health practitioner determines whether in his view continuance of life support is medically indicated for the patient;
2. If the health practitioner determines that continuance of life support is no longer medically indicated for the patient, he advises the patient’s substitute decision-maker and seeks her consent to withdraw the treatment;
3. The substitute decision-maker gives or refuses consent in accordance with the applicable prior wishes of the incapable person, or, in the absence of such wishes, on the basis of the best interests of the patient, having regard to the specified factors in s. 21(2) of the HCCA;
4. If the substitute decision-maker consents, the health practitioner withdraws life support;
5. If the substitute decision-maker refuses consent to withdrawal of life support, the health practitioner may challenge the substitute decision-maker’s refusal by applying to the Consent and Capacity Board: s. 37;
6. If the Board finds that the refusal to provide consent to the withdrawal of life support was not in accordance with the requirements of the HCCA, it may substitute its own decision for that of the substitute decision-maker, and permit withdrawal of life support.”⁴⁷

Minors

Re SD [1983]⁴⁸

S, aged seven, had severe brain damage which required a shunt to be implanted in his brain to drain off excess cerebro-spinal fluid. The shunt malfunctioned and S’s parents refused

⁴⁴ Ibid at [17].

⁴⁵ *Cuthbertson v Rasouli* [2013] 3 SCR 341.

⁴⁶ Ibid at 67.

⁴⁷ Ibid at [116] per McLachlin CJ.

⁴⁸ *Re SD* [1983] 3 WWR 597; *Re SD* [1983] 3 WWR 618.

consent for surgery to fix it, as they wanted him to be allowed to die with dignity. The State intervened on the basis that the child was being deprived of the necessities of life. S was apprehended under s 1 of the Family and Child Service Act 1980 because he was “in need of protection”, as under s 1 (d) he was being “deprived of necessary medical attention”. The British Columbia Provincial Court dismissed the application, granting interim custody to the Superintendent of Child Services, saying the operation was “extraordinary surgical intervention” not “necessary medical intervention” and consequently the child was returned to his parents. The issue was whether an order be made under s 11 (2) (c) Family and Child Service Act 1980 as requested by the Superintendent, or s 11 (2) (b) as requested by the parents.⁴⁹ The Provincial Court recognised two competing rights S had under the Canadian Charter of Rights and Freedoms, Constitution Act 1982. Under s 7 S has a right to life and under s 12 S has the right not to be submitted to any cruel and unusual treatment.⁵⁰ The judge decided that s 7 was outweighed in this case by s 12 and that S should not be subjected to the operation which would amount to cruel and unusual punishment. There was also two schools of thought canvassed in American cases: (1) decisions should be made primarily within the doctor-patient relationship; (2) judicial intervention was required every case involving withdrawal or withholding life-sustaining treatment from an incompetent person.⁵¹ However, the British Columbia Supreme Court reversed the Provincial Court’s decision. Interim custody was granted to the Superintendent and surgery was ordered to be carried out while S was in custody: “It was too simplistic to say that he should be allowed to die in peace.”⁵²

New Brunswick (Minister of Health & Community Services v B (R) (1990)⁵³

This case concerned an application by the Minister of Health and Community Services for the temporary care and custody of a child, as well as authorisation for medical treatment. The girl was ten years old at the time of the application, and had just contracted meningitis as well as being severely mentally disabled as a result of encephalocele. The neurosurgeon treating the child described her as having no quality of life, and believed that “further medical treatment will serve only to prolong (her) suffering.”⁵⁴ Her parents agreed and thought it would be in her best interests to die. However the child’s paediatrician disagreed and thought

⁴⁹ *Re SD* [1983] 3 WWR 597 at 609.

⁵⁰ *Ibid* at 612.

⁵¹ *Re SD* [1983] 3 WWR 597 at 614; *Re SD* [1983] 3 WWR 597.

⁵² *Re SD* [1983] 3 WWR 597; *Re SD* [1983] 3 WWR 618.

⁵³ *New Brunswick (Minister of Health & Community Services) v B (R)* (1990) 70 DLR (4th) 568.

⁵⁴ *Ibid* at 569.

she should be treated with antibiotics. McLellan J found that the neurosurgeon was discriminating against her due to her mental and physical disability which contravenes s 15 (1) of the Canadian Charter of Rights and Freedoms. The judge also found that she had a right to life under s 7 of the Charter and the right not to be subjected to cruel and unusual punishment, under s 12.⁵⁵ “However reasonable or rational their discrimination may appear to them to be, it contravenes the Charter and is thus illegal and wrong.”⁵⁶ Custody, care and control was transferred to the Minister for six months as the Court was satisfied the child was in danger because her parents refused to provide her with medical treatment.

Child and Family Services of Central Manitoba v RL and SLH [1997]⁵⁷

A child, D, was admitted to hospital at just three months old following a brutal attack. Nobody was arrested but following it D was apprehended by the Child and Family Services of Central Manitoba and remained under their care. Due to the injuries he sustained D was in a PVS, and eight months after the attack the Child and Family Services petitioned the Court to be allowed to direct D’s carers to issue a DNR order. D’s doctor recommended such a course of action but D’s parents opposed it.⁵⁸ Section 25 (3) of the Child and Family Services Act 1985-86 states that:

“25 (3) An agency may apply to court for an order
(b) authorizing medical ... treatment for an apprehended child where
(i) the parents ... of the child refuse to consent to such treatment.”

Cumming J at the lower court granted the order sought, holding that the court had jurisdiction under the Act to authorise a negative action as well as a positive one. However the Manitoba Court of Appeal decided that “treatment” in the provision could only be interpreted in a positive sense.⁵⁹ Therefore doctors do not need consent from anybody to refrain from taking active measures:

“... neither consent nor a court order in lieu is required for a medical doctor to issue a non-resuscitation direction where, in his or her judgment, the patient is in an irreversible vegetative state. Whether or not such a direction should be issued is a judgment call for the doctor to make having regard to the patient’s history and condition and the doctor's evaluation of the hopelessness of the case. The wishes of

⁵⁵ Ibid at 570.

⁵⁶ Ibid at 571.

⁵⁷ *Child and Family Services of Central Manitoba v RL* [1997] MJ 568 (QL).

⁵⁸ Ibid at [1].

⁵⁹ Ibid at [13].

the patient's family or guardians should be taken into account, but neither their consent nor the approval of a court is required."⁶⁰

England and Wales Case Law

Adults

Airedale NHS Trust v Bland [1993]⁶¹

"Thousands of words have since been written about the case, eight judges gave opinions, moral philosophers and law experts discussed the judgments, religious leaders pronounced. Yet neither the family nor I understand why it was all so complicated."⁶²

On 15 April 1989 an eighteen year old young man called Anthony Bland set out with two friends to watch Liverpool play Nottingham Forest in a semi-final match at the Hillsborough Football Stadium. 94 people died that day when severe overcrowding led to them being crushed to death. Anthony Bland survived – but was later diagnosed as being in a PVS, in a condition that meant that he was not reliant on a ventilator, he could breathe unassisted, but had no other abilities or awareness and was reliant on ANH. The Hillsborough tragedy created a maelstrom of controversy which was still being felt acutely just three years after the event, and which continued for many years.⁶³ This obviously increased scrutiny on Anthony Bland and his condition, and so the doctor caring for him, Dr Howe, proceeded with caution:

"I decided to inform the Sheffield Coroner, Dr Popper, of our plan to withdraw all treatment, including ANH. It is difficult now to convey my shock on receiving his intimidating reply. Having stated that he had no jurisdiction over any living person, he advised that I would risk a murder charge should I withdraw treatment. He made it clear that he "... could not countenance, condone, approve or give consent to any action or inaction which could be, or could be construed as being, designed or intended to shorten or terminate the life of this young man. This particularly applies to the withholding of the necessities of life, such as food and drink". He requested a reply by return indicating that I had understood his opinion, and that I would not withdraw treatment."⁶⁴

⁶⁰ *Child and Family Services of Central Manitoba v RL* [1997] MJ 568 (QL) at [17].

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

⁶² Jim Howe "The Persistent Vegetative State, Treatment Withdrawal, and the Hillsborough Disaster: *Airedale NHS Trust v Bland*" (2006) 6 (4) *Pract Neurol* 238 at 241. (Sic - there were actually nine judges).

⁶³ The Liverpool fans were initially accused of drunkenness and hooliganism and blamed for the deaths. Although this was shown to not be true it was still felt 20 years later that full disclosure had still not been achieved and a panel was set up in 2010 by the UK Government to oversee the release of documents and analyse these. In 2012 the Hillsborough Independent Panel released their findings Hillsborough Independent Panel "Disclosed Material and Report" 2012.

⁶⁴ Howe (2006) 6 (4) *Pract Neurol* 238 at 240.

This led to an application by the Airedale NHS Trust applying to the Court that ANH could be withdrawn from Anthony Bland. The case was appealed twice, eventually to the House of Lords, who upheld all the lower court decisions that treatment could be lawfully ceased. Essentially *Bland* signalled the first time in England where treatment was allowed to be withdrawn from a patient, with court approval that death would not only be the result, but the desired effect. This case obviously raised very complex moral and legal issues about how death fitted in with Anthony Bland's best interests. The House of Lords found that sanctity of life was not absolute, and was not violated by ceasing to give invasive medical treatment that Mr Bland had not consented to and which conferred no benefit on him.

“... the question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care.”⁶⁵

Bland is one of the most influential cases in the Commonwealth; its importance is hard to overstate. One of the major reasons this case is so revolutionary is that all of the judges expressly acknowledged that this is what they were doing – Anthony Bland would die as a result of the withdrawal, and that this was the desired effect.

“The decision of the House of Lords forms an important part of international jurisprudence on this subject.”⁶⁶

Frenchay Healthcare NHS Trust v S [1994]⁶⁷

S was 24 and had been in a PVS for three years. His gastrostomy tube became removed so the hospital applied for a declaration authorising them not to replace it. S's mother agreed, but his father was more equivocal. The Court of Appeal applied *Bland*: the test is whether the treatment is in the patient's best interests, for S this meant treatment should not be resumed.

W Healthcare NHS Trust v H [2004]⁶⁸

KH had suffered from multiple sclerosis for approximately thirty years and required constant care. She was incapable of making any decisions for herself, and her health had deteriorated to the point where she was doubly incontinent, found it hard to swallow and was constantly disorientated as to the time and place. Although she was conscious, she could not recognise

⁶⁵ *Airedale NHS Trust v Bland* [1993] AC 789 at 868.

⁶⁶ *NHS Trust A v M; NHS Trust B v H* [2001] Fam 348 at 360.

⁶⁷ *Frenchay Healthcare NHS Trust v S* [1994] 2 All ER 403.

⁶⁸ *W Healthcare NHS Trust v H* [2004] EWCA Civ 1324.

anyone, including members of her own family. She had also required feeding by a PEG tube for five years. Her family did not want the tube to be re-inserted after it fell out; her medical carers unanimously thought that it should be. Following the disagreement W Healthcare NHS Trust sought a declaration that re-insertion of the tube was in KH's best interests. Coleridge J permitted it to be re-inserted. KH's brother and daughter appealed, but the appeal was dismissed. The Court of Appeal found that there was no sufficiently clear advance directive established from KH with regard to deprivation of food and water, and furthermore KH was conscious enough to suffer by starvation and would therefore receive benefit from ANH.

Burke

This case is different from all of the other cases about incompetent adults because the adult is actually competent, however it fits within this category because it does deal with issues regarding incapacity. Leslie Burke, 44, suffered from a congenital degenerative brain condition. He had serious physical disabilities but was fully competent. He sought clarification as to when ANH could be withdrawn: specifically judicial review of guidelines issued by General Medical Council (GMC). He did not want treatment withdrawn, preferring to die of natural causes. In the words of the High Court judge he did not want doctors to make a decision that his life was no longer worth living.

R (Burke) v General Medical Council (Official solicitor intervening) [2005]⁶⁹

Munby J in the High Court held that the guidance was amenable to judicial review on four grounds: (1) that there was emphasis on the right of a competent patient to refuse, not require, treatment; (2) that there was a duty on a doctor to find another who would treat if they would not; (3) the guidelines failed to acknowledge the heavy presumption in favour of life-prolonging treatment; and (4) the guidelines also failed to recognise the legal requirement for judicial sanction of withdrawal of treatment in some circumstances.

R (Burke) v General Medical Council (Official solicitor intervening) [2006]⁷⁰

The Court of Appeal allowed the appeal by the GMC. Lord Phillips MR emphasised that caution should be exercised by the courts when dealing this type of issue:

⁶⁹ *Burke v General Medical Council (Official Solicitor Intervening)* [2004] EWHC 1879; [2005] QB 424.

⁷⁰ *Burke v General Medical Council (Official Solicitor and Others Intervening)* [2005] EWCA Civ 100.

“The court should not be used as a general advice centre. The danger is that the court will enunciate propositions of principle without full appreciation of the implications that these will have in practice, throwing into confusion those who feel obliged to attempt to apply those principles in practice. This danger is particularly acute where the issues raised involve ethical questions that any court should be reluctant to address, unless driven to do so by the need to resolve a practical problem that requires the court’s intervention.”⁷¹

It was also held that the best interests test, regarding whether treatment should be provided, should be applied depending on the particular circumstances of the patient.

Burke v The United Kingdom (2006)⁷²

The European Court of Human Rights also dismissed Mr Burke’s appeal. They found a sufficient emphasis on prolonging life existed in British law, and subsequently there was no real risk that ANH would be withdrawn. Additionally they were reluctant to compel doctors to treat:

“In the present case, the Court notes that neither a competent nor an incompetent patient can require that a doctor give treatment which that doctor considers is not clinically justified”.⁷³

W v M [2011] ⁷⁴

M was diagnosed with viral encephalitis, aged 43, in 2003. Her family applied for treatment (ANH) to be withdrawn from her.

“M’s family feel strongly that she would have rejected her current treatment and the rationale for this application is fundamentally based on M’s perceived wishes and feelings.”⁷⁵

In 2007 she had been diagnosed as being in a PVS, however this was later changed to MCS which proved significant for the application:

“this case has demonstrated the crucial role played by the formal assessment tools... The history of this case shows how cases may be misdiagnosed if these tools are not used. M was initially diagnosed as being in a VS. That led the family, advised by the very experienced clinicians and the independent expert instructed at that stage, to make this application. It was only some time after this application was launched that

⁷¹ Ibid at 293.

⁷² *Burke v The United Kingdom* (2006) 19807/06.

⁷³ Ibid at 9.

⁷⁴ *W v M* [2011] EWCOP 2443 (Fam). An earlier judgment dealt with publication restrictions regarding the later hearing. *W v M* [2011] EWCOP 1197.

⁷⁵ *W v M* [2011] EWCOP 2443 (Fam) at [223].

the SMART [Sensory Modality Assessment and Rehabilitation Technique] test was administered and disclosed that M was in fact in an MCS.”⁷⁶

James

On 5 May 2012, David James aged 68, was admitted to hospital due to complications with his stoma. His stoma had been fitted as a result of colon cancer eleven years previously. The complication got sorted, however he developed an infection and, on 24 May, his condition deteriorated to the point that he was admitted to the hospital’s critical care unit. He had multi-organ failure, respiratory failure, cardiovascular failure and renal failure. On 27 May, he was placed on (intermittent) ventilator support. Mr James’ family disagreed with his clinicians that if his condition deteriorated certain treatments should be withheld.

An NHS Trust v DJ [2012]⁷⁷

David James’ medical team applied for certain procedures to be withheld in the event of their patient’s clinical deterioration: cardiopulmonary resuscitation, invasive support for circulatory problems, renal replacement therapy, and intravenous antibiotics if further infectious complications arose. Mr Justice Peter Jackson refused the application for the following reasons:

“(1) Although DJ’s condition is in many respects grim, I am not persuaded that treatment would be futile or overly burdensome, or that there is no prospect of recovery.

(a) In DJ’s case, the treatments in question cannot be said to be futile, based upon the evidence of their effect so far.

(b) Nor can they be said to be futile in the sense that they could only return DJ to a quality of life that is not worth living.

(c) Although the burdens of treatment are very great indeed, they have to be weighed against the benefits of a continued existence.

(d) Nor can it be said that there is no prospect of recovery: recovery does not mean a return to full health, but the resumption of a quality of life that DJ would regard as worthwhile. The references, noted above, to a cure or a return to the former pleasures of life set the standard unduly high.”⁷⁸

⁷⁶ *W v M* [2011] EWCOP 2443 (Fam) at [258].

⁷⁷ *An NHS Trust v DJ* [2012] EWHC 3524 (COP).

⁷⁸ *Ibid* at [84].

Aintree University Hospital NHS Foundation Trust v James (CA) [2013]⁷⁹

Mr James' condition had deteriorated in the two weeks between hearings, and he was now completely dependent on ventilation. Sir Alan Ward (with whom Laws LJ was in agreement with) and Arden LJ allowed the application by the NHS Trust to withhold treatment from Mr James. In doing so they differed in their approaches, but agreed that further treatment would be unduly burdensome.⁸⁰ Mr James passed away soon after the Court of Appeal hearing.

Aintree University Hospital NHS Foundation Trust v James (SC) [2013]⁸¹

This case was the first time the Supreme Court had considered under the MCA whether withdrawal or withholding of treatment was in a patient's best interests. Lady Hale delivered the judgment for the Supreme Court; the Court of Appeal decision was upheld but only because of the deterioration of Mr James' condition. The reasoning from the Court of Appeal was criticised for requiring too high a threshold for futility, and for incorporating a reasonable person standard.

“It follows that I would dismiss this appeal on the ground that the Court of Appeal reached the right result but for the wrong reasons, while the trial judge had reached a result which was open to him having correctly directed himself as to the law.”⁸²

Minors

Re B (A minor) (Wardship: Medical Treatment) (1982)⁸³

This is the earliest prospective end-of-life case examined. A newborn baby with Down syndrome needed an operation to relieve intestinal blockage. Her parents refused to consent to the operation as they thought it kinder to allow her to die. Her doctors then contacted the local authority. She was subsequently made a ward of the court, but the surgeon thought that the wishes of the parents should be respected. An application for an order directing treatment was sought and refused; the judge agreeing that the parents' wishes should be respected. The local authority appealed successfully. Templeman and Dunn LJJ decided that it was in the best interests of the child to have the operation – the case was not about whether parents' wishes should be respected. The life of a child with Down syndrome was not so bad that the child should be condemned to die.

⁷⁹ *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65.

⁸⁰ *Ibid* at [64].

⁸¹ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

⁸² *Ibid* at [48].

⁸³ *Re B* (1982) 3 FLR 117.

R v Cambridge Health Authority, Ex parte B [1995]⁸⁴

B was eleven years old and had acute myeloid leukaemia. Her father sought direction from the court ordering doctors to treat her with chemotherapy and, if this was successful, a bone marrow transplant for her. Each had a 10-20% chance of success and a significant cost (chemotherapy would cost £15,000 and the bone marrow transplant would cost £60,000). Thirteen months before the application B had had a bone marrow transplant and two courses of chemotherapy, but she subsequently relapsed which is why her father sought further treatment. However B's doctors would not treat her, they said that more chemotherapy and another transplant would not be in her best interests. A medical school professor recommending further chemotherapy acknowledged the therapy to be more experimental than standard. Treatment was denied on basis that it was not in B's best interests and not an appropriate use of limited resources, but the lower court judge directed Cambridge Health Authority to reconsider. The appeal from the Authority was upheld. The Court of Appeal stated that the proposed treatment had limited chance of success and it was for Cambridge Health Authority, not the court, to allocate their limited budget for the maximum benefits.

Re C (A minor) (Wardship: Medical Treatment) [1990]⁸⁵

C, a newborn baby with congenital hydrocephalus, was already a ward of the court (unrelated to her condition). An application was made for direction regarding her future care should she contract a serious infection, or should existing feeding methods become problematic. The lower court judge issued an injunction containing specific instructions as to the type of treatment C could be administered:

“it shall not be necessary either, (a) to prescribe and administer antibiotics ... or (b) to set up intravenous fusions or nasal gastric feeding regimes for the minor.”⁸⁶

The Court of Appeal deleted these directions from the lower court judge's direction. They deemed them inconsistent with the general recommendation that treatment to relieve suffering rather than prolong life was appropriate. They did uphold the recommendations that, with consideration to C's best interests as paramount, the court was entitled to approve treatment to ease her suffering rather than prolong her life.

⁸⁴ *R v Cambridge District Health Authority, Ex Parte B* [1995] 1 FLR 1055; *R v Cambridge District Health Authority Ex Parte B* [1995] EWCA Civ 49; 1 WLR 898.

⁸⁵ *Re C (A Minor) (Wardship: Medical Treatment)* [1990] Fam 26.

⁸⁶ *Ibid.*

Re J (A minor) (Wardship: Medical Treatment) [1991]⁸⁷

J was also already a ward of the court unrelated to his condition. He was born prematurely and as a result was severely brain damaged. The grim prognosis was that he would be unlikely to develop even limited intellectual abilities. He was also likely to develop serious spastic quadriplegia, and it was likely that he was both deaf and blind. Unfortunately he probably had a normal pain threshold, and was suffering from his various ailments. When he was five months old an application was made regarding J's future care, especially regarding ventilator support. Scott Baker J approved the neonatologist's recommendation that J should not be revived by mechanical ventilation in the event of further convulsions, and the Court of Appeal upheld this decision. They found that the presumption in favour of sanctity of life did not displace the paramount consideration of the child's best interests – the court can consent to withhold life-saving treatments even where the condition is not terminal.

In Re A (Children) [2001]⁸⁸

Jodie and Mary were born on 8 August 2000 as ischiopagus tetrapus conjoined twins. This meant that they were joined at the pelvis and had four limbs. Jodie sustained the life of Mary, and an operation to separate them was required or they would both die. Just how much longer they would live was uncertain – but estimates were put at between three and six months. The operation would give Jodie a 60-80% chance of living, but Mary would definitely die as her blood supply would be cut off. Jodie and Mary's parents refused to consent to the operation. The Court of Appeal found that the operation was an act of necessity and its purpose was to prolong Jodie's life, but not to cause the death of Mary. Article 2 of the Human Rights Act did not prohibit the operation because "intentionally" only applies to cases where the purpose of the prohibited action was to cause death. The separation of the twins were held to be in both of their best interests, despite only one of them having any chance of survival.

Wyatt

This is a complicated case that had three hearings at the High Court level, and one at the appellate level. It also generated a lot of public interest and debate, and even several

⁸⁷ *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33.

⁸⁸ *In Re A (Children)* [2000] EWCA Civ 254; [2001] Fam 147.

websites.⁸⁹ The cases all centred on the appropriate treatment for Charlotte Wyatt, who was born at 26 weeks with serious medical problems. She had severe brain damage, was blind, deaf and incapable of voluntary movement, and she also had chronic kidney and respiratory problems. Consequently she had not left hospital since birth. Her parents, Deborah and Darren Wyatt, and her medical carers disagreed about her treatment, and the extent of aggressive treatment that should be given to her. Charlotte's doctors were of the opinion that minimal intervention should be practiced, but her parents disagreed with this approach. The acrimony between the parties was bitter. At one stage the parents reported Charlotte's doctors to the police, and it even reached the point that for significant periods of time the parents could only visit Charlotte accompanied by security personnel.

Portsmouth NHS Trust and Wyatt, Southampton NHS Trust Intervening [2004] (7 October 2004)⁹⁰

The first time the parties went to court Charlotte Wyatt was nearly twelve months old. She had minimal cognitive function but did experience pain and distress. Her prognosis was poor; it was considered very unlikely that she would survive past her first birthday.⁹¹ The issue was whether or not artificial ventilation should be given to Charlotte. Doctors disagreed with her parents about whether intensive ventilation should be given, saying it was not in her best interests. Hedley J, using the inherent jurisdiction of the High Court over children, upheld the application by the Trust, and granted permissive relief to not treat Charlotte with intensive ventilation. Furthermore he held that aggressive treatment, even to prolong her life, was not in Charlotte's best interests.

Portsmouth Hospitals NHS Trust v Wyatt (January 2005)⁹²

This is an oral judgment given by Hedley J. It was in response to an application by Charlotte's parents to stay the order given in the previous October because Charlotte's condition had improved. Hedley J refused the application on two grounds: (1) the declarations did not interfere with the practitioners' duty to exercise their judgment in Charlotte's best interests; and (2) there were no clear grounds for varying the orders.

⁸⁹ Including: www.FriendsofCharlotteWyatt.com, 2006.

⁹⁰ *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam).

⁹¹ Charlotte turned three years old on 21 October 2006.

⁹² Unreported.

Wyatt v Portsmouth NHS Trust [2005] (21 April 2005)⁹³

Charlotte was now eighteen months old, and against the odds had survived through the winter. Her oxygen dependency had been reduced from 100% to 50%, and she was more responsive. Her parents applied to have the declarations that had been issued in the October 2004 judgment discharged. Hedley J declined to do so but held that all treatment but intubation and ventilation should be used in event of respiratory collapse. He gave three reasons for this decision: (1) Charlotte was unlikely to survive a respiratory crisis no matter what interventions were given; (2) if she did survive it her condition would have severely deteriorated; and (3) such an invention “would imperil a peaceful death.”⁹⁴ A review of the declarations was tabled for October 2005.

Portsmouth Hospitals NHS Trust v Wyatt [2005] (12 October 2005)⁹⁵

Hedley J granted permission to the Wyatts to appeal on the issue of whether the court should have continued the declarations, and whether they should have been issued ahead of a particular medical crisis. They also wanted leave to appeal on the issue of whether the judge applied the best interests test appropriately. The Court of Appeal dismissed the appeal regarding continuance of declarations and refused them permission to appeal on the issue of best interests. It was, however, referred back to the High Court for a review in September not October.

Portsmouth NHS Trust v W [2005] (21 October 2005)⁹⁶

Charlotte was now two years old, and it was four court cases later. The physicians treating her wanted a declaration, given the difficulties in the relationship so far, stating that they could overrule her parents on medical decisions. Such a declaration would be unprecedented but Hedley J did grant the treating clinician veto over Charlotte’s parents although their wishes were not inconsequential: “parental wishes should be accommodated as far as professional judgment and conscience will permit, but no further.”⁹⁷

⁹³ *Wyatt v Portsmouth NHS Trust* [2005] EWHC 693 (Fam).

⁹⁴ *Ibid* at 484.

⁹⁵ *Portsmouth Hospitals NHS Trust v Wyatt* [2005] 1 WLR 3995.

⁹⁶ *Portsmouth NHS Trust v W* [2005] EWHC 2293 (Fam).

⁹⁷ *Ibid* at [41].

An NHS Trust v MB [2006]⁹⁸

M was 18 months old and had spinal muscular atrophy. The NHS Trust applied for a range of measures, but preferred an option to remove M's endo-tracheal tube and provide the child with palliative care. His parents opposed this, wanting his life to be prolonged for as long as possible. Holman J agreed, and decided against the advice of the medical profession and M's guardian that the current treatment should continue. The material finding was that in his present condition M could still gain benefit from the continuation of his life:

“I must proceed on the basis that M has age appropriate cognition, and does continue to have a relationship of value to him with his family, and does continue to gain other pleasures from touch, sight and sound.”⁹⁹

Central Manchester University Hospitals NHS Foundation Trust v A [2015]¹⁰⁰

Identical twins, aged fourteen months, both suffered from the same progressive neuro-degenerative disorder. Both twins were on ventilation and had been for some months. The NHS applied to the court for a declaration that it was both boys' best interests to have treatment withdrawn. The twins' parents refused to consent:

“The father stressed again how offensive it is to the Muslim beliefs of himself and his wife that life support should be withdrawn before the brain of the respective child “has stopped working finally” in accordance with the resolution of the Islamic Fiqh Council. He said, most eloquently, “I have respect for the law of the United Kingdom, but, please, do not forget that withdrawal of life support goes against our beliefs.”¹⁰¹

However, Holman J was satisfied with medical evidence that showed no prospect of recovery from the severe brain damage both boys had suffered, and granted the application for withdrawal of treatment.

“But it seems to me that artificially to prolong their lives in this particular case lacks any purpose, confers no benefit at all apart from the fact of physical survival, and involves perpetuating the infliction of pain and discomfort for no gain or purpose. It is not in the best interests of either boy that the process be artificially prolonged, and it is in their best interests that nature should now be permitted to take its inevitable course. That is the tragic genetic destiny of each of these boys.”¹⁰²

⁹⁸ *An NHS Trust v MB* [2006] EWHC 507 (Fam).

⁹⁹ *Ibid* at 101 per Holman J.

¹⁰⁰ *Central Manchester University Hospitals NHS Foundation Trust v A* [2015] EWHC 2828 (Fam).

¹⁰¹ *Ibid* at [19].

¹⁰² *Ibid* at [25].



Whānau



Mum – Liz McAuley

For all your love, endless encouragement, and being my #1 supporter. Thanks also for all of the practical help which has made such a big difference.

MaryLeigh Moore

This thesis has benefitted so much from our discussions, your comments on drafts, and your belief in me. Thank you so much for everything. The walk across the stage is not mine alone.

Margaret Tagg

AKA the “Granny Nanny”. “I couldn’t have done this without you” is often used, and therefore read without meaning. But believe me – I really could not have. Thank you.

Schlups – Philip, Kristi, Ella, Lucy and Eva

Thank you so much for the brunches, the many cups of tea (!), and lots of hugs ... but mostly for all five of you being a beloved part of our whānau.

McAuleys – Bob, Jess, Grace and Ava

Thanks for all your love and support, and telling me that “you can do it Jimbo”.

Nana and Grandad – Ethel and Cliff McAuley

Thank you for giving your grandchildren the gift of valuing education (I may have got carried away).

Penny Gray

Thanks to my special Aunty Nib for reading an early draft.

John Tagg

Thank you so much for proof-reading and thanks also to you and HeeJi for help minding the girls.

Andrew Tagg

For being my Eric, my Castle, my Reacher, my Mentalist, my Arrow, my Wesley ... and most of all my Darcy. (Oh – and my proof-reader. That was good too).

Elizabeth and Laura Tagg

Yay – Mummy’s big book is finished ☺ From Laura’s comment that: “Mummy’s big book is stinky” to Elizabeth saying “I’m going to do a PhD too” you covered what this journey has been about. Hard but worth it.

Bibliography

Cases

New Zealand

Auckland Area Health Board v Attorney-General [1993] 1 NZLR 235.

Auckland Healthcare Services Ltd v L [1998] NZFLR 998.

Hutt District Health Board v B [2011] NZFLR 873.

Re G [1997] 2 NZLR 201.

Seales v Attorney-General [2015] NZHC 1239.

Shortland v Northland Health Ltd [1998] 1 NZLR 433.

Shortland v Northland Health Ltd (Unreported) M75/97 NZHC 732.

Australia

Australian Capital Territory v JT [2009] ACTSC 105.

Isaac Messiha (by his Tutor Magby Messiha) v South East Health [2004] NSWSC 1061.

Krommydas v Sydney West Area Health Service [2006] NSWSC 901.

Northridge v Central Sydney Service [2000] NSWSC 1241.

Queensland v Alyssa Grace Nolan (an Infant, by her Litigation Guardian Shaun Nolan) and Bethany Rose Nolan (an Infant, by her Litigation Guardian Shaun Nolan) (2001) QSC 174; [2001] 122 ACR 517.

Re Baby D (No 2) [2011] FamCA 176.

Re BWV; Ex Parte Gardner [2003] 7 VR 487.

Re F; F v F (Unreported, Sup Crt Vic, Vincent J, extract of transcript of proceedings 2 July, 1986).

Re Marion (1990) 14 Fam LR 427, (1991) FLC 92-193.

Re Marion (No 2) 17 Fam LR 336.

Secretary, Department of Health and Community Services v JWB (1992) 106 ALR 385.

Slaveski & Others v Austin Health [2010] VSC 493.

Canada

Ackie v Manocha [2014] 2014 ONSC 669.

Alberta (Child, Youth and Family Enhancement Act, Director) v DL [2012] ABCA 275.

Barbulov v Cirone [2009] CanLII 15889 (ON SC).

Bentley v Maplewood Seniors Care Society [2014] BCSC 165.

Canada (Attorney General) v EF [2016] ABCA 155.

Carter v Canada (Attorney General) [2015] 1 SCR 331.

Child and Family Services of Central Manitoba v RL [1997] MJ 568 (QL).

Children's Aid Society of Ottawa-Carleton v MC CanLII 49154 (ON SC); (2008) 301 DLR (4th) 194.

Cuthbertson v Rasouli [2013] 3 SCR 341.

Golubchuk v Salvation Army Grace General Hospital [2008] MBQB 49 (CanLII); (2008) 290 DLR (4th) 46.

In M (A) v Benes (1999) 46 OR (3d) 271.

Janzen v Janzen [2002] OJ No 450 44 ETR (2d) 217 (Ont SCJ).

Jin (Next Friend of) v Calgary Health Region [2007] ABQB 593 (CanLII); [2008] 2 WWR 723.

London Health Services Centre v K (R) (Litigation Guardian of) (1997) 152 DLR (4th) 724.

Maraachli v Dr Fraser [2011] ONSC 124; [2011] OJ No. 2168.

May v Alberta Health Services [2010] ABQB 213.

New Brunswick (Minister of Health & Community Services) v B (R) (1990) 70 DLR (4th) 568.

Rasouli v Sunnybrook Health Sciences Centre [2011] ONCA 482 (CanLII).

Rasouli v Sunnybrook Health Sciences Centre [2011] ONSC 1500 (Can LII).

Re Durksen (1999) CarswellAlta 1672.

Re IHV 2008 ABQB 250.

Re KP; Minister of Social Services v FP and LP (1990) 69 DLR (4th) 134.

Re LIC [2006] ABQB 130.

Re SD [1983] 3 WWR 597.

Re SD [1983] 3 WWR 618.

Rodriquez v British Columbia (Attorney General) [1993] 3 SCR 521.

Rotaru v Vancouver General Hospital Intensive Care Unit [2008] BCSC 318.

Sawatzky v Riverview Health Centre Inc (1998) 167 DLR (4th) 359.

Scardoni v Hawryluck (2004) 69 OR (3d) 700.

Sweiss v Alberta Health Services [2009] ABQB 691.

England and Wales

Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67.

Aintree University Hospitals NHS Foundation Trust v James [2013] EWCA Civ 65.

Airedale NHS Trust v Bland [1993] AC 789.

B NHS Trust v J [2006] EWHC 3152 (Fam).

Bolam v Friern Hospital Management Committee [1957] 1 WLR 582.

Burke v General Medical Council (Official Solicitor and Others Intervening) [2005] EWCA Civ 100.

Burke v General Medical Council (Official Solicitor Intervening) [2004] EWHC 1879; [2005] QB 424.

Burke v The United Kingdom (2006) 19807/06.

Central Manchester University Hospitals NHS Foundation Trust v A [2015] EWHC 2828 (Fam).

F v F [2013] EWHC 2683 (Fam).

Frenchay Healthcare NHS Trust v S [1994] 2 All ER 403.

An Hospital NHS Trust v S [2003] EWHC 365 (Fam).

In Re A (Children) [2000] EWCA Civ 254; [2001] Fam 147.

In Re P (Statutory Will) [2010] Ch 33

In Re S (Protected Persons) (2009) WTLR 315.

In The Matter Of G (TJ) [2010] EWCOP 3005.

A National Health Service Trust v D [2000] Lloyd's Rep Med 411.

NHS Trust A v H [2001] 2 FLR 501.

NHS Trust A v M; NHS Trust B v H [2001] Fam 348.

NHS Trust v A [2005] EWCA Civ 1145; [2006] Lloyd's Rep Med 29.

The NHS Trust v A (A Child) [2007] EWHC 1696 (Fam).

An NHS Trust v DJ [2012] EWHC 3524 (COP).

NHS Trust v I [2003] EWHC 2243 (Fam).

An NHS Trust v MB [2006] EWHC 507 (Fam).

An NHS Trust v Mrs H, Re (Rev 1) [2012] EWHC B18 (Fam).

The NHS Trust v Ms D [2005] EWHC 2439 (Fam).

Portsmouth Hospitals NHS Trust v Wyatt [2005] 1 WLR 3995.

Portsmouth NHS Trust v W [2005] EWHC 2293 (Fam).

Portsmouth NHS Trust v Wyatt [2004] EWHC 2247 (Fam).

Pretty v United Kingdom (2002) 35 EHRR 1.

R (Pretty) v Director of Public Prosecutions (Secretary of State for the Home Department Intervening) [2002] 1 AC 800.

R v Cambridge District Health Authority Ex Parte B [1995] EWCA Civ 49.

R v Cambridge District Health Authority, Ex Parte B [1995] 1 FLR 1055.

Re AK [2001] 1 FLR 129.

Re B [2002] 2 All ER 449.

Re B (1982) 3 FLR 117.

Re C [2010] EWHC 3448 (Fam).
Re C (A Minor) (Medical Treatment) [1998] Lloyd's Re Med 1.
Re C (A Minor) (Wardship: Medical Treatment) [1990] Fam 26.
Re D [1997] 1 FLR 411.
Re G (Unreported).
Re J (A Minor) (Wardship: Medical Treatment) [1991] Fam 33.
Re L [2004] EWHC 2713 (Fam) [2005] 1 FLR 491.
Re M [2010] 3 All ER 682.
Re R (Adult: Medical Treatment) (1996) 31 BMLR 127.
Re T [1992] EWCA Civ 18; [1993] Fam 95.
Re T (A Minor) (Wardship: Medical Treatment) [1996] EWCA Civ 805.
Re Wyatt [2006] EWHC 319 (Fam).
Re Y (Mental Incapacity: Bone Marrow Transplant) [1996] 2 FLR 787.
Royal Wolverhampton Hospitals NHS Trust v B [2000] 1 FLR 953.
W Healthcare NHS Trust v H [2004] EWCA Civ 1324.
W v M [2011] EWCOP 2443 (Fam).
W v M [2011] EWCOP 1197.
Wyatt v Portsmouth NHS Trust [2005] EWHC 693 (Fam).

Northern Ireland

A Health and Social Care Trust v M [2014] NIFam 3.
In the Matter of A Ward of Court [1995] IESC 1; [1996] 2 IR 73.

Scotland

Law Hospital NHS Trust v Lord Advocate (1996) Scot CS CSIH 2; [1996] 2 FLR 407.

United States of America

Cruzan v Director, Missouri Department of Health (1990) 497 US 261.

In Re Conroy (1985) 98 NJ 321.

In the Matter of Karen Quinlan (1976) 355 A 2d 647.

Schloendorff v Society of New York Hospital (1914) 211 NYR 125.

Legislation

New Zealand

Care of the Children Act 2004.

Health and Disability Commissioner Code of Health and Disability Services Consumers' Rights Regulation 1996.

Judicature Act 1908.

Protection of Personal and Property Rights Act 1988.

Australia

Family Law Rules (2004).

Guardianship Act 1987 (NSW).

Guardianship and Administration Act 1993 (Qld).

Guardianship and Administration Act 1986 (Vic).

Guardianship and Management of Property Act 1991 (ACT).

Medical Treatment Act 1988 (Vic).

Canada

The Constitution Act 1982 (Canada).

Health Care and Consent Act 1996 (Ont).

Manitoba Mental Health Act.

Personal Directives Act 2000 (Alberta).

England and Wales

European Convention for the Protection of Human Rights and Fundamental Freedoms 1953.

Human Rights Act 1998.

Mental Capacity Act 2005.

Northern Ireland

Constitution of Ireland Bunreacht na hÉireann 1937.

Scotland

Adults with Incapacity (Scotland) Act 2000.

Books and Book Chapters

Brian Barry *Political Argument: A Reissue with New Introduction* (Univ of California Press, 1965).

Tom L Beauchamp and James F Childress *Principles of Biomedical Ethics* (7th ed, Oxford University Press, New York, 2013).

Tom L Beauchamp and James F Childress *Principles of Biomedical Ethics* (5th ed, Oxford University Press, New York, 2001).

Allen E Buchanan and Dan W Brock *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge University Press, 1990).

Peter Cane *Responsibility in Law and Morality* (Hart, Oxford, 2002).

Jocelyn Grant Downie, Timothy A Caulfield and Colleen M Flood *Canadian Health Law and Policy* (Butterworths, 2011).

Alice Domurat Dreger *One of Us: Conjoined Twins and the Future of Normal* (Harvard University Press, Cambridge, 2005).

Rebecca Dresser "Dworkin on Dementia: Elegant Theory, Questionable Policy" in Helga Kuhse and Peter Singer (eds) *Bioethics: An Anthology*, (Blackwell Publishing Ltd, United Kingdom, 2006) 365.

Ronald Dworkin *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (First Vintage Books, New York, 1993).

Ronald Dworkin "Life Past Reason" in Helga Kuhse and Peter Singer (eds) *Bioethics: An Anthology*, (Blackwell Publishing Ltd, United Kingdom, 2006) 357.

Joel Feinberg *Harm to Others* (Oxford University Press, New York, 1984).

Charles Foster *Human Dignity in Bioethics and Law* (Hart Publishing, Oxford, 2011).

Jean Giraudoux *Amphitryon 38* (Grasset, 1967).

Thomas Grisso and Paul S Appelbaum *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals* (Oxford University Press, 1998).

John Harris *The Value of Life* (Routledge, London, 1985).

D Micah Hester *Community as Healing: Pragmatist Ethics in Medical Encounters* (Rowman & Littlefield, Maryland, 2001).

Ian Kennedy *Treat Me Right: Essays in Medical Law and Ethics* (Clarendon Press, Oxford, 1991).

Marian Keyes *The Woman Who Stole My Life* (Michael Joseph, 2014).

Helga Kuhse and Peter Singer *Should the Baby Live? The Problem of Handicapped Infants* (Oxford University Press, Oxford, 1985).

Ursula K Le Guin "The Ones Who Walk Away from Omelas" in *The Wind's Twelve Quarters* (Harper & Row, 1975).

Simon Lee *Uneasy Ethics* (Random House, Kent, 2011).

Janine F McIlwraith and William J Madden *Health Care and the Law* (5th ed, Thomson Reuters (Professional) Australia, Prymont, NSW, 2010).

Sheila McLean *Old law, New Medicine : Medical Ethics and Human Rights* (Pandora Press, London, 1999).

Jose Miola *Medical Ethics and Medical Law* (Hart Publishing, Oxford; Portland, 2007).

Ingo Muller *Hitler's Justice – The Courts of the Third Reich* (Harvard University Press, 1992).

George Orwell *Coming up for Air* (Numitor Comun Publishing, 1996).

Patricia Peppen "Informed Consent" in Jocelyn Downie, Timothy Caulfield and Colleen M Flood (eds) *Canadian Health Law and Policy*, (LexisNexis Canada, Markham, Ontario, 2011).

Peter Singer "Is The Sanctity of Life Ethic Terminally Ill?" in Helga Kuhse and Peter Singer (eds) *Bioethics: An Anthology*, (2nd ed, Blackwell Publishing Ltd, Padstow, Cornwall, 2006).

PDG Skegg and Ron Paterson *Medical Law in New Zealand* (Thomson Brookers, 2006).

Daniel Sperling *Posthumous Interests: Legal and Ethical Perspectives* (Cambridge University Press, Cambridge, 2008).

Michelle Taylor-Sands *Saviour Siblings: A Relational Approach to the Welfare of the Child in Selective Reproduction* (Taylor and Francis, Hoboken, 2013).

Kenneth Veitch *The Jurisdiction of Medical Law* (Ashgate Publishing Limited, Cornwall, 2007).

Ben White, Fiona J McDonald and Lindy Willmott *Health Law in Australia* (Thomson Reuters Australia, 2010).

Journal Articles

Michael A Ashby and Danuta Mendelson "Gardner; re BWV: Victorian Supreme Court makes Landmark Australian Ruling on Tube Feeding" (2004) 181(8) MJA 442.

Mélanie Boly and others "Auditory Processing in Severely Brain Injured Patients: Differences Between the Minimally Conscious State and the Persistent Vegetative State" (2004) 61(2) JAMA 233.

Margaret Brazier and José Miola "Bye-bye Bolam: A Medical Litigation Revolution?" (2000) 8(1) MLR 85.

Cameron Stewart "Legal Constructions of Life and Death in the Common Law" (2002) 2 OUCLJ 67.

Daniel Callahan "Pursuing a Peaceful Death" (1993) 23(4) Hastings Cent Rep 33.

John Coggon "Ignoring the Moral and Intellectual Shape of the Law after Bland: the Unintended Side-effect of a Sorry Compromise" (2007) 27(1) LS 110.

Robert A Crouch and Carl Elliott "Moral Agency and the Family: The Case of Living Related Organ Transplantation" (1999) 8(3) Camb Q Healthc Ethics 275.

Richard M Doerflinger "The Ethics of Funding Embryonic Stem Cell Research: a Catholic Viewpoint" (1999) 9(2) Kennedy Inst Ethics J 137.

Jocelyn Downie and Michael Hadskis "In Defence of Consent and Capacity Boards for End-of-Life Care" (2014) 61(10) Can J Anaesth 899.

Rebecca Dresser "Missing Persons: Legal Perceptions of Incompetent Patients" (1994) 46 Rutgers L Rev 609.

John M Finnis "Bland: Crossing the Rubicon?" (1993) 109 Law Q Rev 329.

Andrew D Firlik "Margo's Logo" (1991) 265(2) JAMA 201.

Miriam S Fleming "A Case Study of Child Abuse and a Parent's Refusal to Withdraw Life-Sustaining Treatment" (1999) 26(2) Human Rights 12.

Charles Foster and José Miola "Who's in Charge? The Relationship Between Medical Law, Medical Ethics, and Medical Morality?" (2015) 23(4) MLR 505.

Ian Freckelton "Withdrawal of Artificial Life Support" (2004) 11 JLM 265.

Ian Freckelton "Withdrawal of Life Support: The "Persistent Vegetative State" Conundrum" (1993) 1 JLM 35.

Colin Gavaghan "Saviour Siblings: No Avoiding the Hard Questions" (2015) 41(12) J Med Ethics 931.

Grant Gillett "Honouring the Donor: in Death and in Life" (2013) 39(3) J Med Ethics 149.

Grant Gillett, Lowell Goddard and Michael Webb "The Case of Mr L: A Legal and Ethical Response to the Court-sanctioned Withdrawal of Life-support" (1995) 3 JLM 49.

Muriel R Gillick "Rethinking the Role of Tube Feeding in Patients with Advanced Dementia" (2000) 342(3) N Engl J Med 206.

Simon Halliday, Adam Formby and Richard Cookson "An Assessment of the Court's Role in the Withdrawal of Clinical Assisted Nutrition and Hydration from Patients in the Permanent Vegetative State" (2015) 23(4) MLR 556.

John Harris "Human Beings, Persons and Conjoined Twins: An Ethical Analysis of the Judgment in Re A" (2001) 9(3) MLR 221.

John Harris "Organ Procurement: Dead Interests, Living Needs" (2003) 29(3) J Med Ethics 130.

John Harris "The Right to Die Lives! There is No Personhood Paradox" (2005) 13 MLR 386.

Mark Henaghan "Can You Feel the Law Tonight? Family Law in Action" (2001-2004) 10 Otago L Rev 289.

Barbara Hewson "Killing off Mary: Was the Court of Appeal Right?" (2001) 9(3) MLR 281.

Norman Howard-Jones "On the Diagnostic Term "Down's Disease"" (1979) 23(01) Med Hist 102.

Jim Howe "The Persistent Vegetative State, Treatment Withdrawal, and the Hillsborough Disaster: Airedale NHS Trust v Bland" (2006) 6(4) Pract Neurol 238.

Bryan Jennett "A Quarter Century of the Vegetative State: An International Perspective" (1997) 12(4) JHTR 1.

John Keown "Courting Euthanasia? Tony Bland and the Law Lords" (1993) 9(3) Ethics Med 34.

John Keown "The Legal Revolution: From Sanctity of Life to Quality of Life and Autonomy" (1997) 14 J Contemp Health Law Policy 253.

John Keown "Restoring Moral and Intellectual Shape to the Law after Bland" (1997) 113(Jul) Law Quarterly Review 482.

Robert G Lee and Derek Morgan "Regulating Risk Society: Stigmata Cases, Scientific Citizenship & Biomedical Diplomacy" (2001) 23 Sydney L Rev 297.

Steven Luper "Posthumous Harm" (2004) 41(1) Am Philos Q 63.

Jenny McEwan "Murder by Design: The 'Feel-Good Factor' and the Criminal Law" (2001) 9(3) MLR 246.

Andrew McGee "Finding a Way Through the Ethical and Legal Maze: Withdrawal of Medical Treatment and Euthanasia" (2005) 13(Autumn) MLR 357.

Gemma McGrath and Noella Kreleger "The Killing of Mary: Have We Crossed the Rubicon?" (2001) 8 JLM 322.

Martin M Monti and others "Willful Modulation of Brain Activity in Disorders of Consciousness" (2010) 362(7) N Engl J Med 579.

James Lindemann Nelson "Taking Families Seriously" (1992) 22(4) Hastings Cent Rep 6.

Nicola Peart and Grant Gillett "Re G: A Life Worth Living?" (1998) 5 JLM 239.

Govind Persad, Alan Wertheimer and Ezekiel J Emanuel "Principles for Allocation of Scarce Medical Interventions" (2009) 373(9661) Lancet 423.

Stewart G Pollock "Life and Death Decisions: who Makes Them and by What Standards" (1988) 41 Rutgers L Rev 505.

Richard A Posner "The Jurisprudence of Skepticism" (1988) Mich L Rev 827.

Barbara Prainsack and Alena Buyx "Solidarity in Contemporary Bioethics – Towards a New Approach" (2012) 26(7) Bioethics 343.

Allison B Seckler and others "Substituted Judgment: How Accurate are Proxy Predictions?" (1991) 115(2) Ann Intern Med 92.

John Seymour "Parens Patriae and Wardship Powers: Their Nature and Origins" (1994) 14(2) OJLS 159.

Tali Sharot "The Optimism Bias" (2011) 21(23) *Curr Biol R* 941.

Jeanne Snelling, Lynley Anderson and Andre Van Rij ""Incidental Findings" During Surgery: A Surgical Dilemma or the Price Paid for Autonomy?" (2013) 13(1) *Otago L Rev* 81.

Piotr Szawarski and Vivek Kakar "Classic Cases Revisited: Anthony Bland and Withdrawal of Artificial Nutrition and Hydration in the UK" (2012) 13(2) *J Intensive Care* 126.

Shih-Ning Then "Evolution and Innovation in Guardianship Laws: Assisted Decision-making" (2013) 35 *Sydney L Rev* 133.

Suzanne Uniacke "Was Mary's Death Murder?" (2001) 9(Autumn) *MLR* 208.

Martin Wilkinson "Individual and Family Decisions about Organ Donation" (2007) 24(1) *J Applied Phil* 26.

Ian Wise "Withdrawal and Withholding of Medical Treatment for Patients Lacking Capacity who are in a Critical Condition – Reflections on the Judgment of the Supreme Court in *Aintree University Hospitals NHS Foundation Trust v James*" (2014) 82 (4) *Med Leg J* 144.

Reports and Conferences

Australian Government National Health and Medical Research Council Post-Coma Unresponsiveness (Vegetative State): A Clinical Framework for Diagnosis (18 December 2003).

Angus Dawson "There's So Much More to Life: Socially-Embedded Concepts as the Foundation for Public Health Ethics" (paper presented to Working with Diversity: Bioethics and Health Law Conference, Wellington, New Zealand, 25-28 June 2015).

Grant Gillett "BITC 404 Ethics and Health Care Lecture on Genetics" Bioethics Centre, Dunedin, 13 October 2004).

Grant Gillett *Personal Communication* (15 August 2013).

Ben Gray "Pacific Forum" (paper presented to Working With Diversity: Bioethics and Health Law Conference, Wellington, New Zealand, 25-28 June 2015).

Mental Capacity Act Code of Practice (2007).

New Zealand Government First New Zealand Report on Implementing the United Nations Convention on the Rights of Persons with Disabilities (March 2011)

New Zealand Medical Association Position Statement: Persistent Vegetative State (August 2004).

President's Council on Bioethics *Taking Care: Ethical Caregiving in our Aging Society* (Executive Office of the President, 2005).

Antal Szerletics *Best Interests Decision-making Under the Mental Capacity Act* (University of Essex: Essex Autonomy Project Green Paper Report, 2011).

United Nations Convention on the Rights of Persons with Disabilities.
Victorian Law Reform Commission *Guardianship: Final Report* (2012).

Greg Young, Alison Douglass and John McMillan "Capacity Assessments: A Burden to Doctors or a Benefit to Patients?" (paper presented to Bioethics Seminar Series, Bioethics Centre, Dunedin, 23 March 2015).

Electronic Sources

AAP General News (Australia) (27 May 2001) <www.highbeam.com/doc/1P1-44789265.html>

Kate Allatt "It was Like Being Buried Alive" (2014) <www.stuff.co.nz/life-style/life/10614408/It-was-like-being-buried-alive>

"Anthropology and Science: Science and Personhood" (15 December 2014) <www.theasa.org/asa03/panels/milton.htm>

Sanchia Berg "High Court Orders Two Sisters Must Receive MMR Vaccine" (11 October 2013) <www.bbc.com/news/health-24493422>

Consent and Capacity Board "Consent and Capacity Board" (2012-15) <www.ccboard.on.ca/scripts/english/index.asp>

James Gallagher and Philippa Roxby "Assisted Dying Bill: MPs Reject 'Right to Die' Law" (11 September 2015) <www.bbc.com/news/health-34208624>

Government of Canada Department of Justice "Where Our Legal System Comes From" (30 April 2013) <www.justice.gc.ca/eng/csj-sjc/just/03.html>

Hillsborough Independent Panel "Disclosed Material and Report" (2012) <<http://hillsborough.independent.gov.uk>>

Internet Movie Database "Philip Seymour Hoffman" (31 July 2015) <www.imdb.com/name/nm0000450/>

Patricia Kane "Lawyer Who Got Meningitis at 36 Now Helps People in Africa to Walk Again" (11 January 2015) <www.dailymail.co.uk/femail/article-2905310/I-lost-feet-hands-really-feel-lucky-ve-thrown-double-six-Lawyer-got-meningitis-36-helps-people-Africa-walk-again.html>

The Law Foundation "International Research Fellowship" (2014)
<www.lawfoundation.org.nz/wp-content/uploads/2014/12/2014-article-about-International-Research-Fellow-Winner-Alison-Douglass.pdf>

Office of the Public Guardian "The General Principles" (2015)
<www.publicguardian.qld.gov.au/__data/assets/pdf_file/0010/269308/OPG-Fact-Sheet_The-General-Principles.pdf>

People's Daily Online "Siamese Twin Dies After Surgery in Australia" (28 May 2001)
<http://en.people.cn/200105/28/eng20010528_71219.html>

Alex Perrottet "Turning Off to Life Support" (2004)
<www.onlineopinion.com.au/view.asp?article=2751>

Priests For Life "Baby Joseph" (2011) <www.priestsforlife.org/babyjoseph/>

Terri Schiavo Life & Hope Network "Terri's Fight" (2015) <www.terrisfight.org/>

Scribd "Robin Williams Trust" (31 July 2015) <www.scribd.com/doc/260402133/Robin-Williams-Trust>

Shoshana Ungerleider "I'm a Doctor. Preparing You for Death is as Much a Part of my Job as Saving Lives" (19 October 2015) <www.vox.com/2015/10/19/9554583/doctor-good-death>

United Nations Convention on the Rights of Persons of Persons with Disabilities
<www.un.org/disabilities/convention/conventionfull.shtml>

Tai Walker "Whānau – Māori and Family – Description of Whānau' (Te Ara – the Encyclopedia of New Zealand)" (2014) <www.TeAra.govt.nz/en/whanau-maori-and-family/page-2>

Frederick Wilmot-Smith "Unjust and Expensive" (15 October 2015)
<www.lrb.co.uk/blog/2015/10/15/frederick-wilmot-smith/unjust-and-expensive/>