THE PERSONAL INTEREST AND DECISION-MAKING ABOUT MEDICAL TREATMENT

Susan Frances Cochrane, March 2006

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Signed:

(Susan Frances Cochrane)
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ABSTRACT

This thesis establishes the pivotal role, in the law about decision-making in the doctor-patient relationship, of an aggregate ‘personal interest’ belonging to patients. I argue that the personal interest, and its significance to decision-making in the doctor-patient relationship, has not previously been identified or understood. I further argue that the patient’s entitlement to decide, or usual substitute decision-maker’s responsibility to decide, is usually the most effective means of protecting the personal interest, but that sometimes the personal interest is better protected by recourse to a harm prevention policy. Furthermore, I propose a test to determine whether, in particular circumstances, the personal interest is likely to be more effectively protected by a robust entitlement or responsibility to decide1 or by recourse to a harm prevention policy.

1 The expression ‘entitlement or responsibility to decide’ refers to the patient’s entitlement to decide or the responsibility of the usual substitute decision-maker, as defined in Chapter 4, to decide about medical treatment.
PART 1 IDENTIFYING AND EXPLAINING THE PERSONAL INTEREST

INTRODUCTION

The governing consideration is the right of every human being to make the decisions which affect his own life and welfare and to determine the risks which he is willing to undertake. The presumption is clearly in favour of disclosure of the information which is relevant to the making of a decision. But a doctor is not required to inflict on his patients information which they do not seek and do not want....It is necessary to keep in mind the paramount consideration that a person is entitled to make his own decisions about his life and a doctor should not lightly make the judgment that the patient does not wish to be fully informed.

(F v R, King CJ)²

When I was 19 years old, I was asked to sign a consent form for the first time. It related to the performance of a laparoscopy, a purely investigative procedure, although you could not have known that from the breadth of the language used in the form. I was apprehensive about signing. What happened, I wanted to know, if they got in, had a look around and decided that major surgery was indicated? On the basis of the form, it seemed that they could go ahead and perform it, without giving me the opportunity to decide whether I wanted the surgery at all, or would prefer to explore any alternatives. To me, it seemed self-evident that I should have the right to decide; after all, I had to live with the outcome. Nevertheless, it was explained that the doctors reserved the right to make just such decisions as those which worried me, and I could take it or leave it. I signed the form, but felt rather resentful, and started to wonder who really did have the right to make decisions in the doctor-patient relationship, and where that right might come from.

Some years later, I enrolled in a course on medico-legal issues. For my assignment topic, I decided to look at Rogers v Whitaker,³ then a very recent decision indeed. In

² F v R (1983) 33 SASR 189, 192-3. The notion of the ‘paramount consideration’ was accepted by the High Court in Rogers v Whitaker (1992) 175 CLR 479, 487 (joint judgment).
³ Rogers v Whitaker (1992) 175 CLR 479.
that case, the High Court accepted the statement above by King CJ.⁴ I decided I wanted to find out more about the ‘paramount consideration’. In particular, I wanted to know how ‘paramount’ it really was, and what kinds of considerations (if any) competed with the entitlement to decide. This thesis sets out the investigations that I undertook to understand this, and the conclusions that I have drawn.

The particular contributions of this thesis are, first, to explain the nature and significance of the patient’s personal interest, and the importance of the entitlement to decide in protecting that interest, to identify a harm prevention policy⁵ as counteracting the entitlement to decide and offering an alternative means of protecting the personal interest and, finally, to propose a test to determine when harm prevention legitimately displaces the patient’s entitlement or the substitute decision-maker’s responsibility to decide, to ensure effective protection of the personal interest.

Within the doctor-patient relationship, decisions must be made about whether or not treatment will be administered. The question is: who should make these decisions? The common law in Australia has answered this by recognising that, normally, patients have a ‘paramount entitlement to decide’ about whether or not to undergo medical treatment. This entitlement will, in most cases, be preferred by the law over other considerations that may suggest that someone else should be the decision-maker. Other common law jurisdictions also recognise that patients with decision-making capacity have entitlements to make treatment decisions.⁶ It is this entitlement which is the trigger for a duty imposed on doctors to ‘warn a patient of a material risk inherent in the proposed treatment’.⁷ This duty is imposed because, without provision of information by the doctor to the patient, the patient will not be in a position to exercise the entitlement to decide to make a ‘meaningful decision’.⁸ Only when a patient has sufficient information about such matters as diagnosis, proposed treatment and its risks and alternatives, can a patient exercise the entitlement to decide in any real, practical sense.

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⁴ Rogers v Whitaker (1992) 175 CLR 479, 487 (joint judgment).
⁵ Explained at section 1.4.
⁶ See, for example, Sidaway v Governors of Bethlem Royal Hospital and Ors [1985] 1 AC 871; Matter of Melideo 390 NYS.2d 523 (1976).
⁷ Rogers v Whitaker (1992) 175 CLR 479, 490.
⁸ See Rogers v Whitaker (1992) 175 CLR 479, 489.
To the extent that there is no, or limited, disclosure, the patient is not in a position to exercise the entitlement, and the decision-making is carried out, in effect, by the doctor, who holds that information. I suggest that this is because to the extent that doctors limit or deny patients or substitute decision-makers access to relevant information about proposed treatment, then they effectively control decision-making in the doctor-patient relationship. I believe that this is inappropriate because a decision made by doctors may be dominated by the doctor’s clinical perspective, whereas the position argued throughout this thesis is that decision-making in the doctor-patient relationship has much broader significance for patients, and only patients are in a position to make decisions reflecting that broader significance of treatment to them.

Outline: Chapters 1 and 2 (explaining the significance of the personal interest and harm prevention to the patient’s entitlement to decide and the doctor’s obligation to disclose)

The law’s claim that there is a ‘paramount entitlement’ – a consideration to be preferred over all other considerations – is a large one. This thesis explores the ambit of this claim, not only in the context of the action for negligent non-disclosure of risks, but in the wider context of the law relating to decision-making in the doctor-patient relationship. This exploration is conducted, first, by investigating the likely basis and purpose of any claimed entitlement to decide, arising out of the nature of the doctor-patient relationship. The purpose of that entitlement is to protect the aggregate of patients’ interests: what I describe as an indivisible ‘personal interest’. By understanding both the basis of the entitlement and the circumstances in which the law has displaced it, I believe that it is possible to acquire a clearer idea of the true ambit of the entitlement, and the extent to which the rhetoric about it is justified. I argue that the basis for displacing the entitlement to decide is a harm prevention policy, and that this is the unifying concept underlying all the examples of displacement of the entitlement to decide considered in this thesis. Harm prevention, not beneficence, is in conflict with the entitlement to decide. Chapter 1 notes the necessity for developing a test for determining which consideration should prevail in particular circumstances. I argue that this test, set out at section 4.3, should be recognised crucial in enabling the law to provide proper protection to the personal interest while accepting the need for harm prevention to prevail in certain instances.
Chapter 1 also acknowledges the moral principles of beneficence and respect for autonomy as having particular relevance to the doctor-patient relationship. This thesis observes that commentary on the doctor-patient relationship has developed on the assumption that disputes about decision-making and disclosure in the doctor-patient relationship must be resolved by finding a balance between these two principles, believed to be in conflict with each other. Chapter 1 argues that, to move forward in describing the proper ambit of any entitlement belonging to patients, it is necessary to recognise that the two principles should exist in a complementary relationship, and not one of conflict, and that they should serve the same objective: to protect patients’ personal interests.

This thesis offers an explanation of the relationship between the two principles that, it is argued, explains what is required of patients, doctors and substitute decision-makers. Chapter 1 further argues that, because of the characteristics of the doctor-patient relationship, and the nature of the interests that the law has regarded as meriting its protection, the principle of respect for autonomy justifies the paramountcy, in most cases, of the entitlement to decide. It is argued that beneficence plays complex and multi-layered roles in protecting patients’ interests, whether or not the patient has decision-making capacity and is thus able to exercise the entitlement to decide.

Chapter 2 explores further the implications of the complementary relationship between the autonomy and beneficence principles, focusing in particular on patients without decision-making capacity. The Chapter considers the significance of the beneficence principle, and describes the current understanding of the purpose and scope of the doctor’s obligation to disclose to substitute decision-makers. Chapter 2 proposes that the purpose and scope of that obligation should be understood in light of arguments advanced in Chapter 1 about patients’ personal interests.

Outline: Chapters 3 to 6 (considerations and values displacing the entitlement to decide)

Chapters 3 to 6 of this thesis identify considerations and values that have, from time to time and in various common law jurisdictions, displaced the entitlement or responsibility to decide so that someone other than the patient or usual substitute decision-maker is the decision-maker. Such considerations and values are identified from case law, legislation, and policy literature (such as government reports) that deal
with decision-making in the doctor-patient relationship. These Chapters explore those considerations and values. Chapters 3 to 5 also discuss how, when the entitlement to decide is displaced, the principle of beneficence should operate.

Chapter 3 describes circumstances that relate only to the patient, and that have displaced the entitlement to decide, either by substituting someone other than the patient as decision-maker, or by significantly limiting the purpose or scope of disclosure to the patient (thus leaving the doctor as the effective decision-maker). These circumstances are lack of decision-making capacity (including in situations of emergency) and perceived therapeutic necessity for the patient to receive treatment.

Chapters 4 and 5 describe values, advanced by the state on behalf of the community that, when applied to the doctor-patient relationship, have also displaced the patient’s entitlement to decide. These include a preservation of life value, and values concerned with the protection of vulnerable persons and the preservation of family relationships. While Chapter 4 describes how such values have displaced the patient’s entitlement for the sake of protecting the patient, Chapter 5 describes how the state applies these values for the sake of protecting third parties.

Chapter 6 explores how the test, proposed by me at section 4.3 (to determine whether the entitlement or responsibility to decide should be displaced in favour of a harm prevention policy), can be applied to the circumstances described in Chapters 4 and 5. It does not offer conclusions about the decisions that ought to have been made in particular cases, but offers an illustration of how the test in section 4.3 can be applied to produce an outcome consistent with the arguments advanced in this thesis about the pivotal nature of the personal interest, and how it is best protected.

Outline: Chapter 7 (Conclusions)

Chapter 7 draws together the arguments advanced throughout the thesis, and sets out the conclusions that can be drawn from those arguments.

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9 See section 3.2.5.
Summary

This thesis argues six principal ideas: first, that protecting the personal interest should be the aim of the law about decision-making in the doctor-patient relationship. Second, the thesis argues that the personal interest is generally best protected by a robust entitlement to decide, belonging to patients, or a robust responsibility to decide, belonging to appropriate substitute decision-makers. Third, the patient's entitlement and the substitute decision-maker's responsibility are explained in moral terms by the principles of respect for autonomy and beneficence, which both require doctors to respect patients' formulations (or those of substitute decision-makers) of personal interests. The principle of beneficence also requires doctors to disclose sufficient information to enable the making of meaningful decisions. Fourth, sometimes compliance with a harm prevention policy offers better protection to the personal interests of patients than does a robust entitlement or responsibility to decide. Fifth, sometimes, the harm prevention policy displaces the entitlement or responsibility to decide in order to protect a competing personal interest of a third party. Finally, this thesis argues that a principled test should be used to determine whether the entitlement or responsibility to decide, or a harm prevention policy, will be the more effective means of protecting personal interests, and proposes such a test in section 4.3.

A note about scope

This thesis focuses on the relationship between patients and doctors. This is not intended in any way to detract from the significance of relationships between patients and other health care providers, or of the legal issues that arise out of interactions between such providers and their patients. The reasons that this thesis focuses on the relationship as between doctor and patient are first, that the law about decision-making and disclosure has developed with doctors as its focus and, second, it was necessary to confine the scope of this thesis within manageable limits. Focusing on one class of health care providers offered a reasonable way of doing this.

A note about use of authorities from various jurisdictions

The focus of this thesis is Australian law. However, considerable attention will be paid to authorities from jurisdictions such as England and the United States of America, not only when they are of persuasive value, but also where such authorities can illustrate, by way of example, a particular argument about how and why the entitlement or
responsibility to decide is displaced. Courts in both the United States and England have taken a similar approach to Australia in relation to decision-making in the doctor-patient relationship, with these jurisdictions recognising that patients should normally be the decision-makers, and recognising similar exceptions to this position. Where there is little or no Australian authority, it is useful to look to England and the United States for an indication of a possible Australian approach.

*Putting the problem into the broader context*

In the course of this thesis, the significance of the patient’s personal interest will be demonstrated, and the scope of the patient’s entitlement to decide clarified. In doing so, a firm foundation is laid for future development of legal principle in this contentious area of the law. This is important because vigorous discussion continues about the nature and scope of the duty to disclose, the fulfilment of which duty is a condition precedent for the patient to exercise any real entitlement to decide. For example, the Ipp Review\(^\text{10}\) in 2002 heard from a range of groups advocating changes to the formulation and implementation of the current common law duty to disclose.\(^\text{11}\) Once there is a clearer understanding of the ambit of the underlying entitlement to decide, and the extent and of nature of the limitations on that entitlement, it is to be expected that consideration of the duty to disclose can proceed on a surer footing.

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CHAPTER 1  THE PERSONAL INTEREST - WHAT IS IT, WHAT THREATENS IT, AND HOW BEST TO PROTECT IT

1.1 INTRODUCTION

The aim of this Chapter is to demonstrate that the patient’s personal interest should be recognised as lying at the core of the law about decision-making in the doctor-patient relationship. This aim will be achieved by considering the nature and significance of the patient’s interests, the harm prevention policy that can be a counterforce to the entitlement to decide and an alternative means of protecting the personal interest, and the significance of the moral principles of respect for autonomy and beneficence in protecting the personal interest. The Chapter argues that the principles of respect for autonomy and beneficence play important roles within the doctor-patient relationship because of particular purposes of, and imbalances within, that relationship, and that these principles operate in tandem to protect patients’ interests. It is further argued, however, that (contrary to popular wisdom) the principles are in a relationship of complementarity rather than conflict in protecting those interests.

By establishing the basis for the patient’s entitlement to decide, Chapter 1 clears the way for consideration, in Chapters 3 to 6 of this thesis, of circumstances in which that entitlement is displaced, so that someone other than the patient (or usual substitute decision-maker) becomes the decision-maker. In clearly describing these circumstances, and the unifying idea of harm prevention that explains them, the ambit of the entitlement or responsibility to decide, as the usual means of protecting the personal interest, becomes more precisely defined.

Section 1.2 makes preliminary observations about the purpose of the doctor-patient relationship, before consideration of the personal interest in section 1.3. This section takes up the bulk of the Chapter, reflecting what I argue is the pivotal importance of the personal interest to defining rights and obligations in the doctor-patient relationship. Section 1.4 explains how the personal interest should be protected by the law.

For example, Devereux, while conceding that the autonomy and beneficence principles can co-exist, appears to see their relationship as being one of conflict, so that they are ‘countervailing’ principles: see Devereux in Freckelton and Petersen, 1999, 77.
Section 1.5 considers the principles of respect for autonomy and beneficence that have traditionally been considered to define rights and obligations in the doctor-patient relationship. Section 1.6 concludes the Chapter.

1.2 THE DOCTOR-PATIENT RELATIONSHIP

I am of the view that the doctor-patient relationship has two purposes: to give care and to restore or achieve independence. These purposes will be explained later in this section. I further suggest that the principles of beneficence and respect for autonomy are significant because of how they relate to those purposes. That is, at its simplest, the doctor-patient relationship requires one party to the relationship to care for another party, who needs that care to be given. This is the purpose of care, which is explained in moral terms by the principle of beneficence. The kind of care needed frequently entails intimate physical and psychological contact with the person to whom that care is given. That contact should be understood by the law as affecting all dimensions of a patient’s being, not just physical health and well-being, and may affect a patient’s most personal values and priorities. This idea – that medical treatment has an impact on patients that goes beyond their clinical welfare – will be considered extensively throughout this thesis.

Because of this potential impact on their lives, patients who have the capacity to do so should therefore be allowed to define and express their needs, values and priorities for themselves. In addition, I suggest that it is a principal, and generally assumed, aim of medical treatment to preserve or restore, as far as possible, the patient’s ability to function autonomously. These considerations constitute what I describe as the purpose of independence, which is explained by the principle of respect for autonomy.

13 For consideration of the significance of these principles to the doctor-patient relationship, see, for example, Appelbaum, Lidz and Meisel, 1987; Ashley and O’Rourke, 1997; Downie and Calman, 1994; Ronald Dworkin, 1993; Fulford, Gillett and Soskice, 1994; Gillon, 1985, 1986; Hare, 1993; Katz, 1984; McLean, 1989; Pellegrino and Thomasma, 1988; Singer, 1994.

14 This Chapter assumes that the patient has decision-making capacity. Chapter 2 considers rules for patients without decision-making capacity.
1.3 THE PERSONAL INTEREST: ITS NATURE AND THREATS TO IT

1.3.1 The personal interest and ‘meaningful decision-making’

(a) What is a ‘meaningful’ decision?

Many common law courts, and legislators, have taken the view that autonomy, in the doctor-patient relationship, is expressed through an entitlement to make a meaningful decision. A decision must be meaningful to fulfil the doctor’s duty of care. It is necessary to give content to the notion of a ‘meaningful decision’, to better understand the nature of the entitlement to decide, and its purpose. The idea of a ‘meaningful’ decision is interpreted by this thesis as being based on an understanding, by the patient, of the likely impact of undergoing (or not undergoing) medical treatment on the aggregate of his or her interests, rather than simply on an understanding of the likely impact of the treatment on his or her clinical welfare. The following subparagraphs describe interests that have been identified, by Australian law, as belonging to patients and as meriting protection through the mechanism of requiring consent to medical treatment. They are: the interest in bodily integrity, the interest in health and well-being and the dignity interest. This discussion then argues that those interests, rather than being treated as disparate, functionally discrete interests that may exist in conflict with each other, should be understood as constituting what I describe in this thesis as an aggregate and indivisible ‘personal interest’ belonging to the patient which, in turn, should be understood as the proper subject matter of the principle of beneficence.

(i) The interest in bodily integrity

Even for individuals occupying the role of ‘patient’, and even when they are not recognised as having decision-making capacity, Australian common law recognises an interest in the physical state of one’s embodied self. This interest will be referred to as the ‘interest in bodily integrity’. This interest was the basis for the action for trespass

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15 Rogers v Whitaker (1992) 175 CLR 479, 490.
16 The significance of the consent requirement is considered in more detail in section 1.3.3.
17 In Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, several different terms are apparently used to describe this interest: right to bodily integrity (joint judgment, 223, 254; McHugh J, 311), principle of bodily inviolability (joint judgment, 223, 235, 249), principle of personal inviolability (joint judgment, 224), right to personal inviolability
against the person (or battery), actionable without proof of damage in both civil and criminal law. The legal rule is that, subject to the exigencies of daily life, a person is protected from unwanted physical contact by others. This is because a person has a right to decide what will be done to his or her body. Individuals may therefore seek a legal remedy if medical treatment that involves physical contact is inflicted upon them without their consent.

Its emphasis on control over one’s physical self means that the interest of bodily integrity is justified by the principle of respect for autonomy. It can sometimes be perceived by courts as being in conflict with the patient’s interest in health and well-being. This is because an interpretation of the interest in health and well-being that relies on values relating to the technical expertise of doctors does not accommodate the possibility of another value, protected by the interest in bodily integrity (such as a religious prohibition against receiving blood products), which overrides biological survival. It is biological survival which is the focus of a clinically-defined interest in health and well-being. It should be noted at this point that, in referring to a ‘clinical definition’ of patients’ welfare, I am referring to a practice of defining patients’ welfare solely or predominantly by reference to those factors or indicators that fall within the special technical expertise of the doctor. Similarly, when I refer to ‘clinical values’, I

(joint judgment, 253, 254), right to bodily and personal integrity (joint judgment, 254), the law’s protection of physical integrity (Brennan J, 265), the law’s protection of physical integrity required to protect a person’s unique dignity (Brennan J, 266, 267), personal integrity (Brennan J, 267, 273, 274, 284), physical integrity (Brennan J, 267, 274, 277), right to physical integrity (Brennan J, 268), human integrity (Deane J, 303), autonomy with respect to one’s body (McHugh J, 309), right to control and self-determination in respect of one’s body (McHugh J, 309).

18 Wilson v Pringle [1987] 1 QB 237, 249 (Croom-Johnson LJ). For descriptions of the history of the interest in bodily integrity, see Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, referring to Blackstone’s Commentaries, 1830: 233 (joint judgment), 266 (Brennan J), 310, 312 (McHugh J). See also Slater v Baker & Stapleton (1767) 95 ER 860.

19 Collins v Wilcock [1984] 1 WLR 1172, 1177; approved in Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 233 (joint judgment), 265 (Brennan J), 310-11 (McHugh J). Such exigencies may include the need for emergency medical treatment: Wilson v Pringle [1987] 1 QB 237, 252 (Croom-Johnson LJ).

20 See, for example, Schloendorff v Society of New York Hospital 105 NE 92 (1914), 92, approved in Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 234 (joint judgment), 310 (McHugh J). See also Canterbury v Spence 464 F.2d 772 (1972), 780. For an example of an ‘aberrant’ extension of battery: Mink et al v University of Chicago et al 460 F.Supp. 713 (1978) (nonconsensual administration of a drug); Shultz, 1985, 219, 231 (note 45).

21 Discussed at subparagraph (ii). See also Fv R (1983) 33 SASR 189 (King CJ); Natanson v Kline 350 P.2d 1093 (1960).
mean values drawn from the exercise of technical expertise of the doctor. I argue that patients, on the other hand, are likely to have a more holistic view of what constitutes their welfare, and it is this understanding that they bring to bear in making decisions about treatment.

Although a resolution of a particular dispute may ultimately favour a value other than biological survival, there is nevertheless a perception that the resolution has been reached in the context of a conflict between the interests. Thus, if a patient’s decision is not consistent with his or her clinical well-being, then an inference may be drawn that the patient’s interests are in conflict with each other, rather than that the patient has prioritised his or her interests in a way that gives greater weight to an interest other than the clinical interest, or that the patient’s understanding of health and well-being differs from that which is conventionally accepted by doctors and courts.

In Australian law, consent is a defence to an action in battery and, in the context of medical treatment, is established if the patient knew in broad terms of the nature of the proposed treatment, and agreed to the invasion of his or her bodily integrity. Modern Anglo-Australian courts have consistently held that actions for failure by a doctor to give a patient information and advice about anything more sophisticated than the broad nature of the treatment should be brought in negligence, not battery. Thus, failure to give risk information is not actionable in battery, even though the risk pattern of a particular treatment might, if not (I suggest) for judicial desire to limit doctors’ liability for nondisclosure of risk, be characterised as part of the ‘nature’ of the treatment. The interest in bodily integrity is, as a consequence, explicitly recognised only in a limited range of cases, such as those relating to the sterilisation of disabled minors and to the

22 For further exploration of this point, see Chapter 3 (‘Therapeutic necessity’).
23 McLean, 1989, draws the distinction between ‘technical’ values and outcomes and what she describes as ‘human’ or sometimes ‘moral’ values and outcomes (for example, at 163). For practical purposes, the distinction is the same. However, I prefer to use the term ‘clinical’ to attempt to emphasise that, even beyond strictly ‘technical’ considerations, doctors may also be influenced by values that belong to their own professional culture and that may not be shared by patients.
24 Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 310-11 (McHugh J).
25 Rogers v Whitaker (1992) 175 CLR 479, 490. See also, for example, Reibl v Hughes (1980) 114 DLR (3d) 1, 8-11. The cause of action is for failure to give information, rather than for administering treatment.

Chapter 1
refusal of medical treatment. However, despite declining to regard knowledge of risk as relevant to understanding the nature of medical treatment, Australian courts have recognised that information extending beyond the broad nature of the proposed treatment is necessary to make a meaningful decision about it.

(ii) The interest in health and well-being

The protection and promotion of patients’ health and well-being is frequently appealed to as justification for conduct in the doctor-patient relationship. In particular, a patient’s interest in health and well-being is identified as the objective of conduct conventionally characterised as ‘beneficent’. In this thesis, a patient’s interests are taken to extend beyond the patient’s strictly clinical welfare, to the patient’s spiritual, emotional, intellectual and social well-being (‘extra-physical’ dimensions of the patient’s interests). Accordingly, ‘healing’ can be a sensible aspiration for chronically and terminally ill patients. Whether or not a definition is consciously formed or expressed, competent (and some incompetent) patients have ideas about what ‘well-being’ means to them. However, to understand the way in which Australian law about therapeutic decision-making has developed, it is important to recognise assumptions, made by judges and commentators, about the nature of the interest in health and well-being.


29 There are several definitions of ‘health and well-being’, including the extremely broad definition offered in the Constitution of the World Health Organization, 1946. For discussion of terms such as ‘illness’ and ‘health’, their evaluative nature and socio-political implications, see Ashley and O’Rourke, 1997, Chapter 2; Kennedy, 1983, Chapter 1; Saks, 2002, Chapter 2.

30 Pellegrino and Thomasma, 1988, vii, 67-8, 75. See also Appelbaum, Lidz and Meisel, 1987, 29; McLean, 1989, 7.

31 See, for example, Katz, 1984, 98, 215; McLean, 1989, 5. For the purposes of this thesis, ‘illness’ includes injury.

32 Pellegrino and Thomasma, 1988, 10, 35, 62-6, Chapter 5.

33 In this thesis, ‘competent’ means having decision-making capacity (see Saks, 2002, Chapter 1, note 3, for a similar approach). This thesis will generally refer to possession, or lack of possession, of decision-making capacity rather than using terms such as ‘competent’ and ‘incompetent’ because I consider these to be somewhat pejorative. See also Gunn et al, 1999, 269, which notes that, in the United Kingdom, no distinction is drawn between having decision-making capacity and being competent, unlike in the United States.
First, for the purpose of expressing legal rules to protect the interest, judges have tended to construe the interest in health and well-being narrowly, focusing on a patient’s clinical welfare to the exclusion of the other aspects of the patient’s welfare. Second, it has been assumed by the courts that, because the content of the interest is exclusively clinical, then it can be defined by doctors, on behalf of their patients, within the exercise of their technical expertise (for example, in the recognition of the therapeutic privilege). Third, it is assumed that this interest, defined by one party to the relationship on behalf of the other, constitutes the entirety of patients’ ‘best interests’ to be protected by doctors seeking to act beneficently towards their patients (for example, by application of the ‘flak jacket’ test, described in Chapter 2). Fourth, in each example mentioned in this paragraph, I suggest that it is assumed that the obligations imposed by beneficence can adequately be discharged by protecting and advancing the patient’s clinical welfare.

The most important implication of these assumptions is the contribution they make to the perception of conflict existing between, on the one hand, the interest in health and well-being that is conventionally understood by courts to be protected by beneficence, and, on the other hand, the interest in bodily integrity and the dignity interest, discussed below, which are conventionally understood by judges and commentators to be protected by the autonomy principle. This can be demonstrated by considering alternative interpretations of the interest in health and well-being. An exclusively clinical definition of the interest in health and well-being purports to permit a doctor to define the content of the interest on a patient’s behalf, because of his or her technical expertise. Conflict may be seen to arise if a doctor seeks to act beneficently to protect a patient’s health and well-being but, in defining health and well-being, relies on criteria and priorities that are not shared by the patient, or that are not exhaustive of criteria and priorities that are valued by the patient.

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35 The therapeutic privilege is examined in detail at section 3.5.2.

36 See McLean, 1989, 26; see also Chapter 2 of this thesis for a discussion of the current understanding of ‘best interests’.

37 See paragraph 2.3.2 (c) (ii).
If a broad interpretation of the patient’s interests is accepted, then circumstances other than clinical criteria become relevant to the content of a patient’s health and well-being interest. These circumstances include extra-clinical matters which, this thesis argues, patients are better placed than their doctors to identify and prioritise, because only the patient can take proper account of both the clinical and extra-clinical aspects of his or her interests. Acceptance of a broad interpretation of the patient’s interest would have significant implications for the understanding of what constitutes beneficent conduct. It would be directed at a broader spectrum of matters comprising the ‘good’ of the patient. Most importantly, beneficent conduct would require willingness to defer to each patient’s interpretation of his or her health and well-being. If this were to occur, and a broad interpretation of beneficence were applied, the perceived conflict between beneficence and respect for autonomy would disappear, because beneficence would be understood as complementing respect for autonomy, rather than as an alternative to it. This is because, if beneficence were directed at the patient’s interests – as understood by the patient – beneficence would effectively be responding to and supporting the patient’s own (autonomous) understanding and assertion of his or her values and priorities. It is reasonable to expect that such an interpretation of beneficence would, in turn, influence rules about the scope of, and exceptions to, the obligation to disclose. Accordingly, it is helpful to explain in greater detail why the content of the interest in health and well-being should be defined by the patient.

The patient

The patient is uniquely placed to determine his or her interests in general and, in particular, what health and well-being means to him or her, and whether his or her health and well-being is compromised by particular circumstances. I suggest that this is because ‘health and well-being’, and its impairment, are not purely objective concepts to be given meaning in isolation. They are evaluative concepts that exist in the social context in which each patient functions. This is illustrated by debates over whether states such as homosexuality, chronic fatigue syndrome, occupational overuse syndrome and social infertility are illnesses requiring or meriting medical resources and

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38 As acknowledged by, for example, McLean, 1989, 79.
39 For consideration of when substitute decision-making (rather than decision-making by the patient) is warranted, see Chapter 3.
treatment. Similarly, a decision to undertake proposed treatment is not a decision isolated from other dimensions of the patient’s life. By definition, patients are uniquely placed to determine what measures they are prepared to take to protect their conceptions of health and well-being. This is because, as explained in the discussion of imbalance of effect, it is patients who must undertake, or be the subject of, health care measures, and who must assume the enduring benefit or burden of consequences of health care. Because of this aspect of the doctor-patient relationship (referred to in this thesis as the imbalance of effect), it is for the patient to weigh the anticipated clinical and extraclinical value of proposed care against its potential costs.

The doctor

It may nevertheless sometimes seem that doctors, not patients, are better placed to determine what constitutes a patient’s health and well-being, and whether anticipated benefits of health care outweigh foreseeable, unwanted effects. This is because doctors can be regarded by the law as possessing technical knowledge required to assess states of health and illness, sufficient knowledge of individual patients, and a degree of detachment or objectivity that may be considered necessary for sound decision-making. I believe that this view rests on three assumptions. The first assumption is that health and well-being is a purely clinical state that can be judged solely by those criteria in relation to which doctors can claim to be expert and, also, that clinically-defined good outcomes are more valuable, to all patients in all circumstances, than other kinds of outcome. This assumption is overturned by recognising, as argued above, that health and well-being cannot be understood in isolation from the surrounding circumstances of the patient’s life. On this basis, exclusively clinical criteria provide an inadequate foundation on which to make a determination about an individual’s health and well-being.


41 For judicial recognition of this point, see Rosenberg v Percival (2001) 205 CLR 434, 482, [149] (Kirby J).

42 See paragraph 1.3.2 (b).

43 A doctor who reasonably relies on an exclusively clinical perspective of a patient’s health and well-being is often treated sympathetically by Australian courts: Skene, 1998, 4, 6.
The second assumption is that, even if other kinds of criteria are relevant, a doctor is in a position to identify, weigh and apply them. This assumption is problematic, because it is unrealistic to expect a doctor to be so well-acquainted with each patient to make this possible, particularly in the increasingly prevalent environment of high population mobility and the diminishing presence of the family doctor who sees patients from 'cradle to grave'. The practical consequence of this assumption is that a person's interests and needs, 'in patienthood', are treated as being exhaustive of his or her interests and needs 'beyond patienthood'. This may be valid for a patient who is in an acute, emergency situation. In the absence of contrary information,\(^\text{44}\) it is reasonable to assume that a patient's immediate and strongest interest is in biological survival. For most encounters between doctors and patients, however, this is an over-simplification.

The final assumption is that doctors' opinions and advice will be based on detached and objective considerations, unaffected by personal interests, or by matters extrinsic to the individual patient. This assumption can be challenged because doctors do make decisions about the diagnosis and treatment of their patients relying on information other than purely clinical data and objective criteria.\(^\text{45}\) Such decisions are not necessarily flawed, but it is unreasonable, and unfair to patients and doctors, to expect doctors to act invariably from a position of absolute and detached objectivity.

*The community*

I acknowledge that the community also has an interest in how its members define their interests in health and well-being.\(^\text{46}\) The interest arises from functions such as protection of the welfare of its present and future members, allocation of resources, and ensuring the survival and growth of the community by having healthy citizens who can work for the common good. However, respect for autonomy, if accepted by a community as being relevant to the development of social and political institutions (including legal

\(^{44}\) Such as a card identifying the patient as a Jehovah's Witness who refuses blood products. See, for example, *Malette v Shulman* 67 DLR (4th) 321 (1990).

\(^{45}\) For supporting argument, see Charlesworth, 1993, 134; Katz, 1984, Chapter VII; Kennedy, 1983, Chapter 4; Pellegrino and Thomasma, 1988, 100.

\(^{46}\) See Pellegrino and Thomasma, 1988, 63-4, 72.
rules), should generally preclude the community from dictating its conceptions of health and well-being to individual citizens.47

(iii) The dignity interest

The common law and associated commentary refer to another interest, belonging to patients, in conjunction with the interest in bodily integrity. The recognition of this interest – the dignity interest – suggests acceptance of the proposition that the law should also protect those interests that describe abstract dimensions of identity, personality and self-esteem.48 These are intellectual and spiritual dimensions that individuals and societies have valued throughout history and across cultures. The interest that is believed to protect these dimensions will be referred to as the ‘dignity interest’. As the interest in bodily integrity may be understood to recognise that human beings are embodied beings, the dignity interest recognises that human beings are also ‘ensouled’ bodies. The dignity interest seems to belong to all patients, without regard for whether the patient is, has been or ever will be, recognisable by moral philosophers as a person49 or by judges as having decision-making capacity.50 The dignity interest attaches to human existence, simply by virtue of its humanity.51 Alternatively, it can perhaps been seen as attaching to all patients because recognising such an interest in relation to even the most vulnerable members of the human population maximises the likelihood of its recognition for all members.

By recognising the existence and significance of the dignity interest in the doctor-patient relationship, courts have accepted that what is done to one’s body, by

47 Pellegrino and Thomasma, 1988, 71-2. See Chapters 4 and 5 for discussion of circumstances in which the state substitutes its own version of the patient’s good to intervene in decision-making in the doctor-patient relationship.

48 Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 252, 254 (joint judgment), 266, 267, 273-7 (Brennan J), 303 (Deane J) and 310 (McHugh J). See also Katz, 1984, 87; Pellegrino and Thomasma, 1988, 20, 49, 50 and Chapter 2; Shultz, 1985, 219, 278.

49 For philosophical conceptions of personhood, see Gerald Dworkin, 1988, 31, 80; Ronald Dworkin, 1993; Hare, 1993, Chapters 5, 6 and 10; Klemme and Kuehn, 1999 (in particular, the following essays: Hill, 1980, Andrews Reath, 1989, Siep, 1984); Singer, 1993, Chapter 3 and 110-17; Singer, 1994, 159-83. See also Principle 1 of the Principles of Medical Ethics, published by the American Medical Association in 1980 and set out at Appendix B of Katz, 1984.

50 See, for example, Gillick v West Norfolk AHA [1986] 1 AC 112; Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 266, 276 (Brennan J); Airedale NHS Trust v Bland [1993] AC 789.
oneself or by others, affects one’s extra-physical dimensions.\textsuperscript{52} By necessary implication, courts have also accepted that, as society recognises and protects an individual’s interest in directing what is done to his or her body, society must also recognise and protect an individual’s interest in controlling actions that affect other dimensions of his or her being. Because the dignity interest is an interest that supports a patient’s control over his or her life by allowing a patient to define and interpret what is important in it, it too is perceived to be in a state of conflict with the interest in health and well-being when that interest is defined from a predominantly clinical perspective.

A significant Australian example of appeal to the dignity interest is found in \textit{Re Marion},\textsuperscript{53} in which the High Court was asked to identify who was the proper decision-maker when parents sought the non-therapeutic sterilisation of a disabled minor. The Court rejected clinical or economic considerations as determinative,\textsuperscript{54} and the judges appealed to more abstract concepts, including Marion’s claim to consideration as a human being.\textsuperscript{55} In particular, the judges were concerned that Marion should not, without strict safeguards, be touched in a particular way (that is, by sterilising her for non-therapeutic purposes). This was primarily because the Court accepted that the proposed ‘touching’, while intended to benefit Marion, would profoundly affect her sense of self-worth.\textsuperscript{56} Each judgment in \textit{Re Marion}\textsuperscript{57} suggests that the abstract extra-physical dimensions of individuals are inherently significant and, like bodily integrity, merit protection by the law. Explicit appeals to patients’ extra-physical

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\textsuperscript{51} See Gerald Dworkin, 1988, 31, 110; McLean, 1989, 21; Pellegrino and Thomasma, 1988, 43.

\textsuperscript{52} Department of Health and Community Services (NT) \textit{v} JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 251-3 (joint judgment), 268 (Brennan J), 296, 303, 304 (Deane J). See also Appelbaum, Lidz and Meisel, 1987, 123; Gerald Dworkin, 1988, 95, 113; Pellegrino and Thomasma, 1988, 50.

\textsuperscript{53} Department of Health and Community Services (NT) \textit{v} JWB and SMB (‘Re Marion’) (1992) 175 CLR 218.

\textsuperscript{54} For example, Department of Health and Community Services (NT) \textit{v} JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 272, 275 (Brennan J).

\textsuperscript{55} For example, Department of Health and Community Services (NT) \textit{v} JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 232, 246, 249, 251, 252 (joint judgment), 266, 276 (Brennan J), 296, 303 (Deane J) and 320-1 (McHugh J).

\textsuperscript{56} Department of Health and Community Services (NT) \textit{v} JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 252 (and references cited therein) (joint judgment), 320 (McHugh J). See also McLean, 1989, 22.

\textsuperscript{57} Department of Health and Community Services (NT) \textit{v} JWB and SMB (‘Re Marion’) (1992) 175 CLR 218.
dimensions commonly occur in cases, such as Marion, concerning sterilisation, and in cases about the proposed cessation of treatment of certain patients. These cases raise dramatic ethical and emotional issues about extra-physical dimensions. However, I suggest that even the most mundane therapeutic interaction involves such issues, because the imbalances of effect and authority are present in every doctor-patient relationship, although common practice is to leave them unstated. The failure explicitly and consistently to recognise the involvement of extra-physical dimensions in all therapeutic encounters has, I believe, led to them being equated with, or subsumed by, the patient’s clinical welfare, or perhaps to an assumption that protection of clinical welfare is sufficient protection of all dimensions of the patient’s welfare.

(b) The patient’s aggregate personal interest

The preceding discussion shows that Australian courts have recognised certain kinds of interests as belonging to patients. These have been described using several terms without explanation of what meanings are intended, or of whether and how they are thought to relate to each other. In consequence, otherwise powerful words are reduced to rhetoric, and are unable to do their ‘real work’ of protecting interests that are important to individuals and the community. I propose that, in the context of decision-making in the doctor-patient relationship, notions described as the ‘interest in bodily integrity’, ‘interest in health and well-being’, and the ‘dignity interest’, be replaced with an indivisible aggregate interest; that is, the patient’s personal interest.


56 Described at section 1.3.2.

61 For example, in Smith v Auckland Hospital Board [1964] NZLR 241, 247, Woodhouse J dismissed the relevance of the dignity interest to negligence actions. See also Skene, 1998, 9. For discussion of this tendency to downplay the significance of the dignity interest in relation to clinical well-being, see Katz, 1984, 28, Chapter III; Pellegrino and Thomasma, 1988, 23, 78; Shultz, 1985, in particular, 219, 232.

The content of this interest should be defined by the patient. This is because the interest is so personal and subjective that there are practical difficulties with it being defined by a third party; also, from a theoretical perspective, if one does not have control over such intimate matters, the concept of autonomy really is, in my view, deprived of any meaning. This model is consistent with Gerald Dworkin’s advocacy of a weak, formal and contentless notion of autonomy, which is necessary because ‘people can give meaning to their lives in all kinds of ways’, and because consensus about a conception of autonomy is unlikely. An indivisible aggregate interest also unifies a patient’s interests, recognising the interconnectedness of the patient’s physical and extra-physical dimensions.

To understand the nature of the single interest, it is useful to be able to describe the dimensions separately. However, it should be understood that no single dimension of the personal interest is affected without potentially affecting the other dimensions (for example, a nonconsensual infringement of the interest in bodily integrity can adversely affect self-esteem). It is artificial, I suggest, to perceive the patient’s various interests as existing independently, and in conflict with each other. It should also be understood that because the personal interest, as I define it, embraces the interest in bodily integrity, the health and well-being interest and the dignity interest, the fact that it is defined by individual patients means that it is potentially far broader than the patient’s ‘best interests’, as conventionally understood.

To assert, in effect, that the patient’s body and clinical well-being are ‘in conflict with’ the patient’s mind or soul is to engage in pointless dualism. A useful metaphor to illustrate the relationship between the dimensions, and between the dimensions and the whole, is the essential bodily organs. Without the existence of a body, the essential organs cannot function (and do not have a function) and, if one essential organ is missing, the whole body is impaired. Recognition of an aggregate interest, embracing

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64 See also Singer, 1993, 85-7, 126, 182, 192; Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 252 (joint judgment), quoting from In re Grady 426 A.2d 546 (1981), 471-2.
65 See section 2.3.2.
66 For discussion of the history and implications of this kind of dualism, see Ashley and O’Rourke, 1997, Chapter 2; in particular, 31-34.
all of the patient’s physical and extra-physical dimensions, would (I argue) better reflect
the interconnected, interdependent reality of patients’ interests. Such recognition would
help in clarifying the true relationship between the principles of beneficence and respect
for autonomy. As discussed, if the interest in health and well-being were defined by a
patient, then what constitutes beneficent conduct by the doctor should rely on and
respond to the patient’s interpretation of his or her personal interest, and the doctor’s
beneficence would thus complement the patient’s exercise of autonomy by requiring the
doctor to respect that interpretation.

1.3.2 Threats to the personal interest: medicalisation of decision-making and the
imbalances of effect and authority

The need for some means of protection for the patient’s personal interest is
demonstrated by noting the phenomenon of medicalisation, which is well-documented
in other sources, and describing the two imbalances that are characteristic of the
doctor-patient relationship – the imbalances of effect and authority.

(a) The aggregate personal interest and the need to avoid medicalisation of
decision-making in the doctor-patient relationship

It has been assumed that a patient and a doctor will share the same interests and the
same objectives. In many (if not most) cases, this may be true. However, patients
and doctors may have divergent interpretations of interests, and of the respective
importance of particular interests. The point of divergence seems generally to lie in the
greater weight given by doctors and courts to clinical values (a phenomenon described
in this thesis as the ‘medicalisation’ of decision-making), in preference to other kinds
of values that may be of importance to patients. An important implication of this
divergence is that legal rules about therapeutic decision-making must explicitly
acknowledge and protect the patient’s aggregate interest, to recognise that treatment has
implications extending beyond the clinical dimension. Because of this, patients should

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67 See, for example, McLean, 1999.
68 See Appelbaum, Lidz and Meisel, 1987, 219; Katz, 1984, xviii, 6, 64, 98, 100.
69 Faden and Beauchamp, however, make the point that the fact that objectives do diverge between doctor
and patient is a key reason for the existence of the consent requirement: see Faden and Beauchamp, 1986,
135.
70 Medicalisation of decision-making is a principal theme of, and is explored in greater detail by, McLean,
1999.
be allowed to consider these implications in making their meaningful decisions. This is particularly important because patients bear the preponderance of the peculiarly intimate and enduring effects of health care, and should (in my view) therefore control health care decisions, in most cases. This is the imbalance of effect, which medicalisation of decision-making tends to fail to appreciate, to the detriment of patients’ personal interests.

It is important to recognise medicalisation when it occurs, and to define carefully the range of circumstances in which there is no alternative but to give pre-eminence to clinical values. There are dangers in failing to do so. First, efforts should be made to understand and make clear what is going on in decision-making in the doctor-patient relationship. That is, the patient may be making a decision that will affect various aspects of his or her life (for example, the ability to engage in a particular trade or occupation), and is doing so by bringing to bear (whether consciously or not) values and considerations beyond those that are strictly clinical. If there is no clear understanding that this is occurring, it is impossible to develop sound, universalisable rules that mitigate the imbalances and further the purposes that characterise the doctor-patient relationship. Second, if there is no clear definition of when medicalisation is, and is not, appropriate, then medicalisation of decision-making will occur in cases in which it is not necessary. This was recognised by the High Court in Re Marion. When medicalisation occurs, clinical values assume disproportionate importance in relation to other values that are important to patients when engaging in therapeutic decision-making. Medicalisation of decision-making effectively displaces the patient’s entitlement to decide. This is because, by recognising only, or predominantly, clinical

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71 Subject to the test in section 4.3.

72 Such as an emergency in the absence of any reliable indication of the patient’s wishes; for example, an advance health care directive.

73 As understood by, for example, Lord Scarman in Sidaway v Governors of Bethlem Royal Hospital and Ors [1985] 1 AC 871, 885-6. See also Faden and Beauchamp, 1986, 137.

74 See sections 1.3.2 and 1.3.3.

75 As, for example, in an emergency when there is no indication of a patient’s wishes, and therefore clinical considerations are the only reference point available to the doctor in discharging his or her obligations.

76 Secretary, Department of Health and Community Service (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 251 (joint judgment).

77 McLean suggests that medicalisation threatens human rights: see McLean, 1999, 16.
values, and allowing them to define the disclosure obligation, the doctor has effective control of the decision-making process. Patients should be permitted to pursue non-clinical values that reflect all dimensions of their personal interests. The final danger of failing to recognise and define an appropriate scope for medicalised decision-making is the possibility that, instead of applying even clinical values, the doctor may (consciously or otherwise) apply his or her personal values. This may have occurred in the case of Ms B, whose refusal of life-sustaining treatment, even when she was accepted to have decision-making capacity, was strenuously resisted by hospital staff and administrators.\textsuperscript{78}

In summary, if medicalisation is not recognised, and confined to strictly defined circumstances,\textsuperscript{79} it creates the risk that the principles of beneficence and respect for autonomy, with their necessary connection to the personal interests of patients, will be complied with only when they coincide with clinical values. This undermines the purpose of achieving or restoring independence and, although generally altruistic in intention, also undermines the purpose of care which should be focused on the protection and support of patients’ personal interests.

Thus, the law should also recognise that the doctor-patient relationship always involves extra-clinical dimensions. When the law fails to recognise this, and to take it into account when formulating norms about decision-making and disclosure in the doctor-patient relationship, then medicalisation of decision-making occurs, in which a doctor effectively becomes the decision-maker and the patient’s entitlement to decide is displaced by default.

Because the clinical dimension of human existence does not embrace its whole nature, because medical treatment has implications extending beyond clinical welfare, and because of the imbalance of effect, it is in my view necessary to define the interest in health and well-being from the perspective of each patient. The principle of beneficence should be interpreted in a way that obliges doctors who aspire to act beneficently to respect patients’ meaningful decisions about what constitutes their health and well-being, while recognising that doctors who do so protect themselves from liability.

\textsuperscript{78} Ms B v An NHS Hospital Trust [2002] 2 All ER 449.

\textsuperscript{79} Such as emergencies, which are described in section 3.2.5.
(b) **Imbalance of effect**

The imbalance of effect can be described succinctly. The expression ‘imbalance of effect’ is a shorthand way of saying that, irrespective of the doctor’s skill and conscientiousness, it will always be the patient who bears the consequences, good or ill, of any decision made about medical treatment. For example, if a patient is ignorant of possible adverse effects of a proposed treatment, then he or she is also ignorant of the nature and extent of the imbalance of effect. This is because the patient does not know enough about the treatment to properly determine whether the risk profile is something he or she is willing to accept in light of his or her personal interest.

Health care decisions should be acknowledged by the law as being more intensely personal to each patient than are many other kinds of decision. This is because they are about ‘preserving and repairing’ our most individual physical ‘possession’: our bodies. The patient must ‘wear’ his or her body, bearing its benefits and its burdens. Whatever is done to, or becomes of, one’s body is inherently and inescapably related to one’s extra-physical self. No doctor, however gifted or altruistic, can assume these realities for a patient to relieve the patient’s suffering. This, I believe, provides a compelling practical reason for recognising the patient as decision-maker.

By requiring that patients give a meaningful consent to treatment, the law ameliorates the imbalance, as far as is practicable, by ensuring that the decision made belongs to the patient, as do its consequences. In so doing, consent protects patient autonomy and confines doctors’ responsibility to careful giving of advice, diagnosis and treatment.

(c) **Imbalance of authority**

I suggest that the imbalance of authority is also a defining characteristic of the doctor-patient relationship. It is present in ways not present in other provider-consumer

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81 See, for example, Ashley and O’Rourke, 1997, 38-9; Pellegrino and Thomasma, 1988, 28.


83 See Secretary, *Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’)* (1992) 175 CLR 218, 251-3 (joint judgment), 267-8 (Brennan J), 303 (Deane J).

84 What constitutes a ‘meaningful consent’ is discussed at Appendix A.
or adviser-client relationships, and has had a powerful influence on perceptions held by the community (including judges and policy-makers) about doctors and patients. For current purposes, the significance of possession of authority in respect of another is that the person with authority may seek to use that authority to define and assert not only his or her own interests, but also the interests of another person in the relationship, who does not have comparable authority. However, this imbalance means that the party with more at stake in the relationship is the party with less decisional authority, and therefore less capacity to assert and protect his or her personal interest. In practical terms, this is problematic because there is anecdotal evidence that people want more, rather than less, control over their lives.

The imbalance of authority in favour of doctors should be recognised as deriving from particular attributes of patients and doctors. Attributes of doctors and patients that are, in kind or degree, specific to patients or doctors have been identified and considered in bioethical and sociological literature. The purpose of this section is not to reiterate or summarise these accounts, but to demonstrate how these attributes can influence decision-making in the doctor-patient relationship by creating and reinforcing the relative authority of doctors and the relative disempowerment of patients.

(i) Doctors’ authority

One of the most important attributes of doctors is the publicly-recognised authority that they bring to the doctor-patient relationship, enabling them to assert their own interests, values and perspective in the doctor-patient relationship. Doctors’ authority is given public expression by the recognition of doctors as members of a profession. Western doctors were recognised throughout most of the twentieth century as members of a high status profession. However, this has not always been the case, and its continuation

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85 Freckelton, 1999.
86 See, for example, McLean, 1999, 163.
87 For example, Katz, 1984; Pellegrino and Thomasma, 1988.
88 For example, Freidson in Cox and Mead, 1975; Parsons, 1951; Short, 1985, 1986 and 1996. Writers such as Parsons are still regarded as authoritative: see Cheek, 1996.
89 Various definitions of ‘profession,’ and various ideas about the nature and effects of professionalism, have been suggested: see, for example, Ashley and O’Rourke, 1997, Chapter 4; Katz, 1984, 87-90.
90 See Pellegrino and Thomasma, 1988, Chapter 10.
91 Katz, 1984, Chapter II.
should not be assumed, particularly given increasing use of complementary health care services. Nevertheless, doctors retain sufficient social and political status to allow them to frequently dominate decision-making in individual doctor-patient relationships, and to have significant influence on the way in which all relationships between patients and health care providers are regulated. Doctors’ authority is supported by two pillars, identified by medical sociologists as fundamental to the concept of professionalism: the doctor’s possession of special knowledge and the role of altruist.

The twin pillars: knowledge

Considerable authority conferred on doctors by individuals and society derives from doctors’ possession of esoteric, highly technical knowledge, and from their practise of advanced science and technology. Doctors have knowledge of matters that are vital to patients’ interests, and argue that the complexity of that knowledge both precludes sharing it with patients, and requires that doctors exercise it at their independent discretion. This is the source of an imbalance of knowledge which has been asserted and accepted as justification not only for nondisclosure of information to patients, but also for resisting other forms of lay control over medical practice. This point of view assumes that disclosure is either futile, because patients will not understand information that is disclosed to them, or overly onerous, because patients will demand more disclosure than doctors have the time or other resources to make. It further assumes that the practice of medicine, including decision-making, is primarily a technical

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92 Freidson in Cox and Mead, 1975, 294-6. For example, the medical profession is engaged in lobbying about what kinds of medications can be provided ‘over the counter’ by pharmacists, such as the morning after pill and non-steroidal anti-inflammatories.


94 See, for example, Katz, 1984, Chapters I and II; McLean, 1989, 15.

95 For example, Sidaway v Governors of Bethlem Royal Hospital [1985] 1 AC 871, 899 (Lord Bridge), 904 (Lord Templeman); Tito Report - Final, 1995, [8.5-8.9]. See also application of a ‘professional standard’ to define the duty to disclose as a medical issue: Bolam v Friern Hospital Management Committee [1957] 1 WLR 582 (see also Bolitho v City and Hackney Health Authority [1998] AC 232 and Pearce v United Bristol Healthcare NHS Trust (1998) 48 BMLR 118); Hunter v Hanley (1955) SC 200, 217; Katz, 1984, 81. For argument that the imbalance imposes a duty to communicate more, rather than less, see Ashley and O’Rourke, 1997, 64.

96 See, for example, Katz, 1984, Chapter II, 85, 86 and 89-90.

97 See Sidaway v Governors of Bethlem Royal Hospital [1985] 1 AC 871, 904 (Lord Templeman) and Rosenberg v Percival (2001) 205 CLR 434, 478-9, [143] (Kirby J) for an account of similar arguments.
enterprise in which patients cannot, and should not seek to, share.\textsuperscript{98} If steps are not taken, within a doctor-patient relationship, to redress the imbalance of knowledge as far as is material to the patient’s decision, then the doctor’s authority as a decision-maker within the relationship is preserved, and the patient’s disempowerment in decision-making is reinforced.\textsuperscript{99} This is a key point underpinning the imposition on doctors of an obligation to disclose, if a patient’s entitlement to decide is to be given full recognition.

Assuming that the practice of medicine is primarily the exercise of a technical skill implies that other influences do not have a significant effect on it.\textsuperscript{100} I suggest that this assumption has two main consequences, the first of which is acceptance of the technological imperative. The technological imperative rests on the proposition that the pursuit, possession and exercise of knowledge is a sufficient justification for conduct. Acceptance of this proposition reinforces the doctor’s position of authority at the expense of the patient’s control, because it implicitly de-emphasises values other than clinical values.\textsuperscript{101} This can be demonstrated by considering a particular application of the imperative in the doctor-patient relationship, which proposes that a sufficient justification for conduct is the pursuit of clinically-defined outcomes. Thus, if a state of being is defined (by doctors, scientists, governments or perhaps even commercial ventures) as an illness, then whatever it takes to correct or repair it is thought to be justified. It also proposes that, if a scientific advance can ameliorate or repair a characteristic or trait that an influential entity or group in society regards as undesirable, then it must be used to do so. This kind of argument has been used, for example, by advocates of embryonic stem cell research.

The second consequence of a purely or dominantly technical perception of the practice of medicine is that it contributes to the ascendancy of clinical definitions of patients’ welfare over definitions that take other matters into account. The understanding of medicine as predominantly and rigorously scientific and objective is, in my view,

\textsuperscript{98} Katz, 1984, 88; see also 55, 208, 212, 227, Chapter IV; McLean, 1989, Chapter 5.

\textsuperscript{99} See accounts of connections between political disempowerment and adverse health outcomes: for example, Smallwood, White and Kotiw, 1997; Moore, 1997.

\textsuperscript{100} See Gillon, 1985, Chapter 5; McLean, 1989.

\textsuperscript{101} Katz, 1984, xx; McLean, 1989, 198-9; McLean, 1999, 21.
erroneous. One significant flaw in this approach is that many widely-used treatments have not been scientifically validated, but accepted for medical practice on the basis of anecdotal evidence alone, partly because moves toward evidence-based medicine are comparatively recent. More importantly, as is demonstrated in this thesis, patients may value outcomes other than those which can be described as clinically valuable outcomes and may, if allowed to do so, make decisions based on factors other than those that can be described as clinical values.

The twin pillars: altruism

Doctors’ monopoly on such valuable knowledge might have led to stricter regulation of doctors, if it were not for the social expectation that a doctor ‘promises to seek the good of the patient’. This expectation has been nurtured by doctors who, to encourage acceptance of the altruistic character of their vocation, point to the various codes of ethics that have defined their profession at least since the time of Hippocrates. However, this thesis argues that what constitutes the ‘good’ or ‘welfare’ of an individual patient should be understood as being constituted by the values, beliefs and priorities of that patient, and can be given definition only by the patient; that is, all medical treatment takes place in the broader context of the patient’s life. If, however, altruism is understood to require or allow doctors not to seek the patient’s good as given content by the patient, but to define the good for and on behalf of the patient, then the doctor’s authority extends far beyond the scientific or technological expertise that constitutes doctors’ first pillar of authority.

102 See Katz, 1984, 4-7, 37-45, 95, 173-84, 186-9; Pellegrino and Thomasma, 1988, 143-4. Judges have accepted anecdotal medical evidence to establish a standard of care: see F v R (1983) 33 SASR 189, 198 (Legoe J).


104 For example, the plaintiff in Reibl v Hughes (1980) 114 DLR (3d) 1, who would have postponed surgery until his pension had vested had he been aware of the risks of surgery.

105 Pellegrino and Thomasma, 1988, 66 (emphasis in original); 76, 174, Chapter 9, 205-6.

106 See Katz, 1984, 89.

107 See Chapters 2 and 3 for how patients’ interests may be protected when the patient lacks decision-making capacity.
A third pillar of authority? Doctors as generators and protectors of revenue

The authority of doctors may prove to be either threatened or bolstered by additional roles assumed by doctors (under varying degrees of pressure from governments and private bodies) over the past few decades. They relate to health care financing, and require the doctor to act as generator and protector of public and private revenue. One kind of gatekeeping has long been practised informally to limit the kinds of treatment offered, because of the doctor’s conscience (for example, doctors who refuse to offer particular treatments, such as pregnancy terminations). This kind of gatekeeping has always had the potential to restrict options about which patients can make decisions. Modern gatekeeping may involve protection of public or private revenue. Australian governments rely on doctors (especially general practitioners) to try to contain health care costs, and may intervene directly to prohibit or restrict the provision of certain goods and services. Examples of intervention include the Pharmaceutical Benefits Scheme and the regulation of Medicare rebates for consultations with specialists. Private revenue gatekeeping is required by health maintenance organisations in the United States of America, and may also come to be imposed by private health insurers in Australia through ‘no gap’ agreements.

Finally, commercial imperatives may also come to erode doctors’ political, commercial and social authority. In recent years, commercial pressures on doctors have increased. They are faced with a range of such pressures, including increasing overheads (such as professional indemnity costs) and tight practice margins. It is easy to see how the way in which medical practice is conducted may ultimately come to be affected by any or all of these. While the potential for financial conflict of interest has existed for as long as

108 For a discussion of this role, and the pressures and conflicts to which it exposes doctors, see Pellegrino and Thomasma, 1988, 83, Chapter 14.

109 See also reports of suggestions that lung cancer screening should not be offered to smokers: Robotham, 21 May 2001, National, 3, and comments by Dr Peter Mountford of Stem Cell Sciences and Dr Simon Walker of the South Australian Research and Development Institute that reproductive cloning services will not be offered in Australia: reported in Brook, 17-18 March 2001, 26.


fees have been charged for medical services,\footnote{Pellegrino and Thomasma, 1988, 173-4.} that potential (and public awareness of it) has recently intensified.\footnote{See Freckelton, 2001, 356, noting the commercial conflict of interest existing for doctors practising in principally elective surgery, such as cosmetic surgery. For the conflicts that can arise in research, see Moore \textit{v} Regents of the University of California 793 P.2d 479 (1990); Pahl, 1994; Takach, 1995; Cartwright Report, 1988; Alder Hey Report, 2001.} The ways in which other interests can compete with doctors’ professional independence are described and criticised by Pellegrino and Thomasma,\footnote{Pellegrino and Thomasma, 1988, 122-4, Chapter 14. See also Downie in McLean, 1996; Katz, 1984, 133, 137-8.} and need not be canvassed in detail here.\footnote{It is sufficient for current purposes to note the existence of these pressures, which are a matter of general knowledge, and note the existence of concerns that they may affect doctors’ behaviours. See, for example, Oransky and Lenzer, 2002.} The significance of commercial pressures is that patients (and, indeed, society in general) expect doctors to make treatment recommendations based \textit{solely} on what will benefit the patient. If there is a real risk, based on conflicts of interest, that doctors may conduct their practices, and make treatment recommendations, on the basis of considerations other than their patients’ benefit, then this both diminishes doctors’ status collectively and provides an additional argument as to why doctors should not be the decision-makers in the doctor-patient relationship.

\textit{Another kind of authority}

On the pillars of science and altruism, and over centuries of struggle, doctors have built significant authority that is explicitly recognised by society — a doctor’s script makes available powerful medications that are regulated by government, and a doctor’s letter is often the accepted prerequisite of obtaining paid sick leave and other benefits from employers and other entities. In addition, however, doctors may also exercise what has been described as ‘latent authority’\footnote{See Katz, 1984, Chapter II.} to evoke the ‘placebo effect’, infusing patients with confidence that the proposed treatment will help them and, through infusing confidence, somehow promoting healing.\footnote{Freidson in Cox and Mead, 1975, 285, 294-6.} That is, by providing comfort and reassurance that what they are doing will help the patient, a psychological effect is created (though not presently understood) by virtue of which the healing process is

\begin{itemize}
  \item \footnote{Katz, 1984, 7-9 and 189-95; Pellegrino and Thomasma, 1988, 13.}
\end{itemize}
accelerated, or even effectuated. This latent authority is one of the oldest aspects of the practice of medicine, stemming from a belief that ‘without respect for medical authority, there could be no cure.’\textsuperscript{120} Related to the placebo effect is the assumption that disclosure (especially about risks or other uncertainties) will inhibit the doctor’s placebo effect, slowing or even preventing healing.\textsuperscript{121}

(ii) Patients’ lack of authority

Patients’ relative lack of authority can be understood as emanating from two sources: first, circumstances inherent in and incidental to the fact of illness and, second, circumstances extrinsic to the fact of illness. This section explores these circumstances to show how I believe they create and are used to justify patients’ relative disempowerment.

Disempowering characteristics inherent in illness

Legal rules about patients’ involvement in therapeutic decision-making must not ignore or minimise the fact and incidences of a patient’s illness (what Pellegrino and Thomasma describe as the patient’s ‘existential state’).\textsuperscript{122} The existential state of illness includes, first, the fact of illness, which may itself adversely affect the patient’s decision-making abilities and desires, through pain, fatigue, fear, anxiety, frustration, and by the nature of the disease itself (for example, dementia). Second, as an incidence of the debilitation and anxiety of illness, the patient may also engage in transference, a phenomenon whereby a patient attributes to his or her doctor qualities and functions that extend beyond those properly accorded a health care provider, and that may resemble the attributes of a parent or a magician.\textsuperscript{123} Third, to obtain effective treatment for illness, patients must accept a state of vulnerability in their relationship with their doctors. This is inescapable in the course of all but the most perfunctory of doctor-patient relationships, and arises from the necessity to make what is often an intimate exposure to their medical caregivers.\textsuperscript{124}

\textsuperscript{120} Katz, 1984, 7. Katz explains how faith in doctors’ ability to help has for centuries been regarded as an essential component of the healing process.

\textsuperscript{121} See Katz, 1984, Chapter VII.

\textsuperscript{122} Pellegrino and Thomasma, 1988, 14-5, 17-18, 62, 101; see also Hall, 2002, 477-8.

\textsuperscript{123} Katz, 1984, 142-50; see also Hall, 2002, 481-2.

\textsuperscript{124} See Hall, 2002, 478.
I consider that this exposure consists of three major elements that correspond broadly to phases of diagnosis and treatment: first, reposing confidence (for example, by providing personal information to assist in diagnosis); second, making physical exposure for examination and, third, surrendering to care by another. These elements entail allowing doctors intimate knowledge of, and contact with, patients’ physical and extra-physical dimensions. As a consequence, the imbalance between doctors’ authority and patients’ vulnerability is, I suggest, peculiarly intense and pervasive.¹²⁵

Furthermore, illness and its incidences lower patients’ physical and emotional barriers against contact by others; in particular, by others who give protection and care when patients most need and desire to surrender to care. However, the view that ‘illness destroys autonomy, and that beneficence or paternalism must therefore enter to fill the gap’¹²⁶ is both too narrow (because this thesis understands beneficence as being complementary to respect for autonomy, rather than an alternative to it) and too rigid, because the degree to which a patient is so affected varies not only from patient to patient, but also from time to time for each patient. Three examples illustrate a continuum among patients. At one extreme of the continuum is a patient suffering from an acute, highly debilitating illness, and who is unable to consider, make or express a decision. This patient has compelling physical and emotional needs to be cared for.¹²⁷

Less debilitated is a patient who suffers from a chronic, serious but manageable condition (for example, diabetes) and who requires periodic examination, advice and treatment, but who is able to assume family, employment and social responsibilities. There is no apparent reason to express reservations about the decision-making capacity of such a patient, nor to suggest that he or she is made indefinitely vulnerable by illness. Finally, patients seeking a routine check-up or preventative treatment occupy the other extreme of the continuum, even though certain conventional social barriers against physical contact may be adjusted to permit treatment (for example, to conduct a Pap smear). A similar continuum can be seen for individual patients, as they progress from an acute state of need, in an emergency situation, through the phases of diagnosis, treatment, recuperation and rehabilitation.

¹²⁵ See also Kennedy, 1983, 6.
¹²⁶ Pellegrino and Thomasma, 1988, 145; see also 144-6, 154-5.
These examples show that patients’ needs for care and for independence fluctuate. Patients occupying different positions on the continuum have different kinds and degrees of need. By emphasising the needs of the most vulnerable, and apparently assuming that most patients want reassurance and comfort from their doctors, rather than other forms of engagement, the non-clinical interests of patients in mundane transactions may be ignored by courts, and consequently left unprotected. For example, although judges appear to concede that only some patients are fragile, the broad discretion given to doctors by way of the therapeutic privilege and the balancing process allows the mantle of discretionary nondisclosure to be spread protectively over all patients, to the detriment of those patients’ ability to protect their personal interests through exercising their entitlement to make meaningful decisions.

*Disempowering characteristics external to illness*

It has been observed that an individual who consults a doctor exchanges personhood for patienthood. If so, then the exchange is not equal, because of the deficits attributed to patienthood: dependency, neediness, ignorance, irrationality and surrender. Thus, McLean asks whether, if human beings are ‘inherently entitled to respect’, this entitlement survives the transition to patienthood. The possibility that it does not is raised not only by disempowerment inherent in illness, but also by its external incidences.

External incidences that disempower patients include systemic factors such as deficiencies of consideration and courtesy that are apparently caused by resource constraints: for example, ‘six minute medicine’, waiting lists (and waiting lists to be listed on waiting lists!), long periods spent in waiting rooms and on stretchers, lack of privacy, failure to introduce the treating doctor and discharge ‘quicker and sicker’.

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128 For example, *F v R* (1983) 33 SASR 189, 193 (King CJ); *Smith v Auckland Hospital* [1964] NZLR 241, 249-50. See also Katz, 1984, 7, 11, 19, 83.

129 *Sidaway v Governors of Bethlem Royal Hospital* [1985] 1 AC 871, 899 (Lord Bridge) and 904 (Lord Templeman).

130 For discussion of these concepts, see sections 3.5.2 and 3.5.3.

131 Katz, 1984, 209.

132 For example, Katz, 1984, 87, 100-103, 209-12; McLean, 1989, 6; Pellegrino and Thomasma, 1988, 104, 106.

Other factors include the necessity of emotional self-protection by doctors, which may reduce patients to diseases or case histories. Other factors include the necessity of emotional self-protection by doctors, which may reduce patients to diseases or case histories. Also, the physical environment of health care delivery, with its specialised equipment and routines, may intimidate, rendering patients compliant and unwilling to ‘make a fuss’. Finally, increasing state reliance on doctors as protectors of public revenue, and as providers of patient information for state purposes, may erect another barrier to trust and confidence, as patients perhaps become concerned about possible conflicts of interest. In such circumstances, patients and doctors may be given little opportunity to develop relationships in which their interests can be confidently asserted, negotiated and respected. Instead, patients may be cast as suppliants and their interests disregarded because of what are assumed to be the wider interests of efficiency, or the view that, when a person becomes a patient, clinical considerations comprise the entirety of a person’s interests.

A second incidence of patienthood that affects the assertion and negotiation of patients’ interests is the division, by health care providers, of patients into classes of ‘good’ and ‘bad’ (or ‘difficult’) patients. There has long been empirical evidence to suggest that characteristics attributed to ‘good’ patients include compliance with ‘doctor’s orders’ (and, for in-patients, with hospital routines), stoicism, refraining from complaint and not making work for staff. A patient may be characterised as a ‘bad’ patient by making work and trouble for staff, demanding attention, making complaints or even by misplaced stoicism (for instance, the patient does not want to make trouble and so does not alert staff to legitimate needs). Evidence further suggests that informal sanctions, including denial of care, have been applied to ‘bad’ patients. Knowledge of (or even misplaced belief in) such sanctions may inhibit a patient from asserting or negotiating his or her interests.

134 Katz, 1984, Chapter VII. See also NHMRC, 2004.
137 See Lorber, in Gartly Jaco, 1979. Characterisation as a ‘good’ or ‘bad’ patient may be culturally-based: Pellegrino and Thomasma, 1988, 100. See also Chatterton v Gerson [1981] 1 QB 432, 436, quoting from the general practitioner’s referral to the specialist: ‘as she is a very pleasant and sensible person I do hope that you will be able to help.’
138 Lorber, in Gartly Jaco, 1979, 212-214. See also the Cartwright Report, 1988, reporting instances where Dr Green, whose practices were being considered by the Cartwright Review, referred dissatisfied patients to a psychiatrist.
139 Pellegrino and Thomasma, 1988, 179.
Finally, in few other relationships are the physical, mental and spiritual dimensions of individuals so regularly and so profoundly challenged as in the doctor-patient relationship. For instance, a priest touches only on spiritual dimensions; a doctor must constantly work at and challenge the frontiers of patients’ spiritual, emotional and physical dimensions. Accordingly, a further distinctive incident of doctor-patient relationships, that may contribute to patients’ disempowerment, is the paradox of intimacy and remoteness. Most relationships of intimacy (in which we permit significant physical and extra-physical contact with others) are with those with whom we share close emotional bonds. Such relationships do not involve the detachment and remoteness that health care providers seek and maintain (whether or not justifiably).\textsuperscript{140} I believe that this paradox both challenges social and legal conventions that are socially-valued and defended (such as the prohibition against nonconsensual physical contact, which is waived in situations of medical emergency), and erects barriers of formality and authority that do not exist in other relationships in which we relax prohibitions against contact.\textsuperscript{141}

\textit{(d) Significance of threats to the personal interest}

Because of the imbalances of effect and authority, legal rules about decision-making in the doctor-patient relationship should protect patients from exploitation and reinforcement of their disempowerment, and from dismissal of the significance of their extra-clinical interests in favour of medicalised values. If it were not for the imbalance of effect, the imbalance of authority would not have as much significance. The presence of both imbalances means that the party more affected by the consequences of decision-making has less authority over those decisions, and thus less ability to define and assert his or her personal interest. Medicalisation and the imbalances pose a significant threat to the patient’s personal interest, which the law should find a means to protect against if it is to take the personal interest seriously. While the imbalance of effect is inescapable by the very nature of health care, the challenge in developing legal rules about decision-making in the doctor-patient relationship is to mitigate the imbalance of authority, so that the more affected party is entitled to exercise greater control over weighing the

\textsuperscript{140} See Bastian, 1992.

\textsuperscript{141} Appendix B considers examples from biomedical research to illustrate how the combination of the imbalances of effect and authority can undermine a patient’s personal interest.
effects that he or she is willing to accept, in the context of the entire personal interest. The requirement that patients consent to treatment as an exercise of an entitlement to decide seeks to meet this challenge by conferring on the more affected party in the relationship – the patient – the authority to make the decisions about medical treatment. In doing so, the requirement for consent both protects patients’ autonomy and allows a role for the principle of beneficence, which may properly be understood as shaping the obligation to disclose to allow patients to make meaningful decisions. This is considered further in the following section.

1.4 DIFFERENT MEANS OF PROTECTING THE PERSONAL INTEREST: THE ENTITLEMENT TO DECIDE AND THE HARM PREVENTION POLICY

1.4.1 The entitlement to decide as the usual means of protecting the personal interest of patients with decision-making capacity

Having established the importance of the personal interest, and the existence of threats to that interest, it is necessary to identify a means of protecting it. Currently, the law identifies a paramount entitlement to decide to fulfil this function in most instances, ameliorating the imbalances by ensuring that (in most cases) the party with most at stake has the decisional authority. Throughout this thesis, I will argue that a robust entitlement to decide is, for patients with decision-making capacity, usually the most effective means of protecting the personal interest.

The entitlement to decide reflects an understanding that usually it is only by allowing patients to make their own health care decisions on the basis of adequate information can the law protect the patient’s interests that it recognises as being valuable and as being affected by health care. By imposing on doctors an obligation to disclose, corresponding to this entitlement, the law has tried to ensure that patients are given sufficient information to make a meaningful decision; that is, a decision that reflects their personal interests. In practice, the entitlement to decide is expressed through the requirement that patients give consent to treatment.

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142 See section 4.3 for further consideration of the nature and role of the principle of beneficence.
143 Rogers v Whitaker (1992) 175 CLR 479, 490.
In the doctor-patient relationship, two protective roles are fulfilled by the well-established requirement\(^{144}\) that a patient must give consent to medical treatment for it to be lawful. First, it protects the patient’s autonomy by ensuring that it is the patient who is the decision-maker in the doctor-patient relationship. Second, it protects the doctor’s professional interest in giving care. If patients believe that doctors can be trusted to give them adequate information on the basis of which to make decisions about their health care, this will enhance doctors’ ability to fulfil their roles as trusted professionals, as well as providing doctors with protection against liability by requiring patients to take responsibility for treatment decisions.\(^{145}\) The public reaction to events at Alder Hey\(^{146}\) and the Bristol Royal Infirmary\(^{147}\) (while not involving paradigmatic doctor-patient relationships) may indicate that, if patients and members of the public do not believe that they can trust doctors to provide adequate information, it becomes very difficult for doctors to do their jobs properly.

What clearly emerges from considering the history of the development of consent\(^{148}\) is the idea that the understanding of the role of consent has changed to accommodate community expectations. While consent started off as being a mechanism to further the purpose of care in the doctor-patient relationship (by promoting patients’ trust in doctors),\(^{149}\) the recognition of an entitlement to decide suggests that consent can now be seen as a mechanism to further the purpose of independence in that relationship, enabling patients to define and advance what I have described as their personal interests. Nevertheless, a cautionary note should be added: the continued acceptance of the legitimacy of the therapeutic privilege,\(^{150}\) and the kinds of factors regarded as relevant in undertaking the Australian ‘balancing process’,\(^{151}\) may mean that the role of consent is not an ‘either/or’ proposition. From being about the purpose of care only, it may now

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\(^{144}\) Paragraph 1.4.5 (a) (‘The transition from “bare” to “meaningful” consent’).

\(^{145}\) See Faden and Beauchamp, 1986, 82-3, 87; McLean, 1989, 11.

\(^{146}\) See the Alder Hey Report, 2001.

\(^{147}\) See the Bristol Royal Infirmary Report, 2000.

\(^{148}\) See the Appendix.

\(^{149}\) As in Slater v Baker & Stapleton (1767) 95 ER 860.

\(^{150}\) As in Di Carlo v Dubois [2004] QCA 150.

\(^{151}\) As discussed in section 3.5.3.
be about both the purpose of independence and the purpose of care.\textsuperscript{152} The acceptance of the entitlement to decide as a ‘paramount consideration’\textsuperscript{153} is in my view significant for this thesis because it means that the more recently-understood and richer role of consent is the dominant one within a legal framework that is gradually learning to value both the purpose of care and the purpose of independence.\textsuperscript{154}

I believe that recognition in England and the United States of an action for nondisclosure of information, based on a more complex and fuller understanding of the implications of acceptance of self-determination, paved the way for the recognition, in Australia, of a patient’s entitlement to decide. While the ‘battery or negligence’ question was resolved in Australia almost by default,\textsuperscript{155} by the time the issue of consent to medical treatment was faced in Australian courts, the climate was favourable for the articulation by judges in the High Court of an idea that patients were entitled to make meaningful decisions, and that this entitlement required the disclosure of relatively detailed information about the proposed treatment, to enable patients to make decisions in light of their personal interests.\textsuperscript{156} The High Court sought to reject the relevance of a notion of self-determination to the negligence action.\textsuperscript{157} Despite this, it is clear that the idea of an entitlement to decide, which was accepted by the Court, must logically be based on acceptance of the importance of the principle of respect for patients’ autonomy. The entitlement, justified by the autonomy principle,\textsuperscript{158} is treated by Australian law as the basis for imposing on doctors the general obligation to disclose

\textsuperscript{152} For continued influence of the imperative of care even in light of an acknowledged right of the patient to decide about treatment, see Canterbury v Spence 464 F.2d. 772, 781, 782 (1972); Sidaway v Governors of Bethlem Royal Hospital and Ors [1985] 1 AC 871, 904 (Lord Templeman).
\textsuperscript{153} Rogers v Whitaker (1992) 175 CLR 479, 487.
\textsuperscript{154} The currently-imposed duty of disclosure does not provide a full acknowledgement or vindication of a patient’s entitlement to decide: see McLean, 1989, especially 34, 63; Faden and Beauchamp, 1986; Shultz, 1985; Katz, 1984, especially 26, 82, 84; Robertson, 1981, 111. This conclusion is valid for current Australian law, because of its test for causation, and its acceptance of the therapeutic privilege and the balancing process: see sections 3.5.2 and 3.5.3. For the difficulty posed for plaintiffs by causation tests, see Chappel v Hart (1998) 195 CLR 232, 258 (Gummow J), 264, 270, 272 (Kirby J); Rosenberg v Percival (2001) 205 CLR 434, 483-5, [153], 489, [165] (Kirby J). See also Milstein, 1997, 21.
\textsuperscript{155} Trespass was pleaded at the trial stage of F v R and, having been received adversely, progressed no further: see F v R (1983) 33 SASR 189. See Rogers v Whitaker (1992) 175 CLR 479, 489, 490.
\textsuperscript{156} See Rogers v Whitaker (1992) 175 CLR 479, 487, 489 (joint judgment).
\textsuperscript{157} Rogers v Whitaker (1992) 175 CLR 479, 490.
\textsuperscript{158} See section 1.5.
information beyond that required by the idea of ‘bare’ consent on the basis of which non-disclosure actions were initially brought.

1.4.2 The harm prevention principle as an alternative means of protecting the personal interest

There is an important influence that can conflict with the recognition of a patient’s entitlement to decide. Sometimes it also justifies displacement of the responsibility of a usual substitute decision-maker (such as a parent) to make decisions for a patient without decision-making capacity. Chapters 3 to 5 show that there is a common basis for this displacement; that there is a unifying influence that ties together the otherwise disparate cases considered in these Chapters. This influence is that of harm prevention.  

Essentially, I am arguing that adoption of a harm prevention policy sometimes represents an alternative way of protecting the personal interest, which should always be the central concern of the law in developing rules about decision-making in the doctor-patient relationship. The influence of the harm prevention policy can be seen in the rules about emergency, the therapeutic privilege and the balancing process.  

Chapter 4 demonstrates that a harm prevention policy underlies the displacement of the patient’s entitlement to decide (or the usual substitute decision-maker’s responsibility to decide) to protect the personal interest of patients, especially vulnerable patients. In particular, section 4.3 proposes a test to enable lawmakers to determine, in particular cases, whether the personal interest is afforded better protection through the entitlement to decide or the harm prevention policy, and whether the personal interest of a third party should take precedence over that of the patient, which is the subject matter of Chapter 5.

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159 For the purposes of this thesis, the expression ‘harm prevention’ will be taken as including ‘harm minimisation’.

160 Which are examined in Chapter 3.

161 The test is located in section 4.3 because it is not applicable to the circumstances examined earlier in the thesis as previously-accepted bases for displacing the entitlement to decide. This is because that test is intended to be used to balance wider state, or community, interests against the personal interest of the patient. The circumstances described in Chapter 3 as conventionally accepted as displacing the entitlement to decide (lack of decision-making capacity, emergency and therapeutic necessity) do not involve this kind of balancing process. Rather, they are (as I will show) about the patient’s state of mind, and purport to balance aspects of the patient’s interests against each other. If an indivisible personal interest is recognised, then this foundation for the therapeutic privilege and the balancing process disappears.
Chapter 5 shows that, sometimes, the entitlement or responsibility to decide is displaced in order to afford protection to the competing personal interest of a third party, which may be harmed if a patient’s entitlement to decide were allowed to take precedence. This Chapter also argues that this displacement should only occur if the test proposed in section 4.3 is satisfied.

1.5 THE PRINCIPLES OF RESPECT FOR AUTONOMY AND BENEFICENCE: FOCUSING ON THE PERSONAL INTEREST AND EXPLAINING THE ENTITLEMENT TO DECIDE AND THE HARM PREVENTION POLICY

1.5.1 The contribution of respect for autonomy

This thesis refers to the roles of beneficence and respect for autonomy in explaining the entitlement and responsibility to decide. Furthermore, commentary in this area of the law has been defined by consideration of these principles. It is therefore appropriate to describe briefly how I see the principles of beneficence and respect for autonomy as affecting the protection of the personal interest, considering their contributions and their limitations.

(a) What is the principle of respect for autonomy?

In brief (because the meaning of the principle of respect for autonomy is dealt with comprehensively by other commentators), the principle of respect for autonomy entails never treating others merely as the means to an end, but always also as ends in themselves.\(^\text{162}\) The role that the principle of respect for autonomy should play in the doctor-patient relationship ought not be confused, as I think it has been, by misunderstandings about the nature of that principle. For example, the principle of respect for the autonomy of others has been characterised as imposing a negative duty of noninterference.\(^\text{163}\) This thesis interprets respect for autonomy as requiring positive conduct involving empathy and willingness to engage in conversation with patients.\(^\text{164}\) I consider respect for autonomy to be a principle useful in establishing a normative framework for decision-making in the doctor-patient relationship by justifying the existence of the entitlement to decide that protects the personal interest. I will interpret

\(^{162}\) Klemme and Kuehn, 1999, (in particular, the following essays: Ebbinghaus, 1954, and Guyer, 1995).

\(^{163}\) Pellegrino and Thomasma, 1988, 6, 49. See, in contrast, Katz, 1984, Chapter VIII.

\(^{164}\) As argued in Katz, 1984. See also Freckelton in Freckelton and Petersen, 1999, 119.
this principle as requiring of doctors not merely negative noninterference, but active, compassionate engagement with their patients.\textsuperscript{165}

(b) \textit{The autonomy principle and the entitlement to decide}

The autonomy principle, for the purposes of this thesis, finds practical expression in the patient’s paramount entitlement to decide about medical treatment, first acknowledged in Australian law in \textit{F v R},\textsuperscript{166} and accepted by the High Court in \textit{Rogers v Whitaker}.\textsuperscript{167} The entitlement to decide has two, intimately-related, aspects. First, the entitlement makes clear that the preferred or presumed position is that it is the patient who is the decision-maker. However, much of the thesis is devoted to exploring situations in which the entitlement is displaced, and in which, therefore, a person or entity other than the patient has been entitled or empowered to decide whether a patient should undergo proposed treatment. By undertaking such exploration, the proper limits and significance of the entitlement to decide in protecting the personal interest become easier to understand. Second, the entitlement makes it clear that, to fulfil the normal decision-making role, the patient should be entitled to disclosure of information from the person who holds it: the doctor.\textsuperscript{168} While this thesis focuses on the former aspect of the entitlement, it does pay some attention to the disclosure aspect of the entitlement, first, in an effort to emphasise that without the obligation to disclose, the entitlement is no more than rhetoric and, second, in an effort to clarify how the entitlement should work to protect the personal interest.

(c) \textit{Potential limitations of respect for autonomy in the doctor-patient relationship}

Possible limitations on the role of this principle in the doctor-patient relationship include, first, that giving primacy to the principle of respect for autonomy ignores the ‘existential limitations’ of patienthood (those incidences of patienthood, and illness, that affect the willingness and the ability to make decisions, such as pain and anxiety).\textsuperscript{169} Second, that it would require exhaustive (potentially never-ending) discussions with

\textsuperscript{165} Katz, 1984, Chapters IV, VI; Pellegrino and Thomasma, 1988, Chapter 15. See also Nussbaum, 1996.

\textsuperscript{166} \textit{F v R} (1983) 33 SASR 189, 193 (King CJ).

\textsuperscript{167} \textit{Rogers v Whitaker} (1992) 175 CLR 479, 487, 489 (joint judgment).

\textsuperscript{168} See, for example, Shultz, 1985, 254.

\textsuperscript{169} Pellegrino and Thomasma, 1988, 39, 49, 153-4.
patients and, finally, that autonomy ignores the fact that therapeutic decision-making occurs in the context of a relationship and therefore cannot fit within the context of the doctor-patient relationship and its psychological realities.

Certainly, insistence on an absolutised or, by contrast, a ‘negative noninterference’ model of the principle of respect for autonomy, that requires doctors merely to leave patients strictly alone to make their decisions without advice or guidance, would be vulnerable on these grounds. However, it is difficult to find genuine arguments, in favour of the principle of respect for autonomy, that demand that patients without decision-making capacity be required to make decisions, that doctors refrain from providing guidance or support to patients by providing sufficient information to make meaningful decisions, or that every doctor explains to every patient every medical fact or theory that may be relevant to diagnosis or treatment. Arguments that rely on such propositions are attacking a straw man, and may be disregarded. It is important to avoid the distraction of models of autonomy that have little practical relevance.  

Respect for autonomy does not, in my view, have to ignore the limitations on physical and psychological autonomy that can arise from the realities of patienthood, and should be applied in a more nuanced way than absolutised models to which objections have been made. As I have described it, there is no standard, generic or ‘reasonable’ personal interest in relation to which autonomy of thought and action can be exercised and must be respected. However, the existence of grey areas, arising from the individuality of personal interests, does not deprive the principle of respect for autonomy of usefulness. Rather, it requires care and thoughtfulness in applying it, instead of the ‘quick fixes’ that may seem to be available in paternalistic interactions. Likewise, the conceded impossibility of eliminating all external and internal limitations on the exercise of autonomy does not necessarily justify nondisclosure, but requires the provision of as much information as can be understood, using communication techniques appropriate to a patient’s circumstances.

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171 Appelbaum, Lidz and Meisel, 1987, 45-46. See also Charlesworth, 1993, 22.
172 Tito Report - Interim, 1994, [6.13-6.34]; Tito Report - Final, 1995, Chapter 4, [8.4-8.9], [8.28-8.34].
Arguments that legal rules about decision-making, if emphasising respect for autonomy, would be too resource-intensive are countered by the reality that rules based on genuine beneficence, directed toward all the dimensions of a patient’s interests, would be equally resource-intensive. This is because both kinds of legal framework would demand discussion with patients, and a level of attention to patient’s interests, cares and priorities, that are simply not required as part of a legal framework that tolerates paternalistic, generalised interactions.

Finally, the psychological characteristic of autonomy, and the principle of respect for autonomy, as described in the discourse of moral philosophy, are inherently relational, because they require the existence and interaction of at least two agents: one to be respected and one to respect.\textsuperscript{173} If there were only one person in the world, there would be no need for the ideas of autonomy or respect for autonomy, because the need arises only when a second agent might seek to restrict the conduct of the first person. Once this possibility arises because of the existence of two or more agents, the autonomy of each must be negotiated in the context of a relationship.

1.5.2 The contribution of beneficence

(a) What is beneficence?

As previously observed in this Chapter, beneficence is a principle with particular relevance to the doctor-patient relationship because of the purpose of care, which is one of the pillars on which the relationship rests. If a doctor puts aside his or her interpretation of the patient’s good and instead allows a patient to define and assert his or her personal interest then, in my view, the doctor is acting beneficently by respecting his or her patient’s exercise of autonomy. This should be recognised as an important part of caring for the patient. This Chapter has already given some consideration to the significance of the beneficence principle in the doctor-patient relationship, in the context of considering the autonomy principle and the requirement of consent that derives from it. This section defines beneficence, before turning to an exposition of the relationship between the autonomy and beneficence principles.

\textsuperscript{173} Acknowledged in Pellegrino and Thomasma, 1988, 42.
The principle of beneficence requires an agent to act for the benefit of another. In the context of the doctor-patient relationship, beneficence can be applied to guide whether and how medical care is given to a patient. There is sometimes an assumption made by courts that beneficence should be directed predominantly toward the clinical welfare of the patient. This thesis argues that beneficence should be directed not only at furthering the patient’s clinical welfare, but more broadly, at respecting how patients define and implement their values, priorities and goals. That is, I am offering an interpretation of beneficence that confines it to conduct that protects and supports patients’ personal interests, as defined by the patient (or, the usual substitute decision-maker, as far as practicable), rather than defining beneficence as conduct that serves what a third party such as a doctor or a lawmaker determines to be good.

Beneficence can fulfil this role by giving rise to the doctor’s obligation to disclose to the patient information that is necessary to enable the patient to make a decision based on his or her own understanding of the personal interest; that is, a meaningful decision. In this way, the danger of medicalisation could effectively be countered. It is important to note, also, that such a specific interpretation of beneficence would protect doctors by enabling a clear description of the proper ambit of their responsibility in decision-making about treatment. By explicitly making the patient’s personal interest the subject matter of the principle of beneficence, decision-making responsibility would be unambiguously cast on the patient. This understanding of the purpose of consent casts decision-making responsibility where it belongs: with the patient who bears the imbalance of effect.

I also think that beneficence explains in moral terms the harm prevention policy, described at section 1.4, that this thesis argues acts as a counterforce to the entitlement to decide and, sometimes, the usual substitute decision-maker’s responsibility to decide. It may be thought by some that harm prevention is better explained by the moral principle of nonmaleficence. However, this principle, as described by leading commentators Beauchamp and Childress,\(^\text{174}\) emphasises refraining from conduct, rather than undertaking conduct. Such a principle does therefore not provide an explanation for those instances where lawmakers actively intervene to prevent harm (such as, for

\(^{174}\) See Beauchamp and Childress, 2001, Chapter 4, for a description of this principle.
example, in authorising coercive obstetric intervention, as described in Chapter 5, or legislating to prohibit female genital mutilation, as described in Chapters 4 and 5). Beneficence, which contemplates the taking of positive action, in my view provides a more satisfactory moral explanation for the conduct engaged in by lawmakers to prevent harm to patients and third parties.

As observed earlier in this section, I interpret beneficence as requiring protection of the personal interest. Thus, the harm prevention policy, grounded in this moral principle, should only be permitted to displace the entitlement to decide, (or the usual substitute decision-maker’s responsibility to decide) if it can be shown to better protect the personal interest (whether the patient’s or that of a competing third party or third parties). This thesis proposes that such a showing can only be made by satisfying the test set out in section 4.3, which focuses attention on the personal interest.

(b) Characteristics of beneficence

There may be three principal characteristics of the principle of beneficence that can be regarded as being relevant to the doctor-patient relationship. The first is that because beneficence acknowledges those aspects of patienthood that disempower individuals, it is able to protect patients from adverse consequences of that disempowerment.

Second, it is argued that because the principle of beneficence assumes and emphasises the existence of a relationship, it enhances the prospects of healing, and promotes positive caring by doctors for patients, rather than negative noninterference with patients. It is thought that positive caring promotes patients’ best interests (although I argue that such caring is conventionally only focused on patients’ clinical well-being, and therefore does not address the entire personal interest). Advancing this argument, Pellegrino and Thomasma criticise the principle of respect for autonomy as over-emphasising individualism at the expense of relationships, and contributing to ‘moral atomism’ in the doctor-patient relationship in particular, and in society in general.

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175 Pellegrino and Thomasma, 1988, 49.
176 Pellegrino and Thomasma, 1988, 21-2.
Third, it is argued that, in response to the purpose of care, and patients' disempowering characteristics,\textsuperscript{177} the medical profession has developed an ethos of altruistic service which has been highly valued by patients and by society, and which should not lightly be challenged, or diminished in value.\textsuperscript{178}

(c) Misapprehensions about beneficence

A misapprehension about the nature of beneficence must be discarded, to ensure that it is beneficence, and not a misinterpretation of it, that is considered for the purposes of this thesis. This is an assumption that beneficence is the same as, or permits or requires, paternalistic behaviour. Alternatively, paternalism is seen as merely a pejorative term for 'altruism'. Beneficence, and the altruistic conduct that beneficence prompts, should not be confused with paternalism, although they frequently are.\textsuperscript{179} The difference between these ideas is that beneficence should require a doctor to act to further the interests or goals of his or her patient, as identified by the patient.\textsuperscript{180} Paternalism, on the other hand, permits a doctor to define the interests of the patient, on the patient's behalf, and then to pursue those interests, even if this entails overriding or disregarding the patient's perspective. Thus, doctors have sometimes been perceived as being under some kind of duty to 'force' beneficence on a patient, by acting to further the patient's clinical welfare, without reference to the patient's personal interest. This can be seen, for example, by judicial acceptance in the United States,\textsuperscript{181} England,\textsuperscript{182} and Australia\textsuperscript{183} of the therapeutic privilege, which is discussed in Chapter 3.\textsuperscript{184} Briefly stated, the Australian version of this privilege permits the nondisclosure to patients of material information if the doctor believes that disclosure will either directly harm the patient or

\textsuperscript{177} Pellegrino and Thomasma, 1988, 32.

\textsuperscript{178} Pellegrino and Thomasma, 1988, 26-7.

\textsuperscript{179} Pellegrino and Thomasma, 1988, 9, 29, 36.

\textsuperscript{180} For paternalism as a violation of the dignity of others, see Pellegrino and Thomasma, 1988, 6, 7, 23, 55.

\textsuperscript{181} See, for example, Canterbury v Spence 464 F.2d. 772 (1972).

\textsuperscript{182} See, for example, Sidaway v Governors of Bethlem Royal Hospital and Ors [1985] 1 AC 871.

\textsuperscript{183} See, for example, Rogers v Whitaker (1992) 175 CLR 479 (although the judgment of Gaudron J may suggest that she rejected the therapeutic privilege as understood by the joint judgment). See also Di Carlo v Dubois [2004] QCA 150.

\textsuperscript{184} Section 3.5.2.
will impair the patient’s ability to make a ‘rational’ decision about undergoing treatment.\textsuperscript{185}

Confusion between beneficence, interpreted in this thesis as the idea of doing good by attending to a patient’s aggregate personal interest, and paternalism (interpreted as the idea of attending to a patient’s interest as defined by the doctor, purportedly on the patient’s behalf), is the basis for many attacks on beneficence.\textsuperscript{186} Pellegrino and Thomasma’s characterisation of paternalism as a ‘subversion’ of beneficence and altruism\textsuperscript{187} is accepted for the purposes of this thesis.

\textit{(d) Limitations of beneficence as conventionally understood in the doctor-patient relationship}

The principle of beneficence, if interpreted broadly and directed towards the personal interest as defined by the patient, would indeed protect that interest. However, existing legal interpretations of beneficence tend to be narrow, focusing on the clinical interests of patients, and accepting (even encouraging) paternalism to ensure that the clinical interests are served. Paternalistic reasoning, which may be well-intentioned, can sometimes itself be further degraded to attempt to justify coercive, overreaching conduct in relation to patients, in the cause of protecting and advancing their clinical welfare.\textsuperscript{188} Even in the absence of coercion, a significant attraction of paternalism is that a paternalistic, clinically-focussed approach is simpler, quicker and less expensive to operate than would be systems and resources supporting interactions based on either genuine beneficence or genuine respect for autonomy.\textsuperscript{189} Such interactions require resource-intensive conversations with patients, and health care systems that allow doctors to develop open and trusting relationships with each patient.

Exclusively, or dominantly, clinical interpretations of beneficence threaten rather than support patients’ personal interests. Furthermore, legal culture is unlikely to change without powerful impetus, as has been illustrated by the survival of paternalism through

\textsuperscript{185} In my consideration of the therapeutic privilege, in section 3.5.2, I describe this second possibility as ‘indirect harm’.

\textsuperscript{186} Pellegrino and Thomasma, 1988, 9, 13, 29, 69.

\textsuperscript{187} Pellegrino and Thomasma, 1988, 6, 7, 55.

\textsuperscript{188} Katz, 1984, 112.

\textsuperscript{189} As was noted at paragraph 1.5.1 (c).
consumerist and other rights-based changes in social, political and legal thought. The strong and persistent emphasis on clinical welfare, and the historical acceptance of paternalism by courts as a necessary cost of protecting the clinical welfare of patients, invites concern about the risks of adopting beneficence as a preferred ordering principle.

Interpretations of beneficence that focus on clinical welfare also create problems for therapeutic decision-making because they generally presume that nondisclosure, rather than disclosure, protects the clinical dimension. This is because it has often been assumed by courts first, that clinical recommendations are always in the patient’s best interests and, second, that nondisclosure (especially of uncertainties, such as risk information) enhances patients’ confidence in doctors’ ability, thus activating the ‘placebo effect’. Conversely, it is assumed that disclosure of such information will deter patients from accepting medical advice. These assumptions are based on speculation and anecdote, rather than empirical evidence. They illustrate a paternalism which tends toward the protection of the vulnerable few, at the expense of patients who seek information, rather than reassurance, and whose participation in decision-making is compromised by nondisclosure policies intended to protect the minority.

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190 See, for example, Appelbaum, Lidz and Meisel, 1987, 29-30, 73, 136-40, 202. See also the discussion of therapeutic privilege in section 3.5.2.
191 See, for example, the discussion in Chapter 2 of the ‘flak jacket’ test (paragraph 2.3.2 (c) (ii)) and the discussion in Chapter 5 of coercive obstetric interventions (paragraph 5.2.3 (c) (ii)).
192 A strong example of this assumption is the therapeutic privilege: see section 3.5.2.
193 Katz, 1984, Ch VIII; Rosenberg v Percival (2001) 205 CLR 434, 478-9, [143] (Kirby J); McLean, 1989, 9, 78; Sidaway v Governors of Bethlem Royal Hospital and Ors [1985] 1 AC 871, 880 (Lord Scarman quoting testimony of an expert witness called for the defence), see also 904 (Lord Templeman).
194 Kennedy, 1983, 162; Katz, 1984, 105; Tito Report - Final, 1995, Chapter 2, especially [2.13-2.15] for reliance on anecdote; Tito Report - Interim, 1994, Chapter 6, for evidence that patients do want information. Also, note concerns about the role played in patients’ testimony by ‘hindsight bias’. This bias suggests that, despite the plaintiff-patient arguing that, had he or she known the risks of treatment, treatment would have been refused, such testimony is tainted by poor outcomes, and should not be relied upon (see Ipp Report, 2002, paragraph 7.40 and recommendation 29). Such concerns reflect a view, inconsistent with the assumption noted in the body of the text, that disclosure of risks does not, in practice, have a deterrent effect on prospective patients.

See, for example, Katz, 1984, 86, 89.
Oddly, it is never assumed that information about the risks of not undergoing treatment will frighten a patient — perhaps unnecessarily — into undergoing treatment, and that therefore such risks should not be disclosed. Were such an assumption to be made by the law, patients could be left with the misleading impression that there would be no adverse clinical consequences from not undergoing treatment. This would, of course, be clinically dangerous. It would also exemplify the opposite approach from that which generally informs disclosure rules in the doctor-patient relationship, which is that patients’ interests are generally best served by undergoing clinically-recommended treatment, and that if risk disclosure might inhibit that outcome, then the law should restrict risk disclosure.

Finally, I suggest that beneficence can only ever be an indirect means of protecting patients’ personal interests. Because I argue that what constitutes the personal interest is defined and interpreted by the patient, beneficence is an essentially reactive notion that first requires conduct by the patient in defining and asserting his or her personal interest. Thus, beneficence complements autonomy in the doctor-patient relationship. Beneficence can tell the doctor to respect the patient’s views and decisions, but it cannot tell the doctor what those views and decisions should be.

1.5.3 How respect for autonomy and beneficence are complementary in the doctor-patient relationship

This thesis does not accept the validity of a model that assumes respect for autonomy to be in conflict with beneficence. Rather, this thesis proposes that the autonomy and beneficence principles should both be understood as protecting the patient’s personal interest. Because of this interpretation, these principles stand in a relationship of complementarity, rather than conflict. The merits of both principles underpin decision-making in the doctor-patient relationship.

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197 Or, for patients without decision-making capacity, conduct by their substitute decision-makers (remembering that such patients may, despite the lack of decision-making capacity) nevertheless have strong views on their personal interests, as was recognised in Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218.

This Chapter demonstrates a proper understanding of how the principles of respect for autonomy and beneficence should be seen to underpin decision-making and disclosure in the doctor-patient relationship. The question of who is the decision-maker should be (and generally is) decided by reference to the autonomy principle and, unless that patient lacks decision-making capacity, the principle of beneficence should have nothing to do with the identification of the decision-maker (even though there has been a view, illustrated by the therapeutic privilege that it does). The beneficence principle should be recognised as supporting the autonomy principle by informing the doctor’s duty of disclosure to patients with decision-making capacity, and the choice of, and duties owed by, substitute decision-makers. On this understanding, the beneficence principle is not in competition or conflict with the autonomy principle.

Thus, because of the purposes and imbalances that characterise the doctor-patient relationship, the autonomy and beneficence principles should be understood to coexist. It also follows from the modern view of patient autonomy, expressed through the judicially-accepted entitlement to decide, that beneficence should be understood as reactive to autonomy in the sense that beneficence is informed by the patient’s formulation of his or her personal interest. In other words, the patient’s entitlement to decide is, generally, paramount. The autonomy principle tells us that the patient should generally decide and that the decision must be meaningful, in that it is based on sufficient disclosure to enable a decision to be taken in light of the patient’s personal interest. The beneficence principle should be understood to create the obligation to make that disclosure in a way that pays due respect to the requirements of the autonomy principle; that is, to the patient’s exercise of autonomy in formulating his or her personal interest.

It is clear that the law currently recognises a paramount entitlement to decide belonging to patients, ensuring that patients are normally the decision-makers, and that they receive sufficient disclosure to allow them to make meaningful decisions which protect their personal interests. The significance of the paramountcy of the entitlement is not

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199 Which is discussed in Chapter 3: section 3.5.2.

200 It is recognised, however, that patients may make health care decisions for any reason, or no reason. A decision made for no reason (if there is such a thing) is nevertheless a reflection of how the patient interprets his or her personal interest.
that the entitlement is absolute, but that it should be seen as the starting point for analysing decision-making in the doctor-patient relationship: it is presumed that the patient will be the decision-maker, but this presumption can be, and has been, overcome by considerations and values that are explored in subsequent chapters.

The principle of beneficence should not be thought merely to ‘take over where respect for autonomy leaves off’, that is, it does not operate simply as an alternative when respect for autonomy does not dictate that the patient is the decision-maker (such as when a patient lacks decision-making capacity). Rather, it should be seen as complementary and responsive to respect for autonomy in the sense that it relates to the obligation to disclose, which responds to the patient’s entitlement to decide, and to conduct that follows the making of health care decisions, rather than to the identification of the party with decision-making power. Beneficence would thus operate in tandem with the autonomy principle even when the patient is exercising the entitlement to decide. This is because the purpose of care, noted at the beginning of this Chapter, always applies within the doctor-patient relationship.

(a) Beneficence and patients with decision-making capacity

In relation to patients who are exercising the entitlement to decide, I argue that the principle of beneficence should be understood to reinforce the autonomy principle by defining the content of the doctor’s obligation to disclose. This is because I consider that the principle of beneficence obliges a doctor to respond to the exercise of a competent patient’s autonomy by disclosing adequate information to enable the patient to exercise that autonomy in the form of a decision that is meaningful to the patient. This thesis argues that a meaningful decision is one in relation to which the patient has had an opportunity, by virtue of adequate disclosure, to make in the context of his or her personal interest. Thus, by recognising the existence of the patient’s personal interest by making adequate disclosure, the doctor would be given the opportunity to act beneficently and minimise medicalised decision-making.

201 As, for example, suggested by Devereux in Freckelton and Petersen, 1999, 77.
(b) Beneficence and patients without decision-making capacity

In relation to patients who are unable to exercise the entitlement to decide (for example, because of lack of decision-making capacity or because the state intervenes in decision-making), the beneficence principle should inform the disclosure obligation and define the substitute decision-maker’s decision-making duty. Also, for patients without decision-making capacity, the beneficence principle should inform the content of the decision by the substitute decision-maker. When beneficence is informing the content of a decision-making obligation owed by substitute decision-makers, it will do so by directing the decision-maker’s attention to the entirety of the patient’s personal interest. These points are explained fully in Chapter 2.

(c) A note about doctors’ control over their work

Doctors have traditionally asserted, and been recognised as having, an interest in protecting their autonomy as members of a profession.202 In this context, ‘autonomy’ has a narrow and negative interpretation, and refers to a doctor’s entitlement to treat patients according to his or her own conscience and clinical judgement, free from external control.

In particular, professional autonomy is concerned principally with freedom from lay control, whether by government agencies, or by private bodies such as health insurance funds and health maintenance organisations,203 rather than with freedom from peer review or supervision. Such positions are justified not by doctors’ professional autonomy as an end in itself, but as being instrumental in achieving a socially-valued end: provision of high quality health care. Doctors tend to resist lay control or scrutiny when it is perceived as threatening their ability to give primacy to their patients’ interests. Similarly, perceptions and fears that doctors may be held accountable by parties other than their peers or their patients have excited concerns that such accountability may be in conflict with patients’ interests.204 This suggests that


203 See, for example, Choudhry and Brennan, 2001; Dr Ian Pryor (then President, Australian Medical Association, ACT), Letters to the Editor, The Canberra Times, 26 July 2001.

204 See, for example, Metherall, 25 September 2000; Donohoe, Letter to the Editor, 16 February 2001; Daily Telegraph, 19 March 2001; Cook, 28 March 2001; Contractor and Noonan, 29 March 2001;
‘professional autonomy’ is important to doctors not because of their professional status as such, but because their independence is important to secure a particular outcome for their patients. It is apparent that appeals to ‘professional autonomy’ emphasise the principle of beneficence, rather than that of respect for autonomy, as the term is used in this thesis, and that such appeals are not inconsistent with arguments for respect for patients’ autonomy in decision-making in the doctor-patient relationship.

1.6 CONCLUSION

This thesis is concerned with the protection of the patients’ personal interest. Normally, the law allows the patient to make decisions about medical treatment, recognising that this is usually the best form of protection for that interest. However, this presumption may be displaced on the basis of harm prevention. This thesis argues that this should be done only if the test proposed in section 4.3 is satisfied. That test applies wherever it is proposed to balance the patient’s personal interest against a harm prevention policy protecting competing public considerations or the personal interest of third parties. These circumstances are considered in Chapters 4 and 5. This Chapter considers the principles of respect for autonomy and beneficence, which have conventionally been regarded as shaping the law in this area. The argument in this Chapter shows that beneficence should be understood as supporting the autonomy principle in its work, by defining the disclosure obligation which is the prerequisite of meaningful decision-making by the patient, in light of the personal interest. Chapters 2 to 5 offer some further discussion as to how the principle of beneficence could work in tandem with the principle of respect for autonomy. From this, it emerges that beneficence informs the identification of substitute decision-makers and their obligations, and the doctor’s disclosure obligation, whether it be to patients or to substitute decision-makers.

This analysis is undertaken to show the true, complementary relationship between beneficence and respect for autonomy, and to indicate how patients’ personal interests are to be protected when, for the reasons explored in subsequent Chapters, the entitlement to decide is displaced. Without a clear understanding of how the relationship between the two principles should work, the scope and significance of the patient’s

entitlement to decide, as a protection for the personal interest, is not properly comprehensible. The discussion undertaken in this Chapter, and reinforced in subsequent chapters, illustrates that conventional wisdom seems to misunderstand the role of the beneficence principle, first, by conceiving of it as being in conflict with the autonomy principle and, second, by understanding it in terms that overemphasise clinical values at the expense of other aspects of patients’ interests.

Thus, I argue that patients have a personal interest which the law should protect, even at the expense of doctors’ professional independence and compliance with altruistic traditions. According priority to the recognition and protection of patients’ personal interests is necessary because of the imbalances of effect and authority, and the potential for medicalisation. To be of practical value, legal rules about decision-making and disclosure in the doctor-patient relationship should address these imbalances. Because of the inescapability of the imbalance of effect, it is necessary for legal rules to address it, first, by explicitly acknowledging the individual and holistic nature of patients’ personal interests, and the intimate and enduring nature of the effects that health care can have on them. Second, legal rules should mitigate, as far as possible, the imbalance of authority. Two normative principles are important for these purposes — respect for autonomy and beneficence. These can be seen as corresponding to, and explaining, the purposes of independence and care that direct the doctor-patient relationship. This Chapter argued that the autonomy and beneficence principles should be understood as operating in tandem to underpin the doctor-patient relationship.
CHAPTER 2  THE PERSONAL INTEREST OF PATIENTS WITHOUT DECISION-MAKING CAPACITY – THE ROLE OF BENEFICENCE

2.1 INTRODUCTION

Particular consideration should be given to patients without decision-making capacity, and how their personal interest might best be protected. That is what this Chapter is about. It is a necessary precursor to the consideration, in following Chapters, of when the usual substitute decision-maker’s responsibility to decide is a less effective protection for the personal interest than implementation of a harm prevention policy.

It is widely accepted in common law and in relevant statutory provisions that, if a patient lacks decision-making capacity, a substitute decision-maker ought to be appointed. Because of the significance of the personal interest described in Chapter 1, that person ought to be someone as well-acquainted as possible with the patient’s personal interest (so that the substitute decision-maker’s decision is meaningful in the terms described in Chapter 1). This would enable substitute decision-makers to comply with the beneficence principle by making decisions aligned as closely as possible with patients’ personal interests.

This Chapter argues that current law about the purpose of disclosure to substitute decision-makers does not comply with the beneficence principle because it does not direct attention to the entirety of the patient’s personal interest which should be the focus of that principle. I have already argued that decision-making, in the absence of adequate disclosure, is meaningless. This is because a patient can make a decision in the

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205 See, especially, paragraph 3.2.1 (a) for a definition of decision-making capacity for the purposes of this thesis.

206 In Chapters 2 and 3, ‘substitute decision-maker’ describes persons and entities (including courts and tribunals) who make health care decisions for others. For the purposes of these Chapters, ‘substitute decision’ refers to decisions made by any person or entity (including a court or tribunal) other than the patient. In Chapters 4 and 5, references will be made to ‘usual substitute decision-makers’. This includes parents, guardians, persons appointed by powers of attorney and advance health care directives. I draw a distinction between such persons and instruments of state, such as courts and tribunals, making decisions that may displace decisions taken by usual substitute decision-makers. In such cases, I refer to the entitlement to decide or responsibility to decide being displaced by state intervention.

207 Whether by statutory mechanisms, or private instruments, such as enduring powers of attorney or advance health care directives.
context of his or her personal interest only if he or she has access to material information about the proposed treatment. ‘Meaning’ should be seen as deriving from the patient (or the patient’s substitute decision-maker) being given the opportunity to weigh up the information about treatment against the background of all circumstances of the patient’s life. That opportunity is afforded by disclosure of material information. Accordingly, this Chapter considers the significance of the principle of beneficence in shaping the doctor’s disclosure obligation and the substitute decision-maker’s decision-making obligation (with particular reference to the best interests test, which has been taken by the common law in Australia and England, for example, to define the substitute decision-maker’s obligation to the patient).

By undertaking this examination of what kind of disclosure should be made to substitute decision-makers, it is hoped to emphasise the role of disclosure in supporting the patient’s entitlement to decide and the substitute decision-maker’s responsibility to decide. To do this, Chapter 2 further develops arguments and themes identified in Chapter 1, relating to the personal interest and the ‘medicalisation’ of decision-making. This thesis does not seek to describe the kinds of decisions that should be made by substitute decision-makers, or to consider in detail matters such as the selection of a substitute decision-maker and how to resolve disputes between persons who may advance competing claims to be identified as substitute decision-makers. Instead, Chapter 2 makes proposals of a formal kind about the basis on which doctors should be required to make disclosure to substitute decision-makers, to enable the substitute decision-makers to act beneficently, and thus protect patients’ personal interests. By acting in accordance with these proposals, doctors could themselves also be said to act beneficently.

To make these proposals, it is necessary first to describe in some further detail the role of the beneficence principle, and the actors to whom it should apply. This Chapter then considers how the law currently envisages the purpose of disclosure and the implications of the currently-applied ‘best interests’ test for decisions made for patients without decision-making capacity.

208 That is, a reflection of the patient’s personal interest.
209 That is, the undue emphasis on clinical values at the expense of other kinds of values and interests.
2.2 THE ROLE OF THE PRINCIPLE OF BENEFICENCE

Fundamental to this thesis is the premise that a patient's lack of decision-making capacity is not relevant to the patient's legal or moral claim to be treated beneficently. In considering the application of the principle of beneficence in the doctor-patient relationship, common law courts have not accorded significance to the status of moral or legal personhood. The courts have accepted that a patient has claims on the legal and health care systems, for treatment in accordance with the beneficence principle, simply by virtue of his or her status as a human being.

Accordingly, Chapter 1 argues that the principles of beneficence and respect for autonomy are fundamental to the doctor-patient relationship because of the purposes of care and independence and the imbalances of authority and effect that apply within the relationship. Whether or not a patient possesses decision-making capacity, these purposes and imbalances are present (although their degree of presence varies between patients). I have also argued that the autonomy and beneficence principles should be understood as operating in tandem within the doctor-patient relationship.

The beneficence principle should be given content in a way that, as far as is reasonably possible, furthers the purposes of care and independence and mitigates the imbalances of effect and authority. That is, the various roles of beneficence, described in the following paragraph, are directed towards providing care, maximising autonomy, minimising the impact of treatment (especially minimising the risk of adverse outcomes) and lessening the imbalance of knowledge by triggering the doctor's obligation to disclose.

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210 For more detailed information on such issues, see for example QLRC Report No. 49, 1996.

211 See, for example, Department of Health and Community Services (NT) v JWB and SMB ("Re Marion") (1992) 175 CLR 218; Airedale NHS Trust v Bland [1993] AC 789, especially 820; Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961. See also Eburn, 1997, in relation to the claims of a living abortus; Hinds, 1995, in relation to anencephalic infants.

212 As recognised in Department of Health and Community Services (NT) v JWB and SMB ("Re Marion") (1992) 175 CLR 218, 266 (Brennan J).

213 For example, in an emergency situation, part of the objective of medical treatment is to restore the patient, as far as possible, to the condition that he or she was in before the emergency. That is, an aim of treating a concussed patient is to put a previously healthy patient back into an alert, cognitively functional state (to maximise their autonomy). Similarly, rehabilitation treatment is about enabling patients to live as independently as possible, both physically and mentally. For discussion of decision-making in emergencies, see section 3.2.5.
The principle of beneficence should be understood as playing four major roles in relation to patients without decision-making capacity. In relation to patients in respect of whom a substitute decision-maker is making a treatment decision (such as a patient without decision-making capacity), the principle of beneficence should define, first, the content of the doctor’s obligation to disclose to the substitute decision-maker. Second, the principle of beneficence should define the kind of decision that must be made by the substitute decision-maker; that is, a decision which reflects (as far as reasonably possible) the patient’s personal interest, and not simply a decision that furthers the patient’s clinical welfare with little or no regard to the patient’s other interests. Third, beneficence should be seen as the source of an obligation, imposed on substitute decision-makers, to give to patients as much information as practicable (taking into account the patients’ limitations) to enable the patient to understand that medical treatment is proposed, and the nature and effects of that treatment. This is because the lack of decision-making capacity does not necessarily imply lack of awareness, and being given information about medical treatment may help to ease fears, as well as to secure compliance. Fourth, in relation to patients without decision-making capacity (and patients to whom the therapeutic privilege applies), the principle of beneficence should be the source of the obligations imposed on doctors and substitute decision-makers to take certain steps after treatment is given, such as monitoring the patient for complications and side-effects and ensuring that relevant information (for example, past adverse drug reactions) is made available to subsequent health care providers and substitute decision-makers.

2.3 THE PERSONAL INTEREST AND THE PURPOSE OF DISCLOSURE

If a patient has decision-making capacity and no other circumstances exist to displace the entitlement to decide on the basis of the test proposed in section 4.3, then the purpose of disclosure is regarded by common law as being to enable the patient to make a meaningful health care decision. This thesis argues that meaning derives from the content of the patient’s personal interest, as defined by the patient. Persons other than the patient can only ever have limited access to its content, and to an understanding of

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215 See section 3.5.2.
the relative weightings and priorities that a patient accords to dimensions of his or her personal interest. However, if a person lacks decision-making capacity, then someone other than the patient should be the decision-maker in relation to the health care decision. This section considers how this affects the purpose of disclosure. By doing so, it further teases out the role of the beneficence principle in decision-making in the doctor-patient relationship.

As foreshadowed, the decision made for the patient should still be ‘meaningful’, but what can give ‘meaning’ to a substitute decision, made with the substitute decision-maker’s necessarily limited access to the patient’s personal interest? The answer currently given by common law courts in Australia and England is that the decision must be in the best interests of the patient. The purpose of a doctor’s disclosure to a substitute decision-maker is therefore understood as enabling the substitute decision-maker to make a decision that is in the patient’s best interests.

This section describes how the personal interest should be understood in relation to patients without decision-making capacity, and shows how the traditional best interests test is insufficient to protect it, because the best interests test may place undue emphasis on the clinical welfare of such patients, at the expense of the other dimensions of their personal interests. That is, the best interests test tends towards medicalisation, despite judicial statements to the effect that best interests should not be equated with best clinical interests. The best interests test does not, therefore, comply with the principle of beneficence (other than in the exceptional emergency cases). Finally, this section proposes an alternative purpose of disclosure for substitute decision-making that does comply with the principle of beneficence as interpreted by this thesis, by requiring doctors to make sufficient disclosure to substitute decision-makers to allow them to make decisions with reference to the patient’s personal interest.

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217 This thesis recognises that, the more profound the patient’s disability, the more limited is the extent to which the patient may be able to identify and express values and wishes.

218 This Chapter does not examine the approach taken in United States jurisdictions, which seems to favour a substituted judgment test for the lawfulness of treatment given to patients without decision-making capacity. See, for example, Matter of Quinlan 355 A.2d 647 (1976).

219 See, for example, In re S (Adult Patient: Sterilisation) [2000] 3 WLR 1288, 1296 (Butler-Sloss P), 1302 (Thorpe LJ).

220 See also section 3.2.5.
2.3.1 The nature of the personal interest of patients to whom the best interests test applies

(a) To whom does the best interests test apply?

The common law in Australia and England applies the best interests test at least to health care decisions made in relation to children without decision-making capacity, and to other patients who have never possessed decision-making capacity. The test may also be applied to patients who have previously possessed capacity, but who have not made clear their wishes about certain circumstances. They may have given indications (formally or otherwise) of their intentions, but these indications may not provide sufficiently specific guidance to a substitute decision-maker. The best interests test has in such cases been used by courts to 'fill in the gaps'. For example, the father of Anthony Bland gave evidence that his son would not have wanted to live in a persistent vegetative state. However, Anthony Bland (who was 17 years old when injured in the collapse of the Hillsborough Stadium) had never specifically spoken of what his wishes might be if such an injury befell him. On this basis, the English Court of Appeal and the House of Lords held that the proper question was whether continuation of treatment would be in his best interests.

(b) Nature of the personal interest for patients without decision-making capacity

Australian common law recognises that interests in bodily integrity and human dignity belong to all patients, however impaired. They are universal. Re Marion emphasised that, so far from being the case that the interests of a profoundly disabled patient are reduced to his or her clinical welfare, the fact of limited or no access to the patient's

221 See, for example, Department of Health and Community Services (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218, 240 (joint judgment).
222 See, for example, the 'health care principle' described in QLRC Report No. 49, 1996, volume 2, 358-9.
225 Airedale NHS Trust v Bland [1993] AC 789, 809 (Sir Thomas Bingham MR), 818 (Butler-Sloss LJ), 833 (Hoffman LJ), 858 (Lord Keith of Kinkel), 866, 872 (Lord Goff of Chieveley), 884 (Lord Lowry), 891, 896-7 (Lord Mustill).
226 See Department of Health and Community Services (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218. For the similar approach that is taken in England, see for example Airedale NHS Trust v Bland [1993] AC 789; Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961.
awareness and understanding requires substitute decision-makers and doctors to take extra care to identify and protect the extra-clinical dimensions of the patient’s personal interest.\textsuperscript{227} At the minimum, therefore, the status of all patients as human beings, not as mere ‘functions’\textsuperscript{228} or ‘object[s] of concern,’\textsuperscript{229} must be taken into account in substitute decision-making,\textsuperscript{230} because no patient’s personal interest is exhausted by the interest in their clinical welfare.\textsuperscript{231} Above all, every patient must be treated as possessing full humanity; lack of decision-making capacity is not relevant to the requirement to show respect for a patient’s interests.

I suggest that the personal interest of a profoundly disabled patient should be regarded as including the interest in bodily integrity, the dignity interest\textsuperscript{232} and, of course, the patient’s status as a human being. In \textit{Bland}, it was suggested in the English Court of Appeal that the rights of patients without decision-making capacity included the rights to be cared for, to be well-remembered, to be respected and ‘to avoid unnecessary humiliating and degrading invasion of his body for no good purpose.’\textsuperscript{233}

Accordingly, I argue that even for profoundly disabled patients who have no way of developing or expressing choices or preferences, and in relation to whom there is no other way to discern specific content of personal interest, the content of the personal interest should not be considered to fall within the exclusive province of medical observation or recommendation. For this reason, no health care decision made for even the most profoundly disabled patient should ever be made on exclusively, or even predominantly, clinical criteria. The principle of beneficence which should require substitute decision-makers to make decisions for patients without decision-making

\textsuperscript{227} Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 266-8 (Brennan J). Contrast patients with decision-making capacity, who are able to define and assert their personal interests for themselves.
\textsuperscript{228} See Hinds, 1995, 194.
\textsuperscript{229} Airedale NHS Trust v Bland [1993] AC 789, 820 (Butler-Sloss LJ); 829 (Hoffman LJ).
\textsuperscript{230} See Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218; Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961.
\textsuperscript{231} Except, possibly, in emergencies: see section 3.2.5.
\textsuperscript{232} The dignity interest should be taken to include the interests in self-perception and self-esteem referred to by the High Court: see Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 239, 252-4 (joint judgment), 267-8 (Brennan J).
\textsuperscript{233} Airedale NHS Trust v Bland [1993] AC 789, 822 (Butler-Sloss LJ).
capacity should be understood to require that such decisions take into account the entirety of patients’ personal interests.

2.3.2 Focus of best interests test on the clinical welfare of patients without decision-making capacity

(a) Content of the best interests test

Two points should be noted at the outset about the current best interests test for substitute decision-making. First, some concept of a best interests test underpins substitute decision-making cases in common law countries such as Australia, England and Canada. The idea of decision-making to protect and promote the interests or welfare of a vulnerable patient is grounded in the principle of beneficence. The test seems simple on its face: it prohibits the making of a decision unless it is in the best interests of the patient.

It should be implicit in this test that the decision-maker must focus on the patients’ needs, preferences and aspirations (where expressed) to make a decision that takes into account the patient’s personal interest, so that the decision tends to enable the patient to ‘lead a life in keeping with [her] needs and capacities’. Consistent with such an approach, the High Court in Re Marion explicitly recognised the significance of proposed sterilisation to the extra-clinical dimensions of a disabled patient’s personal interest, and rejected the tendency to ‘medicalise’ decisions about sterilisation of disabled children, by relying unduly on clinical values and priorities.

However, while the identified purpose of disclosure (to enable a substitute decision-maker to make a decision in the patient’s best interests) is, on its face, consistent with the beneficence principle, it is all too tempting for courts to equate ‘best interests’ with ‘best clinical interests’, defined predominantly (sometimes even

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234 See, for a Canadian example, Re Eve (1986) 31 DLR (4th) 1, 30.

235 Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 260 (joint judgment).

236 See Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 239, 252-4 (joint judgment), 267-8 (Brennan J).

237 Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 251 (joint judgment); 323 (McHugh J, criticising in particular the House of Lords in In re F [1990] 2 AC 1). See also the comments of Butler-Sloss P in In re S (Adult Patient: Sterilisation) [2000] 3 WLR 1288, 1296 that ‘the focus of judicial decisions has been to rein in excessive medical enthusiasm.’
exclusively) by reference to clinical criteria. As this section shows, this has undermined recognition of, and protection for, the entirety of the interests of patients without decision-making capacity.

Second, a major difference between an entitlement to decide exercised by patients with decision-making capacity and a responsibility to decide exercised for other patients is that only a patient with decision-making capacity, acting on his or her own behalf, can assume a risk of dire consequences when it is otherwise apparently not in his or her best interests to do so. By contrast, the law recognises the validity of a substitute decision only if it is in the person's best interests. This is consistent with the beneficence principle as I have defined it, because the interests of a vulnerable patient should not be compromised by another person, when the patient is not in a position to define and assert his or her personal interest.

(b) Clinical welfare dominates 'best interests'

I suggest that the expression 'best interests' is vague, and can mask pre-judgments and enable decision-makers (including judges) to draw conclusions, based on their own subjective perceptions, which they may then use the best interests test to justify. In Re Marion, McHugh J, appearing to recognise this, argued for specific criteria against which to judge 'best interests'. However, although the majority in that case acknowledged the inherent uncertainty of the best interests test, it was held that mandatory judicial authorisation in respect of a non-therapeutic sterilisation was sufficient protection for a patient (presumably on the assumption that judges are trained to make decisions on relevant considerations only, and to recognise and resist other influences). I am not confident that the majority position (or the recent English

238 See McLean, 1999, 102, 105, 107. See also further discussion below as to why it is tempting to rely on exclusively clinical criteria in making substitute decisions.

239 See In the Matter of Robert Quackenbush 383 A.2d 785 (1978). That is, a patient with decision-making capacity can make a decision on any basis he or she chooses, even with fatal consequences: see, for example, Re T (Adult: Refusal of Treatment) [1993] Fam 95; Re C (Refusal of Medical Treatment) [1994] 1 FLR 31.

240 Department of Health and Community Services (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218, 320-2.

241 In Airedale NHS Trust v Bland [1993] AC 789, Lord Browne-Wilkinson (at 883) thought that the Bolam test (see Bolam v Friern Hospital Management Committee [1957] 1 WLR 582) would provide sufficient protection of patients' welfare by virtue of its reliance on professional opinion. This approach
position that clinical welfare does not exhaust the patient’s interests)\textsuperscript{242} is sufficient to protect the personal interests of vulnerable patients, because of the unwillingness of judges to be explicit about what constitutes ‘best interests’, both generally and for particular cases.\textsuperscript{243} In the absence of such explication, ‘best interests’ provides little useful guidance to doctors or substitute decision-makers about how particular kinds of information are to be identified and weighed for relevance,\textsuperscript{244} and may disguise the consideration of irrelevant factors.\textsuperscript{245} The consequence is decision-making that may be idiosyncratic, arbitrary and unaccountable\textsuperscript{246} and dominated by a single criterion or group of criteria, according to the predisposition of the substitute decision-maker.\textsuperscript{247} In particular, I am concerned that substitute decision-making on the basis of the best interests test may be skewed towards a patient’s clinical welfare at the expense of other dimensions of his or her personal interest.

This means that patients who rely on substitute decision-makers may be more vulnerable than other patients to the possibility that the extra-clinical dimensions of their personal interests will be discounted by a doctor making a ‘self-executing medical decision’,\textsuperscript{248} in the form of a recommendation to a substitute decision-maker.\textsuperscript{249} Also, even if a decision is made by a nominated substitute decision-maker rather than by a doctor, the substitute decision-maker may hesitate to base his or her decision on anything but what is perceived to be objective clinical advice, for reasons discussed below. If this is so, the patient may be left without an advocate for the entirety of his or her personal interest.

represents a clear example of medicalisation of the best interests test, because it equates patients’ best interests with responsible medical opinion.

\textsuperscript{242} See, for example, \textit{In re S (Adult Patient: Sterilisation)} [2000] 3 WLR 1288, 1296 (Butler-Sloss P), 1302 (Thorpe LJ).


\textsuperscript{244} \textit{Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’)} (1992) 175 CLR 218, 270 (Brennan J). See also Blackwood, 1994, 256, on the risks for doctors relying on their views of ‘best interests’.

\textsuperscript{245} Cica, 1993, especially 214-6.

\textsuperscript{246} Brennan J refers to an ‘unexaminable discretion’: \textit{Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’)} (1992) 175 CLR 218, 271. See also Brennan J in \textit{In the matter of P v P} (1994) 181 CLR 583.

\textsuperscript{247} \textit{Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’)} (1992) 175 CLR 218, 271; \textit{Re Eve} (1986) 31 DLR (4th).

\textsuperscript{248} I am indebted to Shultz, 1985, for this term.

\textsuperscript{249} \textit{Airedale NHS Trust v Bland} [1993] AC 789, 875 (Lord Lowry), 884 (Lord Browne-Wilkinson).
her personal interest, and is less likely than other patients to have decisions made for him or her that take into account the full personal interest, as far as it can reasonably be determined by the substitute decision-maker.

This is inconsistent with the beneficence principle which, I argue, demands that attention be paid to the patient's aggregate personal interest, not just the patient's clinical welfare. While patients who possess decision-making capacity are legally entitled to make decisions on the basis of matters other than clinical welfare, there is significant risk that decisions made in relation to patients without decision-making capacity may focus only on their clinical welfare. This is unfairly discriminatory, because the difference in treatment is based on an irrelevant criterion: the lack of decision-making capacity in relation to health care. This incapacity is irrelevant, first, because lack of decision-making capacity is not invariably accompanied by the absence of personal preferences or values. Second, even if a patient does lack any capacity to identify and express preferences or values, the patient's clinical welfare does not represent the sum of his or her humanity, and it is that humanity that, as Re Marion recognised, demands recognition, even where unaccompanied by expressions of the personal interest. Thus, although a patient with decision-making capacity is allowed, by the law, to make idiosyncratic decisions and substitute decision-makers may not make such decisions, there is commonality in that both groups are entitled, because of the beneficence principle, to receive as much disclosure as is necessary to put them in a position to make meaningful decisions; that is, decisions reflective of their personal interests.

Medicalisation of decision-making for impaired patients by reduction of their best interests to clinical interests only (or even predominantly) is medical and judicial paternalism, not beneficence as understood for the purposes of this thesis. This is, in my


251 That a patient lacking decision-making capacity may nevertheless have views that should be taken into account by substitute decision-makers is recognised by the Guardianship and Administration Act 2000 (Qld), subparagraph 80D (3) (b) (i). This provision requires the Guardianship and Administration Tribunal to seek a child's views and wishes to assess whether a proposed sterilisation of that child is in his or her best interests.

252 Department of Health and Community Services (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218.

253 That is, decisions that appear to be contrary to best interests, however understood.
view, because such reduction involves defining a person's interests for them, rather than acting to advance the patient's interests as defined, as far as possible, by the patient. It should be remembered that in all but the most extreme cases of impairment, patients are able to define and express their interests at some level, and this definition and expression must be taken into account by substitute decision-makers in acting to discharge their obligations of beneficence. Even if patients are not able to express their views, this thesis argues that their best interests are not exhausted by their clinical welfare, and a substitute decision-maker is obliged to decide by reference to the patient's entire personal interest, even if specific wishes and preferences cannot be taken into account.

The best interests test is susceptible to medicalisation (that is, undue emphasis of clinical values) because of assumptions about the nature of clinical information. First, such information is generally presented and perceived as being free from subjective judgements. This assumption was rejected in Chapter 1. Clinical information is also perceived as having a degree of certainty that other kinds of information do not. The appearance of certainty provides comfort and reassurance for patients, families and doctors, although it is only an appearance, the practice of medicine offering few certainties. Nevertheless, the perceptions of objectivity and certainty make clinical information attractive as a basis for substitute decision-making.

For conscientious substitute decision-makers, these perceptions may provide greater confidence that the information used for decision-making is certain and objective, and immune from prejudices and stereotypes that have, in the past, undermined the protection and care of vulnerable patients. These have included the prejudices that led to sterilisation on the basis of criteria including race, class and disability. However, the practice of modern medicine is not value-free, and doctors are not isolated from judgmentalism, biases or tunnel-vision. For example, research reported in 1995 indicated that Victorian general practitioners held negative perceptions about adolescent patients that affected the medical care provided to them. Research reported in the

254 Acknowledged in Department of Health and Community Services (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218, 250 (including note 27), 251 (joint judgment); Re Eve (1986) 31 DLR (4th) 1, 22, 23 (and references); see also Buck v Bell 274 US 200 (1927). See Brady, Briton and Grover, 2001; Brady and Grover, 1997, Chapter 2; Cica, 1993, 224-6.

British Medical Journal in 2004 indicated that a randomly selected sample of 46 general practitioners tended to stereotype patients with chronic fatigue syndrome as having certain undesirable traits. This was found to be as a result of

...the lack of a precise bodily location; the reclassification of the syndrome over time; transgression of social roles, with patients seen as failing to conform to the work ethic and 'sick role' and conflict between doctor and patient over causes and management.256

The apparent objectivity and certainty of clinical information can also seem attractive to less conscientious substitute decision-makers, because it provides a comparatively simple and convenient basis on which to make decisions, and does not require what may be painstaking, frustrating and time-consuming communication with family members or with patients for whom communication presents great difficulty.

Thus, in a health care environment of institutional resource constraints and severe staff shortages, information that is directed towards the clinical welfare of the patient has the dual attraction of seeming to be low risk and (comparatively) easy to obtain and apply in decision-making. However, the risks that substitute decision-makers seek to avoid, by relying on clinical information and expertise, can be overcome by applying to substitute decision-making the criteria proposed in section 2.3.3.

(c) Illustrations of medicalisation of the best interests test

From an examination of the way in which the best interests test has been applied by Anglo-Australian judges emerges two significant concepts: the perception of conflicting interests belonging to patients and the 'flak jacket' test. Taken together, these concepts (as well as that of the therapeutic privilege, discussed in Chapter 3)257 illustrate the domination of the best interests test by clinical considerations, at the expense of other dimensions of patients' personal interests.

(i) Conflicting interests

The tendency towards medicalisation of the best interests test is, in my view, an unsurprising consequence of the characterisation of clinical welfare as a separate interest rather than as part of the personal interest described in Chapter 1, of the belief

that it may conflict with other interests belonging to the patient and third, of the assumption that the conflict can be resolved by a process in which the various interests of an individual are ‘balanced’ against each other.

I suggest that, to the extent that the law views the various interests of patients as existing in a state of conflict, this may have given rise to the view that they can be weighed against each other. If the law attempts to ‘weigh’ the various interests, then I believe that it is easy to see how clinically-defined and apparently objectively-measurable health and well-being can trump such immeasurable and apparently subjective concepts as the patient’s dignity interest. This is why, if the law is to take seriously the personal interest, it should abandon any artificial notion of purporting to ‘weighing’ a patient’s interests against each other, and recognise the personal interest as indivisible.

Even if a conflict between interests did exist, it is doubtful that it could be resolved by balancing a patient’s clinical welfare against other interests. In Re Marion, Brennan J expressed doubts about the usefulness of the balancing process to determine the best interests of a patient without decision-making capacity, remarking that ‘The values on either side of the balance are not comparable.’ This observation is true in all disclosure cases, including those involving patients with undisputed decision-making capacity, but in relation to whom a balancing process has nevertheless been applied by Australian judges to determine the scope of disclosure.

The various interests that are said in this thesis to comprise a patient’s personal interest, while not capable of isolation or discrete existence, are not of like character or quality. The personal interest is, I argue, best understood as an aggregate of disparate interests, fully known and comprehensible only to the person to whom the aggregate belongs; that is, the patient. Relative priorities are a matter of individual judgement and may change

257 See section 3.5.2.
258 See, for example, Rogers v Whitaker (1992) 175 CLR 479 and F v R (1983) 33 SASR 189.
259 For the futility of such an exercise, see the judgment of Brennan J in Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218.
260 Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 277.
261 See section 3.5.3.
frequently during a person’s life. The balancing process has only appeared to work satisfactorily because the (generally) unstated assumption is that the interest in clinical welfare should be given greater weight, in a perceived conflict, than other interests. The operation of this assumption is also demonstrated by judicial acceptance of the therapeutic privilege.  

(ii) Flak jacket test

Second, medicalisation of the purpose of disclosure for patients lacking decision-making capacity can be discerned from cases in which there is a dispute between children and adult carers about a health care decision (for example, a child wishes to refuse treatment, and the parent wants the treatment administered, or vice versa). In such cases, the dominant legal policy is to protect doctors from liability in battery, allowing them to treat a child provided only that someone with colourable authority has given consent. This policy has been judicially translated in England into a ‘keyholder’ or ‘flak jacket’ test for validity of consent, as advanced by Lord Donaldson MR (who prefers the description ‘flak jacket’). The flak jacket test assumes that the purpose of disclosure is not to facilitate a meaningful decision, whether by the child or by an adult carer, but to ensure, for the protection of the doctor, that a valid consent can be regarded as having been given. The test requires the presence of the following elements to provide protection to a doctor who is seeking to rely on a consent.

First, the treatment proposed or performed must comply with the Bolam test (that is, the treatment would be acceptable to a responsible body of professional opinion) and also be in the ‘best interests’ of the patient. Second, the treatment must be provided without negligence. Third, the person on whose consent the doctor seeks to rely must possess decision-making capacity and must, in other respects, be someone whom the doctor reasonably believes to have authority to give consent (for example, a doctor could not rely on the consent of an adult whom the doctor knew to be a stranger to the

262 See section 3.5.2.


264 See Bolam v Friern Hospital Management Committee [1957] 1 WLR 582. See also Airedale NHS Trust v Bland [1993] AC 789, 870 (Lord Goff of Chieveley). For a view that the Bolam principle should
child). Fourth, the treatment must otherwise be lawful and not against public policy. It could not, for example, be used to protect a doctor who performed a procedure that amounts to female genital mutilation.\(^{265}\)

Australian common law has appeared to accept the existence of a right, belonging to young people, to accept or refuse treatment.\(^{266}\) It is nevertheless difficult to imagine an Australian court finding a doctor to have committed battery if either a parent or a child with decision-making capacity seeks to refuse recommended treatment when the other party consents.\(^{267}\) It is much more likely that the court would find some way to hold that the doctor had obtained a valid consent from the individual who did agree to the treatment, whether child or parent, so that no legal significance would be attached to the refusal of the other party. This is likely because the policy of protecting doctors that underlies the ‘flak jacket’ test also underlies the approach to validity of consent taken in \textit{Chatterton v Gerson},\(^{268}\) which was accepted as good law by the High Court in \textit{Rogers v Whitaker}.\(^{269}\) The way in which the ‘flak jacket’ test medicalises the purpose of disclosure is described in the following paragraphs.

Provided that the doctor has obtained the consent of one party, then treatment may lawfully be given, and the doctor ‘wears a flak jacket’ against claims of battery by a party challenging the consent.\(^{270}\) The practical implication is that a doctor needs only one person to consent to treatment, but refusal must be unanimous to be effective. Even if there is unanimous refusal, it is still open to a doctor to seek declaratory relief from a court exercising a \textit{parens patriae} or other welfare jurisdiction.\(^{271}\) This approach, no doubt at least partly intended to enable young people to be given treatment for their clinical benefit, shows a bias in favour of acceptance of clinical recommendations made

\begin{itemize}
\item not be determinative of best interests, see \textit{Airedale NHS Trust v Bland} [1993] AC 789, 898 (Lord Mustill) and MacFarlane, 2003, 139.
\item For discussion of the prohibition against female genital mutilation, see paragraph 4.3.3.
\item See \textit{Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218}; see also QLRC Report No. 51, 1996, volume 1, 72-4.
\item For a legislative approach, in which a child’s consent can be respected \textit{if supported by medical opinion}, despite parental objections, see \textit{Consent to Medical Treatment and Palliative Care Act 1995 (SA), s 12.}
\item \textit{Chatterton v Gerson and Anor} [1981] I QB 432, 443.
\item \textit{Rogers v Whitaker} (1992) 175 CLR 479, 490.
\item \textit{In re R (A Minor) (Wardship: Consent to Treatment)} [1992] Fam 11, 23.
\end{itemize}
by the treating doctors, even if other doctors might without negligence disagree with those recommendations.\textsuperscript{272} Although that policy intention is essentially benevolent, it presents problems because there is often no single view among doctors about a patient’s best interests, even if ‘best interests’ is given an interpretation based on criteria that purport to be objective and purely clinical. Indeed, common law courts have expressly recognised that doctors may, without negligence, hold divergent views on matters of diagnosis and treatment.\textsuperscript{273} The flak jacket test effectively allows a doctor to choose which decision to act upon, producing self-executing medical decisions.\textsuperscript{274} Such decisions may not, because of doctor’s limited frame of reference,\textsuperscript{275} be consistent with the beneficence principle as defined in Chapter 1 because they need not take into account anything other than the patient’s clinical welfare, whereas beneficence, as understood in this thesis, requires a more holistic approach.

Fundamentally, the ‘flak jacket’ test is flawed because of its misunderstanding of what is now accepted (by virtue of authoritative judicial recognition of the paramount entitlement to decide) as being the most important purpose of obtaining consent. The leading advocate of the ‘flak jacket’ test appears to believe that the dominant purposes of consent are clinical benefit and protection of doctors from battery claims.\textsuperscript{276} Although the protection of doctors is an important purpose underlying the requirement that doctors obtain consent from patients before treatment, this purpose is derivative of the patient’s entitlement to decide; without that entitlement, there would be no liability

\textsuperscript{271} For example, under the \textit{Family Law Rules 2004}, Division 4.2.3.
\textsuperscript{272} See \textit{In re J (A Minor) (Child in Care: Medical Treatment)} [1993] Fam 15, 27 (Lord Donaldson MR).
\textsuperscript{273} See \textit{Bolam v Friern Hospital Management Committee} [1957] 1 WLR 582, which holds that as long as a responsible body of medical opinion accepts a particular course of action as appropriate, it matters not that an equally responsible body of medical opinion would prefer an alternative course of action. In 1998, an additional requirement was imposed by the House of Lords - that the opinion not be ‘irrational’: \textit{Bolitho v City and Hackney Health Authority} [1998] AC 232. See also \textit{Pearce v United Bristol Healthcare NHS Trust} (1998) 48 BMLR 118, 124. For examples of courts applying a Bolam approach (that, asking if a particular course is acceptable to a responsible body of doctors) to determine whether a proposed course of action is in the patient’s best interests (and thereby applying medicalised values to determine the best interests issue), see \textit{Airedale NHS Trust v Bland} [1993] AC 789; \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961.
\textsuperscript{274} See \textit{Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’)} (1992) 175 CLR 218, 251 (joint judgment); \textit{Airedale NHS Trust v Bland} [1993] AC 789, 875 (Lord Lowry). The decisions are self-executing because the doctor effectively makes the decision by needing only to persuade one relevant person of the merits of his or her recommendation.
\textsuperscript{275} \textit{Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’)} (1992) 175 CLR 218, 251 (joint judgment).
for the doctor in treating without consent. Furthermore, the purpose of clinical benefit, though still manifest in the continued acceptance of the therapeutic privilege and the balancing process, should not continue to be accepted as a purpose of disclosure, to the extent that it may undermine the entitlement to decide by acting as a limitation upon it (for example, when a doctor decides that he or she should not disclose a risk because to do so might deter a patient from undergoing treatment and thus impair his or her clinical welfare).

Consequently, if a doctor treats a patient who has decision-making capacity without consent, then I suggest that the doctor has committed a wrong by failing to respect the patient’s autonomy. If the doctor treats a patient without decision-making capacity, and does so without the consent of the substitute decision-maker, I suggest that the doctor’s fault is that he or she has failed to allow the substitute decision-maker to discharge his or her responsibility to act in accordance with the beneficence principle, by making a decision that protects the patient’s personal interest, and by adequately explaining the decision to the patient. Such a failure is itself a breach, by the doctor, of his or her own obligation of beneficence.

While seeking not to trivialise doctors’ legitimate concerns that they treat people lawfully, and are protected from frivolous or vexatious litigation, it must be remembered that consent (whether by the patient or by a substitute decision-maker) is not a procedural formality, but a substantive safeguard for the personal interests of all patients. Despite this, the primary policy objective of the flak jacket test is to protect a doctor from claims that he or she has treated a young person without valid consent. It does not ensure that the exercise of decision-making capacity by a young person is protected, in accordance with the entitlement to decide. Nor does it ensure that a substitute decision-maker can make a beneficent decision. By its focus on protecting clinical judgements at the expense of the exercise of meaningful decision-making by patients or substitute decision-makers, the use of the flak jacket test illustrates medicalisation of the best interests test.

276 See In re W (A Minor) (Medical Treatment: Court’s Jurisdiction) [1993] Fam 64, 84.
Medicalisation of the best interests test: subordinating the extra-clinical dimensions of the doctor-patient relationship

Medicalisation of the best interests tests has two aspects: the elevation of the clinical aspect of the doctor-patient relationship, described in the preceding paragraphs, and a corresponding subordination of other aspects, dealt with in this subsection. Subordination is possible because, accompanying the recognition that substitute decision-making must take into account a patient’s ‘background, upbringing, education, convictions and temperament,’\(^{277}\) are two beliefs that, although inconsistent, nevertheless operate concurrently in judicial consideration of decision-making in the doctor-patient relationship. The first of these is a belief that the extra-clinical dimensions of the doctor-patient relationship can, if a perceived conflict between clinical and other values arises, be treated as extrinsic to the purpose of the relationship.\(^{278}\) An example can be seen in the recent debate over the use of embryonic stem-cells for therapeutic purposes. Advocates of research into such therapy sometimes employ arguments to the effect that such treatment holds considerable promise for grave conditions such as Parkinson’s Disease and Alzheimer’s Disease, and that moral concerns should not be determinative of the question of whether to allow or prohibit the use of embryonic stem cells for these purposes. In this way, the moral dimension of health care is divorced from, then subordinated to, the clinical or scientific dimension.

The second belief is that medical issues subsume moral issues, so that the medical profession is qualified to pronounce on moral matters, as an aspect of the public authority described in Chapter 1 as attributed to doctors. This belief may arise from a number of circumstances. First, recent technical and scientific developments in clinical research and practice raise moral issues, often in very dramatic ways. However, this does not mean that doctors or researchers have any particular standing to speak on the moral issues raised by their work (although they do have special standing to speak about its compliance with relevant professional codes of ethics). An assumption that they do confuses technical authority with moral authority.\(^{279}\) Technical expertise entitles practitioners to be treated as authoritative when they offer theories and observations in


\(^{278}\) See Stewart, 1997, 393-4.

\(^{279}\) See, for example, McLean, 1999, especially 18-19.
their field of expertise, and explanations of these. However, as has been argued elsewhere, \textsuperscript{280} technical expertise should not be taken to confer any particular authority to make statements about the moral implications of medical and scientific practice and research, or even about the nature of the moral decisions, arising from this work, that may be required to be made by the community.

Second, with the increasing secularisation of society, it is possible that doctors are seen as the ‘new priests’. Doctors possess complex information that is crucial to biological survival, and practise arcane arts. In addition, the doctor-patient relationship invites (and frequently requires) doctors to assume the roles of confessor and adviser, confidants of our most intimate and volatile secrets. If doctors have taken the place of clergy, they may be perceived as having assumed, together with the confessor/adviser role, the role of moral teachers. Third, perhaps because medical advances are seen as means to ends which have clear moral dimensions, doctors may be seen as being entitled to speak on the merits of both the means and the ends, and to advise on the relative merits of means among which the community may choose.

Despite attempts to subordinate the moral to the medical, and to subsume the moral into the medical, the purposes of independence and care and the imbalances of authority and effect that underpin the doctor-patient relationship should still be recognised as enlivening the application of the moral principles of respect for autonomy and beneficence (as argued in Chapter 1). The fundamental significance of these purposes and imbalances in the doctor-patient relationship means that, at all times, that relationship should be understood as having a moral focus that is distinct from its clinical aspect.\textsuperscript{281} That focus is on protecting patients’ personal interests. This is most apparent in emotionally-charged cases that raise issues of life and death or of great social or political significance. In such cases, it seems that there is heightened judicial, political and community sensitivity to the extra-clinical dimensions of patients’ personal interests.\textsuperscript{282}

\textsuperscript{280} See, for example, McLean, 1999.
\textsuperscript{281} Which is a major theme in McLean, 1989.
\textsuperscript{282} For example, cases involving the withdrawal of treatment or the sterilisation of disabled children.
I argue that these dimensions, the purposes of independence and care, the imbalances of authority and effect and, above all, the personal interest, are present in all doctor-patient relationships, no matter how mundane or fleeting. This is less well-recognised, so that although Lord Templeman rejected the view that a doctor is in a position to determine the best interests of a girl seeking contraceptive treatment and advice (expressly because of the extra-clinical implications), his Lordship had previously been content to hold that a doctor can judge the best interests of an adult patient considering major, invasive and risky surgery.283

Furthermore, I argue that the moral character of the relationship is in no way altered or diminished by reason of the incapacity of a patient to make health care decisions, or to form and express values, preferences or a sense of self. Rather, the severity of the imbalance of authority in such cases (notwithstanding the presence of a substitute decision-maker) should be understood to intensify the obligation of care owed by doctors and substitute decision-makers. This is necessary to protect the patient’s personal interest, the patient’s assertion of which is threatened by the imbalance of authority. Accordingly, doctors should only form judgements about clinical issues, because only such issues fall within the parameters of the doctor’s true authority. The issue of whether a particular course of action serves the patient’s personal interest is beyond the scope of such judgements.

(e) Why reliance on a medicalised test does not comply with the beneficence principle

There are four reasons why I argue that medicalisation of the best interests test is inconsistent with the application of the principle of beneficence to patients without decision-making capacity. First, it perpetuates the myth that the practice of medicine is value-free and that health care decisions can, and even should, be similarly value-free. This myth is particularly dangerous in relation to vulnerable patients, because they have traditionally been the victim of many medical (and judicial) misconceptions and stereotypes. A test that does not make explicit relevant and irrelevant factors can operate

283 Gillick v West Norfolk AHA [1986] 1 AC 112, 201-5; Sidaway v Governors of Bethlem Royal Hospital and Ors [1985] 1 AC 871, 904-5.
to their disadvantage without an awareness by the community of how or why this is so.  

Second, the best interests test attempts to mask subjective and unaccountable decisions made under the guise of an ‘objective’ test, and leaves actual operation of the test as a matter of uncertainty. This does not benefit patients, carers or health care providers. Third, the perception of objectivity ignores the reality that the personal interest of a patient is inherently subjective. Finally, the vagueness of the best interests test leaves open the possibility that Australian judges may, like English courts, be inclined to apply a Bolam-type test\(^{285}\) to define the best interests of patients without decision-making capacity, particularly if there is a conflict between carers, substitute decision-makers and doctors. This would mean that a clinical view of what constitutes a patient’s best interests can be assumed (wrongly) to define the course of action that would advance the patient’s entire personal interest.\(^{286}\) Although this would be incompatible with the principle of beneficence as defined in this thesis, it could occur because, although the Bolam test has not been as persuasive in Australia in relation to setting standards of care for health care decision-making,\(^{287}\) clinical perspectives on best interests offer an attractive option for the difficult exercise of substitute decision-making, for reasons described earlier in this Chapter. Views expressed by commentators such as Cica and Kennedy,\(^{288}\) to the effect that the best interests tests operates simply as a figleaf for the individual judgement of a substitute decision-maker, seem to be justified.

### 2.3.3 Making the personal interest central to decision-making for patients without capacity: framing an alternative test to define the purpose of disclosure to substitute decision-makers

A purpose of disclosure that is framed as requiring disclosure for the purpose of enabling a substitute decision-maker to decide in the patient’s ‘best interests’ is not, 

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\(^{284}\) Acknowledged in *Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 250 (including note 27), 251 (joint judgment); *Re Eve* (1986) 31 DLR (4th) 1, 22, 23 (and references cited there). See also Brady, Briton and Grover, 2001; Brady and Grover, 1997, Chapter 2. See also *Buck v Bell* 274 US 200 (1927) as an example of irrelevant factors being taken into account.

\(^{285}\) *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.

\(^{286}\) And that it would be necessary only for that clinical view to be shared by a responsible body of doctors, not that there be a consensus on what constituted the patient’s best interests.


therefore, a purpose that is necessarily consistent with the beneficence principle. This is because it assumes that a meaningful substitute decision may be made on the basis of predominantly clinical information, and encourages over-reliance by substitute decision-makers on medical information. I accept that, when defining the purpose of disclosure, it is necessary to take into account the exigencies of the doctor-patient relationship, and the limited frame of reference within which doctors must work. Nevertheless, I suggest that disclosure should include ways in which proposed and alternative treatments might reasonably be expected to affect dimensions of the personal interest other than clinical welfare, including self-perception and identity, personal relationships, spiritual life, and occupational and financial matters. For example, if a doctor prescribes a medication, a material risk of which is to adversely affect the expression of sexuality (for example, some psychotropic drugs), the doctor should disclose that risk. More importantly, a broader definition of the purpose of disclosure would make clear to substitute decision-makers that they cannot, in the discharge of their functions, rely principally on clinical information and advice, but should take into account a more extensive range of information.

It is necessary therefore to frame the purpose of disclosure in a way that makes explicit the need for substitute decision-makers to make a meaningful decision by directing their minds to the entirety of the personal interest of the patients. Accordingly, this section offers a ‘personal interest test’ for the purpose of disclosure to substitute decision-makers. The test does not purport to offer guidance as to the substance of particular substitute decisions. Instead, it aims to establish criteria against which proposed decisions by substitute decision-makers can be judged to be meaningful in the sense of reflecting, as far as possible, the patient’s personal interest. The purpose of disclosure, from a doctor’s perspective, is then to assist a substitute decision-maker to make a meaningful decision in accordance with these criteria. From the perspective of the substitute decision-maker, the purpose of disclosure by the doctor is to enable the substitute decision-maker to take clinical information and advice into account in the broader context of the patient’s personal interest, so that the substitute decision-maker can act beneficently by making meaningful decisions for the patient and by giving the patient an appropriate explanation. It should be emphasised that, without proper disclosure from the doctor, the substitute decision-maker is unable to comply with his or
her obligations of beneficence, because disclosure by the doctor is a precondition of meaningful decision-making.

(a) Substitute decision-makers should have regard to the interests of the patient, and not of others

First, a substitute decision-maker should generally make a decision based on the personal interest of the patient alone. Brennan J took the view that the only utility of the existing best interests test was to emphasise 'that the first and paramount consideration is the interests of the child, not the interests of others.' This point of view is consistent with the view taken by McHugh J that a substitute decision-maker is subject to obligations that are of a fiduciary character, and that include the obligation to avoid conflicts of interest. The possibility of conflicts of interest is one reason why non-therapeutic sterilisation of disabled children is a decision in relation to which parents and other carers cannot act as substitute decision-makers. While recognising the good faith of the majority of substitute decision-makers, the High Court recognised that the interests of carers and family members may be given inappropriate weight in deciding whether to sterilise a disabled child.

(b) Substitute decision-makers should make decisions that enhance the entire personal interest

Second, as emphasised in this Chapter, a substitute decision-maker should make a decision that enhances the patient's personal interest. This would assist the substitute decision-maker to mitigate the imbalances of the doctor-patient relationship. For example, the imbalance of effect may be mitigated by making decisions that minimise the risk of adverse consequences to be suffered by the patient, whether by

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289 See Chapter 5 for circumstances in which the interests of third parties may be taken into account.
290 Department of Health and Community Services (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218, 273.
291 Department of Health and Community Services (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218, 317, 322.
292 See also GWW and CMW (1997) FLC 92-748, in which a single judge of the Family Court of Australia held that, because of the potential for conflicts of interest, judicial authorisation was necessary in respect of a proposed harvest of bone marrow or peripheral blood from a child for the benefit of his maternal aunt.
293 Department of Health and Community Services (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218, 251-2 (joint judgment), 272 (Brennan J). See also George, 1996, 230-1.
materialisation of risks or as a result of undergoing treatment against his or her will.\textsuperscript{294} The imbalance of authority can be mitigated by ensuring that the patient is not further disadvantaged by reason that he or she is not able to seek and evaluate information on his or her own behalf. In particular, the doctor must give disclosure about risks and alternatives that enables a substitute decision-maker to make a decision that does not unnecessarily compromise reasonably foreseeable decisions that the patient could make if the patient recovers or acquires decision-making capacity.\textsuperscript{295}

In determining the content of the patient’s personal interest, the substitute decision-maker should have regard to choices, preferences or beliefs expressed by the patient,\textsuperscript{296} to the extent that the patient is (or has been) capable of giving expression to his or her personal interest. Even if the patient has never had decision-making capacity, the patient may nevertheless have formed or expressed preferences and choices, and may be vulnerable to distress if these seem to be taken lightly or overridden by caregivers. Such distress may be particularly acute if the patient is not able to comprehend the reasons for a course of action taken on his or her behalf. The High Court demonstrated its appreciation of such distress, and its importance, in relation to disabled persons who have undergone involuntary sterilisation. The judges referred to damage to the self-esteem and self-perception of patients who did not have the capacity to make decisions, but who nevertheless had self-awareness, and expectations about how to express that self-awareness.\textsuperscript{297} In the case of patients who have never had, and never will have, self-awareness of any kind, or the capacity to communicate it, then the beneficence principle requires a substitute decision-maker to make decisions that respect the patient’s humanity.

\textsuperscript{294} See Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 251-3 (joint judgment); 267 (Brennan J); 320 (McHugh J).

\textsuperscript{295} See also Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 320 (McHugh J).

\textsuperscript{296} See ALRC Report No. 57, 1992, paragraph 6.21.

\textsuperscript{297} Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 251-3 (joint judgment); 267 (Brennan J); 320 (McHugh J).
Third, the beneficence principle, as defined in Chapter 1, requires a substitute decision-maker to consider whether the purpose of proposed treatment is therapeutic or non-therapeutic. There are some kinds of procedure which, if they are proposed for a non-therapeutic purpose, cannot be consented to, or cannot be consented to by certain substitute decision-makers. A notable example of the latter kind of treatment is non-therapeutic sterilisation of female children. Certain special features of the procedure persuaded the High Court that only judicial authorisation would give sufficient protection to patients. The special features identified by the Court might also apply to proposed non-therapeutic treatment that related to matters such as gender identity and sexuality. An even stricter view was taken by Brennan J, who followed the approach taken by the Canadian Supreme Court in Re Eve to hold that non-therapeutic sterilisations could never be consented to or authorised by any substitute decision-maker.

Except for these kinds of cases, the purpose of the treatment is relevant for the proposed test, but not determinative. If proposed treatment meets all the other criteria described in this section, its non-therapeutic purpose does not necessarily mean that it would be inconsistent with the beneficence principle to allow a child to undergo the treatment.

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298 See section 3.3 for the distinction between therapeutic and non-therapeutic treatment.

299 See Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 274 (Brennan J). See also In re S (Adult Patient: Sterilisation) [2000] 3 WLR 1288, 1298 (Butler-Sloss P). For criticism of the distinction in sterilisation cases, see Cica, 1993, 186-96.

300 See Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 240 (joint judgment). See also GWW and CMW (1997) FLC 92-748.

301 Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 246 (joint judgment quoting In re F [1990] 2 AC 1, 56 (Lord Brandon)), 249-52 (joint judgment), 296, 303 (Deane J), 320-1 (McHugh J). See subparagraph 4.3.4 (b) (ii) for a consideration of the special features of sterilisation.

302 Such as sex reassignment surgery: see, for example, In re A (1993) 16 Fam LR 715. Although the proposed procedures in GWW and CMW (1997) FLC 92-748 were not irreversible, the possibility of a conflict of interests (combined with the lack of benefit to the child patient) seems to have been sufficient to influence the judge to hold that ‘special features’ justified the requirement of judicial authorisation.


304 Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 277.

305 As defined in Chapter 1.
Parents routinely and without challenge consent, on behalf of their children, to treatment and other invasive procedures that are carried out for purposes that are social, religious or financial (for example, some orthodontic treatment is non-therapeutic).\textsuperscript{306} Such procedures may be shown, using the other criteria proposed in this section, to be otherwise consistent with the beneficence principle.

However, unless the proposed treatment can be seen, by clear and convincing evidence, to meet the other criteria described in this section, it should not be considered to be consistent with the beneficence principle, as I have defined it. The reason for imposing this onus of proof is to reflect the seriousness of authorising medical treatment on behalf of another person. The gravity of this function is intensified if the proposed treatment is non-therapeutic. This is because, although non-therapeutic treatment may offer benefits of a non-clinical kind (for example, cosmetic benefits), the imbalance of effect in relation to non-therapeutic treatment means that the patient is assuming a set of risks arising from the treatment, rather than exchanging risks relating to the existence of an injury or illness for those of the proposed treatment.\textsuperscript{307}

(d) A substitute decision-maker should take into account proportionality of the proposed treatment\textsuperscript{308}

A substitute decision-maker should also consider whether proposed treatment offers benefits that are proportional to its material risks. The doctor should disclose information that is reasonably material to this consideration.

(e) A substitute decision-maker should avoid the converse of medicalisation

Cica has identified an additional problem affecting the application of the best interests test. The problem is the converse of medicalisation, which should be addressed by any test proposed in relation to the purpose of disclosure.\textsuperscript{309} Her concern is that the best interests test is so vague that it may be used to authorise the use of invasive medical

\textsuperscript{306} On whether male infant circumcision has a therapeutic purpose, see: RACP Paediatric Policy, 2004; QLRC, Circumcision of Male Infants, 1993, Richards, 1996; Haberfield, 1997.

\textsuperscript{307} See section 3.3, and the contrast between non-therapeutic treatment as requiring an assumption of a pattern of risks, and therapeutic treatment, as requiring the exchange of the risks of the patient’s injury or illness for those of treatment of that injury or illness.

\textsuperscript{308} See Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 274 (Brennan J); Cica, 1993, 194.
treatment to attempt to solve what she characterises as social problems relating to caring for patients with disabilities (for example, dealing with menstruation). Although broadening the best interests test is generally to the patient’s advantage because it draws attention to the entirety of the personal interest, Cica is right to express this concern, because the use of medical means to solve non-medical problems exacerbates the imbalances of effect (by exposing the patient to the risks of treatment) and authority (by imposing on the patient an invasion of his or her bodily integrity). The answer, however, is not to narrow the range of relevant considerations to focus only on the patient’s clinical needs, but to ensure that considerations taken into account are particular to the individual patient, and that (as far as possible) they do not reflect stereotypes or social prejudices, and offer the least invasive or restrictive means of protecting and promoting the entirety of the patient’s personal interest.

Substitute decision-maker’s starting point should be a presumption against treatment

Finally, it is useful to consider the concern, expressed by Brennan J in Re Marion, about a lack of ‘hierarchy’. Because the dimensions of the personal interest are not discrete, the construction of a hierarchy to resolve conflicts between these dimensions would serve only to reinforce perceptions of separateness and conflict. However, it is helpful to impose a presumption against treatment. Such a presumption would be consistent with the acknowledged universality and importance of the interest in bodily integrity. Although the presumption would not be taken to arise in an emergency, it could in other cases be rebutted only by evidence that proposed treatment is more likely than not to enhance the patient’s personal interest. This presumption would provide some safeguard against the medicalisation of substitute decision-making, by countering the apparent bias in favour of treatment.

2.4 CONCLUSION

This Chapter argued that both doctors’ and substitute decision-makers’ obligations should be directed to the entirety of the patient’s personal interest, as far as it can be

309 Cica, 1993, 195, 197-8, 216-7, 222. See also Brady, 1996.
310 Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 271.
understood, rather than to (for example) a clinically-interpreted understanding of the patient’s ‘best interests’. Accordingly, this Chapter sought to clarify the implications of a holistically-understood principle of beneficence for decision-making in the doctor-patient relationship. It did so by examining in some detail how the personal interest should operate in defining the purpose of disclosure by the doctor to a substitute decision-maker, and considering the nature of the substitute decision-maker’s obligation to decide.

This Chapter has shown that a patient’s possession or lack of decision-making capacity has had a significant influence on the way in which the common law defines the purpose of disclosure by a doctor to a decision-maker. If the patient is the decision-maker, then the purpose of disclosure is to enable the patient to exercise his or her entitlement to make a meaningful decision. If a doctor must disclose to a substitute decision-maker, because the patient is not able to exercise the entitlement to decide himself or herself, then the purpose of disclosure has been accepted by the common law as being to enable the decision-maker to make a decision in the best interests of the patient. As shown in this Chapter, ‘best interests’ risks being defined from a predominantly clinical perspective, rather than from a perspective that focuses on the entirety of the patient’s personal interest. On this basis, it is concluded that when a substitute decision-maker is involved, the purpose of disclosure may be medicalised and, because it is not directed to the entire personal interest, the purpose is inconsistent with the beneficence principle (because that principle should, as I have argued above, be aimed at the protection of the personal interest).

Second, if my proposed approach to the purpose of disclosure is accepted, then whether a substitute decision is ‘meaningful’ will depend on whether the substitute decision reflects, as far as can reasonably be determined by the substitute decision-maker, the patient’s personal interest. This conclusion flows from two themes of this section: first, that the relevant responsibility of substitute decision-makers is a robust responsibility to decide, not merely a power to endorse decision-making by doctors (just as the entitlement to decide, to be exercised by competent patients, is not merely a power to

311 It is also consistent with a suggestion made by McLean, 1999, 95.
assent to doctors’ decisions). The second theme is that although a medicalised best interests test has conventionally been accepted by courts as a valid and sufficient expression of beneficent conduct, the beneficence principle, when properly understood, requires a broader understanding which enables the protection of the entirety of the patient’s personal interest.

In this Chapter, I have offered evidence from authoritative case law to support the view that, for example, the best interests test is dangerously susceptible to medicalisation. For example, I referred to the judgment of McHugh J in *Re Marion*, which acknowledges that an assessment of ‘best interests’ is a conclusion, not a standard or a principle, although it is often used as such. This means that application of the test can mask prejudgements. Such prejudgements may not be consistent with full appreciation of the patient’s personal interest. Other judgments in that case regret the lack of opportunity, in applying the conventional test, for persons such as teachers and social workers to offer evidence as to patients’ present and future capacities. The flak jacket test discussed in this Chapter also provides evidence of medicalisation of decision-making on behalf of those lacking decision-making capacity.

This Chapter has proposed a new test that re-defines the purpose of disclosure by doctors by reference to patients’ personal interests, thus minimising the potential impact of medicalisation. The significance of the proposed test for purpose of disclosure to substitute decision-makers is that it takes a holistic approach towards patients’ interests, which is consistent with the way in which this thesis sees the role of the principle of beneficence: to protect patients’ personal interests, whether defined by patients themselves or by substitute decision-makers.

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312 See, for example, *Gray v Grunnagle* 223 A.2d 663 (1966).

313 *Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’)*(1992) 175 CLR 218, 320.
PART 2 PROTECTING THE PERSONAL INTEREST: WHEN IS THE ENTITLEMENT TO DECIDE NOT THE MOST EFFECTIVE MEANS?

INTRODUCTION

In Chapters 3 to 5 of this thesis, I consider circumstances in which lawmakers have taken the view that the entitlement to decide, or the usual substitute decision-maker’s responsibility to decide, does not provide the most effective protection for the personal interest.

To date, these circumstances have appeared to be, and have been considered as, a random collection of *ad hoc* situations. This thesis argues, however, that underlying the displacement of the entitlement to decide in these cases is a harm prevention policy, and an unstated (because not properly understood) view either that this policy can sometimes provide better protection for patients’ interests or that this policy is appropriately applied to give precedence to the competing interests of a third party. In section 4.3, I propose a test which would allow lawmakers to determine on the basis of explicit criteria when the entitlement to decide (or usual substitute decision-maker’s responsibility to decide) should apply, and when *either* the patient’s personal interest is better protected by the harm prevention policy *or* it is appropriate to displace the entitlement to decide, or the usual substitute decision-maker’s responsibility to decide, to protect the personal interest of a third party.

Part 2 of this thesis identifies the circumstances in which the entitlement or responsibility to decide is displaced in decision-making in the doctor-patient relationship. This is done by examining decided cases and legislative provisions, to identify and evaluate circumstances in which the entitlement or responsibility to decide has been displaced, and other means employed to protect the personal interest, whether it be of the patient or of a third party. When the entitlement or responsibility is displaced to protect the patient, I suggest that it is usually because there is perceived to be some threat of harm to the patient’s decision-making process; for example, through
lack of capacity (including when the therapeutic privilege or balancing process is thought to apply) or through undue influence by third parties (leading to prohibitions on conduct such as euthanasia, assisted suicide, or female genital mutilation.

Chapter 3 considers circumstances that can be characterised as relating to the patient’s decision-making capacity, which have influenced courts to displace the entitlement to decide. Chapters 4 and 5 describe certain values that have influenced legislatures as well as judges to displace the entitlement to decide on the basis of preventing harm to patients or third parties.
CHAPTER 3 DISPLACING THE ENTITLEMENT TO DECIDE -
LACK OF DECISION-MAKING CAPACITY AND
PERCEIVED THERAPEUTIC NECESSITY

3.1 INTRODUCTION

This Chapter considers two kinds of circumstances in which courts have held that, rather than the entitlement to decide operating, a substitute decision-maker should make treatment decisions: first, when the patient lacks decision-making capacity and, second, when there is a perceived therapeutic necessity for treatment and the doctor believes the patient might decline it for what seems, to the doctor, to be insufficient reason. This Chapter argues that only in the first instance should the patient’s entitlement to decide be displaced. Because displacement for lack of capacity is relatively uncontroversial, more attention will be paid to displacement of the entitlement to decide on the basis of perceived therapeutic necessity.

The circumstances described in this Chapter are not circumstances to which the test in section 4.3 can usefully be applied. This is because that test is intended to be used to balance wider state, or community, interests against the personal interest of the patient. The circumstances described in this Chapter (lack of decision-making capacity, emergency and therapeutic necessity) do not involve this kind of balancing process. Rather, they are (as I will show) about the patient’s state of mind.

Thus, the test in section 4.3 is not applicable in these circumstances, and I have used other arguments, explained in this Chapter, to determine whether lack of capacity or application of either a therapeutic privilege or a balancing process justifies displacement of the entitlement to decide as a preferable way of protecting the patient’s personal interest.

_Lack of decision-making capacity_

Courts have treated a patient’s lack of decision-making capacity as a basis on which to displace the ‘paramount entitlement to decide’ recognised by the High Court as belonging to patients. The possession of decision-making capacity is relevant to the

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application of the entitlement to decide because it is an essential element of the psychological attribute of autonomy. If a patient does not possess that attribute, then the autonomy principle does not apply and the entitlement to decide is not triggered in relation to that patient. In such a case, a substitute decision-maker must exercise decision-making authority for the patient. This Chapter will identify the elements and circumstances of possession of decision-making capacity, and consider rules about the identification of decision-makers. The implications of lack of decision-making capacity for the purpose of disclosure by doctors were considered in Chapter 2.

This thesis accepts that, when a patient lacks decision-making capacity, the patient’s entitlement to decide is displaced and a substitute decision-maker, acting in accordance with the principle of beneficence, should decide for the patient.

**Therapeutic necessity**

Courts in Australia, England and the United States have accepted apparent therapeutic necessity of treatment as a basis on which to displace the entitlement to decide. The aim of this Chapter in considering therapeutic necessity as the basis for a form of *de facto* substitute decision-making is to show, first, that therapeutic necessity is not a ground on which the entitlement to decide should be displaced because displacement on this ground does not serve the personal interest. Second, this Chapter argues that, in any event, the legal rules that have been applied in circumstances of therapeutic necessity, to allow nondisclosure by doctors, have not required doctors’ compliance with the principle of beneficence as I have described it.

These aims are achieved by comparing cases at each extreme of a continuum, along which exists the range of circumstances in relation to which legal rules must be applied. The cases are examined to identify and challenge the assumptions on the basis of which doctors have been permitted to have regard to therapeutic necessity to identify themselves as decision-makers in the doctor-patient relationship, and to define their

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315 Katz, 1984, 106.
316 See Saks, 2002, 47.
317 For example, Rogers v Whitaker (1992) 175 CLR 479; Tai v Saxon (unreported) Full Court of Supreme Court of Western Australia, 8 February 1996; Di Carlo v Dubois [2004] QCA 150.
318 For example, Sidaway v Governors of Bethlem Royal Hospital and Ors [1985] 1 AC 871.
duty of disclosure by reference to clinical values. On the basis of this examination, it is argued, first, that a doctor’s prediction that disclosure will lead to refusal of treatment should not be taken to justify displacement of the entitlement to decide, regardless of the possible consequences of refusal. Second, a balancing process should not be applied as a limitation on the scope of disclosure. Third, beneficence, in any event, requires more than mere nondisclosure. Finally, the autonomy and beneficence principles, as defined in this thesis, often require of doctors the same kind of conduct.

3.2 IDENTIFICATION OF DECISION-MAKERS AND LACK OF DECISION-MAKING CAPACITY

3.2.1 The elements and circumstances of possession of decision-making capacity

This section proposes a definition for possession of capacity that will be relied on in this and subsequent chapters. The definition is comprised of positive and negative aspects. First, elements of the possession of decision-making capacity are identified. Second, circumstances in which that capacity cannot be said to have been exercised are described.

(a) Elements of capacity

There is extensive literature on the elements that the common law requires for an individual to be regarded as possessing decision-making capacity.\(^{320}\) The purpose of this Chapter is not to revisit this literature, but to provide a framework within which persons are generally understood by judges and commentators to possess capacity to make decisions about treatment. A leading Australian formulation of the test of whether someone has decision-making capacity refers to a person who has ‘sufficient understanding and intelligence to enable him or her to understand fully what is proposed.’\(^{321}\) Similarly, in *Gillick v West Norfolk AHA*, Lord Fraser referred to a patient

\(^{319}\) For example, *Canterbury v Spence* 464 F.2d. 772 (1972).

\(^{320}\) Many Australian jurisdictions have enacted statutory tests for capacity; these largely reflect common law statements: see Stewart and Biegler, 2004, 327; see references at note 12.

\(^{321}\) *Department of Health and Community Services (NT) v JWB and SMB* (‘Re Marion’) (1992) 175 CLR 218, 237 (joint judgment), quoting *Gillick v West Norfolk AHA* [1986] AC 112, 183-4 (Lord Scarman). This approach factors in the notion that, the more complex the proposed decision, the higher the threshold for capacity. See also *Re MB (Medical Treatment)* [1997] 2 FLR 426, 436 (Butler-Sloss LJ); Gunn et al, 1999, 273.
who possesses decision-making capacity as being ‘capable of understanding what is proposed, and of expressing his or her own wishes.\footnote{132}

The following capabilities are, I suggest, fundamental to these formulations: the capabilities to understand and retain information, and to consider information in the context of the entirety of one’s personal interest.\footnote{133} In addition, a person must be willing to believe (though not necessarily agree with) information provided to him or her,\footnote{134} and to be able not to hold patently false beliefs.\footnote{135} Finally, the capability to communicate a decision should be included for pragmatic reasons, although it is not inherent in the possession of decision-making capacity. This is because, without a means to communicate the results of the exercise of the other capabilities by the patient, doctors and other persons are not in a position to respect the patient’s autonomy, because there is no way of knowing what must be respected.\footnote{136}

These capabilities focus on process, rather than on predicted outcomes or decisions.\footnote{137} It is conceded that a predicted or actual decision might appear to be so unreasonable as to put a doctor on inquiry about a decision-maker’s possession of the capabilities described above.\footnote{138} However, if the law is to protect a genuine entitlement to decide, then a determination about capacity should be independent of any prediction, however

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\footnote{132}{\textit{Gillick v West Norfolk AHA} [1986] AC 112, 169 (Lord Fraser of Tulleybelton). See also \textit{Re C (Refusal of Medical Treatment)} [1994] 1 FLR 31 and \textit{Re Bridges} [2001] 1 QdR 574, in which a single judge was interpreting the capacity provisions of the \textit{Powers of Attorney Act 1998} (Qld).}

\footnote{133}{See, for example: Stewart, 1999, 9; Katz, 1984, 106. For cases in which the patient refused to believe information, see for example, \textit{Re Bridges} [2001] 1 QdR 574 (patient refused to believe she had kidney disease when she had only 1-2\% renal function) and \textit{Norfolk and Norwich HealthCare (NHS) Trust v W} [1992] 2 FLR 613 (patient refused to believe she was pregnant).}

\footnote{134}{See \textit{Re C (Refusal of Medical Treatment)} [1994] 1 FLR 31, Thorpe LJ, accepted by Butler-Sloss LJ in \textit{Re MB (Medical Treatment)} [1997] 2 FLR 426, 436-7. See also Gunn et al, 1999, 292, quoting Grisso and Appelbaum, 1998, 81, which describes this capability as the capability to ‘appreciate’ information about one’s condition and the proposed treatment.}

\footnote{135}{Saks, 2002, refers to a ‘negative capability’: the capacity not to hold patently false beliefs: see 182, and 186-7, on the nature of ‘patently false beliefs’. For the purposes of this thesis, I will refer to a capability to believe as shorthand for the negative capacity described by Saks.}

\footnote{136}{See Saks, 2002, 179; Devereux, 1999, 80. See also \textit{Auckland Area Health Board v Attorney-General} [1993] 1 NZLR 235 (patient with Guillain-Barré Syndrome).}

\footnote{137}{See McLean, 1989, 47; see also \textit{St George’s NHS Trust v S} [1998] 3 All ER 673, 693. For a contrary view, see Mendelson, 1996, ‘Trespass’.}

\footnote{138}{According to Gunn et al, ‘Lack of congruity with the view of the doctor or other health care provider has perhaps been the major reason for questioning the decision-maker’s capacity’: Gunn et al, 1999, 296.}
apparently reliable, about the nature and perceived merits of the decision.\textsuperscript{329} Otherwise, the entitlement to decide degenerates into a mere power to endorse decisions effectively made by a third party; usually, a doctor.

(b) Circumstances in which capacity has not been exercised

Mere assent, submission or acquiescence to a doctor’s recommendation does not constitute an exercise of the entitlement to decide. Health care decision-making requires participation that is active and voluntary. Passive acceptance of an act proposed by someone else is not decision-making,\textsuperscript{330} nor is a purported consent affected by fraud\textsuperscript{331} or given under coercion. While it is accepted for the purposes of this thesis that, in some circumstances, the exigencies of illness or injury may impede a person from taking an active role in decision-making, it is important to protect the autonomy of all patients by taking active involvement in decision-making as the presumptive position. Otherwise, a real danger exists that the entitlement to decide will itself be treated as the exception, rather than the rule.

3.2.2 The general rule about identifying the decision-maker

Under Australian common law, the general rule governing identification of the decision-maker in a doctor-patient relationship is that, in the absence of an emergency, medical treatment should be preceded by a meaningful choice to be made by the patient.\textsuperscript{332} This rule is an expression of the principle of respect for autonomy. In acknowledging the existence of the patient’s entitlement to decide, the High Court also recognised that, to be able to exercise it, patients must be given legally-enforceable access to information on which to base meaningful decisions.\textsuperscript{333} As explained in Chapter 1, this thesis defines as meaningful those decisions which reflect the patient’s personal interest, as defined by the patient, as far as possible.

\textsuperscript{329} Although an order seems to have been made by the Chief Justice of the Supreme Court of Queensland on precisely this basis in \textit{State of Queensland v D} [2004] 1 QdR 426. However, this decision was based on an \textit{ex parte} hearing and without comprehensive reference to relevant authorities, so it is unclear what weight it should be given.

\textsuperscript{330} See \textit{Gray v Grunnagle} 223 A.2d 663 (1966), 669; \textit{R v Wollaston} (1872) 26 LT 403, 404 (Kelly CB). See also \textit{Beausoleil v La Communauté des Soueurs de la Charité de la Providence et al} (1964) 53 DLR (2d) 65; Young, 1986, 20-6.

\textsuperscript{331} The common law may narrowly construe fraud: see, for example, \textit{R v Mobilio} [1991] 1 VR 339.

\textsuperscript{332} \textit{Rogers v Whitaker} (1992) 175 CLR 479, 489 (joint judgment).
This recognition is the judicial source of the doctor’s duty, grounded in the principle of beneficence, to disclose sufficient information to enable the patient to make a meaningful decision about proposed treatment. Thus, as the patient’s entitlement to decide and the doctor’s duty to disclose are intimately connected (the entitlement cannot genuinely be exercised in the absence of disclosure), so too are the autonomy and beneficence principles which, I have argued in Chapter 1, operate in tandem as the moral basis of the two aspects of the entitlement to decide: the patient’s role as autonomous decision-maker, and the doctor’s role as beneficent provider of information about the proposed decision.

The patient’s entitlement to decide is, however, prima facie, and can be rebutted in a particular case. A party seeking to establish that someone other than the patient should be the decision-maker bears the burden of proving that the patient does not have decision-making capacity, or that the criteria in section 4.3 are met. The burden may be discharged by evidence relating to matters including age or mental illness, and may, in a particular case, be so obviously rebutted that it is unnecessary to articulate this step (for example, in relation to a very young child). It is nevertheless necessary to explicitly identify the step in constructing and comprehending legal rules about decision-making and disclosure in the doctor-patient relationship.

3.2.3 Extending the application of the general rule: assisted and previous decision-making

For the purposes of this thesis, if a person is able to exercise decision-making capacity, but requires assistance to do so, then the autonomy principle is taken to apply to that person. Also, if a particular health care decision is of a kind in relation to which a person, while in possession of decision-making capacity, made an advance health care directive or analogous instrument, then the autonomy principle is taken by me to apply

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335 Although note empirical evidence suggesting that ‘There is not necessarily a correlation between mental health status and capacity to make decisions’: Gunn et al, 1999, 283.
336 For example, it has been argued that the method of delivering information an individual can improve that individual’s decision-making capacity: see Gunn et al, 1999.
in relation to the decision. This Chapter is not concerned with such cases, in which the patient has had an opportunity to define his or her personal interest.

3.2.4 Presumptions about capacity

In most areas of the law, decision-makers are presumed to be competent, and matters affecting the validity of their decisions are exceptions that must be proved. The entitlement of patients to decide about treatment is consistent with this presumption. However, it is useful to identify presumptions that are made about the decision-making capacity of members of particular groups.

Adults are presumed by the law to have decision-making capacity. In relation to children, and to adults with mental disabilities, mental illnesses and other cognitive impairments, Australian courts have held that a lack of decision-making capacity cannot be assumed. Australian law-makers and policy framers have tried to avoid, in relation to patients with apparent decision-making disabilities, presumptions that lack of capacity to undertake one kind of decision-making activity precludes the possession of capacity for others. Recent law reforms have sought to give such patients as much assistance as possible to exercise what decision-making capacity they may have, or be able to develop. This policy is consistent with the purposes of independence and care, because care involves nurturing and maximising independence. The policy is not novel, and is consistent with the position of children in relation to decision-making about treatment. As children mature, it is accepted by the law that their capacity to exercise

337 For the need for specificity in advance directives, see Stewart, 1999. For argument that specificity should be directed to outcomes, not particular treatments, see Fried et al, 2002. For discussion about the legislative frameworks for advance care directives, and other means by which individuals can (for example) refuse treatment, see Ccons, in Freckelton and Petersen, 1999, and Mendelson, also in Freckelton and Petersen, 1999.

338 See QLRC Report No. 49, 1996, volume 1, 29-30. For an argument that doctors should be protected, by a specific defence, when they treat patients who have refused to be assessed for capacity or patients who appear to lack capacity, see Stewart and Biegler, 2004, 340-1.

339 For consideration of various statutory and common law mechanisms by which courts and tribunals can make decisions on behalf of children, see Keough, 2003.


341 For example, the Guardianship and Administration Act 2000 (Qld), section 5; QLRC Report No. 49, 1996, volume 2 and QLRC Report No. 51, 1996, volume 2; see also Re C (Refusal of Medical Treatment) [1994] 1 FLR 31, especially 36, for an example of the English approach.

342 See, for example, the Guardianship and Administration Act 2000 (Qld).
autonomy increases. There is no single point at which autonomy is assumed to exist, however, and a ‘transitional stage of shared authority’ has been judicially recognised and accepted, despite the difficulties that may arise from conflicts between children, carers and doctors during this stage.

### 3.2.5 Identifying substitute decision-makers

Cases that raise questions about the identification of the decision-maker are resolved by identifying one of the following parties as the decision-maker in a particular case: the patient, another person with a familial or social relationship to the patient (such as a parent, spouse or adult child), a person appointed by the patient, a person authorised under legislation (such as an Adult Guardian or Public Advocate), or a tribunal or court. It is beyond the scope of this thesis to consider in detail how substitute decision-makers should be selected. These matters are dealt with in State and Territory legislation; I am concerned with considerations and values on the basis of which the patient’s entitlement to decide is displaced, rather than with the consequences of that displacement. However, it is useful to identify, without going into detailed descriptions of legislative mechanisms, basic principles that should be involved in the identification of substitute decision-makers.

Broadly, a substitute decision-maker is involved in decision-making as a result of one of two kinds of circumstance. First, a substitute decision-maker will be involved when an emergency situation exists. For the purposes of this thesis, an emergency situation exists if the patient lacks decision-making capacity, there is an urgent need for medical treatment to preserve life or function and there is no previously-appointed substitute decision-maker reasonably available to make a treatment decision for the patient. An example might be a victim of a car accident. In such a situation, and despite the general assumption that an ‘implied’ or assumed consent exists, the doctor may be understood to be acting as a substitute decision-maker. This is the only circumstance described in

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343 For example, *Department of Health and Community Services (NT) v JWB and SMB ('Re Marion')* (1992) 175 CLR 218, 293-4 (Deane J). See also *Gillick v West Norfolk AHA* [1986] AC 112, 170-1 (Lord Fraser of Tullebelton); *Hewer v Bryant* [1970] 1 QB 357, 369 (Lord Denning MR).


345 See, for example, *Guardianship and Administration Act 2000* (Qld), section 15; *Medical Treatment Act 1988* (Vic), section 5A. See also Kerridge et al, in Freckelton and Petersen, 1999.

346 See also *Marshall v Curry* [1933] 3 DLR 260; *Murray v McMurchy* [1949] 2 DLR 442.
this thesis where I accept that a doctor should act as a substitute decision-maker.\textsuperscript{347} This is an exceptional case because the exigencies of such situations mean that it is necessary to treat the patient’s clinical welfare as exhaustive of his or her personal interest at the time. These exigencies are that there is an urgent need for treatment, and there is no opportunity to elicit from anyone information about the nature of the patient’s personal interest (unless there is reasonably available information to the contrary).\textsuperscript{348}

Second, a substitute decision-maker becomes involved because of non-urgent or on-going conditions or characteristics of the patient, including mental disability or illness of a patient. In such instances, a substitute decision-maker may have been selected by the patient prior to onset of a disabling illness (for example, through an enduring power of attorney or advance health care directive), or may be appointed for the patient by a guardianship tribunal where the patient has not appointed someone.\textsuperscript{349} In any case where a court or tribunal is selecting a substitute decision-maker other than someone like a Public Advocate or Adult Guardian, the person selected is likely to be someone close to the patient, such as a spouse or partner, another family member or maybe even a close friend. Such persons should be expected by courts to have a reasonable idea of the patient’s values, priorities and preferences (that is, the content of the personal interest), and to make meaningful decisions that, by definition, take these into account.\textsuperscript{350} In some cases, however, concerns about the sensitive nature of the proposed treatment,\textsuperscript{351} or the existence of potential conflicts of interest of persons close to the patient,\textsuperscript{352} may prompt a tribunal or court to appoint a public officer, such as a Public Advocate, to be the substitute decision-maker. Additionally, of course, parents

\textsuperscript{347} And, for the purposes of this thesis, the expression ‘substitute decision-maker’ will not, except in this section, be taken to include a doctor.

\textsuperscript{348} Contrary information might include a card identifying the patient as a Jehovah’s Witness and indicating that blood products should not be administered: see Malette v Shulman 67 DLR (4th) 321 (1990).

\textsuperscript{349} This may be because the patient has never had capacity, or it may be because the patient never got around to making an instrument such as advance health care directive, or was resistant to the idea of doing so.

\textsuperscript{350} See, for example, Airedale NHS Trust v Bland [1993] AC 789, 887-8 (Lord Mustill).

\textsuperscript{351} For example, the situation with BWV, described in Chapter 4: see BWV [2003] VCAT 121, in which the Public Advocate was appointed as limited guardian in relation to a proposed decision to withdraw artificial nutrition and hydration from a woman suffering severe dementia, probably caused by Pick’s Disease.
are generally expected to act as substitute decision-makers for their children, until their children form sufficient decision-making capacity in accordance with the principles articulated in Re Marion.³⁵³

However appointed, the selection of a substitute decision-maker should be all about identifying someone who, in the circumstances, is best placed to comply with the principle of beneficence by making a meaningful decision for the patient. In an emergency, where prompt treatment is of critical importance and the patient’s lack of decision-making capacity forces his or her lack of participation, the doctor is best placed to make a decision for the patient’s benefit which, because of the exigencies of the case, is necessarily defined by his or her clinical welfare. In the case of adult patients with on-going conditions that cause capacity to deteriorate, the person should ideally be selected by the patient.³⁵⁴ If that is not practicable, then the appropriate tribunal or court should select someone on the basis that the person is best equipped and can reasonably be expected to make decisions that reflect and protect the entirety of the patient’s personal interest.

Once a substitute decision-maker is identified and commences performing his or her functions, then (as discussed in Chapter 2) I suggest that beneficence requires that the doctor makes sufficient disclosure to the substitute decision-maker to enable that person to exercise his or her own obligations of beneficence: that is, to decide on the basis of the patient’s personal interest, and to give the patient an explanation of the proposed treatment that is appropriate to the patient’s circumstances and limitations.

3.3 THERAPEUTIC NECESSITY AND DECISION-MAKING IN THE DOCTOR-PATIENT RELATIONSHIP

This Chapter argues that the duty to disclose should not be affected by the perceived existence of a state of ‘therapeutic necessity’. Such a state does not affect the materiality

³⁵³ A concern of the Court in Secretary, Department of Health and Community Service (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218.

³⁵⁴ In which case, selection of the substitute decision-maker is an exercise of the patient’s autonomy: for example, in the early stages of Alzheimer’s Disease, a person will generally have sufficient decision-making capacity to execute a document such as an enduring power of attorney or advance health
of information. Nor does it affect the patient’s ability or desire to make decisions. Furthermore, a perception of ‘therapeutic necessity’ is not a matter of objective fact, because it necessarily derives from perceptions about states of ‘health’ and ‘illness’, which are themselves subjective. They may be influenced by preconceptions and unexamined assumptions made by doctors with little input from patients. Sometimes, perceptions of therapeutic necessity reflect medical fashions, trends, or simply the technological imperative. States of being that in one era or culture are regarded as normal, or simply to be accepted, may in other cultures or eras be regarded as requiring medical intervention (for example, homosexuality, and physical features and attributes that are ‘treated’ by cosmetic surgery). Nevertheless, common law courts have accepted, although without expressly articulating, a notion of ‘therapeutic necessity’, and that acceptance has had a powerful influence on the development of the law about disclosure and decision-making in the doctor-patient relationship. Because of this, it is necessary to understand the concept of ‘therapeutic necessity’, as recognised by judges.

Therapeutic necessity of proposed health care can be described as existing on a continuum. At one extreme is health care that is necessary to save life. Towards that end of the continuum is health care that is necessary to prevent or cure illness, to manage symptoms of illness (including by palliative care) or for rehabilitation. At the other extreme of the continuum is health care that is required for no therapeutic reason, but which may arise from social, religious, or financial concerns. The term ‘non-therapeutic’ health care will be used in preference to ‘elective’ health care because, in legal principle, each patient with decision-making capacity has a right to refuse medical treatment, regardless of consequences. On that basis, all treatment care directive. A patient may also exercise autonomy by not only selecting a substitute decision-maker, but also by directing the kinds and content of decisions that the substitute decision-maker may make.

See, for example, the list of ‘non-diseases’ in Smith, 2002, which includes bags under the eyes and white hair.

For example, some pregnancy terminations and sterilisations, some male infant circumcisions, and the sale of organs by live donors.

See, for example, Sidaway v Governors of Bethlem Royal Hospital [1985] 1 AC 871, 904-5 (Lord Templeman).
given to patients with decision-making capacity is ‘elective’, subject to the operation of the values described in Chapters 4 and 5.\textsuperscript{358}

Various points on the continuum can be distinguished in three ways. The simplest distinction can be made by considering the consequences, for a patient’s clinical welfare, of refusing proposed treatment. The possibility that refusal of treatment could lead to a patient’s death, or serious disability, means that the relevant treatment occupies a point on the ‘therapeutic necessity’ end of the continuum. If refusal of treatment would have no clinical consequences, then the proposed health care is likely to be non-therapeutic. This Chapter argues that this kind of comparison seems to have influenced Australian judges, so that if refusal of treatment seems to be a matter of life or death, the entitlement to decide is subject to significant qualification.\textsuperscript{359}

The second kind of distinction between cases on various points of the continuum is drawn by describing the nature of the ‘risk pattern’ to which the patient is exposed before undergoing treatment. If treatment is proposed for non-therapeutic purposes, then the patient is not exposed to any particular group of risks (or effects), relating to his or her clinical welfare, before undergoing treatment. An individual undergoing non-therapeutic treatment assumes a set of risks to his or her clinical welfare that relates to the treatment, and the individual’s ‘starting position’ is one in which the individual is not affected by the incidents of illness. On other points on the continuum, the patient exchanges one set of risks (related to the illness that the treatment seeks to address) for another (those associated with the treatment).\textsuperscript{360} If a patient’s choice is to accept medical treatment, it may therefore be made on the basis that the possible adverse effects of the treatment are preferable to, or more palatable than, those of the illness.

The third distinction can be related to the patient’s initiation of and control over the course of a doctor-patient relationship, in the context of the imbalance of authority between doctor and patient. At the non-therapeutic extreme of the continuum, the

\textsuperscript{358} See also Shultz, 1985, 272. Note that, within the doctor-patient relationship, not all that is done is done for a therapeutic purpose, which is why I prefer to use the term ‘doctor-patient relationship’ to ‘therapeutic relationship’.

\textsuperscript{359} See for example Katz, 1984, 208. See also Tai v Saxon (unreported) Full Court of Supreme Court of Western Australia, 8 February 1996; Di Carlo v Dubois [2004] QCA 150; State of Queensland v D [2004] 1 QdR 426.

\textsuperscript{360} Corbett, 1997, 166, 172-3.
relationship between doctor and patient more closely approaches equality than in other circumstances. This is because the patient is more likely to have control over various aspects of the proposed health care, including the initiation of discussions about the possibility of intervention and the timing of seeking intervention, (possibly) the choice of medical practitioner and, finally, deciding without urgency whether the anticipated benefits of the proposed intervention outweigh risks assumed in undergoing it. Furthermore, an individual seeking non-therapeutic treatment is not exposed to the disempowering circumstances related to the existence of illness (such as pain, fear and anxiety), which contribute to the imbalance of authority. Cases on points of the continuum that involve increasing degrees of therapeutic necessity are differentiated by a gradual lessening of the patient’s control over such matters. For example, in a life-threatening emergency, the patient has no control over timing and, in most cases, little control over the kind of intervention that is used to achieve a particular outcome. It may be that the patient’s only control (if, indeed, he or she is conscious and lucid) is about whether or not to accept whatever intervention is proposed.

3.4 THE CASES USED TO ILLUSTRATE THE SIGNIFICANCE OF THERAPEUTIC NECESSITY

The cases compared for the purposes of this Chapter’s consideration of therapeutic necessity are *Battersby v Tottman* and *Rogers v Whitaker*. In *Battersby v Tottman*, the treatment for the patient’s serious mental illness was perceived to be therapeutically necessary. The use of melleril at eight times the recommended dosage was regarded as essential to save her from suicide, and to enable her to live independently. Nondisclosure of the dosage-related risk of melleril retinopathy was regarded as necessary first, to prevent harm from disclosure itself (whether by the patient committing suicide, or becoming more severely affected by her mental illness) and, second, to minimise the possibility of the patient refusing the treatment as a consequence of disclosure. For the purpose of considering the therapeutic privilege, this case is the most useful Australian instance. In *Rogers v Whitaker*, the proposed

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361 *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.
363 *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.
364 As agreed by Mulheron, 2003, 206.
surgery was not necessary to save Ms Whitaker's life, and her principal aim in seeking medical assistance was not restoration of sight to her injured eye, but merely the improvement of its appearance, scarred from a penetrating injury suffered when she was a child (although the surgeon was hopeful that he would be able to return some sight to the eye).\textsuperscript{366} The High Court acknowledged the non-therapeutic nature of the surgery.\textsuperscript{367}

There are factual similarities between these cases: both patients undertook treatment that posed undisclosed material risks to their eyesight, and both became blind when those risks materialised. Both offered evidence that, had they been aware of the risks, they would not have undergone the treatment. In both cases, the risk materialised, the patients' evidence was accepted, and causation was established without any suggestion by the judges that the patients' evidence was affected by hindsight bias.\textsuperscript{368} Both patients were treated by the courts as possessing decision-making capacity at the time of agreeing to the treatment, notwithstanding that Ms Battersby was being treated for serious mental illness when she agreed to the melleril treatment. Both the High Court and the Supreme Court of South Australia accepted and applied the statement of the relevant law about decision-making and disclosure (that is, that the patient has a paramount entitlement to decide) made by King CJ in \textit{F v R}\textsuperscript{369}. Yet Ms Whitaker recovered damages for negligent nondisclosure of risk and Ms Battersby did not.

This Chapter argues that the difference in outcome is explicable because refusal of their respective treatments was likely to have had very different results in each case. Ms Whitaker's refusal of treatment would have had no adverse effect on her clinical welfare. In Ms Battersby's case, refusal to accept the treatment could have resulted in her death. I suggest that this circumstance influenced the approach of the South Australian Supreme Court in its identification of the decision-maker, and its definition of the purpose and scope of disclosure, so that it used the legal principles of the

\textsuperscript{365} Rogers \textit{v Whitaker} (1992) 175 CLR 479, 491 (joint judgment).
\textsuperscript{366} Rogers \textit{v Whitaker} (1992) 175 CLR 479, 483.
\textsuperscript{367} Rogers \textit{v Whitaker} (1992) 175 CLR 479, 491 (joint judgment), 492 (Gaudron J).
\textsuperscript{368} The danger of hindsight bias was considered in \textit{Rosenberg v Percival} (2001) 205 CLR 434, 441-2, [16] (Gleeson CJ), 456, [68] (Gummow J), 483, [151] (Kirby J); see also Mendelson, 2001, 365-6. For a recommendation that plaintiffs' testimony about causation that may be affected by hindsight bias should be inadmissible: see the Ipp Review, 2002, 7.40, recommendation 29 (g).
\textsuperscript{369} \textit{F v R} (1983) 33 SASR 189, 192-3.
therapeutic privilege and the balancing process to ‘qualify’ the application of the entitlement to decide.\(^{370}\) The majority of the Court held that Dr Tottman’s decision to withhold information was justifiable on two grounds: first, the doctor’s prediction that disclosure would persuade Ms Battersby to refuse the treatment (which the doctor believed was therapeutically necessary) and, second, the doctor’s prediction that disclosure would cause direct harm by exacerbating her precarious mental condition.\(^{371}\) The dissenting judge, Zelling J, held that Dr Tottman’s nondisclosure of the risk was unjustifiable. Section 3.5 explores how the majority judges’ perception of therapeutic necessity affected the recognition of Ms Battersby’s entitlement to decide. In particular, it argues that a predicted refusal of treatment, by a patient with decision-making capacity, should not justify nondisclosure of material information under the therapeutic privilege. Section 3.5 also considers the view that a risk of direct harm arising from disclosure itself, such as the risk of suicide, could justify nondisclosure, provided that safeguards are applied to protect the patient from any consequences of his or her ignorance of the undisclosed information. Even if this position were to be accepted, however, the decision that Dr Tottman was not negligent was in my view wrong. His nondisclosure was inconsistent with the beneficence principle as I have defined it because, although harm arising from disclosure itself was reasonably foreseeable, the view of the dissenting judge, that the doctor failed to apply safeguards required by the beneficence principle, is preferable.

### 3.5 HOW DOES THERAPEUTIC NECESSITY AFFECT THE ENTITLEMENT TO DECIDE?

If a doctor can persuade a court that a patient’s treatment was ‘therapeutically necessary’, the general rule that the patient is the decision-maker about medical treatment can be displaced by the therapeutic privilege, which allows nondisclosure of information that would otherwise be material to the making of a meaningful decision, and effectively leaves decision-making to the doctor. In addition, the balancing process may also be used to limit the scope of disclosure. I will show that the aim of both the therapeutic privilege and the balancing process is to prevent harm to the patient which is perceived as being caused by disclosure of information essential to the making of a

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\(^{370}\) See sections 3.5.2 and 3.5.3 for descriptions of the therapeutic privilege and the balancing process.

\(^{371}\) Leading to suicide or hysterical blindness.
meaningful decision. This section explores how these consequences of therapeutic necessity are, first, inconsistent with a robust entitlement to decide and, second, fail to provide an alternative means of protecting the patient’s personal interest.

3.5.1 The entitlement to decide: identification of decision-makers and the purpose of disclosure

(a) The general rule about identification of the decision-maker

As previously stated, the general rule governing identification of the decision-maker in a doctor-patient relationship is that, in the absence of an emergency, medical treatment should be preceded by a choice to be made by the patient.\(^{372}\) In *Rogers v Whitaker*,\(^{373}\) there was no suggestion that the entitlement to decide should have been displaced, or that anyone but Ms Whitaker was the decision-maker in relation to her surgery. The general rule was applied. In *Battersby v Tottman*,\(^{374}\) the identification of the decision-maker was affected by the application of the therapeutic privilege to a patient who, though in a precarious mental and emotional state, was not held by her doctor or by any judge to lack decision-making capacity. That Ms Battersby was regarded as having requisite capacity to agree to treatment is apparent by the absence of any suggestion either that her consent to the treatment was invalid or that, despite her serious mental illness, an independent substitute decision-maker\(^{375}\) should have been involved. If her decision-making capacity was as precarious as the judges accepted it to be in their judgement about the applicability of the therapeutic privilege, then it is difficult to see a reason for the silence on these points.

In particular, if Ms Battersby’s decision-making capacity was truly as precarious as the doctor said he believed it to be, then an independent substitute decision-maker should have been appointed (in accordance with the principles discussed at section 3.2.5) to weigh the risks and benefits of the proposed treatment. It was unsatisfactory for the doctor to act as a *de facto* substitute decision-maker because he clearly (from his own evidence) was not minded to have regard to how the patient, who was accepted to have

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\(^{372}\) *Rogers v Whitaker* (1992) 175 CLR 479, 489 (joint judgment).

\(^{373}\) *Rogers v Whitaker* (1992) 175 CLR 479.

\(^{374}\) *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.

\(^{375}\) For the purposes of this section and remaining Chapters, a doctor is not considered to be an independent substitute decision-maker.

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capacity, defined her personal interest. In Ms Battersby’s view, blindness was not an acceptable risk; in the doctor’s, it was. A substitute decision-maker who was prepared to weigh the risks and benefits in the context of Ms Battersby’s view of her personal interest may have come to the same conclusion as the doctor, in the end, but would have been required to do so, by the terms of this thesis, only after properly considering Ms Battersby’s low tolerance of the risk of blindness.

(b) The purposes of disclosure

Three possible purposes of disclosure are contemplated in the two principal cases examined in this Chapter: first, to enable patients to make meaningful decisions about matters affecting their lives (in particular, medical treatment), second, to enable patients to monitor their health and, third, to persuade patients to co-operate with doctors’ recommendations.

The first purpose derives from the general rule that patients are decision-makers in the doctor-patient relationship and was given prominence in both Battersby v Tottmar and Rogers v Whitaker. In Battersby v Tottman, the appellate court accepted the view expressed by King CJ in F v R, that the purpose of disclosure is to enable a patient with decision-making capacity to make a meaningful decision. Presumably, it was in an attempt to demonstrate compliance with that general rule, in relation to a patient whose decision-making capacity had not been successfully challenged (despite her fragility, her consent to treatment was accepted as validly given), that the majority judges sought to apply the therapeutic privilege, rather than drawing attention to the failure to identify a substitute decision-maker. By doing so, the judges seemed to imply that the patient had been allowed to make a meaningful decision of her own, albeit on the basis of limited information. In Rogers v Whitaker, the joint judgment accepted

376 Rogers v Whitaker (1992) 175 CLR 479, 487.
377 Battersby v Tottman and State of South Australia (1985) 37 SASR 524.
378 Rogers v Whitaker (1992) 175 CLR 479.
379 Battersby v Tottman and State of South Australia (1985) 37 SASR 524.
381 Battersby v Tottman and State of South Australia (1985) 37 SASR 524, 527 (King CJ), 535 (Zelling J), 540-541 (Jacobs J).
382 Rogers v Whitaker (1992) 175 CLR 479.
that the purpose of disclosure is to give patients sufficient information to make meaningful decisions about proposed treatment.

Consistent with the entitlement to decide, disclosure should be made of information that would be material to other related and foreseeable decisions. This might, for example, include information that a person has a predisposition to develop a certain condition, the possession of which might be material to the person’s family or occupational decisions. This is necessary to ensure that patients’ ability to make other reasonably foreseeable decisions, at the time of receiving treatment and in the future, is not compromised by ignorance of material information. For example, if Ms Battersby had recovered her mental health before retinopathy began to develop, she should have been told of the risk. This would have enabled her to make meaningful decisions about further treatment for depression (if needed), and would have made her aware that she had been exposed to the risk of retinopathy and might need to take particular measures, such as undergoing periodic examinations. If Ms Battersby had not recovered her mental health, then it would have been important to take reasonable steps to ensure that Ms Battersby’s future caregivers and health care providers were aware of the information. Even in emergency cases, when disclosure preceding treatment is not required, reasonable steps should be taken (subsequent to the patient regaining capacity) to give patients information about what has been done (or not done), and why, and about any reasonably foreseeable consequences of the treatment they received.

The trial judge in *Battersby v Tottman* identified a second purpose of disclosure: to enable patients to monitor their own health. This furthers the purpose of independence because patients become more knowledgeable about when to seek advice and treatment to prevent harm. The purpose of care is furthered by enabling the patient to avoid harm caused or exacerbated by ignorance. This purpose requires disclosure of information additional to risk information. For example, diagnostic information about a predisposition to a particular illness might put a patient on the alert for indications that the illness is developing. Accordingly, even if the entitlement to decide is displaced, compliance with the beneficence principle, as I have defined it, is not exhausted by

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nondisclosure. Instead, special thought and care should be used to give the patient, or a substitute decision-maker, enough information to enable the patient’s health and well-being to be properly monitored by the patient, or a carer. If the case is exceptional, as the judges thought Ms Battersby’s case to be, and the only possible way to act beneficently is accepted as being to make no disclosure at all because of the risk of direct harm predicted from disclosure, then beneficence should require the doctor to monitor the patient in accordance with a standard of care that takes into account the patient’s ignorance of material, but undisclosed, information.  

A third possible purpose of disclosure emerges from *Battersby v Tottman.* The judges were confronted with a doctor who had effectively taken into his own hands the decision about undergoing treatment, by withholding information which the doctor (correctly) believed would convince his patient to reject recommended treatment. By condoning Dr Tottman’s conduct, the judges accepted that, in relation to Ms Battersby, the dominant purpose of disclosure was to persuade her to accept and co-operate with the doctor’s recommendations. Thus, if the doctor purports to become a substitute decision-maker, then the purpose of disclosure is not that which was identified in *Rogers v Whitaker* (that is, to enable the patient to make a meaningful decision) and information that may deter a patient from accepting treatment is taken to fall outside the duty to disclose.

### 3.5.2 The therapeutic privilege: *de facto* substitute decision-making

This section argues that perceived therapeutic necessity does not justify displacement of the general rule about identifying the decision-maker. This aim is achieved by considering the ‘therapeutic privilege’ in some detail. *Battersby v Tottman* demonstrates the application of the therapeutic privilege to an ostensibly autonomous

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385 For the importance of such information, see *Gates v Jensen* 595 P.2d 919 (1979).
386 See paragraph 3.6.2 (a).
387 *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.
388 *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524, 527 (King CJ), 533 (Zelling J), 542 (Jacobs J).
389 See, for example, *In the Matter of the Application of Jamaica Hospital* 491 NYS.2d 898 (1985), where the Court appointed the doctor as the substitute decision-maker.
391 *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.
patient in a precarious mental and emotional state, on the basis of a doctor’s prediction that disclosure would cause her to make a decision with possibly catastrophic clinical consequences. Because the therapeutic privilege was used to justify nondisclosure of material information to a patient considered capable of giving a valid consent to treatment, and although it appears rarely to be relied on in litigation,\(^{392}\) it is important to consider the nature of the privilege, and whether its application is consistent with the entitlement to decide.

The therapeutic privilege is one of three conventionally-recognised exceptions to the general rule about identification of the decision-maker (the other two exceptions are emergency\(^{393}\) and waiver,\(^{394}\) neither of which were regarded as being relevant in Rogers v Whitaker\(^ {395}\) or Battersby v Tottman\(^ {396}\)). The therapeutic privilege is based on seven overlapping propositions. It is important to try to describe them separately to understand how the therapeutic privilege, which is conventionally regarded as limiting the scope of disclosure, operates as an undeclared form of substitute decision-making that is inconsistent with the entitlement to decide.

In summary, the propositions are first, that disclosure of particular information will harm the patient and, second, that refusal of treatment is a relevant harm to be averted by the privilege. The third proposition is that serious direct harm arising from disclosure is a relevant harm to be averted by the privilege. The fourth proposition is that risk disclosure is the kind of disclosure that causes relevant harm. Fifth, the therapeutic privilege assumes that compliance with the principle of beneficence requires only nondisclosure by the doctor. The sixth proposition is that nondisclosure of material information does not adversely affect the validity of a patient’s decision. Finally, the therapeutic privilege assumes that the possible adverse consequences of refusing treatment are more serious than the possible adverse consequences of accepting it.

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\(^{392}\) How often it is relied on in actual clinical practice would be the subject for another research project. Mulheron, 2003, argues that the rarity of its use indicates that the privilege should be abolished (for example, at 202). I agree with Mulheron’s conclusion; however, I think the examples she uses are not, I think, persuasive, because in most of them, the plaintiff failed on the elements, and the privilege was not considered. The arguments that I think support abolition of the privilege are set out in this Chapter.

\(^{393}\) For an explanation of emergency, see section 3.2.5.

\(^{394}\) For a discussion of waiver, and the problems it presents, see Faden and Beauchamp, 1986, 38-9.

\(^{395}\) Rogers v Whitaker (1992) 175 CLR 479.

\(^{396}\) Battersby v Tottman and State of South Australia (1985) 37 SASR 524.
That disclosure will harm the patient

The first proposition is that disclosure may cause serious physical or psychological harm to a patient. This proposition implies that doctors have a legal duty to prevent emotional distress and physical harm. It seems, however, unlikely that doctors would be prepared to accept explicit imposition of such a general obligation to prevent emotional distress and physical harm arising from disclosure, the breach of which could sound in damages. In any event, not only is distress so grave as to harm the patient not a real issue in most doctor-patient relationships, the proposition ignores the reality that individuals must cope with even severe distress when making many important decisions. Anglo-Australian law does not generally seek to protect them from unwanted consequences of such decisions. Furthermore, doctors do not always accurately predict the severity of patients’ reactions to disclosure and, even when acting with utmost good faith, cannot always differentiate between patients who want reassurance and those who want information. This is partly because, in the exigencies of the doctor-patient relationship, doctors must often make assumptions about such matters, with only limited opportunities to understand the diverse circumstances that relate to their patients’ personal interests.

That refusal of treatment is a relevant kind of serious harm

Having decided that Ms Battersby had capacity to decide about what he considered to be necessary treatment, Dr Tottman also had to ensure she would not refuse. This section is about the second proposition underlying the therapeutic privilege: that refusal of treatment is a relevant kind of serious harm to be averted by the doctor, based on the perceived necessity for the patient to undergo treatment.

Essentially, the second proposition is that refusal of treatment which a doctor believes to be therapeutically necessary is, because of its predicted adverse consequences for the patient, a kind of serious harm which doctors must avert by withholding information.

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397 F v R (1983) 33 SASR 189, 192-3; Rogers v Whitaker (1992) 175 CLR 479, 486; Sidaway v Governors of Bethlem Royal Hospital [1985] 1 AC 871, 889 (Lord Scarman); Canterbury v Spence 464 F.2d 772 (1972), 789; Battersby v Tottman and State of South Australia (1985) 37 SASR 524, 527-8, 534-5. For a discussion of jurisdictions which do not extend the privilege to a risk of physical harm, and the broader Australian interpretation, see Mulheron, 2003.

This assumes that there is a ‘right’ decision to be made, that the doctor knows what it is, and is allowed (or even obliged) to withhold information to encourage that patient to make it. In light of this assumption, it is unsurprising that in empirical studies conducted by the Law Reform Commission of Victoria in the late 1980s, 46% of doctors reported that a reason underlying their nondisclosure of risks was to ‘reinforce the possibility of treatment, or prevent the likelihood of the patient refusing the treatment.’

This section describes the proposition and how it worked in *Battersby v Tottman*, demonstrating that the therapeutic privilege tends to equate decision-making capacity with a patient’s disposition to make a decision that the doctor accepts, and that incapacity may be thought to be evidenced by a predicted refusal to do so. The proposition that there is a ‘right decision’, which the doctor knows, is central to the therapeutic privilege, and contradicts the judicially-recognised claim of all patients with decision-making capacity to refuse treatment. That claim, recognised by the High Court in the form of an ‘entitlement to decide’, vanishes if nondisclosure is justified by a prediction about how a patient might exercise the entitlement, and a judgement that a particular exercise of the entitlement is wrong because it does not accord with a doctor’s recommendation. This is not because the doctor’s prediction may be wrong (although this is possible), but because the right to refuse treatment belongs to every patient with decision-making capacity, regardless of the consequences of its exercise.

The personal interest, by its nature, contemplates the making of idiosyncratic decisions which are ‘right’ by no criteria other than the patient’s own wishes. However, coexistence of the right to refuse treatment and a therapeutic privilege triggered by predicted refusal of treatment necessarily implies that refusal is

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399 Law Reform Commission of Victoria, Doctor and Patient Studies, 1989, 8; see also 13, Table 10A. For an example of this in practice, see *McKellar v Blake*, unreported, New South Wales Court of Appeal, 30 October 1998. The publication by the NHMRC of its latest guidelines on communicating with patients suggests that this sentiment may still exist: NHMRC, *Communicating with patients: advice for medical practitioners*, 2004, http://www.nhmrc.gov.au/publications/synopses/e58syn.htm

400 *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.

401 According to Gunn et al, ‘Lack of congruity with the view of the doctor or other health care provider has perhaps been the major reason for questioning the decision-maker’s capacity’: Gunn et al, 1999, 296.

402 See also Gerald Dworkin, 1988, 120; McLean, 1989, 96; *Guardianship and Administration Act 2000* (Qld), section 5.


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simultaneously a prerogative of competent patients and a reason to deny them the opportunity to make their own decisions.

In addition, reliance on predicted refusal of treatment as a justification for nondisclosure exacerbates the imbalance of authority by implicitly casting patients as supplicants who must justify having access to information that is material to making a meaningful decision and thereby exercising autonomy.\(^\text{404}\) It is accepted that, in the context of the purposes and imbalances of the doctor-patient relationship, it is necessary to be concerned about the effect of distressing information on a fragile patient. However, it is important not to draw a conclusion about a patient’s decision-making capacity based on a prediction that the patient will refuse treatment thought by the doctor to be ‘therapeutically necessary’.

It is implicit in each judgment of the Court that, had Ms Battersby been likely to accept the treatment, even knowing of the risks, the doctor would not have withheld disclosure from her (although any subsequent legal claim about materialisation of the risk would have failed for want of causation). The trial judge, and the majority of the appeal judges, accepted Dr Tottman’s prediction of likely refusal as sufficient reason to apply the therapeutic privilege. A similar argument would, it appears, have been accepted by at least some of the Law Lords in Sidaway v Governors of Bethlem Royal Hospital,\(^\text{405}\) and even by Ipp JA in circumstances where treatment is therapeutically necessary.\(^\text{406}\)

This position is taken because, first, the therapeutic privilege equates the ‘right’ decision with a decision that a doctor accepts or, at least, with a decision based on reasons that a doctor accepts as valid. This perpetuates the notion that treatment decisions are, and should be, made on the basis of clinical factors, of which doctors have specialist knowledge, and which are directed primarily at clinical welfare. This, I suggest, undervalues other dimensions of the patient’s personal interest. In addition, the therapeutic privilege allows doctors to assume a model of decision-making skewed

\(^{404}\) See also Magnusson and Opie, 1998, particularly at 110.

\(^{405}\) See, for example, Sidaway v Governors of Bethlem Royal Hospital [1985] AC 871, 891, 895 (Lord Diplock), 899 (Lord Bridge), 904-5 (Lord Templeman). Even Lord Scarman would have been prepared to accept a therapeutic privilege argument: see McLean’s discussion of the case: McLean, 1989, 121-2.

\(^{406}\) Tai v Saxon (unreported) Full Court of Supreme Court of Western Australia, 8 February 1996.
towards clinical values, without requiring discussion to determine whether this prioritisation reflects the wishes of a patient with decision-making capacity.

Second, the therapeutic privilege assumes that decisions with which doctors disagree are wrong, and perhaps evidence that the patient’s decision-making capacity is impaired. Application of the privilege is justified as necessary to protect a patient’s decision-making capacity, although nondisclosure of information that is known to be material means that the patient’s capacity is deliberately directed towards a decision pre-selected by the doctor. Because of this, the therapeutic privilege can be applied to withhold information from patients who are not formally found to lack decision-making capacity. The common law understanding of decision-making capacity allows doctors to withhold disclosure unless they believe that their patients will make ‘reasonable decisions’, producing an outcome that is acceptable to the doctor. This interpretation is available because English and Australian judges have not so far suggested objective criteria on the basis of which to distinguish between a patient who would use disclosed information in a ‘reasonable’ or ‘balanced’ way, to make a ‘proper evaluation’, and a patient who would use the information in an ‘unreasonable’ way, and who should therefore attract the application of the therapeutic privilege. I suggest that the failure to draw such a distinction, and to provide guidance about how it should be applied, undermines the entitlement to decide, by leaving it open for the outcome of the decision-making process, rather than the process of decision-making itself, to be the subject matter of inquiry about decision-making capacity.

Finally, the case illustrates a problem identified by McLean. Patients are put in a ‘Catch-22’ situation by the combined operation of the existing tests for causation and the availability of the therapeutic privilege on the basis of a predicted refusal of treatment. The situation arises if a plaintiff first establishes the existence of a duty of

\[\text{Rogers v Whitaker (1992) 175 CLR 479, 494 (Gaudron J). It is this intention that underlies Lord Templeman's concept of a 'balanced judgment': Sidaway v Governors of Bethlem Royal Hospital [1985] 1 AC 871, 891, 904-5. See also F v R (1983) 33 SASR 189, 193 (King CJ).}\]

\[\text{See paragraph 3.2.1 (a). For a contrary view, see Mendelson, 1996, 'Trespass'.}\]

\[\text{See McLean, 1989, 124. McLean also notes that the fact of distress does not necessarily detract from the validity of the decision, but is in fact part of the patient's decision-making framework: see, for example, McLean, 1989, 118.}\]
care by showing that an undisclosed risk is a material risk and, second, satisfies the causation test by establishing that, had he or she known about the risk, he or she would not have undergone the treatment. However, the same evidence that enabled the plaintiff to clear those hurdles can theoretically be used to erect another, by justifying a doctor’s nondisclosure on the grounds of therapeutic privilege.

The principal effect of identifying a ‘therapeutic necessity’ seems to be to elicit from doctors a stronger than usual degree of benevolence towards patients, expressed through a policy of protecting patients’ clinical welfare in preference to other dimensions of patients’ personal interest. However, a robust entitlement to decide should instead require such benevolence to be expressed through imposing on doctors an obligation to undertake clear communication with patients, and through respect for the patient’s wishes. If this does not happen, then two consequences flow. First, in cases of perceived ‘therapeutic necessity’, patients have the entitlement to make only decisions acceptable to their doctors. Second, doctors might then implicitly bear the burden of a legally-enforceable duty to ensure that therapeutically necessary treatment is accepted. It is unlikely that such propositions, if explicitly put to the Australian community in the present climate of insistence on consumer choice and institutional transparency, and on restricting doctors’ liability, would be regarded as constituting an acceptable policy.

Nondisclosure, on the ground that Ms Battersby may have declined melleril, was inconsistent with her entitlement to decide. This had not been displaced by any lack of decision-making capacity on the part of the patient. It was also inconsistent with the beneficence principle, because it assumed (wrongly) that Ms Battersby’s view of her personal interest was (or should be) congruent with Dr Tottman’s view of what her personal interest should have been.

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410 For the Australian formulation of causation, see for example Rosenberg v Percival (2001) 205 CLR 434, 441-2, [16, 17] (Gleeson CJ), 442, [19], 443-7, [24-36], 449, [44-45] (McHugh J), 452, [56], 450-4, [83-91] (Gummow J), 472-3, [125], 475-6, [136], 483-9 [153-166] (Kirby J).


412 For examples of cases that explicitly link the availability of the privilege to the existence of an objectively-established ‘therapeutic necessity’, see Di Carlo v Dubois [2004] QCA 150 at paragraph 81 per McMurdo J; Tai v Saxon, unreported, Full Court of the Supreme Court of Western Australia, 8 February 1996, per Ipp J; Hook v Rothstein 316 SE.2d 690 (1984).
Developing legal rules that are consistent with the autonomy principle should entail acceptance of the proposition that the kind of decision made by a patient with decision-making capacity is irrelevant, however unreasonable, distressed or idiosyncratic, and however deleterious its effects on the patient’s clinical welfare. The autonomy principle requires the separation of the determination about a patient’s capacity from predictions (however apparently reliable) about the consequences of his or her health care decisions. Therefore, the test for decision-making capacity must be interpreted in a way that accepts the validity of unreasonable, distressed or idiosyncratic decisions, and that focuses on whether the patient can carry out the deliberative process of decision-making, as described above. It may be that it is impossible, in a particular case, to draw a hard and fast distinction between process and outcome. Even when this is so, however, the ‘default’ emphasis on the clinical welfare dimension of the personal interest must be recognised to ensure that a counterbalance is applied and the patient’s entire personal interest protected.

(c) That a real risk of serious direct harm is a relevant kind of harm

The third proposition is that a real risk of serious direct harm is also a kind of harm that should trigger the operation of the therapeutic privilege. Because of Ms Battersby’s severe mental illness, Dr Tottman feared that disclosure would cause her direct physical harm, in the form of attempting suicide or developing ‘hysterical blindness’. There were two possible ways of dealing with this risk, and this paragraph explores them to determine which is preferable, in light of the importance that is currently accorded by Australian common law to the patient’s entitlement to decide.

The first option is, of course, nondisclosure of the risk to the patient. This was the option chosen by Dr Tottman. The adoption of this approach means that the patient is making a decision without reference to information that the doctor knows (or at least

413 See McLean, 1989, 118, who regards a patient’s distress as a legitimate part of the patient’s decision-making framework, rather than as necessarily detracting from the patient’s exercise of autonomy.

414 See Katz, 1984, 118-21. For the view that the New Zealand Code of Health and Disability Services Consumers’ Rights does not accommodate the idiosyncratic patient, see Manning, 2004, 194.

415 See the capabilities described in section 3.2.1.

416 Battersby v Tottman and State of South Australia (1985) 37 SASR 524, 527 (King CJ), 533 (Zelling J). See also Jacobs J at 542.
believes) would be of significance to the patient. Such a decision, it may be argued, is not – by definition – a meaningful decision in the sense understood in this thesis. This is because risks are being imposed on the patient which the patient may not have accepted, in considering the treatment in the context of his or her personal interest. Thus, the course of action adopted has in fact displaced the entitlement to decide, and left the doctor as the de facto substitute decision-maker,\(^{417}\) since it is the doctor who has made the effective decision about the proposed treatment. On the other hand, however, it could be argued that if disclosure were made, and a risk of serious direct harm materialised, the imbalance of effect would be exacerbated (because the patient would be suffering serious adverse consequences), and the purposes of care and independence might be impaired, because of the patient’s state following disclosure. In any event, if this option is taken, the principle of beneficence should also require the implementation of certain safeguards to ensure that the patient does not suffer from his or her ignorance of relevant information. Such safeguards, which were not adopted by Dr Tottman, should include monitoring the patient for materialisation of an undisclosed risk (in Ms Battersby’s case, this would have required close monitoring of her for signs of melleril retinopathy), and making disclosure following abatement of the risk, to enable Ms Battersby to make future decisions about treatment for her depression (that is, in light of the fact that she was already exposed to the risk of melleril retinopathy).\(^{418}\)

The second option is to acknowledge that what the doctor fears is that disclosure of the risk will seriously impair the patient’s ability to respond appropriately to disclosure by making what the doctor considers to be a proper or reasonable decision about undergoing treatment because of the predicted effect of disclosure. This fear should, if its recognition by the law is to be in any way consistent with the law’s recognition of an entitlement to decide, amount to more than a fear about refusal of treatment; it should be a fear about direct physical harm, such as suicide. If there is such a fear, and it is reasonably held, then I suggest that what this is really about is a reflection of the doctor’s concern about the capacity of the patient to carry out a reflective process as part of decision-making, rather than reacting to disclosure in a self-harming or destructive way. If this is the case, then the proper course of action is not for the doctor

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\(^{417}\) See, for example, Katz, 1984, 99-100, cautioning against this.
to assume the responsibilities of a *de facto* decision-maker, but to arrange for the formal appointment of an independent substitute decision-maker who will be in a position to have full disclosure made to him or her as a precursor to making a meaningful decision that, as discussed in Chapter 2, reflects an understanding of the patient's broader personal interest. On balance, I think this approach is preferable, as being more likely to ensure the protection of the personal interest, rather than focusing on clinical well-being.

(d) *That risk disclosure is the kind of disclosure that causes relevant harm*

The duty to disclose is not restricted to the disclosure of material *risk* information, but is a duty to disclose 'all relevant information'.\(^{419}\) Relevance, according to the High Court,\(^{420}\) is to be determined by the patient's decision-making needs, as tested against the needs of a reasonable person in the patient's position, and against any enlargement of those needs that has been indicated by the patient's conduct at the time the information is to be provided.\(^{421}\) In *Rogers v Whitaker*\(^{422}\) and *Battersby v Tottman*,\(^{423}\) the disclosure of risk information was emphasised, because it was the materialisation of an undisclosed risk that caused harm.\(^{424}\) However, this emphasis may obscure the reality that meaningful decision-making requires a range of information other than risk information.\(^{425}\)

Gaudron J indicated that the provision of risk information does not exhaust the scope of the duty of disclosure, and specifically held that a patient 'may have special needs or concerns which, if known to the doctor, will indicate that special or additional

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\(^{418}\) For further discussion about the importance of disclosure to future decision-making, see paragraph 3.6.2 (b).

\(^{419}\) *Rogers v Whitaker* (1992) 175 CLR 479, 490.

\(^{420}\) *Rogers v Whitaker* (1992) 175 CLR 479.


\(^{422}\) *Rogers v Whitaker* (1992) 175 CLR 479.

\(^{423}\) *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.

\(^{424}\) *Rogers v Whitaker* (1992) 175 CLR 479, 482 (joint judgment), 492-493 (Gaudron J); see also *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.

\(^{425}\) See Katz, 1984, 82.
information is required. In particular, Gaudron J suggests that the provision of such information is merely the minimum required to fulfil the duty of care, and mentions, in a footnote, other matters identified in the American case of Canterbury v Spence as being within the scope of the duty to disclose. These include the presence of a bodily abnormality, a failure to respond to treatment, any need to take precautions to restore, maintain or improve health and well-being, and the possible benefits of alternative treatments. Acceptance of the need for disclosure of a range of information is also apparent in the Chief Justice’s judgment in Battersby v Tottman although, as in Rogers v Whitaker, the application of the duty to risk information was understandably emphasised. King CJ referred to his judgment in F v R and, in particular, to his statement that the duty to disclose requires disclosure of information that is necessary to make ‘informed decisions concerning [the patient’s] future and, in particular, whether to undergo the proposed treatment.

In principle, the therapeutic privilege could operate to excuse nondisclosure of any relevant information that would otherwise fall within the scope of the duty of care to disclose. Although discussions about the therapeutic privilege have conventionally focused on risk disclosure, other kinds of information (for example, diagnostic information about an illness with a poor prognosis), are at least as likely to cause severe distress. The explanation for this selectivity might be that only risk information is seen as being likely to cause a specific kind of harm: deterring patients from undergoing treatment that is believed to be therapeutically necessary (whereas, for example, dire diagnostic information may be seen as more likely to encourage patients to undergo treatment). Existing common law could potentially allow the therapeutic privilege to be extended (inconsistently with a robust entitlement to decide) to any other material

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429 Battersby v Tottman and State of South Australia (1985) 37 SASR 524.
430 Rogers v Whitaker (1992) 175 CLR 479.
433 Sidaway v Governors of Bethlem Royal Hospital [1985] 1 AC 871, 891, 895 (Lord Diplock).
information that could deter patients from exercising the common law right to refuse treatment.

(e) That compliance with beneficence requires nondisclosure

Fifth, the therapeutic privilege assumes that if the entitlement to decide is displaced, on the basis of harm prevention, in favour of applying the therapeutic privilege, then the principle of beneficence simply requires nondisclosure. It is seldom that other forms of compliance are canvassed, such as the possibility that the principle of beneficence may still require means of disclosure that are carefully adapted to the needs and abilities of individual patients, as may be revealed through detailed discussions with patients.\textsuperscript{434} This would initially be more complex and resource-intensive than nondisclosure and, as acknowledged by the High Court, requires the exercise of special skill in relation to ‘unusually nervous, disturbed or volatile patients’\textsuperscript{.435} The introduction of legal rules that imposed such a duty would need to be supported by a social policy commitment to provide the resources and education necessary to comply with it. However, although the initial disclosure may be resource-intensive, recent research indicates that disclosure minimises complaints and litigation, and may therefore be more efficient, in the long-term, than nondisclosure.\textsuperscript{436}

(f) That nondisclosure of material information does not affect the validity of the decision

The therapeutic privilege raises the possibility that patients make ‘decisions’ on such limited information as to deprive their decision-making of meaning. Ms Battersby’s decision to accept melleril constituted a valid consent to treatment in accordance with the rule stated in \textit{Chatterton v Gerson},\textsuperscript{437} which was accepted by the High Court as reflecting Australian law.\textsuperscript{438} However, the deliberate omission of information, known by

\textsuperscript{434} See, for example, Katz, 1984, 78, 98, 201-2, 227-9.
\textsuperscript{435} \textit{Rogers v Whitaker} (1992) 175 CLR 479, 490 (joint judgment). For discussion of disclosure to ‘especially worried, querulous or emotionally labile’ or ‘unreceptive’ patients, see Freckelton in Freckelton and Petersen, 1999, 118-9.
\textsuperscript{436} See, for example, research done by the Open Disclosure Consortium: http://www.nsh.nsw.gov.au/teachresearch/cpiu/open_disclosure.shtml. See also the NHMRC Guidelines 2004.
\textsuperscript{437} \textit{Chatterton v Gerson and Anor} [1981] 1 QB 432.
\textsuperscript{438} \textit{Rogers v Whitaker} (1992) 175 CLR 479, 489 (joint judgment).
the doctor to be material to the patient, necessarily meant that although Ms Battersby’s consent might have been soundly-based from the doctor’s perspective, it was not a meaningful exercise of the entitlement to decide, and amounted to no more than a passive assent that in no way reflected her personal interest, in the terms defined by this thesis. Following the approach taken in Battersby v Tottman, a patient’s status as decision-maker can be rendered void, without a formal finding of incapacity, by a doctor who anticipates (rightly or wrongly) the patient’s refusal of treatment, and withholds what he or she knows to be material information in order to prevent this refusal. Australian law thus assumes that decisions, even when made without information which has been withheld specifically to produce them, are nevertheless ‘meaningful’.

By so assuming, and despite judicial declarations about the paramount entitlement to decide and the relevance of extra-clinical matters to patients’ decisions, the duty of care as defined by the High Court assumes that health care decisions are primarily clinical. Under this approach, patients are allowed their decision-making roles only if they satisfy doctors of their ability to make decisions that doctors consider, from positions of necessarily partial knowledge of their patients’ interests, to be soundly-based. Jacobs J seemed to go even further by referring to a ‘right’, belonging to doctors, to decide to withhold material information from patients. This is significant because, in the absence of emergency or other circumstances raising compelling public interest, no judgment dealing with decision-making in the doctor-patient relationship has been prepared explicitly to identify doctors as decision-makers in relation to patients with decision-making capacity. Even the more conservative judgments in Sidaway v Governors of Bethlem Royal Hospital and Ors regard the patient as the decision-maker, although some of the Law Lords appear to assume that a reasonable patient will accept the doctor’s advice.

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439 Battersby v Tottman and State of South Australia (1985) 37 SASR 524.
440 Battersby v Tottman and State of South Australia (1985) 37 SASR 524, 542.
441 For a discussion of the delegation, by judges to doctors, of decision-making about the lawfulness of abortions, see subparagraph 5.2.3 (c) (i). See also In the Matter of the Application of Jamaica Hospital 491 NYS.2d 898 (1985), for a case in which the court conferred on the doctor authority to act as substitute decision-maker.
442 See, for example, Sidaway v Governors of Bethlem Royal Hospital and Ors [1985] AC 871, 894-895 (Lord Diplock), 904 (Lord Templeman).
Because disclosure to patients is a necessary precondition of meaningful decision-making, conferral of such a right as suggested by Jacobs J would amount to displacement of the entitlement to decide. It would allow doctors to fulfil their legal duty of disclosure in a way that would be understood and intended to reduce or eliminate the possibility of a decision to decline treatment that a particular doctor recommends as being therapeutically necessary. However, although the judgment of Jacobs J was not explicitly accepted in other judgments, the practical effect of the right suggested by Jacobs J is no different from the effect of the operation of the therapeutic privilege: to encourage acceptance of doctors’ advice. Jacobs J is merely expressing the same legal principle in terms of being a doctor’s right, rather than part of a doctor’s duty. To suggest, in such circumstances, that patients have a genuine entitlement to decide masks the weight given by judges to doctors’ views and perceptions, especially about therapeutic necessity, at the expense of the views and perceptions of patients, which are often hidden from doctors’ view, deliberately or by the exigencies of health care delivery.  

(g) That consequences of rejection of treatment are more serious than consequences of accepting it

This proposition is about the weighting that is implicitly given to harm that can arise from a decision about treatment. It is apparently assumed that rejection of therapeutically necessary treatment will generally be detrimental to the patient, even though not all treatments recommended by all doctors are effective, and the way in which many effective treatments are efficacious is not completely understood. It is also assumed, although not expressly stated, that adverse effects which may materialise in the course of therapeutically-necessary treatment are more speculative, or less serious, or both, than the consequences of refusal of that treatment. These assumptions may generally be correct, but cannot be relied upon to be universally so, and therefore should not be the basis for a doctor’s unilateral displacement of the patient’s entitlement to decide. Thus, in Battersby v Tottman, the doctor was prepared to assume that even irreversible blindness would be of less gravity to the patient than her mental illness.

443 See, for example, Skene, 1998, 4, 6-7.
444 See, for example, Cornwell, 2001; Katz, 1984, 189-95, 197-8.
445 Battersby v Tottman and State of South Australia (1985) 37 SASR 524.
This view, although clearly not shared by the patient (a fact known to Dr Tottman), was accepted as reasonable by the majority judges.446

(h) Effect of therapeutic privilege on entitlement to decide

In my view, the therapeutic privilege displaces the entitlement to decide because it deprives patients with decision-making capacity of information needed to make meaningful decisions. It does so with the purpose producing a decision that doctors believe will prevent (or at least, minimise) harm to the patient; that is, a decision to accept clinically-indicated treatment.447 The practical effect of applying the therapeutic privilege is that, if ‘therapeutic necessity’ is perceived to exist, decision-making capacity may be allowed to be exercised only in a way that a doctor accepts as valid. The decision that is permitted by the law to have a genuine effect on whether or not treatment is given is an antecedent decision, made by the doctor, that the treatment is therapeutically necessary, and that information that may persuade the patient to reject treatment should therefore not be disclosed. In making that decision, the doctor is permitted to assume that refusal of treatment is an unsound exercise of the entitlement to decide; an assumption based on value judgements that are rarely made explicit. To protect a robust entitlement to decide, legal rules should instead ensure that all patients with decision-making capacity are given sufficient information to be able to make meaningful decisions. This precludes application of the therapeutic privilege for otherwise competent patients in respect of whom doctors predict refusal of ‘therapeutically necessary’ treatment, on grounds that doctors consider invalid.448

The Court in Battersby v Tottman449 interpreted and applied the doctor’s duty to disclose in a way that displaced the entitlement to decide with the object of preventing

446 But see Battersby v Tottman and State of South Australia (1985) 37 SASR 524, 534-5 (Zelling J). For an account of the patient’s view, see 543 (Jacobs J).

447 For a similar conclusion about the therapeutic privilege, see Chelmsford Report, vol 6, 86. While the Law Reform Commission of Victoria concluded that the therapeutic privilege should remain (see Report 24, 1989, 18, 24, 26), it also concluded that patients wanted more information than they were, at the time, receiving. This was so even though empirical studies conducted by the Commission found that 38% of patients surveyed agreed that there were circumstances in which a doctor was justified in withholding information if disclosure would harm the patient. See Law Reform Commission of Victoria, Doctor and Patient Studies, 1989, 39, Tables 21B and 22B. However, younger patients were less likely to support nondisclosure (Doctor and Patient Studies, 1989, 48-9). For the view that the therapeutic privilege is a ‘recipe for paternalism’, see Faden and Beauchamp, 1986, 37.

448 This seems to be the view indicated by Gaudron J in Rogers v Whitaker (1992) 175 CLR 479, 494.

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either direct harm (suicide or hysterical blindness) or indirect harm (refusal to take melleril). The Court purported to justify Dr Tottman’s nondisclosure as being necessary to preserve Ms Battersby’s autonomy, while using the therapeutic privilege and the balancing process to deny her a genuine opportunity to exercise it by defining and asserting her personal interest. This accommodation of therapeutic necessity demonstrates two concerns that influenced the trial and majority judges, and which the High Court seems to have accepted as valid. The first concern is for the patient’s clinical welfare as the pre-eminent good requiring protection by doctors and judges. Second, it is evident that the Court was concerned to ensure its judgment would protect doctors who, even though not respecting the patient’s autonomy, are regarded as having acted in good faith, with the intention of preventing harm.

3.5.3 The balancing process

(a) How the scope of disclosure is defined

In Rogers v Whitaker,\(^4\) the High Court appears to conceptualise the relationship between decision-making and disclosure as consisting of two strands that derive from what this thesis argues is the principal purpose of disclosure: to enable patients to make meaningful decisions (that is, decisions reflecting the personal interest). These strands define the boundaries of the duty to disclose.\(^5\) The subject matter of the first strand is the character of information: for the duty to disclose to exist in relation to particular information, that information must be necessary to enable the making of a meaningful decision.\(^6\) The second strand focuses on the character of the doctor-patient relationship: because of the imbalance of knowledge between doctor and patient, the doctor must disclose such information as is required to make meaningful decisions, because the information is not otherwise accessible to the patient. The scope of the duty is thus defined by the necessity for doctors to be accountable to patients for information

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\(^4\) Battersby v Tottman and State of South Australia (1985) 37 SASR 524.

\(^5\) Rogers v Whitaker (1992) 175 CLR 479.

\(^6\) Rogers v Whitaker (1992) 175 CLR 479, 490.

\(^4\) Whether information is material may be established by a patient’s conduct: Rogers v Whitaker (1992) 175 CLR 479, 489, 490, 491; see also Rosenberg v Percival (2001) 205 CLR 434, 438, [5], 442, [17] (Gleeson CJ); 459, [79], 459-60, [81] (Gummow J); 475, [134], 477, [141], 482-3, [150] (Kirby J), 497, [200], 501, [212] (Callinan J).
that doctors possess, and which is necessary to enable patients to make meaningful decisions.

**What is the balancing process?**

Australian courts have held that a doctor must determine the scope of his or her duty to disclose using a balancing process. Australian courts have taken the view that doctors are permitted to balance various factors relating to a proposed decision against each other to determine whether, in a particular case, the scope of disclosure is expanded or contracted. A range of factors is considered to be relevant: the entitlement to decide, the nature of the matter to be disclosed, the nature of the proposed treatment,\(^{453}\) the patient’s desire for information, the patient’s temperament and health and general surrounding circumstances.\(^{454}\) Various of these factors seem to relate to a notion of therapeutic necessity, although it is not explicitly mentioned. This section considers how therapeutic necessity has, in fact, been taken into account in the balancing process.

The balancing process described by King CJ in *F v R*\(^{455}\) was accepted in *Rogers v Whitaker*\(^{456}\) and *Battersby v Tottman*\(^{457}\). In particular, the High Court’s acceptance of an emphasis on clinical welfare in determining the patient’s ‘best interests’ may be discerned in the majority’s approval of the judgment of King CJ in *F v R*.\(^{458}\) However, Ms Whitaker was not pursuing a therapeutically valuable outcome. Application of the balancing process was not required because there was no perception of any conflict between Ms Whitaker’s clinical welfare and other dimensions of her personal interest.

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\(^{453}\) This thesis does not accept the proposition, put in *Haughian v Paine* (1987) 40 CCLT 13, that, if the treatment is not necessary to save life, disclosure is required. This is because the converse proposition – that disclosure is not required if treatment is life-saving – would undermine the right to refuse treatment. See also Law Reform Commission of Victoria, Report 24, 1989, 40.


\(^{456}\) *Rogers v Whitaker* (1992) 175 CLR 479.

\(^{457}\) *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.

The balancing process did play a significant role in *Battersby v Tottman*,\(^{459}\) in which a life-threatening conflict was perceived to exist between Ms Battersby’s clinical welfare and her entitlement to decide. Notwithstanding the assertion of a patient’s ‘paramount entitlement to decide’, and the acceptance that Ms Battersby had such a right, King CJ and Jacobs J took the view that, to determine the scope of their duties to disclose, doctors must take into account the range of factors identified by King CJ in *F v R*.\(^{460}\) Dr Tottman had concluded that Ms Battersby’s mental and emotional fragility, and the risks that her mental illness posed to her physical and mental health, outweighed her desire for information, her known concerns for her eyesight, and the dosage-related risk of retinopathy. The trial judge and the majority appeal judges were satisfied with the way in which Dr Tottman had balanced the relevant factors. Dr Tottman’s failure to disclose the risk of melleril retinopathy was therefore not characterised as a breach of the duty to disclose, although it had deprived Ms Battersby of the opportunity to make a decision consistent with her known views, and what I characterise as her personal interest.

(c) Problems with the balancing process

The conclusion reached by Dr Tottman and the majority judges may reflect the priorities of many individuals who might find themselves in a situation similar to that of Ms Battersby, but it should not simply be assumed as inevitable for every patient. This is because the notion of therapeutic necessity which underlies much of the process is subjective, and whether an individual patient perceives the existence of a therapeutic necessity depends at least partly on dimensions of his or her personal interest that are not within the scope of medical expertise. An example of this is an individual who is infertile and who may, or may not, regard this as a circumstance requiring medical intervention.

A further problem with the balancing process is that although the entitlement to decide is described as ‘paramount’, its formulation by King CJ leaves unstated the relative weight or priority the other factors will be accorded. In any event, despite assertions of paramountcy, an otherwise competent patient’s right to decide may apparently be

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\(^{459}\) Battersby v Tottman and State of South Australia (1985) 37 SASR 524.

‘trumped’ if a doctor believes that the patient may, on disclosure of particular information, be deterred from undergoing ‘therapeutically necessary’ treatment. That is, if the doctor believes that the patient’s interests are best served by ensuring consent to treatment by failing to disclose information that might deter a patient from treatment (such as, of course, risk information). Thus, the law can be regarded as purporting to use the balancing process, based on perceived therapeutic necessity, as an alternative means of protecting the patient’s interests.

*Battersby v Tottman* illustrates this. The majority and the dissenting judge disagreed about how the balancing process should treat a risk that all agreed to be serious. The majority judges found that the gravity of the risk weighed against disclosure, because it was so serious that its disclosure might have exacerbated Ms Battersby’s unstable state. Zelling J, however, regarded the gravity of the risk as strongly inclining the balance towards disclosure. The dissenting judge noted evidence that the most serious risk posed by melleril was death from cardiac arrest, and considered that ‘When one deals with effects as serious as the ones I have detailed...the patient must be allowed to make her own decision, whether the doctor thinks she is well enough to do so or not.’ Zelling J therefore held that concerns about the plaintiff’s possible reaction to disclosure, however severe they may be, were ‘no answer’ to the failure to disclose such a serious risk. This difference of opinion shows a ‘Catch-22’ situation in addition to that created by the concurrent operation of existing tests for causation and the therapeutic privilege. A prerequisite for imposing a duty to care to disclose information is that the information be material to decision-making. However, in applying the balancing process, a serious risk can weigh either for or against disclosure, depending on whether the treatment is regarded as therapeutically necessary and whether the risk may, in the doctor’s judgement, deter acceptance of treatment and thus threaten harm to the patient.

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461 *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.
462 *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524, 534 (Zelling J).
464 *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524, 534.
465 See, for example, *Tai v Saxon*, unreported, Full Court of Supreme Court of Western Australia, 8 February 1996.
3.6 ARE THE THERAPEUTIC PRIVILEGE AND THE BALANCING PROCESS CONSISTENT WITH THE BENEFICENCE PRINCIPLE?

3.6.1 Respecting the entirety of the patient's personal interest

The entitlement to decide having been displaced, however incorrectly, on the grounds of therapeutic necessity, the judges in *Battersby v Tottman*\(^{466}\) should have applied rules that were consistent with the beneficence principle as described in this thesis, which requires a doctor to protect and promote the patient's personal interest. This section considers whether the application of the therapeutic privilege or of the balancing process complies with the beneficence principle.

3.6.2 Beneficence and the therapeutic privilege

If the therapeutic privilege continues to be accepted as valid and as applicable in a particular case, special considerations should be taken into account to determine what is required to protect and promote the personal interest as required by the principle of beneficence advanced in this thesis. This is because patients for whom treatment is recommended as a therapeutic necessity, and from whom material information is withheld because of this, may pay a twofold price for the calm, deliberative and rational decision to accept health care that is the aim of the therapeutic privilege. First, the patient is deprived of the opportunity to take steps to safeguard his or her health and well-being, in particular against materialisation of the undisclosed risk.\(^{467}\) This is because the decision is made without knowledge of material information that is withheld specifically because of its potential significance to the patient's decision-making. Second, the patient is deprived of the opportunity to make a decision based on all information material to the personal interest (for example, the cumulative effect of risks).\(^{468}\) Although it is unlikely that it would ever be fair or practicable to impose on a doctor a duty to disclose all possible risks, this is nevertheless a 'cost' of nondisclosure that must be taken into account in developing legal rules. Related to this second cost, the patient is also deprived of information that may be material to other foreseeable

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\(^{466}\) *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.

\(^{467}\) As is made particularly clear by the facts of *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.

\(^{468}\) For judicial concern about establishing causation by reference to the effect on a patient’s decision of cumulative risks, see *Hribar v Wells* (1995) 64 SASR 129, 130 (King CJ). For an alternative view, see 143-4 of that decision (Bollen J).
decisions. This section considers whether the judgments in *Battersby v Tottman* took these matters into account to impose rules consistent with the principle of beneficence.

(a) **Protecting the patient’s clinical welfare**

Fundamentally, the purpose of the therapeutic privilege is to protect the clinical welfare of patients. Yet this purpose is frustrated if, having withheld material information to secure a patient’s clinical welfare, a doctor does not take reasonable steps to ensure that the patient’s clinical welfare is not then threatened by materialisation of an undisclosed risk, or other consequences of undisclosed information. A patient who does not know about a risk is unable to monitor for it, and specific surveillance becomes part of the doctor’s duty of care. This duty arises from the doctor’s decision to adopt a course of conduct, the effect of which is to deprive the patient of the opportunity to exercise his or her independence in relation to accepting medical treatment. Its imposition would recognise that doctors’ compliance with the principle of beneficence is not exhausted by refraining from disclosure.

In *Rogers v Whitaker*, no question was raised about whether or not Dr Rogers took reasonable steps to watch for and prevent the materialisation of sympathetic ophthalmia. By contrast, the adequacy of Dr Tottman’s measures to monitor for the appearance of melleril retinopathy was considered by each judge. King CJ admitted that the adequacy of the precautions taken by Dr Tottman caused him ‘considerable anxiety,’ and remarked that the doctor’s explanation of this omission was not ‘particularly convincing.’ However, the Chief Justice concluded that he could not hold that the doctor’s conduct was ‘so erroneous’ as to fall outside the conduct of a doctor acting with ordinary competence and reasonable care. In making this finding, King CJ was perhaps influenced by evidence that, however early in its development melleril retinopathy was detected, the outcome for Ms Battersby might not have been any better. Jacobs J may also have accepted that nondisclosure of a material risk imposes a specific duty on the doctor to monitor the patient, although he too found the

469 *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.


471 *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.

defendant’s steps to have been adequate. The trial judge, too, was apparently satisfied that a consequence of risk nondisclosure is that a doctor is required to take precautions to prevent harm coming to the patient as a result of materialisation of the undisclosed risk. Nevertheless, the trial judge held, first, that the precautions taken by the defendant doctor were adequate and, second, that any more active monitoring might have endangered the plaintiff’s life by putting her on inquiry about the risk. Zelling J, agreeing that monitoring for the materialisation of risk is a specific part of the doctor’s duty of care, was not satisfied with the precautions adopted by Dr Tottman, and appeared to disbelieve the defendant’s explanations for not adopting more stringent monitoring procedures.

It can be concluded that the trial judge, the majority judges and the dissenting judge all accepted the proposition that, if a patient is not made aware of a material risk, then a doctor who has withheld information about it must take reasonable steps to ensure that any materialisation of the risk is detected as soon as is practicable, to prevent harm to the patient’s interests. What constitutes reasonable steps in a particular case should be judged in light of matters that include the patient’s ignorance of the existence of the risk, and the gravity, probability and reversibility of the risk. Thus, even though a doctor who does disclose a risk still has a duty of care to monitor for its materialisation (because he or she will be aware of relevant signs or symptoms that are not apparent to the patient), the duty of care that is imposed on a doctor who withholds information must be adjusted to ensure, as far as reasonably possible, that the patient is not harmed by his or her ignorance.

(b) Protecting the patient’s entitlement to decide

In Battersby v Tottman, King CJ affirmed his position, originally stated in F v R, that the doctor’s duty is to disclose information that enables patients to make ‘informed

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473 Battersby v Tottman and State of South Australia (1985) 37 SASR 524, 528.
474 Battersby v Tottman and State of South Australia (1985) 37 SASR 524, 542.
477 Battersby v Tottman and State of South Australia (1985) 37 SASR 524.
decisions’ about their future and, in particular, about ‘whether to undergo proposed treatment.'\(^{479}\) In these references, and in the affirmation of the ‘paramount consideration’, the Chief Justice acknowledged the patient’s entitlement to decide. The other majority judge cautiously acknowledged the existence of the entitlement, warning that it was not ‘so absolute or unqualified as to be unrealistic.'\(^{481}\) It is unclear what Jacobs J thought might be unrealistic about a patient’s entitlement to decide, short of impaired decision-making capacity, or the existence of an emergency. Jacobs J seems almost to suggest that the existence of therapeutic necessity should always outweigh the judicially-recognised entitlement to decide.\(^{482}\) Subsequent decisions in the High Court have not taken the opportunity to endorse the approach taken by Jacobs J, and have preferred the approach taken by King CJ in \(F v R.\)\(^{483}\) However, some subsequent appellate decisions have expressed views to the effect that, the greater the therapeutic necessity, then the more attenuated may be the duty to disclose.\(^{484}\)

Permitting nondisclosure in relation to a patient who, but for his or her predicted refusal of particular treatment, would be considered to have decision-making capacity, undermines the patient’s entitlement to decide about other matters affecting his or her life, as well as the entitlement in relation to the particular treatment decision in question. For example, if disclosure of material information is never made (even after a successful treatment in which undisclosed risks do not materialise), then it is conceivable that a patient may be deprived of information that is relevant to future decisions. This may be the case, for example, if the risk arose from a particular characteristic or predisposition of the patient, which may have a bearing on employment or relationship decisions to be made by the patient. Information about alternative treatments (for the patient’s future

\(^{479}\) For the view that there is an implied contractual duty imposed on doctors to disclose information that might be relevant to the ‘future medical treatment or physical or mental wellbeing of a patient’, see \(Breen v Williams\) (1995-1996) 186 CLR 71, 78 (Brennan CJ); see also 91 (Dawson and Toohey JJ).

\(^{480}\) \(Battersby v Ttotman and State of South Australia\) (1985) 37 SASR 524, 527 (King CJ), quoting his judgment in \(F v R\) (1983) 33 SASR 189, 192.

\(^{481}\) \(Battersby v Tottman and State of South Australia\) (1985) 37 SASR 524, 541, 544.

\(^{482}\) See \(Battersby v Tottman and State of South Australia\) (1985) 37 SASR 524, 539, 542.

\(^{483}\) \(F v R\) (1983) 33 SASR 189, 193. See also \(Rogers v Whitaker\) (1992) 175 CLR 479, 487.

\(^{484}\) \(Di Carlo v Dubois\) [2004] QCA 150 at paragraph 81 per McMurdo J; \(Tai v Saxon\), unreported, Full Court of the Supreme Court of Western Australia, 8 February 1996, per Ipp J, writing the lead judgment. In \(Di Carlo v Dubois\), the therapeutic privilege was held not to apply to the facts of the case, but its existence was unequivocally affirmed by McMurdo J.
health care decisions), diagnostic information (for example, about predispositions to certain conditions), and treatment errors may all be relevant to reasonably foreseeable decisions to be made by a patient. In Ms Battersby’s situation, for example, had her mental illness been cured before signs of melleril retinopathy began to appear, then Dr Tottman should have disclosed to her that she had been exposed to a risk that could appear after her discharge from hospital, and informed her of the signs, such as pigmentation of the skin, that might indicate its materialisation. Both the autonomy and beneficence principles should have required disclosure of this risk, to enable Ms Battersby to make decisions in the future about her treatment, and to protect her welfare generally.

In conclusion, the therapeutic privilege by its nature displaces the entitlement to decide in relation to a particular health care decision. To ensure compliance with the beneficence principle and thus protect the personal interest, legal rules should ensure that formal and independent substitute decision-making processes are used if the patient’s decision-making capacity is actually impaired, to promote the making of a meaningful decision. Second, if courts continue to accept the proposition that the privilege applies if there is a risk of direct harm (so allowing doctors to become de facto substitute decision-makers), then legal rules should ensure protection for the patient’s interests.

That is, the beneficence principle should be understood to require the use of the following safeguards in the event of nondisclosure to the patient on the basis of predicted direct harm. First, records should be kept of the nature of the treatment that is given, what information is given to the patient about it and what information has been withheld. Records about the reasons for withholding information should also be kept. Record-keeping of this kind is important as a means of ensuring that important information about the patient’s treatment is not lost, and is accessible in the future, so that the imbalance of effect is not exacerbated by ignorance on the part of the patient or the patient’s care-givers. It is also important as a way of ensuring that the doctor’s actions are transparent, and can, if necessary, be reviewed. Second, while these records

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485 See, for example, Gates v Jensen 595 P.2d 919 (1979). See also Shultz, 1985, 230.
486 For discussion of the relatively expansive approach taken to disclosure by New Zealand, see Manning, 2004.
should perhaps not, in strictly-defined circumstances, be accessible to the patient while impairment of capacity or potential for harm exists, certain other persons should have access to them. These other persons may include other health care providers, the patient’s carer or substitute decision-maker (if any) and, possibly, the patient’s legal representative. Third, the doctor should both comply with a specific standard of care, by monitoring the patient for materialisation of undisclosed consequences.

Such rules were not adopted by Dr Tottman, nor described by the judges in Battersby v Tottman.

(c) Other dimensions of the patient’s personal interest

As discussed in Chapter 1, doctors are necessarily limited in the scope of their knowledge of their patients, with their primary focus understandably being on the clinical welfare of their patients. The exigencies of the doctor-patient relationship mean that even the best and most conscientious of doctors can seldom have a detailed knowledge of their patients that extends much beyond their clinical welfare. However, patients do not make health care decisions on the basis of exclusively clinical information, or by reference only to their clinical welfare. A doctor who exercises a discretion to withhold information on the basis of therapeutic necessity has already assumed, perhaps without recognising the assumption, that the patient prioritises his or her clinical welfare in a way that is consistent with the doctor’s perception of what those priorities ought to be. The way in which this undermines the patient’s personal interest, and reduces the decision about health care to a self-executing medical decision, can be seen by comparing Rogers v Whitaker with Battersby v Tottman.

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487 For the relationship between the common law therapeutic privilege and statutory provisions that exempt doctors from providing access to material that may harm a patient or a third person: Holmes v Northern Territory of Australia [1997] HREOCA 40 (23 July 1997).
488 Battersby v Tottman and State of South Australia (1985) 37 SASR 524.
489 See, for example, Reibl v Hughes (1980) 114 DLR (3d) 1, in which financial considerations concerning the vesting of a pension would have been relevant to the patient’s decision about the timing of a proposed surgical procedure.
490 See, for example, Shultz, 1985; in particular, 246, 254.
491 Rogers v Whitaker (1992) 175 CLR 479.
492 Battersby v Tottman and State of South Australia (1985) 37 SASR 524.
Although Ms Whitaker's clinical welfare could have been enhanced by the surgery, which might have led to a recovery of sight in her injured eye, there was no therapeutic necessity for the surgery that was performed. Doctor and patient were in agreement about what were the possible benefits of accepting the treatment, although only the doctor was aware of the material risk. The imbalance of effect was created by the risk of sympathetic ophthalmia, and not by Ms Whitaker's pre-existing injury, with which she had lived for many years and with which she was content to go on living. Doctor and patient agreed that the surgery was the subject matter of a choice to be made by the patient against a background of the patient's personal circumstances, values and priorities. It was common ground that the materialisation of the undisclosed risk was the worst possible outcome for Ms Whitaker, short of death.

In Battersby v Tottman, there are competing views even on what constituted the patient's clinical welfare. The patient's evidence was stark: she would have preferred to live with her mental illness and the risk of suicide than to become blind. Her evidence must have been regarded as credible on this point, because it was the basis for Dr Tottman's successful reliance on the therapeutic privilege. The doctor, believing the known risk to be reversible, was of the view that curing the mental illness had a higher priority than avoiding the risk. The doctor's view of what constituted Ms Battersby's clinical welfare, and its relative priority, prevailed in the courts, displacing the entitlement to decide of a patient whose decision-making capacity had been effectively accepted by her doctor and by the courts.

The Chief Justice and Jacobs J emphasised that the consequences of refusal of treatment could have been life-threatening. They also emphasised the therapeutically-valuable outcome of the treatment, in that Ms Battersby was cured of her mental illness. Zelling J, in dissent, did not consider that therapeutic necessity justified nondisclosure to a patient whose incapacity had not been formally established, or determined

493 Rogers v Whitaker (1992) 179 CLR 479, 491 (joint judgment).
494 Battersby v Tottman and State of South Australia (1985) 37 SASR 524.
495 See, for example, Battersby v Tottman and State of South Australia (1985) 37 SASR 524, 539 (Jacobs J).
496 Although this occurred after she was taken off the melleril, Jacobs J accepted that the melleril treatment nevertheless contributed to her cure: Battersby v Tottman and State of South Australia (1985) 37 SASR 524, 539.
independently of the predicted refusal of treatment. Zelling J treated Ms Battersby’s evidence in a way that is similar to the way in which the High Court treated Ms Whitaker’s evidence about refusal.\(^{497}\) His reasoning was that only Ms Battersby could decide whether or not the prospect of recovery from her mental illness was worth the risks posed by Dr Tottman’s treatment, because only she could define the content and relative priority of her clinical welfare.\(^{498}\) The dissenting judge took the view that Dr Tottman’s conduct in overriding Ms Battersby’s views amounted to the doctor making his own determination about her priorities,\(^{499}\) having dismissed as irrational and dangerous what he knew would be the patient’s own evaluation. I suggest that, by substituting his priorities for those of a patient with decision-making capacity,\(^{500}\) the doctor failed first, to comply with the autonomy principle by not accepting the decision-making role of Ms Battersby, whom he recognised as having decision-making capacity and, second, to comply with the beneficence principle by failing to take proper precautions in monitoring Ms Battersby for the manifestation of melleril retinopathy. Thus, by dismissing what I have argued to be the proper roles of both principles in decision-making in the doctor-patient relationship, the doctor prevented proper assertion and protection of the personal interest, either through the entitlement to decide or by alternative rules that advanced Ms Battersby’s interests, as defined by her.

\((d)\) Was Dr Tottman beneficent?

Nondisclosure of otherwise material information has been permitted if disclosure itself is likely to directly result in serious physical or psychological harm, and if adequate safeguards are applied.\(^{501}\) However, by failing to apply legal rules (including safeguards) that took into account the entirety of the patient’s personal interest, I argue that Dr Tottman did not comply with the beneficence principle. It perhaps should also

\(^{497}\) Battersby v Tottman and State of South Australia (1985) 37 SASR 524, 535 (Zelling J).

\(^{498}\) Ms Battersby gave evidence that she would not have accepted the risk of blindness to treat her mental illness: Battersby v Tottman and State of South Australia (1985) 37 SASR 524, 543.

\(^{499}\) See also Katz, 1984, 118-21, 173-4; Pellegrino and Thomasma, 1988, 72; Shultz, 1985, 272.

\(^{500}\) The High Court has held that patients who entirely lack capacity nevertheless have dimensions to their interests other than the clinical welfare dimension, and that these must not be disregarded in therapeutic decision-making: see Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 238 (joint judgment), 266, 268 (Brennan J), 293 (Deane J), 311 (McHugh J).

\(^{501}\) The majority judges in Battersby v Tottman accepted that adequate safeguards were applied: Battersby v Tottman and State of South Australia (1985) 37 SASR 524.
have been noted that the Court would have been very reluctant to accept the course of action that I argued is appropriate in ‘direct harm’ cases; that is, to require the arrangement for an independent substitute decision-maker. Had the Court taken this point, and accepted that Ms Battersby did not have decision-making capacity, then they would have been confronted with the prospect of finding that Dr Tottman had committed a battery (because, lacking capacity, Ms Battersby had not given a valid consent). Such a finding would have been contrary to the judicial mood of the day (and probably to the judicial mood in Australia today).

3.6.3 Beneficence and the balancing process

The balancing process has the apparent appeal of being flexible and inclusive, by its reference to a range of broadly-described factors. This may create the impression that the purpose of the balancing process is to take into account all aspects of a patient’s circumstances, thus promoting and protecting the entirety of the patient’s personal interest. However, the focus of the balancing process is more limited, precluding its use in a way that complies with the beneficence principle. There are three reasons for this.

First, as previously indicated, the apparent existence of therapeutic necessity may weight a balancing process in favour of nondisclosure of material information with the object of protecting a patient’s clinical welfare, in preference to other aspects of the personal interest. This is because no rules have been identified as applying to safeguard the personal interests of patients from whom information has been withheld. By leaving open the relative weightings to be given to the relevant factors, the balancing process effectively allows doctors to define and rely on their own constructions of patients’ personal interests. Second, the range of factors included is open-ended and, unlike the therapeutic privilege, the balancing process can be applied to withhold otherwise material information even from patients whose decision-making capacity is in no doubt at all, and without even any apprehension of serious harm arising from disclosure. Third, the balancing process may be applied without requiring dialogue between doctor and patient to give substance to the doctor’s evaluations and predictions, or to discern other aspects of the personal interest, which beneficence requires the doctor to protect.

Thus, the ‘paramount entitlement’ has been displaced when a doctor forms a view that the entitlement to decide should be exercised in a certain way, and that this exercise requires nondisclosure of otherwise material information. The doctor may, currently,
justify this by reference to the sensitivity of the matter to be disclosed, the necessity for
the proposed treatment to be administered, and the patient's temperament and health.\textsuperscript{502}
I believe that this is inconsistent with a robust entitlement to decide because it allows
nondisclosure on the basis of factors that are irrelevant to whether particular information
is necessary for meaningful decision-making (such as the patient's temperament and
health). I suggest that temperamental and health issues may affect the manner of
disclosure to a patient with decision-making capacity, but should not affect whether
disclosure occurs.

3.7 CONCLUSIONS

3.7.1 Paramount entitlement to decide displaced: lack of capacity and perceived
therapeutic necessity

The entitlement to decide is not triggered for patients without decision-making capacity.
This is because such patients lack the psychological attribute of autonomy that is a
prerequisite for the application of the entitlement to decide. The protection of the
personal interest belonging to such patients is considered in Chapter 2.

Another basis on which Anglo-Australian courts have displaced the patient's
entitlement to decide is perceived therapeutic necessity of treatment which, the doctor
fears, the patient may refuse. Thus, the difference between \textit{Rogers v Whitaker},\textsuperscript{503} and
\textit{Battersby v Tottman}\textsuperscript{504} lies not in Ms Battersby's mental illness (because she was
treated by the doctor and the courts as having capacity), but in the likelihood of her
refusing treatment that Dr Tottman regarded as essential for her clinical welfare, as he
defined it. Therapeutic necessity has been treated as justifying displacement of the
entitlement to decide for two reasons.

First, clinical welfare is defined by doctors and is regarded as being either exhaustive of
the patient's personal interest, or at least more important than other dimensions of the
patient's personal interest.\textsuperscript{505} Judges have been reluctant to find liable a doctor who fails

\textsuperscript{502} For an example of temperament influencing a decision not to disclose to a patient with
decision-making capacity, see \textit{Gover v State of South Australia and Perriam} (1985) 39 SASR 543, 547,
549, 552, 563, 567-8.
\textsuperscript{503} \textit{Rogers v Whitaker} (1992) 175 CLR 479.
\textsuperscript{504} \textit{Battersby v Tottman and State of South Australia} (1985) 37 SASR 524.
\textsuperscript{505} See Shultz, 1985, 249.
to disclose information from motives of protecting the patient’s clinical welfare, because the doctor is seen as ‘just doing his job’.

Second, it is assumed by lawmakers that a decision by a patient is more reasonable and more meaningful if material information is withheld, and that withholding information on this basis is sufficient beneficent conduct.

However, ‘therapeutic necessity’ is connected with neither the ability nor the will to exercise autonomy, so it should not be seen as triggering the use of a substitute decision-maker. Furthermore, ‘therapeutic necessity’ does not convert material information into information that is not material. Finally, the possibility of harm arising from predicted refusal of treatment by a patient with decision-making capacity does not, I suggest, justify nondisclosure.

Attempts to prevent such harm by refraining from disclosure are, in my view, inconsistent with the autonomy and beneficence principles, and thus prevent protection of the personal interest. For these reasons, therapeutic necessity is not a ground on which to displace the entitlement to decide. While seeking to prevent harm, it does not do so on a basis that provides proper protection to the personal interest, which should be the focus of the law about decision-making in the doctor-patient relationship.

3.7.2 Compliance with the beneficence principle: application of therapeutic privilege in cases of direct harm

If a doctor reasonably foresees that disclosure itself will cause serious harm to a patient, nondisclosure has been regarded by the law as being justifiable. If this ground for the therapeutic privilege continues to be accepted as legitimate, certain limitations should apply: such nondisclosure should only ever be permissible while the potential for harm exists, and in respect only of the distressing information. The duty to disclose other material information, and to use certain safeguards, should apply. When the risk of harm has passed, then the autonomy and beneficence principles should require disclosure to the patient of all material information (including information about risks to which the patient has been exposed and which are material to the patient’s reasonably foreseeable decision-making needs). This would be the minimum necessary to protect the personal interest. The better view is that fears of direct harm reflect concerns about

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capacity, and are more appropriately addressed through the appointment of an independent substitute decision-maker (that is, a substitute decision-maker other than the doctor), to ensure that a meaningful decision about treatment can be made. This view is consistent with that taken by Gaudron J in Rogers v Whitaker.\textsuperscript{507} There, the judge held that there was no basis for a therapeutic privilege that did not rest on emergency or a lack of decision-making capacity.

3.7.3 Compliance with the beneficence principle: application of balancing process in cases of therapeutic necessity

The High Court has recognised the existence of an entitlement to decide, and the necessity for doctors to disclose information on the basis of which to exercise the entitlement. I have argued that this entitlement usually provides the best protection for the personal interest of a patient with decision-making capacity. Furthermore, disclosure of health care information should be required not only for a particular health care decision, but is necessary to protect the patient’s autonomy in respect of future health care decisions and other reasonably foreseeable decisions. These boundaries are indicated by the High Court in Rogers v Whitaker.\textsuperscript{508} However, the balancing process, which limits the disclosure of otherwise material information (potentially to the extent that the doctor again becomes the \textit{de facto} decision-maker), should be discarded.

It is correct that the nature of the treatment, the patient’s desire for information and the nature of the matter to be disclosed are relevant to materiality. Nevertheless, if a patient has decision-making capacity, then the patient’s temperament and health, and general surrounding circumstances, do not necessarily affect either the ability or will to decide, or the materiality of the information. There is no competition between these matters, to be decided by weighing them against each other. The only role that these factors should have is to guide doctors in considering how, and not whether, to disclose.

Thus, if a patient has decision-making capacity, the law should recognise him or her as having a robust entitlement to decide. If a patient lacks capacity and there is not an emergency, an independent substitute decision-maker (other than the doctor) should be obliged to make a decision that reflects the patient’s personal interest, as far as can

\textsuperscript{507} Rogers v Whitaker (1992) 175 CLR 479, 494.

\textsuperscript{508} Rogers v Whitaker (1992) 175 CLR 479.
reasonably be known. If there is an emergency, then this is the only circumstance in which the doctor should be allowed to act as a substitute decision-maker.

3.7.4 **Conduct required by autonomy and beneficence principles**

I suggest that the autonomy and beneficence principles often require of doctors the same kind of conduct: listening to patients, respecting their decisions, giving them the information they need to function as independent agents as far as practicable during and after treatment and, where necessary, protecting them from harm that may arise from ignorance. In undertaking such conduct, courts should recognise that doctors are not in a position to understand the entirety of their patients' personal interests and that protection of clinical welfare does not exhaust compliance with the principle of beneficence.\(^{509}\)

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509 See Katz, 1984, 226.
CHAPTER 4  VALUES THAT DISPLACE THE ENTITLEMENT TO DECIDE - PREVENTING HARM TO PATIENTS

4.1 INTRODUCTION

Chapters 4 and 5 of this thesis describe how certain values, identified by the state as being important to the well-being of the community, are used to justify state intervention in decision-making in the doctor-patient relationship. In particular, state intervention displaces the entitlement to decide, or the usual substitute decision-maker’s responsibility to decide. I will argue in this Chapter that such displacement occurs in pursuit of a harm prevention policy, manifested in certain public values. Without necessarily recognising it is doing so, the state is implicitly assuming in these cases that application of a harm prevention policy is sometimes a better means of protecting patients’ personal interests than the entitlement to decide or the usual substitute decision-maker’s responsibility to decide. That assumption is, I argue, made on the basis of values identified in this Chapter.

It is helpful to put Chapter 4 into context by considering how it relates to what has been done so far, and what remains to be done, in this thesis. In Chapter 3, this thesis identified matters, relating solely to the state of the patient, that displaced the entitlement to decide (that is, the patient’s lack of decision-making capacity and perceived therapeutic necessity of treatment). This Chapter also considers matters relating to the patient. However, those matters are values that are independent of a particular patient’s situation, although they may be perceived as affecting patients’ personal interests. Such values are also considered in Chapter 5. There, I describe circumstances in which the entitlement to decide or the usual substitute decision-maker’s responsibility to decide is displaced for the benefit of a third party, whose personal interest is in competition with that of the patient. In this Chapter, the

510 In Chapters 4, 5 and 6, references to displacing the entitlement to decide should, unless the contrary is indicated, be taken to include references to displacing the usual substitute decision-maker’s responsibility to decide, in favour of the state acting as decision-maker. In these Chapters, the expression ‘usual substitute decision-maker’ is used to distinguish such persons from courts or tribunals, which are (in the examples considered in those Chapters) acting as a state decision-maker rather than as adjudicators about decisions made by individuals.
concern of the thesis begins to move outwards from the patient’s wishes, choices and circumstances, to external influences.

Section 4.2 provides an introduction to the work to be done not only in this Chapter, but also in Chapter 5. Section 4.3, as foreshadowed, proposes a test by which to establish whether the entitlement to decide (or the substitute decision-maker’s responsibility to decide) should be displaced. It is important to bear in mind that this test is formal in nature, and offers a process, rather than offering conclusions about how individual cases should be (or should have been) decided. Section 4.4 describes values that have affected the freedom of patients or usual substitute decision-makers to make decisions about treatment. It does so by way of examples of conduct which fall (or which would, but for state intervention, fall) within the ambit of the doctor-patient relationship, but in relation to which the state has precluded any decision-making, or has assumed the decision-making role on a case-by-case basis. Section 4.5 sets out the conclusions drawn from this Chapter.

4.2 SETTING THE CONTEXT FOR CHAPTERS 4 AND 5

4.2.1 Purposes of state intervention

State intervention is concerned primarily with preventing harm to persons; for the purposes of this Chapter, the relevant harm relates to the patient, and not (as in Chapter 5) to a third party. Because of this apparently altruistic intention, it might be thought that the state is complying with the beneficence principle, and its intervention is therefore not objectionable. However, when the state intervenes in decision-making by a patient or substitute decision-maker, it generally does so on the basis of its own view of what constitutes harm to the patient. In this way, the state’s conduct is not always beneficent, in the terms defined for the purposes of this thesis, because it is not necessarily related to, or focused on, the actual content of the patient’s personal interest; nor on the patient’s view of what harms he or she seeks to avert. When the state

For an explanation of what constitutes the patient’s ‘personal interest’ for the purposes of this thesis, see section 1.3.1. Beneficence has as its subject matter the personal interest of the patient, which is defined by the patient or, for patients without decision-making capacity, with reference (as far as reasonably possible) to the patients wishes and values: see Chapter 2.
substitutes its own view of the personal interest for that of the patient, the state is, in my view, acting paternalistically. This Chapter recognises that, in some instances, paternalism on the part of the state has been justified on the basis of several important values, but only when the criteria in section 4.3 are satisfied.

4.2.2 Controversial issues

Chapters 4 to 6 advance arguments that are illustrated by reference to controversial conduct such as euthanasia and assisted suicide, withdrawal of treatment, coercive obstetric intervention, non-therapeutic sterilisation of disabled minors and abortion. It is beyond the scope of this thesis to argue for a normative position about, or to undertake a comprehensive review of, issues and literature relating to such conduct. These Chapters seek only to show how decision-making in the doctor-patient relationship has been affected by state intervention that occurs on the basis of certain values, in pursuit of a harm prevention policy, and how the test in section 4.3 could be applied to determine if state intervention is justifiable.

4.3 PROTECTING THE PERSONAL INTEREST: A TEST FOR DISPLACING THE ENTITLEMENT TO DECIDE IN FAVOUR OF HARM PREVENTION IN CERTAIN CIRCUMSTANCES

I have acknowledged that the entitlement to decide is displaced from time to time, in favour of competing values or interests, on the basis of harm prevention. However, unless this displacement is closely scrutinised, and occurs only on a principled basis, there is a risk that indiscriminate harm prevention will overrun the entitlement to decide, leaving the patient’s personal interest unprotected. To prevent that, I propose a test to determine whether displacements (both those which have already occurred, and those which may occur in the future) are justifiable. In proposing this test, my aim is to produce principled, predictable outcomes (though conceding that, in such matters as those considered in this thesis, it is impossibly completely to eliminate all subjectivity). The test is partially drawn from Pretty and Rodriguez, in which judges sought to

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512 Whether defined by a patient with decision-making capacity or on a patient’s behalf by his or her usual substitute decision-maker.

513 R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1; Pretty v United Kingdom (2002) 35 EHRR 1. See also Compassion in Dying v State of Washington 79 F.3d 790 (1996), 816, 836. See subparagraph 4.4.1 (c) (iii) for a summary of facts in Pretty.
determine whether blanket prohibitions on assisted suicide legitimately displaced the entitlement to decide. The matters described here are also influenced by the 'special features' of non-therapeutic sterilisation of minors, which were explored in Re Marion, and (most importantly) by the significance of the personal interest. Paragraphs (a) and (b) of the test are drawn from case law; paragraph (c) has been developed by me for the purposes of this thesis, to emphasise that the personal interest should be the central concern of the law about decision-making in the doctor-patient relationship.

4.3.1 Role of the test in balancing interests and values

A balancing process is appropriate as between patients' personal interests and broader community values that are to be protected by the state. This is because while it is inappropriate for someone other than the patient himself or herself to purport to separate and attribute discrete weights to the various aspects of a patient's single personal interests (as is purportedly done in the exercise of the therapeutic privilege and the balancing process described in Chapter 3), values asserted by the state on behalf of the community can be distinguished from patients' personal interests, and accorded relative weight by society as a whole, through the agency of the state. This section makes a proposal as to how that should be done in the circumstances examined in Chapters 4 and 5.

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514 Rodriguez v British Columbia 107 DLR (4th) 342 (1994). The facts of this case are relevantly similar to those in R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1.

515 It should be remembered that, within the doctor-patient relationship (that is, the doctor-patient relationship), things may be done that are not therapeutic in purpose. For example, sterilisations that are performed for purposes other than to treat a disease or disorder, cosmetic surgery or male infant circumcision for religious or cultural purposes. Notwithstanding the lack of therapeutic purpose, the activity is occurring within a doctor-patient relationship.

516 Secretary, Department of Health and Community Service (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218. See paragraph 4.3.4 (b) for a summary of facts in Re Marion.

517 In Chapter 3, I reject the proposition that a balancing process should be applied by doctors and judges in respect of the various dimensions of patients' personal interest. Therefore, it is unnecessary to apply this test to determine whether interventions of kinds considered in Chapter 3 are legitimate. In Chapter 3, I explain my acceptance of lack of decision-making capacity and emergency as grounds for the displacement (or non-applicability) of the entitlement to decide, and my rejection of the therapeutic privilege as a basis for such displacement.

Chapter 4
4.3.2 Limitations of the test

This test is formal in nature, because it does not seek to indicate how the balance between patients’ personal interests and ‘community values’ should be struck in particular cases (although Chapter 6 gives some indication of how this might be done in particular circumstances).

4.3.3 Explanation of the test

(a) The nature and gravity of the value protected

The first matter to be considered is whether the state can demonstrate the existence of a compelling value or objective that is shared by a substantial proportion of the community. The greater community consensus there is about a particular value, then the better may (subject to consideration of other elements of this proposed test) be the state’s case for intervening. The value or objective must be capable of clear identification, and must involve preventing a harm. The risk of that harm should be demonstrated, by clear and convincing evidence, to be real and significant and not fanciful or remote. If the state cannot produce convincing evidence of a need to intervene to prevent a harm by protecting an important, widely-agreed upon value, then the state fails at the first hurdle in establishing a reason for intervening to preclude decision-making by a patient or usual substitute decision-maker, or becoming the decision-maker on a case-by-case basis.

It is useful to bear in mind that whether conduct can be characterised as a harm or a good can be the cause of disagreement. For example, for most people, in most situations, death is something to be postponed for as long as possible. However, Dianne Pretty was terminally ill with motor neurone disease that would kill her within months, possibly weeks. In bringing her claim that it should be lawful for her husband to assist her to commit suicide (because she could not do this unaided), Ms Pretty could be understood as asserting that, for her, death ‘brought forward’ by an assisted suicide would be a good, while her continued existence and later death, in a hospice and under sedation, was a harm that she sought to prevent.

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(b) Intervention must be proportionate, minimally intrusive, rational and fair

The second matter to be considered is the means by which the intervention will be achieved. In this regard, the state should first consider whether the means by which proposed intervention will be implemented is proportionate to the harm concerned. For example, the blanket prohibition on assisted suicide has been defended on the basis that it is proportionate both to the importance of the values being protected (preservation of life and protection of vulnerable patients) and to the gravity and irrevocable nature of the harm being prevented. Conversely, the blanket prohibition has been attacked as being a disproportionate means of furthering state objectives.519

Second, the state should consider whether the proposed means of intervention are minimally intrusive and whether they impose an unduly harsh burden on patients. For example, the state should be required to justify the blanket prohibition on assisted suicide in terms of whether or not less intrusive measures would be effective in achieving its objectives of conferring benefit or preventing harm; such as, whether a regulated approach to euthanasia, along Dutch lines, would be effective.520 Meanwhile, Dianne Pretty and Sue Rodriguez argued that preventing them from obtaining assistance to end their lives was unduly harsh, even cruel. The state must be prepared to address such arguments and to ameliorate those burdens as far as possible, if it is to justify intervention.

Third, the means of intervention should be rational in the sense of being defensible by clear, reasoned arguments that are based in universalisable principle. The means of intervention should also be fair, and not arbitrary. Dianne Pretty advanced arguments that the prohibition against assisted suicide was not fair, because it objectionably discriminated against the disabled. Her argument ran that, following the decriminalisation of suicide, able-bodied persons were free to end their lives at a time, and in a way, of their choosing. Disabled persons, however, were prevented from choosing such a course of action to the extent that they required assistance to bring about their deaths, and such assistance remained unlawful. The rejoinder to this argument was that because the decriminalisation of suicide did not confer a right to

suicide (nor should it be understood to imply any state approval or encouragement of suicide), there was no right that disabled persons were being prevented, by objectionable discrimination, from exercising. Conversely, the judges were concerned that permitting assisted suicide would itself have an adverse effect on disabled patients, by effectively making it easier for third parties to persuade them that assisted suicide was in their best interests. This concern assumed, rightly or wrongly, that disabled persons were more vulnerable to these representations, and that permitting assisted suicide would discriminate against them by exposing them to such pressures.

(c) Implications of displacement for the personal interest

The final matter to be considered is the impact of the proposed intervention on the patient’s personal interest. The state’s intervention can affect the personal interest in one of two ways. First, the state’s intervention can seek to substitute the state’s interpretation of the personal interest for the patient’s understanding of their own personal interest (as with the prohibition of assisted suicide in relation to individuals such as Dianne Pretty or Sue Rodriguez). Alternatively, the state’s intervention can seek to support or protect the patient’s personal interest as understood by the patient (as with the regulation of non-therapeutic sterilisation of disabled minors).

That is, in some cases, the state is saying to patients: ‘This is what your personal interest should look like: you should want this, or that.’ This occurred in Dianne Pretty’s case. In other cases, the state is trying to support the patient’s own understanding of their personal interest. The state is saying, ‘We’ll try and enhance your ability to make your own choices by protecting you from undue external influences’. This may be said to occur in relation to the regulation of non-therapeutic sterilisation or the prohibition of

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520 For discussion of the Netherlands system, and the possibly unique cultural and social factors that underpin it, see Cosic, 2003, Chapter 7.

521 R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1, 19-20 (Lord Bingham of Cornhill), 30-1 (Lord Steyn), 39-40 (Lord Hope of Craighead) (Lord Scott of Foscote agreed with the opinions of these Law Lords: at 45); Pretty v United Kingdom (2002) 35 EHRR 1, paragraphs 88-9. Similar arguments were advanced in Rodriguez v British Columbia 107 DLR (4th) 342 (1994).

522 As argued in Chapter 1, even the most severely-impaired patients, such as Anthony Bland, have a personal interest that goes beyond clinically-defined interests, such as previously-held religious beliefs that should be taken into account. See Airedale NHS Trust v Bland [1993] AC 789, 822 (Butler-Sloss LJ).
female genital mutilation. The following subparagraphs set out the matters relevant to state intervention in respect of each alternative.

(i) *If state seeks to substitute its version of personal interest*

If an intervention will affect a particularly private, intimate aspect of a patient’s life or affect it in an enduring way, then the state should be reluctant to intervene. All cases in which the state intervenes in a way that affects the bodily integrity dimension of the personal interest will be cases involving intimate, enduring effects to some degree. The state must be cautious in intervening because of the imbalance of effect and the purpose of independence: it is the patient who will have to live with the outcome of the intervention, for good or ill. Even an intervention that is intended to confer benefit can have adverse consequences. The more intimate the aspect of life impinged upon, and the more enduring, irreversible or final the effect, the heavier will be the burden on the state in demonstrating the propriety of intervention. Thus, in *Pretty*, the burden for the state to meet in showing that it could justifiably intervene should have been very high. This was because, by telling Ms Pretty that her husband could not assist her to die in a manner and at a time of her choosing, the state was effectively foreclosing the only expression of her personal interest that Ms Pretty may have had left to her.

(ii) *If state protecting patient’s personal interest*

Before the state seeks to intervene with the intention of supporting or protecting a patient’s personal interest, it must take into account whether its intervention will minimise a real and significant risk to the patient’s personal interest. For example, the state may take into account whether or not its intervention will protect a patient from abuse or exploitation by a third party. The state should take into account whether, in the absence of its intervention, the patient is at risk of being subjected to conduct that will have a serious or enduring effect on the patient, or that will effect the patient in a particularly private, intimate aspect of his or her life (such as a non-therapeutic sterilisation performed for reasons not related to the welfare of the patient).

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523 As noted in *Price v Sheppard* 239 NW.2d 905 (1976), 910.

524 *R (on the application of Pretty) v Director of Public Prosecutions* [2002] 1 All ER 1.
Essentially, the question of whether and how to intervene to prevent a harm will come down to a balancing exercise between, on the one hand, the state's interest (and, indeed, its function) in preventing harm, either in furtherance of competing public values or the competing interests of a third party and, on the other hand, the individual's interest in pursuing his or her own personal interest in his or her own way, irrespective of whether that does harm. The intention of the discussion in this section was to draw attention to the kinds of matters that should be taken into account in performing that balancing exercise, and to again emphasise that the starting point must always be the patient's entitlement to decide that is derived from the principle of respect for autonomy or, if the patient lacks decision-making capacity, the usual substitute decision-maker's responsibility to decide, that derives from the principle of beneficence. This is because the entitlement or responsibility to decide usually, in my view, offers the best means of protection for the patient's personal interest. The onus is on the state to justify whether and how it intervenes.

4.4 VALUES THAT DISPLACE THE ENTITLEMENT TO DECIDE TO PROTECT PATIENTS

4.4.1 Preservation of life

(a) What is meant by 'preservation of life'?

In modern secular discussion, the preservation of life value refers to a fundamental premise that all human life is equally and intrinsically valuable. The significance of this value is that the importance and inviolability of any human life is independent of

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525 Rees v United Kingdom (1987) 9 EHRR 56.

526 Cases in this section are drawn mainly from other common law jurisdictions. For consideration of the 'puzzling' lack of authority on end of life cases in Australia, see Morgan and Veitch, 2004, 108. At present, the only 'end of life' case is Gardner; re BWV [2003] VSC 173 (29 May 2003). See also Corns in Freckelton and Petersen, 1999, 45.

527 Also known by such terms as 'the sanctity of life ethic': see, for example, Magnusson, 1997, 'Sanctity'; see also Keown, 1997, especially 483-6. In the Supreme Court of Victoria, the term 'inviolability of life' was preferred: Gardner; re BWV [2003] VSC 173 (29 May 2003), Morris J.

528 See, for example, Universal Declaration of Human Rights, Article 3; International Covenant of Civil and Political Rights, Article 6; European Convention for the Protection of Human Rights and Fundamental Freedoms, Article 2. See also Ronald Dworkin, 1993, Chapter 3; Airedale NHS Trust v Bland [1993] AC 789, 863-4 (Lord Goff of Chievely); Auckland Area Health Board v Attorney-General
how useful, enjoyable or significant it may be to society, other members of society, or even the individual whose life it is. The starting point in consideration of the application of this value to any particular case is the assumption that to prolong someone’s life is to confer a benefit upon him or her.

This section identifies preservation of life as a value to which the state has appealed to justify intervention in decision-making that falls (or that, but for state intervention, might fall) within the ambit of the doctor-patient relationship. The concept of preservation of life has been the subject of substantial and complex literature. This thesis does not seek to canvass this literature, but aims simply to indicate the role that the preservation of life value has played, and continues to play, as a justification for state intervention in decision-making in the doctor-patient relationship.

(b) A value relating to a judgement external to the patient

The preservation of life value emphasises community perceptions about what is worthy of protection by the law. In particular, the preservation of life value justifies the assertion by the state of an interest in protecting and defending all human life, and is an obvious basis for legislative prohibitions against killing and assault generally. Its independence from the significance that the individual places on his or her own life indicates that the preservation of life value is not focused on the individual’s wishes or choices. Accordingly, the value extends to the preservation of life against the wishes and the asserted personal interest of a patient (as in the case of prohibiting euthanasia and assisted suicide) and to prohibiting less serious consensual conduct that infringes

[1993] 1 NZLR 235, 244 (Thomas J). See also United States cases referred to in Compassion in Dying v State of Washington 79 F.3d 790 (1996), 851. This thesis concerns only beings who are human.


530 In Compassion in Dying v State of Washington 79 F.3d 790 (1996), both the majority and leading minority opinions recognised a state interest in preventing suicide as a sub-interest of the state’s interest in preserving life. However, doubt has been expressed as to whether an interest in preventing suicide is an interest that is sufficiently distinct from the preservation of life value to justify its existence as an ‘independent consideration’: see Matter of Conroy 486 A.2d 1209 (1985), 1224.


532 Ronald Dworkin, 1993, 71-3 (subjective value).
the bodily integrity dimension of the personal interest (for example, the infliction of grievous bodily harm).^{533}

It could be argued that the preservation of life value is also influential in the principles that allow medical treatment to be given without consent in emergency situations.^{534} The presumption is that most people want to survive,^{535} and there is a further (generally valid) presumption that the provision of medical treatment is the most effective way of fulfilling that desire. In emergency situations, doctors are permitted to treat patients without express consent^{536} on the basis of what has been treated as, in effect, an implied, or perhaps 'assumed', consent.^{537} I, however, prefer to characterise doctors' conduct in emergency not as acting on an implied consent, but as acting as substitute decision-makers.^{538} Whether the 'implied consent' or 'substitute decision-maker' analysis is preferred, medical treatment provided in these circumstances rests on an assumption that the patient would, if he or she were in possession of decision-making capacity, consent to treatment to preserve life or to prevent harm. In the absence of information about other dimensions of the patient's personal interest that may affect a decision to consent to or refuse treatment (such as identification as a Jehovah’s Witness, members of which Church refuse blood products),^{539} a doctor must, for pragmatic reasons, focus on the clinical health and well-being of the patient. It is the only information that the doctor has about the patient. Actions taken to protect the patient’s clinical welfare will be justifiable, in these circumstances, on the basis of the beneficence principle in a *unique* instance in which that principle can be said (within the terms of this thesis) to be directed solely at the patient’s clinical welfare. Generally, the assumption underlying the provision of medical treatment in emergencies will prove to

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533 For example, sado-masochistic conduct: *R v Brown* [1993] 2 All ER 75.
534 For discussion of what, for the purposes of this thesis, constitutes an emergency, see section 3.2.5.
537 For a statutory approach to the provision of medical treatment in an emergency, see the *Guardianship and Administration Act 2000* (Qld), section 63.
538 See section 3.2.5.
have been well-founded, although the judicial recognition of a right to refuse treatment\textsuperscript{540} indicates that it is an assumption may be disproved in individual cases. Making explicit the assumption that underlies ‘implied’ consent in emergencies provides an example of the influence of the preservation of life value.

(c) What does this value protect: life universally or life of particular quality?

(i) Is quality of life a relevant consideration?

There is some doubt about what, precisely, this value protects: life regardless of its quality, or only life of a particular quality? This section considers whether a notion of quality of life is relevant; in particular, by looking at two concepts, the judicial acceptance of which seems to depend on quality of life judgements. Those concepts are the principle of double effect and the omission/commission distinction. These concepts have most prominence, for current purposes, in end-of-life cases. Before examining these concepts, however, it is useful to consider how courts have treated explicit appeals to notions of ‘quality of life’.

In \textit{Compassion in Dying}, the United States Court of Appeals (Ninth Circuit) held that the state could assert an interest in preserving life in general, irrespective of any perceptions about its quality.\textsuperscript{541} In BWV’s case, which considered an application for the appointment of a guardian of a woman terminally ill with what was believed to be Pick’s Disease (a form of dementia), the Victorian Civil and Administrative Tribunal emphasised the relevance of the quality of treatment available, rather than the quality of life, to questions about withdrawing or withholding medical treatment.\textsuperscript{542} Similarly, in \textit{In re J}, Balcombe LJ held that the preservation of life value precluded the evaluation, by courts, of the quality of life of persons without decision-making capacity.\textsuperscript{543}

On the other hand, the opinions of the Law Lords in \textit{Bland}\textsuperscript{544} do seem to take into account the quality of Anthony Bland’s life, in drawing a conclusion that the

\textsuperscript{540} See, for example, \textit{In re T (Adult: Refusal of Treatment)} [1993] Fam 95, 113 (Lord Donaldson of Lymington MR).

\textsuperscript{541} \textit{Compassion in Dying v State of Washington} 79 F.3d 790 (1996), 817.

\textsuperscript{542} \textit{BWV} [2003] VCAT 121. See also Keown, 1997, 485.

\textsuperscript{543} \textit{In re J (A Minor) (Wardship: Medical Treatment)} [1991] 2 WLR 140, 154.

\textsuperscript{544} \textit{Airedale NHS Trust v Bland} [1993] AC 789.
withdrawal of treatment was lawful. This conclusion was reached on the basis that treatment, although life-sustaining, no longer conferred a benefit on Anthony Bland, and was therefore not in his best interests. Implicit in this judgement of ‘benefit’ must be a judgement on the usefulness of the treatment, the quality of life, or possibly both. While most of the Law Lords took the view that withdrawal of treatment was in Anthony Bland’s best interests and took into account factors that (as is explained in the following paragraph) relate to quality of life judgements,545 Lord Mustill rejected the relevance of quality of life as a consideration546 and held that Anthony Bland had no best interests of any kind.547 His decision to allow treatment to be discontinued rested on the basis that because Anthony Bland had no best interests, this meant that he had no interest in being kept alive.548

While judges may not want to be seen as overtly evaluating the quality of life of a particular individual, it seems that they in fact do precisely this, although the exercise is camouflaged in the language of ‘best interests’, and by deference to medical opinion about the usefulness of treatment. The question of usefulness of treatment is tied to assessments of quality of life because it is interpreted as a question that focuses on whether the treatment confers a benefit.549 Whether a benefit is conferred depends on something more than the mere presence of biological life; it depends on the quality of that biological life, as determined by the damage done to it by injury, disease process or congenital defect, and on whether treatment can in any way enhance that quality. For individuals such as Anthony Bland, BWV and J, there is no question of any of these being possible, because the debilitation caused by their respective conditions was not susceptible of amelioration.

Thus, the preservation of life value, as interpreted by the House of Lords, does not extend to the preservation of life when that life is deprived of quality to a certain (though imprecisely-defined) extent and withholding or withdrawal of treatment is

545 Airedale NHS Trust v Bland [1993] AC 789, 859 (Lord Keith of Kinkel), 789, 867, 868, 870 (Lord Goff of Chieveye), 878 (Lord Browne-Wilkinson).
549 The object of all medical treatment is to confer a benefit: Airedale NHS Trust v Bland [1993] AC 789, 857, 859 (Lord Keith of Kinkel).
being considered. The judgement about when quality of life has deteriorated to a point at which treatment is regarded as futile is, in England, effectively made by doctors. It may well be the case that this can also be said of Australian law. There is not enough case law in Australia to form a considered view on that point, although the decisions of the Victorian Civil and Administrative Tribunal and the Victorian Supreme Court in the litigation concerning BWV suggests that medical opinion was strongly persuasive.

(ii) Quality of life and the application of the principle of double effect

Quality of life judgements may also contribute to the acceptance by the law, the medical profession and the community, of ‘double effect’ terminal sedations, in which a terminally ill person is gradually given increased doses of medication, in the knowledge that, ultimately, the dose will be fatal. These sedations are conventionally distinguished from euthanasia (in the form, for example, of a single, lethal dose known as a ‘bolus’) and assisted suicide, on the basis that death is not an intended effect, but a ‘side effect’ of pain relief. The principle of ‘double effect’ originated in Roman Catholic doctrine, and holds that it is morally permissible to bring about an evil result when the intention is to obtain a good result. Whether this is a distinction without a difference is a difficult and controversial question which is beyond the scope of this analysis. However, it may be that the difference lies, not in principle, but in the


551 See BWV [2003] VCAT 121 and Gardner; re BWV [2003] VSC 173 (29 May 2003). See also the limitation on the operation of advance health care directives in Queensland as they apply to a direction to withhold or withdraw artificial hydration or nutrition: Powers of Attorney Act 1998 (Qld), paragraph 36 (2) (b).

552 See Pretty v United Kingdom (2002) 35 EHRR 1, 23, referring to Re J [1991] Fam 33. Such conduct is explicitly protected from being the subject of prosecution by the Criminal Code (Palliative Care) Amendment Act 2003 (Qld), which inserted section 282A into the Queensland Criminal Code. The provision requires the conduct in question to be reasonable palliative care; reasonableness is to be determined expressly by reference to good medical practice.


554 For the criteria on which the principle rests, see Ashley and O’Rourke, 1997, 191-3. See also Compassion in Dying v State of Washington 79 F.3d 790 (1996), 823, footnote 95.
palatability of certain courses of action to patients, family members, doctors and society.\footnote{See, for example, the comments of surgeons participating in a survey conducted in 2001. The survey was published in Douglas et al, quoted in Cosic, 2003, 78. See also McLean, 1999, 119, on the relationship between the principle of double effect and the preservation of life value.}

**(iii) Quality of life and the act/omission distinction**

It should be emphasised that, no matter how far quality of life is perceived to have deteriorated, euthanasia and assisted suicide are not permitted. Only two forms of conduct that will result in the end of life are permissible: ‘double effect’ conduct, described above, and conduct that can be described as an omission. These mark the outer limits of the relevance of quality of life judgements. Because of this, this Chapter must consider the nature of the act/omission distinction. This is done here, and also in paragraph 4.4.2 (a), in connection with the relevance of the distinction to voluntariness of decision-making.

The importance of exploring the distinction between acts and omissions becomes clear by comparing the situations of patients such as Dianne Pretty with the situations of patients such as the severely-disabled infant in *In re J*.\footnote{In re J (A Minor) (Wardship: Medical Treatment) [1991] 2 WLR 140.} J, born prematurely, suffered from severe brain damage and was resuscitated by the invasive means of mechanical ventilation. Five months after birth, J was again placed on a ventilator. Even the most optimistic predictions indicated a severely shortened life expectancy. It was also predicted that he would be quadriplegic, and probably blind, deaf and mute. It was likely, however, that he experienced pain. The matter came to court to seek judicial approval of doctors’ recommendations to withhold further resuscitation if J should again stop breathing. The Master of the Rolls described the problem in relation to J thus: ‘What is being balanced is not life against death, but a marginally longer life of pain against a marginally shorter life free from pain and ending in death with dignity.’\footnote{In re J (A Minor) (Wardship: Medical Treatment) [1991] 2 WLR 140.}

This description could equally describe the fears and aspirations expressed by Dianne Pretty, who sought immunity from prosecution for her husband in the event that he assisted her to commit suicide. Dianne Pretty, aged 43, was soon to die from the effects of motor neurone disease. Her death would take the form of starvation or
choking, as the muscles supporting swallowing and breathing progressively deteriorated. In the absence of sedation, Ms Pretty would remain alert and aware of what was happening to her. What happened to Ms Pretty, at the insistence of the law, is arguably more cruel, because of her awareness of what was happening to her, than what would have happened to Anthony Bland after the judicially-sanctioned withdrawal of his treatment and leading up to his death. Anthony Bland was in a persistent vegetative state following injuries suffered at the collapse of the Hillsborough Stadium and was irrevocably insentient.

The most important point to make is that, in relation to conduct that will bring about death, omissions (withdrawal or withholding treatment from patients without decision-making capacity, and refusal of treatment by patients with decision-making capacity) are permissible in common law jurisdictions, while acts (such as euthanasia and assisted suicide) are not. The characterisation of conduct as an omission allows advance health care directives refusing particular treatment, or authorising the withholding or withdrawal of treatment in specified circumstances. It allows substitute decision-makers to form a judgement that withholding or withdrawing treatment in cases such as that of J, BWV or Anthony Bland is in the patient’s best interests. However, if conduct is characterised as an act, then it is not open to a patient or a substitute decision-maker to request it. Thus, choice is relevant to omissions that may bring about death, but not to acts. The question is: what is the nature and validity of this distinction that, in some instances, permits the entitlement to decide to be overridden by the state in apparent pursuit of a harm prevention policy?

It is said by some that there is a ‘sharp distinction’ between acts and omissions, although others are less convinced. What actually occurs in cases involving

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557 *In re J (A Minor) (Wardship: Medical Treatment)* [1991] 2 WLR 140, 145; see also 155 (Taylor LJ).


559 See *R (on the application of Pretty)* v *Director of Public Prosecutions* [2002] 1 All ER 1; *Pretty v United Kingdom* (2002) 35 EHRR 1; *Rodriguez v British Columbia* 107 DLR (4th) 342 (1994).

560 *Airedale NHS Trust v Bland* [1993] AC 789, 893 (Lord Mustill); see also *Rodriguez v British Columbia* 107 DLR (4th) 342 (1994), 404-5 (Sopinka J), referring to commentators upholding, and criticising, the distinction.
omissions is worth considering. For example, the withdrawal of a process called a percutaneous endoscopic gastrostomy (‘PEG’) was under consideration in BWV’s case in the Supreme Court of Victoria. The PEG process delivered nutrition, hydration and some medications (such as pain relief) to BWV. It had been introduced to her, using a surgical procedure, some years previously. Removal of it would require an active intervention, as opposed, for example, to something like ceasing to administer antibiotics. Nevertheless, Morris J was able to characterise the withdrawing of the process as an omission, on the basis that the PEG process was merely facilitating something that would be ceased (artificial nutrition and hydration). Yet without the PEG process, there could be no nutrition or hydration. The point is not necessarily that the judge in this case, or the judges in other such cases, wrongly characterised the conduct. The point is that the characterisation, while critically important in determining whether or not the state will intervene to prohibit consent to conduct, may not in practice be a clear, ‘bright line’ distinction.

Instead, there may be at least a suspicion that maintaining this distinction allows judges, doctors, and carers to make decisions to allow conduct that will bring about death in cases in which life no longer seems to be a benefit and death seems not to be a harm, while continuing to prohibit other conduct that is seen as being dangerous, in that it renders the patient too susceptible to harm through abuse and exploitation, so that the patient may be inhibited in defining and asserting his or her personal interest. The distinction may also serve to preserve the image of the medical profession, as perceived by both doctors and the lay community, as preservers rather than takers of life. While withdrawal or withholding of treatment should also be recognised as susceptible to abuse and exploitation, there seems to be a sense that the danger in such cases is less serious. In addition, although opponents of euthanasia express concern about the adverse effects on health care professionals of requiring them to perform voluntary euthanasia and assist in suicides, it can be seen from the cases of Ms B and Anthony Bland that doctors and nurses can also be adversely affected by seeing through


563 See paragraph 4.3.2 (a) for further discussion in relation to voluntariness.

the consequences of legally-permitted refusal of treatment and withdrawal of treatment.\textsuperscript{565}

It seems to be the case that there is difficulty in drawing a convincing practical distinction between omissions and acts, by reference to either their nature or their effects on others, or both of these things. This difficulty indicates significant uncertainty about how to identify the best balance between compassion for people whose lives have become futile and burdensome to them, so that they autonomously form a wish to end them, and the fear of abuse of vulnerable patients who may, to the detriment of their true personal interest, be badgered into refusing treatment or submitting to what would be, effectively, involuntary euthanasia.\textsuperscript{566}

\textit{(d) Preservation of life is not an absolute value}

In light of preceding discussions about the permissibility of double effect sedation and omission conduct, it is apparent that the preservation of life value is not absolute, despite its importance as a value that is fundamental to the continued existence of any community.\textsuperscript{567} There are circumstances in which preservation of life is accorded less weight than other values.\textsuperscript{568} However, ambivalence and ambiguity about the precise circumstances in which the preservation of life value should be accorded less weight than other matters\textsuperscript{569} is evident in the subtleties employed by judges in drawing the act/omission distinction, and by the community in apparently accepting the reliance on the principle of double effect to justify terminal sedation. This ambivalence and

\textsuperscript{565} Ms B v An NHS Hospital Trust [2002] 2 All ER 449, 463, 473; Airedale NHS Trust v Bland [1993] AC 789, 796 (Sir Stephen Brown P in the Family Division), 898 (Lord Mustill). Lord Goff of Chieveley (at 870) referred to evidence that sedation could suppress those symptoms of death that would distress nurses, family members and other observers.

\textsuperscript{566} See section 4.3.2.

\textsuperscript{567} See, for example, Airedale NHS Trust v Bland [1993] AC 789, 826 (Hoffman LJ), 859 (Lord Keith of Kinkel), 864-5 (Lord Goff of Chieveley), 894 (Lord Mustill). See also Compassion in Dying v State of Washington 79 F.3d 790 (1996) 817, 818; McLean, 1999, 116, 118. Keown argues that what the courts have interpreted as not being absolute is a doctrine of vitalism, and that the preservation of life value (when correctly interpreted as a prohibition on intentional killing) is absolute: see Keown, 1997. However, this proposition does not seem to have been accepted in Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961. For a discussion of this case, see section 5.2.2.

\textsuperscript{568} For statements that, in some situations involving terminally ill patients, the value is weakened, see Compassion in Dying v State of Washington 79 F.3d 790 (1996), 819, 820, 851.

\textsuperscript{569} See Airedale NHS Trust v Bland [1993] AC 789, 880 (Lord Browne-Wilkinson).
ambiguity is also evident in the caution with which judges have treated the right to refuse life-saving and life-sustaining treatment.\(^{570}\)

A further example of the ambiguities involved in the extent to which the preservation of life value is protected by the law is provided by the apparent identification, by McLean and Magnusson, of an anomaly in relation to the permissibility of the withdrawal of treatment from patients without decision-making capacity.\(^{571}\) The anomaly arises from the state's prohibition against a person with decision-making capacity enlisting assistance to die, irrespective of his or her possession of decision-making capacity and irrespective of his or her suffering and distress at continuing to live or the prospect of a distressing, undignified death. The state will, however, in abrogation of the preservation of life value, permit withdrawal of life-sustaining treatment from a person who may not have expressed a view on whether he or she wishes life to be sustained (although his or her wishes, if known, will be taken into account).

The effect of this anomaly is that if a patient is strong enough and in a position to express a view on the matter, then he or she is not permitted to make a decision that will result in what society considers to be an unacceptable harm: death. This is because the state views death as a harm to be prevented, if necessary by disregarding the patient's personal interest by a prohibition on conduct that might otherwise fall within the doctor-patient relationship. On the other hand, if a patient is helpless and lacking in decision-making capacity, then life-saving or life-sustaining treatment may be withheld or withdrawn if medical opinion is to the effect that treatment is futile or that the quality of life is diminished beyond an undefined point.

McLean and Magnusson identify this as an anomaly by implicitly suggesting that enlisting assistance to die is analogous with the withdrawal of treatment. If the act/omission distinction is rejected, then there is an analogy between enlisting assistance to die and the withdrawal of treatment. This means that the anomaly identified by McLean and Magnusson must be acknowledged. However, there is no analogy (and no

\(^{570}\) See, for example, *In re T (Adult: Refusal of Treatment)* [1993] Fam 95, 113 (Lord Donaldson of Lymington MR); *Qumsieh v Guardianship and Administration Board & Anor* [1998] VSCA 45 (17 September 1998), which is discussed in detail under the heading 'An Australian position?' in subparagraph 5.2.3 (c) (ii).
anomaly) if the validity of the act/omission distinction is accepted.\(^572\) Nevertheless, the practical difficulties with drawing that distinction raise the suspicion that the permissibility of omission conduct, and of double effect sedation, allows courts to avoid being explicit about end-of-life decision-making. This failure to be explicit hinders recognition of the matters that are actually taken into account by the courts in making end-of-life decisions and, more broadly, hinders the development of a clear understanding about the limits of the ‘paramount entitlement to decide’, and the significance and role of the personal interest.

(e) Tension between entitlement to decide and preservation of life value

Insofar as the preservation of life value is asserted by the state in a way that disregards the wishes and choices of a patient with decision-making capacity, it can be characterised as a value that exists in tension with the entitlement to decide and that, in certain circumstances, displaces it with a view to harm prevention.\(^573\) The state may do so, in my view, because it assumes that the patients’ interests are better protected by state action based on harm prevention than by allowing the patient to decide in favour of death. Furthermore, I believe that the state is concerned that such decisions by patients (that is, those in favour of death) are, generally, too susceptible to extrinsic influences to represent authentic expressions of patients’ interests.

An example of this tension is provided by the case of \textit{R (on the application of Pretty) v Director of Public Prosecutions}.\(^574\) In that case, the preservation of life value was a powerful influence against the granting of Pretty’s claims by judges in England and Strasbourg. Ms Pretty had clearly articulated the course of action that she believed would best advance her personal interest. This consisted of her husband taking steps to assist her in committing suicide. Ms Pretty was unable to commit suicide unaided because of the effects of the motor neurone disease from which she was suffering and from which she would shortly die. There was no evidence as to the nature of the steps


\(^{572}\) For discussion of the distinction, see subparagraph 4.3.1 (c) (iii) and paragraph 4.3.2 (a).


\(^{574}\) \textit{R (on the application of Pretty) v Director of Public Prosecutions} [2002] 1 All ER 1. See also \textit{Pretty v United Kingdom} (2002) 35 EHRR 1.
Mr and Mrs Pretty were contemplating as being necessary to achieve Ms Pretty’s desired outcome. The judges apparently accepted that Ms Pretty had decision-making capacity and had formed her view free from undue external influence, being instead motivated by her own fear and horror at the nature of the death that would be inflicted on her by the disease. However, the judges decided that the preservation of life value required that her death should not be hastened by assisted suicide. Ms Pretty would die in a hospice, probably under sedation. This was not her choice, and the tension between the entitlement to decide and the preservation of life value, driven by the influence of a harm prevention policy, is evident in this case.  

(f) Is the preservation of life value still influential?  

Lack of consensus about when the preservation of life value is sufficiently compelling to justify interference with decision-making by patients or their substitute decision-makers has influenced commentators such as Mendelson and Magnusson to argue that the preservation of life value is being substantially eroded. This section briefly notes the arguments put by Mendelson and Magnusson, but concludes that the preservation of life value still wields considerable and highly significant influence in decision-making in the doctor-patient relationship.  

Mendelson argues that the principle of respect for autonomy was originally formulated with the intention of protecting individuals from survival-threatening actions (such as murder and serious assault) by assailants. She expresses concern that the principle has now been distorted to justify choices resulting in self-annihilation through, for example, the refusal of life-saving and life-sustaining treatment. Thus, she argues that the principle of respect for autonomy has been transformed from a principle that supports the preservation of life value by justifying prohibitions against killing and assault to a principle that undermines the preservation of life value by justifying life-ending decisions such as those relating to the refusal, withholding or withdrawal of treatment.  

575 A similar example is seen in Rodriguez v British Columbia 107 DLR (4th) 342 (1994). Unlike R (on the application ofPretty) v Director of Public Prosecutions [2002] 1 All ER 1, however, the decision in Rodriguez was not unanimous: the decision was split five judges to four. Rodriguez dealt with articles of the Canadian Charter of Rights and Freedoms that raised similar concerns to those raised by the articles of the European Convention on Human Rights considered in Pretty: see Pretty v United Kingdom (2002) 35 EHRR 1, 37.  

Magnusson points to four circumstances, evident in jurisdictions including the United States, England and Australia, as evidence for erosion of the preservation of life value. First, he refers to changing definitions of death that require only higher brain death, rather than whole-of-brain death. These definitions can be appealed to as justification for withdrawing or withholding treatment from a patient. Second, like Mendelson, he refers to the permissibility of refusal, by patients with decision-making capacity, of life-saving treatment. Third, Magnusson notes judicial statements that there is no duty to continue futile treatment in respect of certain patients lacking decision-making capacity and, finally, he identifies judicial and legislative moves in the past decade to permit individuals to receive medical assistance to die.

(i) Preservation of life and the technological imperative

Notwithstanding these arguments, however, the preservation of life value remains a powerful influence on state intervention in decision-making in the doctor-patient relationship. Certain observations may be made to counter the arguments put by Mendelson and Magnusson. First, much of the ambiguity and controversy about the scope of the preservation of life value has developed as an inevitable consequence of the development and implementation of life-saving and life-sustaining technologies, and the insistent pressure of the technological imperative, described in Chapter 1. The change in the nature of appeals to the principle of respect for autonomy, identified by Mendelson and noted above, can perhaps be seen as an expression of concern about the implications of technological advances in life-saving and life-sustaining technologies. As these technologies become more widely used, the nature of death changes; increasingly, more people in our community will die from chronic or degenerative diseases than from trauma or acute illness. This can be a source of great fear and

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582 See, generally, McLean, 1999, Chapter 7, for discussion of the technological imperative.
dread. Perhaps, when the principle of respect for autonomy had the survival-protecting meaning that Mendelson describes, people did not feel the need to exercise their autonomy to refuse invasive and burdensome measures to prolong life in circumstances that they considered degrading and intolerable.

Certainly, modern life-prolonging technologies render possible that which was unimaginable when Blackstone articulated the ideas of personal inviolability which have been relied on as the foundation for the modern rights to refuse treatment and to self-determination generally. The rapidity of technological change, in areas of fundamental concern such as defining the beginning and end of life, has meant that there has been little opportunity for community consensus to develop, or even for reasoned debate among those (including doctors, hospital administrators, judges and legislatures) who must adjudicate on how, in what circumstances, and for what purposes, the technologies will be used or withheld to create, save and sustain biological life. Instead, the technological imperative is allowed to drive clinical intervention and decision-making about that intervention, without a clear understanding of what is being preserved, and why, and what harms are characterised as being unacceptable.

What is happening is perhaps not the erosion of the preservation of life value, but a gradual working out of its scope. Ambiguity and controversy about what precisely it is that is to be preserved may have arisen because of the life-extending possibilities offered by modern technologies. That is, questions such as ‘what is life?’, and ‘when does it end?’ have become less susceptible of straightforward answers. Not too long ago, the question about the end of life was answered simply by reference to the absence of a pulse, and was conceptualised as the end of biological life. Life-saving and life-sustaining technologies have opened the door for the answer to this question to be thought of by some in terms not of the end of biological life, but of the end of

583 As noted in Pretty v United Kingdom (2002) 35 EHRR 1, 37. See also McLean, 1999, 140.
584 See Blackstone, 1775, Book 1, Chapter 1, 129. See also Mendelson, 1996, ‘Trespass’, 67.
585 For discussion of the technological imperative, see subparagraph 1.3.2 (c) (i), and McLean, 1999, for whom the technological imperative, and its implications for decision-making in the doctor-patient relationship, are major themes. For the argument that the pressure of the technological imperative reflects confusion as to the purpose of medical treatment, see McLean, 1999, 139.

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subjectively-determined quality of life, or even perhaps the end of cognitive or sentient life.

As mentioned above, people have become concerned about what the technological imperative means for the way in which they may die: will they be maintained indefinitely and without escape on machines? It may be that people are retreating, not from the idea that human life is to be preserved, but from what is offered by technology to prolong biological life. Instead, people may be pursuing an interpretation of the personal interest that does not regard death as the ultimate harm to be avoided at all costs. The questions raised by the technological imperative are receiving incremental answers from judges as cases like Anthony Bland’s and Dianne Pretty’s come before the courts. However, there have been judicial calls for legislative guidance, to be developed following extensive public debate about the social, moral, economic and political considerations that may mean that the preservation of life value should be accorded less weight in particular circumstances, at the edges of what members of the community recognise as being life.

(ii) Continued influence of preservation of life value

It is still the case that euthanasia, assisted suicide, and other forms of intentional killing and infliction of bodily harm are prohibited, on the basis of the state’s concern with the preservation of human life. Moves in the past decade by the Northern Territory to permit euthanasia were defeated by Commonwealth legislation which was introduced through a private member’s bill. The preservation of life value underlies arguments

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589 R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1.
591 For English cases in which ‘mercy killings’ were nevertheless treated as unlawful, see directions to the jury referred to in Airedale NHS Trust v Bland [1993] AC 789, 892 (Lord Mustill).
593 The Hon Kevin Andrews MP introduced the Euthanasia Laws Bill (now the Euthanasia Laws Act 1997). The Bill was passed on a conscience vote in both Houses.
against decriminalising or legalising euthanasia or assisted suicide, although opponents of euthanasia and assisted suicide do rely on other arguments, such as the protection of vulnerable individuals and preserving the integrity of the medical profession.

The preservation of life value also endures in judicial insistence on scrutinising applications to withdraw treatment. In England, members of the Family Division, the Court of Appeal and members of the House of Lords each expressed the view that proposals to withdraw treatment from patients should be subject to judicial regulation, for the purposes of protecting patients and doctors and reassuring family members and the public generally. The indications are that this approach will continue, despite the weight given to medical opinion by the courts, until Parliament intervenes or a settled jurisprudence develops.

(g) Preservation of life and medicalised decision-making

A final observation to be made about the preservation of life value is that, in the absence of clear legislative guidance, courts have turned to doctors to make the substantive decisions in end-of-life cases. As a consequence, clinical values are given substantial, often determinative weight. For example, in relation to the withdrawal of treatment from Anthony Bland, reliance was placed on the views of a responsible body of medical opinion, about both Anthony Bland’s clinical state and prospects, and about the entirety of his best interests. In this case, medical opinion strongly indicated that no therapeutic purpose was to be served by the continuation of treatment. Therapeutic

594 See, for example, R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1, 6, 7 (Lord Bingham of Cornhill), 25 (Lord Steyn), 35 (Lord Hope of Craighead), 40-2 (Lord Hobhouse of Woodborough). See also Devereux, 2002.

595 For concern about protecting the integrity of the medical profession, see for example, Washington v Glucksberg 521 US 702 (1997), 731.

596 Airedale NHS Trust v Bland [1993] AC 789, 805-6 (Sir Stephen Brown P), 813, 815-6 (Sir Thomas Bingham MR), 824 (Butler-Sloss LJ), 859 (Lord Keith of Kinkel), 862, 874 (Lord Goff of Chieveley), 875-6 (Lord Lowry), 885 (Lord Browne-Wilkinson). Lord Goff recommended that the requirement for judicial regulation should be kept under review, with a view to eventual relaxation.

597 See, for example, Airedale NHS Trust v Bland [1993] AC 789, 883-4 (Lord Browne-Wilkinson, who added the requirement that a medical view be reasonable).

598 Airedale NHS Trust v Bland [1993] AC 789, 856, 859 (Lord Keith of Kinkel), 871 (Lord Goff of Chieveley), 884 (Lord Browne-Wilkinson). See also In re J (A Minor) (Wardship: Medical Treatment) [1991] 2 WLR 140, 150 (Lord Donaldson of Lymington MR), rejecting the view that reliance on medical opinion is an abrogation of the judicial function.
purpose was implicitly equated with his best interests. This equation should have been made explicit to demonstrate the influence of clinical values on end-of-life decision-making. I suggest that a broader approach should have been taken, to recognise the breadth of Mr Bland’s personal interest. Such an approach may well have yielded the same ultimate answer to the question in that case, but an explicit recognition and understanding of the personal interest would have placed the law on a surer and more certain footing for future development in difficult cases.

The ‘medicalisation’ of end-of-life decision-making, and its reliance on a ‘responsible body of medical opinion’ as determinative of applicable values is unsatisfactory. If the doctor’s recommendation is likely to be upheld by the law provided it is reasonable and supported by a responsible body of medical opinion, the law becomes unpredictable in its application to individual cases. This is because whether a patient’s decision is implemented will depend on the particular views of the doctor he or she has consulted, and this may often be a matter of chance, rather than of choice. Doctors who advocate implementation of Bolam tests to set standards of care for diagnosis and treatment do so on the basis that it will provide them with certainty. But uncertainty for patients results because it comes down to the luck of the draw whether the particular doctor consulted is amenable to a certain course of action that may be favoured by the patient or substitute decision-maker. Given that many patients and their families may not be in a position to ‘doctor shop’ for a sympathetic doctor, whether a patient’s treatment would be withdrawn or withheld would, on the English approach, come down to the opinion of the particular doctor, provided it was reasonable, not irrational, and shared by a responsible body of medical opinion.

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599 See, for example, Keown, 1997, 497.

600 Bolam v Friern Hospital Management Committee [1957] 1 WLR 582, as modified by Bolitho v City and Hackney Health Authority [1998] AC 232. Although the Bolam approach has never been as popular in Australia as in England, the Ipp Review, 2002, recommended the adoption of a modified Bolam approach to the determination of questions of breach of duty of care by doctors. A number of States have enacted or proposed legislation that provides a defence to doctors (and other ‘professionals’) who act in accordance with competent professional practice (although this does not apply to failure to warn claims). See, for example, Civil Liability Act 2002 (NSW), section 50; Civil Liability Act 2003 (Qld), section 22; Civil Liability Act 2003 (Tas), section 22.

Suggestions that broad support from the medical profession is a prerequisite for liberalisation of euthanasia law also indicate deference to clinical values. Certainly, concern about the effect of legalisation of euthanasia on doctors, and on the standing of the medical profession, has been expressed. However, it could be argued that what many doctors are already prepared to do, in terms of ‘double effect’ sedation and withdrawing life-saving or life-sustaining treatment, may have similar effects on doctors and other health care providers, but has not apparently had a negative effect on the standing of the medical profession.

The consequence of medicalisation of end-of-life decision-making is that the scope of the preservation of life value then also becomes defined by reference to clinical values, with insufficient regard being paid to other kinds of values that are equally relevant to the protection of the personal interest as I have defined it (such as ethical and religious values). I believe that this is undesirable because the question of what it is that the state should seek to protect from harm requires a complete answer, by reference to the whole personal interest, not one given by reference to only one kind of values.

(h) Status of preservation of life value today

The preservation of life value remains a powerful influence on state intervention in decision-making in the doctor-patient relationship. The preservation of life value has been used by the state to justify prohibition of consent to conduct (such as assisted suicide) and regulation of conduct (such as withdrawing or withholding treatment) that might otherwise be undertaken by a patient, or his or her usual substitute decision-maker. However, it is difficult, in many circumstances, to conclude that the preservation of life value, which is acknowledged not to be absolute, should be upheld

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603 See, for example, Compassion in Dying v State of Washington 79 F.3d 790 (1996), 826-8, 851, 854-5; Pretty v United Kingdom (2002) 35 EHRR 1, 26, 30.

604 See, for example, Ms B v An NHS Hospital Trust [2002] 2 All ER 449. See also Compassion in Dying v State of Washington 79 F.3d 790 (1996), 834-6, for discussion of the implications of cases in which, in the absence of doctors assisting with suicide, family members have assumed this role, and Airedale NHS Trust v Bland [1993] AC 789, 880 (Lord Browne-Wilkinson referring to the days when ‘To the great advantage of society, [doctors] took the responsibility of deciding whether the perpetuation of life was pointless.’)
at the expense of either the entitlement or the responsibility to decide when the question of harm relates *solely* to the patient.

Thus, for the purposes of this Chapter, the state should be required to justify its intervention by saying to a patient who seeks euthanasia or assisted suicide: your death is a harm which the state considers should be prevented, and this intervention by the state is better protection of your personal interest than allowing you to decide for yourself. This would be a high hurdle for the state to clear, as reflected by the criteria in section 4.3.

In respect of individuals like Dianne Pretty or Sue Rodriguez, such an assertion may seem to many to be cruel. It is an extreme example of paternalism, particularly if it is accepted that one’s dying is part of one’s living, or if it is recognised that the manner of one’s death may be the only expression of the personal interest that can be left to certain patients. Meanwhile, as technology continually increases life-saving and life-sustaining capabilities, fundamental questions such as ‘what is life?’ and ‘what is death?’ seem no longer to be susceptible to straightforward answers. This kind of ambiguity means that decision-making in the doctor-patient relationship is becoming more value-laden, and thus more closely linked to individuals’ personal interests. Accordingly, either the patient’s entitlement to decide or the substitute decision-maker’s responsibility to decide should, all things being equal, prevail, and appeals to the preservation of life value should be argued with increased clarity and specificity as to what is being protected by the proposed state intervention and why such protection requires state intervention in decision-making in the doctor-patient relationship.

### 4.4.2 Protection of vulnerable patients from undue influence, abuse or exploitation

The second value to be considered is that of the protection of vulnerable patients (the ‘protective value’), which has two aims. The first aim of this value is to protect the entitlement to decide (and thus, the personal interest) belonging to patients who, though possessing decision-making capacity, are unusually vulnerable to undue influence that objectionably affects the voluntariness of their decision-making. I acknowledge that it...
should be a responsibility of the state to protect the assertion of autonomy, free from undue influence, by those who are unable or less able to protect it for themselves, such as the aged, the terminally ill, the young, the disabled and the poor. The second aim of the value is to protect patients without decision-making capacity from abuse or exploitation, in the present or future. The aims are closely linked, and are also connected with the preservation of life value (for example, the prohibition against assisted suicide is based both on the preservation of life value and concerns about undue influence and abuse). Accordingly, this protective value may be seen as being primarily concerned with enhancing, rather than restricting, the personal interest of patients with decision-making capacity, and enhancing substitute decision-makers’ compliance with the principle of beneficence in respect of patients who lack decision-making capacity.

(a) Protection from undue influence: the problem of volunatariness for patients with decision-making capacity

In Chapter 3, decision-making capacity was defined in terms of the following capabilities: to understand and retain information, to consider information in the context of the entirety of one’s personal interest, to believe (thought not necessarily agree with) information given to him or her, to communicate a decision, and to not hold patently false beliefs. The protective value treats as important not only these capabilities, but the capability of forming desires and wishes, free from what are considered to be unacceptable external influences or constraints. Of course, decisions that each of us make every day are subject to external influences or constraints. Whether unacceptable influence or constraint has brought about a particular decision is a matter for judgement on the individual facts, and may take into account matters such as the perceived intellectual or emotional fragility of the decision-maker (even if the decision-maker has

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606 See, for example, Rodriguez v British Columbia 107 DLR (4th) 342 (1994), paragraph 257; Compassion in Dying v State of Washington 79 F.3d 790 (1996), 801, 807.

607 See, for example, Magnusson, 1997, ‘Sanctity’, especially 70, 72, note 419; Newell, 1996, 28, 34; R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1, 18 (Lord Bingham of Cornhill, quoting the Report of the House of Lords Select Committee on Medical Ethics, page 49, paragraph 239). There are reports that this Bill is shortly to be reconsidered, in light of perceived changes of public opinion about euthanasia and in the context of the introduction of a private member’s bill (the Patients (Assisted Dying) Bill) introduced into the House of Lords: see Dyer, 22 November 2003. On 10 March 2004, this Bill was read a second time by Lord Joffe and referred to a Select Committee. A House of Lords Committee released a report on the Bill on 4 April 2005, in which it was recommended that the Bill be reintroduced for debate in the next Parliamentary session. I have been unable to determine whether this has occurred.
decision-making capacity), the relationship between the decision-maker and the ‘influencer’, and the gravity of the decision. The central question should be: does the decision ‘belong’ to the decision-maker, in the sense that it reflects the decision-maker’s personal interest?

Protection of patients who, though possessing decision-making capacity, are nevertheless perceived as unusually vulnerable, is an objective of the blanket prohibitions on assisted suicide that were the subject of discussion in Pretty and Rodriguez. In both cases, the majority judges were influenced by concerns that allowing assisted suicide would threaten the lives of vulnerable patients by making it easier for unscrupulous individuals close to them to persuade patients that it was in their best interests to die. These concerns were strongly persuasive, although they were not directly relevant to the cases at hand. It was, for example, generally accepted that Dianne Pretty’s desire for her husband to assist in her suicide was authentic and freely formed, and that her husband had no unscrupulous intentions. Nevertheless, the Law Lords took the view that it would be too easy for other spouses, having killed their partners, to say ‘he, or she, wanted it’, or to manipulate their partner into feeling that he or she was too great a burden, or their sufferings too dreadful to witness, leading the partner into believing that death was a benefit to others and a final duty to be discharged. Thus, ‘voluntary euthanasia’ would effectively slide into ‘involuntary

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608 See paragraph 3.2.1 (a).
609 See, for example, In re T (Adult: Refusal of Treatment) [1993] Fam 95, 111-114 (Lord Donaldson of Lymington MR), 117, 118-120 (Butler-Sloss LJ); see also Mendelson, 1996, ‘Trespass’, especially at 55; Re Duck 171 DLR (4th) 761 (1999).
610 See In re T (Adult: Refusal of Treatment) [1993] Fam 95, 113 (Lord Donaldson of Lymington MR).
611 R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1; see also Pretty v United Kingdom (2002) 35 EHRR 1, 39.
613 R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1, 17, 18 referred to the Report of the House of Lords Select Committee on Medical Ethics expressing these concerns: (Lord Bingham of Cornhill). The majority judgment written by Sopinka J in Rodriguez v British Columbia 107 DLR (4th) 342 (1994), 411, referred to a Working Paper by the Canadian Law Reform Commission, which expressed similar concerns.
614 These concerns, as they apply to persons other than the patient in a particular case, are discussed more fully in Chapter 6.
euthanasia’. This is part of the ‘slippery slope’ argument against permitting voluntary euthanasia and assisted suicide.\(^{615}\)

However, it should be noted that concerns about voluntariness do not bar the permissibility of refusal of treatment, which is potentially subject to the same pressures. Because of this, it seems at least possible that what lies at the heart of the state’s refusal to countenance positive measures such as euthanasia and assisted suicide is the act/omission distinction. Perhaps, in relation to vulnerable patients, the concern is not just about undue influence or distortion of the patients’ will, but rather the extent to which, in euthanasia or assisted suicide, the ‘influencer’ can play a more active role as agent in bringing about death. Perhaps the difference between, on the one hand, refusal of treatment, withdrawal of treatment and withholding treatment and, on the other hand, euthanasia and assisted suicide, lies in the extent to which the state perceives that a person other than the patient may play an active role as an agent. In relation to conduct characterised as an act, the agency of a third party, whether doctor or lay person, is typically perceived to be more direct and far less amenable to being construed as anything but the cause of death. In addition, the belief that agents can be corrupted, and may improperly encroach on a patient’s interests in pursuit of ulterior ends, may lie at the heart of the state’s objective in protecting vulnerable patients from being encouraged to commit an act with fatal consequences.

In relation to omissions and ‘double effect’ conduct, the agent may be perceived to be ‘one step removed’ from the cause of death. In relation to omissions, for instance, judges have been able to satisfy themselves that a real distinction exists between any positive act of an agent (such as the doctor’s removal of some life-sustaining technology, like BWV’s PEG process) and the actual cause of death. In relation to ‘double effect’ conduct, it has likewise been possible for the community to recognise and accept the existence of a distinction between double effect terminal sedation and bolus injections, characterising death caused by the former as a knowable, likely, but nevertheless unintended, ‘side effect’. Yet sometimes a side effect is so immediate and so inevitable that it should not properly be so described. It is perhaps understandable

\(^{615}\) For discussion of the validity of ‘slippery slope’ arguments, see Hare, 1993, 101-4. See also Airedale NHS Trust v Bland [1993] AC 789, 873 (Lord Goff of Chieveley explaining why allowing withdrawal of treatment is not part of a ‘slippery slope’ to allowing euthanasia).
that this kind of action is treated as being permissible. However, the failure to be explicit about what is actually happening creates its own risk of dishonesty and abuse, through decision-making the true nature of which may be, I suggest, camouflaged for the sake of social and emotional palatability.

(b) Protection of vulnerable patients without decision-making capacity

The second aim of protecting vulnerable patients relates to patients without decision-making capacity. Here, the state is not concerned with the voluntariness of the patient’s decision-making, but with the fact that they are unable to make decisions. This inability makes such patients vulnerable to harmful decisions being made for them by others. The state is concerned to prevent this. In relation to patients who may later develop decision-making capacity, the state is concerned to protect future expressions of their personal interests.

For example, female genital mutilation is now typically carried out on very young girls, who may be subject to significant pressure from family members to submit to highly invasive procedures that have serious short and long term consequences, without countervailing therapeutic benefit.\(^616\) Also, courts exercising *parens patriae* or welfare jurisdictions in relation to proposed non-therapeutic sterilisations of minors have expressed concern about the vulnerability of those persons in relation to whom power is being exercised, and are mindful of the abuses that have been committed towards vulnerable persons, with the blessing of the state, in the past.\(^617\) The courts are equally mindful of the harm, both physical and psychological, that can be caused by well-intentioned, yet misguided, actions.\(^618\) The judicial intention in giving effect to the protective value is that, rather than being an abuser as has been the case in the past, the state should guard against abuse, and so prevent harm.

There is a real risk that patients who are vulnerable because of their lack of decision-making capacity will be subject to conduct, such as non-therapeutic

\(^{616}\) See QLRC Report No. 47, 1994, 9 (referring to Hosken, 1982, 28) and Chapter 7 of that Report.

\(^{617}\) For a history of sterilisation of women with intellectual disabilities, see Goldhar, 1991. See also *Department of Health and Community Services (NT) v JWB and SMB ('Re Marion')* (1992) 175 CLR 218, 250-1 and references at note 28 (joint judgment), 300 (Deane J) and 318 (McHugh J).

\(^{618}\) See *Department of Health and Community Services (NT) v JWB and SMB ('Re Marion')* (1992) 175 CLR 218, 250-252 (joint judgment), 272 (Brennan J).
sterilisation or female genital mutilation, that later restricts their freedom to make their own choices in expression of their autonomy (such as reproductive decisions). There is evidence that this risk has materialised in respect of female genital mutilation and sterilisation of disabled minors. This emphasises the need for the state to be concerned about the weakening of the protective value in relation to vulnerable patients, whose bodily integrity may, in the absence of strong support for this value, be infringed against their will and to the detriment of their ability to define and express what I have characterised as their personal interests.

(c) Protective value not absolute

As the value of preservation of life is not an absolute value, neither is the protective value. For example, courts have judged as permissible the withdrawal of treatment from patients who are vulnerable because they lack decision-making capacity but for whom treatment is judged by medical opinion to be futile.

4.4.3 Health and well-being

As a further justification for intervening in decision-making in the doctor-patient relationship, the state appeals to values that focus on protection of the personal interests of patients, both those with and without decision-making capacity. This section considers the influence of the health and well-being dimension of the personal interest, while section 4.4.4 considers the influence of the personal interest as a whole. The health and well-being dimension is singled out for the purposes of this Chapter because of the emphasis that it has been given as a discrete interest. It has been appealed to as a justification for the exercise by the state of coercive powers. The example considered here is the state’s intervention by prohibiting consent to female genital mutilation.

The state has often sought to influence the way in which individuals define and pursue their interests in health and well-being. Examples of such attempts include public health campaigns relating to smoking, safe sex and skin cancer. In the instance the prohibition

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619 In relation to the sterilisation of disabled minors, see section 4.3.4 (b). In relation to female genital mutilation, see QLRC Research Paper on female genital mutilation, 1993.


621 See, for example, Airedale NHS Trust v Bland [1993] AC 789.
against consent to female genital mutilation, the state intervenes more directly on the basis that it is protecting the health and well-being dimension of the personal interest of individuals. However, while acknowledging that concepts of health, well-being and illness are the subject of social and political interpretations, the argument of this thesis is that ‘health and well-being’ should be given content by the individual as a dimension of his or her personal interest. Generally, the state should not seek to assume a role in protecting what it (rather than the individual) deems to be the individual’s personal interest. It may, however, intervene on the basis of other values, provided that the matters proposed in section 4.3 are properly considered.

Female genital mutilation: protecting the personal interest for the future

(a) Why is it prohibited?

A strong example of state intervention to protect the health and well-being of patients is the prohibition against consent to female genital mutilation by or for minors. The basis for the prohibition is that there are no credible claims of therapeutic benefit, and there is substantial evidence that short and long term harm is an inevitable consequence of practices falling within its ambit. This may be contrasted with male infant circumcision, in respect of which claims of therapeutic benefit have not been disproved, and in respect of which serious harm arises not as an inevitable consequence of the procedure, but rather from the materialisation of risk. The state

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622 See Chapter 1, references at footnote 40.
623 Not all communities take an individualistic approach to the states of health and illness: see, for example, Te Puni Kōkiri Report, 1999, especially Chapter 3.
624 Crimes Act 1900 (ACT), Part 4; Crimes Act 1900 (NSW), s 45; Criminal Code Act (NT), ss 186B and 186C; Criminal Code (Qld), ss 323A and 323B; Criminal Law Consolidation Act 1935 (SA), ss 33A and 33B; Criminal Code Act 1924 (Tas), ss 178A and 178B; Crimes Act 1958 (Vic), ss 32, 33. For overseas legislation, see QLRC Report No. 47, 1994, Chapter 11.
625 The basis for the prohibition, as it applies to adult patients, is discussed in Chapter 6.
627 Although there is ‘no universally accepted, unequivocal’ medical reason for male infant circumcision: QLRC Research Paper on male infant circumcision, 1993, 18. The Royal Australasian College of Physicians has issued a policy statement to the effect that there is no evidence of therapeutic benefits that outweigh the risks, and advises doctors to warn parents of the possibility of future legal action: Judy Skatssoon, ‘Doctors: no reason to circumcise boys’, The Canberra Times, 19 May 2003. The policy can be found at http://www.racp.edu.au/hpu/paed/circumcision/index.htm.
628 QLRC Research Paper on male infant circumcision, 1993, Chapter 8. This Chapter is not concerned with determining whether the distinction between male infant circumcision and female genital mutilation
has weighed the harm caused by female genital mutilation against the justifications for it that are based in social and cultural practices. The extra-clinical dimensions of the personal interest do encompass the social and cultural practices that are relevant to female genital mutilation, and Chapter 2 cautions against giving undue emphasis to clinical welfare at the expense of other dimensions. However, it is strongly arguable that a decision to subject a minor to female genital mutilation over-emphasises social, cultural and traditional dimensions and pays too little regard to the minor’s clinical welfare. In any event, in striking a balance between social, cultural and traditional dimensions and clinical welfare, the state has made a determination to prohibit consent to female genital mutilation. Because female genital mutilation is generally carried out on children and young girls who have not reached puberty, it can reasonably be inferred that the protective value has also been influential in the imposition of this legislative prohibition.

(b) What if there were no legislative prohibition?

It is likely that, even in the absence of a legislative prohibition, consent to authorisation of female genital mutilation in relation to minors would not be permissible, because of its damage to the health and well-being dimension of the personal interest. It is highly improbable that, at common law, a decision-maker could lawfully consent to a procedure that amounted to female genital mutilation, for reasons explored in subsequent paragraphs.

This thesis identifies three kinds of decision-makers in doctor-patient relationships: patients, usual substitute decision-makers and the state. None of these would be regarded by Australian common law as having capacity to consent to, or to authorise, female genital mutilation. First, a minor patient would not be considered

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629 Female genital mutilation is not a religious practice, although it is often thought of in that way: QLRC Report No. 47, 1994, 19-20. See also QLRC Research Paper on female genital mutilation, 1993, 9.


631 This thesis identifies emergencies as the only instances in which the doctor may properly act as a substitute decision-maker: see section 3.2.5.
Gillick-competent\(^{632}\) to consent to surgery that constituted female genital mutilation. This is because the *Gillick* approach to determining the intelligence and maturity (and through these attributes, the decision-making capacity) of a particular child necessarily takes into account matters such as the invasiveness and seriousness of the proposed procedure and the gravity of consequences of a decision to consent to or refuse treatment. Thus, a ten year old is likely to be accepted as having decision-making capacity to consent to having a broken arm set, but is less likely to be regarded as having the capacity to consent to invasive cosmetic surgery, or to refuse live-saving treatment. Second, the harmful consequences of female genital mutilation mean that it would be very difficult to establish that a decision, by a parent or carer as the usual substitute decision-maker, to consent to such surgery would be a decision that enhanced the personal interest of a child, or that would satisfy the traditional best interests test discussed in Chapter 2.\(^{633}\) Similarly, if an application were to be brought before a court or a tribunal for judicial authorisation, it is highly improbable that such surgery would be considered to be in the best interests of the minor.\(^{634}\) The degree of harm occasioned by all but the least intrusive of female genital mutilation practices\(^{635}\) is so severe and enduring that it would almost certainly be determinative of any application for judicial authorisation.

The prohibition against consent to female genital mutilation by or on behalf of minors (and other patients without decision-making capacity) is intended to prevent harm to their health and well-being. It could also be argued that the prohibition is intended to balance cultural and traditional aspects of patients’ interests against the serious limitations that female genital mutilation would place on their future choices about important and highly personal matters such as child-bearing.

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\(^{632}\) *Gillick v West Norfolk AHA* [1986] AC 112, accepted by the High Court in *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (*Re Marion*) (1992) 175 CLR 218.

\(^{633}\) See section 2.3.3 for a proposed alternative to the best interests test.

\(^{634}\) As required by *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (*Re Marion*) (1992) 175 CLR 218.

\(^{635}\) QLRC Report No. 47, 1994, 7, referring to the practice described there as circumcision, and distinguishing it from practices described as excision and infibulation (pharaonic circumcision).
4.4.4 The personal interest

(a) The personal interest and non-intervention by the state

Interests of patients, other than the health and well-being interest, have influenced state intervention in the doctor-patient relationship. This influence is most apparent in the recognition that, generally, the patient is entitled to make treatment decisions, even in respect of certain practices with no therapeutic benefit and significant risks; for example, procedures like liposuction or ‘botox’ treatments. Individuals make decisions about such matters in light of their own interpretations of the content of their personal interests. Decision-making in respect of most treatment is unregulated in the sense referred to in this paragraph; it is a minority of potential interventions in respect of which the state prohibits consent or refusal, or assumes the decision-making role on a case-by-case basis. Activities such as invasive cosmetic surgery, male infant circumcision and personal adornment, and risky practices such as some sports (both ‘extreme’, and more conventional, sports), are apparently permissible on the bases first, that no value is regarded as of sufficient weight to justify state intervention and, second, on a judgement by the state about the kind and degree of risk-taking or self-harming behaviour that should be tolerated by the community. I argue that the state’s non-intervention is justifiable because a robust entitlement to decide, shaped by autonomy, is usually the best protection for the personal interest. However, sometimes, the personal interest is best protected by the harm prevention policy.

(b) The personal interest as justification for regulation: non-therapeutic sterilisation of minors

Protection of the personal interest of a certain group of individuals has, I suggest, influenced the state, through the judiciary, to adopt a regulatory role in respect of decision-making about a limited class of procedures. Judicial authorisation is required in respect of proposed non-therapeutic sterilisations of minors, and other procedures that share the special features of non-therapeutic sterilisation. This section examines

636 This is not to say that they are unregulated in other senses. For example, there may be requirements that practitioners be licensed, or that procedures be carried out only in accredited premises: see Public Health Act 1991 (NSW), ss 10AC, 10AD and 51; Public Health (Skin Penetration) Regulation 2000 (NSW); Health Act 1937 (Qld), section 100A and Health Regulation 1996 (Qld), Part 15.

637 Although there is evidence to suggest that, even following the High Court’s decision in Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR...
the basis for such regulation by considering the distinction between therapeutic and non-therapeutic procedures and the special features of non-therapeutic sterilisation. It suggests that the interest being protected should be recognised as being the entire personal interest of the patient, and that the effect of state intervention is not, as in other instances, to substitute the state’s version of an individual’s personal interest for that of the individual, but that is should be seen as allowing a patient to evolve and assert his or her own personal interest, where possible. This section is based on consideration of Re Marion. That case involved a 14 year old girl who was severely intellectually disabled, with considerable physical disabilities and behavioural problems. Her parents asked the court to determine who could consent to or authorise proposed surgical procedures (a hysterectomy and an ovariectomy) that would have the effect of preventing pregnancy and menstruation, and ameliorating the behavioural difficulties that accompanied Marion’s hormonal fluctuations.

(i) The distinction between therapeutic and non-therapeutic sterilisation

This section explores how the High Court has treated the distinction between therapeutic and non-therapeutic sterilisations. There was a broad consensus in the High Court that different purposes may underlie proposed sterilisations, and that these purposes are relevant in determining who can authorise, or consent to, a proposed sterilisation of a disabled minor. The joint judgment, accepting the existence of a distinction, took the view that a parent can consent to therapeutic sterilisation, but only a court can authorise the performance of a non-therapeutic sterilisation of a minor. This is because of the special features of non-therapeutic sterilisation, which are discussed below. Although Deane J was of the view that there is little practical value

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218, the seeking of judicial authorisation is the exception, rather than the norm: Brady and Grover, 1997; Brady, Briton and Grover, 2001, especially at 61; Sandor in Freckelton and Petersen, 1999, 17-20. See also the comments of Nicholson CJ (as he then was) of the Family Court of Australia on the Four Corners programme, ‘Walk in my Shoes’, broadcast by the Australian Broadcasting Corporation on 16 June 2003, about the number of applications for judicial authorisation (17 in the 11 years following Re Marion).

638 Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218.

639 Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 253.

640 Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 253.
in the distinction, Cica has suggested that this might be because of his extremely narrow view of what constitutes a therapeutic sterilisation, focusing exclusively on physical health. Cica goes on to argue persuasively that, in fact, some form of the distinction underpinned the analysis undertaken by Deane J as to the permissibility of parental consent to, or judicial authorisation of, sterilisation of a minor.

A therapeutic sterilisation was defined by the joint judgment as a sterilisation effected as an incidental result of surgery which is intended to cure a disease or correct a malfunction. The proposed sterilisation of Marion was characterised as being non-therapeutic. Brennan J, in a separate judgment, was the most emphatic of the judges in supporting the distinction which was originally drawn in the Canadian case of Re Eve. His Honour held (like the Canadian Supreme Court but unlike the joint judgment in the High Court) that neither a parent nor a court can consent to or authorise a non-therapeutic sterilisation.

The willingness of most of the judges to accept that parental power includes the power to consent to certain sterilisations can be attributed to the therapeutic character of such sterilisations. When sterilisation is intended to cure a disease or correct a malfunction, the Court takes the view that the minor’s interest in clinical health and well-being prevails over any other dimension of the personal interest that might weigh against sterilisation. In such circumstances, the Court is willing to entrust decision-making to parents (in the justifiable belief that they will be guided by doctors). The Court is less likely to consider that other dimensions of what I have described as the personal interest

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641 Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 296-7. Brennan and McHugh JJ both acknowledged practical difficulties in implementing the distinction: see 279, 322.

642 Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 289; Cica, 1993, 191-3.


644 Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 253. See also the discussion of therapeutic purpose by Brennan J at 269-74, which gives a broad interpretation of what is ‘therapeutic purpose’, 322 (McHugh J) and the narrow, ‘conventional medical purpose’ approach adopted by Deane J (289, 295).

645 Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 253 (joint judgment).


647 Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 277, 279, 283-5.
are of sufficient importance to require judicial scrutiny or protection. Moreover, there is a perception of objectivity of therapeutic purpose (analogous to the perceived objectivity of therapeutic necessity discussed in Chapter 3). That is, it is judicially accepted that the existence of a therapeutic purpose can be identified and defined with objectivity and certainty. Because of this perception, the Court is not particularly concerned about the possibility of conflicts of interest between the minor and other persons, such as parents or carers. One commentator, however, has expressed concern that, because of the relative freedom from scrutiny of therapeutic sterilisations, proposed procedures are brought within the ambit of 'therapeutic sterilisation' by artificially characterising social reasons for sterilisation as psychological, and hence medical, reasons.  

The Court has been more concerned to assert a decision-making role in relation to non-therapeutic sterilisations on the basis that, in the absence of a therapeutic purpose, sterilisations should only be carried out if other dimensions of the patient’s interests require it. Determination of whether sterilisation would enhance the entirety (and not just the clinical welfare dimension) of a minor’s interests is perceived by the Court to be more susceptible to interpretations that may serve interests other than those of the minor for whom the procedure is proposed. That is, the patient’s personal interest is at risk from extrinsic influences (including from usual substitute decision-makers), and therefore the usual substitute decision-makers should not be part of the decision-making process. This is, I suggest, the basis for the identification of the special features of non-therapeutic sterilisation.

(ii) Special features of non-therapeutic sterilisation

The special features of non-therapeutic sterilisation were recognised, in one form or another, in each judgment.  Although McHugh J argued that there was no principled reason to distinguish sterilisation from other surgery to which parents could consent, his judgment seems even so to have been influenced by the grave and invasive nature of

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649 For example, Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 249-54 (joint judgment), 268, 277 (Brennan J), 296, 303, 306-7 (Deane J).
the procedure and the possibility of conflicts of interest between the patient and usual substitute decision-makers. The first of the special features is that sterilisation is invasive, irreversible and major surgery which constitutes a substantial and enduring infringement of the patient’s interest in bodily integrity. Its effect, like that of female genital mutilation, is to remove biologically healthy organs to serve a non-therapeutic purpose. To justify this, there should be particularly compelling reasons related to the protection and enhancement of the personal interest. Thus, Brennan J held that non-therapeutic sterilisation of a disabled minor could be justified only if a non-therapeutic purpose were to be accorded ‘a higher value than the preservation of her physical integrity’. Brennan J did not think this was possible, believing that no non-therapeutic purpose could justify the procedure; hence his prohibition of non-therapeutic sterilisations. Other members of the Court, as mindful as Brennan J of effects of sterilisation on various dimensions of patients’ interests (such as bodily integrity, self-perception and self-esteem), took the view that, in certain circumstances, a sufficiently high value could be accorded to make a compelling case for non-therapeutic sterilisation.

The second special feature of sterilisation is that a decision to undertake it carries a significant risk of being wrong about the answers to factual questions on which the Court’s ‘best interests’ judgement must rest. The High Court noted three particular reasons why this risk exists. The first reason is the complexity of the question of decision-making capacity. Like the House of Lords in Gillick, the High Court recognised that the question of whether a minor possesses decision-making capacity can be answered neither by reference solely to the minor’s age nor by reference to whether or not the minor has a disability. In addition, the Court acknowledged that, in the

650 Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 319.
651 Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 322.
652 Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 275.
653 Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 232, 251, 252 (joint judgment); see also 267 (Brennan J).
654 Gillick v West Norfolk AHA [1986] AC 112.
655 Secretary, Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 237-8, 250 (joint judgment), 320 (McHugh J).
past, determinations about the possession of decision-making capacity have been improperly influenced by race, class and gender biases. The second reason which creates a significant risk of a wrong decision is that decision-making about sterilisation has often been dominated by medical professionals, at the expense of contributions from practitioners of other disciplines (such as psychologists, social workers or teachers) who might be able to offer an alternative view about a minor’s interests and present and future capacities. This has resulted in decision-making dominated by clinical values, and not sufficiently balanced by other values. The third reason underlying the perception of risk of a wrong decision is the potential existence of conflicts of interest between usual substitute decision-makers such as parents or carers, other family members, and the minor. While it is not suggested that these individuals do not have a legitimate interest in the matter, or that their views are not generally motivated by the best intentions, the possibility of conflict was seen by the Court as an additional reason for requiring judicial scrutiny.

The third special feature of sterilisation is that the consequences of a wrong decision are particularly grave. This feature is more expansive in scope than the first feature described above, because the first feature focuses on the gravity of the infringement of the interest in bodily integrity. This feature is concerned with the patient’s broader interests. In identifying this feature, the Court was essentially recognising, first, that sterilisation has a powerful and enduring effect on all dimensions of the personal interest and, second, that judicial scrutiny should be used to provide some protection for the personal interests of patients who cannot assert it (or even define it) themselves. The Court emphasised the social and psychological consequences of sterilisation for self-image and self-esteem.

On the basis of these special features, the High Court took the view that judicial scrutiny of proposed non-therapeutic sterilisations was necessary to protect the interests

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656 Secretary, Department of Health and Community Services (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218, 238-9, 250 and references at note 27 (joint judgment).


658 See, for example, Secretary, Department of Health and Community Services (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218, 272-3 (Brennan J), 303 (Deane J).

659 Secretary, Department of Health and Community Services (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218, 249, 252 (joint judgment), 268 (Brennan J).
of minors who might be subject to such procedures. I suggest that this view should be acknowledged as amounting to a recognition that judicial authorisation was necessary to protect Marion’s personal interest from harm that might otherwise have been caused by third parties, intentionally or not.

(c) Judicial authorisation of sterilisation is based on a harm prevention policy

Because sterilisation of the disabled is not a clear cut issue, the High Court took the view that the best protection that could be afforded disabled minors (mainly girls) in developing and asserting their personal interests could be found in requiring applicants to seek judicial authorisation. This was because of the special features of sterilisation. Underlying each of these special features was, in my view, a policy that it was the role of the Court (whether exercising the parens patriae or a statutory child welfare jurisdiction) to prevent harm to disabled minors by scrutinising applications for involuntary sterilisation, and weighing the various factors to form a view on whether the proposed procedure was in the ‘best interests’ of the minor.

(d) The relationship between the test proposed by the joint judgment and the test proposed by me in section 4.3

Both the joint judgment’s test and my test are both aimed at identifying the proper decision-maker in a particular instance: the judges’ test aims at determining whether it is necessary to seek judicial authorisation for a proposed procedure, and the test proposed at section 4.3 of this thesis aims at determining whether there are principled reasons why a patient, or usual substitute decision-maker, should not decide about treatment. My test, however, is broader than that of the High Court, which focuses on the nature of particular procedures and the effect that a wrong decision about such procedures will have on the patient. The High Court’s test is thus confined only to a specific class of cases. My test applies to all cases in which it is proposed to displace the entitlement to decide in favour of competing values or interests, and takes into account circumstances and values unrelated to the patient, where that is relevant. In some cases, such as those relating to judicial authorisation of sterilisation and tissue

660 In GWW and CMW (1997) FLC 92-748, the judge found that sufficient special features existed (that is, lack of benefit and possible conflict of interests) to make judicial authorisation the appropriate mechanism for decision-making about tissue harvesting from a minor. See also In re A (1993) 16 Fam LR 715 (gender reassignment).
harvesting from patients without decision-making capacity, my test serves a dual purpose: guiding both whether and how the state should intervene in particular cases.

(e) Role of beneficence in non-therapeutic sterilisations of disabled minors

The regulation of non-therapeutic sterilisations of disabled minors, through requiring judicial authorisation, should be seen as protecting their personal interests and recognising that neither age nor disability necessarily precludes the recognition and protection of a patient’s entitlement to decide. If, on the facts, the minor will never be in a position to exercise his or her autonomy, then the aim of the state in assuming decision-making responsibility should be to ensure that decisions comply with the beneficence principle by protecting the minor’s personal interest.

4.5 CONCLUSIONS

4.5.1 Displacement of the entitlement to decide and the responsibility to decide to prevent harm

This Chapter shows that, in relation to decision-making in the doctor-patient relationship, two things can be displaced. First, the entitlement to decide can be displaced on the basis of certain values that are protected by the state. That is, patients with decision-making capacity do not always have an entitlement to decide about treatment, because that entitlement may be ‘trumped’ by values such as the preservation of life and protective values. Second, in relation to patients without decision-making capacity, the state may also intervene in decisions about treatment, that would otherwise be made by the usual substitute decision-maker. That is, the responsibility to decide is displaced by the state.

These displacements occur, I suggest, on the basis that of an assumption by lawmakers that what I have described as the patient’s personal interest is better protected, in some circumstances, by the state than by the patient or the usual substitute decision-maker. However, no unifying theory has been put forward about when such displacement should occur.

661 See paragraph 5.2.4 (b) for discussion of tissue harvesting from patients without decision-making capacity.
If courts and legislators were to openly declare that what is being pursued by them is a policy of harm prevention, then the law would become clearer. For example, while the arguments about conduct that is presently prohibited (assisted suicide and euthanasia) are fairly clear, it is less clear why the law has allowed other positive, death-causing conduct, such as the administration of increased dosages of opiates with the ostensible aim of relieving pain rather than causing death, even where death is the foreseeable, indeed inevitable, outcome. As described in this Chapter, the doctrine of double effect and the act/omission distinction, which are conventionally used to explain this permissiveness, have an air of unreality, even disingenuousness, about them which makes them unsatisfying as explanations for prohibiting some conduct and permitting other conduct, when both forms of conduct have the same result. If, however, it were to be recognised that what is actually going on is the protect of the personal interest through harm prevention, then the law's approach is more readily comprehensible.

This is because what courts and legislators seem to fear in relation to positive conduct such as assisted suicide and euthanasia is that the direct involvement of a third person could lead to exploitation and abuse of vulnerable patients, especially the aged, the disabled or the socially isolated. Gradually increasing the administration of opiates, by persons such as doctors or other palliative care practitioners, is perhaps less likely to excite these fears, because of the high regard in which such persons are held. The risk of harm perhaps does not seem as great, and courts and legislators seem to feel more comfortable about allowing this practice to continue, than about allowing other kinds of practices to be started, especially where those practices may involved ‘untrained’ persons such as partners, family and friends. The rights and wrongs of this are not a subject within the scope of this thesis. The point being made here is that those practices which have traditionally been considered permissible are, in my view, so considered because they are perceived (correctly or not) as posing fewer risks to vulnerable patients, and as being more controlled by persons recognised as having high status.

Open acknowledgement of the harm prevention policy, and application of the test in section 4.3, may still support the permissibility of withdrawal or refusal of treatment.

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662 See Chapter 1 for a discussion of the status of doctors (section 1.3.2).
while maintaining opposition to riskier kinds of conduct. The advantage would be an enhancement of the transparency with which the law approaches these difficult and value-laden cases. I suggest that when transparency of the law about decision-making in the doctor-patient relationship is enhanced, patients’ personal interests are likely to be given more respect. This is because when one is open about the exceptions to a rule (such as the rule that the entitlement to decide generally best protects the personal interest), the nature and scope of the rule itself becomes clearer, stronger, and thus more robust within what can then be seen to be its true parameters.

4.5.2 State intervention may support or substitute patient’s personal interest

State intervention, of a kind described in the preceding subsection, may either support or disregard the personal interest of patients, with a view to preventing harm. The state may intervene with the intention of supporting the actual personal interest of a patient. In general, however, the effect of state intervention that prohibits consent or prohibits refusal is to disregard a patient’s personal interest, and to substitute and promote what the state considers to be the patient’s best interests, defined by reference to the values described in this Chapter. When this occurs, the state is acting paternalistically. I am arguing that paternalism may be justified, for the purposes of this thesis, if it better protects patients’ personal interests than can a robust entitlement to decide. Whether this is so in a particular case should be determined by applying the test proposed in section 4.3.664

663 Unless there is a possibility of harm to others, as discussed in Chapter 5.
664 See Chapter 6 for how this may be done.
CHAPTER 5  VALUES THAT DISPLACE THE ENTITLEMENT TO DECIDE - PREVENTING HARM TO THIRD PARTIES

5.1 INTRODUCTION

Previous Chapters have shown how the patient’s entitlement to decide (and the usual substitute decision-maker’s responsibility to decide) is displaced by circumstances and values relating to the patient: his or her decision-making capacity, therapeutic necessity and values that prevent harm to the patient. Chapter 5 moves the focus away from the patient, showing that circumstances that do not relate to the patient may also be used, by the state, to justify intervening in decision-making in the doctor-patient relationship. Thus, the state may require a patient to undergo treatment to prevent harm to a third party whose personal interest is in conflict with that of the patient. In doing so, the state overrides two fundamental principles that have been identified as applying to the provision of treatment and that correspond to the autonomy and beneficence principles: first, that treatment be consensual, so that the refusal of a patient with decision-making capacity is respected and, second, that treatment be for the benefit of the patient. Because of the seriousness of overriding these principles, this thesis argues that the question of whether circumstances justify displacement should be determined by using a balancing test that takes into account the criteria described in section 4.3.

This Chapter demonstrates how appeals to the preservation of life value, the value of protecting vulnerable persons (the protective value), and the value of preservation of family relationships have been used by the state to justify its intervention.

Chapter 5 divides third parties into two groups: those who are related to the patient (dealt with in section 5.2) and those who are not (considered in section 5.3). The purpose of the distinction is primarily one of convenience. However, there is a practical distinction between the groups, in that the kinds of benefits and harms discussed in section 5.2 seem to me to be more direct and less speculative in nature than those described in section 5.3. Also, while the circumstances described section 5.3 involve

more speculative, less direct risks of harm to third parties, the harms described tend to involve potentially larger numbers of individuals.

Section 5.4 considers the application of the beneficence principle to the patient when his or her entitlement to decide is displaced to prevent harm to a third party and, finally, section 5.5 sets out the conclusions to be drawn from this Chapter.

5.2 PREVENTING HARM TO RELATED THIRD PARTIES

5.2.1 The preservation of life value

Chapter 5 considers how the preservation of life value has led to the state taking over the decision-making role from a patient, or from a patient’s usual substitute decision-maker (for example, in the case of children, from the parents).

Relationship with the protective value

The preservation of life and protective values are considered by this Chapter on the basis that the state has taken the view that ‘unacceptable’ decisions may, but for state intervention, be made by patients or usual substitute decision-makers. For the purposes of this Chapter, decisions are regarded by the state as ‘unacceptable’ if they are perceived by the state as being likely to have an adverse effect on the application of the preservation of life value, or the protective value, to third parties. In particular, the state is concerned to protect persons who are regarded by the state as being more vulnerable than others because of factors such as incapacity or dependency. This Chapter combines consideration of these two values because, in the context of protecting third parties, they generally operate in tandem. That is, the state intervenes to further the preservation of life value, and thus prevent harm to vulnerable third parties.663

5.2.2 The preservation of life value and the sacrifice of a conjoined twin

Possibly the most intellectually and emotionally difficult circumstance described in this thesis is that of conjoined twins who will both die at some point in the near future if they remain conjoined, but whose separation will cause the death of one twin, while being likely to prolong the life of the other. This situation has arisen in two cases that

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663 See Chapter 6 for how this might be done.
will be referred to in this Chapter, for the purpose of demonstrating, first, that the state has assumed the decision-making role, regardless of the wishes of the parents (as the usual substitute decision-makers for children) and, second, that the state justified its intervention by appealing to the preservation of life and protective values. The two cases are the English Court of Appeal case of *Re A* and *State of Queensland v Nolan and Anor*, a Supreme Court decision of Chesterman J. Before turning to analysis of the issues raised that are relevant to this thesis, it is helpful to provide context by setting out an account of the complex facts of *Re A*. Analysis of the issues relating to conjoined twins and the preservation of life and protective values will concentrate on this case because it provides significantly more detailed reasoning of those issues than is offered by *Nolan*.

(a) **Facts of Re A**

The judgment of Ward LJ sets out the facts of this case. Briefly, they are that Mary and Jodie were ischiopagus tetrapus twins (joined at the lower abdomen, with four lower limbs). Their conjointure was detected during Rina Attard’s pregnancy. The Attard family lived on Malta, where there were not the facilities to cope with the complications of conjointure. Under existing arrangements between Malta and the United Kingdom, Rina and Michelangelo Attard travelled to England for treatment during pregnancy and for the delivery of the babies. They were under the care of St Mary’s Hospital in Manchester. The Attards wanted as little intervention as possible and, during the pregnancy, the obstetrician modified his usual practices to accommodate the Attards’ wishes.

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667 For a judicial example of this link being made, see *Rodriguez v British Columbia* 107 DLR (4th) 342, (1994) 404 (Sopinka J, with whom Gonthier J concurred).


674 One of the Maltese doctors had studied at St Mary’s and suggested they seek treatment there: *Re A (children) (conjoined twins: surgical separation)* [2000] 4 All ER 961, 970.


Chapter 5
Each twin had her own brain, heart, lungs and other vital organs. However, Mary’s brain development was severely limited, her heart was enlarged, and her lungs rudimentary. The problems with her heart and lungs meant that she could not oxygenate and pump blood through her body, but depended on Jodie to do this for her through a shared artery. A heart/lung transplant was not a realistic option and, had Mary not been conjoined with Jodie, she would not have been viable after birth.

Although the children seemed content, there was expert testimony that Jodie was not growing (although Mary was), and that Jodie was a ‘sparkling’, ‘with it’ baby, while Mary was only responsive at a very basic level (her responses of pleasure and pain could not be differentiated). The prognosis if the girls remained conjoined was accepted by the Court as being bleak; Ward LJ found that if surgery were not performed, then both twins would die within a few months. The deaths would be caused by Jodie’s heart failing, as it became unable to bear the strain of supporting two growing bodies. On the other hand, if separation were to occur, Mary’s death very shortly after separation was inevitable, but Jodie’s prospects of a healthy life were good.

Testimony did, however, differ as to the extent to which Jodie would require surgical intervention and reconstruction after separation. The judges criticised the parents for taking too pessimistic a view of Jodie’s prospects post-separation, and it seems that Jodie did well after the surgery, although she remained hospitalised for nine months.

The parents, after consultation with a priest, refused to consent to separation. Their view was that it was impermissible to sacrifice Mary for Jodie’s benefit, even if that meant that the twins could then both be expected to die within months. The Court accepted that some hospitals would have respected this point of view.

676 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 973.
677 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 979. There was evidence that survival for a few years might be possible (at 976).
683 Such as Great Ormond Street Hospital in London: see Hewson, 2001, 283.
not inclined to accept the parents’ decision. A declaration was sought, to the effect that surgery to separate Mary and Jodie would be lawful. Ward LJ, though taking the view that the Court was required to decide the dispute, indicated that had St Mary’s accepted the parents’ decision, no criticism of that course of action could have been made.\textsuperscript{684}

The decision of the Court of Appeal, on appeal from the judgment of Johnson J, was not appealed from, although Ward LJ had made statements to the media to the effect that it should go before the House of Lords, and had made arrangements to ensure that the Law Lords could hear the matter urgently.\textsuperscript{685}

The central issue was whether the judges could find a basis on which to declare the proposed surgery to be lawful, despite the fact that it would inevitably cause Mary’s death. The case was decided primarily by reference to the common law, although the judges took into account the human rights legislation that was shortly to become part of domestic law in England.\textsuperscript{686} The preservation of life and protective values underlie the three judgments, which each held that the proposed conduct would be lawful. Ward LJ relied principally on a concept of quasi self-defence, although his reasoning also contains elements of a defence of necessity, which formed the basis for the judgment of Brooke LJ. Robert Walker LJ found that the proposed surgery was lawful on two bases: the application of the principle of double effect and a finding that the surgery would be in the best interests of both girls.

\textit{(b) Is there a third party?}

Consideration of the separation of conjoined twins is relevant to this Chapter only insofar as a third party can be said to be in existence. There is a range of forms of conjoined twins, existing on a continuum from children born with extra limbs or organs to sets of fully-formed twins joined in such a way that separation is a relatively minor undertaking, offering both twins excellent prospects of healthy lives as singletons. At the former end of the continuum, it is unreasonable to speak of a third party. However, there are many ‘degrees of separation’, and some degrees may not offer a clear answer

\begin{footnotes}
\item[684] Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 987.
\item[685] Hewson, 2001, 283.
\end{footnotes}
to whether a third party can be said to exist. In neither case discussed in this Chapter is
this an issue. It was accepted in \textit{Re A},\footnote{See, for example, \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 996 (Ward LJ), 1025-1026 (Brooke LJ), 1053 (Robert Walker LJ).} and assumed in the similar case of \textit{Nolan},\footnote{\textit{State of Queensland v Nolan and Anor} [2001] QSC 174 (31 May 2001).} that two beings with full legal personhood and, in the terms described by this thesis, full
personal interests, were in existence.\footnote{Sheldon and Wilkinson note that doctors who treat conjoined twins tend to treat them as two patients: Sheldon and Wilkinson, 1997, 151-2.} For the purposes of this Chapter, Mary was the
patient for whom treatment was proposed, and Jodie was the third party in relation to
whom the doctors sought to prevent harm.

\textit{(c) Who is the decision-maker?}

What brought Mr and Mrs Attard into the British judicial system, and led to the state’s
intervention, was the Attards’ refusal, as the usual substitute decision-makers for Mary
and Jodie, to accept medical advice from a particular group of health care providers
(that is, those at St Mary’s). Ward LJ noted that there had been ‘public concern as to
why the court is involved at all’,\footnote{\textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 987 (Ward LJ).} and acknowledged that what the court was being
asked to arbitrate was a ‘difference of opinion’\footnote{\textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 987 (Ward LJ).} However, he took the view that the
Court was the only arbiter of such a difference, and that it was not open to the court to
refuse to hear the matter.\footnote{\textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 987 (Ward LJ).} Given that Ward LJ found that the alternative course of
letting the twins live out their lives conjoined would have been above criticism,\footnote{\textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 987 (Ward LJ).} it is
difficult to see why this is so. This was not the kind of case in which the parents could
be said to have demonstrably failed to take into account Jodie’s best interests, thus
breaching their duties as usual substitute decision-maker, and providing a clear basis for
state intervention. Nevertheless, the Court’s decision meant that the state became the
decision-maker. It was held that, the Court having been appealed to for judgment, its
role was to act as original decision-maker, looking at the matter afresh. It was not the
Court’s role simply to act as a reviewer of the decision made by the parents, in which it
sought merely to determine whether the parents’ decision was reasonable. The Court

\footnotesize{687} See, for example, \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 996 (Ward LJ), 1025-1026 (Brooke LJ), 1053 (Robert Walker LJ).


\footnotesize{689} Sheldon and Wilkinson note that doctors who treat conjoined twins tend to treat them as two patients: Sheldon and Wilkinson, 1997, 151-2.


\footnotesize{693} \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 987.
took this view on the basis that, if the Court simply acted as a reviewer of reasonableness, this would be inconsistent with the welfare, or best interests, test that the Court is required to apply in making medical treatment decisions about patients who lack decision-making capacity.694

(d) How the decision to support separation was made

(i) Purpose of medical treatment

The first question to be asked is whether the proposed separation was medical treatment at all. The licence that doctors are given to invade patients’ bodily integrity is, in my view, conditional on the assumption that doctors are doing so to further a beneficial purpose. Even when there is no therapeutic purpose, such as with elective cosmetic surgery, doctors are perhaps assumed to be acting for a beneficial quasi-therapeutic purpose: to repair, ameliorate or prevent a real or perceived flaw. Accordingly, the first step in analysing the lawfulness of the proposed surgery is first to consider whether there was a condition to be treated and, if so, to determine whether the proposed treatment had a therapeutic, or at least quasi-therapeutic, purpose.

Was there a medical condition?

Although it may seem obvious that, following separation, Jodie had a prospect of a healthy life (and thus medical intervention could be characterised as treatment for a condition suffered by Jodie, who would shortly die without separation), Annas identifies a more fundamental theme running throughout the judgments, particularly those of Ward LJ and Robert Walker LJ. The theme is one of individuation: that is, being conjoined is something of which one should seek to be ‘cured’.695 Perhaps this perception is the reason why there was so much strong public sympathy, around the world and across very different cultures, for the quest of Laden and Laleh Bijani, who died in the process of being separated, following strenuous efforts to find doctors prepared to undertake the surgery.696


695 See, for example, Annas, 2001, 1106-1107.

Robert Walker LJ is explicit about the significance of physical separateness. He makes physical separation a prerequisite of the possession of bodily integrity and dignity (and thus, of personal interests, as described in this thesis). It is surely incorrect for Robert Walker LJ to deny that conjoined twins who remain thus, whether from choice or from necessity, should be denied the protections that bodily integrity and the dignity interest confer, at least as against the ‘outside world’, if not against each other. Nevertheless, by making separation a *sine qua non* of bodily integrity and human dignity, and by according these interests a very high value indeed, Robert Walker LJ provided himself with a basis on which he felt able to determine that separation was in the best interests of both Jodie and Mary. Robert Walker LJ took the view (unlike the other judges) that separation would, in fact, be in Mary’s best interests, as it would confer on her (albeit very briefly) the bodily integrity that nature had denied her. Separation was thus, in his view, lawful medical treatment.

Hewson takes the argument about the perceived nature of conjointure further than Annas, arguing that each of the judges saw the fact of conjointure as more than merely a disease to be treated; she refers to the ‘monster factor’, influencing the judges to order that separation was lawful (despite explicit rejection of such an influence by the judges). Hewson, one of the counsel appearing in the matter, points to characterisations of Mary as ‘parasitic’, ‘sucking the lifeblood’ from Jodie, ‘killing’ Jodie, as being permanently in debt to Jodie, and suggests that the Court never seemed to recover from seeing a photograph of the twins.

Certainly, it seems from the language used by Ward LJ in describing the twins, the reliance of Brooke LJ on a principle of necessity, and the approach by Robert Walker LJ...
to individuation of bodily integrity and human dignity, that conjointure (even without the threat to Jodie) was regarded as a circumstance that would merit clinical intervention, and that the purpose of such intervention could, in the Court's eyes, be characterised as therapeutic.

Was separation beneficial treatment?

Assuming that there was a medical condition to be treated, it must be emphasised that courts have viewed the fundamental purpose of medical treatment as being to confer a benefit. This quality of medical treatment is, I suggest, a foundation of medical ethics and legal principles relating to medical care. In this case, however, the notion of benefit was not felt by the judges to provide a satisfactory guide to what ought to be done, since the majority of the judges accepted that what would be likely to benefit Jodie would harm Mary. Conversely, what would prolong Mary's life to its maximum possible extent would shorten what length of life Jodie might otherwise enjoy. Even in respect of Jodie's prognosis, the best interests calculus did not provide a clear cut answer for the court, because opinions differed as to the degree of likely post-separation disability Jodie would suffer. It seems to have been accepted by the judges that, if some possibilities materialised, she would be subjected to prolonged and burdensome interventions, perhaps requiring indefinite separation from her family. In this context, it should be noted that the common law, at least in England, does not require parents to consent to burdensome treatment for their children, even if that treatment is necessary to save the child's life.

Furthermore, the finding that surgery would not be in Mary's best interests was a problem because, as Ward LJ pointed out, the proposed treatment had to be in the best interests of a child before a parent's decision to refuse it could be overridden by the state. Ward LJ described in detail the basis on which the proposed separation would be likely to benefit Jodie, but could not find a benefit for Mary. He held that, like

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705 See, for example, Airedale NHS Trust v Bland [1993] AC 789, 795 (Lord Keith of Kinkel).
706 Re T (A Minor) (Wardship: Medical Treatment) [1997] 1 All ER 906; see also Annas, 2001, 1108.
708 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 998.
Anthony Bland,\textsuperscript{709} Mary had no best interests.\textsuperscript{710} Brooke LJ took the same position.\textsuperscript{711} It was only Robert Walker LJ who found that separation was in the best interests of both.\textsuperscript{712} Because the other two judges were unable to find that separation would be in the best interests of both girls, some other principle had to be found by them to justify saving one life at the expense of another, that was perceived to be of poor quality, and doomed to death in any event.

\textit{(ii) Was there a defence, justification or excuse?}

The central legal difficulty of the case was that the inevitable consequence of separation would be Mary’s almost instantaneous death. Each judge was satisfied that the elements of murder would be made out on the facts. They were therefore forced to determine whether there was a defence, justification or excuse that could render the conduct lawful. It is in the consideration of this aspect of the case that the influence of the preservation of life and protective values is most evident.

The judges considered a range of possibilities before each reaching the conclusion that the conduct would be lawful. Among the possibilities dismissed by each was the argument that the act of separation could be characterised as an omission, rather than a commission.\textsuperscript{713} Ward and Brooke LJJ also rejected the argument that the principle of double effect\textsuperscript{714} was applicable, although Robert Walker LJ seemed to apply it, holding that Mary would not be intentionally killed and that the purpose of the operation was not to kill her but to provide her and Jodie with ‘separateness’. He further held that Mary would die not from the surgery, but because she was not viable.\textsuperscript{715}

\footnotesize{\textsuperscript{709} See \textit{Airedale NHS Trust v Bland} [1993] AC 789, 897 (Lord Mustill).

\textsuperscript{710} \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 998, 1004; see also 1057 (Robert Walker LJ).

\textsuperscript{711} \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 1030.

\textsuperscript{712} \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 1070.


\textsuperscript{714} \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 1012 (Ward LJ), 1030 (Brooke LJ).

\textsuperscript{715} \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 1070. Ward and Brooke LJJ held that the principle of double effect had no application to the facts: \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 1012, 1030. For a discussion of the application of the principle to the separation of conjoined twins, see Sheldon and Wilkinson, 1997, 160ff.}
Self-defence and the idea of an unjust aggressor

Ward LJ found the basis for lawfulness of the proposed operation in a concept of quasi self-defence, modified to apply to the specific circumstances of the case. He rejected the language of ‘unjust aggressor’, as did Robert Walker LJ. The term ‘unjust aggressor’ has been used, in relation to conjoined twins, to describe the perception that the weaker twin is ‘dragging the other down to death’, and ‘unjustly’ requiring the sacrifice of the life of the stronger twin. Thomasma et al trace the use of such language back to early Christian positions on the permissibility of war and capital punishment. Such language makes clear the underlying problem: that here are two personal interests in stark conflict. The challenge for the Court was to resolve, or otherwise get around, the conflict. It did so, I suggest, by implicitly using harm prevention to underpin each judgment. Each judgment, whichever legal device it purports to employ to justify the separation of the twins, is predicated on the idea that it is better to try and save the salvageable life, even at the expense of shortening the life of the less viable twin, than to allow both twins to die together. This is harm prevention at its plainest.

The argument based on quasi self-defence is put using a range of analogies; Brooke LJ had recourse to such well-known analogies as the corporal and the Zeebrugge ferry and the pilotless aircraft. In the Zeebrugge ferry situation, there was an accident in which passengers were thrown into the water. The only way to safety was up a rope ladder, and that route was blocked by a young man who was immobilised by cold or fear or both. An army corporal, who was one of the people whose route was blocked, pulled the young man off the ladder, allowing the others to reach safety. The story of the pilotless aircraft postulates action to bring down a pilotless aircraft in an unpopulated field, killing the passengers (who are doomed to die anyway), but avoiding the additional deaths that would result if the plane crashed in a populated area.

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716 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1017.
719 Thomasma et al, 1996, 8.
720 Thomasma et al, 1996, 8.
Although Robert Walker LJ also refers to these and other well-known analogies, he suggests that there are no useful analogies to be drawn, and that the situation faced by the Court of Appeal was unique. Robert Walker LJ may have been correct that analogies are not helpful; certainly, the ones employed by the judges here are not comparable to the situation of Mary and Jodie. The analogies referred to by the judges, including the Zeebrugge ferry and the pilotless aircraft, were situations of extreme urgency, in which a split second decision had to be made. Under these circumstances, it is understandable to me that justifications be sought somehow to exculpate those who were reacting to exigent circumstances to save their lives and the lives of others. Most people would, I think, be very reluctant to condemn their actions; there must always be a ‘there but for the grace of God go I’ feeling in making such judgements. The proposed separation surgery did not carry the same urgency. Moreover, there was an alternative course of action that would have been accepted as beyond criticism by a responsible body of medical opinion and even apparently by the Court.

Although the Court of Appeal judges rejected the language of ‘unjust aggressor’, I suggest that they nevertheless treated Mary as such, in their depiction of her using emotive and pejorative terms, which characterised her as being ‘positively culpable’. Furthermore, Ward LJ speaks of the need to strike a balance that achieves fairness and justice between the children. On the basis that he believes Mary had ‘little right to be alive’, and was ‘killing Jodie’, he strikes that balance in Jodie’s favour. The remarks that Ward LJ makes about achieving fairness and justice as between the children confers an adversarial character on the relationship which echoes the language of maternal/foetal ‘conflict’ discussed later in this Chapter. Recourse to such adversarial characterisations and language demonstrates the difficulty that the law, and

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723 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1066.
725 Hewson, 2001, 294.
726 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1010.
727 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1010.
729 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1011.
730 See paragraph 5.2.3 (b).
other normative systems, seem to face in defining the interests of, and duties owed to, beings who are not physically separate. Nevertheless, in light of such characterisation by Ward LJ, it is unsurprising that the judge should have been able to find that a justification for the proposed surgery was to defend Jodie against Mary’s ‘parasitism’, if not actual attack. This analysis is unsatisfactory. As Robert Walker LJ points out, when cautioning against overstating the possibility that the treatment could be justified as defensive of Jodie, it is ‘absurd’ to depict Mary as an unjust aggressor, expressly or by implication.\textsuperscript{731}

Designated for death

Finally, Ward LJ takes the view that, in any event, Mary is designated by nature for death\textsuperscript{732} because of her congenital disabilities. This contributes to his finding that allowing her life to be foreshortened by the proposed treatment is fair as between the children, and the lesser of two evils, as is discussed below. However, a different view could have been taken: that both Mary and Jodie were, because of the manner of their conjointure, destined for death. The view taken by Ward LJ seems to lead to a weighing of the preservation of life value as it applies to each twin, and the relative merits of extending the protection of that value to each.\textsuperscript{733} The balance was held to favour intervention to preserve and prolong Jodie’s life.

Necessity

The judgment of Brooke LJ focuses mainly on the criminal law aspect of the case. In particular, the judge provides a detailed exposition of the history of the doctrine of necessity as a defence, examining common law and policy developments, and noting the regrettable lack of legislative clarification of the elements, and availability, of the defence. Critically, Brooke LJ notes that in 1999, the Court of Appeal held that the defence of necessity is not available for crimes such as murder, attempted murder and

\textsuperscript{731} Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1067.

\textsuperscript{732} Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1010. This is a view shared by Brooke LJ: Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1051. See Annas, 2001, 1107, for criticism of the ‘destined for death’ argument.

\textsuperscript{733} See Hewson, 2001, for the argument that the judges’ decisions were about the relative merit of each child.
some treason offences. However, after considering the policy reasons underlying this limitation, Brooke LJ nevertheless makes the defence available to the doctors at St Mary’s.

The first policy reason considered by Brooke LJ is that the defence of necessity is not traditionally available in response to a charge of murder because it raises the question of who should be judge of whether it is necessary that a life be taken. The force of this objection can be seen in cases such as *R v Dudley and Stephens*. In that historic case, some shipwrecked sailors, in a lifeboat and running desperately short of food and water, killed the youngest and weakest among them so that they could live off his body until rescue arrived. Their deliberate choice of the ship’s boy was considered objectionable. It seems that the survivors (who were later rescued and tried for murder) may have escaped conviction had their choice been random; for example, had it been arrived at by the drawing of lots. In *Re A*, Brooke LJ (and possibly Ward LJ) seem to have answered this concern – that a killer may not be the arbiter of his or her own ‘necessity’ to kill – by taking the view that Mary was destined by nature, or even (bizarrely) ‘self-designated’, for death. In effect, there was the view that the choice had already been made for Mary, and not by the agency of the doctors or the judges.

A second policy objection to the availability of the defence of necessity is the difficulty of identifying a measure for the comparative value of lives. In *Dudley and Stephens*, the measure seems to have been the weakness and illness of the ship’s boy; a measure not so far removed from that employed to determine that Mary had ‘little right to be alive’. However, Ward LJ noted that the relevant question was not the merits of the

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736 *R v Dudley and Stephens* (1884) 14 QBD 273.
740 *R v Dudley and Stephens* (1884) 14 QBD 273.
lives in question, but of the proposed treatment.\textsuperscript{742} For Mary, there was no available treatment that would be worthwhile, whereas there was a range of options for Jodie that, once she was successfully separated, were thought to be likely to secure for her a relatively normal life.

Finally, Brooke LJ notes the policy objection that the availability of a defence of necessity to a charge of murder would ‘mark an absolute divorce of law from morality.’\textsuperscript{743} The judge responds to this by saying that ‘it is not at all obvious that this is the sort of case...marking an absolute divorce from law and morality.’\textsuperscript{744} Certainly, the facts of this case do not, I think, lend themselves to a decision that either course of action would be morally repugnant or morally right, beyond all doubt. This was acknowledged by the Court.\textsuperscript{745}

On the basis that Brooke LJ considers these policy objections not to apply in this ‘exceptionally rare event,’\textsuperscript{746} the judge accepts that the elements of an applicable necessity defence are present. These are that:

(i) the act is needed to avoid inevitable and irreparable evil; (ii) no more should be done than is reasonably necessary for the purpose to be achieved; and (iii) the evil inflicted must not be disproportionate to the evil avoided.\textsuperscript{747}

Some comment should be made on the application of these elements to \textit{Re A}.\textsuperscript{748} First, it is evident that both Ward and Brooke LJJ took the view that the imminent death of two children, when the life of one could be prolonged, was an ‘evil’. Certainly, the death of both children without separation was accepted by all parties to be inevitable, and it would clearly be irreparable. Moreover, the judges took the view that there was proportionality between the consequence of the proposed act (the death of one child) and the consequences of failing to perform that act (the death of both children).

\textsuperscript{742} \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 1010.
\textsuperscript{743} \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 1051.
\textsuperscript{744} \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 1051.
\textsuperscript{746} \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 1051.
\textsuperscript{747} \textit{Re A (children) (conjoined twins: surgical separation)} [2000] 4 All ER 961, 1052.
However, it is equally clear that the parents took the view that sacrificing one twin to prolong the life of the other was an even greater evil than allowing their daughters to die together, and that the preservation of life value required that both should live as long as possible. This is the nub of the dispute between the parents, the Church and St Mary’s. A further comment can be made about the second and third of these elements. They relate closely to criteria for state intervention described at section 4.3. How those criteria apply in these circumstances is considered in Chapter 6.

An alternative construct of necessity: a necessary choice between two evils

Another way in which Ward LJ justifies his decision is by referring to it as a necessary choice between the ‘lesser of two evils’.

By implication, through his use of the ‘Sophie’s choice’ metaphor, he criticises Mr and Mrs Attard for having failed to make that choice. Drawing awkwardly on the story in which a woman is forced by Nazis to choose which of her children will be executed, he echoes the findings of necessity made by Brooke LJ. Ward LJ held that the central problem was an irreconcilable conflict of duties owed by the doctors to Mary and to Jodie. In responding to that problem, Ward LJ held that the doctors at St Mary’s had to be allowed an escape route, and referred to the need to allow doctors ‘freedom of choice’. The tenor of these statements, like the application of the doctrine of necessity by Brooke LJ, assumes that there was no reasonable alternative but to operate, and that it was the task of the Court to find a way to justify that course of action, and so protect the doctors from criminal and civil liability.

Yet there was, as Ward LJ himself acknowledged, an alternative that the law would not have criticised. The choice in favour of surgery was not ‘necessary’; Ward LJ at least would not have criticised St Mary’s for respecting the Attards’ decision. But there

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748 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961.
750 See also the judgment of Robert Walker LJ: Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1065.
751 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1015-1016. Chesterman J seems to have taken the view that the doctors in Nolan were faced with a similar conflict: State of Queensland v Nolan and Anor [2001] QSC 174 (31 May 2001).
752 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1015.
was nevertheless a strong feeling among the judges that the choice was necessary. That was because of the way in which the preservation of life value was interpreted, and the reliance on the idea of harm prevention to uphold that value and thus protect Jodie’s personal interest.

The Attards, backed by their Church, took the view that the preservation (or sanctity) of life value prohibited the sacrifice of one life for the purpose of prolonging another. They, too, had weighed the alternatives in the balance and had struck that balance in favour of letting the twins live as long as they could, together, rather than sacrificing Mary. Their stated reasons for choosing this course of action were diverse. They included their family’s religious beliefs, as well as concerns about Jodie’s likely level of disability following separation surgery (although the Court of Appeal found that their concerns were based on rather pessimistic predictions). The Attards were worried that the paucity of facilities and resources on Malta would mean that Jodie would be separated from them for indefinite periods to undergo treatment.

The judges, on the other hand, felt strongly that the preservation of life value required life to be saved where medical science and technology meant that there was a good possibility that it could be saved. Ward and Brooke LJJ accepted that the preservation of life value required them to accept that Mary’s life was of equal worth to that of Jodie.

The judges interpreted the preservation of life value as requiring action to prolong life where it was possible to do so, where there was a ‘right to be alive’, and where failure to act would result in the loss of both lives, and thus inflict greater harm than sanctioning an act that would end the life of the less twin, prematurely. Ward LJ’s idea that he and the doctors were faced with a ‘Sophie’s choice’, which he believed that the parents had declined to confront, can only have been driven by the view that letting both children

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754 See Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1068, for an outline of the submissions made by the Archbishop of Westminster.

755 See also Ashley and O’Rourke, 1997, 256, for discussion of the Roman Catholic prohibition against the ‘killing of one person as a means of therapy for another’.


758 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1009.
die was an untenable solution. The technological imperative, the deference to clinical values in preference to the values adhered to by the childrens’ parents and, above all, the idea of harm prevention, weighed the balance heavily in favour of findings that the proposed surgery was lawful.

In holding that the doctors had to be provided with an escape route and with freedom of choice, Ward LJ was both medicalising the decision-maker (because, by being given the freedom of choice, the doctors became the de facto decision-makers whose decision the Court simply rationalised in legal terms) and the decision-making process. The need for an escape route for doctors is predicated on the assumption that the preservation of life value only had one acceptable manner of implementation. While repudiating the view that the Attards were driven by an idiosyncratic set of religious values, and despite emphatic assertions of sympathy with the parents’ situation, the use of the ‘Sophie’s choice’ analogy, and the remarks to the effect that the consequences of the parents’ course of action would be to kill Jodie, show little sympathy with the parents’ values. The approach taken by Ward LJ also gives little weight to the principle that parents are not always required to consent to burdensome treatment for children, if the treatment is not in the best interests of the child.

**Is Re A about necessity or about chance?**

The problem with the finding by Brooke LJ of the availability of a defence of necessity, and by Ward LJ of a necessary choice favouring the lesser of two evils, is that there was no real necessity, because another alternative, acceptable to the Court, was reasonably

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765 *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 All ER 906; see also Annas, 2001, 1108. For the weight to be given to parents’ views about best interests in borderline cases, see *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 All ER 906, 911 (Butler-Sloss LJ), 918 (Waite LJ). Here, the evidence was not beyond doubt that separation would be in even Jodie’s best interests.
available.\textsuperscript{766} Had the children been born at, or transported to, another hospital such as Great Ormond Street, the case may never have come to court. The presence of the Attard family before the Court of Appeal was a matter of chance: the staff at one particular hospital did not support the decision made by the parents.\textsuperscript{767} This was not a case of the kind described by Butler-Sloss LJ in \textit{In re S (Adult Patient: Sterilisation)},\textsuperscript{768} in which there were two lawful options for the judge to choose between, only one of which could satisfy the best interests test. Here, the best interests test could not provide an answer, because of Mary’s situation, and the uncertainty surrounding Jodie’s prognosis.

In this case, the Attard family were subjected to an unfortunate lottery, created by the unwillingness of the medical staff to uphold the Attards’ decision as to what was best. Had the Attards been sent to another hospital, they need not have undergone the traumas of litigation. As it was, their ability to act as substitute decision-makers was thwarted by the fact that the staff at the hospital to which they were sent held a particular view about separation, and were prepared to go to court to enforce that view. While particularly dramatic, the Attards’ situation is not unusual in this regard. Not all patients get to choose their own doctors, after all, and so may be unable to ‘doctor shop’ for one who is sympathetic to their values and priorities. In this case, the apparent willingness of Ward LJ to accept either possible outcome as correct (a hospital providing supportive care only until both twins died, or a hospital acting to separate the twins) confers on the particular hospital and doctors the role of \textit{de facto} decision-makers, able to implement their own interpretation of what the preservation of life value (and what the children’s competing personal interests) require.\textsuperscript{769} This ability is enhanced by the likelihood that many patients and substitute decision-makers, if faced with the fact that their health care providers disagree with their views and are willing to go to court to uphold the clinically-defined view, will choose not to contest the matter.

\textsuperscript{766} Hewson, 2001, especially 288, 293, 296, 298. See also Lugosi, 2001, 160-1, criticising the application of the necessity doctrine to these facts.

\textsuperscript{767} Hewson, 2001, 293. See also Annas, 2001, 1108.

\textsuperscript{768} \textit{In re S (Adult Patient: Sterilisation)} [2000] 3 WLR 1288, 1299.

\textsuperscript{769} Annas, 2001, 1108.
Future uncertainty

A significant difficulty arising from this case is its lack of guidance for future cases of this kind, which leaves everyone – hospitals, health care professionals and parents – in a state of uncertainty. Indeed, the concession apparently made by Ward LJ (that either course of action would have been acceptable) can give little basis for confidently relying, in analogous circumstances (such as the Nolan case)\(^{770}\) on any legal principle set forth in his judgment. This is unfortunate, because similar cases will recur; increasingly sophisticated medical technology means that more such twins will survive birth (as did Bethany and Alyssa Nolan). The only thing that can be said with confidence is that doctors would be wise, before undertaking separation procedures in analogous circumstances, to seek approval of the court, as was done in Nolan\(^{771}\). The courts will then make decisions on a case-by-case basis. If the decision in Nolan\(^{772}\) is a guide, then it seems unlikely that an Australian court would depart from the interpretation of the preservation of life value, and the determination to pursue a policy of harm prevention, that was applied in Re A\(^{773}\).

Difficulties might also arise in less clear cut circumstances. It is undeniable that the judgment of the Court of Appeal has a strong emotional, as well as utilitarian, appeal. The idea of intervening to preserve a life where both lives might otherwise be lost is compelling. In this case, the facts were as unambiguous as is likely to occur with conjoined twins: the Court found that the children could not survive, conjoined, for more than a few months. There was credible evidence that, if separated, Jodie could hope for a long and relatively healthy life. There was no doubt that Mary would die during separation surgery.

But it is easy to imagine cases which would be more ambiguous, and which may cause a court considerably more distress even than the Court of Appeal experienced in Re A\(^{774}\). For example, imagine a pair of conjoined twins who have survived into at least late

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\(^{771}\) Although Ward LJ did not endorse a suggestion that the hospital was obliged to seek a resolution in the court: Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 987.


\(^{774}\) Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961.
adolescence and who are Gillick-competent. Imagine one suffers a health crisis (such as cardiomyopathy) and becomes dependent on the other for a particular organ function, but is still able to articulate his or her views and opinions. What if the healthy twin cannot physically sustain both bodies, to separate the twins means the death of the stricken twin, and that twin refuses separation? This thesis cannot predict what a court would do if faced with such a situation although, as will be seen later in this Chapter, courts have refused to compel adults with decision-making capacity to undergo surgery to save another.

The quasi self-defence and necessity avenues explored by Ward and Brooke LJ in Re A would seem to be applicable, as does the underlying interpretation of the preservation of life value to further the harm prevention policy: that it is better to prolong one life, while sacrificing another, than to lose two lives. Furthermore, although Ward LJ explicitly sought to limit the terms of the quasi self-defence principle to the narrow facts of the case, conjoined twins who share common organs and structures might attract similar ‘debt-based’ language as the judge applied to Mary. Nevertheless, it is hard to imagine any court welcoming the prospect of declaring that a separation would be lawful in circumstances in which it would inevitably cause the death of an adult with decision-making capacity who had refused intervention. Similarly, it is unclear what a court would do in a case similar to that of the Bijanis, if one twin decided against separation. It may seem unlikely that a court would order a person, whether conjoined or not, to undergo high-risk elective surgery against her will.

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775 See Gillick v West Norfolk AHA [1986] AC 112, accepted as persuasive in Secretary, Department of Health and Community Service (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218, 237 (joint judgment).


779 This thesis makes no prediction about the psychological likelihood of conjoined twins taking these positions. Certainly, history (including the Maids of Biddenden in the twelfth century and the celebrated ‘Siamese twins’, Chang and Eng Bunker, in the twentieth century) indicates a willingness to die with one’s conjoined twin.

780 There were allegations, made by the twins’ step father and reported in the media, that Laleh Bijani had wanted to change her mind: see, for example, Eddie Fitzmaurice, ‘Twins were duped claims grieving dad’ 13 July 2003, http://www.smh.com.au/articles/2003/07/12/1047979650355.html.

781 Not even the coercive obstetric intervention cases in England and the United States require such sacrifice; see subparagraph 5.2.3 (c) (ii).
Alternatively, a possible answer (although certainly not a happy one) is for the court to authorise separation on the basis of the dependency between the twins. For example, if Twin A becomes ill, so that he or she is dependent on Twin B in such a way that Twin B’s life is seriously and imminently at risk. Then, it would be understandable for a court to hold that, because Twin A will die in any event once Twin B dies, and is thus wholly dependent on Twin B, it is justifiable to foreshorten Twin A’s life. Such an argument relies on a harm prevention policy, choosing what may be characterised as a lesser harm over a greater. This is, in plain language, what happened to Mary and Jodie. I do not say that this is a satisfying solution. I am simply pointing to this as a clearer, more transparent and more direct way of applying the harm prevention principle in these dreadful cases, and thus providing a more solid foundation for future development of the law.

The point of identifying this discussion is to illustrate the limits of the law – and perhaps of any normative system – in dealing with the extremely difficult issues raised by beings who are not physically separate and who have competing personal interests. As it was, it appears that the judges in Re A782 and in Nolan783 made decisions based on their interpretations of the preservation of life and protective values, and the weight of the medical evidence, and reasoned backwards from that to a finding that separation would be lawful.784 However, in cases where there is a reasonable and legitimate scope for a ‘difference of opinion’, where there is no question of abuse or neglect by the parents,785 and where values other than clinical values are so plainly relevant to decision-making, then the court should perhaps not interfere with the exercise of the parents’ decision-making responsibility as usual substitute decision-makers.

(iii) Role of preservation of life and protective values

The preservation of life and protective values, and how to prevent harm by upholding those values, were at the core of Re A.786 Both sides of the dispute relied on these values

784 See Annas, 2001, 1104; Lugosi, 2001, 158. See also Thomasma et al, 1996, 9, discussing the separation of the Lakeberg twins.
785 See Annas, 2001, 1104, suggesting this would be the only basis for court intervention in such a case.
786 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961.
to advance their cases. The key to the decision was that, unlike the earlier American conjoined twins Amy and Angela Lakeberg, the proposed surgery was likely to achieve a favourable result for at least one of the twins. If Jodie’s prospects had been gloomier, then her parents’ wishes may have been respected. As it was, there was a perception, based on an interpretation of the preservation of life value, that the surgery was therapeutically necessary to prolong a life. The perceived therapeutic necessity, combined with the inevitable loss of two lives if nothing were done, proved an irresistible influence over the Court of Appeal in holding not merely that the proposed separation was lawful, but that it was necessary and should be done.

I am not persuaded by the reasoning as explained in the judgments. However, I suggest that the ultimate decision of the Court of Appeal was explicable (and should have been so explained by the judges) by a policy of harm prevention and protection of the personal interest of the more viable twin, on whom the weaker twin was, in any event, dependent. Ward, Brooke and Robert Walker LJJ in Re A should have focused on harm prevention as the policy underlying their judgments, rather than contorting concepts such as self-defence, necessity and best interests to achieve what was, admittedly, an understandable objective: to save the stronger twin. As it is, the judgments provide a weak and confused guidance for future development of the law in similar and analogous situations.

5.2.3 The preservation of life value and intervention to save a foetus

The state has assumed the role of decision-maker in doctor-patient relationships to preserve the lives of foetuses. Examples of such intervention include the regulation of abortion, irrespective of the wishes of competent patients, and the performance of coercive obstetric interventions, irrespective of whether or not the patient (that is, the woman) consents. In authorising such intervention, the state becomes the decision-maker, displacing the patient’s entitlement to decide. In determining the bases on which such intervention occurs, it is necessary to consider three issues: the status of the foetus as a ‘third party’ whose personal interest may be in competition with that of

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787 Thomassa believes that the separation of Amy and Angela Lakeberg was futile, and should not have been attempted: Thomassa et al, 1996.


789 For the purposes of this Chapter, ‘foetus’ will include ‘embryo’, as in Seymour, 2000.
the patient, the relationship of the foetus to its mother, and how the state exercises its decision-making role.

(a) Is the foetus a third party for the purposes of this thesis?

Seymour has argued that consideration of the status of the foetus, per se, is unhelpful, and that the focus of analysis should be on the context in which foetal interests are sought to be protected.\(^{90}\) This Chapter considers the status of the foetus, however, for the purpose of identifying interests, other than interests belonging to patients, that are relevant to state intervention in decision-making in the doctor-patient relationship.

The law has accorded the foetus status as a third party.\(^{791}\) This is despite longstanding and widespread controversy over its moral personhood,\(^{792}\) and repeated assertions in England and Australia that legal personhood (and the crystallisation of contingent rights in areas such as tort and succession law) is achieved only upon live birth.\(^{793}\) In a range of cases, Anglo-Australian courts have held that a child in utero has no legal standing.\(^{794}\) The position in the United States is more complex, because of its constitutional arrangements. However, even when asserting the ‘compelling interest’ of preservation of life in respect of a viable foetus, to regulate or proscribe late term

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\(^{90}\) See Seymour, 2000, Chapter 8.

\(^{791}\) That is, a foetus is not a ‘legal non-entity’: see Seymour, 2000, 145.


\(^{793}\) See Seymour Report, 1995, 43-4. See also Johnsen, 1986, 601-3 and Finer, 1991, 247-9, for the development of recognition of contingent rights of the foetus in the United States. For Australian cases on the crystallisation of rights on live birth, see, for example, Watt v Rama [1972] VR 353 and X and Y v Pal and Ors (1991) 23 NSWLR 26. For a Canadian example of such an approach, see Cherry v Borsman (1991) 75 DLR (4th) 688, affirmed (1992) 94 DLR (4th) 488, especially 504-5. However, recent legislation about harming foetuses in the course of assaulting pregnant women may confer on foetuses the status of legal persons: see, for example, Russell, 2004.

\(^{794}\) See, for example, Paton v British Pregnancy Advisory Services Trustees and Anor (1979) QB 276 and Paton v United Kingdom (1980) 3 EHRR 408; K v Minister for Youth and Community Services; Re Infant “K” (1982) 8 Fam LR 250; K v T [1983] 1 QdR 396; Attorney-General (Qld) (Ex Rel Kerr) and Anor v T (1983) 57 ALJR 285; In re F (in utero) [1988] Fam 122; C v S and Anor [1988] 1 QB 135; In the Marriage of F (1989) 13 Fam LR 189; Burion v Islington Health Authority; De Martell v Merton and Sutton Health Authority [1993] QB 204; Re MB (Medical Treatment) [1997] 2 FLR 426. For Canadian examples of this approach, see Re A (in utero) (1990) 72 DLR (4th) 722, 728; Re Baby R (1988) 53 DLR (4th) 69, 77, approved in Tremblay v Daigle (1989) DLR (4th) 634, 663. A different view seems to have been taken in In the Matter of Baby P (An Unborn Child) [1995] NZFLR 577: see Scott, 2002, 148. There, it was held that the protection of relevant child welfare legislation extended to unborn children. However, a foetus has been held to be part of a single entity with its mother for the purposes of a New Zealand statutory compensation scheme, allowing the mother to recover damages: Harrild v Director of Proceedings (CA 92/02, 25 June 2003), discussed in Morris, 2004.
abortions under the decision in *Roe v Wade*, the state seems generally to be asserting its own interest in the preservation of life, rather than necessarily to be acting on behalf of a being with its own interests.

In any event, this section will show that, in acting to advance the preservation of life and protective values, the state is in fact treating the foetus as a being worthy of its protection. For example, in the United States, the foetus has been considered to be an appropriate subject for the exercise of both the common law *parens patriae* jurisdiction, and some statutory wardship or child welfare jurisdictions. The position is less clear in England, where the Court of Appeal refused to exercise its wardship jurisdiction in respect of the unborn child of a woman who was mentally ill. However, the authorisation, by English courts, of the performance of caesarean sections where the woman refuses such intervention, indicates a willingness to protect the life of the foetus as a third party, irrespective of its lack of legal personhood.

(b) Relationship of foetus with mother

One writer has remarked that there is a ‘cottage industry’ of commentary on the maternal/foetal relationship. It is not the purpose of this Chapter to add to that ‘industry’, nor to add in a general sense to the important body of specifically feminist scholarship in this area, but rather to comment specifically on how the entitlement to decide, belonging to pregnant women with decision-making capacity, has been

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796 But there are suggestions to the contrary: see, for example, *Re Fetus Brown* 689 NE.2d 397, 402.

797 See, for example, *In re Madyun*, reported at the Appendix to the judgment in *In re AC* 573 A.2d 1235 (1990), at 1259; *In the Matter of the Application of Jamaica Hospital* 491 NYS.2d 898 (1985). See also Cherry, 2002, 597-600; Haberfield, 1995, 20-2, 35-7.

798 Seymour Report, 1995, 87; Chapter 7. See also Seymour, 2000, 9-12, where Seymour also examines Canadian cases and legislation which have treated the foetus as meriting the protection of the law.


801 *Oberman*, 2000, 452. This Chapter only deals with women refusing medical treatment; it does not deal with other forms of maternal conduct that may harm the foetus, such as use of alcohol or illicit drugs, or smoking.

802 Although I have drawn from writers such as McLean, Purdy, Cherry, Oberman and Scott, and am indebted to their views on the issues raised in this section of the thesis.
displaced for the benefit of the foetus as a third party whose interests may be perceived to compete with those of their mothers. To comment meaningfully on this displacement, it is necessary to identify the three principal models that have been used to describe how the law should characterise the maternal/foetal relationship. Such identification has been performed by commentators such as Seymour, whose analysis is relied upon for the purposes of this Chapter.803

The first of the models804 describes the foetus as part of the woman’s body, much in the nature of an organ such as the liver or gall bladder. Seymour acknowledges the superficial appeal that this model has for supporters of women’s rights to make decisions about treatment throughout pregnancy, but argues that this model secures maternal autonomy at too high a price.805 Seymour does not favour this model for a number of reasons, including that he does not believe that it reflects the physiological facts,806 or how women experience pregnancy, that it is an oversimplification of a complex relationship, and that it is inadequate to address the legal problems that have arisen in relation to the maternal/foetal relationship.807 Moreover, Seymour points out that acceptance of this model would be inconsistent with the established legal position that while a foetus is not a legal person, it nevertheless is a being that merits the law’s protection. This is because the first model goes further than denying legal personhood to the foetus; such a model would disallow any possibility of the state acting to advance values (such as the preservation of life and protective values) in relation to the foetus, in contexts in which the law has expressed a willingness to protect foetal life.808

The second model809 describes the foetus as an entity separate from its mother. According to this model, both mother and foetus have legal personhood; unsurprisingly, this model creates the greatest potential for perceiving the maternal/foetal relationship

805 Seymour, 2000, 193.
806 See Seymour, 2000, 191.
808 See Seymour, 2000, 193.
as adversarial. The unfortunate outcome of conflicts of interest, which arise from adversarial relationships, is that there must be a ‘winner’ and a ‘loser’. Seymour, together with McLean and Petersen, argues that doctors have advocated this model, and have implemented it by according the foetus status as a separate ‘patient’ to be treated. Seymour highlights the role of clinical values in according the foetus separate status, suggesting that ‘the separate-entities model is a peculiarly medical perception of the relationship.’ He also notes the influence of technology in the identification and treatment of the foetus as a separate patient. The separate entities model is rejected by Seymour. A principal reason for his rejection is that he notes that ‘The more the individuality of the foetus is stressed, the less the individuality of the woman is recognized’. As recognition of the woman diminishes, she becomes perceived as a ‘container, incubator or life-support machine’. Like the ‘body part’ model, Seymour rejects this second model as a distortion and an oversimplification of pregnancy, as well as lending itself to the perpetuation of an unhelpful perception of conflict. He observes that this model, too, would require a departure from case law that has traditionally denied legal personhood to foetuses, at least in the context of the pregnant patient’s refusal of medical treatment.

The model that Seymour favours is the ‘indivisibly linked model’, based on the concept, articulated by Karpin, that the maternal/foetal relationship is best described in terms of

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810 See Seymour, 2000, 194.
812 Seymour Report, 1995, 50; McLean and Petersen, 1996, 233-4. Scott seems to suggest that there is a conflict between maternal and foetal interests: see Scott, 2002, 178, note 325.
813 Seymour Report, 1995, 50. See also Seymour, 2000, 196.
816 Seymour Report, 1995, 51; see also 52 and Seymour, 2000, 195.
819 Although the ‘separate entities’ model may have played some role in cases relating to antenatal negligence: see Seymour, 2000, 198-9.
'Not-One-But-Not-Two'.  While accepting that this third model is difficult to explain, he argues that it

... avoids the objectionable features of a model built on separate entities with conflicting rights, while at the same time allowing for a foetus to be treated as having some interests which the law can protect.

Moreover, Seymour argues that it better accommodates the realities of the maternal/foetal relationship, with its ability to recognise both foetal and maternal interests and to take into account the entire context in which foetal interests are sought, by some, to be protected. In addition, under the version of this model accepted by Seymour (in which the foetus has rights against third parties who harm it, but not against its mother), the woman's entitlement to decide is given precedence, so that the pregnant woman decides what the foetus' interests are and 'whether they will be protected'. Seymour favours this model because he believes it is more nuanced, better able to accommodate the experiences and perceptions of pregnancy held by both pregnant women and the 'outside world', and more consistent with existing judicial authority. Significantly, Seymour's third model allows a foetus to be a 'third party' for the purposes of this Chapter, in respect of whom the preservation of life and protective values have influenced the state to assume a decision-making role, and who may be perceived, within the terms advanced by this thesis, as having a personal interest along the lines of that enjoyed by Anthony Bland or Baby J.

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821 See Seymour, 2000, 190.
823 See Seymour, 2000, 199-200.
826 An alternative third model, depending on drawing a 'distinction between de jure unity but de facto separateness' is described in Scott, 2002, especially 176.
(c) How the state exercises its decision-making role

(i) Abortion: what parties and values are being protected?

Three questions arise in relation to how the state exercises its decision-making role in relation to abortion: first, who is the relevant third party; second, on the basis of which values does the state act to protect the third party; and, third, how the state exercises its decision-making role in this context.

Who is the relevant third party?

Abortion is an example of state intervention to regulate decision-making on a case-by-case basis. Intervention occurs principally in reliance on the preservation of life and protective values as they relate to the foetus. In the United States, for example, it has been accepted since Roe v Wade that, after a certain point in pregnancy, the state’s interest in preserving potential life becomes sufficiently compelling to outweigh any entitlement to decide belonging to the pregnant woman. Accordingly, the state intervenes to proscribe or regulate late-term abortion on the basis of the preservation of life and protective values. This is consistent with Seymour’s third model which, while denying legal personhood to the foetus, allows its existence to be taken into account when determining whether the state should displace the entitlement to decide of a patient with decision-making capacity. That is, for the purposes of this thesis, harm to a foetus should be (and is) seen as a harm that might be prevented, depending on how the conflict of personal interests is resolved.

Attempts have been made to argue that the fathers of foetuses are third parties whose rights as fathers can be vindicated by an injunction preventing a woman from terminating her pregnancy. Such attempts have been consistently unsuccessful in Anglo-Australian courts.

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827 For a discussion on the application of the sanctity of life value to abortion, see Ronald Dworkin, 1993. See also Seymour, 2000, 171.


829 See, for example, Paton v British Pregnancy Advisory Service Trustees and Anor [1979] QB 276; Paton v United Kingdom (1980) 3 EHRR 408; K v T [1983] 1 QdR 396; Attorney-General (Qld) (Ex Rel Kerr) and Anor v T (1983) 57 ALJR 285; C v S and Anor [1988] 1 QB 135; In the Marriage of F (1989) 13 Fam LR 189 (the judge found that he had jurisdiction to issue an injunction but declined to so exercise his discretion). The issue was expressly left undecided in Roe v Wade 410 US 113 (1973), 165, note 67.
How is abortion regulated? Protected values and the delegation of regulated decision-making to doctors

Displacement of the patient’s entitlement to decide about abortion occurs because the preservation of life and protective values in relation to the foetus influence the state to take control of abortion decision-making, in an effort to prevent harm to a competing personal interest. However, the state balances the preservation of life and protective values that may be seen as protecting foetuses’ personal interests against women’s health and well-being. Where these conflict, the state has favoured the health and well-being of women. Because the focus is on the health and well-being interest, the state has delegated its regulatory function to doctors, as the state’s currently-accepted arbiters of what the health and well-being interest requires in particular cases.

This is evident in the case of Roe v Wade. Often perceived as a case about women’s rights, I think it is more properly characterised as being about doctors’ professional independence. In England, the state delegates its regulation of abortion decision-making to doctors, conferring on doctors a broad discretion to undertake abortions when a woman’s health requires it. Judges have previously indicated reluctance to interfere with this discretion, in the absence of ‘clear bad faith and an obvious attempt to perpetrate a criminal offence.’

For an alternative view, see Finer, 1991, 254, arguing that ‘a mother holds the child, in part, for the equitable benefit of the father.’

830 Whether successfully or not is beyond the scope of this thesis.

831 This has been the case at least since the English case of R v Bourne [1939] 1 KB 687. See McLean, 1999, 77; Scott, 2002, 276-285.

832 For support for the view that Australian abortion law does not recognise a patient’s entitlement to decide, but is medicalised, see Rankin, 2001, 231, 241 and references at note 88; Rankin, 2003, 322 and references at notes 26 and 26. See also, Petersen, in Freckelton and Petersen, 1999, 32-3.


In interpreting and administering the relevant legislative provisions that restrict the availability of abortion, Australian judges have relied on medical opinion about a threat to the health of the patient as being necessary to outweigh the preservation of life and protective values that may be advanced as arguments for preventing harm to the foetus. It is significant that, in this context, judges seem to have extended their understanding of the patient’s ‘health’ to include social and economic considerations, and to include ‘health’ both during and after pregnancy. This may well have resulted in more liberal availability of abortion than is suggested by the language of relevant legislation and, arguably, in greater recognition of the importance of the patient’s personal interest and the entitlement to decide that protects this interest. However, judges have accorded this recognition only indirectly, through the prism of doctors’ perceptions about various aspects of patients’ interests, of which (as is fully argued in Chapter 1) doctors necessarily have only limited understanding. This indicates that, insofar as the availability or otherwise of abortion infringes or upholds the preservation of life and protective values, it does so by a vehicle of judicial decision-making which is heavily medicalised, and recognises the personal interest of the patient only indirectly. As a consequence, the entitlement to decide belonging to the patient is displaced, as the doctor becomes the decision-making delegate of the state.

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836 See: Crimes Act 1900 (NSW), ss 82-4; Criminal Code Act (NT), ss 172-4; Criminal Code (Qld), ss 224-6; Criminal Law Consolidation Act 1935 (SA), ss 81-2A; Criminal Code Act 1924 (Tas), ss 164-5; Crimes Act 1958 (Vic), ss 65-6; Criminal Code (WA), s 199. For the complex position in the Australian Capital Territory, see Rankin, 2003.

837 The last few decades have seen very few prosecutions for abortion. However, the relevant provisions have been judicially interpreted for the purposes of wrongful birth actions. See, for example, CES v Superclinics (Australia) Pty Ltd (1995) 38 NSWLR 47.

838 See, for example, R v Davidson [1969] VR 667, which significantly liberalised the administration of abortion law: see Petersen in Freckelton and Petersen, 1999, 34.


840 Henderson, 1996, 153. For a short discussion about the availability of abortion in Australia, see Petersen in Freckelton and Petersen, 1999.

841 For the origins of the application of medicalised values to abortion decisions, see McLean, 1999, Chapter 4; see also Roe v Wade 410 US 113 (1973), especially 141-6.

Coercive obstetric intervention

This section explores certain instances in which the state has required patients to undergo treatment, regardless of whether or not they consented, primarily to prevent harm to a foetus.\(^{843}\) The kinds of treatment described in this section are caesarean sections and blood transfusions.\(^{844}\) The basis on which these procedures have been required could also apply to other forms of treatment to ensure the well-being and safe delivery of foetuses.\(^{845}\) This section will consider the basis on which coercive obstetric intervention occurs, how that intervention has occurred in the United States, England and Australia, and how intervention fits into the framework of the indivisibly linked model, which recognises the foetus as a third party, eligible for the state’s protection of its competing personal interest.

Intervention on basis of preservation of life and protective values

When a court orders a caesarean, or a blood transfusion for a woman in labour, it is seeking to save the life of the foetus.\(^{846}\) Although such intervention may also save the life of the mother, this is cannot be the basis of the court’s action, because a person with decision-making capacity has the right to refuse even life-saving treatment.\(^{847}\) Thus, the order is made with the intention of saving the life of the unborn child,\(^{848}\) even – on rare occasions – if the child is not yet viable.\(^{849}\) In making such orders, courts (and

\(^{843}\) Although some interventions may also be expected to benefit the patient: see, for example, Jefferson v Griffin Spalding County Hospital Authority 274 SE.2d 457 (1981); Tameside and Glossop Acute Services Trust v CH [1996] 1 FLR.

\(^{844}\) For medical evidence of the benefits of such treatment, see Seymour Report, 1995, Chapter 3.

\(^{845}\) Such as intrauterine foetal treatment: for examples, see Seymour Report, 1995, 23-31. Although, in Taft v Taft 446 NE.2d 935 (1983), the Supreme Judicial Court of Massachusetts declined to order that a woman undergo a cervical cerclage to guard against miscarriage due to an incompetent cervix. For argument that there should be a legal obligation on women to undergo intrauterine foetal therapy, as it ceases to be experimental, see Robertson, 1982.


\(^{847}\) See, for example, In re T (Adult: Refusal of Treatment) [1993] Fam 95; see also Re Bridges [2001] 1 QdR 574. For a contrary view, see State of Queensland v D [2004] 1 QdR 426, a decision made on the basis of preventing harm to both patient and child, although with scant reference to relevant authority that might have provided guidance on the state of jurisprudence on this point.

\(^{848}\) See Seymour Report, 1995, 82; Raleigh Fitkin-Paul Morgan Memorial Hospital v Anderson 201 A.2d 537 (1964), 538 (blood transfusion); Jefferson v Griffin Spalding County Hospital Authority 274 SE.2d 457 (1981), 458, 460 (caesarean section); In re Madyun, reported at the Appendix to the judgment in In re AC 573 A.2d 1235 (1990), at 1259, 1262 (caesarean section). See also Cherry, 2002, 594.

\(^{849}\) See, for example, In the Matter of the Application of Jamaica Hospital 491 NYS.2d 898 (1985) (blood transfusion for pregnant woman at 18 weeks gestation). The Court exercised its parens patriae
commentators) are postulating an exception to the general proposition that there is no
‘duty to rescue’ that requires an adult of decision-making capacity to undergo treatment
for the benefit of another.\(^{850}\)

I suggest that this exception is based on several assumptions. The first assumption on
which this exception is premised is that there is a foetus deserving of rescue.\(^{851}\) The
second assumption on which this exception may be based (particularly in respect of
viable foetuses) is that, if a woman carries a child beyond the point at which an abortion
would be lawful, she has voluntarily assumed a responsibility to take all measures
necessary to ensure the safe delivery of a healthy child.\(^{852}\) Alternatively, (for example,
where the foetus is not yet viable) this exception rests on a rationale that a duty to
rescue has been triggered by the putative ‘rescuer’ having imperilled the individual to
be rescued in the first place. It is thought that, by conceiving a child, this is what a
woman has done.\(^{853}\) The suggestion has been made that pregnancy is a unique state for
these purposes, because it creates a unique and peculiar state of dependency (if not
‘peril’), in which the child is, in effect, ‘captured’ or ‘imprisoned’.\(^{854}\) Finally,
commentators who support coercive obstetric intervention draw analogies with the use
of the state’s coercive powers to authorise infringements of bodily integrity for public
health and public order purposes,\(^{855}\) and private purposes such as involuntary organ
donation by persons without decision-making capacity.\(^{856}\)

jurisdiction. Seymour notes that the question of the status of the foetus is rarely raised explicitly in cases
dealing with coercive obstetric intervention, with the exception of this case: see Seymour, 2000, 175.

\(^{850}\) See, for example, \textit{McFall v Shimp} 10 Pa.D&C.3d 90 (1978); accepted in \textit{In re AC} 573 A.2d 1235

\(^{851}\) McLean and Petersen, 1996, 238.

\(^{852}\) See \textit{In re AC} 573 A.2d 1235 (1990), 1255 (dissent); Haberfield, 1995, 9; Finer, 1991, 253, 258;
Robertson, 1982, 359. See also Seymour, 2000, 10, citing \textit{Re A (in utero)} (1990) 72 DLR (4th) 722, 728;
Scott, 2002, 270-6. For the complexities surrounding the question of whether a pregnancy can be said to
be voluntary, and the implications for duties that may be owed by the woman to the foetus, see Scott,

\(^{853}\) Finer, 1991, 258.

\(^{854}\) \textit{In re AC} 573 A.2d 1235 (1990), 1255 (dissent); Finer, 1991, 263; Witting, 1994, 205-6; Haberfield,
1995, 9-10.

\(^{855}\) See, for example, Robertson, 1982, 354; Finer, 1991, 265.

\(^{856}\) See paragraph 5.2.4 (b). For an argument that choosing not to abort, or voluntarily becoming pregnant,
does not imply that a woman has a duty to consent to any or all treatment proposed for the foetus’ benefit,
see Scott, 2002, 99.
United States approach: weighing compelling state interests against the entitlement to decide

Cases from the United States provide examples of how the preservation of life and protective values are applied to justify the prevention of harm by coercive obstetric intervention. Four state interests have been held to be sufficiently compelling to outweigh the right of the individual to refuse treatment: the preservation of life value, the ‘protection of innocent third parties’, the interest in preventing suicide, and the integrity of the medical profession. Other than the integrity of the medical profession, these interests are based on the preservation of life and protective values described in this thesis, and are aimed at harm prevention. United States authorities favouring coercive obstetric intervention are predicated on the view that the preservation of life of a potential child (in particular, a viable foetus) is a sufficiently compelling state interest to justify interference with constitutionally-protected liberty and privacy interests that underpin the right to refuse medical treatment.

In cases such as Raleigh Fitkin, Jamaica Hospital, Jefferson, and Madyun, those state interests, which are, I suggest, expressions of a harm prevention policy, have been weighed against the entitlement to decide and have prevailed. The significance of these cases to the development of the law about coercive obstetric interventions warrants some consideration of their facts. In the early case of Raleigh Fitkin, a hospital sought the Court’s intervention to allow it to administer blood transfusions to a pregnant woman in her thirty-second week of pregnancy. The woman’s health care providers were concerned that a transfusion might be needed because of a probability that the woman might haemorrhage severely. The woman was refusing the blood transfusions because of her religious beliefs (she was a Jehovah’s Witness). In deciding this case, the Supreme Court of New Jersey referred to its earlier decision in State v

858 Raleigh Fitkin-Paul Morgan Memorial Hospital v Anderson 201 A.2d 537 (1964).
859 In the Matter of the Application of Jamaica Hospital 491 NYS.2d 898 (1985).
860 Jefferson v Griffin Spalding County Hospital Authority 274 SE.2d 457 (1981).
861 In re Madyun, reported at the Appendix to the judgment in In re AC 573 A.2d 1235 (1990), 1259.
862 Raleigh Fitkin-Paul Morgan Memorial Hospital v Anderson 201 A.2d 537 (1964).
Perricone, in which it held that the state’s interest in a child’s welfare justified the state ordering blood transfusions for a child over parental objections. In *Raleigh Fitkin*, the Court held that the state’s interest extended to an unborn child, and was sufficiently compelling to override the patient’s refusal.

*Jamaica Hospital* also concerned the provision of a blood transfusion to a pregnant patient who was objecting on religious grounds (she, too, was a Jehovah’s Witness). Unlike *Raleigh Fitkin*, however, this case concerned a patient whose pregnancy had not yet reached the point of viability; accordingly, the state’s ‘compelling interest’ to prevent harm to the third party foetus should have been regarded as weaker, relative to the interests of the patient. Lonschein J of the Supreme Court, New York, nevertheless held that the state’s interest in the preservation of life was sufficient, in the case of a ‘mid-term’ foetus, to outweigh the patient’s interests. The judge held that this decision was consistent with other authority, including *Raleigh Fitkin* and *Jefferson*.

*Jefferson* and *Madyun* are both cases concerning the performance, over the patient’s objections, of caesarean sections. In *Jefferson*, a hospital sought authorisation for the performance of a caesarean section, and any necessary blood transfusions, if the woman concerned presented herself to hospital (at the time of the application she was an outpatient who had been visiting the hospital for ante-natal care).

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865 *Raleigh Fitkin*-Paul Morgan Memorial Hospital v Anderson 201 A.2d 537 (1964), 538. For criticism of this case as unprincipled and ignoring long-established concepts of self-determination and bodily integrity, see Scott, 2002, 129, 141.
867 *Raleigh Fitkin*-Paul Morgan Memorial Hospital v Anderson 201 A.2d 537 (1964).
869 *In the Matter of the Application of Jamaica Hospital* 491 NYS.2d 898 (1985), 900.
870 *Raleigh Fitkin*-Paul Morgan Memorial Hospital v Anderson 201 A.2d 537 (1964).
871 *Jefferson* v Griffin Spalding County Hospital Authority 274 SE.2d 457 (1981). This is also consistent with the recognition, in *Planned Parenthood of Southeastern Pennsylvania v Casey* 505 US 833 (1992), 846, that the state’s interest in foetal life starts at conception; see also Seymour, 2000, 150, 172.
872 *Jefferson* v Griffin Spalding County Hospital Authority 274 SE.2d 457 (1981).
873 *In re Madyun*, reported at the Appendix to the judgment in *In re AC* 573 A.2d 1235 (1990), 1259.
874 *Jefferson* v Griffin Spalding County Hospital Authority 274 SE.2d 457 (1981).
The hospital’s concern arose because Ms Jefferson, who was 39 weeks pregnant, had been found to have a complete placenta praevia, which means that the afterbirth is between the baby and the birth canal. The doctor told the court that there was a ‘99% certainty that the child [could not] survive natural child birth.’

Evidence was also given that performance of the proposed caesarean would give the baby (and the mother) an almost 100% chance of survival. Mrs Jefferson and her husband were both of the view that the proposed treatment was unnecessary, because their religious beliefs persuaded them that whatever happened, it would be God’s will. Relying on decisions such as *Raleigh Fitkin* and *Roe v Wade*, the Supreme Court of Georgia held that the preservation of life of the unborn child outweighed the mother’s interests.

*Madyun* was a 1990 decision of the Superior Court of the District of Columbia. Ms Madyun was experiencing her first pregnancy and was at term. After her waters broke, her labour did not progress. Ms Madyun was advised that a caesarean section was necessary to save the child, who was at serious risk of infection (which could cause disability or death) following Ms Madyun’s waters breaking. However, she and her husband rejected the proposed treatment, on the basis of their religious beliefs (the Madyuns were Muslims). In addition, however, there was evidence that neither Ms Madyun or her husband believed that the foetus was endangered by the failure of the labour to progress, and that they believed that the health care providers were not allowing enough opportunities for vaginal delivery to get underway. The Court held that, given the advanced state of pregnancy, and the ‘significant risks to the fetus versus the minimal risks to the mother,’ there was a compelling state interest in the preservation of the life of the Madyun’s baby.

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875 *Jefferson v Griffin Spalding County Hospital Authority* 274 SE.2d 457 (1981), 458.
876 *Raleigh Fitkin-Paul Morgan Memorial Hospital v Anderson* 201 A.2d 537 (1964).
878 *Jefferson v Griffin Spalding County Hospital Authority* 274 SE.2d 457 (1981), 460.
879 *In re Madyun*, reported at the Appendix to the judgment in *In re AC* 573 A.2d 1235 (1990), 1259.
880 *In re Madyun*, reported at the Appendix to the judgment in *In re AC* 573 A.2d 1235 (1990), 1263.
881 *In re Madyun*, reported at the Appendix to the judgment in *In re AC* 573 A.2d 1235 (1990), 1262.
882 *In re Madyun*, reported at the Appendix to the judgment in *In re AC* 573 A.2d 1235 (1990), 1264.
883 *In re Madyun*, reported at the Appendix to the judgment in *In re AC* 573 A.2d 1235 (1990), 1262-3. The Court referred to the decision of the Supreme Court of Georgia in *Jefferson v Griffin Spalding County Hospital Authority* 274 SE.2d 457 (1981).
Later cases, however, seemed to indicate a changing approach in some United States jurisdictions. In *In re AC*, an appellate court held, on a full hearing on the merits, that a lower court should not have ordered the performance of a caesarean section on a terminally ill woman who was 26 weeks pregnant and whose consent to the procedure was doubtful. The Court held that judges must ‘abide by those wishes [of a patient with decision-making capacity] unless there are truly extraordinary or compelling reasons to override them.’ The Court also noted that undesirable consequences would flow from coercing caesarean sections, such as damage to the trust necessary between patients and health care providers. The Court held that cases in which state interests are so compelling as to outweigh the entitlement to decide would be ‘extremely rare and truly exceptional.’ It was held that the Angela Carder case did not fall into this category. However, by allowing for the possibility of ‘exceptional’ cases, and by failing to repudiate *Madyun*, the Court may have inadvertently diminished the authoritative force of its decision by confining it to facts in which the prospects for the foetus were not bright and the intervention not only may have had no benefit for Ms Carder, but may even have foreshortened her life.

Nevertheless, a subsequent appellate case in Illinois seemed to reinforce the spirit of the Carder decision, holding that

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884 *In re AC* 573 A.2d 1235 (1990). For a fuller discussion of this case, see Seymour, 2000, 24-6. 885 For discussion of the ‘dehumanising’ implications of the original decision in this matter, see Scott, 2002, 256-9. 886 *In re AC* 573 A.2d 1235 (1990), 1247. 887 *In re AC* 573 A.2d 1235 (1990), 1248. 888 *In re AC* 573 A.2d 1235 (1990), 1252. 889 *In re AC* 573 A.2d 1235 (1990), 1241, 1252. 890 See Haberfield, 1995, 29. For the view that the caesarean may not have had this effect, see Scott, 2002, 256; but see also 259.
a woman’s competent choice refusing medical treatment as invasive as a caesarean section during her pregnancy must be honoured, even in circumstances where the choice may be harmful to her fetus.  

In *In Re Baby Boy Doe*, the Appellate Court of Illinois further held that ‘the potential impact upon the fetus is not legally relevant’. That is, the prevention of harm to a foetus as a third party is not a basis on which to displace a patient’s entitlement to decide. In this case, which might have been seen as falling outside the scope of the apparent limits of the decision in *In re AC*, the woman’s pregnancy had advanced past 35 weeks, the placenta was not delivering sufficient oxygen to the baby, and a caesarean was recommended. It was declined on religious grounds. The Court preferred the authority of *AC* to that of *Jefferson* or *Madyun*, and distinguished *Raleigh Fitkin* on the basis that it dealt with what the Court saw as the less invasive procedure of a blood transfusion. It left open the question of whether it would have ordered a blood transfusion, if recommended by medical opinion, and rejected the idea of balancing the patient’s interests against those of the foetus. The Court noted the invasiveness and risks, to the mother, of a caesarean section. Interestingly, the Court denied that the preservation of life value extended to the potential life of a foetus. It argued that the value applied only to the patient. The Court also denied the relevancy of the protective value. It held that this value did not extend to foetuses, but to family members; in particular, children of a person who refused treatment.

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895 *Jefferson v Griffin Spalding County Hospital Authority* 274 SE.2d 457 (1981).
896 *In re Madyun*, reported at the Appendix to the judgment in *In re AC* 573 A.2d 1235 (1990), 1259.
897 *Raleigh Fitkin-Paul Morgan Memorial Hospital v Anderson* 201 A.2d 537 (1964).
903 See consideration of preservation of family relationships value, section 5.2.4.
Following *Doe*, in which the Court left open the question of whether it would have ordered a blood transfusion, the case of *Re Fetus Brown* was considered by the Appellate Court of Illinois. This case involved a woman who had just passed her thirty-fourth week of pregnancy. She underwent a cystoscopy and a procedure to remove a urethral mass. In the course of this, she lost a lot of blood, and her haemoglobin levels dropped below acceptable levels. This was a danger both to Ms Brown and to the foetus she was carrying. Given that Darlene Brown was a Jehovah’s Witness, the doctors attempted to use alternative methods to redress the blood loss, but this was unsuccessful. Medical opinion indicated that, in the absence of a blood transfusion, Ms Brown’s chance of survival was five per cent.

The State filed for wardship and custody of Baby Doe, a foetus. Mr and Ms Brown were represented and Ms Brown was present at the hearing. The trial court granted the State’s petition and the hospital administrator was appointed to act as ‘temporary custodian’ of the foetus ‘with the right to consent to one or more blood transfusions for Darlene Brown, when advised of such necessity by any attending physician’. Subsequent to this, transfusions were carried out, over the physical resistance of Ms Brown, who later alleged that the doctors ‘yelled at, forcibly restrained, overpowered and sedated’ her. Both mother and foetus survived. The Appellate Court subsequently found that the lower court had erred in making its orders. The Court explicitly disagreed with the holding of the Court in *Doe* that a blood transfusion is a ‘relatively non-invasive and risk-free procedure’, and held that Ms Brown’s right to refuse medical treatment extended to the right to refuse a blood transfusion, on the grounds that blood transfusions are invasive treatment.

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906 *Re Fetus Brown* 689 NE.2d 397 (1997), 400.
907 *Re Fetus Brown* 689 NE.2d 397 (1997), 400.
908 Certiorari was later denied: see Scott, 2002, 142, note 143.
911 Though the Court noted Ms Brown’s ‘disparate ethical and legal obligations’: *Re Fetus Brown* 689 NE.2d 397 (1997), 400, 405.
The combined effect of *AC*,912 *Doe*913 and *Brown*914 may be, in cases of proposed coercive obstetric intervention, to tip the balance away from state interests that prevent harm to third parties and towards the patient’s entitlement to decide. To some extent, at least, the idea of there being competing interests in such cases has been rejected.

However, the reservations expressed in each of these cases leave open the possibility that courts in other jurisdictions may continue to hold that the preservation of life and protective values that express the harm prevention policy in relation to third parties outweigh the entitlement to decide,915 particularly in cases in which the pregnancy is well-advanced, the procedure is seen as minimally invasive and as posing a low level of risk to the mother, there is a good chance of benefit to the unborn child and the mother’s reasons for refusal are treated as frivolous or otherwise unworthy of respect. Indeed, writing in 2002, Cherry argues that despite policy positions taken by bodies such as the American Medical Association recommending against coercive intervention in the treatment of pregnant women, ‘physicians and hospitals nevertheless increasingly resort to the legal system in order to compel non-consensual treatment on pregnant women.’916

*English approach: a question of capacity?*

The preservation of life and protective values influenced a court in England to authorise coercive obstetric intervention. In 1993, Sir Stephen Brown P heard and decided a case within 50 minutes, in which he made a declaration allowing the performance of a caesarean section on a woman who was six days overdue with her third child.917 The baby was in a position of transverse lie and, in the absence of a caesarean, it was strongly possible that the uterus could rupture, killing the child and its mother. The patient refused a caesarean on religious grounds. The case was brought before the Court as a matter of extreme urgency. In his brief decision, the judge held that the question of overriding the refusal of a pregnant patient with decision-making capacity had been left

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917 *In re S (Adult: Refusal of Treatment)* [1993] Fam 123.
open by the Master of the Rolls in *In re T (Adult: Refusal of Treatment)*.⁹¹⁸ The judge then purported to rely on *In re AC*⁹¹⁹ as authority for the proposition that American courts would make the declaration sought. It seems clear that this reliance was misplaced.⁹²⁰ It appears that, in this hasty decision, Sir Stephen Brown P overrode the refusal of a patient with decision-making capacity. The paucity of reasons offers little material on which to form a firm view, but the inference is strong that he made his decision on the basis that it was necessary to preserve the life of mother and child. Because *In re T (Adult: Refusal of Treatment)*⁹²¹ is authority for the proposition that a patient with decision-making capacity can refuse even life-saving treatment on his or her own behalf,⁹²² it appears that the preservation of life value, aimed at preventing harm to the unborn child, was the foundation for the decision. If so, this indicates acceptance that the entitlement to decide may have been displaced on the basis that there were competing personal interests, and that the harm prevention policy supported saving a life at the expense of curtailing the personal interest of the patient.

Subsequent coercive obstetric intervention cases in England, however, have relied on a finding that the patient lacked decision-making capacity,⁹²³ and that the proposed treatment would be in the patient’s best interests. They have rejected the proposition that the preservation of life and protective values in relation to a foetus are to be weighed against the patient’s entitlement to decide.

In *CH’s case*,⁹²⁴ the case for a finding of lack of capacity appears to have been reasonable; the patient had been seriously debilitated by paranoid schizophrenia for some years. The judge held that the performance of a caesarean section was necessary for the birth of a healthy baby (the baby was exhibiting signs of intra-uterine growth retardation, caused by problems with placental function).⁹²⁵ The judge further held that,

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⁹²⁰ As noted by Seymour, 2000, 28; see also Scott, 2002, 115. For a possible explanation of how this happened, see Scott, 2002, 120-1.
⁹²² See also *Matter of Melideo* 390 NYS.2d 523 (1976), 524.
⁹²³ A point also noted by Scott, 2002, 111; see also 154.
on the medical evidence, the delivery of a healthy child was necessary treatment of the patient’s mental disorder within the meaning of the relevant mental health legislation, which allowed nonconsensual treatment to be provided for mental disorders of patients.926

In Re MB (Medical Treatment),927 a woman consented to the performance of a caesarean (recommended because her baby was in an incomplete breech position), but refused to accept the venepuncture necessary to administer anaesthetic.928 MB was declared by the Court of Appeal to be suffering from a temporary impairment of her decision-making capacity, despite medical evidence that she was not suffering from a psychiatric disorder.929 The Court further found that, given the woman had consented to the caesarean and was likely to suffer harm if the baby was stillborn or disabled, the caesarean (and all related procedures necessary to effect it) was in her best interests.930 MB dismissed the authority of the decision by Sir Stephen Brown P in S’s case,931 holding in obiter dicta that if a patient with decision-making capacity declines treatment, persuasion – not coercion – is required.932 The Court of Appeal recognised that the consequence of this decision was that the refusal of particular treatments by some women would end in a stillbirth or the birth of a seriously disabled infant.933 However, it was held that coercive treatment of a patient with decision-making capacity, even if pregnant with a viable child, ‘would be an unwarranted invasion of the right of the woman to make the decision’.934 Moreover, Butler-Sloss LJ, delivering the decision of the court, held that there was no ‘jurisdiction to take the interests of the foetus into

926 Tameside and Glossop Acute Services Trust v CH [1996] 1 FLR 762, 773-4, accepting that this was a ‘broad interpretation’ of the relevant provision. Scott suggests that a preferable approach might have been to characterise treatment falling within the scope of the common law doctrine of necessity: see Scott, 2002, 171.

927 Re MB (Medical Treatment) [1997] 2 FLR 426. For a more detailed consideration of this case that can be given in this thesis, see Scott, 2002, 142-162.

928 Because of her needle phobia: Re MB (Medical Treatment) [1997] 2 FLR 426, 438 (Butler-Sloss LJ).

929 Re MB (Medical Treatment) [1997] 2 FLR 426, 430 (evidence of Dr F).

930 Re MB (Medical Treatment) [1997] 2 FLR 426, 439 (Butler-Sloss LJ).

931 In re S (Adult: Refusal of Treatment) [1993] Fam 123. The Court in MB also dismissed the Master of the Rolls’ proposed limitation of the right to refuse in In re T (Adult: Refusal of Treatment) [1993] Fam 95, 102: Re MB (Medical Treatment) [1997] 2 FLR 426, 440 (Butler-Sloss LJ).

932 Re MB (Medical Treatment) [1997] 2 FLR 426, 438 (Butler-Sloss LJ).

933 Re MB (Medical Treatment) [1997] 2 FLR 426, 438.

934 Re MB (Medical Treatment) [1997] 2 FLR 426, 438 (Butler-Sloss LJ).
account in a case such as the present appeal and the judicial exercise of balancing those interests does not arise.\textsuperscript{935} That is, the Court effectively found there not to be a situation of competing personal interests; rather, the focus of the law’s protection remained the patient. In reaching this conclusion, Butler-Sloss LJ took into account those cases in which English courts have declined to find that a foetus has legal personhood.\textsuperscript{936}

In \textit{St George’s NHS Trust v S},\textsuperscript{937} a woman at 36 weeks of pregnancy was diagnosed with pre-eclampsia, a condition that could lead to death or serious disability for both herself and her child if she were allowed to undergo natural childbirth. She was seen by two doctors and a psychiatric social worker, who advised her to undergo a caesarean section. This she refused to do, with the outcome that she was detained in a mental hospital under the Mental Health Act 1983. There was some suggestion that S was suffering from depression. Nevertheless, she did not receive any treatment for a mental disorder while detained in the mental hospital,\textsuperscript{938} and she was soon transferred to a second hospital, which made an \textit{ex parte} application (though no proceedings were issued) to the Court, asking that the requirement for her consent to a caesarean be dispensed with. A caesarean section was later performed, in reliance on the Court’s order, which had been made without evidence being led, and without notification of the matter being given to S, or to the solicitors whom the hospital knew to have been instructed by S. In addition, Hogg J proceeded on the (false) basis that S had already been in labour for 24 hours, and that danger to her and to the child was imminent.\textsuperscript{939} The Court did not consider whether or not S had decision-making capacity,\textsuperscript{940} although there were indications that the second hospital, at any rate, treated S as having capacity, because they offered her a consent form for signature prior to administering anaesthetic.\textsuperscript{941} Following the caesarean, S was returned to the mental hospital where she was originally detained. After a further two days there, during which she again received

\begin{footnotes}
\item[935] \textit{Re MB (Medical Treatment)} [1997] 2 FLR 426, 440 (Butler-Sloss LJ); see also 444.
\item[936] Such as \textit{Paton v British Pregnancy Advisory Service Trustees} [1979] QB 276; \textit{In re F (in utero)} [1988] Fam 122; \textit{C v S and Anor} [1988] 1 QB 135; \textit{Burton v Islington Health Authority; De Martell v Merton and Sutton Health Authority} [1993] QB 204.
\item[937] \textit{St George’s NHS Trust v S} [1998] 3 All ER 673.
\item[938] \textit{St George’s NHS Trust v S} [1998] 3 All ER 673, 677.
\item[939] \textit{St George’s NHS Trust v S} [1998] 3 All ER 673, 682.
\item[940] \textit{St George’s NHS Trust v S} [1998] 3 All ER 673, 682.
\item[941] \textit{St George’s NHS Trust v S} [1998] 3 All ER 673, 684.
\end{footnotes}
no treatment for any mental disorder, her detention was terminated and she discharged herself (against advice). S appealed against the declaratory relief that had purported to dispense with the need for her consent and sought judicial review of her detention in the mental hospital, her transfer to the second hospital and her subsequent return to the mental hospital.

Judge LJ, delivering the judgment of the Court of Appeal, held that, in pursuing the course of action that led to S’s detention and forcible treatment, the doctors had been focusing not on the mental health issues that were used as a vehicle to detain and forcibly treat S, but on the diagnosis of pre-eclampsia.\(^{942}\)

It was held that a pregnant woman with decision-making capacity

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\text{is entitled not to be forced to submit to an invasion of her body against her will, whether her own life or that of her unborn child depends on it. Her right is not reduced or diminished merely because her decision to exercise it may appear morally repugnant.}^{943}\]

This case illustrates two legal dangers in relation to coercive obstetric intervention: first, the dangers of the urgent processes engaged in, which may lead to a court being misled (whether positively or by omission) and, second, the possibility that findings of lack of capacity, based on the patient’s decision, or predicted decision (rather than on an evaluation of decision-making capabilities),\(^{944}\) may wrongfully be used to justify coercive treatment.\(^{945}\) However, it may be that the procedural and substantive flaws in \textit{St George’s case}\(^{946}\) will not be repeated; it was decided after \textit{In re S (Adult: Refusal of Treatment)}\(^{947}\) and before \textit{MB}.\(^{948}\)

\(^{942}\text{St George’s NHS Trust v S [1998] 3 All ER 673, 679-80, 697.}\)

\(^{943}\text{St George’s NHS Trust v S [1998] 3 All ER 673, 692.}\)

\(^{944}\text{See section 3.2.1.}\)

\(^{945}\text{St George’s NHS Trust v S [1998] 3 All ER 673, 692-3. Seymour cautions against the temptation of using a predicted refusal of treatment as a basis for a finding of lack of decision-making capacity: Seymour Report, 1995, 120.}\)

\(^{946}\text{St George’s NHS Trust v S [1998] 3 All ER 673; see the comments of the Court of Appeal at 699-702.}\)

\(^{947}\text{In re S (Adult: Refusal of Treatment) [1993] Fam 123.}\)

\(^{948}\text{Re MB (Medical Treatment) [1997] 2 FLR 426.}\)
On the basis of MB\textsuperscript{949} and the St Georges case,\textsuperscript{950} therefore, it seems beyond question that, in England, if a woman has decision-making capacity, her refusal of treatment must be respected, and her entitlement to decide is not displaced to prevent harm to a third party. However, both CH\textsuperscript{951} and MB\textsuperscript{952} suggest that if a finding of lack of decision-making capacity, or emergency,\textsuperscript{953} can plausibly be made, then it will not be difficult for a court to find further that the treatment which is believed to give the foetus the best chance for a safe and healthy birth is also in the patient’s best interests.\textsuperscript{954}

Given the procedural short-comings that, as shown in this section, have a tendency to characterise such decisions, it is not unreasonable to suggest that courts will be open to making findings of lack of capacity and best interests.

An Australian position?

There is little Australian authority on coercive obstetric intervention.\textsuperscript{955} There is one reported decision that might give an indication of how Australian jurisprudence might develop, although it is deeply unsatisfactory as a guide to future decisions. It is a single judge decision of the Chief Justice of the Supreme Court of Queensland. State of Queensland \textit{v} D\textsuperscript{956} involved a prisoner with a personality disorder. At the time of the \textit{ex parte} application for an order to allow D to be treated without consent, and (if necessary) restrained to receive such treatment, D was already in labour, and was expected to deliver that afternoon. It is unclear from the report why it was left so late to bring the application. The orders appear to have been made on the basis of a \textit{temporary}

\textsuperscript{949} Re MB (Medical Treatment) [1997] 2 FLR 426.
\textsuperscript{950} St George’s NHS Trust \textit{v} S [1998] 3 All ER 673.
\textsuperscript{951} Tameside and Glossop Acute Services Trust \textit{v} CH [1996] 1 FLR 762.
\textsuperscript{952} Re MB (Medical Treatment) [1997] 2 FLR 426.
\textsuperscript{953} Re MB (Medical Treatment) [1997] 2 FLR 426, 432. Note that this thesis defines ‘emergency’ in a restrictive manner (see paragraph 3.2.5), and a central component of that definition is, in any event, a lack of decision-making capacity. Thus, the exception proposed in this case is not inconsistent with the proposals made in this thesis, which accepts that if there is a lack of capacity, then the entitlement to decide is not triggered. Any broader definition of emergency, however, risks swallowing up the entitlement to decide that MB purports to uphold.
\textsuperscript{954} See also Scott, 2002, 173-4.
\textsuperscript{955} Seymour identifies a case in which a Family Court judge held that he would be willing to hear an application for an order authorising a caesarean section: Seymour Report, 1995, 4, 81, referring to New South Wales Medical Defence Union, \textit{NSW}Defence Update, No 3 (June, 1993), 5-6.
\textsuperscript{956} State of Queensland \textit{v} D [2004] 1 QdR 426.

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incapacity, along the lines of *MB* \(^{957}\) (that case appears to have been the only relevant authority drawn to the judge’s attention by the Queensland Solicitor-General). The reliance on temporary incapacity was necessary because evidence from the psychologist was that D had decision-making capacity.

While de Jersey CJ seems to have been seeking to make a decision broadly consistent with *MB*, \(^{958}\) I am of the view that the decision is potentially broader than most recent judicial approaches in England and the United States, in two important respects. First, from a procedural point, the Court in this case seems to have been easily persuaded that *ex parte* proceedings were appropriate, \(^{959}\) while noting that *MB* \(^{960}\) contemplated that proceedings seeking orders to allow coercive treatment of pregnant women should allow the women to make submissions and be represented. The problems with *ex parte* proceedings were amply demonstrated in the case of *St George’s NHS Trust v S*, \(^{961}\) to which the Supreme Court of Queensland was not, apparently, referred. I am concerned with the lateness of the stage at which the application was brought because, had the application been brought earlier in the pregnancy (as there seems there was grounds to do), D could have been served with process in a manner appropriate to her mental state and representation could have been organised for her. Had that occurred, submissions might have been put that more accurately and comprehensively reflected the state of existing authority in comparable jurisdictions.

The limited scope of cases drawn to the attention of the Court is cause for concern, because it raises questions about whether, had the Court been fully informed, it would have made the second significant departure from current judicial approaches. This departure was to the effect that coercive treatment was justified for the benefit of *both* the mother and the unborn child, if the mother seemed inclined to irrationally or unreasonably refuse treatment. \(^{962}\) As has been emphasised throughout this thesis, the right to decide irrationally or unreasonably or idiosyncratically is fundamental to a

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957 *Re MB (Medical Treatment)* [1997] 2 FLR 426.
958 *Re MB (Medical Treatment)* [1997] 2 FLR 426.
959 The Court relied on *Drew v H* [1999] NSWSC 610, a case relating to the management of property.
960 *Re MB (Medical Treatment)* [1997] 2 FLR 426.
961 *St George’s NHS Trust v S* [1998] 3 All ER 673.
robust entitlement to decide that can protect the personal interest. This has been acknowledged in cases dealing generally with the entitlement to decide (such as Rogers v Whitaker),\(^{963}\) as well as in modern cases (described above) dealing specifically with coercive obstetric intervention. By making an order that allowed coercive obstetric treatment of a patient with decision-making capacity on the basis of a judicially-expressed fear of harm to the patient (rather than to a third party), de Jersey CJ is going significantly further than recent judgments in England and the United States. However, because the application was heard *ex parte* and only a single relevant authority was reportedly drawn to his attention, it is unclear whether the judge was conscious of the radical nature of his decision. Indeed, it seems that the judge may have fallen into the same traps as Sir Stephen Brown P in *In re S (Adult: Refusal of Treatment)*,\(^{964}\) or the first instance judge in *St George’s NHS Trust v S*.\(^{965}\)

Because of this, I think that only limited weight can be given to this case as a guide to future decisions which may (I hope) be made on a more considered basis. I am of the view that preference should be given to the approach most recently taken in *MB*,\(^{966}\) so that a court should only order coercive obstetric intervention if it finds a lack of decision-making capacity, and *also* finds that the proposed treatment will protect the patient’s personal interest. However, there should be a strong presumption that such an order should only be made after hearing from both parties, and that presumption should only be displaced by showing that the applicant had no reasonable opportunity to bring the application at a time which would have allowed service of notice of the proceeding on the respondent so that the respondent could seek representation and make submissions to assist the court.

*The indivisibly linked model and the approaches in the United States and England*

The more recent approaches taken by reported decisions in the United States and England to deny coercive treatment are consistent with the indivisibly linked model of the maternal/foetal relationship, which accepts that the law can extend protection to the

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\(^{963}\) *Rogers v Whitaker* (1992) 175 CLR 479.

\(^{964}\) *In re S (Adult: Refusal of Treatment)* [1993] Fam 123.

\(^{965}\) *St George’s NHS Trust v S* [1998] 3 All ER 673.

\(^{966}\) *Re MB (Medical Treatment)* [1997] 2 FLR 426.
in utero infant while denying it legal personhood. Thus, these approaches take account of the interests of the third party while rejecting a model of conflict. The position that coercive obstetric intervention is permissible in certain instances is consistent with advancing the preservation of life and protective values to prevent harm to foetuses while not recognising legal personhood. These instances include, in United States’ jurisdictions, ‘exceptional cases’ and non-invasive procedures. In England, coercive obstetric intervention is permitted when the best interests of an incompetent patient are served by such intervention. That is, coercive obstetric intervention is permitted in the United States on the basis of a competing interests model, in which the interests of the patient will usually prevail. Such intervention is permitted in England on the basis only that it will advance the interests of the patient who lacks decision-making capacity.

(d) Conclusion

The following conclusions can be drawn from the discussion of the preservation of life and protective values in relation to the foetus. First, common law jurisdictions such as the United States and England (and possibly Australia) treat the foetus as a third party meriting the law’s protection. This is consistent with Seymour’s third model of the maternal/foetal relationship. Second, because the foetus is treated as worthy of the protection afforded by the preservation of life and protective values, abortion is regulated (and in such a way that clinical values dominate decision-making), and coercive obstetric intervention is undertaken. Despite some evidence of changing attitudes towards such intervention, exceptions allowed by recent United States and English authorities, and the only existing Australian authority, leave the door very much open for the state to intervene on the basis of prevention of harm through the preservation of life and protective values, whether on a compelling interest, balance of

967 See also, for example, the approach taken by the House of Lords in Attorney-General’s Reference (No. 3 of 1994) [1997] 3 All ER 936, dealing with the status of the foetus as a victim of a criminal act; see especially Lord Mustill at 943, 948.
968 See also St George’s NHS Trust v S [1998] 3 All ER 673, 687 (Judge LJ): ‘a 36-week foetus is not nothing’
970 In re Baby Doe 632 NE.2d 326 (1994).
971 Re MB (Medical Treatment) [1997] 2 FLR 426.
interests or best interests test. Clinical values are important in this decision-making process, too, as medical evidence often dominates the urgent hearings that characterise judicial intervention in these matters.

Coercive obstetric intervention is quite evidently based on a policy of harm prevention. The relevant predicted harm may be to the child, the mother, or both. In any case, coercive obstetric intervention is based on a prediction of harm, and action taken to reduce the risk of materialisation of that harm, at the expense of the patient’s entitlement to decide about medical treatment. Recent United States and English cases provide some indications that courts will be rather more cautious in endorsing such action, and more willing to allow women to make their own decisions about harm. The only available Australian authority, *State of Queensland v D*, displays reasoning of such paucity and (possibly unintended) radicalism that I am unwilling to rely on it to draw any substantive conclusions about the future development of the law in Australia.

Overriding the decision of a competent patient is a serious infringement of that patient’s autonomy. It represents a substantial compromise of the entitlement to decide which is upheld in other circumstances and which is essential to protect the personal interest. We may find the decision of a woman that puts at risk the life and health of her child to be incomprehensible and morally repulsive. However, society is (in my view) compelled to respect it because, if we do not, we potentially compromise the autonomy (and, consequently, personal interests) of all other patients with decision-making capacity. This is because, by not respecting the decisions of pregnant women, we open

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972 See Scott, 2002, 112, 120-5, showing that *In re AC* 573 A.2d 1235 (1990) may be confined to its particular facts: a dying woman, the question of capacity not properly dealt with, the substitute judgement test not applied properly, her wishes ignored, the risks to her, and a non-viable foetus.

973 See *In re Madyun*, reported at the Appendix to the judgment in *In re AC* 573 A.2d 1235 (1990), at 1259.

974 As in *CH’s* case, where the mother was a paranoid schizophrenic, for whom birth of a healthy child was predicted to be therapeutically beneficial and thus in her ‘best interests’: *Tameside and Glossop Acute Services Trust v CH* [1996] 1 FLR 762.

975 As in *Jefferson’s* case, where the mother had a complete placenta praevia: *Jefferson v Griffin Spalding County Hospital Authority* 274 SE.2d 457 (1981). See also *State of Queensland v D* [2004] 1 QdR 426.

976 *State of Queensland v D* [2004] 1 QdR 426.

977 By departing from recent United States and English authority to justify intervention on the basis of the mother’s well-being, despite her refusal of treatment.
the door to overturning competent decisions in circumstances where it is questionable that the test in section 4.3 applies.

5.2.4 The preservation of family relationships value

The second value that will be considered in this Chapter is a value of preservation of family relationships. On the basis of this value, common law courts have ordered that patients undergo treatment, regardless of their consent or refusal, to prevent harm to a third party who is in a familial relationship with the patient. Two examples illustrate this: the judicial authorisation of blood transfusions and the judicial authorisation of organ harvesting from patients without decision-making capacity.

(a) Blood transfusions

The previous section, dealing with the preservation of life value, referred to some cases in which blood transfusions have been ordered, irrespective of the patient’s wishes, for the purpose of preventing harm to a foetus as third party (for example, **Raleigh Fitkin**[^78] and **Jamaica Hospital**[^79]). This section refers to cases in which blood transfusions have been authorised for the purpose of preventing harm to the interests of children already born, to preserve the parental relationship and to prevent abandonment of the children by the patient’s death.

The courts in **Georgetown College**,[^80] **Saikewicz**[^81] and **Wons**[^82] identified four state interests that, in certain circumstances, could be sufficiently compelling to justify

[^78]: Raleigh Fitkin-Paul Morgan Memorial Hospital v Anderson 201 A.2d 537 (1964).

[^79]: In the Matter of the Application of Jamaica Hospital 491 NYS.2d 898 (1985).

[^80]: Application of the President and Directors of Georgetown College Inc 331 F.2d 1010 (1964), 1008-1009. This case concerned the administration of a series of blood transfusions to a woman who objected to it on religious grounds (she was a Jehovah’s Witness). Unlike other blood transfusion cases canvassed in this Chapter, the patient here was not pregnant, nor had she recently given birth. She was suffering from a ruptured ulcer. For the view that this case is of ‘highly dubious authority’, see Scott, 2002, 133, note 96.

[^81]: Superintendent of Belchertown State School v Saikewicz 370 NE.2d 417 (1977), 425-427. This case concerned whether to provide burdensome life-prolonging treatment to a terminally ill disabled person, and held that ‘the most significant of the asserted State interests is that of the preservation of human life’ (at 425). It was held, on the basis of a substituted judgment test, that the patient would have declined the treatment, and that there was no state interest sufficiently compelling to counterbalance that decision. For a discussion of this case, see Annas et al, 1977, 156-8.

[^82]: Public Health Trust of Dade County v Wons 541 So.2d 96 (1989), 97, which was another case involving a hospital seeking authorisation to administer blood transfusions over the objections (based in religious belief) of a patient. However, it was held that the state’s interest in preservation of the family
overriding the constitutionally-protected liberty and privacy rights that underpin a patient’s right to refuse treatment in the United States. As previously noted, one of these state interests is the protection of innocent third parties. The court in *In re Baby Boy Doe* held in *obiter dicta* that

The ‘third parties’ referred to in this context are the family members, particularly the children, of the person refusing treatment. Where an individual’s decision to refuse treatment will result in orphaning an already-born child, courts have indicated that this is one factor they might consider.

In two cases, this has been a factor that a court has considered, and found to be sufficiently compelling to justify overriding a patient’s refusal of a blood transfusion. In addition, *Doe* (which declined to authorise the performance of a caesarean section against a patient’s wishes) left open the question of whether it would have ordered a blood transfusion, which it perceived as being less invasive than a caesarean section. While many in the community would agree with this view, it is nevertheless important to keep in mind that, to a patient who is a Jehovah’s Witness (for example), a blood transfusion is a highly invasive process that is regarded as analogous to rape. This must be considered when, in applying the criteria described at section 4.3, a view is being formed about whether the proposed intervention is proportionate and minimally intrusive.

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unit did not outweigh the patient’s right to refuse the transfusion, recommended because of the patient’s dysfunctional uterine bleeding (a recurring condition). In identifying the four state interests, the Court relied on its earlier decision in *Satz v Perlmutter* 379 So.2d 359 (1980).


985 *Application of the President and Directors of Georgetown College Inc* 331 F.2d 1010 (1964); *In re Dubreuil* 603 So.2d 538 (1992). In *In the Matter of the Application of Jamaica Hospital* 491 NYS.2d 898 (1985), the Court adverted to this state interest, but did not use it as a basis for judgment, because of the paucity of evidence: see page 900. See also *State ex rel Swan v Pack* 527 SW.2d 99 (1975), which held that the state could prohibit the handling of poisonous snakes for religious purposes in furtherance of the state interest in avoiding the ‘unnecessary creation of widows and orphans’ (at 113). See also *Holmes v Silver Cross Hospital of Joliet* 340 F.Supp 125 (1972), 130, in which the court did not have sufficient information to express a view on whether fatherhood of a young child was relevant to the exercise to the right to refuse life-saving treatment.


987 See Chapter 6 for how the test in section 4.3 might be applied in such cases.

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In the older of the two cases authorising a transfusion, the patient was bleeding from a ruptured gastric ulcer and refused a blood transfusion on religious grounds. She had a seven month old child, and the Court held that the state, acting in its parens patriae jurisdiction, would not permit the patient to refuse treatment when the consequence would be abandonment of a child. The Court further held that it was the responsibility of the patient to care for her child, and this meant that she must submit to the proposed treatment. That is, the interests of the child competed with, and prevailed over, those of the mother.

*In re Dubreuil* concerned a patient who had received a caesarean section, and whose post-operative bleeding was not controlled. The patient was a Jehovah’s Witness and declined a blood transfusion. She had (including the newborn) four children, the eldest of whom was 12 years old. The Court held that the state’s interest in preventing harm to third parties ‘outweighed’ the patient’s right to refuse the proposed treatment. It further held that there was no evidence before it as to the father’s ability to care for the children. On this basis, it authorised the blood transfusion. There was, however, a strong dissent by Warner J, who argued that the state does not prevent parents from engaging in hazardous activities to prevent them from orphaning their children; neither does the state force a parent, who would voluntarily abandon a child, to continue to care for him or her. Moreover, the dissenting judge held that the balance of interests struck by the Court constituted a failure to adopt the least intrusive means, by dismissing the caring options presented by the childrens’ father, extended family and Church. He based his conclusion about the appropriate weight to be given to the state’s interest, relative to the patient’s wishes, on a view that the factors identified in *Saikewicz* and

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988 *Application of the President and Directors of Georgetown College Inc* 331 F.2d 1010 (1965).
989 *Application of the President and Directors of Georgetown College Inc* 331 F.2d 1010 (1965), 1008.
990 *In re Dubreuil* 603 So.2d 538 (1992).
991 *In re Dubreuil* 603 So.2d 538 (1992), 540.
992 *In re Dubreuil* 603 So.2d 538 (1992), 541.
993 *In re Dubreuil* 603 So.2d 538 (1992), 545.
994 *In re Dubreuil* 603 So.2d 538 (1992), 546.
Wons are simply matters to be taken into account, and that the courts in these decisions did not accord a weight to those matters.

(b) Tissue harvesting from patients without decision-making capacity

A person with decision-making capacity can refuse to donate tissue for the benefit of a third party. The Court in McFall v Shimp, which upheld this position, relied on the status of the individual in society, and feared that an opposite conclusion would raise the spectre of practices engaged in under the Nazis or the Spanish Inquisition. In accepting this view, courts have distinguished between moral and legal obligations; the community may deplore the refusal of a family member to donate a kidney or bone marrow, but the state will not force him or her to undergo a harvesting procedure.

However, the position is different for a person without decision-making capacity. Tissue can, under authorisation from a court, be taken from such a patient, irrespective of consent. Courts in Australia, England and the United States have been inclined to agree that the parens patriae jurisdiction extends to finding that an involuntary tissue donation would be in the best interests of the donor (for the purposes of this Chapter, the putative donor is ‘the patient’ and the intended recipient the ‘third party’). This is so even though judicial relief means that the patient must undergo invasive treatment such as skin grafts from a minor.
as bone marrow harvesting or a nephrectomy with no prospect of a therapeutic benefit and with the usual risks of surgery.

A range of factors may be taken into account by a court in determining whether a patient will benefit from providing tissue for the benefit of a third party. The most crucial of these is the existence of a close relationship between the patient and the intended recipient. The lack of such a relationship has been determinative. Another important factor is the perception that other family relationships which the patient has will be maintained or enhanced if the patient provides tissue for a family member (for example, In re Y focussed on the relationship between the patient and her mother; the intended recipient was her sister). Other factors taken to be relevant to determining best interests of the patient include: the patient’s apparent or assumed wishes, the effect of refusal of the application on the patient, whether other family members (especially parents) support the proposed intervention, the availability (or otherwise) of alternative treatments or compatible donors, present and future dependency of the patient on the intended recipient, the magnitude of risks to the patient, and even the expected benefit to the intended recipient. Finally, at least one judge and one commentator have taken the view that to prohibit tissue harvesting from patients

1004 For example, in Curran v Bosze 566 NE.2d 1319 (1990), 1331. See also Little v Little 576 SW.2d 493 (1979), 500, confining the scope of its decision to parents and siblings.

1005 In re Y (Mental Patient: Bone Marrow Donation) [1997] Fam 110, 115. See also Hart v Brown 289 A.2d 386 (1972), 389; GWW and CMW (1997) FLC 92-748, 84,109 (there, the Court expressly indicated that it would have been opposed to the procedure if the intended recipient were a stranger).

1006 In re Y (Mental Patient: Bone Marrow Donation) [1997] Fam 110, 113; Little v Little 576 SW.2d 493 (1979), 498-9; GWW and CMW (1997) FLC 92-748, 84,105 and 84,109 (there, to ensure the proposed patient’s wishes would be heard, though he was not Gillick-competent, he was separately represented and joined as a party).


1008 Contrast Little v Little 576 SW.2d 493 (1979) and Hart v Brown 289 A.2d 386 (1972) with Curran v Bosze 566 NE.2d 1319 (1990), 1343-5, in which the mother’s strong disapproval of the proposed intervention was (together with the lack of relationship between intended patients and intended recipient) decisive.


1011 In re Y (Mental Patient: Bone Marrow Donation) [1997] Fam 110, 115-6; Curran v Bosze 566 NE.2d 1319 (1990), 1333; GWW and CMW (1997) FLC 92-748, 84,110.

1012 See Hart v Brown 289 A.2d 386 (1972), 391. The bleak prognosis for the intended recipient in Curran v Bosze 566 NE.2d 1319 (1990) was referred to by the Court (at 1333).
without decision-making capacity, as Cheyette advocates,\textsuperscript{1013} is to deny such patients their full humanity and their place in family relationships, and to cast a person without decision-making capacity as ‘a receiver, a taker, but never a giver....forever excluded from doing the decent thing, the charitable thing.’\textsuperscript{1014}

Concern has been expressed about best interests determinations made on the basis of such findings, with one commentator arguing, in effect, that such determinations mask the real basis for the decision: to advance the interests of a third party.\textsuperscript{1015} It is further argued that what is being undertaken is in reality not a determination of best interests, but a balancing process of the patient’s interests against those of the third party.\textsuperscript{1016} Cheyette also criticises tissue harvesting in these circumstances by arguing that there are flaws in the research suggesting that benefits accrue to tissue donors.\textsuperscript{1017} Morley rejects Cheyette’s arguments,\textsuperscript{1018} although he argues that parents, rather than courts, should be the decision-makers in such matters, because of the non-clinical value judgements involved.\textsuperscript{1019}

The question of whether patients without decision-making capacity should undergo involuntary procedures for the benefit of third parties continues to arise. In recent times, it has arisen in the context of children who are conceived for the purpose of providing tissue to a third party, usually a terminally ill sibling.\textsuperscript{1020} Although it is true to say that children have for ever been brought into the world for a variety of reasons, some

\textsuperscript{1013} Cheyette, 2000, 465.

\textsuperscript{1014} Lousier v Pescinski 226 NW.2d 180, 184 (1975) (Day J, in dissent). See also Morley, 2002, especially 1243. For an alternative approach, in which the Court held that the showing of a benefit was not necessary, and that it was sufficient if the parents’ decision was ‘fair and reasonable’, see Nathan v Farinelli Civ. No. 74-87 (Mass. July 3, 1974), quoted in Annas et al, 1977, 85; see also 87-8.

\textsuperscript{1015} Case, 2003, 211.

\textsuperscript{1016} Cheyette, 2000, especially 485.

\textsuperscript{1017} Cheyette, 2000, 477-480.

\textsuperscript{1018} Morley, 2002, 1223.

\textsuperscript{1019} Morley, 2002, 1219, 1236, 1248.

\textsuperscript{1020} See, for example, R (on the application of Quintavalle) v Human Fertilisation and Embryology Authority [2003] 3 All ER 257 (English Court of Appeal). This case was concerned with whether tissue typing, in conjunction with preimplantation genetic diagnosis, was allowed under particular legislation, when it was for the purposes of achieving the conception and subsequent birth of a child who did not suffer from beta thalassaemia major, and whose cord blood could be used to treat a sibling suffering from the disorder. The Court of Appeal upheld this interpretation of the legislation; however, leave to appeal to the House of Lords has been given: R (Quintavalle) v Human Fertilisation and Embryology Authority (Secretary of State for Health intervening) [2004] 1 WLR 441.
laudable, some not (or for no reason at all), it is quite a different thing to bring a child into the world for the express purpose of requiring it to undergo invasive treatment.\textsuperscript{1021} The 'best interests' test is then, in my view, a mere formality, because the decision about the patient's best interests has already been made, sometimes even before he or she is implanted in the womb.

(c) \textit{Future directions?}

As the law stands, it is open for a court in the United States to authorise a blood transfusion against the wishes of a patient with decision-making capacity, on the basis that preserving the patient's life prevents harm to third party children. It is unlikely that an English court would reach the same conclusion, because courts in England have shown themselves to be reluctant to interfere with decisions made by patients with decision-making capacity. However, as with coercive obstetric interventions, if a plausible finding of lack of decision-making capacity could be made in respect of a person in a parental or guardianship relationship with minors, then a court may well find that it is in the patient's best interests to receive treatment.\textsuperscript{1022} I think it is likely that an Australian court would take a similar approach, intervening if a plausible showing of lack of capacity could be made.

In relation to involuntary tissue donations by patients without decision-making capacity, it appears that Australian courts confronted with the issue will continue to adopt an approach at least nominally directed towards the best interests of the patient, even if it masks an underlying competition between the risks and benefits to the patient with the potential harm to the intended recipient, if harvesting does not proceed. This is consistent with both the preservation of the family value and the preservation of life value.\textsuperscript{1023}

\textsuperscript{1021} This was not the case in Quintavalle \textit{(R (on the application of Quintavalle) v Human Fertilisation and Embryology Authority) [2003] 3 All ER 257} (English Court of Appeal), in which it was proposed to use cord blood when the child was born.

\textsuperscript{1022} Note that 'Best interests are not limited to best medical interests': see \textit{Re MB (Medical Treatment)} [1997] 2 FLR 426, 439 (Butler-Sloss LJ).

\textsuperscript{1023} See Annas et al, 1977, 87.
5.3 PREVENTING HARM TO UNRELATED THIRD PARTIES

The state may intervene in therapeutic decision-making to prevent harm to third parties unrelated to the patient, if there is a real risk that respecting the patient’s entitlement to decide might reasonably be expected to seriously harm an unrelated third party. That is, this section considers another form of competition between personal interests of patients and third parties, even though the third parties may not be capable of precise identification by the state when it intervenes in the patient’s decision-making.

This section moves the focus of the thesis even further away from the patient, to third parties who have no particular relationship with the patient, but whose interests may nevertheless be affected by decisions that might be made by, the patient. To a significant extent, the values considered here are familiar from previous discussions in this thesis, but their application is different. For example, harm to third parties may be more difficult to connect to the relevant circumstances, or to quantify as ‘serious’, if those ‘others’ are unrelated to the patient, and the threat of harm in question is potential, or speculative, rather than direct and actual, which was the kind of harm considered in the examples described earlier in this Chapter.

5.3.1 The connected values of preservation of life and protection of vulnerable persons unrelated to the patient (the ‘protective value’)

The preservation of life and protective values are considered here on the basis that the state has taken the view that ‘unacceptable’ decisions may, but for state intervention, be made by patients. Decisions may be regarded by the state as ‘unacceptable’ if they are perceived as being likely to have an adverse effect on the application of the preservation of life value, or the protective value, to unrelated persons. That is, intervention is based on predicted harm to indeterminate individuals. In particular, the state is concerned to protect persons who, for whatever reason, are regarded by the state as being more vulnerable than others to pressures that may hinder their assertion of their interests. This Chapter combines consideration of these two values because, in the context of protecting unrelated third parties, they generally operate in tandem. That is, the state intervenes to prevent harm to the preservation of life value in respect of vulnerable third
parties whose interests compete with those of the patient. The value of protecting vulnerable individuals unrelated to patients has been used to justify state intervention in decision-making by prohibiting euthanasia, assisted suicide and female genital mutilation of adults.

(a) Preservation of life of vulnerable persons and euthanasia / assisted suicide

Upholding the preservation of life value in respect of vulnerable persons has been appealed to as a justification for the imposition of blanket bans on conduct such as voluntary euthanasia and assisted suicide. In this connection, the case of Pretty, both in the House of Lords and in the European Court of Human Rights, falls again for consideration. Ms Pretty argued that the state, in refusing to grant immunity from criminal liability to her husband (if he were to assist in her suicide), was in breach of rights recognised under the European Convention for the Protection of Human Rights and Fundamental Freedoms.

In that case, Ms Pretty asserted that she had a fundamental interest to die at a time, in a place, and in a manner of her own choosing, rather than to await what was generally conceded to be a very unpleasant death in the course of motor neurone disease. She saw this interest as deriving from the principle of respect for her autonomy, which she believed extended to the manner of her death as well as to the manner in which she would live her life. Dianne Pretty was strongly of the view that no one but herself and her family would be affected by the carrying out of her wishes. This was the nub of the disagreement between Dianne Pretty and the Government, which took the view that to grant immunity from prosecution to Mr Pretty would compromise the state’s interests. These interests were in upholding the preservation of life value and, in particular, in upholding that value in respect of members of classes which it perceived

1024 For a judicial example of this link being made, see Rodriguez v British Columbia 107 DLR (4th) 342 (1994), 404 (Sopinka J, with whom Gonthier J concurred).
1025 R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1.
to be vulnerable, such as the aged, ill, and socially isolated.\footnote{See also Washington v Glucksberg 521 US 702 (1997), 728-730 (judgment of Court delivered by Rehnquist CJ); see also 782-3 (Souter J, concurring).} Values such as those asserted by the state in Pretty\footnote{R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1; Pretty v United Kingdom (2002) 35 EHRR 1.} carry great weight in the balancing exercise between individual and state interests, and are regarded as prerequisites for the functioning of an ordered, civilised society.\footnote{The weight that such values will carry may rest on the facts of each case: see, for example, Compassion in Dying v State of Washington 79 F.3d 790 (1996), 817, 820.}

It was accepted by members of the House of Lords, and the European Court of Human Rights, that Ms Pretty was not a vulnerable person, and that her wish to be assisted to commit suicide was formed freely and voluntarily. It was generally agreed that her wishes in this regard were not compromised by pressure from others. Thus, Ms Pretty’s decision could fairly be said to authentically reflect her personal interest, as described in this thesis. It was nevertheless held, given the weight of the state’s interests in the particular case, that Ms Pretty’s own lack of vulnerability did not constitute a reason to weaken the universality of the prohibition against assisted suicide.\footnote{R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1, 13 (counsel’s submission referred to by Lord Bingham of Craighead).}

A blanket prohibition against assisted suicide was imposed under subsection 2 (1) of the Suicide Act 1961.\footnote{The House of Lords Liaison Committee has recommended the establishment of an ad hoc select committee to re-examine community sentiment about euthanasia and assisted suicide: Owen Dyer, ‘Parliament to look again at issue of ‘assisted dying’ for terminally ill patients’, 22 November 2003, http://bmj.bmjournals.com/cgi/content/full/327/7425/1186-c. On 10 March 2004, the Patients (Assisted Dying) Bill) was read a second time by Lord Joffe and referred to a Select Committee. On 10 March 2004, this Bill was read a second time by Lord Joffe and referred to a Select Committee. A House of Lords Committee released a report on the Bill on 4 April 2005, in which it was recommended that the Bill be reintroduced for debate in the next Parliamentary session. I have been unable to determine whether this has occurred.} Ms Pretty argued that such a prohibition was disproportionate to the objective the state was seeking to achieve in protecting the lives of vulnerable citizens.\footnote{R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1, 18 (Lord Bingham of Comhill), 24 (Lord Steyn), 37, 38 (Lord Hope of Craighead).} The Director of Public Prosecutions argued that a universal prohibition against assisted suicide was necessary and proportionate to protect the preservation of life value in respect of vulnerable persons. It was held in the House of Lords that the adequate discharge of the state’s responsibility to protect the preservation of life value

\footnote{R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1, 13 (counsel’s submission referred to by Lord Bingham of Comhill).}
in respect of vulnerable individuals who may be harmed by liberalisation of the law requires rules that apply to the entire community, not just to those members who are vulnerable.\textsuperscript{1036} Lord Hope of Craighead held that a blanket prohibition on assisted suicide is necessary to avoid abuses that put vulnerable lives at risk.\textsuperscript{1037} The Law Lords were primarily concerned with what they perceived to be the vulnerability of other persons in Ms Pretty's situation, and situations analogous to it, and did not consider the prohibition to be disproportionate to the objective sought.\textsuperscript{1038} They, like opponents of euthanasia and assisted suicide, were concerned at the possibility that the weakening of the universal prohibition might facilitate the use of undue influence, coercion and pressure on vulnerable persons to persuade them that it is their duty, or in their best interests, to submit to euthanasia or assisted suicide.\textsuperscript{1039}

Lord Bingham of Cornhill noted that a House of Lords Select Committee had identified as vulnerable to such influence, coercion and pressure those persons who are elderly, lonely, sick or distressed.\textsuperscript{1040} His Lordship expressed a concern that such persons would, if the universal prohibition were to be relaxed, feel pressure upon them to request an early death, even in the absence of actual encouragement to do so.\textsuperscript{1041} The European Court of Human Rights agreed that the vulnerability of terminally ill persons, as a class,

\textsuperscript{1036} See \textit{R (on the application of Pretty) v Director of Public Prosecutions} [2002] 1 All ER 1, 40 (Lord Hobhouse of Woodborough).

\textsuperscript{1037} \textit{R (on the application of Pretty) v Director of Public Prosecutions} [2002] 1 All ER 1, 38. For the view that relaxation of the blanket prohibition in the United States would be advantageous, not prejudicial, to the interests of persons generally considered to be vulnerable, see \textit{Compassion in Dying v State of Washington} 79 F.3d 790 (1996), 825.

\textsuperscript{1038} As did the European Court of Human Rights: see \textit{Pretty v United Kingdom} (2002) 35 EHRR 1, 39.

\textsuperscript{1039} See, for example, \textit{R (on the application of Pretty) v Director of Public Prosecutions} [2002] 1 All ER 1, 16, 18 (Lord Bingham of Cornhill, quoting the report of the House of Lords Select Committee on Medical Ethics (HL Paper 1993-94 21-I), 49 at paragraph 239). See also Lord Hope of Craighead at page 38.

\textsuperscript{1040} \textit{R (on the application of Pretty) v Director of Public Prosecutions} [2002] 1 All ER 1, 18 (Lord Bingham of Cornhill referring to the report of the House of Lords Select Committee on Medical Ethics (HL Paper 1993-94 21-I), 49 at paragraph 239), 24 (Lord Steyn). See also \textit{Compassion in Dying v State of Washington} 79 F.3d 790 (1996), 852 (Beezer J, dissenting); \textit{Washington v Glucksberg} 521 US 702 (1997), 731-2 (Rehnquist CJ, delivering the judgment of the Court).

\textsuperscript{1041} \textit{R (on the application of Pretty) v Director of Public Prosecutions} [2002] 1 All ER 1, 18 (Lord Bingham of Cornhill referring to the report of the House of Lords Select Committee on Medical Ethics (HL Paper 1993-94 21-I), 49 at paragraph 239). See also Lord Steyn (at page 24). This is also a fear that has been voiced by indigenous groups in Australia and disability advocates in the United States of America: see Cosic, 2003, 89, 165.
provided a sufficient rationale for the prohibition against assisted suicide. She argued that exceptions could be made, and safeguards adopted, that would strike a more appropriate balance between upholding her interests and those of the state. The Government, however, took the view that making exceptions would irremediably compromise the state's interests in preventing harm to vulnerable third parties, and that it would be too difficult to implement safeguards that would successfully protect against abuse. This argument was upheld.

Abuse of any exceptions to the blanket ban is feared as the inevitable consequence of such exceptions. This is the 'slippery slope' argument; that is, it is impossible to draw principled distinctions between categories of cases, and thus the relaxation of the prohibition against assisted suicide and voluntary euthanasia would ultimately lead to the relaxation of the prohibition against involuntary euthanasia. Concern has been expressed about the difficulty in formulating adequate safeguards, which would be necessary to preserve distinctions between cases, and thus avoid a 'slippery slope' effect. There is evidence that abuse of limited permissions to engage in assisted suicide has materialised (particularly in The Netherlands, where a regulated form of physician-assisted suicide is permitted), and that vulnerable persons have been persuaded, against their free will and their interests, to submit to conduct by others (including doctors), amounting to involuntary euthanasia.

1043 Pretty v United Kingdom (2002) 35 EHRR 1, 31. For the Government's response to this argument, see also page 32.
1044 See Pretty v United Kingdom (2002) 35 EHRR 1, 42. See also Washington v Glucksberg 521 US 702 (1997), 783-7 (Souter J, concurring).
1048 See House of Lords Select Committee on Medical Ethics (HL Paper 1993-94 21-1); Magnusson, 1997, 'Sanctity'; Rodriguez v British Columbia 107 DLR (4th) 342 (1994), 403 (Sopinka J, with whom Gonthier J concurred); Pretty v United Kingdom (2002) 35 EHRR 1, 32, referring to the existence of 'some evidence' to this effect; Washington v Glucksberg 521 US 702 (1997), 734 (Rehnquist CJ,
Because of these concerns, the importance of protecting the preservation of life value in respect of vulnerable persons overrode Ms Pretty’s entitlement to decide and, in effect, condemned her to die at a time, in a way and in a place not of her choosing. Dianne Pretty died in a hospice two weeks after the ruling by the European Court of Human Rights.\footnote{Cosic, 2003, 155.} This ending to Ms Pretty’s story represented the protection of the state’s interest in preventing harm to unrelated third parties at an exceptionally high personal cost to the patient herself.\footnote{As acknowledged by the European Court of Human Rights: see Pretty v United Kingdom (2002) 35 EHRR 1, 38.}

However, fears of abuse of vulnerable persons have not given rise to a prohibition on conduct such as withdrawing treatment from patients lacking decision-making capacity and allowing patients with decision-making capacity to refuse treatment. Both of these kinds of conduct could be predicted to have similar effects on the interests of members of the wider community, by weakening the influence of the preservation of life value and opening the door for undue influence on substitute decision-makers to authorise withdrawal, or on patients to refuse life-saving treatment. However, those effects are apparently not perceived as being sufficiently strong to influence the state to prohibit these kinds of decision. This differential treatment is likely to rest on the arguments described in Chapter 4 for distinguishing refusal of treatment and withdrawal and withholding of treatment, on the one hand, from assisted suicide and voluntary euthanasia, on the other. The criticisms of such distinctions (which relate to the principle of ‘double effect’ and the omission/commission distinction) that are advanced in Chapter 4 apply in this context, also.

(b) The protective value and female genital mutilation of adults

The protective value in relation to unrelated third parties may also be justification for restrictions on decision-making about non-lethal infringements of bodily integrity by adults with decision-making capacity. As has been seen, the operation of Dianne Pretty’s entitlement to decide was displaced, despite Ms Pretty’s undoubted

delivering the judgment of the Court), 785 (Souter J, concurring); Compassion in Dying v State of Washington 79 F.3d 790 (1996), 852-3 (Beezer J, dissenting). Other commentators argue that the asserted evidence is equivocal or has been misinterpreted: see, for example, Sunstein, 1997, 1145; Cosic, 2003, 88-9, 103; Morris, 2003, 83-4.
capacity, for the sake of those more vulnerable than she to extrinsic pressures that may compromise their personal interests, as described in this thesis. In that case, the protective value operated in tandem with the preservation of life value; state intervention was justified by reference to the severity of harm that might ensue if it did not impose a blanket prohibition on assisted suicide. However, the protective value has also been successfully relied on in instances where the harm in question falls short of being life-threatening. One example of this is the universal prohibition in Australian jurisdictions against female genital mutilation.

For the reasons set out in Chapter 4, only adults would be regarded as having decision-making capacity in relation to female genital mutilation. The prohibition against the performance of female genital mutilation on minors is readily justifiable by reference to the protection of vulnerable patients. However, even in relation to adults with decision-making capacity, female genital mutilation has been prohibited. This prohibition may give rise to a situation analogous to that in which Dianne Pretty found herself: an adult woman with decision-making capacity may decide, on the basis of her entire personal interest, that her health and well-being would be enhanced by undergoing female genital mutilation. She may view compliance with tradition and custom as essential to her health and well-being. For an individual with decision-making capacity, a view that her personal interest is best served by undergoing female genital mutilation should not lightly be dismissed. The content of the health and well-being dimension of her personal interest is a matter for her alone. It is, however, open to the state to protect vulnerable persons from pressure to undergo such procedures, at the expense of compromising the personal interests of the less vulnerable.

Accordingly, relevant legislation provides that (subject to exceptions such as procedures with a genuine therapeutic purpose) purported consent to practices falling within the definitions of female genital mutilation is ineffective, even if given by an individual with decision-making capacity. In enacting such prohibitions, the States and Territories may have taken into account the risk that a person’s consent to such practices may be compromised by significant familial, cultural and economic pressures to

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1051 Paragraph 4.3.3 (a).
1052 See, for example, Crimes Act 1900 (ACT), ss 74, 76, 77; Crimes Act 1900 (NSW), ss 45 (5); Criminal Code Act (NT), s 186D; Criminal Code (Qld), ss 323A (2) and Crimes Act 1958 (Vic), s 34.
conform to tradition and custom. In contemplation of this kind of situation, relevant legislation excludes, expressly or impliedly, cultural, religious or social custom from consideration when determining whether the procedure would have a therapeutic purpose.\textsuperscript{1053}

The state has taken the view that effective protection may only be possible by imposing a universal prohibition.\textsuperscript{1054} As with the prohibitions against euthanasia and assisted suicide, the prohibition against female genital mutilation will displace the entitlement to decide of persons with demonstrable capacity to withstand external pressure for the sake of protecting from potential harm third parties who may be less able to withstand this pressure, and thus effectively protect their own personal interests. Each of these prohibitions relies on the protective value and demonstrates a conflict of competing personal interests. Such conflicts should be resolved by reference to the criteria in section 4.3.\textsuperscript{1055}

5.3.2 Basis of state protection of unrelated third parties

(a) State intervention to protect unrelated third parties based predominantly on harm prevention

The state intervenes to prohibit and regulate conduct on the basis of the value of advancing the preservation of life value in relation to vulnerable persons. In doing so, the state effectively predicts, and acts to prevent, harm to indeterminate individuals (such as the lonely, the sick and the distressed) while according a lesser weight to certain and concrete harm to known individuals (for example, Dianne Pretty’s death in a manner not of her choosing). Such intervention is justified by a concern that the conduct of particular individuals not cause harm to others, and possibly by a consequentialist analysis that is concerned with minimising potential harm to many, at the expense of actual harm to the few. Thus, the view may be taken that it is a cost of living in a community that individuals accept the practical need to yield, from time to time, to the

\textsuperscript{1053} See \textit{Crimes Act 1900 (ACT), Part 4}; \textit{Crimes Act 1900 (NSW), ss 45 (3)}; \textit{Criminal Code Act (NT), ss 186B (3)}; \textit{Criminal Code (Qld), ss 323A (3)}; \textit{Criminal Law Consolidation Act 1935 (SA), ss 33 and 33A}; \textit{Crimes Act 1958 (Vic), s 32}. Therapeutic purposes may include reconstructive genital surgery following childbirth or cancer treatment, or as part of sexual reassignment.

\textsuperscript{1054} For an alternative view, arguing that prohibition of female genital mutilation is unacceptably paternalistic, see Rogers, 2003.

\textsuperscript{1055} See Chapter 6 for how this might be done.

Chapter 5
interests of others, even at great personal sacrifice, when those others’ interests are threatened by a real risk of serious harm (even if that risk is, at the relevant time, purely speculative). Because of the gravity of reaching this conclusion, with its implications for the entitlement to decide, this assessment should only be reached after conducting a balancing process that takes into account the criteria mentioned in section 4.3.\textsuperscript{1056}

The displacement of the entitlement to decide in these circumstances challenges the importance accorded by the modern common law to the individual’s interest in bodily integrity. This is so even though the interest in bodily integrity has, for some time, been regarded by the judicial branch of the state as being of central importance in the doctor-patient relationship. The key to the state’s willingness to override the patient’s entitlement to decide, with the object of protecting a third party, is that the state is pursuing an aim relating to protecting the community from what the state perceives to be a real risk of sufficiently serious harm.

(b) State intervention based on balancing exercise

Whether and how to displace the entitlement to decide in relation to an individual is a question to be determined by undertaking a balancing process. This process requires the weighing of many values. Sometimes it is difficult to clearly identify the nature and relative weight of particular factors at play in relation to given circumstances. For example, the case of Pretty\textsuperscript{1057} involves a tangle of values about independence and autonomy on the one hand and the interests of the general community and (in particular) of vulnerable members of that community on the other. It is, I think, misleading to represent that an organised balancing process is being undertaken in the judgments.

Instead, it seems to me more accurate to describe the decisions in cases such as Pretty\textsuperscript{1058} reflecting perceptions of such matters as community tolerance for certain kinds of behaviour (such as the withdrawal or refusal of treatment), and the weight accorded by society to values such as the preservation of life and protective values. However, although it may seem that the state’s approach to various kinds of conduct is

\textsuperscript{1056} How this might be done is shown in Chapter 6.
\textsuperscript{1057} R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1.
\textsuperscript{1058} R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1.
disparate, and unlinked by any unifying theory, this thesis argues that, in fact, a harm prevention policy underlies all state interventions considered by it.

It is, in any event, useful to seek to impose some clarity on what has been described as the ‘balancing process’. This is because the outcome of that process is serious: it may justify the intervention of the state in some of the most intimate aspects of our lives. Accordingly, this thesis proposes that certain matters must be taken into account in undertaking the balancing process, using the criteria described at section 4.3. Although acceptance of this proposed test would not remove the subjectivity of the assessments made about state intervention, it would make intervention more transparent and more accountable by tying it to specified relevant matters. This would put state intervention on a firmer, more defensible, footing while also ensuring that proper regard is paid to the entitlement to decide in its usual role as the most effective protection for patients’ personal interests.

5.4 GIVING EFFECT TO THE BENEFICENCE PRINCIPLE

This section considers the role that the beneficence principle should play in protecting patients’ interests when the state displaces the entitlement to decide (or the usual substitute decision-maker’s responsibility to decide). Although this is not the focus of the thesis, it is helpful to offer consideration of this kind to throw light on the relationship between the autonomy and beneficence principles as described in this thesis, and to emphasise the complementarity of that relationship in the protection of patients’ interests through redressing the imbalances, and furthering the purposes, that are characteristic of the doctor-patient relationship.

If the state intervenes and assumes the decision-making role in relation to medical treatment, it should be incumbent on the state to actively identify opportunities to comply with the beneficence principle, and protect the patient’s personal interest as far as is possible consistent with the objective of intervention (that is, to prevent harm to a third party). Only in this way can the imbalances of effect and authority be palliated and the purposes of care and independence furthered, by minimising risks and hardships caused to a patient by intervention (especially intervention requiring a patient to submit to treatment), and allowing the patient as much decision-making freedom as possible, consistent with the objective of intervention. This is particularly important, given that
the state is intervening not to benefit the patient, but to prevent harm to a third party, at the expense of the patient.

For example, in relation to the Attard twins, once the state had intervened to declare that separation would be lawful, it was incumbent on the state to ensure that Mary would continue to receive appropriate treatment and care, 'to ensure that she suffers the least pain and distress and retains the greatest dignity until her life comes to an end.' In relation to a woman who is subjected to coercive obstetric intervention, efforts should, in my view, be made to ensure that, within the scope of the order made, the woman is still free to make her own decisions about treatment, and that she receives appropriate care and respect. A final example of how the beneficence principle should apply can be offered in relation to organ donation by a patient without decision-making capacity. If an order is made authorising the taking of organs or tissue, the state should take reasonable steps to ensure that risks are minimised as far as reasonably practicable, and the best care is given (particularly if risks materialise), and that the patient is given the maximum scope consistent with his or her capacities to express his or her own views on the process. A particular disclosure issue is also raised in this context: the patient’s primary carer (who may also be the primary carer of the third party) should be given full disclosure of the nature of the donation procedure and its risks to the patient, as well as information about short and long-term mental and physical effects of the procedure on the patient.

The importance of the beneficence principle, as described in this thesis, cannot be overstated when a patient is being required to undergo treatment to benefit a third party. Where it is ignored, such as in Angela Carder’s case, I also suggest that the state’s intervention loses any moral authority it might otherwise have, as a measure taken to prevent harm to a vulnerable third party.

5.5 CONCLUSIONS

The first conclusion that can be drawn from this Chapter is that the state is willing to displace the entitlement or responsibility to decide for the purpose of preventing harm to vulnerable third parties. In some cases, the harm done to patients as a consequence of

displacement has been severe (such as the harm to Mary Attard and Dianne Pretty); even forced obstetrical interventions that ostensibly benefit the patient can be significantly counter-productive. Nevertheless, the courts have undertaken balancing exercises (whether or not explicitly) and have found that, in some instances at least, a third party is entitled to the law’s protection as against what I have characterised as the patient’s personal interest.

Second, the emphasis placed by the law on physical individuality leads to strained reasoning both in relation to conjoined twins and to issues arising from the maternal/foetal relationship. As stated previously in this Chapter, neither the law nor other existing normative systems may be equipped to cope with beings who are not physically separate. It may be that a solution (let alone a ‘happy ending’) can never be found in some cases; the indivisibly linked model that is appropriate to assist in providing solutions in the maternal/foetal relationship will not assist with respect to conjoined twins such as the Attards. This is because two legal persons are involved in such cases, and must be accorded the full complement of rights and interests. In such circumstances, conflicts of interest are inevitable, and so far there is no satisfactory way in which they can be resolved. The arguments of quasi self-defence, necessity and best interest, in the terms they were made in Re A, were unpersuasive, as was the approach taken in the sparsely-reasoned Nolan case.

This Chapter has identified some problems for which the law does not yet have a solution, or in relation to which attempts at a solution have not produced an outcome that is consistent with either the autonomy or the beneficence principle. That the law does not have all the answers to all possible problems is hardly a new idea; however, this Chapter shows that technological advances can give rise to a ‘judicial

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1061 See also Sheldon and Wilkinson, 1997, 151.
1062 See McLean and Peterson, 1996, 237.
1065 See, for example, Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961.
1066 See, for example, Application of the President and Directors of Georgetown College Inc 331 F.2d 1010 (1965), 1018 (Burger, Circuit Judge, dissenting).
imperative', where judges feel themselves bound to decide on any dispute brought before them, particularly if there is a possibility of saving a life by exploiting such advances. There are instances in which judicial intervention is inappropriate and counter-productive, and in relation to which the best efforts of neither medicine nor law will produce a happy ending.

Third, clinical values have been accorded significant weight in judicial decision-making considered in this Chapter. The Court in *Re A* medicalised the decision-maker and the decision-making process, while the regulation of abortion rests on a delegation of decision-making authority to doctors. Medical evidence dominates hearings about coercive obstetric intervention. Yet, the decision about Mary and Jodie shows that the application of clinical values does not provide a predictable basis for judicial decision-making. Had Mary and Jodie been born at another hospital, for example, the law would have accepted the children living out their lives conjoined. This lottery is unsatisfactory for patients and substitute decision-makers, because it clouds already stressful times with even greater uncertainty. The law as it currently stands does not, in my view, give sufficient scope for non-clinical values to be considered, in accordance with the requirements of the beneficence principle, as described in this thesis.

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1068 *Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961.*
CHAPTER 6  APPLYING THE TEST IN SECTION 4.3 TO CIRCUMSTANCES DESCRIBED IN CHAPTERS 4 AND 5

6.1 PURPOSE OF CHAPTER 6

This Chapter has the limited objective of providing an indication only of how the criteria described in section 4.3 might be applied, when an opportunity arises to undertake a fuller consideration than is possible in the context of this thesis. That is, Chapter 6 concerns itself with describing a process, rather than prescribing an outcome, in particular cases. Accordingly, I confine my consideration to arguments and evidence already made and referred to in this thesis. There is no doubt that many of the issues discussed in this Chapter need more detailed consideration, and public debate, in another forum to determine substantively the appropriate outcome of applying the test in section 4.3 to circumstances described in Chapters 4 and 5.

6.2 CIRCUMSTANCES DESCRIBED IN CHAPTER 4 (PREVENTING HARM TO PATIENTS)

While I accept that the state does, in fact, displace the entitlement to decide (and usual substitute decision-makers’ responsibility to decide) with a view to harm prevention, I nevertheless argue that this should only ever be done if the criteria proposed in section 4.3 are satisfied. As observed earlier in this thesis, this should be a high hurdle to clear. To demonstrate this, I will consider the prohibitions against assisted suicide, female genital mutilation of children and the regulation of non-therapeutic sterilisation of disabled patients, and look at how the criteria in section 4.3 can be applied.

6.2.1 Prohibiting assisted suicide

By prohibiting assisted suicide (as in the Pretty and Rodriguez cases considered previously in this thesis),^{1069} the state is seeking to pursue the preservation of life value, particularly for the vulnerable. As was shown in Chapter 4,^{1070} this value is widely accepted in our community as being an important, compelling value that appropriately

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^{1069} R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1; Pretty v United Kingdom (2002) 35 EHRR 1; Rodriguez v British Columbia 107 DLR (4th) 342 (1994).

^{1070} See section 4.4.1.
forms the basis for state action (such as the general prohibition against killing). In addition, the harm that the state is seeking to prevent in these cases is a serious one: death against the true wishes of the patient. The risk of that harm materialising can, I think, be fairly characterised as serious, and not remote or fanciful. Accordingly, the first part of the test in section 4.3 is satisfied.

It could be argued, however, that a prohibition on assisted suicide, for instance, is not proportionate, minimally intrusive, rational and fair, as required by the test in section 4.3. This, in essence, was the argument submitted by Ms Pretty and Ms Rodriguez. They argued, for example, that a blanket prohibition, intended to protect the unusually vulnerable, unfairly prohibits authentic choices by individuals who are seeking freely to exercise their decision-making capacity. They argued, in effect, that a more closely-defined prohibition, or more relaxed regulation, would be more proportionate and less intrusive. They also argued that the prohibition was unfair because it discriminated against the disabled, preventing them from carrying out an act (suicide) that would be lawful were they able-bodied. Although this argument was also rejected by the relevant courts, the submissions put by Ms Pretty and Ms Rodriguez squarely raised doubts about whether the state should be regarded as discharging its onus to prove that the personal interest of individuals whose decisions authentically reflect their interests is better protected by state intervention than by a robust entitlement to decide.

Finally, the prohibition on assisted suicide is seeking, not to enhance the patient’s own expression of his or her personal interest, but to substitute the state’s view of what that personal interest should be (thus, the state is not necessarily acting beneficently, as defined by this thesis). This is an argument against the state’s prohibition of assisted suicide, particularly when the state is dealing with adults of undoubted capacity, such as Ms Pretty. Given the intrinsically personal nature of death, such an intervention requires very strong arguments indeed to justify it on the terms I have proposed in this thesis. To the extent that the prohibition is intended to protect patients themselves

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1071 As observed by commentators referred to in Chapter 4.

1072 R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1; Pretty v United Kingdom (2002) 35 EHRR 1; Rodriguez v British Columbia 107 DLR (4th) 342 (1994).
(rather than third parties), it is strongly arguable – on the evidence canvassed in Chapter 4 – that the state has not discharged its burden of showing that its intervention better protects the personal interests of patients than does a robust entitlement to decide.\footnote{That is, because I have defined beneficence as being properly directed towards the protection of the personal interest.}

Rather, I think that the personal interest might be better protected by establishing an exemption from the prohibition against attempted suicide. That exemption would apply only to a limited class of individuals for whom the prohibition, based on upholding the preservation of life value, could be said to provide no benefit whatever, because of the parlousness of their condition. Thus, it would apply both to justify acts in the form of assisted suicide for persons such as Dianne Pretty and Sue Rodriguez, whose deaths were so tormented, and to explain existing permissions for omissions in the form of withholding treatment to patients such as Anthony Bland\footnote{Airedale NHS Trust v Bland [1993] AC 789.} or Baby J.\footnote{This does not preclude a different conclusion from being drawn when the intention of the prohibition is to protect the personal interests of vulnerable third parties, as discussed in Chapter 5.} For such patients, it is arguable that their personal interest is not served by sternly upholding the preservation of life value, when so doing inflicts a greater harm than would be inflicted by compromising that value in a particular case. For patients such as Dianne Pretty, choosing the manner of death through assisted suicide may be the only way left in which to express their personal interests. Likewise, for patients such as Anthony Bland, a quiet death sooner rather than later may be the best expression of those elements of the personal interest that remain to them. If this is so, giving full effect to the personal interest could justify different outcomes in different cases; that is, assisted suicide would remain impermissible in cases where the personal interest might (for example) be advanced by effectively treating or palliating a mental illness, or other chronic disease. But it would become permissible for those like Dianne Pretty, in the grip of a terminal illness that, in the absence of personality-robbing sedation, guarantees a death which few could embrace with sanguinity.

These different outcomes emphasise the individuality of the personal interest; while the best interests test could (for example) deliver predictable results in like cases, the
inherent subjectivity of the personal interest will never do that. Perhaps therein lies both its power, and the basis on which it might be strenuously resisted by lawmakers (and doctors): it does not, and never should, possess the ‘reasonable person’ objectivity currently so much a part of the law about decision-making in the doctor-patient relationship.

If this view were accepted, there would be no need for dubious distinctions between acts and omissions, and contorted constructions such as the doctrine of double effect, which I have criticised in Chapter 4 of this thesis. I acknowledge the practical difficulty, however, of identifying with certainty the individuals who fall within this class. There would be many clear cases, but many that would not be so clear; for example, individuals suffering from severe mental illnesses which have proved resistant to available treatments. It may be that further consideration reveals a true slippery slope, on which can be drawn no principled distinctions on which such an exemption should rely.

My proposed exemption, therefore, is only a tentative view. There is extensive literature on this contentious subject, and it is beyond the scope of this Chapter to give a conclusive answer to the question of whether section 4.3 is satisfied in relation to assisted suicide. Further investigation and community debate would be necessary to give such an answer.

6.2.2 Prohibiting female genital mutilation of children

By prohibiting female genital mutilation of children, the state is seeking to prevent damage to children’s health and well-being, both in the present and future. The seriousness of that harm, and its inevitability in all but the least intrusive forms of female genital mutilation, are well-documented and, in my view, beyond serious dispute. The protection of children from harm, generally, is I think a widely-accepted community aim. The risk of such harm occurring is, according to the sources referred to in this Chapter, a real one. On this basis, the prohibition appears to clear the first hurdle of the criteria in section 4.3.
By carefully defining, in relevant legislation, what is meant by ‘female genital mutilation’ and, in particular, by excluding (for example) reconstructive surgery and gender reassignment surgery, the state may arguably have satisfied the test that intervention be proportionate and minimally intrusive. In addition, the intervention is arguably rational and fair in that the prohibition applies to all, without discrimination and tends, within its legislative framework, to be likely to achieve its aim of preventing harm to children (unlike coercive obstetric intervention where, as argued in Chapter 5, intervention has a tendency to undermine its own aims). However, an argument may be made that the measure constitutes indirect, or constructive, discrimination against members of particular populations. This is an issue that, I think, merits further attention with particular regard to relevant human rights legislation dealing with indirect discrimination, as well as legislation dealing with the protection of children’s welfare.

Finally, I am of the view that state intervention to prohibit female genital mutilation in children is likely to enhance, not detract from, patients’ personal interests. This is because while the prohibition on assisted suicide effectively substitutes the state’s view of the personal interest for that of the patient and closes off the possibility of choice, prohibiting female genital mutilation of children preserves choices for the future, such as reproductive choices. On this basis, therefore, I think that the test in section 4.3 will probably be satisfied in relation to the prohibition against female genital mutilation of children, because the state’s displacement of the usual substitute decision-maker’s responsibility to decide is likely to offer better protection for the child’s personal interest.

6.2.3 Requiring judicial authorisation of non-therapeutic sterilisation of patients without decision-making capacity

In this section, I move from considering blanket rules (as in the preceding sections of this Chapter) to considering instances where the state intervenes on a case-by-case basis. Here, the use of the test in section 4.3 is more complicated. While its primary role remains the same – to determine whether the personal interest is better protected by state intervention than by allowing (in the cases considered in this section) the usual substitute decision-maker’s responsibility to decide to operate as normal – it may also serve a secondary purpose, by providing some indication about the nature of the decision that ought to be made by the state. These considerations apply also to other examples considered in this Chapter, such as judicial authorisation of tissue harvesting.
from patients without decision-making capacity. This is precisely because, where case-by-case consideration is required, the decision about whether to intervene will be inextricably bound up with the question of how to intervene.

The High Court has clearly (and, in my view, persuasively) articulated the basis on which the state intervenes in decision-making about non-sterilisation of patients without decision-making capacity. It has set out special factors, that are applicable to certain kinds of procedures, establishing judicial authorisation as a crucial means of protecting the personal interest of disabled people. However, to further demonstrate how the test in section 4.3 applies, it is useful to examine the potential application of that test to such procedures as those considered by the High Court in Re Marion.

By requiring judicial authorisation before these procedures are undertaken, the law is seeking to prevent harm by protecting especially vulnerable patients. In addition, by specifically considering the patient’s health and well-being interest in requiring judicial authorisations, courts are mindful that non-therapeutic sterilisation, according to the definitions accepted by members of the High Court in Re Marion, involves the removal or impairment of function of otherwise healthy organs.

In circumstances likely to come before the courts, protection is needed from two kinds of ‘threat’. First, the threat that disabled patients may be exploited, and their personal interests deliberately disregarded and undermined by unscrupulous or uncaring family members, carers and health care providers. Second, and (I hope) more common, the ‘threat’ that conscientious, loving and concerned third parties may take a view of the patient’s interests that does not embrace the totality of their personal interests, and that is overly reliant on clinical considerations.

The protection of vulnerable people from such threats is a serious, compelling community interest. It is likely to be regarded as important by a substantial proportion of the community and, in relation to disabled persons, it has been recognised that they

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1077 These factors were described at section 4.4.4.
1078 Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218.
1079 Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218.
have too often been compromised. Thus, the risk of materialisation of the threats identified above appears to be a real and foreseeable one. The risk has materialised in the past and may well, unless adequate safeguards are in place, materialise in the future, to the detriment of the disabled. In my view, and as observed previously in this thesis, there is clear and convincing evidence of risk to the interests at stake. The first hurdle is likely to be cleared by the state in justifying its intervention.

Second, sterilisation can be highly invasive, with the risk of serious adverse consequences for the patient. Because of this, it is vital to test whether the proposed intervention to authorise sterilisation is proportionate and minimally intrusive. To meet these criteria, the Court should ensure that convincing evidence is led to establish that the proposed means of sterilisation are proportionate to the problem being addressed and is minimally intrusive. As is clear from the High Court’s judgment and the literature referred to in Chapter 4, courts already seek to do this, taking into account whether other means would be effective to deal with the problem. For example, if the problem being addressed is a phobia of blood, it may be important to consider whether a long-acting contraceptive such as Norplant or Depo-provera would be effective.

In addressing this part of the test in section 4.3, the court should also have regard to whether authorising sterilisation is rational or fair. This tends to be a somewhat different exercise from that undertaken in relation to blanket measures, such as the prohibitions against assisted suicide or female genital mutilation of children. There, the universality of the measure may help to establish fairness, for example. In this case, rationality and fairness can best be established by evidence showing that the proposed measure is, in the particular circumstances, a reasonable means of addressing the issue. This perhaps relates to the concern expressed by Natasha Cica that social problems (such as carers’ unwillingness to deal with menstruation) are being addressed by medical means. In my view, Cica raises a legitimate point, and this aspect of the test should be carefully considered on a case-by-case basis.

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1080 As by the High Court in Department of Health and Community Services (NT) v JWB and SMB (Re Marion) (1992) 175 CLR 218. See also Goldhar, 1991; Brady and Grover, 1997; Brady, Briton and Grover, 2001 and Cica, 1993.

1081 For example, premature menopause and osteoporosis.

As for fairness, I think that the principle of universalisability could usefully be applied. For example, to the extent that the proposed measure would be applied to a patient who was not disabled, this may help to establish that intervention is justified. This aspect of the test raises concerns about the value of evidence, led in various cases, that sterilisation is proposed to ameliorate the consequences of a prospective patient being an attractive girl with a friendly disposition or sexual inclinations,\textsuperscript{1083} who may be led into sexual intercourse by an exploitative ‘partner’, and become pregnant.\textsuperscript{1084} On my test, this would not be a sufficient basis to authorise non-therapeutic sterilisation because it could not be universalised to apply to a friendly and attractive 12 year old girl without a disability.\textsuperscript{1085} Such evidence, if proposed as the sole or dominant reason for proposed sterilisation, should result in the intended treatment failing the test of fairness. There must be much more to justify non-therapeutic sterilisation; including, for example, evidence showing that other, perhaps less intrusive, methods of contraception would be ineffective or even dangerous,\textsuperscript{1086} and that both menstruation and pregnancy pose insurmountable problems that constitute a genuine and serious threat to the personal interest of the patient. Again, however, this should be judged on a case-by-case basis.

Finally, and most importantly, the court must consider the impact of the proposed intervention on the patient’s personal interest. In this case, as I argued fully in Chapter 4, the proposed intervention is squarely intended to protect the patient’s personal interest. This criterion may well be met, if appropriate evidence is led.

No blanket conclusion can be drawn about the judicial authorisation of sterilisation of disabled patients. It is essential to make such decisions on a case-by-case basis, as is currently done. However, I have shown how the test in section 4.3 may be satisfied if appropriate evidence is presented to the court.


\textsuperscript{1084} The danger of such conclusions being drawn was referred to by Brennan J in \textit{Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’)} (1992) 175 CLR 218, 275-6.

\textsuperscript{1085} As acknowledged by Brennan J in \textit{Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’)} (1992) 175 CLR 218, 275-6.

\textsuperscript{1086} See, for example, the evidence led in \textit{Re Elizabeth} (1989) 13 Fam LR 47, that contraceptive drugs would aggravate the child’s other medical conditions.
6.3 CIRCUMSTANCES DESCRIBED IN CHAPTER 5 (PREVENTING HARM TO THIRD PARTIES)

In Chapter 5, I considered circumstances in which the state has intervened to displace the entitlement to decide belonging to the patient (or the responsibility to decide, borne by the usual substitute decision-maker), and the state has assumed the decision-making role to prevent harm to third parties. Here, it is useful to consider how such intervention can be justified, using the test proposed in section 4.3. Accordingly, this Chapter undertakes such a consideration in relation to interventions discussed in Chapter 5, by way of illustrating how the criteria in section 4.3 may be applied when the interests of a third party are being weighed against those of a patient. This Chapter emphasises that, even if the state is seeking to prevent harm to third parties by upholding important values, the state should not disregard the implications of its interventions for patients.

6.3.1 The separation of conjoined twins

If the state (through a court) proposes to intervene in circumstances similar to those in which Mary and Jodie Attard found themselves, then it should take into account the kinds of matters described in section 4.3.

The basis for the court’s intervention in the proposed separation of Mary and Jodie Attard was the widely-shared preservation of life value. However, it should be remembered that, in this case, what was required was the preservation of one life by the foreshortening of another. This was the dilemma at the heart of the case: could the court find a justification for this when, in other circumstances, the common law does not demand self-sacrifice?1087

Given that the proposed measure was intended to save Jodie’s life, then taking another (less viable)1088 life, which was dependent on Jodie’s continued existence, is arguably proportionate. However, the proposed treatment could not, I argue, be characterised as minimally intrusive (because of the magnitude and inevitable consequences of the procedure), and was far from self-evidently rational, as can be seen from the ambivalence of Ward LJ, which was fully described in Chapter 5.

1087 See, for example, McFall v Shimp 10 Pa.D&C.3d 90 (1978), as well as the general approach taken to abortion cases where, if the life of the woman is endangered by continuation of the pregnancy, most common law jurisdictions permit termination (see section 5.2.3).
In considering whether the criteria of rationality and fairness are met, I take the view that the judgment of Ward LJ is flawed by his acknowledgement that allowing the twins to live out their lives conjoined, and receiving supportive medical care, would have been legally permissible. If either course of action (separation, or failure to separate supplemented by the provision of supportive care until the twins died) would have been acceptable to the Court, then the preservation of life interpretation adopted by the judges seems to be arbitrary, despite the extensive attempts by the Court to justify and explain its decision in terms of doctrines such as self-defence and necessity. The judges seem to have taken the view that the outcome was fair as between the children, Ward LJ doing so explicitly, in a way that suggests (perhaps unconscious) conceptualisation by the judge of the twins’ relationship with each other as essentially adversarial, again, however, this is not such a clear outcome as to justify state interference with the parents’ decision. It was not the situation, as in some other cases involving the treatment of minors, that there was more than one possible answer, but only one possible answer that met the English best interests test. The best interests test was of no help here, as was explained fully in Chapter 5. In summary, this was because Mary either had no best interests or, even if she did, the fact that separation would immediately cause her death meant that it would, in my view, be absurd to suggest that such a procedure served those interests. Also, the evidence as to whether separation would serve Jodie’s best interests was equivocal, as explained in Chapter 5. Thus, while separation may have served Jodie’s interests, there was no way in which it could fairly be said to serve Mary’s. Furthermore, on the evidence reported, the fact that the Attard family came before the Court at all was a matter of chance, which depended on the hospital to which they had been sent. For these reasons, it is arguable that the Court’s intervention was neither rational nor fair.

The part of the test in section 4.3 that deals with implications for the patient’s personal interest raises particular problems in cases such as that of the Attard twins. It is important to emphasise that, in this case, the state is effectively substituting its own

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1088 See the description of the twins’ respective conditions in paragraph 5.2.2 (a).
1089 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1010.
1090 See, for example, subparagraph 5.2.2 (d) (i).
1091 I reject the view of Robert Walker LJ that Mary’s best interests were served by separation that would, however briefly, confer on her a separate physical existence.

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version of Mary's personal interest by saying that she is designated for death. In doing so, it is making a choice for Mary – Mary’s death – which patients cannot ordinarily make for themselves in advancement of their own articulation of their personal interests. Nor, on current law, can a usual substitute decision-maker make such a decision on behalf of a patient without decision-making capacity, if it involves the commission of an act (as was the case here). Let us be very clear about this: the Court of Appeal's ruling may have been the only thing standing between the doctors and convictions for murder. This was acknowledged in the judgments. These judgments reversed the general rule about acts and omissions,¹⁰⁹² but failed to advance sound reasons why such a momentous departure from precedent was acceptable. In fact, the judges failed to acknowledge that they were departing from precedent in this contentious area of the law.

What the judges should have done was to openly and clearly acknowledge that what they were trying to do was prevent a greater harm by sanctioning what, in their view (although not that of the parents) was a lesser harm. This could have been supported by explaining that application of the harm prevention policy in such a way is justified in a very limited range of circumstances where the life of one individual depends upon that of another, and that second individual’s life is seriously imperilled by the condition of the first (including the condition of dependency, as Mary was dependent upon Jody).¹⁰⁹³ By doing so, the Court would have had no need to cast the twins’ relationship in a regrettably adversarial light (as did Ward LJ), to contort the defence of necessity (as did Brooke LJ), nor to make an almost farcical (if the case were not so tragic) characterisation of Mary’s interests being served by foreshortening her life (as did Robert Walker LJ). Had this been done, the law in this area would have been in a position to be developed in a rational and transparent way in like cases.

However, given the state of the law following the judgment of the Court of Appeal in the Attard’s case, it is difficult to see that it satisfies the second criterion of the test in section 4.3 either by advancing the personal interest of the less viable twin (which it did not, except on the rather distorted approach of Robert Walker LJ, which gave disproportionate weight to physical individuation) or substituting it for a personal

¹⁰⁹² That acts ending life are not permissible, although omissions ending life are.
interest defined by the state. After all, given the general insistence on the importance of 
the preservation of life value and the general rule that the law does not require 
self-sacrifice, the state could hardly be seen to suggest that a child’s personal interest is 
best defined by such self-sacrifice.

Thus, the form that state intervention took in this case arguably failed the test in 
section 4.3, and the decision of the usual substitute decision-makers should have 
prevailed. However, as discussed above, I have indicated an alternative ground (the 
dependency approach) which may go some way to satisfy section 4.3 in appropriate 
circumstances. This may, subject to further consideration, provide an answer to the 
difficult questions raised by conjointure.

6.3.2 Abortion

Chapter 5 considered state regulation of abortion as an instance where the state, 
protecting the live of foetuses as third parties, intervenes in patients’ decision-making. 
As noted at the outset of Chapter 4, it is beyond the scope of this thesis to advance 
conclusive views on the desirability of such procedures as abortion. However, testing 
the permissibility of the state’s current interventions against the criteria described in 
section 4.3, on the basis of arguments canvassed in Chapter 5, is squarely within the 
scope of this thesis.

In effectively delegating decision-making about abortion to doctors, the state displaces 
the patient’s entitlement to decide with the aim of preventing harm to foetuses. As was 
established in Chapter 4, the preservation of life value is a compelling one which is 
widely shared in the community. What is less clear, however, is whether the 
community widely accepts that the value applies to foetal life in the same way, or to the 
same extent, as it applies to the lives of born children, or whether foetal interests should 
be seen as competing with those of mothers. This is so even though the law has 
accepted that a foetus is an entity warranting the law’s protection in certain limited 
circumstances. In my view, the controversy about this issue is so extensive and 
intense as to raise real doubt about whether the first hurdle created by the test in 
section 4.3 is, in fact, cleared. Like assisted suicide, this is an area where further

\[1093\] As explained in section 5.2.2, under the heading ‘Future uncertainty’.
investigation is needed before giving a conclusive answer to whether the test in section 4.3 can be satisfied, and state intervention justified.

The criterion of proportionality is, perhaps, reflected by certain jurisdictions in their use of gestational age as a basis on which to determine whether a proposed abortion is permissible. It appears that, the earlier in the gestational period, the more willing the state is to allow the patient’s exercise of the entitlement to decide, on the basis that the preservation of life value is not sufficiently enlivened in the foetus as third party to justify state intervention in women’s interests during the early stages of pregnancy. Alternatively, it may perhaps be considered that an argument based on dependency (such as that which I previously described in relation to conjoined twins),\(^{1095}\) applies. That is, as long as the foetus remains dependent on the woman’s body for survival, the preservation of life value should be less powerful in relation to it. This would particularly be the case if the foetus’s continued existence put the life or health and well-being of the woman at risk (for example, if the woman has uterine cancer and must have a hysterectomy to prevent the cancer from spreading).

Once a foetus is viable,\(^ {1096}\) then the preservation of life value may well become more compelling, and thus the criterion of proportionality may be satisfied. This appears to be accepted by the community, in light of reports of abortion at a late stage of pregnancy that generate significant social and political concern.\(^ {1097}\)

The question of minimal intrusiveness of the state’s regulation of abortion is an interesting one. I suggest that any measures that have the effect of requiring a woman to carry a child to term may be a significant intrusion on the interests of that woman. The well-known physical and psychological implications of pregnancy and childbirth are, I think, sufficient evidence of this. However, as in the case of judicial authorisation for sterilisation considered earlier in this Chapter, the state intervenes on a case-by-case basis and it is on that basis that this aspect of the test must be considered. Continued

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\(^{1094}\) As explained in Chapter 5: paragraph 5.2.3 (a).

\(^{1095}\) See section 5.2.2, under the heading ‘Future uncertainty’.

\(^{1096}\) A point which is being reached at progressively earlier gestational ages, depending on the health care services available.
pregnancy may be more intrusive to some patients than to others.\textsuperscript{1098} Or, if the decision to abort is made at a very late stage in pregnancy, it might be argued that continuing pregnancy until natural completion is not unduly intrusive, given the third party interests at stake.

I do not think state intervention, as currently practised, is necessarily rational. This is because it has been devolved to doctors, on the implicit assumption that the decision to abort is primarily a clinical one, falling properly within doctors' expertise. I do not think that modifications of the common law allowing doctors to take into account patients' socio-economic interests provide adequate protection for patients' personal interests, for the reasons set out in Chapter 5.\textsuperscript{1099} To the extent that the state seeks to justify its intervention by reference to the interests of patients, therefore, I think it may fail on this element.

An argument could also be made, using the test in section 4.3, to support the view that state intervention is unfair. It is well beyond the scope of this thesis to canvass the economics of abortion. However, it seems at least open to doubt whether all women, even in Australia, have access to equitable opportunities in considering alternatives about abortions. For example, there has been much public discussion in recent times (particularly in the context of the debate about RU486) concerning special difficulties that may be faced by women in rural and remote areas of Australia in accessing abortion services. If the state's approach to regulating abortion means that where a woman lives determines how reproductive decisions can be made by or about her, then this is arguably unfair.

Finally, state intervention in regulating abortion can be aimed at one of two objectives. First, it can be aimed at substituting the state's view of the patient's personal interest for that actually held by the patient; that is, with a view to protecting the patient 'from herself'. This has not been considered in this thesis, which (in Chapter 5) focused on

\textsuperscript{1097} For example, it is a matter of public record that Senator Julian McGauran took a close interest in the reported case of a woman who underwent a late term abortion of a foetus that was believed to suffer from a genetic disorder.

\textsuperscript{1098} For example, a girl or very young woman, or a woman who becomes pregnant in certain situations, such as rape. It is important to emphasise that I am not suggesting that continued pregnancy is only intrusive in such circumstances; merely, that it may be more intrusive for some women.

\textsuperscript{1099} See subparagraph 5.2.3 (c) (i).
regulating abortion with the aim of protecting a third party, the foetus. In this context, I have accepted that the law recognises foetuses as entities worthy of protection, even if they are not regarded as having their own interests. On this basis, perhaps intervention may be legitimate, provided the other criteria in section 4.3 are, following further investigation and well-informed community debate, satisfied.

6.3.3 Coercive obstetric intervention

There are three reasons why it is helpful to consider whether coercive obstetric intervention can be justified using the criteria proposed in section 4.3. First, the Australian position on coercive obstetric intervention remains unclear for the time being, because of lack of considered authority on the point. Second, the loopholes left by AC and Doe, the flexibility of the best interests test applied in England and the radical approach taken in State of Queensland v D, mean that the apparent trend (in England and the United States) away from coercive obstetric intervention may not be a reliable guide to future judgments in Australia and elsewhere. Third, coercive obstetric intervention lends itself to this analysis because the maternal/foetal relationship has so often been expressly analysed in terms of balancing interests against each other.

Section 4.3 argues that, to justify coercive intervention by the state to protect a third party at the expense of a patient’s interests, the state must identify a compelling value or

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1100 Which may, for example, be the case in the United States, where the regulation of abortion seems based on an interest belonging to the state, in preservation of life, rather than an interest inhering in foetuses themselves.

1101 I should not be understood as predicting the likelihood that a well-informed and rational debate will ever occur.

1102 See Seymour Report, 1995, 83, for proposed criteria to be used to balance maternal and foetal interests. It is important to remember that this Report was prepared before the changing trend emerged in England.

1103 I note that Seymour recommends the enactment of State and Territory legislation providing that ‘it is unlawful for a doctor to carry out, on a properly advised and mentally competent pregnant woman, a medical procedure to which she has declined to give consent.’ (Seymour Report, 1995, 104-5).


objective. As explained in Chapters 4 and 5, the preservation of life and protective values have been accepted in common law jurisdictions as being compelling, even when they relate to a being without legal personhood, such as a foetus. This view is consistent with the indivisibly linked model, and supports intervention.

Second, the proposed intervention must be proportionate, minimally intrusive, rational and fair. To take these in turn, it could be argued that even an invasive procedure such as a caesarean section is proportionate to the objective of saving a potential life. After all, a caesarean section is routine and fairly safe surgery (to the point that it is the delivery method of choice for some women). Accordingly, the test of proportionality may be met. It is unlikely, however, that a caesarean section could be considered to be minimally intrusive; certainly, the Doe Court rejected such a characterisation. It certainly could not, in my view, be considered minimally intrusive if enforcement of a court’s decision required physical force or restraint. This is a problem to which most courts have been sensitive. Courts appear to have made orders for coercive obstetric intervention in the hope that, when presented with a court order, most women will submit without the requirement for further restraint. In any event, the practical efficacy of subjecting a pregnant woman to a contempt order is not free from doubt, and it may well be that the community reaction to such a course of action would be unfavourable. A further difficulty with enforcement is that it may discriminate unfairly between assertive and timid women, because assertive women may well ‘call the court’s bluff’ and refuse to submit even if a contempt order were threatened. Most courts would be

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1107 For an alternative approach, in which a woman must have a serious reason (relating to self-determination and/or her bodily integrity) to refuse treatment which is likely to benefit a near-term foetus, see Scott, 2002, especially Chapter 1, 107, 218-9. For fear of medical intervention as a sufficiently serious reason, see Scott, 2002, 240.


1109 In Jefferson v Griffin Spalding County Hospital Authority 274 SE.2d 457 (1981), Smith J concurring held that there was no less intrusive alternative than a caesarean to deal with the clinical problem: at 461.

1110 In re AC 573 A.2d 1235 (1990), 1244; In re Baby Doe 632 NE.2d 326 (1994), 335; Tameside and Glossop Acute Services Trust v CF [1996] 1 FLR 762, 774. See also Nelson et al, 1986, 757, arguing that oversight by the state of aspects of a woman’s life that may affect the health of a foetus would be intrusive and difficult to enforce. However, the Court in State of Queensland v D [2004] 1 QdR 426 was less concerned; perhaps because the patient was a prisoner. Whether or not this should have been a relevant consideration in such a decision is beyond the scope of this thesis.

1111 See Hewson, 1992, 1546. See also Oberman, 2000, 482. In addition, the use of force to restrain a pregnant woman may have undesirable clinical consequences: see Annas, 1982, 17.
reluctant to take this course, although at least one woman has been returned to hospital under police escort to undergo a caesarean.

Other kinds of enforcement issues may arise in relation to interventions that seem minimally intrusive, such as diet and drug therapy. These treatments might assume a different character if they became part of a regime that was enforced by the state’s coercive power. Imagine, for example, if the state attempted (on pain of civil or criminal penalty) to require all women who were actively seeking to get pregnant, or even who might get pregnant, to take folic acid supplements to prevent neural tube defects in potential children. In my view, such state oversight, and enforcement, of the daily diet of all women of reproductive capacity could not be characterised as minimally intrusive.

There is a legitimate concern that coercive obstetric interventions, encouraged by advances in medical technology that enable the foetus to be seen by ‘outsiders’, as well as to be separately treated, and that reveal links between pre-conception practices and the welfare of foetuses, will be used to justify increasingly intrusive and pervasive regulation of the behaviour of all women of reproductive age. This seems to be a true slippery slope, because it is difficult to find, in the judgments thus far, principled reasons for limiting state decision-making to cases where birth of a viable foetus is imminent.

While it could be argued that intervention on the basis of medical advice is self-evidently rational and value-free, (whereas the women’s decisions are

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1112 See In re AC 573 A.2d 1235 (1990), 1244. For general comments about the use of force, see Scott, 2002, 259-60.

1113 Pemberton v Tallahassee Memorial Regional Medical Center 66 F.Supp.2d 1247 (1999); Cherry, 2002, 606. The use of force was also authorised in State of Queensland v D [2004] 1 QdR 426, possibly because the patient was a prisoner, but without apparent consideration of whether this would undermine achievement of the clinical objectives being pursued.

1114 See Haberfield, 1995, 36.

1115 See also Seymour, 2000, 227-8 and references therein. On the question of maternal liability for general conduct, see also Scott, 2002, 296-349, especially 336-7, 340-3.

1116 For a contrary view, dismissing the prospect of a ‘slippery slope’ of intervention, see Witting, 1999, 107.

1117 The assumption which is generally made: McLean, 1999, 67. See also Haberfield, 1995, 40. See Oberman, 2000, 454, arguing that doctors create the perception of a conflict between women and
sometimes characterised as irrational or even self-indulgent) I suggest that there are several reasons why coercive obstetric intervention may, in fact, be an irrational way of resolving a dispute between a pregnant patient and her doctor. These are as follows.

The non-discriminatory nature (and thus rationality in terms of the section 4.3 test) of decisions to intervene was called into question, at least in the United States, some time ago by a 1987 survey, still referred to by commentators, which showed that 81% of court orders had been made in respect of black, latino or asian women; 25% were in respect of women of non-English speaking background, and all were in relation to public patients at teaching hospitals. These outcomes may be the result of other contributing factors, but they should at least give pause for thought as to the basis on which decisions to undertake coercive obstetric intervention are made, both in the United States and elsewhere.

The first reason for arguing that decisions made in favour of coercive obstetric interventions may be irrational is that the cases are characteristically brought before a court at the eleventh hour, when the judge is placed under enormous ‘life or death’ pressure. This happened at first instance in the Angela Carder case and in In re , as well as in State of Queensland v D. Such circumstances do not lend themselves to reasoned responses, reflecting principle and precedent, because the haste and drama of the moment place judges under considerable pressure, and usually from only one side of the dispute. The consequences of this can, I respectfully suggest, be observed in the

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1118 See, for example, In re Madyun, reported at the Appendix to the judgment in In re AC 573 A.2d 1235 (1990), 1259, 1263.
1120 See, for example, Seymour, 2000, 21, 218, 233, 235; Scott, 2002, 115, note 1.
1122 Cherry, 2002, 619.
1124 In re S (Adult: Refusal of Treatment) [1993] Fam 123.
1126 An example of how things can go wrong in these circumstances is provided by St George’s NHS Trust v S [1998] 3 All ER 673, and the hearing before Hogg J (see Judge LJ at 688 on the need to resist pressure to authorise nonconsensual treatment, even where life is represented to be at stake). See also Annas, 1982, 17; Seymour, 2000, 218-9, and the cases referred to therein.
poor quality of some of the judgments. Second, accounts of forced intervention risk damaging the trust that is essential to a useful doctor-patient relationship, and may deter women (particularly women of particular religious and cultural backgrounds) from seeking treatment,\(^{127}\) or may even encourage abortion.\(^{128}\) By tending to bring about outcomes so at odds with the value that intervention seeks to advance (preservation of life), intervention is in my view shown to be potentially irrational. Third, the fact that the time for hearing these cases can be so attenuated has meant that women are often unrepresented and their interests not heard (in Carder’s case,\(^ {129}\) not even the patient’s usual doctor had the opportunity to give evidence). The evidence presented can be dominated by the clinical perspective, meaning that little weight can be given to countervailing factors arising from the patient’s broader personal interest. In one case, for example, the doctor was actually appointed the patient’s guardian, leaving little, if any, room for consideration of non-clinical factors.\(^ {130}\)

Finally, the rationality of decisions made by judges in the heat of the moment may be questioned because, in such situations, they appear to be particularly susceptible to reach a conclusion on intuitive grounds, and then develop arguments that rationalise that conclusion (as perhaps occurred in Re A,\(^ {131}\) discussed above). Part of the difficulty with the potential to reason backwards, at least in England and possibly Australia, is that it might lead to reasoning backwards from a view that intervention is therapeutically desirable or necessary to a determination, based on that view, that a woman lacks decision-making capacity because of the predicted nature of her decision. That is, a potentially ‘bad’ decision means that the patient has questionable decision-making capacity,\(^ {132}\) and therefore court intervention can be justified on the basis of a best interests finding. Such a finding will almost certainly be made unless

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\(^{127}\) See Seymour, 1994, 35; In re AC 573 A.2d 1235 (1990), 1248; Haberfield, 1995, 2, 38-9 (intervention may also damage relationship with infant).


\(^{129}\) In re AC 573 A.2d 1235 (1990).

\(^{130}\) In the Matter of the Application of Jamaica Hospital 491 NYS.2d 898 (1985). For the possibility that coercive intervention may damage women’s health, see for example, Scott, 2002, 92 and note 85. State of Queensland v D [2004] 1 QdR 426 left much of the decision-making up to the doctor.

\(^{131}\) Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961. See also McLean, 1999, 64.

\(^{132}\) For a caution against this danger, see Seymour Report, 1995, 120; Seymour, 2000, 331-2, 366.
someone shows that intervention will kill or seriously harm the woman (and it is not clear who would make this showing in an *ex parte* proceeding).

A further criterion to be taken into account in determining whether the state should intervene to displace the entitlement to decide for the benefit of a third party is fairness. I suggest that fairness of such decisions may be questionable under the criteria in section 4.3, given that the decisions so often occur without any notice being given to the woman, in circumstances in which even if notice is given, she is placed at a disadvantage (because she is in labour), she may be unrepresented (even if the hospital finds time to brief counsel), and generally, what are described somewhat cavalierly in *Jamaica Hospital* as ‘the usual formalities’ are dispensed with. These considerations underline the importance of dialogue between patient and doctor well in advance of the due date. This in itself, however, is not an adequate safeguard, because some women may not be in a position to secure pre-natal care and others may not, for a range of reasons, be able to find a doctor sympathetic to their views. Seymour, noting the shortcomings of court procedures in dealing with disputes between women and doctors about obstetrical intervention, concludes that

> All of these criticisms combine to suggest that the legal process provides procedures which are too clumsy and insensitive to respond to the issues raised when medical intervention in the life of a pregnant woman is being considered.

Finally, the matters set out in section 4.3 require the state to take into account whether it is advancing the patient’s personal interest (as with the regulation of sterilisation of disabled minors) or substituting its own version of the personal interest (as with the prohibition of assisted suicide). Neither is the case in relation to coercive obstetric interventions. Rather, the state is seeking effectively to advance the competing personal interest of a potential person. The weight to be given to such an interest

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1133 *In the Matter of the Application of Jamaica Hospital* 491 NYS.2d 898 (1985), 899.

1134 As acknowledged by Seymour, 2000, 328.

1135 Seymour Report, 1995, 87; see also Seymour, 2000, 238, 365.

1136 This is because, as discussed in Chapter 5, the common law has accepted a pregnant woman’s right to refuse medical treatment, even if her own life is at risk.
remains indeterminate under Australian law, although English authority has (as was explained in Chapter 5) explicitly rejected such considerations.

Thus, when coercive obstetric interventions are viewed against the criteria described in section 4.3, it becomes apparent that it may be difficult to justify such intervention in accordance with the criteria proposed by this thesis as being necessary to justify state intervention and displace the entitlement to decide of a patient with decision-making capacity. This conclusion is consistent with that reached by Seymour, to the effect that legal coercion of a patient with decision-making capacity may be counterproductive and inappropriate in the doctor-patient relationship. Seymour takes the view that, although the consequence of the alternative (allowing women with decision-making capacity to be the decision-makers in all cases) will be that some babies will be stillborn or disabled, the price of the state assuming the decision-making role is too high, because it threatens the entitlement to decide of all patients.

6.3.4 Tissue harvesting from patients without decision-making capacity

Chapter 5 considered the basis on which the state permits, on a case-by-case basis, tissue harvesting from patients without decision-making capacity. It was argued that this was done on the basis of the preservation of the family and preservation of life values. Like other examples of conduct canvassed in this Chapter, blanket answers have not been considered appropriate. However, this Chapter considers the kinds of arguments that could be brought to bear in applying the criteria in section 4.3 to determine whether it is justifiable for the state to intervene, in these cases, by displacing the responsibility to decide of the usual substitute decision-maker. In most of the cases likely to arise in this category, the usual substitute decision-maker has often been the

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1137 I agree with Scott that a woman’s moral responsibility is another matter: see, for example, Scott, 2002, especially 171-2.

1138 Seymour Report, 1995, 86-7, 89-92, 95, 128, 213; Seymour, 2000, 232-6, 238. For the limits of the law generally in resolving disputes about childbirth, see Seymour, 2000, 375-7. For whether a doctor could be held liable by the woman or child for respecting a woman’s refusal: see Seymour Report, 1995, 178; for a mother’s liability: see 194, 200. See also Boatright, 2001, 934-5. Seymour notes that courts may have a role where, for example, there is uncertainty about the patient’s decision-making capacity: Seymour Report, 1995, 98.

parent of both a disabled child (the putative donor who is, for the purposes of this thesis, the patient) and a child suffering from a life-threatening illness (the putative donee). The purpose of this consideration is not to advance a view about whether such harvesting is always good or always bad, but to consider whether the test in section 4.3 can be satisfied so that the state should intervene to make a decision in place of the usual substitute decision-makers. As with judicial authorisation of sterilisation of the disabled, the test in section 4.3 here serves a dual purpose. That is, the test in section 4.3 can be used to determine both whether and how to intervene, because of the case-by-case consideration that is necessary in this context.

In Chapter 5, I observed the compelling nature of the interest in the preservation of the family. In the kinds of cases considered in Chapter 5, that deal with tissue harvesting, this value is at risk because the putative donor and donee are generally in a close family relationship, which will be lost if the donee dies without a transplant. Indeed, as discussed in that Chapter, the existence of such a relationship has been the pivot on which judicial decision-making on such cases has turned. Evidence to the effect that if no donation is made, other family relationships will be compromised or even destroyed is also routinely offered, demonstrating that there is, or at least that there is perceived to be, a real risk to this value unless the state intervenes in the matter at hand.

I have also, earlier in this thesis, explained in detail the compelling nature of the preservation of life value which, in the cases being considered here, relates to the putative donee. This value is at risk in these cases because the putative donee is generally suffering from a life-threatening condition.

Thus, the values at stake are the kinds of values that have, in other contexts, been regarded as justifying state intervention in decision-making about treatment.

On one view, the question of proportionality could easily be dealt with in these circumstances. The risks of harm to the third party are likely to be significant in both

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1140 See section 5.2.4.
1141 See the cases considered at paragraph 5.2.4 (b).
1142 See the cases considered at paragraph 5.2.4 (b).
magnitude and likelihood, and the values being protected are unquestionably important and widely shared. The removal of tissue that can regenerate (such as bone marrow), is not needed by the putative donor (for example, cord blood from a ‘saviour sibling’) or the function of which can be assumed by remaining tissue (such as when removal of a kidney or part of a liver is contemplated) might well be seen as proportionate to the risk to the putative donee. On the other hand, it will be necessary, in accordance with the test in section 4.3, to take into account such matters as the prospects of successful donation and the putative donee’s post-donation prospects. If those prospects are poor, conducting an invasive procedure on a putative donor may not be proportionate, or rational.1144

The intrusiveness of the contemplated procedure on the putative donor must also be carefully considered. Procedures such as the harvesting of bone marrow and the removal of a kidney are well-known to be difficult and painful for the donor, sometimes requiring long periods of recuperation. The test in section 4.3 requires that a procedure that is chosen will be as minimally intrusive on the patient as possible.

The rationality and fairness of such procedures may be, I think, open to serious question, because decisions made to harvest tissue from patients without decision-making capacity are not necessarily universalisable, and are arguably discriminatory against the vulnerable disabled. As observed in Chapter 5, common law courts will accept (though not perhaps approve of) a decision made by a patient with decision-making capacity not to undergo a tissue harvesting procedure for the benefit of a third party.1145 I am uncomfortable with the idea that such procedures may be inflicted on vulnerable patients without decision-making capacity, on the basis of a calculus that purports to conclude that such procedures are in the patient’s best interests, while perhaps truly focusing on the interests of the third party (as is argued by Cheyette).1146 If the law’s concern is in fact the interests of the third party, then this should be made transparent, and an assessment can then be made on that basis whether it is both rational and fair to perform on vulnerable patients uncomfortable and perhaps

1143 See section 4.4.1.
1144 As in, for example, Curran v Bosze 566 NE.2d 1319 (1990).
risky procedures that may not benefit them. Where a patient, for example, is so disabled as to not be able to form relationships, it may be difficult to see what benefit they might gain by involuntarily participating in the harvesting process.

However, there are cases when such a benefit may exist; for example, where the putative donee is financially responsible for the putative donor. Also, some patients without decision-making capacity will be in a position to form and articulate views on proposed tissue harvesting; for example, the young boy in *GWW*. Such precedents emphasise the case-by-case nature of the decisions that must be made in these kinds of matters.

For such matters, the crux of the application of the test in section 4.3 is likely to be in the final element of that test, which focuses on implications of state intervention for the patient’s personal interest. Such intervention is, I think, a very clear case of the state seeking to protect the personal interest of the patient from being overridden (even with good intentions) by the usual substitute decision-maker (as can also happen when sterilisation of the disabled is proposed). In many of the cases about tissue harvesting considered in Chapter 5, the putative donor and donee are siblings, and the usual substitute decision-maker would be a parent of both donor and donee. As with parents caring for a disabled child for whom they are considering non-therapeutic sterilisation, such parents, however loving, may be in a dire situation. They may, for instance, be in a situation where a previously healthy child has been stricken with a terminal illness, and they look to siblings (or even potential siblings) for histocompatible tissue. This is quite understandable. However, where that sibling is not in a position, whether because of youth or disability, to define and assert his or her personal interest, then the parents are potentially confronted with an acute conflict between the best interests of their various children.

This kind of conflict can, I think, be regarded as giving rise to the kinds of special circumstances that would justify judicial intervention to decide about sterilisation of

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1148 *GWW and CMW* (1997) FLC 92-748.
disabled children. These special features—in particular, the grave nature of what is proposed, the risks of what is proposed and the danger that the broader personal interest of the putative patient will be discounted in pursuit (however well-intentioned) of extraneous interests—should be taken together with the gravity of the values at risk, and the serious and intrusive nature of the proposed procedure. On the basis of this combination of factors, I think that the state may discharge its burden under section 4.3. That is, the personal interest is likely to be best protected by the state displacing the usual substitute decision-maker’s responsibility to decide and acting as decision-maker through judicial authorisation, on a case-by-case basis.

6.3.5 Prohibition of female genital mutilation of adults

Chapter 5 observed that the prohibition of female genital mutilation extends to adults. In so extending the prohibition, the state displaces the entitlement to decide of women with demonstrable decision-making capacity and becomes the decision-maker, prohibiting consent to defined kinds of conduct. It is comparable to the situation in which Dianne Pretty and Sue Rodriguez found themselves: their entitlements to decide were displaced, not because they needed protection from influences that might undermine their personal interests, but because others, facing similar situations, may not be able to withstand the pressures that would transform voluntary euthanasia or assisted suicide into involuntary euthanasia.

Chapters 4 and 5 identified evidence that strongly supports the view that female genital mutilation is an inherently harmful procedure that carries with it no prospect of benefit to those on whom it is practised (and is thus distinguishable from male infant circumcision). In relation to female genital mutilation, the value that the state is seeking to further is thus the health and well-being value. I do not think that the importance of this value in society could be a matter for serious dispute. In addition, the evidence referred to above shows that female genital mutilation, when practised, poses a real and significant threat to that value. The magnitude of that risk in Australia will be, perhaps, dependent on the proportion of the population coming from cultures

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1149 It should be emphasised that such a case is distinguishable from that of Rina and Michelangelo Attard, also considered in Chapter 5. There, there was not a conflict of ‘best interests’; as explained in that Chapter, the best interests approach conventionally used was of no assistance.
that engage in these practices. In addition, the level of social and cultural pressure that may be brought to bear on women in these cultures is intense, and has been well-documented by the literature on female genital mutilation to which I have referred in Chapters 4 and 5.

Accordingly, I conclude that the state may arguably clear the first hurdle of justifying intervention by being able to point to a compelling, widely-shared value that is seriously threatened by a particular practice that is harmful to those on whom it is practised.

It can be argued that the criterion of proportionality is also satisfied. The harm inflicted in the course of, and as a result of, female genital mutilation can be severe, depending on the form of the practice being used. For example, the most extreme form of the practice, pharaonic infibulation, is known to potentially cause severe and long-lasting pain and chronic urinary tract infections (which can, unsurprisingly, lead to permanent and irreversible kidney damage). It should also be remembered that even the least invasive forms of the practice are an infringement of the patient's bodily integrity and carry significant risks of infection and impairment (for example, of sexual or reproductive functioning). In addition, although a universal prohibition (like the universal prohibition of euthanasia and assisted suicide) may have harsh consequences for individuals who genuinely believe that their personal interests are best advanced by undergoing this practice, a true slippery slope argument applies, making it unduly difficult for the state to make principled distinctions, in advance, between those in need of its protection and those who are not. Accordingly, I believe that the blanket prohibition is proportional to the harm which the state seeks to avert by its intervention.

It could further be argued that the criterion of minimal intrusiveness is satisfied. The legislative definitions of female genital mutilation, referred to in Chapters 4 and 5,\(^\text{1151}\) have been carefully crafted to ensure that they capture only the forms of conduct that will harm, and not forms of conduct that are intended to heal, restore or otherwise provide genuine therapy. For example, reconstructive surgery is exempted, so that patients recovering from violent sexual assaults, serious burns or genital cancers may

\(^{1150}\) For more detailed discussion of the distinction between female genital mutilation and male infant circumcision, see paragraph 4.4.3 (a).

\(^{1151}\) References to relevant provisions can be found in paragraph 4.4.3 (a).
undergo treatment to restore form and function. Thus, the statutory prohibitions are designed to target a very specific form of conduct. In my view, this could arguably establish minimal intrusiveness.

Rationality and fairness may also be established. The means that the state has adopted (a blanket prohibition) are closely and clearly aligned with the objective sought. Furthermore, this may not be a discriminatory measure: all members of the community are bound by the prohibition, without regard to factors such as ethnicity, culture, country of origin or social and economic means.  

Finally, this is an instance in which the state (in protecting vulnerable third parties from harm to their health and well-being), is effectively substituting its version of the patient’s personal interest. It is rejecting any characterisation of the patient’s personal interest that would incorporate undergoing female genital mutilation. Now, although this is demonstrably an intrusion into a particularly private, intimate aspect of a patient’s life, with a potentially enduring effect, I do not think that it is necessarily an impermissible intrusion. This is because, if the prohibition were to be relaxed, empirical evidence referred to in this thesis shows us that the personal interests of vulnerable women are likely to be detrimentally affected in a serious and enduring way. This is an instance where it should perhaps be acknowledged that it is a price of living in a society that, occasionally, one is required by society to accept even substantial and invasive intrusions on one’s personal interest, to preserve the personal interests of third parties.

Such cases should be distinguished from other instances in which the state (perhaps less permissibly) substitutes its own version of the individual’s personal interest; for example, as it did with Dianne Pretty. This is because prohibiting female genital mutilation preserves the individual’s choices for the future, whereas the state’s prohibition against Ms Pretty’s husband assisting in her suicide foreclosed the only choice that Dianne Pretty had left to her: the manner of her death. Thus, although the prohibition against assisted suicide may, following further investigation and debate, be found to be justified in accordance with the test in section 4.3, it would never be

\[1152\] Subject to consideration, as outlined in paragraph 6.2.2, of the argument about indirect discrimination.
justifiable as an advancement of the personal interest of patients such as Dianne Pretty and Sue Rodriguez.

Accordingly, I conclude that the state may, using the test in section 4.3, be entitled to displace a patient’s entitlement to decide about female genital mutilation in order to protect the competing personal interests of vulnerable third parties.

6.4 CONCLUSION

This Chapter has shown, in practical terms, how the test set out in section 4.3 can be used to argue for, or against, state intervention in decision-making about medical treatment, by displacing either the patient’s entitlement to decide or the usual substitute decision-maker’s responsibility to decide. Chapter 6 has also demonstrated that it may provide a framework within which the state can determine the form which its intervention ought to take, to best protect the personal interest of either the patient or a third party. In doing so, this Chapter has drawn together examples of state intervention canvassed in Chapters 4 and 5, identifying common themes and considerations, such as the prevention of harm policy, expressed through values such as the preservation of life value, the preservation of family relationships value, the protective value, and the health and well-being value.

The variety of the circumstances in cases where the test in section 4.3 is applicable means that its use would not be straightforward. Rather, as medical treatment occurs in the broader context of an individual’s life, the question of state intervention will be enmeshed in moral, social, political and economic considerations. However, this Chapter has demonstrated the value of the test in section 4.3 in providing a principled and explicit set of criteria against which these considerations can fully be discussed and debated, both at the level of abstract principle and of concrete, everyday practice.
PART 3 CONCLUSIONS

In Chapter 7, I set out the conclusions that can be drawn from the arguments made throughout this thesis.
CHAPTER 7 CONCLUSIONS

7.1 OVERVIEW OF CHAPTER

7.1.1 Contribution of thesis

My thesis is that the protection of the personal interest should be the aim of the law in relation to decision-making in the doctor-patient relationship, that the personal interest is generally best protected by a robust entitlement or responsibility to decide,\textsuperscript{1153} but that sometimes application of a harm prevention policy provides better protection. I further argue that the question of whether the harm prevention policy is likely to provide better protection for the personal interest in particular cases should be answered by applying the test proposed in section 4.3. The particular contributions of this thesis are to identify and describe the personal interest and to propose the test in section 4.3. This Chapter draws together the arguments that I have used to advance this thesis, presenting a series of normative principles that can be distilled from discussions in the preceding Chapters.

7.1.2 Departure from previous approaches

Previous judicial and academic commentary on the patient’s entitlement to decide has focused on a perceived conflict between the principles of respect for autonomy (giving rise to patients’ rights) and that of beneficence (giving rise to doctors’ duties), and how to resolve that conflict in particular cases. I believe that, in adopting such a focus, and in failing to apply a principled test to determine when to displace the patient’s entitlement to decide or the substitute decision-maker’s responsibility to decide, lawmakers have sometimes erred and, in erring, have failed to provide a sound basis for future development in the law about decision-making in the doctor-patient relationship, as new circumstances arise. Instances of error have, I suggest, included acceptance of the therapeutic privilege and the balancing process, and approaches taken to coercive obstetric intervention and the separation of conjoined twins.

To overcome these problems, this thesis turns attention away from the issue of autonomy versus beneficence, and the sterile analysis it created, and argues that if the
law focuses on the personal interest, the principles of respect for autonomy and beneficence are, in any event, given their due. They can be recognised as being complementary, rather than conflicting, and as supporting a robust entitlement to decide that protects the personal interest.

I will now set out a series of ten principles that can be distilled from the arguments made in this thesis.

7.2 FIRST PRINCIPLE: THAT THE LAW ABOUT DECISION-MAKING IN THE DOCTOR-PATIENT RELATIONSHIP SHOULD AIM TO PROTECT THE PERSONAL INTEREST

The principal argument of this thesis is that the aim of the law in relation to decision-making in the doctor-patient relationship should be to protect the patient’s personal interest, as I define it in Chapter 1. There, I argue that the personal interest is best understood as an aggregate of the various interests that have been attributed by judges as belonging to patients. They include the interest in bodily integrity, the health and well-being interest, and the dignity interest. I argue that, rather than conceptualising these interests as separate and potentially conflicting, they should be understood as being interdependent elements of a single personal interest, the content of which should be defined by the patient.

This is a significant contribution to thinking about decision-making in the doctor-patient relationship because courts (and legislatures) have traditionally taken the view, first, that one of the elements of the personal interest – the interest in health and well-being – should be given content by doctors. Second, and even more importantly, lawmakers have traditionally assumed that elements of what I describe as the personal interest can (and sometimes should) be balanced against each other to justify displacement of the entitlement to decide (as with the therapeutic privilege and the balancing process described in Chapter 3). This thesis rejects both of these views, emphasising the role of the patients (even many patients without decision-making capacity) to define the

1153 References to a responsibility to decide refer to cases in which a substitute decision-maker is involved.

Chapter 7
content of their own welfare and emphasising the indivisibility of the personal interest.\textsuperscript{1154}

7.3 SECOND PRINCIPLE: THAT THERE ARE IDENTIFIABLE THREATS TO THE PERSONAL INTEREST WHICH THE LAW MUST SEEK TO AVOID

I have referred to the importance of protecting the personal interest. To make this a meaningful point, it is necessary to identify what may threaten the personal interest. I am specifically concerned with threats created by the way in which the law about decision-making in the doctor-patient relationship has developed.

7.3.1 The threat posed by medicalisation

The first threat to the personal interest is medicalisation. When the law accords medicalised values precedence over a patient's interpretation of what constitutes his or her own good,\textsuperscript{1155} then medicalisation potentially undermines the patient's personal interest. This is because if medicalised values are accorded precedence, then a third party is effectively deciding what is good for the patient, by reference to values not necessarily shared by the patient, or given the same priority by the patient. Sometimes, medicalised values are allowed by the law to dominate decision-making in the doctor-patient relationship, under the cloak of a misunderstood notion of beneficence in which doctors define patients' welfare, rather than allowing patients to define their interests for themselves. When this occurs, then other considerations can easily be overwhelmed, when these considerations should play as important a role in the process as seems right to the patient (or substitute decision-maker).

Essentially, medicalisation of decision-making about treatment creates or exacerbates the risk that decisions will be made that do not fit within the entire context of the patient's life, which embraces his or her financial and occupational circumstances, relationship circumstances, religious and cultural mores. It is important that decisions be permitted to reflect this, because medical treatment is not performed in a vacuum. It is not enough, in my view, to urge doctors to take a broad view of what constitutes a patient's good (for example, by taking into account social and economic factors, as is

\textsuperscript{1154} And, accordingly, rejecting the notion of balancing elements of patients' personal interest against each other, on which the therapeutic privilege and the balancing process, described in Chapter 3, rely.
required in relation to abortion). This is because not even the best doctor has a full understanding of how those factors play out in a particular patient’s life, even if the doctor is well-acquainted with the patient. The patient or, if applicable, an appropriate substitute decision-maker, is in the best position to formulate what constitutes good for the patient.

Of course, allowing medicalised values to take precedence can be the intent of lawmakers who may distrust patients’ ability or will to make decisions in the best interests of themselves or certain others. But such a view overlooks the critical point that because it is the patient who must bear the consequences of the treatment then, subject to findings of incapacity or the application of the test in section 4.3, it is the patient who should make the decision about treatment.

Thus, while medicalised decision-making may seem seductive in its deceptively apparent objectivity, certainty and rationality, I have argued that such decision-making offers a false hope for harm prevention, and for the protection of what I have described as the patient’s personal interest. This is because, in my view, the harms that matter are not necessarily the harms feared by doctors or judges or legislators. The harms that truly matter are the harms that the patient, or a conscientious and honest substitute decision-maker, thinks that matter, in light of the patient’s personal interest. That is why medically-defined ‘therapeutic necessity’ is not a basis for displacing the entitlement to decide of competent patients, and why the test proposed in section 4.3 is crucial to determining when to displace the entitlement or responsibility to decide.

7.3.2 The threat posed by the imbalances of authority and effect

The second threat to the personal interest is the interaction of the imbalances of authority and effect. This interaction means that the party to the relationship who has more at stake – the patient – is potentially in a weaker position to assert himself or herself as the decision-maker, and thus to protect his or her own interpretation of the personal interest from an interpretation that may be imposed on the patient by the more

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1155 As, for example, it has done by its recognition of the therapeutic privilege and flak jacket test, and approaches taken to regulating abortion and coercive obstetric intervention.

1156 See section 7.6 for the importance, to protection of the personal interest, of appointing an appropriate substitute decision-maker where a patient lacks decision-making capacity.
powerful party, the doctor. Such an interpretation is prone to medicalisation, as described in section 7.3.1. Whether such imposition is inadvertent, or deliberate but well-intentioned, is irrelevant. An imposition of a decision by the doctor on the patient should be recognised as being an exercise in paternalism that is inconsistent with the patient’s personal interest.

This is because the reality is that the patient is best placed to determine whether proposed treatment fits in with his or her priorities, values and circumstances. In addition, there is evidence suggesting that people want more, rather than less, control over their lives. This is the practical expression of the personal interest described in Chapter 1, and which should be the subject of the law’s protection. Thus, lawmakers should focus on ensuring that patients (and their substitute decision-makers) are allowed to make decisions that reflect and advance the patient’s self-defined personal interests.

On a more theoretical level, if an individual with decision-making capacity is not permitted (all things being equal) by the law to make decisions about such an intimate matter as medical treatment, then it is difficult to see what role personal autonomy does have in society. The caveat ‘all things being equal’ recognises that there are circumstances in which the paternalism inherent in distrusting patients to make decisions that are good for themselves or others may be justifiable, as an appropriate means of protecting the personal interest. These circumstances should be established using the section 4.3 test.

This means, then, that the doctor’s role should be understood by the law more narrowly than is suggested by judges who refer to, or conceive of, doctors having ‘freedom of

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1157 My definition of emergency presupposes lack of decision-making capacity: see section 3.2.5.
1158 As noted, for example, by McLean, 1999, 163.
1159 It should be remembered that patients without decision-making capacity may nevertheless have views and preferences that should be taken into account by substitute decision-makers in formulating their views of patients’ personal interests. Even where this is not the case (because the patient is so severely impaired), a disabled patient will have a personal interest that goes beyond clinical well-being, and embraces other elements, as was recognised in cases such as Department of Health and Community Services (NT) v JWB and SMB (‘Re Marion’) (1992) 175 CLR 218 and Airedale NHS Trust v Bland [1993] AC 789.
1160 Conclusions about this test are offered at section 7.11.
choice. Doctors, except in emergencies as described in section 3.2.5, should not be the decision-makers. Instead, their role should be understood as being (in relation to the decision-making process) advisory in nature, offering information, advice and guidance; sometimes, perhaps, even persuasion (as was suggested by Butler-Sloss LJ in MB), but never coercion and never imposition of a decision on a patient or a substitute decision-maker.

7.3.3 The threat posed by the conventional ‘conflict’ analysis of the roles of autonomy and beneficence

This thesis referred to the tendency of judges and commentators to believe that rules about decision-making and disclosure in the therapeutic relationship must strike a balance between beneficence and respect for patients’ autonomy. This belief seems to have sprung from a notion that these principles exist in a state of conflict, with doctors’ attempts to act beneficently towards their patients potentially thwarted by those very patients. This is nonsense. Patients, no less than their doctors, are seeking a good outcome. What lies at the heart of the conflict theory is that what constitutes a ‘good’ outcome is sometimes the subject of dispute between the patient, the doctor and the state. Generally, the law interprets a good outcome as being an outcome that produces a result that satisfies a doctor’s clinical criteria, such as the prolongation of life, and that serves a clinically-defined notion of the health and well-being interest, perhaps in isolation from other aspects of the personal interest. Yet the prolongation of life is not always considered a good by those whose life is being prolonged. This was the case for Dianne Pretty and Sue Rodriguez.

Conceptualising these moral principles as existing in a state of conflict is not only apparently futile (because no satisfying answer has emerged in about fifty years of debate), but counterproductive. This is because it contributes to an adversarial view of the doctor-patient relationship (for example, commentary framed in terms of doctors’

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1161 Re A (children) (conjoined twins: surgical separation) [2000] 4 All ER 961, 1015.
1162 Re MB (Medical Treatment) [1997] 2 FLR 426.
1163 See, for example, F v R (1983) 33 SASR 189 and Devereux, 1999.
1164 R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1; Pretty v United Kingdom (2002) 35 EHRR 1; Rodriguez v British Columbia 107 DLR (4th) 342 (1994).
duties versus patients' rights). This way of thinking has also, as previously observed, led to the unhelpful idea of balancing patients' interests against each other. These blind alleys distract attention from, and thus threaten the vigorous protection of, what is truly at stake in the doctor-patient relationship: the patient's personal interest.

Furthermore, while courts and commentators have asserted an apparent tension between beneficence and autonomy, what is not acknowledged is an underlying tension between patients' autonomy and the fear that patients cannot be trusted to do the 'right thing'. Perhaps the appeals to beneficence as the basis for nondisclosure and doctors' decision-making in certain cases are merely camouflage for preventing harm by ensuring that the true decision-makers are trusted and objective professionals, not potentially over-emotional patients.

7.4 THIRD PRINCIPLE: THAT THE PRINCIPLES OF BENEFICENCE AND RESPECT FOR AUTONOMY SHOULD PROTECT THE PERSONAL INTEREST

The principles of beneficence and respect for autonomy do, in my view, have important roles to play in relation to decision-making in the doctor-patient relationship. I have argued that these principles should focus on the protection of the patient's personal interest.

The principle of respect for autonomy should be regarded as explaining and justifying the patient's construction and implementation of his or her personal interest. That is, this principle provides an explanation, in moral terms, of why the personal interest should be taken seriously by courts and legislatures. In addition, the principle justifies resistance against a third party, such as a doctor, imposing his or her values and priorities on patients. Over several centuries, moral philosophers from various schools have identified as important to a moral society the need to recognise the autonomy of

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1165 See, for example, the judgment of Jacobs J in Battersby v Tottman and State of South Australia (1985) 37 SASR 524. See also Cherry, 2002; Gallagher, 1987; Haberfield, 1995; Johnsen, 1986; Skene, 1998.

1166 As recognised by Brennan J in Secretary, Department of Health and Community Service (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218.

1167 For example, in cases relating to coercive obstetric intervention, such as In re Madyun, reported at the Appendix to the judgment in In re AC 573 A.2d 1235 (1990), 1259.

1168 This point has been considered in detail and at length by numerous commentators, and it is not necessary to retell that field here.
the individual. Formulating and expressing the personal interest through decision-making in the doctor-patient relationship is, I suggest, an important exercise of autonomy, because of the intimacy of what is done in that relationship and its widespread implications for various aspects of a patient’s life.

The principle of beneficence should be regarded by the law as having a role in all doctor-patient relationships, regardless of whether the patient has decision-making capacity. Even if the patient is fully capable of exercising his or her autonomy, the doctor should be required to act beneficently by recognising that each patient has his or her own version of what constitutes a good outcome (which may or may not coincide with the doctor’s view) and respecting the patient’s view of what constitutes his or her personal interest. That is, beneficence is not simply a ‘default’ principle that applies when the principle of respect for autonomy does not; for example, if the patient lacks decision-making capacity. Instead, beneficence should always be recognised as having a role to play, and that role is not narrowly focused on clinically-defined health and well-being.\^1169

This is clearly a broad interpretation and, by requiring that attention be paid to patients’ aggregate personal interests, is admittedly more complex and more demanding of doctors than an interpretation focusing merely on the protection of patients’ clinical well-being. However, if lawmakers are serious about the importance they have conventionally attached to the constituent elements of the personal interest, and to the significance of a meaningful decision\^1170 in protecting that interest, then it is necessary for beneficence to be accorded this broader interpretation. For patients lacking decision-making capacity, the principle of beneficence should be recognised as having a more complex role to play, and this was described in Chapter 2.

Finally, if my alternative approach – of focusing on protecting the personal interest rather than the relative importance of, or emphasis on, the principles of respect for autonomy and beneficence – is accepted, one concluding point should be emphasised about the respective roles of those principles. That is, they both require doctors to

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\^1169 See, for example, Saks, 2002, Chapter 1, arguing that lawyers’ focus tends to be on the protection of autonomy, while doctors’ focus tends to be on the protection of health and well-being.

\^1170 See Rogers v Whitaker (1992) 175 CLR 479, 490.
engage in particular kinds of conduct that focus on and respect patients' personal interests. In the conventional conflict model, respect for autonomy seems unfortunately to be prone to be misunderstood as doctors abandoning patients to their erratic and irrational whims, while beneficence is seen as a 'counterforce', trying to pull patients, even if against their will, into the 'clinical line'. If the approach for which I have argued were to be adopted, then respect for autonomy and beneficence would be complementary, in the sense that both principles would require doctors (and lawmakers) to both trust patients to define their own good, within the limits of their abilities (or trust substitute decision-makers to do this for patients), and would require doctors to work to fulfil that definition through discussion with patients.\footnote{As recommended, for example, by Katz, 1984.}

7.5 **FOURTH PRINCIPLE: THAT THE PERSONAL INTEREST IS USUALLY BEST PROTECTED BY A ROBUST ENTITLEMENT TO DECIDE, BELONGING TO PATIENTS**

The law should recognise a robust entitlement to decide, belonging to patients, as usually being the most effective way to protect the personal interests of patients with decision-making capacity. This is because a robust entitlement to decide allows patients to make their own decisions in a way that reflects these interests, and can thus be characterised as being likely to produce 'meaningful decisions'.\footnote{Rogers \textit{v} Whitaker (1992) 175 CLR 479, 490.} However, a critical test for the effectiveness (or the robustness) of such an entitlement will be how easy it is to displace. To effectively protect the personal interest against the threats described above, the law should ensure that displacement of the entitlement to decide occurs only in clearly-defined and predictable circumstances.\footnote{See sections 4.3 and 7.11 for how this might be done.}

7.6 **FIFTH PRINCIPLE: THAT, FOR PATIENTS WITHOUT DECISION-MAKING CAPACITY, APPROPRIATE SUBSTITUTE DECISION-MAKERS SHOULD BE APPOINTED TO PROTECT PATIENTS' PERSONAL INTERESTS**

Special consideration needs to be given to the protection of the personal interest of patients without decision-making capacity. This is because history shows us that the interests of such patients have often been dismissed, overlooked or otherwise compromised; sometimes with benign intentions, but sometimes to serve objectives in
no way connected with the welfare of the patient (for example, to further a political agenda).

I have argued that the most effective protection for such patients is usually to be found in the recognition of a robust responsibility to decide belonging to appropriate substitute decision-makers. For the purposes of this thesis, an ‘appropriate’ substitute decision-maker is not the patient’s doctor, except in the limited case of emergency, described at section 3.2.5.\textsuperscript{1174}

In some instances, the question of who is an appropriate substitute decision-maker has an easy answer. In the case of children, one or both parents will usually be the substitute decision-maker. Also, patients with decision-making capacity may execute instruments that appoint someone to act as substitute decision-maker if the patient loses capacity. If a court or tribunal is charged with appointing a substitute decision-maker, then that body should be mindful of the significance of the personal interest, and should consider who is best placed to know what the personal interest of the patient is. In doing so, it should be acknowledged that only the patient can fully know the content of his or her personal interest; even the best and most conscientious substitute decision-maker with a long-standing and intimate relationship with the patient will only have, at best, an outline. The aim of courts and tribunals should be to appoint a person who is best able to know and assert the patient’s personal interest. If this is not done, then the personal interests of patients without decision-making capacity are exposed to what I consider to be an unacceptable risk of being left unprotected.

\textbf{7.6.1 Why aren’t doctors generally the appropriate substitute decision-makers?}

The law should recognise that doctors are not well-placed to determine the content of patients’ personal interests, particularly under the pressurised and, significantly for current purposes, \textit{impersonal} circumstances in which much medical care is delivered today.

Currently, the law permits doctors to impose (consciously or otherwise) a medicalised ‘gloss’ over what he or she understands to be the patient’s personal interest, and not

\textsuperscript{1174} See also section 7.6.2.
give appropriate weight to other values that are important to the patient.\textsuperscript{1175} That is, the doctor is permitted by the law to attribute to the patient medicalised values not held by the patient, or not given the same priority by the patient as other values, such as religious or cultural values. Examples of this occurring can be seen in \textit{St George’s NHS Trust v S},\textsuperscript{1176} and the case of Ms B.\textsuperscript{1177} In their turn, judges also may impose a medicalised gloss by endorsing a doctor’s nondisclosure on the basis of medicalised values; an example of this occurring is \textit{Battersby v Tottman}.\textsuperscript{1178} There are other risks, too. In addition to medicalised values, doctors and judges may, consciously or otherwise, impose on patients’ various social, political, religious and ethical values of their own. That is documented to have occurred over several decades in the authorisation and conduct of sterilisation of disabled minors, as was acknowledged by the High Court in \textit{Re Marion}.\textsuperscript{1179} The effects of substituting a doctor’s or judge’s construction of a patient’s personal interest for the patient’s own are potentially devastating, as was acknowledged by the High Court, which stressed the damage to self-esteem and self-image that can be caused when one’s wishes and preferences seem to be taken lightly, or dismissed altogether.\textsuperscript{1180} This should reinforce the importance, argued for throughout this thesis, of allowing all patients, as far as is possible within their limitations, to construct and implement their own understandings of their personal interests.

\textbf{7.6.2 The limited emergency exception: when doctors are the appropriate substitute decision-makers}

In emergencies, the entitlement to decide is not displaced; because the patient lacks capacity, there is no entitlement to decide to be protected. However, what is to be protected should be, as always, the personal interest. In the circumstances of emergency as defined in this thesis, the only information available about a patient in such circumstances is his or her clinical condition, which the doctor is well-placed to

\begin{footnotesize}
\begin{enumerate}
\item As may occur if the therapeutic privilege or the balancing process are applied.
\item \textit{St George’s NHS Trust v S} [1998] 3 All ER 673.
\item \textit{Ms B v An NHS Hospital Trust} [2002] 2 All ER 449.
\item \textit{Battersby v Tottman} and \textit{State of South Australia} (1985) 37 SASR 524.
\item \textit{Secretary, Department of Health and Community Service (NT) v JWB and SMB (‘Re Marion’)\textsuperscript{(*)}} (1992) 175 CLR 218.
\item \textit{Secretary, Department of Health and Community Service (NT) v JWB and SMB (‘Re Marion’)\textsuperscript{(*)}} (1992) 175 CLR 218; for example, at 252 (joint judgment).
\end{enumerate}
\end{footnotesize}
determine. Recognition of the emergency exception can be explained by a policy of harm prevention (discussed at section 7.9), because the exception seeks to ensure that incapacitated patients can still lawfully receive treatment for their injuries or illnesses, while respecting as much of their personal interests as can reasonably be known in the circumstances.

The reason why it is, in my view, justifiable to allow doctors to be the decision-makers in emergencies is that in these circumstances (and these circumstances only), it is reasonable to regard the interest in survival as congruent with the entire personal interest, because of the lack of information about other elements of that interest. In no other circumstance should it be regarded as permissible to allow a patient’s personal interest to be treated as congruent with their clinical welfare. For example, even where a patient’s interests are severely attenuated by catastrophic illness, injury or disability (such as was the case for Anthony Bland, Baby J and Mary Attard), interests other than clinical well-being still exist, such as those identified by Hoffman LJ in relation to Anthony Bland.

7.7 SIXTH PRINCIPLE: THAT SUBSTITUTE DECISION-MAKERS SHOULD BE OBLIGED TO PROTECT PATIENTS’ PERSONAL INTERESTS

The role of a substitute decision-maker should be to reach his or her own view about whether proposed medical treatment protects and advances the patient’s personal interest. That view should be informed (as far as possible) by the substitute decision-maker’s understanding of the patient’s interests, beliefs, values and priorities. It is not, in my view, the role of a substitute decision-maker merely to acquiesce in a clinician’s recommendation, which may be framed by reference to predominantly clinical considerations. This is what I mean by recommending a robust responsibility to decide, belonging to substitute decision-makers other than doctors.

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1181 Such as a Jehovah’s Witness identity card, or a reasonably available advance health care directive refusing proposed treatment.


1183 In re J (A Minor) (Wardship: Medical Treatment) [1991] 2 WLR 140.


As I observed in Chapter 2, both conscientious and less scrupulous substitute decision-makers alike may (albeit for different reasons) be tempted simply to adopt a doctors’ recommendations as their own decisions. This temptation should be resisted. It is true that following a doctor’s recommendation may seem like a prudent, low-risk, easily defensible position. But that recommendation may not take into account the broader implications of proposed treatment in a patient’s life. That such implications exist, and are important to all patients, was recognised by each judge in Re Marion.1186

This is the principal Australian judgment recognising the interests that comprise the personal interest and the dangers of medicalisation. Unfortunately, however, the cautionary tale told by the High Court about those dangers seems to have been regarded as specific to those cases exhibiting the special features described in Re Marion,1187 rather than having a broader application to doctor-patient relationships, all of which involve the personal interest of the patient.

7.8 SEVENTH PRINCIPLE: THAT DOCTORS SHOULD BE OBLIGED TO MAKE SUFFICIENT DISCLOSURE TO SUBSTITUTE DECISION-MAKERS

To enable substitute decision-makers to exercise a robust responsibility to decide that can protect the personal interest of patients without decision-making capacity, it is necessary that they receive from doctors sufficient disclosure of material information. By ‘sufficient’, I mean that the information should enable the substitute decision-maker to make a decision about medical treatment that reflects the patient’s personal interest, as far as can reasonably be known by the substitute decision-maker. To ensure this, the law should prescribe a test for disclosure by doctors to substitute decision-makers that requires attention be paid to the entire personal interest.

Chapter 2 examined the current best interests test for the purpose of disclosure to a substitute decision-maker, and concluded that the law allows doctors’ disclosure to rely too much on medicalised values, giving rise to the risk that other values will be over-looked. This is a risk exacerbated by application of the ‘flak jacket’ test, and was

1186 Secretary, Department of Health and Community Service (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218.

1187 Secretary, Department of Health and Community Service (NT) v JWB and SMB ('Re Marion') (1992) 175 CLR 218, especially 250-253 (joint judgment).
recognised by the High Court in *Re Marion*. Regrettably, the High Court did not take the opportunity to tie the best interests test to clear, transparent criteria that would enhance the likelihood of non-clinical factors being taken into account by substitute decision-makers.

Because of this deficiency, I have proposed an alternative test for the purpose of disclosure by doctors to substitute decision-makers. This test is aimed explicitly at maximising the chance of protection of the incapacitated patient’s entire personal interest, by spelling out relevant factors to be taken into account in framing the doctor’s obligation to disclose to a substitute decision-maker. The test is also aimed at preventing the kinds of harm that understandably worry judges, legislators and policy-makers (such as that incompetent persons will not receive treatment, will be exploited by unscrupulous substitute decision-makers promoting their own interests or will have their interests dismissed or downplayed by well-meaning but exhausted carers). Finally, the test expressly requires that non-clinical factors be taken into account, paying due regard to the kinds of intangible interest that were identified by the High Court as belonging to patients. By proposing an alternative test for disclosure that focuses on the personal interest of patients without decision-making capacity, I hope to assist doctors and substitute decision-makers to act beneficently (that is, to protect the patient’s personal interest).

### 7.9 EIGHTH PRINCIPLE: THAT A HARM PREVENTION POLICY EXPLAINS DISPLACEMENT OF THE ENTITLEMENT OR RESPONSIBILITY TO DECIDE, AND MAY OFFER BETTER PROTECTION OF THE PERSONAL INTEREST

Across a diverse range of interactions between patients (or their usual substitute decision-makers) and doctors, the law constructs rules that curtail patients’ entitlements to decide, and substitute decision-makers’ responsibilities to decide, about medical treatment. Accordingly, I believe that judicial statements about the paramountcy of the

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1188 *Secretary, Department of Health and Community Service (NT) v JWB and SMB (‘Re Marion’) (1992)* 175 CLR 218.

1189 *Secretary, Department of Health and Community Service (NT) v JWB and SMB (‘Re Marion’) (1992)* 175 CLR 218.
entitlement to decide, and about the role of human rights in the doctor-patient relationship, deserve to be treated with circumspection, if not downright scepticism.

This thesis canvasses a diverse range of displacements of the entitlement and responsibility to decide which, at first blush, may seem to have little or even nothing in common, but which instead appear as a disparate set of isolated examples. This thesis has shown that all of these cases evidence a displacement of the patient’s entitlement to decide, with a common goal or objective: to protect the personal interest (whether of patients or third parties) by preventing harm. In these cases, judges and legislators have regarded consent as carrying less weight than a risk of harm, despite the fact that consent is generally regarded as a prerequisite to medical treatment.\(^{1191}\)

I think that, at some level, judges and legislators recognise that the most effective way in general to prevent harm is to recognise the patient’s entitlement to decide. In most cases, therefore, lawmakers are prepared to let patients make their own decisions, and are prepared to trust patients to make decisions based on enlightened self-interest. In these cases, there is perhaps an intuitive recognition that the burden of assuming risk should fairly go to the person who will bear the consequences of its materialisation. That is, the patient. An example of this approach can be seen in Rogers v Whitaker.\(^{1192}\) In such a case, where there is no risk to a third party, where the procedure is ‘elective’ in every sense and the risk (though very small) would have grave consequences for the patient were it to materialise, the judges (I suspect) had no difficulty in endorsing the recognition by King CJ of a ‘paramount entitlement to decide’.\(^{1193}\)

The conclusion that can be drawn across the cases where the entitlement or responsibility to decide has been displaced is that displacement tends to occur whenever a risk of harm is of a kind or degree that excites in judges or legislators an apprehension that patients may exercise the entitlement or responsibility to decide unacceptably.\(^{1194}\)

\(^{1190}\) See, for example, the judgment of Kirby J in Rosenberg v Percival [2001] HCA 18; (2001) 205 CLR 434.

\(^{1191}\) Rogers v Whitaker (1992) 175 CLR 479.

\(^{1192}\) Rogers v Whitaker (1992) 175 CLR 479.

\(^{1193}\) Rogers v Whitaker (1992) 175 CLR 479; F v R (1983) 33 SASR 189.

\(^{1194}\) Such as declining treatment perceived to be ‘therapeutically necessary’ or the risk of death from assisted suicide.
In particular, there seems to be an apprehension that patients will decide by reference to idiosyncratic or individual values. This apprehension is especially strong if there is a perception that decision-making by patients might lead to results that are inconsistent with medicalised values. As described in Chapter 1, there seems to be a perception that medicalised values are rational, objective and value-free, and therefore form an attractive and legitimate basis for judicial and legislative decision-making. As McLean argues throughout her 1999 work, this view of medicalised values is false.\textsuperscript{1195}

This point is, of course, a generalisation; there are exceptions. The recent English approach to coercive obstetric intervention may indicate some judges’ willingness to accommodate idiosyncratic decision-making.\textsuperscript{1196} However, the nature of the qualifications (for example, of emergency and lack of capacity) imposed in the cases prevents one from being confident that decisions such as \textit{MB}\textsuperscript{1197} can be relied on as a solid foundation for consistent and predictable recognition of a robust entitlement to decide for patients with decision-making capacity. This is because such qualifications appear from existing precedents to be easily established to the satisfaction of judges in cases of coercive obstetric intervention.

To provide greater confidence that a robust entitlement or responsibility to decide will be allowed by judges to protect patients’ personal interest, it is necessary to draw boundaries between cases in which the entitlement or responsibility to decide is likely to adequately protect the personal interest, and cases in which the harm prevention policy is likely to provide better protection for the personal interest. I propose that such boundaries be drawn by application of the test proposed in section 4.3.\textsuperscript{1198}

\textbf{7.10 NINTH PRINCIPLE: THAT PERCEIVED THERAPEUTIC NECESSITY SHOULD NOT BE A BASIS FOR DISPLACING A COMPETENT PATIENT’S ENTITLEMENT TO DECIDE}

A paternalistic attitude that patients cannot be trusted to make the ‘right’ decisions (and the assumption that there are ‘right’ decisions to be made that are knowable by third

\textsuperscript{1195} McLean, 1999.

\textsuperscript{1196} For example, \textit{Re MB (Medical Treatment)} [1997] 2 FLR 426. Although the decision of de Jersey CJ in \textit{State of Queensland v D} [2004] 1 QdR 426 is explicit in rejecting such decision-making.

\textsuperscript{1197} \textit{Re MB (Medical Treatment)} [1997] 2 FLR 426.

\textsuperscript{1198} See also section 7.11.
parties such as doctors and judges) is evidenced in judgments such as *F v R* \(^{1199}\) and *Battersby v Tottman*, \(^{1200}\) and in the persistence of the therapeutic privilege as shown by *Di Carlo v Dubois*. \(^{1201}\) Although it was in *F v R* \(^{1202}\) that an Australian judge first clearly articulated the existence of a patient’s entitlement to decide, the same judge, in the same case, also articulated the existence of a therapeutic privilege that justifies nondisclosure of material information if a doctor reasonably believes that the patient’s decision would not be ‘rational’ (presumably, as defined by the doctor). Even though the therapeutic privilege is not, apparently, widely relied upon in litigation, its existence and modern acceptance (such as in the *dicta* in *Di Carlo v Dubois*) \(^{1203}\) is, I believe, significant evidence of an attitude of distrust that appears to shape the approach of lawmakers to decision-making by patients (and their substitute decision-makers) in the diverse range of cases considered in this thesis.

Chapter 3 shows how perceptions of therapeutic necessity are believed by judges to justify nondisclosure of material risks to patients with decision-making capacity, on the basis that, in such cases, refusal of purportedly therapeutically necessary treatment is a relevant harm to be prevented. Although there has been some suggestion that the therapeutic privilege, which is based on perceptions of therapeutic necessity, no longer has practical value, \(^{1204}\) this is not a view that is shared by judges, as can be seen in *Di Carlo v Dubois*. \(^{1205}\)

I have shown that judges regard a doctor’s apprehension that disclosure of material facts will lead to a patient’s refusal of ‘therapeutically necessary’ treatment as justifying interference in a patient’s entitlement to decide about medical treatment. This interference is meant to ensure that the patient undergoes a recommended treatment, thus averting the harm anticipated from refusal of treatment. The availability of the privilege is regrettably combined with what seems to be a judicial reluctance to require

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\(^{1199}\) *F v R* (1983) 33 SASR 189.

\(^{1200}\) *Battersby v Tottman and State of South Australia* (1985) 37 SASR 524.

\(^{1201}\) *Di Carlo v Dubois* [2004] QCA 150.

\(^{1202}\) *F v R* (1983) 33 SASR 189.

\(^{1203}\) *Di Carlo v Dubois* [2004] QCA 150.

\(^{1204}\) Mulheron, 2003.
doctors to adopt safeguards to protect patients from the consequences of their enforced ignorance of material information. In these circumstances, neither autonomy nor beneficence are given their due, as is required by their significance in the doctor-patient relationship. The personal interest is not protected because preference is explicitly given to clinical values over patients’ formulations of the personal interest, even when these are known to doctors (as was the case in Battersby v Tottman).

In my view, cases of potential therapeutic privilege should be treated by doctors and judges as going to questions of capacity: if the patient has decision-making capacity, then the entitlement to decide should operate. If the patient does not have capacity, then a substitute decision-maker should be appointed, and the principles proposed in Chapter 2 applied.

Chapter 3 rejects the balancing process described in F v R. This process also, in my view, relies on perceptions of therapeutic necessity for treatment and an assumption that patients’ interests can be balanced against each other to produce an outcome. I have rejected this assumption because I have constructed a personal interest that is indivisible, and therefore should not be treated by the law as if elements of it conflict or can be weighed against each other. This is fully argued in Chapter 1.

In F v R, the Chief Justice listed a number of factors that, in his view, should be taken into account when determining what to disclose to patients. They seem to me to centre on harm prevention. Some of these factors go neither to capacity to decide, nor to materiality of information. To the extent that they are relevant at all to the question of decision-making in the doctor-patient relationship, they go to the question of how,

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1205 Di Carlo v Dubois [2004] QCA 150; see also Tai v Saxon (unreported) Full Court of Supreme Court of Western Australia, 8 February 1996.
1206 As in Battersby v Tottman and State of South Australia (1985) 37 SASR 524. See, in particular, paragraph 3.5.2 (c).
1207 Battersby v Tottman and State of South Australia (1985) 37 SASR 524.
1208 Subject to the application of the test proposed in section 4.3.
1210 See section 1.3.
rather than whether, to disclose. This is consistent with the approach taken by the joint judgment in *Rogers v Whitaker*.

The balancing process, relying on neither capacity nor materiality, is potentially a greater threat to the entitlement to decide, and consequently to the personal interest, than is the therapeutic privilege. At least the therapeutic privilege directs attention to the mental state of the patient, which may be sufficiently fragile to warrant appointment of an appropriate substitute decision-maker (other than the doctor). The balancing process, on the other hand, confers on doctors and judges an effectively unexaminable discretion that may be used to restrict disclosure with a view to preventing harm by inducing a patient, through suppression of material information, to accept clinically-recommended treatment. Because disclosure of material information is a prerequisite of a meaningful exercise of the entitlement to decide, using the balancing process to restrict disclosure potentially undermines the entitlement to decide of patients with decision-making capacity and, in doing so, threatens patients’ personal interests.

7.11 **TENTH PRINCIPLE: THAT DISPLACEMENT ON THE BASIS OF HARM PREVENTION SHOULD SATISFY A TEST TO ENSURE PROTECTION OF THE PERSONAL INTEREST**

As observed above, what can be identified in the diverse instances of displacement of the entitlement or responsibility to decide discussed in this thesis is an underlying policy of harm prevention. Judges and legislators seem to have used the admonition to ‘do no harm’ as the unacknowledged subtext to justify interventions through judgments and statutory provisions that displace the ‘supertext’ of the patient’s entitlement to decide. But this raises a question: why do judges and legislators not allow patients to exercise their entitlements to decide, in the hope that a combination of enlightened self-interest and altruism towards others will guide patients towards decisions favoured or mandated by the policy of preventing harm? The answer is straightforward, and has been foreshadowed throughout this thesis: in certain circumstances, patients are not trusted by judges and legislators first, to do what is good for them and, second, to do what is good for others.

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Articulating this view is unpalatable for Australian lawmakers in 2006. It is redolent of a paternalism that most commentators deem to have been abandoned over two decades ago, with cases such as *F v R*[^1213] and *Rogers v Whitaker*[^1214] bringing forth a new era in the understanding of the role of consent in medical treatment. This new understanding, adverted to in Chapter 1 and Appendix A, is that consent is not merely about securing the co-operation and confidence of the patient (in the belief that this promotes better clinical outcomes) but that it is necessary to allow the patient to act autonomously. The view is that so to act is the patient's entitlement, and seems to have emerged from a range of social, economic and political developments the consideration of which is beyond the scope of this thesis, but which can be said to have contributed to the development of a consumerist society, in which the emphasis tends to be on patients' rights, not doctors' duties.

While courts seem to feel that patients and lay substitute decision-makers (such as the Attards)[^1215] are not equipped to make appropriate decisions about harm, they conversely seem to feel that doctors are ideally equipped to do so. Certainly, doctors might be the ideal decision-makers if decisions about treatment were taken in a vacuum-sealed existence in an isolation or emergency ward. But life, as the commercial reminds us, is 'v. messy'; everyone's life has dimensions and aspects that will be influenced by, and have implications for, any decision about medical treatment. No doctor, however brilliant, however conscientious, can have enough of an appreciation of these to be adequately equipped to make decisions for patients, except in closely-defined instances of emergency.[^1216]

I am not saying that the harm prevention policy should never displace the entitlement or responsibility to decide. I recognise that, sometimes, a harm prevention policy is the more effective means of protecting the personal interest and, in such circumstances, *should* displace the entitlement or responsibility to decide. However, an implicit distrust of patients to make good decisions about harm prevention is not, of itself, in my view a sufficiently principled and transparent basis on which to displace a patient's

[^1216]: See section 3.2.5.
entitlement to decide. Displacement on such grounds is bound to lead to inconsistent outcomes, and to such encroachments on the entitlement or responsibility to decide as to render that entitlement or responsibility unable to protect the personal interest. Displacement should occur only sparingly, and on the basis of careful reasoning. In the absence of such a considered approach, the personal interest may be at the mercy of judicial and legislative caprice in pursuing the harm prevention policy in an indiscriminate way, or in a way that promotes medicalised decision-making that can threaten the personal interest.

Accordingly, I have argued that therapeutic necessity is not a basis for displacing the entitlement to decide and proposed a principled test to be used to determine whether, in a case where community values or the interests of third parties compete with the personal interest of a patient, the harm prevention policy should take precedence over the entitlement to decide in protecting the personal interest.

The test sets out as preconditions for displacing the entitlement to decide in favour of harm prevention: first, that prevention of harm, by displacing the entitlement to decide in a particular case, is necessary to uphold a widely-shared and compelling value. Second, the displacement of the entitlement must be shown to be a proportionate response that is minimally intrusive, rational and fair. There should be a presumption of non-displacement in applying these criteria. This is because, generally, the entitlement or responsibility to decide is the most effective protection for the personal interest.

To some extent, these criteria are derived from existing case law. Important contributions of this thesis are, first, to incorporate a new criterion, focusing on the patient’s personal interest and, second, to spell out a purpose for the test that is both far broader, yet more clearly targeted, than previously contemplated by lawmakers and commentators. Existing case law uses criteria from existing case law such as Pretty in an ad hoc collection of cases to establish the legitimacy of state intervention, without reference to a stated purpose. I propose using such criteria, in addition to the personal interest element of the test, to ensure that a principled and consistent approach is taken

1217 For example, R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1; Pretty v United Kingdom (2002) 35 EHRR 1.

1218 R (on the application of Pretty) v Director of Public Prosecutions [2002] 1 All ER 1; Pretty v United Kingdom (2002) 35 EHRR 1.
to *all* cases in which it is proposed to displace the entitlement or responsibility to decide in favour of competing values or interests, with the explicit purpose of determining whether it is justifiable to displace the entitlement or responsibility in favour of pursuing a policy of harm prevention.

The test I propose, while not eliminating subjectivity in judgement, offers new clarity, transparency and accountability in resolving cases in a principled way where the entitlement to decide competes with the harm prevention policy. It should be used in circumstances where the patient’s ability to make a free decision may be threatened by undue influences (such as assisted suicide, euthanasia and female genital mutilation) and in circumstances where the personal interests of more than one individual compete (such as abortion, the separation of conjoined twins and coercive obstetric intervention).

Chapters 4 to 61219 demonstrate the pivotal role of the test in section 4.3 by describing instances where the entitlement or responsibility to decide has been displaced, showing how that displacement can be ascribed to pursuit of the harm prevention policy and demonstrating how the test in section 4.3 may be applied in certain circumstances. Once such a test is applied, it may emerge that certain legislative or judicial interventions in medical decision-making are not legitimate. Determining this is not the purpose of this thesis, which is proposing a process, rather than prescribing outcomes for particular cases.

The point of applying the test is to ensure that the benefits of displacement of the entitlement to decide outweigh the benefits of allowing the patient or a substitute decision-maker to determine how best to implement the patient’s personal interest. Where the anticipated harm is to the patient, the ultimate test of displacement in this kind of case should be: will it better promote the patient’s personal interest than allowing the patient to decide? If the anticipated harm is to a third party, the crux of the issue is whether the risk of harm to the third party, if the entitlement or responsibility to

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1219 The test in section 4.3 is not used in Chapter 3 because, as was explained in that Chapter, the consideration under examination there (therapeutic necessity) involved not a balance between state interests and the personal interest, for which the test is designed, but purportedly between the patient’s own interests. As argued in Chapter 3, I reject such a balancing process as flawed because I have defined the personal interest as indivisible, and (in addition) more generally reject perceived therapeutic necessity of treatment as a basis for displacing the entitlement to decide of patients with decision-making capacity.
decide is given precedence, is of greater gravity than the risk to the patient if the entitlement is displaced.

7.12 CONCLUDING REMARKS

This thesis provides a solid foundation on which the law about decision-making in the doctor-patient relationship can be further refined and developed, with appropriate reference to its proper purpose: to protect patients’ personal interests. Chapters 1 and 2 demonstrate that judges, legislators and substitute decision-makers should focus on the personal interest as the subject matter for protection, abandoning the conventional ‘autonomy versus beneficence’ conflict model. Lawmakers should develop a greater trust in patients and substitute decision-makers to make their own decisions, formulate personal interests, and accept the consequences. Chapters 1 and 2 also demonstrate the basis of the entitlement or responsibility to decide. They argue that the patient’s entitlement, or the usual substitute decision-maker’s responsibility, to decide should be the presumptive position, as a necessary precondition of properly protecting the patient’s personal interest.

Chapters 3 to 6 demonstrate that, ultimately, the entitlement or responsibility to decide should be displaced only where a patient does not possess decision-making capacity, or where a harm prevention policy can be demonstrated (on the basis of the test described at section 4.3) to prevail and tip the balance away from the entitlement or responsibility to decide, in favour of another means of protecting either the patient’s personal interest or that of a competing third party.

I have described shortcomings in the protection currently given to the patients interests, offered an explanation for those shortcomings by reference to the harm prevention policy (and judgments made on the basis of that policy), and I now offer an alternative, principled approach to resolving questions about decision-making in the doctor-patient relationship. This approach uses a test with explicit criteria to balance prudent harm prevention against vigorous protection of a robust entitlement to decide (and substitute decision-makers’ responsibilities to decide), to determine the most effective means, in particular cases, of protecting that which truly is paramount – the personal interest.
APPENDIX A WHAT IS CONSENT?

(a) The transition from ‘bare’ to ‘meaningful’ consent

Developments in how consent (and its prerequisite, disclosure) in the doctor-patient relationship have been treated by the courts have been comprehensively traced by a number of commentators. It is beyond the scope of this thesis to canvass or summarise this literature in detail. However, for the sake of comprehensiveness, it is helpful to bear in mind some salient points, drawn from the law in the United States, England and Australia.

Examinations of sources dealing with medical ethics from Hippocratic traditions, through the medieval era and Age of Enlightenment and even into the twentieth century tend to emphasise a particular purpose of obtaining consent. That is, to secure both the confidence and cooperation of the patient. The belief was that a patient who was given enough information to know the nature of what was to be done to him or her would be more compliant, and more trusting, and that this combination of compliance and trust would enhance the chances of success of the treatment. Conversely, there was also a belief that ‘too much’ disclosure, especially disclosure of uncertainty, would be ‘inimical to the moral duty of the physician to take responsibility for the patient’s care’. Thus, the purpose of consent was seen as furthering the purpose of care, as described in Chapter 1. This characterisation of the purpose of consent was evident both in the old case of Slater v Baker and Stapleton, and in the more modern case of In re W (A Minor) (Medical Treatment: Court’s Jurisdiction). Such a purpose is

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1220 See, for example, Robertson, 1981; Katz, 1984; Shultz, 1985; Faden and Beauchamp, 1986; McLean, 1989, to which sources the discussion in this section is indebted.

1221 As noted by Faden and Beauchamp, 1986, 67, and Katz, 1984, 16, even more progressive Enlightenment writers such as Gregory and Rush, who advocated some disclosure to patients, nevertheless accepted that deception of patients was appropriate in certain clinical situations, in order to promote achievement of a good clinical outcome.

1222 See Katz, 1984, 6.

1223 See Demy, 1971, cited in Faden and Beauchamp, 1986, 90. This is a view that continued to have currency: see, for example, the opinion of Lord Templeman in Sidaway v Governors of Bethlem Royal Hospital and Ors [1985] 1 AC 871.

1224 See Faden and Beauchamp, 1986, 117.

1225 Slater v Baker and Stapleton 95 ER 850 (1767). See also Katz, 1984, 49.

1226 In re W (A Minor) (Medical Treatment: Court’s Jurisdiction) [1993] Fam 64.
consistent with a model of the doctor-patient relationship which emphasised doctors’ authority and patients’ obedience to that authority and which conferred on the doctor the responsibility for making decisions about treatment.

However, early in the twentieth century, another purpose of consent began to emerge: to enable a patient to exercise a right to self-determination. At this point, however, the cases were concerned principally with what might be termed a ‘bare’ consent, which required only that the patient be told of, and agree to, the procedure which was actually performed. Thus, in American cases such as *Pratt v Davis*, *Mohr v Williams*, *Rolater v Strain*, and the much-quoted case of *Schloendorff*, plaintiff-patients successfully complained to courts that what had been done to them by their doctors was not the procedure about which they had been told, and to which they had consented. The cause of action relied upon was battery, or trespass to the person, and the courts upheld the complaints on the well-established basis that a surgical operation was assault unless preceded by the consent of the patient. In *Schloendorff*, Justice Cardozo held that the foundation of this principle was the competent adult patient’s right to determine what would be done to his or her body.

There the law rested for over forty years until patients began to be more sophisticated (and assertive) in their complaints about lack of information, and started to argue that what had appeared to be their consent to treatment was, in fact, no such thing, because although they had been given information about what was to happen to them, they had not been given information about the risks posed by the proposed treatment.

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1228 See Mendelson, 1996, ‘Trespass’, 59. For the idea that the strain that this places on doctors has not been adequately considered, see Katz, 1984, xvii.
1229 *Pratt v Davis* 79 NE 562 (1906).
1230 *Mohr v Williams* 104 NW 12 (1905).
1231 *Rolater v Strain* 127 P 96 (1913).
1232 *Schloendorff v Society of New York Hospital* 105 NE 92 (1914).
1234 *Schloendorff v Society of New York Hospital* 105 NE 92, 93 (1914).
The reasons behind this increasing sophistication are complex, and go far beyond the scope of this thesis to social and political changes that had come about following a depression and a war, and changes in medical practice itself, making it ‘increasingly technical, powerful and impersonal’.

They relate to, amongst other things, notions of civil rights shared by all human beings, and increasing scepticism about authority figures in general and medical practitioners in particular, following the revelations at the Nuremberg Trials.

The upshot was that patients became increasingly dissatisfied with the authority-obedience model of the doctor-patient relationship, and began to lay claim to a more fully-realised right to self-determination. There was an emerging judicial view that this right could be the justification for demanding that consent be based on more than a bare understanding of the nature of the procedure to be undertaken and that patients should assume a decision-making, rather than a merely ‘assenting’, role.

Accordingly, cases such as *Salgo v Leland Stanford Jr. University Board of Trustees*, *Natanson v Kline* and *Canterbury v Spence* were brought to the courts by patients who successfully claimed that they were not given enough information, although they had been told about the nature of the proposed treatment. These cases marked a shift, not only in the acceptance of the notion that self-determination required more than the ‘bare’ consent suggested by earlier cases, but also in the form of action in which the complaints were brought. *Salgo*, for example, seems to have been analysed as a battery action, while *Natanson* marked

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1236 See Katz, 1984, 55, for the timidity with which complaints about consent and disclosure issues were raised prior to the 1950s.


1238 See Katz, 1984, 59.


1241 *Canterbury v Spence* 464 F.2d. 772 (1972). Following *Canterbury*, a considerable amount of legislative activity in American states (prompted by fears of a ‘litigation crisis’) strictly circumscribed actions complaining that information on which consent was based had been inadequate: see Faden and Beauchamp, 1986; Katz, 1984, especially at 82.

1242 In which, it should be remembered, only a ‘bare’ consent was relevant on the facts. See Faden and Beauchamp, 1986, 124-5; Katz, 1984, 51-2.


the first occasion in which the doctor’s duty to give information to a patient was framed in negligence.1245

Certainly, by the time that English courts squarely faced the issue of risk disclosure,1246 judges in that jurisdiction had no hesitation in holding that nondisclosure of risks did not invalidate a purported consent, and that a ‘bare’ consent was therefore sufficient to negative battery. The courts there had long accepted the proposition that consent to invasive medical procedures was necessary;1247 the question raised in the case of Chatterton v Gerson1248 was whether that consent had to be on the basis of disclosure of information that was more detailed than a mere description of the nature of the proposed treatment. Chatterton1249 answered that question by saying that nondisclosure of more detailed information went to negligence, rather than battery, and did not negative consent. In doing so, however, it did recognise that the doctor owed a duty of care to provide the patient with more detailed information.1250 This duty was nevertheless controlled by considerations of the patient’s clinical welfare, as was subsequently made clear in the opinions of the majority Law Lords in Sidaway v Governors of Bethlem Royal Hospital and Ors.1251 In that case, however, it should be acknowledged that even the conservative approach taken by the majority Law Lords recognised the patient as the decision-maker,1252 and that Lord Scarman, while agreeing with the other Law Lords that the facts did not establish the defendant doctor’s negligence, took an approach that closely resembled that adopted in Canterbury v Spence.1253

1245 Although ‘consent cases’ continued to be brought in battery for several years after Natanson: Faden and Beauchamp, 1986, 129.
1246 Having managed to avoid confronting the issue in cases such as Hatcher v Black, The Times, 2 July 1954 and Bolam v Friern Hospital Management Committee [1957] 1 WLR 582: see McLean, 1989, 101-3 and Robertson, 1981, 114-6. See also Chatterton v Gerson and Anor [1981] 1 QB 432, 442.
1251 Sidaway v Governors of Bethlem Royal Hospital and Ors [1985] 1 AC 871.
1252 See, for example, Sidaway v Governors of Bethlem Royal Hospital and Ors [1985] 1 AC 871, 897 (Lord Bridge of Harwich); 903-4 (Lord Templeman). For a detailed consideration of the opinions in Sidaway, see McLean, 1989, 110-122.
The preference of courts in the United States, England (and, as is indicated below, Australia), for framing more complex consent issues in negligence rather than battery analysis, derives from several factors. Chief among these are two reasons of judicial policy. The first of these concerns how medical treatment is perceived as an act, and 'lies less in doctrinal finesse than in the perceived need for a more elastic and doctor-friendly standard [than that provided by battery]. Besides, one is loathe to equate a healing physician to a violent ruffian.' That is, a doctor's conduct in treating a patient in good faith and without negligence does not carry the anti-social, and even malevolent, connotations suggested by the term 'battery'. Accordingly, judges have tended to believe that it would be 'against the interests of justice' and 'deplorable' to hold a doctor liable in battery if his or her 'only' fault was failure to disclose risks.

The second principal reason for preferring negligence to battery relates to the esteem in which the jurisdictions in question have tended to hold the medical profession, and fears about expanding the grounds on which doctors can be held liable to their patients. This is because the battery action is one that allows little scope for the law to impose exceptions and qualifications on liability; in other words, less scope to control the scope of liability. The negligence action, on the other hand, provides a range of opportunities for controlling the scope of liability. These include the framing of the duty of care (so that, for example, English and most United States courts have tended to favour a 'professional practice' standard for disclosure), the framing of the test for causation, and

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1254 See also Reibl v Hughes (1980) 114 DLR (3d) 1, 8, 10-11, for the Canadian view that the negligence action is more appropriate when what is complained of is nondisclosure of risk information.

1255 Katz, 1984, 69, argues that the choice between battery and negligence is a judicial policy choice between respect for autonomy and paternalism. See also Robertson, 1981, 126.


1259 See Sidaway v Governors of Bethlem Royal Hospital and Ors [1985] 1 AC 871, 883 (Lord Scarman), referring to Hills v Potter (Note) [1984] 1 WLR 641 (Hirst J).


the acceptance of the therapeutic privilege and the Australian 'balancing process.' Not surprisingly, amidst continued claims of a 'medical litigation crisis' and in the face of continued strong lobbying by health care providers to limit liability, the negligence approach will remain much more appealing in Australia for the foreseeable future.

This summary of how actions about consent to medical treatment have evolved in the last hundred years is necessarily brief. It oversimplifies the progression of judicial thinking on the matter (which was certainly not linear) and the debates that surrounded the shift from battery actions to negligence actions.

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1262 See sections 3.5.2 and 3.5.3 for explanation and discussion of the therapeutic privilege and the balancing process.

1263 Faden and Beauchamp, 1986, 60.

1264 I have deliberately refrained from using, or discussing, the term 'informed consent' because I think to do so would create more confusion than it could resolve in the space available here. For more comprehensive and nuanced treatment of how (and why) the debates on the shift from battery to negligence took place, it is necessary to turn to sources that have as a focus the history of consent to medical treatment, such as Faden and Beauchamp, Katz, McLean and Robertson.
APPENDIX B USING BIOMEDICAL RESEARCH TO ILLUSTRATE THREATS TO THE PERSONAL INTEREST

I have described the imbalances of effect and authority that are characteristic of the doctor-patient relationship and that threaten full realisation of the personal interest by patients. The purpose here is to show, in practical terms, what can happen when consent is ignored in another, similar, relationship where those imbalances also exist; that is, the relationship between researcher and subject in biomedical research. That relationship is, in my view, characterised by the same kinds of imbalance which characterise the doctor-patient relationship. Similarly, both relationships are treated by the law as requiring the consent of the person affected by the imbalances. Because of these shared characteristics, I think it is illuminating of the role of imbalances in the doctor-patient relationship to show how imbalances in the research relationship have, in the absence of vigorously-enforced consent requirements to protect the personal interests of research subjects, operated to the detriment of those subjects.

From at least the latter part of the twentieth century, there has been clear recognition by international and domestic law of the research subject’s entitlement to decide about participating in research. The Nuremberg Code and the Declaration of Helsinki laid the foundation for modern sensibilities about the decision-making role of research subjects. These instruments are now supplemented by domestic instruments, such as those published in Australia by the National Health and Medical Research Council. Modern principles require that research subjects give their consent to participation in both biomedical and behavioural research. However, researchers have consistently, and

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1265 This Code was set out in 1948, in the judgment of United States v Karl Brandt: Faden and Beauchamp, 1986, 153. For background on the development of the Code, see Annas et al, 1977, 6-9.

1266 Adopted in 1964 by the 18th World Medical Assembly: Faden and Beauchamp, 1986, 156, note 20.

1267 See the National Statement on Ethical Conduct in Research Involving Humans, http://www.nhmrc.gov.au/publications/humans/contents.html, in particular, clauses 1.7 to 1.12, which also set out instances in which consent is not required, and the Human Research Ethics Handbook—Commentary on the National Statement on Ethical Conduct in Research Involving Humans, http://www.nhmrc.gov.au/hrecbook/misc/contents.html. These are published in accordance with the National Health and Medical Research Council Act 1992; see, in particular, s 8. For explicit disclosure requirements in relation to research and teaching in New Zealand, see Right 7 (6) (a) and (b) of Code of Health and Disability Services Consumers’ Rights, discussed in Manning, 2004, 205-6.
for their own reasons, declined to recognise that entitlement. This discussion shows that other values have been regarded, by researchers, as having sufficient importance to displace the entitlement to decide, and the consequences of that displacement for research subjects.

Issues surrounding the operation of consent in a biomedical research context are complex. They include issues relating to randomised and double blind studies, the use of special or vulnerable groups and the inducement of participation in research as the only way to access certain medical benefits. Also, in relation to cadaveric research, there is the question of consent by relatives. It is not necessary to canvass such issues here. For the purposes of this Chapter, it is necessary only to observe that values driving research have conflicted with the entitlement to decide, and that persons responsible for carrying out research have sometimes unilaterally decided that research objectives taken priority over the subjects’ entitlement to decide.

Faden and Beauchamp relate a history of abuses of subjects in biomedical and behavioural research. In some instances, conflicting values were principally those of advancement of knowledge. For example, a study conducted at the Jewish Chronic Disease Hospital was aimed at determining whether ‘a decline in the body’s capacity to reject cancer transplants was caused by [the patient’s] cancer or by debilitation.’ To determine this, the researcher injected cancer patients with live cancer cells. Although

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1268 For a history of informed consent in the research context, see Faden and Beauchamp, 1986, Chapters 5 and 6. For the view that, despite formal instruments to the contrary, ‘soft law’ allows the displacement of the entitlement to decide to further research, see Case, 2003, 214.

1269 Such as students and staff members of research institutions, prisoners, members of armed forces, the mentally ill or disabled, critical care patients and children: see Dickens, 1986, 95, 97-100; Annas et al, 1977, Chapters 3 (children) and 4 (prisoners) and Appendix V (members of armed forces). For research issues unique to the critical care situation, see Saver, 1996.

1270 See Mastroianni, 1998, 181 (leading to the view that participation in research is itself a ‘right’).

1271 Which has been the subject of three major inquiries in England alone: see the Bristol Royal Infirmary Report, 2000; the Alder Hey Report, 2001; the Isaacs Report, 2003.

1272 Who would not, simply by virtue of kinship, have the legal authority to give or withhold consent for treatment during the patient’s life.


1274 Faden and Beauchamp, 1986, 161. See pages 161-162 for an account of this study, and its consequences for the development of principles concerning obtaining the consent of research subjects.
some patients were advised that they were participating in an experiment, they were not told what it involved.\textsuperscript{1275} In 1966, the researchers were censured for their conduct.

The same kind of motivation—the advancement of knowledge—seems to have underpinned the conduct reported in the Bristol Royal Infirmary and Alder Hey Reports. The Bristol Royal Infirmary Inquiry was concerned with the paediatric cardiac service provided by that Infirmary between 1984 and 1995. As a part of that Inquiry, investigations were made into the treatment of the bodies of children who had died during or after surgery; in particular, the retention of organs and tissues for purposes not related to diagnosis. The retained organs and tissues were intended to be used for purposes such as research and teaching. The Alder Hey inquiry arose with an increase, consequent on the Bristol inquiry, of public awareness of, and concerns about, retention practices.

It is acknowledged that, insofar as these inquiries focussed on concerns about the treatment of deceased patients and their body parts, they did not deal with the paradigmatic doctor-patient relationship. However, the retention practices disclosed in the course of these inquiries demonstrated what the public, and the next of kin of the deceased, felt to be an abuse of power, a lack of care and respect for deceased patients, and any ‘entitlement to decide’ belonging to family members. Whether or not it is accepted that the next of kin, particularly the parents of the children at Bristol, had ‘interests’ in a legal sense, or a right to demand a particular standard of care for their deceased family members, it is difficult to deny the validity of their concerns about how research interests seemed to take precedence over intuitively-felt (rather than legally imposed) ‘duties of care’ towards deceased patients, and relatives’ intuitively-felt ‘rights’ to consent or withhold consent to research using patients’ body parts.

In such instances as these, researchers may have been motivated by powerful desires to advance knowledge and medical science, and to benefit other patients. The researchers, consciously or not, gave these values precedence over the interests of parents in the health care of their children, and in the disposal of their children’s bodies and body parts after death. Although contemporary law did not require parents’ consent to be

\textsuperscript{1275} The plaintiffs in \textit{Mink et al v University of Chicago et al} 460 F.Supp. 713 (1978) were in a similar situation, although they were not even informed that they were participating in research.
sought in all relevant cases, the reaction (both among interested parties, such as parents, and the general public) to events at Bristol and Alder Hey demonstrated that the law was not consistent with modern expectations about decision-making in the therapeutic context (if not in the paradigmatic doctor-patient relationship). Changes in law and practice were recommended following both inquiries, and were aimed at giving fuller recognition to those interests which had been overridden by researchers, and redressing the imbalance of authority between researchers and subjects and their family members.

Other instances exhibited less attractive motivations for overriding the entitlement to decide. During the Third Reich, a capacity to see certain groups as being less than human allowed researchers to carry out appalling experiments, despite the 1931 introduction of domestic laws that strictly regulated human experimentation and the use of ‘new therapies'. The motivation behind such experiments was at least partly to affirm the superiority of the Aryan race: a political motive. The case of Moore provides an example of researchers deceiving a patient, and ignoring the requirement of consent, for the sake of money as much as for the advancement of knowledge. In that case, a potential $3 billion was at stake from the commercialisation of a cell line, the Mo-cell line, developed from Mr Moore’s tissues. These tissues were taken from him under the guise of providing on-going monitoring and treatment following the removal of his spleen to combat hairy cell leukaemia. The splenectomy was therapeutically indicated. However, requiring Mr Moore to travel regularly from Seattle to California over the course of several years, so that Dr Golde and his associates could remove blood, bone marrow, sperm, urine and other substances, was for the furtherance of commercial and research interests of Dr Golde and others, and not (as had been represented to him) for Mr Moore’s benefit.

Thus, a mix of motivations might underlie the conduct of a researcher in displacing a research subject’s entitlement to decide. Because of this, and prompted by the abuses of the Nazis, the international community acted from the late 1940s to introduce codes of

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Faden and Beauchamp, 1986, 154. The Nazis were not the only ones to see ‘research’ subjects as subhuman: the use of poor African-American men in the Tuskegee syphilis experiments exhibits similar characteristics: see Faden and Beauchamp, 1986, 165-7.

conduct that set out criteria to be met by researchers, and that represented a particular view about the significance of requiring the consent of research subjects.

Such instruments seem to represent a general consensus in society that an individual should not be required to assume risks, without his or her knowledge, to participate in research that will not benefit him or her, even if such research has great social utility because it is likely to result in benefits for large groups of people.\textsuperscript{1278} The work done at Alder Hey, and as part of the research programmes described in the Isaacs Report, for example, was likely to be of great value. Like the Bristol and Alder Hey inquiries, the Isaacs Report was concerned with the retention and use of cadaveric organs (specifically, brains). In making his report, the Chief Medical Officer noted the strong public interest in research that can only be conducted using cadaveric tissue.\textsuperscript{1279} However, the means by which the researchers secured human tissue to work on (that is, without relatives’ consent), and the way in which that tissue was treated, was the subject of strong public disapproval, at least partly because it engendered concerns that doctors were abusing their power, acting for ulterior purposes in the post-mortem ‘care’ of their patients, and that they were indifferent to the views and beliefs of family members.\textsuperscript{1280} Accordingly, the Chief Medical Officer emphasised the sensitivity of such activities, and the importance of securing consent from the parties (including, if practicable, from the patient before death or incapacity).\textsuperscript{1281}

In conclusion, it can be argued that, despite formal efforts over several decades by states to assert the primacy of the entitlement to decide belonging to research subjects, researchers (including those working under state auspices) have continued unilaterally

\textsuperscript{1278} They also emphasise the fundamental need, which is part of the imperative of care, for people to be able to believe that their doctors are acting in their interests, and not for the furtherance of purposes that are extrinsic to the doctor-patient relationship.

\textsuperscript{1279} By way of example, the Report refers to research differentiating different forms of dementia: see Isaacs Report, 2003, Chapter 46.

\textsuperscript{1280} There has been public disquiet in Australia about the use of tissue following post-mortems: see, for example, Scomazzon and Bell, 2001. I am not asserting that relatives had a legal right to consent, or refuse, what was done to their family members’ bodies, but simply that there was strong public feeling that relatives should have had a say in what was done, and that this feeling was not anticipated or respected (once it was known) by researchers.

\textsuperscript{1281} The Isaacs Report notes evidence from researchers that consent from relatives was not sought to avoid distressing them (Chapter 23). However, as was the case for relatives of patients concerned in the Bristol and Alder Hey inquiries, Mrs Isaacs argued that she would have been less distressed had she been given the opportunity to make her wishes heard.
to displace the entitlement to decide in favour of other values. The imbalance of authority has been exacerbated by researchers arrogating to themselves the entitlement to decide about undergoing research, and the imbalance of effect has been exacerbated by researchers exercising that ‘entitlement’ in a way that exposed subjects to risks and conduct (including conduct post-mortem) that they would not necessarily themselves have chosen to accept.
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