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Article (Published Version)

Morgan, Derek and Veitch, Kenneth (2004) Being Ms B: B, autonomy and the nature of legal regulation. *Sydney Law Review*, 26 (1). pp. 107-130. ISSN 0082-0512

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Being Ms B: B, Autonomy and the Nature of Legal Regulation

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Abstract

In this article, we question the apparent simplicity of medical law's construction of 'life and death' cases as a clash between the sanctity of life principle and patient autonomy. Our main purpose in doing so is to try to understand more fully the nature of law's regulation of the existence and non-existence of life. Specifically, we argue that, by broadening the understanding of autonomy in this area beyond a simple concern for patients' rights and self-determination, to include a focus on the individual generally, it becomes possible to identify some of the legal practices that are central to the manner in which law regulates the threshold between life and death. Through an analysis of a recent case in English law — *Re B (an adult: refusal of medical treatment)* — (although Australian jurisdictions presently disclose no similar, authoritative case, ours presently is *almost* an arbitrary choice) — we demonstrate the central role played in this regulation by tests for mental capacity, questions of character, explanation, and imagination. We conclude that medical law, at least in this context, can be theorised as a normalising practice — one in which the determination of norms often occurs *through* patients.

* Cardiff Law School. An earlier version of this paper benefited from the reviews of two anonymous referees to whom we are indebted for critical and constructive comments.

1. Introduction

It is something of a puzzlement that Australia has no *definitive* case on death. Most common law jurisdictions have explored, in their superior courts in the past ten years, arguments that have engaged sanctity of life arguments and right to die claims. *Airedale National Health Service Trust v Bland*¹ and *Pretty v United Kingdom*² in England & Wales; *In Re Quinlan*,³ *Cruzan v Director, Missouri Department of Health*,⁴ *Washington v Glucksberg*⁵ and *Quill v Vacco*⁶ in the United States; *Auckland Health Board v JMB*⁷ in New Zealand; and *Rodriguez v British Columbia (Attorney General)*⁸ and *Nancy B v Hotel-Dieu de Quebec*⁹ in Canada⁹ have each engaged fundamental questions of death and dying. Australian jurisdictions have, of course, generated statutory law on assistance in dying and advance refusals of treatment,¹⁰ and the scholarly literature is large, and, in the case of Margaret Otlowski's magnum opus¹¹ and Roger Magnusson's groundbreaking study,¹² definitive. But how Australian courts would approach sanctity of life and right to die arguments remains moot. There would, however, be little doubt that the keen legal embrace of autonomy that has been characteristic of judicial involvement in matters of medical practice and death in recent years, would feature squarely.

It is that core ethical concept and its reception in the common law that we intend to explore in this paper. It is not, however, our intention to describe the different notions of autonomy that might be discerned in medical law, with a view to adopting, and arguing for, an endorsement of one definition rather than another. To date, the discussion of autonomy in the academic legal literature has predominantly been confined to the criticism of cases where the judiciary has not recognised or upheld the appeal to the autonomy, or rights, of patients. The subsequent arguments have called for the acknowledgment of more patient autonomy by the courts in future. In other words, the overriding concern has been a quantitative one — more autonomy; more patients' rights; less professional medical power; more intervention by the courts in setting standards. In short, such arguments have, to a large degree, concerned the emancipation, through law, of patients from clinical capture by the medical model.

1 [1993] 1 All ER 821 (hereinafter *Bland*).

2 [2002] 2 FCR 97.

3 355 A 2d 647 (1976).

4 497 US 261 (1990).

5 521 US 702 (1997).

6 117 S Ct 2293.

7 [1993] 1 NZLR 235.

8 (1993) 82 BCLR (2d) 273 (SCC).

9 86 DLR (4th) 385.

10 *Rights of the Terminally Ill Acts* 1995, 1996 (NT); *Medical Treatment Act* 1988 (Vic) ss3–9; *Natural Death Act* 1988 (NT) ss3–7; *Medical Treatment Act* 1994 (ACT) ss4,5, 10–12, 20–23; *Consent to Medical Treatment and Palliative Care Act* 1995 (SA) ss7–11.

11 Margaret Otlowski, *Voluntary Euthanasia and the Common Law* (1997).

12 Roger Magnusson, *Angels of Death: Exploring the Euthanasia Underground* (2002).

There is no doubt that these arguments have been important, and may, indeed, have contributed to the current judicial fixation with an idea of autonomy based on rights to self-determination. They have, however, tended to proceed in an either/or manner — *either* sanctity of life holds the winning hand *or* the individual's right to self-determination ought to trump this traditional ethic. Here, we propose to investigate how the idea of autonomy lives within the common law when it comes to address the various problems created by medical practice and technology. To this end, our approach to autonomy is more concerned with the ethos that has developed recently within the common law that seeks to place more emphasis on the individual who comes into contact with medical practice. We are interested in autonomy as an instance of law's turn towards the individual generally, and not solely, or even principally, with calls for patients' rights and emancipation. As such, we intend to examine the legal practices that have grown up around autonomy and that help to determine the manner in which it operates in relation to the potential death of sick individuals. What do those practices impact upon and live off? We will seek to demonstrate that they exist in a *symbiotic* relationship with other factors, such as questions of identity and character, both of which are central to an understanding of the nature of legal regulation in cases involving life and death. If there is deeper resonance to the rhetorical chorus of 'rights to die', the same can be said of the rhetoric with which autonomy has come to occupy a central place in medical law. This essay is a preliminary examination of some of what informs this rhetoric, and we focus on the English case of *Re B (an adult: refusal of medical treatment)* to illustrate our argument.¹³

2. *Death, Dying, Rights*

'Right to die' arguments are, on one account, complex, confused, confusing, and controversial. Leon Kass has referred to what he believes is the lexical hopelessness of a narrowly conceived, literally constructed notion of a right to die.¹⁴ He has written that: 'I do not think that the language and approach of rights are well suited either to sound personal decision-making or to sensible public policy in this very difficult and troubling matter.'¹⁵ In arguing from this premise, he concludes that there is no firm philosophical or legal argument for a 'right to die': 'My body and my life, while mine to use, are not mine to dispose of.'¹⁶ And John Finnis has dismissed as mere sloganising the use of a term such as 'euthanasia' which, he claims, is devised 'for service in a rhetoric of persuasion' because it 'has no generally accepted and philosophically warranted core of meaning.'¹⁷

Max Charlesworth, on the other hand, has identified much of the prose for which the 'right to die' stands as a shorthand expression. Seen as the expanded notion of controlling the manner and the means, the geography and the grail, of

13 [2002] 2 All ER 449 (hereinafter *Re B*); Dame Elizabeth Butler-Sloss P handed down judgment on 22 March 2002.

14 Leon Kass, 'Is There a Right to Die?' (1993) 23 *Hastings Center Report* 34.

15 *Id* at 34.

16 *Id* at 39.

one's death, 'this developing recognition of the right of a person freely to determine and control, so far as is possible, the mode of his death'¹⁸ is part of the attempt to recapture the right to preside at one's death, the loss of which is bemoaned by writers as diverse as Ivan Illich and John Gray. Illich, for example, has complained that: '[S]ociety, acting through the medical system, decides when and after what indignities and mutilations [the sick person] shall die ... Western man has lost the right to preside at his act of dying ... Mechanical death has conquered and destroyed all other deaths.'¹⁹

Concern with death, dying and euthanasia is really nothing new; but has there been a change in the engagement?²⁰ There are two central points to the movement of the compass which are definitive — one as a response to movements in the other. There has been, first, as remarked upon by so many before, *the medicalisation of death* (if not life more generally). The medical management of death and dying is perhaps one of the most salient changes in the general practice of Western medicine in the past century. More and more people now die after an explicit decision has been made, either to withdraw or not to start treatment. Much modern medicine 'is pathological in its denial of death' and reflects the broader culture of which it is a part 'in refusing to recognise that we may thrive in dying, even as our souls may perish in senseless longevity.'²¹ Fear of dying, of the possible manner of death and indeed of death itself, are important parts of the human condition.²² Paul Ramsay suggests that awareness of dying constitutes an experience of ultimate indignity in, and to, the self who is dying.²³ In our dread we are capable of doing much harm; harm that may extend to patients, their families, the medical team and society at large.

17 John Finnis, 'A Philosophical Case Against Euthanasia' in John Keown (ed), *Euthanasia Examined: Ethical, Clinical and Legal Perspectives* (1995) 23–35 at 23. Or, as otherwise put, 'When I use a word,' Humpty Dumpty said, in a rather scornful tone, 'it means just what I choose it to mean – neither more nor less.' 'The question is,' said Alice, 'whether you *can* make words mean so many different things.' 'The question is,' said Humpty Dumpty, 'which is to be master – that's all.' 'Humpty Dumpty' in Lewis Carroll, *Through the Looking Glass* printed in Martin Gardner (ed), *The Annotated Alice* (1965) at 268–69.

18 Max Charlesworth, *Bioethics in a Liberal Society* (1993) at 37.

19 Ivan Illich, *Limits to Medicine: Medical Nemesis: The Expropriation of Health* (1976) at 210. See Frederick Nietzsche, 'Twilight of the Idols' in *The Complete Works of Frederick Nietzsche* at 88, quoted in Ronald Dworkin, *Life's Dominion: An Argument about Abortion and Euthanasia* (1993) at 212.

20 Daniel Callaghan offers interesting reflections on this question, while concluding that '[t]here is no clear and obvious explanation...'. See his 'Foreword' in Keown, above n4 at xiv.

21 John Gray, *Beyond the New Right: Markets, Government and the Common Environment* (1993) at 167.

22 John Saunders, 'Medical Futility: CPR' in Robert Lee & Derek Morgan (eds), *Death Rites: Law and Ethics at the End of Life* (1994) at 72–90. The Royal College of Nursing in evidence to the House of Lords Select Committee on Medical Ethics suggested that '... many people are not necessarily afraid of death, but are afraid of the manner of death.' House of Lords Select Committee *Report of the House of Lords Select Committee on Medical Ethics*, HL Papers 21–I (1994) at [187].

23 Paul Ramsay, 'The Indignity of "Death with Dignity"' (1974) *Hastings Center Studies* 47.

Secondly, this medicalisation of death and dying has been one factor that has created the conditions for the emergence of a 'right to die' discourse. And, while it may be clear that such claims do not enjoy any extensive philosophically agreed core of meaning, we all know what they mean, and what others mean when they deploy them. The rhetoric of *rights to die*, like all advertising slogans and expressions, both debases as well as encapsulates something larger.²⁴ It is syntactical and symbolic shorthand about timing and temperament, attendants and attitude, place and purposes.

The House of Lords in its deliberative capacity has set itself against euthanasia,²⁵ and in its judicial capacity against relaxation of the rule prohibiting assisted suicide.²⁶ Lord Steyn in *Ex parte Pretty* summarised the present position in English law:

By virtue of legislation suicide is no longer an offence ... Mercy killing in the form of euthanasia is murder and assisted suicide is a statutory offence ... A competent patient cannot be compelled to undergo life saving treatment. Under the double effect principle medical treatment may be administered to a terminally ill patient to alleviate pain although it may hasten death. This principle entails a distinction between foreseeing an outcome and intending it. [In *Bland*] the House of Lords held that under judicial control it was permissible to cease to take active steps to keep a person in a permanent vegetative state alive. It involved the notion of a distinction between doctors killing a patient and letting him die. These are at present the only inroads on the sanctity of life principle in English law.²⁷

Bland recognised, controversially, that the sanctity of life in English law was not an absolute value. Lord Goff said that 'the sanctity of life must yield to the principle of self determination,'²⁸ and Lord Keith that 'a person is completely at liberty to decline to undergo treatment even if the result of his doing so is that he will die.'²⁹ *Ex parte Pretty*, as Michael Freeman³⁰ and Richard Tur³¹ have argued, is rapidly coming to seem to be the anomaly in English law. To that extent the Chinese walls that have been constructed around these different forms of dying and bringing about death — entailing a distinction between foreseeing an outcome and intending it — seem to be closing in. Both death and the 'right' to it would appear to be finding legal footholds as the courts are increasingly forced to reveal their hand. Yet, in English law, the discourse of the 'right to die' has largely been absent as a mechanism to be used to justify the progressive erosion of the traditional value

24 See Charlesworth, above n5 at 34.

25 House of Lords Select Committee, above n9.

26 *R v DPP; Ex parte Pretty* [2001] UKHL 61 (hereinafter *Ex parte Pretty*).

27 [2001] UKHL 61 at [55].

28 [1993] AC 789 at 864.

29 *Id* at 857.

30 Michael Freeman, 'Denying Death its Dominion: Thoughts on the Diane Pretty Case' (2002) *Medical Law Review* 245.

31 Richard Tur, 'Legislative Technique and Human Rights: The Sad Case of Assisted Suicide' [2003] *Crim LR* 3.

placed on life. It is, rather, through the idea of autonomy that substantive aspects of ‘right to die’ claims have featured in the common law. That, again, is the focus of this examination.

3. *Chronicle of a Death Unfolding — On the Woman B*

We glean that the case of Ms B is no ordinary case from the way in which Butler-Sloss P frames the facts; the case involves ‘the tragic story of an able and talented woman of 43 who has suffered a devastating illness which has rendered her a tetraplegic. Her expressed wish, both verbally and in a written ‘advance directive,’³² is not to be kept artificially alive by the use of a ventilator.’³³ Neurological surgery was successful to the extent that it allowed her to move her head and speak, but thereafter, she made several requests for ventilation to be withdrawn, and, as a result, repeated assessments were made of her mental capacity to decide to refuse the treatment. Eventually, although it was decided that she *did* have this capacity, (and the *hospital* treated her as such), the *clinicians* were not prepared to withdraw the ventilator. The doctors’ dilemma — the court describes their position in robust terms as having been *unjust*; the Trust, on the other hand, *failed* in its responsibilities to them as clinicians — is summed up in Butler-Sloss P’s review of the evidence of the lead clinician in the case:

[Dr C] had studied and spent her professional life trying to do her best to improve and preserve life. She did not feel able to agree with simply switching off Ms B’s ventilation. She would not have been able to do it. She felt she was being asked to kill Ms B.³⁴

In her application, B had sought a declaration that she indeed had mental capacity to refuse treatment and she asked the court to declare that her continued artificial ventilation amounted to an unlawful trespass to her person.³⁵ Although popularly phrased a case involving a ‘right to die’, *Re B* apparently involved the legally less prosaic but nonetheless potent choice to accept or refuse medical treatment. It is not a case about euthanasia or physician assisted suicide, although there may have been times when Ms B might have been forgiven for wishing that it was. This is why it is little short of idle to proclaim that *Re B* is a case *merely* of refusal of treatment; of course it is. But it is not so much a question about what *B* means — in one way that is quite a straightforward enquiry — but rather where it fits. It would be more than idle to pretend that the case does not arise within and against

32 On living wills, or advance statements, see British Medical Association, *Statement About Advance Directives* (1992); *Re C* [1994] 1 WLR 290; *Bland*, above n1 at 860a–b (Lord Keith) and 866b–e (Lord Goff). For the Court of Appeal’s consideration of this point, see [1993] 1 All ER 821 at 843a (Lady Justice Butler–Sloss), 835–36 (Sir Thomas Bingham) and 852–54 (Lord Justice Hoffman). See also *Re AK* (2000) 58 BMRL 151.

33 *Re B*, above n13 at 452.

34 *Id* at 463.

35 Of course, there is a limitation to the relief here; the declaration can, by definition, only address her mental capacity *as at the date that the declaration is granted*. It cannot, for example, declare what her *future* state might be, or if assessed, might be assessed to be.

the background of what Roger Magnusson has called, in a related context, the erosion — the ‘slow death’ — of the doctrine of the sanctity of life.³⁶

The public reportage of the case would make it appear quite straightforwardly as an argument between Ms B — who argued that the law provided that her immediate death should be a foregone conclusion — and her doctors, cast in the role as engineers of the human soul, who argued that that should be a conclusion foregone. A careful reading of Butler-Sloss P’s decision, however, makes it clear that not only were the factual issues involved more complex than this but also that the legal sequelae that flow from this complexity call for a more nuanced understanding. Her judgment suggests that a doctor’s legal duties flow differently for a patient deemed to be mentally ‘competent’ and one who is assessed as mentally ‘incompetent’, and that the complexity is deepened by the possibility of bringing both the question of a patient’s ambivalence about the withdrawal of medical treatment, and the failure to experience alternative forms of treatment, to bear on such assessments. Butler-Sloss P clarifies that the doctors must, legally, make several inter-related judgments and that, *on the basis of those judgments*, depends the nature of their legal duties. Far, then, from being a simple monotone case, *Re B* involves not just one but many shades of grey against which background even the most powerful argument might be occluded or dimmed. And, while the case would seem to be a further entry in the library recording the clash between traditional Hippocratic values and modern medical law’s apparent insistence on, and regard for, autonomy and rights, we will argue that there is much more going on beneath the surface that demands a re-orientation of our standard ways of thinking.

4. *Autonomy and Mental Capacity*

Lord Justice Ward in *Re A (Children)*³⁷ averred that ‘deciding disputed matters of life and death is surely and pre-eminently a matter for a court of law to judge.’³⁸ It followed that:

This court is a court of law, not of morals, and our task has been to find, and our duty is then to apply the relevant principles of law to the situation before us — a situation which is quite unique.³⁹

Many lawyers would unhesitatingly endorse such powerful sentiments. We want to suggest, however, that they might also engender certain unease. That doubt might be prompted by asking what characteristics a court of law possesses that ranks it above all other means a society could offer for resolving a dispute concerning life and death.⁴⁰ And, of course, the answer traditionally afforded might well be that it is the impartiality of law — to be guaranteed through the neutrality of legal principles — that marks out courts as the privileged social site

36 See Magnusson, above, n12 at 54 et seq.

37 [2000] 4 All ER 961.

38 Id at 968.

39 Id at 969.

for ruling on any such disputes. The consequence of this self-proclaimed social pre-eminence is that, while life and death may engage a range of values and attract a plethora of discussions — moral, philosophical, historical, sociological, political, scientific, to name but a few — *disputes* about them are best thought of in *legal* terms.

This judicial need easily and clearly to *distinguish* between, to separate, law and morals, encounters and embraces some difficulty in medical law, given the historical foundations of medicine as an ethical practice.⁴¹ Ian Kennedy, amongst others, has reminded us of the moral basis of medical practice and the extent to which this *necessarily* involves its practitioners in the world of practical, normative ethics for which their education and training has traditionally little prepared them. Although this has not gone without drawing stinging ripostes⁴² and more thoughtful, reasoned responses,⁴³ we have — properly — insisted on the practice of modern medicine involving, implicating, indeed *being* an ethical one. Thus, it can really come as no surprise (indeed it may be thought to be a cause of celebration) when debates about contested practices within the art of medicine come to be conducted in essentially moral terms, and that changes in medical practice come to be rehearsed in moral language. Are debates in law, then, so distinct? Not all members of the judiciary are so concerned to fence off the common law from all possible incursions by moral reasoning when it is brought to judgment in contested areas or instances of medical practice.⁴⁴ Indeed, Lord Justice Ward's own essay in utilitarian ethics, in which his judgment in *Re A (Children)* is embedded, demonstrates this only too well. It is important to stress, however, that, in medical law, this play between morals and law is not confined to grand statements that seek to preserve the purity of the common law. Rather, the implicit characteristic of maintaining a distinction between the technical (which seeks to ensure impartiality) and the moral (associated with complexity, difference, and values) has filtered down from such elevated levels to occupy a more significant position in individual cases. One such example, the legal distinction made between autonomy and mental capacity, can be found in *Re B*. To make any proper sense of this distinction, however, we need briefly to survey its history.

The idea of autonomy in medical law has traditionally manifested itself as an end-point; it is a *goal*, the attainment of which is becoming ever more important. In 1992, Lord Donaldson MR delivered a significant judgment that contained a re-statement⁴⁵ of the underlying value of autonomy and a (slight) amplification of its nature:

40 A question addressed, for example, in Guido Calabresi's classic polemic with Phillip Bobbitt, *Tragic Choices: The Conflicts Society Confronts in the Allocation of Tragically Scarce Resources* (1978).

41 On this, see, for example, Albert Jonsen, *A Short History of Medical Ethics* (2000).

42 See J A Davies, 'Whose Life is it Anyway?' (1986) 292 *British Medical Journal* 1128.

43 Of which the most accessible is Anne Maclean *The Elimination of Morality* (1993) at 187.

44 See, for example, the judgment of Lord Steyn in *McFarlane and Another v Tayside Health Board* [1999] 4 All ER 961.

45 The importance of autonomy as a value in medical law extends back at least to Cardozo J's judgment in *Schloendorff v Society of New York Hospital* 105 NE 92 (NY, 1914).

An adult patient ... who suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent.⁴⁶

His comments appear to bolster the esteem in which the courts hold the sovereignty of the patient. As Martyn Evans has summarised it: ‘When doctors acknowledge a patient’s freedom to make “bad” choices seemingly against his or her clinical interests, they acknowledge the triumphing of science by ethics and they confront the uneasy blend of the biological and the biographical in the human person.’⁴⁷ Donaldson’s reference to the *option* of giving reasons for decisions purports to place the individual with ‘no mental incapacity’ beyond the scope of inquiry. The problem, however, has been this — how do we arrive at this ‘good’? By what method(s) are we able to turn to an individual and say: ‘You can now exercise your autonomy’? If the end-point in law has its roots in ethics, the journey towards it can, by contrast, be seen to pride itself on the apparently neutral technicalities of procedure. It has been this urgency to create a noticeable division between the nature of the end-point and the method of arriving at it, that has characterised the common law’s approach to autonomy in the health care context.

The assessment of individuals lies at the heart of the journey to medical law’s end-point of autonomy. This assessment manifests itself in various forms, the most common of which is the extent to which individuals can be said to have ‘mental capacity’ or to be ‘mentally competent’. While the ideas of capacity and competency have common features (such as ability and talent), it is usually stressed that their use in the legal context refers to a particular notion of competency or capacity. In the medico-legal context, for an adult to be legally competent, the main factor to be considered is the state of his or her mind.⁴⁸ The answer to the question: ‘Should this individual be allowed to exercise his or her right to self-determination?’, is discovered by asking, initially: ‘To what extent

46 *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 at 102. The latter comment in relation to reasons had first been noted by Lord Templeman in *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital and Others* [1985] AC 871 at 904: ‘If the doctor making a balanced judgment advises the patient to submit to the operation, the patient is entitled to reject that advice for reasons which are rational, or irrational, or for no reason.’ Of course, there may be both logical and morally significant reasons – not all related to autonomy – for distinguishing between making a choice and reasons for rejecting advice.

47 Martyn Evans, ‘Philosophy and the Medical Humanities’ in Martyn Evans & Ilora Finlay (eds), *Medical Humanities* (2001) at 251.

48 This is the approach commonly adopted in Australian statutory tests of understanding. For example, the *Powers of Attorney Act* 1998 (Qld) sched 3 and the *Guardianship and Administration Act* 2000 (Qld) sched 4 define capacity as ‘(a) understanding the nature and effect of decisions about the matter; and (b) freely and voluntarily making decisions about the matter; and (c) communicating the decisions in some way.’ Similar definitions can also be found in the *Guardianship Act* 1987 (NSW), s33(2); *Guardianship and Administration Act* 1995 (Tas) s36(2) and *Guardianship and Administration Act* 1986 (Vic), s36(2). See also *Re Bridges* [2001] 1 Qd R 574.

does he or she satisfy the requirements of the decision-making process set out by the common law?'. This process takes the form of a series of three questions, the specific purpose of which is to decide whether the individual has understood the nature, purpose and effects of a proposed medical treatment. If he or she has done so, mental capacity is deemed to exist and nothing ought to stand in the way of the individual's exercise of autonomy. The three elements to be satisfied are the following: (a) has the individual been able to comprehend and retain information provided by the physician regarding medical treatment?; (b) has he or she believed that information?; and, (c) has he or she weighed the information, balancing risks and needs, when arriving at his or her choice?⁴⁹

In *Re B*, this legal distinction between autonomy and mental capacity was, once again, central to the management of the dispute. From the outset, Butler-Sloss P was careful to stress that this was a case about ascertaining the presence or absence of an individual's *mental capacity to make decisions about medical treatment*. This, she said, was not to be confused with the *nature of the patient's decision*, however grave the consequences of Ms B's refusal of treatment would be. The patient's decision may 'reflect a difference in values rather than an absence of competence.'⁵⁰ In other words, doctors, and presumably the courts, must exclude consideration of what a patient has decided when trying to establish whether he or she has sufficient mental capacity to make a decision about treatment.

There are several problems with this legal attempt to create a distinction between mental capacity and autonomy. Those problems strike not only at the root of one of the guiding distinctions in medical law, but, more importantly, demand a re-orientation in our thinking about the nature and operation of law in this area.

A. *Capacity and Decisions*

The first difficulty with the distinction arises even before beginning to consider the elements of the test for mental capacity or, to put it more realistically, the assessment of individuals. The problem is this: how can you ascertain a patient's mental capacity without being concerned with the nature of what he or she decides? The general point is captured by Ian Kennedy:

When devising tests for incapacity, are we talking about the patient or are we talking about a decision taken by the patient? The answer must be that we are concerned with both. We are concerned to establish that the patient meets certain criteria and one of the ways in which we seek to determine this is by examining the decision reached by the patient. The two, the patient and the decision, are inextricably intertwined. The trouble is that the moment we admit this, that the content of a patient's decision is relevant in the determination of capacity, we face the problem of autonomy simply being overwhelmed by paternalism It is its

49 See *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 All ER 819 (Thorpe J). It should be noted that, while this test to ascertain mental capacity was endorsed by Butler-Sloss LJ in *Re MB (An Adult: Medical Treatment)* [1997] 2 FCR 541, her manner of formulating it seems to have rendered the second stage inapplicable.

50 *Re B*, above n13 at 450.

desire to avoid this (inevitable) conflation of decision with decision-maker that led the Court of Appeal [in *Re MB*]⁵¹ to want to be seen to nail its colours to the mast of patient autonomy.⁵²

While Kennedy sees the patient's decision as one possible means by which to *examine* mental capacity, we would suggest that it is the very nature of the patient's decision that results in the *need* to question and assess his or her mental capacity *to make decisions*. What would be the point of tests to establish mental capacity if the nature of one's decisions was beyond investigation? If Ms B had agreed with the medical staff to continue with ventilation, there would have been no need to question, or assess, her capacity. So, in fact, contrary to what Butler-Sloss P argues, and although supported by a line of judicial authority, the first *pre-requisite* for the establishment of tests for mental capacity is revealed as *a consideration of the nature of a patient's decision*. In other words, a decision is required, and one whose nature offends medical practice, the ethics of the medical profession, the personal values of the medical staff, or whatever. It is important, then, to note that tests for mental capacity arise *as a result of the nature of the patient's decision*.

This conflation of the nature of decisions and the assessment of mental capacity can be seen further in the following statement from Butler-Sloss P's judgment in *Re B*:

I shall ... have to consider in some detail her ability to make decisions and *in particular the fundamental decision whether to require the removal of the artificial ventilation keeping her alive*. It is important to underline that I am not asked directly to decide whether Ms B lives or dies but whether she, herself, is legally competent to make that decision. [Emphasis added.]⁵³

The question to be asked is this: is this woman legally competent to decide whether she lives or dies? In other words, the assessment of her mental capacity is to be measured against the 'fundamental' nature of the decision to be made — that between life and death. But the point is, surely, that she has already made such a decision. She clearly, then, has the ability to make the decision. What the law is interested in, however, is something completely different — that is, does she have *the ability to decide as she has*. *This* ability has nothing to do with *actually making a decision*. If it had, there would have been little reason to seek the intervention of the courts. Rather, it is, fundamentally, to do with ruling on the existence or destruction of life as such and, specifically, whether Ms B can persuade a judge that she deserves to flout the importance that law often places on the maintenance of human life. Thus, the real point of legal tests for mental capacity seems not to be to assess some projected future or, indeed, past ability to make a choice between life and death, but to assess whether the person making that decision can construct a convincing case why he or she reaches the standard of the 'ability' that law expects in such circumstances. The nature of his or her decision is crucial in that it triggers *this* type of assessment.

51 *Re MB*, above n49.

52 Ian Kennedy, 'Commentary' (1997) 5 *Med L Rev* at 321.

53 *Re B*, above n13 at 454–455.

B. Accounting for Reasons

The second difficulty with the legal distinction between tests for mental capacity and the nature of patients' decisions (or, the 'autonomy' stage) can be seen by returning to Lord Donaldson's statement above in *Re T*. He stresses that adult patients who are not assessed as lacking mental capacity may choose freely with regard to medical treatment that has been offered to them. There is no need for them to prove to others that their decisions are reasonable; indeed, there is no obligation to offer reasons for their decisions. But this 'freedom' and, in particular, the reference to irrationality and the non-existence of reasons, sits uneasily with the final criteria of the three-stage legal test for determining mental capacity. The problem revolves around the question why, if an individual need give *no* reasons for making a decision, he or she must demonstrate that they have taken account of *anything* when making that decision? In other words, there is no need to give reasons for a decision, but it *is* necessary to show that you have performed a reasoning process in arriving at a decision. The important point is that the last stage of the test for mental capacity involves deciding or choosing, and the method of arriving at that decision or choice. The legal procedure as it currently stands would seem to read something as follows: (a) decision (effectively refusal of medical treatment); (b) assessment of mental capacity, including the weighing of information provided and the balancing of risks and needs when arriving at a decision; (c) finding of no mental incapacity; (d) the individual has a right to choose or make a decision for whatever, or no, reason at all. Lord Donaldson's frequently cited words about individuals being able to decide as they see fit for whatever or no reason at all, would appear to be superfluous given that decisions must, *in the first instance*, conform to a certain procedure, one of the purposes of which is to assess *how* patients make decisions — how they weigh information, balance it and so on. If this is so, then what interests those assessing mental capacity is, as we shall soon see, the whole decision-making, or reasoning, process, including the various factors (such as values and beliefs) against which the treatment information is weighed, balanced, and so on. The procedure of assessment *cannot* conveniently omit consideration of those wider aspects.

This notion of autonomy as it currently exists in medical law cannot, then, be thought of as a separate stage that follows on from assessments of the mental capacity of patients. Rather, the extent to which the former is deemed to exist at all is wholly dependent on the procedure adopted for assessing the mental capacity of individuals to make decisions they have already taken. Before going on to discuss the consequences of this conflation, it is worth noting one further important aspect of Lord Donaldson's judgment in *Re T*.

As we have noted, the law envisages the assessment of individuals as occurring at the level of mental capacity. The nature of decisions is considered to be distinct and, assuming mental capacity is deemed to exist, beyond investigation. But Lord Donaldson's judgment makes it clear that, even where the individual is considered not to lack mental capacity, and therefore has a right to make a decision about treatment for whatever, or no, reason, assessment of the way in which the individual chooses to exercise this right is still possible:

[J]ust because adults have the *right to choose*, it does not follow that they have in fact exercised that right. Determining whether or not they have done so is a quite different and sometimes difficult matter. And *if it is clear that they have exercised their right of choice*, problems can still arise in determining what precisely they have chosen. [Emphasis added.]⁵⁴

How does the common law seek to justify questioning the choices that it has declared individuals are capable of making?

It is important to note that Lord Donaldson takes care not to base his qualification of the right to choose on any criticism that could be made of the nature or merits of the patient's reasons for choosing to consent to, or refuse, medical treatment — how could he when, by his own 'test', reasons for refusal need not be rational or even exist?⁵⁵ Instead, as his judgment on the facts of this particular case reveals, it is to ostensibly technical matters, such as the extent of third party influence on the patient's decision and the scope of a patient's refusal, that we ought to turn to find reasons for overriding his or her right to choose. So, where patients have exercised their right to choose, and Lord Donaldson comments that 'problems can still arise in determining what precisely they have chosen', he is referring, in the instant context, to whether T's refusal of a blood transfusion was intended to apply to a changed set of medical circumstances. Thus, what appears is a second level of inquiry — namely, an assessment of the *legally autonomous* individual's manner of choosing. How did this individual choose? What did he or she mean to express in that choice? What were the boundaries of its application? Despite the existence of a right to choose, judicial discretion can still intervene to question the nature of its exercise in an individual case. What is interesting is to probe the origin of this discretion; for if a right of choice has been exercised by an individual, it would seem strange to ascribe, as Lord Donaldson tries to do, the need to question it to the indecisiveness of that individual.

In order to appreciate the beginnings of this doubt, it is necessary to emphasise the circumstances in which it comes to exist. We have now reached the end-point of autonomy, where the right of choice is viewed as an important ethical value. As such, Lord Donaldson acknowledges that the woman's appeal is not only concerned with the right to choose to refuse medical treatment; it is also 'about the "right to choose how to live."⁵⁶ It is unsurprising, then, to find that Lord Donaldson hints at a broader conflict of interests:

The patient's interest consists of his right to self-determination — his right to live his own life how he wishes, even if it will damage his health or lead to his premature death. Society's interest is in upholding the concept that all human life is sacred and that it should be preserved if at all possible. It is well established that

54 *Re T*, above n46 at 102 (Lord Donaldson MR).

55 It is, however, illuminating to note a comment made by Lord Donaldson in another 'competency' case decided only one month before *Re T* — 'I personally consider that religious or other beliefs which bar any medical treatment or treatment of particular kinds are irrational...'. See *Re W (A Minor) (Medical Treatment: Court's Jurisdiction)* [1993] Fam 64 at 80.

56 *Re T*, above n46 at 102 (Lord Donaldson MR).

in the ultimate the right of the individual is paramount. But this merely shifts the problem where the conflict occurs and calls for a very careful examination of *whether, and if so the way in which, the individual is exercising that right*. In case of doubt, that doubt falls to be resolved in favour of the preservation of life for if the individual is to override the public interest, he must do so in clear terms. [Emphasis added.]⁵⁷

This classic conflict between two public interests (the interest in rights to self-determination and the interest in the preservation of life) is interesting because, if the patient is declared as having a right to choose, then no such conflict ought to exist at all. If, as Lord Donaldson argues, there is no need for reasons, far less rational ones, to be given for refusing treatment, why should any further ‘careful examination’ of the manner in which an individual decides be necessary? This question is an interesting and difficult one that calls for much deeper examination. For the present, we will observe only that the assessment of the way in which an individual chooses to exercise his or her *right to choose* does not cease even after it has been decided that he or she does, in fact, have such a right.

5. *Explanation, Character and Imagination*

This convergence of the technical (tests for mental capacity) and the evaluative (the nature of decisions or the ‘autonomy’ stage) produces situations that have an important bearing on understanding the nature of medical law. We will first outline some of those situations and, in the following section, discuss how they are symptomatic of the way in which law regulates questions of life and death.

As the assessment of mental capacity and the nature of patients’ decisions merge, so individuals must explain the reasons for their decisions. For example, in *Re B* — through questions designed to assess whether she had been ambivalent in her views about the withdrawal of ventilation, and why she did not want the proffered one-way weaning programme⁵⁸ — the patient was *required to explain* what she thought about dying and the manner in which this would occur. In order to justify her choice, she had to speak not only of her decision and the reasons behind it, but also of her suffering. This general requirement is captured by Marinos Diamantides, discussing the case of *State of Tennessee v Northern*.⁵⁹ This, he claims, appears to have made the right to refuse treatment ‘subject to an existential requirement: the patient must take a pro-active attitude towards his or her suffering. They must speak “of it”....’⁶⁰

57 *Id* at 112.

58 The purpose of this programme is gradually to reduce the number of breaths supplied by the ventilator, thereby allowing the patient’s body to become accustomed to breathing without assistance again. If difficulty in breathing occurs, the patient is not given artificial ventilation again, but, rather, is only sedated.

59 563 SW 2d 197 (1978) (Tenn Ct App).

60 Marinos Diamantides, *The Ethics of Suffering: Modern Law, Philosophy and Medicine* (2000) at 64.

This is also illustrated in *Re B*, where it becomes impossible for Ms B to confine her explanations about the possible treatment alternatives to the level of technical benefit or risk. If the third vector of the legal test for mental capacity envisaged such a neutral assessment, for Ms B, to talk about ventilators and one-way weaning programmes was *to talk about death*, her values, and beliefs. So when, for example, Mr Francis QC, representing the hospital Trust, asked her whether what she wished for was to die or not to remain alive in her present condition, part of her explanation was that she found the idea of living in this condition intolerable. It was a question directed to uncovering the root of the nature of her decision.

This requirement for Ms B to speak of the nature of her decision led to an assessment of how well, in the judge's opinion, she had spoken of it; moreover, Ms B was fortunate in *remaining* competent to speak to the court. This also required a judgment of her *character* in deciding whether she was to be considered as having mental capacity.⁶¹ This is illustrated by Butler-Sloss P's comments in her judgment:

Her wishes were clear and well-expressed. She had clearly done a considerable amount of investigation and was extremely well-informed about her condition. She has retained a sense of humour and, despite her feelings of frustration and irritation which she expressed in her oral evidence, a considerable degree of insight into the problems caused to the hospital clinicians and nursing staff by her decision not to remain on artificial ventilation. She is, in my judgment, an exceptionally impressive witness. Subject to the crucial evidence of the consultant psychiatrists, she appears to me to demonstrate a very high standard of mental competence, intelligence and ability.⁶²

Who is this woman? Does she communicate and, if she does, does she do so effectively? Does she incorporate within her communication more than simply references to her own predicament? From Butler-Sloss P's summary, it is clear that Ms B is considered not only to be articulate, but also knowledgeable about her condition, capable of responding to her situation with humour, and appreciative of the problems her decision had caused to those caring for her. This latter aspect seemed particularly important to the judge. It was something that needed to be overcome or spoken of in properly lucid terms. Its negative implication had to be sufficiently compensated for by her general attitude and demeanour, something that she clearly managed to do owing, amongst other things, to her insight, intelligence, and ability. The overall impression given by the judge was that Ms B had reached certain *unspecified standards of character and persuasiveness* that

61 Assessments of individuals' characters and personalities have also been important in other areas of medical law, particularly where allegations of negligence are made against doctors who have not disclosed information about the potential risks of medical treatment. In this regard, see, for example, *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital and Others* [1985] AC 871 and *McAllister v Lewisham and North Southwark Health Authority and Others* [1994] 5 Med LR 343.

62 *Re B*, above n13 at 462.

made her *deserving* of having her decision upheld. What is clear is that, if such a grave decision were to be condoned, there needed to be much more than a bare explanation of the risks and benefits of medical treatment. In other words, here, the law, in ascertaining the existence of mental capacity, demands much more of the patient than its own tests appear to require.

But it was not merely the court's assessment of this woman that mattered. Given that such cases required 'the highest degree of scrutiny',⁶³ the evidence of the two consultant psychiatrists called to testify was, according to Butler-Sloss P, 'crucial'. While there was much emphasis placed on the need to respect the values individuals often express through their decisions about medical treatment, and to reiterate that questions of mental capacity were to be distinguished from the nature of individuals' decisions, the importance attached to the evidence of psychiatrists in the ascertainment of mental capacity confirms the depth and range of possible factors the law considers may validly impinge on the state of an individual's mind. Questions were raised, for example, regarding the possibility of psychological regression, the patient's childhood experiences, and whether she suffered from mental illness. Thus, while those temporary factors were not sufficiently evident in this case to render B mentally incompetent to refuse medical treatment, the broader significance lies in their validity to the legal process, and, consequently, the importance of the expert to this process.

The President's stress on the division between assessing people's mental capacity and the way in which they choose their own ends was, in part, intended to define the proper role of the medical expert in such matters. The legitimate authority of the expert is to be confined to the technical and neutral matter of assessing the individual's mind with a view to ruling on capacity. However, the psychiatrist is not only involved in assessing the extent to which individuals can understand and retain specific treatment information, believe it, and weigh it in arriving at a choice; he or she is also concerned to assess the possible causes of why individuals decide as they do. Is there something in this person's past (an incident or experience), for example, that might explain their decision? But to ask such a question with the purpose of establishing the presence or absence of mental capacity is to find oneself in the role of examining lives, the courses they have taken, the influences that have shaped them, the decisions that have affected them. In other words, the investigation of such factors has, as its purpose, the identification of any untoward events in the past that may *explain* why the individual chooses as he or she does. It is the nature of Ms B's decision — choosing death over life — that is, once more, central to the need to involve psychiatrists in the first place, and the 'crucial' nature of psychiatric evidence can surely only rest in the extent to which it can uncover reasons or causes in the course of an individual's life that may help to explain such an odd decision. Once again, the law's reliance on this type of inquiry obviously enlarges the scope of the factors that can be taken into account in assessing mental capacity *and* tends to confirm the suspicion that there is much more at stake here than the assessment of Ms B's ability to weigh the risks and benefits of medical treatment.

63 Id at 468.

A further result of the conflation of mental capacity and autonomy is the emergence of the importance of *imagination* — something that played a significant part in Butler-Sloss P’s judgment. One of the expert psychiatrists, Dr Sensky, reiterated the importance of distinguishing the patient’s decision from the assessment of her mental capacity. It was imperative, he said, to begin by focusing on the individual and his or her capacity to make decisions. In so far as values were concerned, the patient’s subjective values had to be taken into account and respected. In order to clarify his point, Dr Sensky referred the court to Kim Atkins’ paper ‘Autonomy and the Subjective Character of Experience’,⁶⁴ on which Butler-Sloss P was later to rely.

The thrust of Atkins’ paper — itself based on Thomas Nagel’s seminal essay ‘What is it like to be a bat?’⁶⁵ — is that, while human beings experience and perceive in a similar way to one another, there is always something irreducibly unique about their experiences and perceptions. Drawing on Nagel, Atkins argues that it is this uniqueness that grounds both the subjective character of experience and the value of respecting the autonomy of individuals. Given the nature of this experience, it is impossible to know objectively what it would be like to be another human being. We can, however, *imagine* not just what it would be like for *me* to be in the position of another human being in a specific set of circumstances, but, also, what it would be like *to be that other human being* in that same set of circumstances. Atkins argues that the importance of such imagination stems from the need ‘to act from respect for that [other] person’s autonomy’.⁶⁶

The hypothesis, Atkins’s hypothesis that Butler-Sloss P endorses, as we might indeed have imagined, has triggered an enormous literature in the philosophy of mind.⁶⁷ It invokes the problem of ‘other minds’ — the philosophical proposition, a very Cartesian notion, that the mental contents (what others think) is a mystery to us and therefore ‘internal’. This view suggests that others always remain a mystery to us and that we can only hazard, or guess, what is in their mind.⁶⁸ Butler-Sloss P’s response to this conundrum is to say that we can resolve this problem with empathy. This gets us some way, we believe, to an understanding of one of the ways in which this problem is falsely set up. We do, in fact, operate in a world of common meanings, of linguistic signs, of cultural propositions, which means that we do have access to the embodied and emotional nature of reason, even of another; reading people, then, is *inevitable*, albeit here, unnecessary.

This thesis, however, adds nothing to the process of resolving Ms B’s case. It is not obvious that the argument is being used or deployed in a way that Atkins would have intended for it. This is clear from both the example she uses in discussion — a patient on a right ventricular assist device ‘*where the ill person is*

64 Kim Atkins, ‘Autonomy and the Subjective Character of Experience’ (2000) 17 *Journal of Applied Philosophy* 71.

65 Thomas Nagel, ‘What is it Like to be a Bat?’ in Thomas Nagel (ed), *Mortal Questions* (1979) at 165-180.

66 Atkins, above n64 at 78.

67 Ngairé Naffine, of the University of Adelaide, alerted us to this.

68 See Mary Warnock, *Imagination and Time* (1994) for an accessible discussion.

incapable of exercising his or her autonomy’ [Emphasis added.]⁶⁹ — and in her conclusion to the paper:

There is, for each of us, something that it is like to be “me”, and it is called the subjective character of experience. Our subjectivity grounds the value we attach to persons and personal autonomy. When we are faced with the regrettable position *of having to make dire decisions on behalf of another*, the only way to act so as to respect that person’s autonomy is to promote a consideration of that person’s subjective perspective. [Emphasis added.]⁷⁰

Atkins, therefore, envisages the thesis of the subjective character of experience as applying to situations, unlike that of Ms B, where individuals are clearly unable to communicate their views directly (for example, where they are unconscious), either contemporaneously or through the medium of an applicable advance statement. And here, as we have shown above, the legal conditions for believing that the individual’s very choice may be invoked are likely to be absent. ‘Was she legally competent to make the decisions she has made?’ is *not* the same as asking, as Atkins demands, that to respect her autonomy we must ask of the other’s subjective perspective, because competence is set up as an objective, and not a subjective, concept. It is clear from Atkins’s argument, and her example, that it is directed to, and if deployed might have been of much more assistance in, cases such as *Bland* and *Re F*, or even in B’s case, if the court had decided that she was incapable of making decisions for herself. Advocating the subjective character of experience in those cases might not only have produced a different result, especially in *Re F*,⁷¹ if not in *Bland*, but would certainly have given the law a different shape. Butler-Sloss P is, however, adamant that the thesis ought to apply to Ms B’s circumstances: ‘[W]e have to try inadequately to put ourselves into the position of the gravely disabled person and respect the subjective character of experience.’⁷²

If we accept (which at least seems arguable these days) that there are irreducible differences between us that separate us as subjects, then it may be appropriate to ask that we imagine what it would be like for me to be on a ventilator *in the same condition, and all other things being equal*, as B finds herself. We may wonder, however, what it would be or what it would entail to ask that we imagine — or think — that we *are* Ms B. Still less is it clear what it adds *to what Ms B is saying*. In other words, what added value is there to imagining that we are Ms B, *rather than just doing as she asks*?

Of course, we can understand the good intentions of Butler-Sloss P in adopting this thesis of experiential imagination. Medical staff must try to understand the

69 Atkins, above n64 at 76.

70 Id at 78.

71 See, Derek Morgan & Robert Lee, ‘Sterilisation and Mental Handicap: Sapping the Strength of the State?’ (1988) 15 *J Law & Society* 229.

72 [2002] 2 All ER 449 at 472. The aspirational character of the thesis is, to some extent, captured in Bob Dylan’s ‘Positively 4th Street’: ‘I wish that for just one time you could stand inside my shoes and just for that one moment I could be you.’

position of individuals such as Ms B and, by so doing, appreciate the values of the chronically ill. Nonetheless, and in addition to the point that this process seems superfluous in a case such as Ms B's, there is no necessity that imagination need work in any particular manner. To imagine is itself an evaluative process that does not lose this characteristic by pretending to think we are someone else. It is surely possible to come to either conclusion (acceptance/continuation or refusal/withdrawal of medical treatment) after taking into account a variety of factors that we consider are relevant when we try to imagine that we are the ill person in their circumstances. Thus, leaving aside the fundamental problems that imagination poses, let us say I imagine myself to be individual X who is unconscious on a ventilator. I come to the conclusion that she would wish to continue with ventilation and, therefore, continue to provide ventilation. A fairly unremarkable conclusion, one may think. But is the point not that it says more about the conscious individuals who pretend to be X than it does about X in a position where values mean nothing to him or her? We cannot entirely leave our values and identities behind even when we pretend to be someone else. In other words, it is not irrelevant to acknowledge that we are always trying to understand *ourselves* even when we are attempting to imagine not being ourselves, but someone else — just like medical staff who, in a similar situation, have to contend with their identities as members of the medical profession and all the values that that involves. The main point is, though, that this is another mechanism by which the assessment of individuals occurs in an attempt to respect their autonomy more realistically. This evaluative technique, therefore, helps us to understand a further element of the legal practices surrounding autonomy in medical law.

Let us summarise a couple of the main points made so far. Medical law's distinction between the nature of patients' decisions, and their mental capacity to make those decisions, corresponds to the emphasis it places on the division between autonomy (in the sense of a right to choose) and legal tests to establish mental capacity. We have argued, however, that this division is untenable when one considers the legal practices, and the tests themselves, more carefully. The result is that the law's own tests for mental capacity work to confound the purpose for which they were originally designed — that is, to ensure neutrality by establishing a technical procedure that seeks to prevent account being taken of the nature of the patient's decision and the reasons behind it.⁷³

We have also tried to demonstrate that those tests, and the law's discussion of patients' rights to choose generally, are intimately bound up with what we would call law's 'threshold' function — that is, its central task of deciding on the borders that exist between life and death. Given the significance of this function, it is

73 A related point has been made by Jonathan Montgomery in his discussion of religious beliefs in healthcare law. See Jonathan Montgomery, 'Healthcare Law for a Multi-Faith Society' in John Murphy (ed), *Ethnic Minorities, Their Families and the Law* (2000) at 161–179. However, Montgomery does not think there is anything wrong with the legal tests for competence per se. Rather, it is the manner in which law applies these to the facts of specific cases that he believes is problematic. We have argued that both aspects contribute to undermining the law's claim to neutrality.

possible to witness broader assessments of the individual occurring — something that is consistent with the focus on explanation, character and imagination as techniques of assessment. This situation further works to undermine the distinction law attempts to make between autonomy and tests for mental capacity.

While to point out this aspect of law's inconsistency is important, it does little to further our understanding of the nature of legal regulation in this area, save to say that law's tests, and the practices associated with them, contradict its stated objectives. In order to expand our understanding of this regulation, it is necessary to ask three questions: First, why is it that, in relation to medical practice, new situations of life and death have been created in the last forty years or so; secondly, what were some of the reasons for the increased focus on autonomy — in the general sense that we have sought to describe it — in medicine during this same period; and, finally, what have those general changes meant for the nature of legal regulation in the medical law sphere? Finally, we offer some preliminary reflections on these questions in English and, we anticipate, Australian law.

6. *Consequences for Law's Identity*

A. *The impact of Technological Development*

Medical law offers a fascinating and important window through which to view some significant metamorphoses in contemporary society. *Re B* is a further case that illustrates the complex relationships amongst death, life, dying, living, the individual and law. The increasing importance — and shifts in meaning — of those different factors owe much more to movements external to law than to any nostalgic belief in the instrumentalism of the latter. It is not possible to discuss all the reasons for those transformations here. Rather, we confine ourselves to a brief discussion of the impact that a couple of technological developments have had in transforming what were then traditional understandings of life and death.

Peter Singer provides a useful account of two related developments — the redefinition of death in the 1960s and the emergence of the ventilator — that had significant consequences for what he calls our 'traditional ethic' — that is, the sanctity of life principle.⁷⁴ The invention of the mechanical ventilator or respirator in the 1950s was intended to replace the function of the brain stem (which makes breathing and heartbeat possible) and, thereby, maintain the lives of individuals long enough for them to make a full recovery from whatever physical intrusion they were suffering. While it undoubtedly had this effect for some, others continued to live without recovering consciousness. As this process could continue indefinitely, the question arose as to the value of persisting with ventilation in such circumstances.

In the 1960s, questions surrounding organ transplantation, especially that of the heart, became pertinent to the discussion regarding artificial ventilation. In order for the heart to be transplanted successfully, it needed to be removed as quickly as possible after death. The many irreversibly unconscious individuals receiving

⁷⁴ Peter Singer, *Rethinking Life & Death: The Collapse of Our Traditional Ethics* (1994).

ventilation in hospitals then came to be seen as a potential source of life-saving organs for other individuals awaiting transplant surgery. The problem was that the removal of an unconscious individual's heart would amount to murdering him or her. It was this obstacle, together with the futility of providing ventilation to such individuals, that led, in 1968, to the recommendation by the Harvard Brain Death Committee that the definition of death be altered from one of the cessation of breathing and circulation to one of irreversible cessation of all brain function.⁷⁵ Those falling within the latter category — the functioning of whose organs could be maintained artificially by means of ventilation — could therefore be declared dead and provide a source of organs for transplantation to those who needed them.⁷⁶

Those early technological developments obviously altered not only the scientific definition of death but produced new types of death and different categories of patient — the individual who will recover sufficiently to be removed from the ventilator; the patient who will remain unconscious, even with the assistance of the machine; and those, like Ms B, who, while conscious, will be *unlikely* to survive without the assistance of artificial ventilation.⁷⁷ The latter two indicate the effects that developments in medical technology have had on traditional understandings of death and individuals', and their families', experiential relationships with it. There is, therefore, a real sense in which advances in modern science have delivered *Ms B* — like Tony Bland and Stephen Blood before her — not only to the ward of the hospital, but also to the precincts of the court.

B. The Rise of the Patient and His or Her Autonomy

If technological change produced, and continues to produce, novel perceptions of life and death, it also contributed to the emergence of patient autonomy as a central idea during roughly the same period. However, it took the birth of bioethics as an academic discipline in the late 1960s and early 1970s to highlight the connection between the two.

In his work on the history of medical ethics, Albert Jonsen refers to Joseph Fletcher, who, in 1949, 'affirmed that in all these problems [of medical ethics], it was the patient who had the right to decide what should be done ... The bioethics that would emerge some 20 years [later] was built around the concept of the autonomy of the patient'.⁷⁸ The emergence of bioethics, however, did not occur simply as a result of the call for an increased focus on the views of patients. Jonsen

75 For a simple explanation and review, see Christopher Pallis, *ABC of Brainstem Death* (1983) and 'Death' *The New Encyclopaedia Britannica* (15th ed, 1986).

76 For a trenchant criticism of this development and a survey of equally forceful objections, see Martyn Evans, 'Against the definition of brain stem death' in Morgan & Lee (eds), *Death Rites*, above n22 at 1.

77 There was a 5 per cent chance that she would survive without ventilation if it were to be withdrawn. She would then become a legal cousin to Diane Pretty, whose almost contemporaneous struggle to achieve a *subjectively defined* 'good death' with dignity failed to gain legal sanction, but for different reasons, in the English courts and the European Court of Human Rights.

78 Jonsen, above n41 at 94.

also traces the birth of this new discipline to the intense research agenda being conducted in the United States between 1945 and 1965. As we have indicated, during this period organ transplantation began and the ventilator was invented. The emergence and success of such new operations and technology brought with them, among other things, a pressing set of ethical dilemmas, the most significant of which concerned the nature and meaning of life and death. As discussions relating to such issues proliferated, Jonsen says that '[b]ioethics inherited the task of delineating the principles and values that would shape those ethical dimensions'.⁷⁹ That those principles would include patient autonomy seemed not to be in doubt. Given the often brutal experiments conducted by Nazi physicians on non-consenting prisoners in concentration camps during World War II,⁸⁰ purportedly in the name of science, it would have been inconceivable if patient autonomy had not formed a crucial part of the emerging discipline of bioethics. This discipline, and the integral place of autonomy within it, was thus born of two very different types of research — one whose intentions were altruistic; the other whose practices and consequences were horrific.

The need for patient autonomy to form the bedrock of the new discipline also reflected deeper anxieties which, while clearly including the new technological developments in scientific medicine, were not confined to these:

The new concerns about medical technology, combined with a growing skepticism in all areas of life about the impartiality of professional experts, summoned a principle unfamiliar to traditional medical ethics but familiar to philosophers: the freedom of persons to judge what is in their benefit without interference from others.⁸¹

Thus, along with developments in medical technology, it was scepticism of professionals that contributed to the emergence of patient autonomy as a central feature of the new bioethics. Indeed, to a large extent, those very developments gave rise to bioethics itself, and a *symbiotic* relationship seemed to arise between patient autonomy and bioethics — patients needed a powerful voice for their views to be heard, and bioethics required a core principle upon which to found a credible discipline. Thus, as well as progress in medical technology and the existence of a sceptical public, it would seem that the institutional needs of a new discipline — bioethics — were central in placing the patient not only at the heart of medical practice, but at the forefront of debate concerning future developments in scientific medicine. And, as the previous quotation indicates, the emphasis on freedom from interference helped shift the status of patients from those who would readily submit to the wonders of medicine to those of *individuals* who would now confront medicine, and the circumstances it was capable of producing, with their own estimations of what was acceptable.

79 Id at 111.

80 On this, see, for example, George Annas & Michael Grodin (eds), *The Nazi Doctors and the Nuremberg Code: Human Rights in Human Experimentation* (1992). For a more philosophical study of the camps, see Giorgio Agamben, *Remnants of Auschwitz: The Witness and the Archive* (Daniel Heller-Roazen trans, 1999 ed) [trans of: *Quel che Resta die Auschwitz*].

81 Jonsen, above n41 at 116–117.

C. *The Nature of Legal Regulation*

It is our argument that points A. and B. of this section are both partially responsible for the approach of the law we see in *Re B*. First, the situation in which Ms B found herself would not have arisen without the ventilator. Its workings produced circumstances in which life and death retained no clear distinction for her. Speaking about her life attached to the ventilator was, as we pointed out earlier, also to speak about her death. Identifying the threshold between the two seemed no easy task for her. Similarly, this question of the threshold between life and death becomes the principal axis around which law must operate. And, while Butler-Sloss P was unwilling to view the court's function in such terms, we have already seen how some senior members of the judiciary are not only acknowledging this role, but claiming law's pre-eminence where disputes regarding this threshold emerge. Deciding what the boundaries of life as such are is becoming one of the core functions of medical law.

Secondly, there is no doubt that autonomy is a central idea in medical law. But we would argue that, despite the judiciary's protestations to the contrary, it should not be thought of today primarily as the freedom from external interference that Jonsen described its meaning as having in the early days of bioethics. Rather, the manner in which we have described the operation of autonomy in *Re B*, together with the various practices that have emerged around it, suggests that autonomy is now more widely connected to an obsession with the individual generally. It is no longer simply about patients' rights to choose; it is a notion that, in many ways, describes a whole subject — medical law — and how that subject ought to be studied and practised. Moreover, there is a real sense in which the individual situations of those like Ms B — we are thinking of the cases of *Bland*, *Blood*, *Pretty* and (we might say) so on — are very public affairs. As those situations pass from the hospital to the court, they never escape institutional control and management. The critical point, though, is that this *control* occurs through a focus on the individual and, in particular, through the filter of the legal emphasis on *autonomy*.

This combination of life, death, and autonomy has implications for the nature of legal regulation here. In his discussion of bio-power, Michel Foucault says of law:

I do not mean to say that the law fades into the background or that the institutions of justice tend to disappear, but rather that *the law operates more and more as a norm*, and that the judicial institution is increasingly incorporated into a continuum of apparatuses (medical, administrative, and so on) whose functions are for the most part regulatory. *A normalizing society is the historical outcome of a technology of power centered on life.* [Emphasis added.]⁸²

Foucault's discussion of bio-power centred, of course, on the methods used to 'correct' lives in certain institutions (disciplinary mechanisms) and, later, the

⁸² Michel Foucault, *The Will to Knowledge: The History of Sexuality, Volume 1* (Robert Hurley, trans, 1978) at 144.

conduct of lives in the population generally (bio-politics). The proliferation of medical, and now human genetic, technologies means that the biological aspects of life are becoming more important as bases from which evaluations about people and the ways in which they live can be conducted. Thus, as Paul Rabinow has recently pointed out, Foucault's bio-power needs contemporary elaboration, to encompass the very building blocks of life itself — DNA.⁸³ So, even if Foucault's notion of life requires expansion, his reference to law as a norm appears now particularly useful as a way of understanding how medical law operates in cases involving decisions about life and death.

Re B illustrates that the combination of life, death, and autonomy does not result in a polarised battle between the sanctity of life principle and the freedom to live one's own life as one sees fit. Decisions are not made by simply choosing one as opposed to the other. Rather, and as the significance of character, explanation, imagination, and tests for mental capacity indicates, the law operates in a much more subtle manner, regulating what it considers to be the threshold between life and death by constructing norms through patients. Through the power to maintain life technologically, and with the increased focus on the individual, those are the techniques that have arisen in medical law to allow it to be described as a normalising practice. If life is to be allowed to end ('this grave decision', as Butler-Sloss P refers to it in *Re B*) and the individual has priority, the search for norms must occur through that individual. The question that Foucault used to describe the essence of the modern criminal tribunal⁸⁴ — 'Who are you?' — is becoming increasingly useful as a means of capturing a fundamental aspect of the medical law arena.

83 See Paul Rabinow, *French DNA: Trouble in Purgatory* (1999).

84 Michel Foucault, 'About the Concept of the "Dangerous Individual" in Nineteenth-Century Legal Psychiatry' in Michel Foucault, *Power: Essential Works of Foucault 1954–1984* Vol 3 (ed, James Faubion) (trans. R Hurley and others) (2001) at 176–200.