

7-1-1993

## Withholding and Withdrawing Life Support from Adults at Common Law

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### Citation Information

Gilmour, Joan M.. "Withholding and Withdrawing Life Support from Adults at Common Law." *Osgoode Hall Law Journal* 31.3 (1993) : 473-541.

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## Withholding and Withdrawing Life Support from Adults at Common Law

### Abstract

This article examines the circumstances in which life support can legally be withheld or withdrawn from adults. It analyzes the situation of patients who are both capable and incapable of making decisions, taking into account recent jurisprudence in Canada, the United States, and the United Kingdom. Where competence is not an issue, both law and modern medicine espouse a strong normative commitment to patient self-determination. However, when no clear indication of the patient's treatment preference can be ascertained because of decisional incapacity, then the question of terminating life support is much more difficult. The author describes and analyzes the two legal standards that have evolved in the three countries to guide treatment decisions: the substituted judgment standard, which has been particularly prominent in the United States, and the best interests test. Both have been problematic in application. With respect to the best interests test prevalent in Canada, the few analogous cases that have been decided to date have been marked by an emphasis on the single criterion of the presence or absence of non-relievable pain. The author concludes that while judgments will rightly be rooted in caution, Canadian courts can and ought to develop a more encompassing series of considerations to ground decisions about ending life support. The author then begins to develop principles that could guide decision making in this area.

### Keywords

Advance directives (Medical care)--Law and legislation; Right to die; Capacity and disability

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# WITHHOLDING AND WITHDRAWING LIFE SUPPORT FROM ADULTS AT COMMON LAW<sup>©</sup>

BY JOAN M. GILMOUR\*

This article examines the circumstances in which life support can legally be withheld or withdrawn from adults. It analyzes the situation of patients who are both capable and incapable of making decisions, taking into account recent jurisprudence in Canada, the United States, and the United Kingdom. Where competence is not an issue, both law and modern medicine espouse a strong normative commitment to patient self-determination. However, when no clear indication of the patient's treatment preference can be ascertained because of decisional incapacity, then the question of terminating life support is much more difficult. The author describes and analyzes the two legal standards that have evolved in the three countries to guide treatment decisions: the substituted judgment standard, which has been particularly prominent in the United States, and the best interests test. Both have been problematic in application. With respect to the best interests test prevalent in Canada, the few analogous cases that have been decided to date have been marked by an emphasis on the single criterion of the presence or absence of non-relievable pain. The author concludes that while judgments will rightly be rooted in caution, Canadian courts can and ought to develop a more encompassing series of considerations to ground decisions about ending life support. The author then begins to develop principles that could guide decision making in this area.

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## I. INTRODUCTION

Advances in medical technology in the last thirty years have made it possible to sustain life for extended periods of time in situations where not long ago, death would have been a certainty. This new capability is particularly apparent when one considers “life support” technologies, that is, artificial means of sustaining life through the support of the body’s needs, including respiration, circulation, nutrition, and waste disposal. To take just a few examples, it was only in the 1960s that cardiopulmonary resuscitation and total parenteral nutrition (complete intravenous feeding) were introduced and that the use of modern ventilators outside operating and recovery rooms became widespread.<sup>1</sup> It was not until the late 1960s and early 1970s that governments in Canada and the United States funded dialysis extensively, making it accessible for the first time to large numbers of those in need.<sup>2</sup> With these changes in life-sustaining medical

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<sup>1</sup> U.S. Congress, Office of Technology Assessment, *Life-Sustaining Technologies and the Elderly* (Washington, D.C.: U.S. Government Printing Office, 1987) at 40-41 and 428 [hereinafter *Life-Sustaining Technologies*].

<sup>2</sup> In Ontario, haemodialysis and peritoneal dialysis were included in the Ontario Medical Services Insurance Plan, which came into existence in 1966 (correspondence from S. Davidson, Legal Services Branch, Ministry of Health (2 July 1992)). Relative to the United States, see G. Calabresi & P. Bobbitt, *Tragic Choices* (New York: W.W. Norton, 1978) at 235 and note 118, noting the 1972 Social Security amendments in that country extending Medicare to cover the costs of haemodialysis.

technologies have come other changes as well, perhaps most significantly in the type and number of patients who are considered for and placed on life support.<sup>3</sup> Technology originally developed to support potentially curable patients through crisis has been extended to patients with far less favourable prognoses.

Increasingly, though, life-sustaining technologies that were originally welcomed wholeheartedly are now viewed with some reservation. Clinical and personal experience with various forms of life support has demonstrated that they do not offer a panacea to all. While it is true that life support has saved many lives, it is also true that it is frequently ineffective and is associated with high mortality<sup>4</sup> and numerous potentially serious complications.<sup>5</sup> Life support can in some instances keep patients who are terminally ill alive for longer than would otherwise be possible, and can maintain some patients who are in a

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<sup>3</sup> *Life-Sustaining Technologies*, *supra* note 1 at 1. By way of example, see *ibid.* at 428, noting that when modern mechanical ventilators first became available outside operating and recovery rooms in the United States in the 1960s, each major hospital usually had just one intensive care unit, to which patients were admitted only if they seemed likely to recover in the judgment of the I.C.U. director and the family physician. Now, the capacity to provide ventilation, the settings in which it can be instituted and maintained, the types of patients who are ventilated, and the conditions from which they suffer have all expanded greatly. For comments on other such changes, see *ibid.* at 44.

<sup>4</sup> Either immediately, or in the sense that the patient does not survive to be discharged from hospital. See, for example, R. Van Hoeyweghen *et al.*, "Survival After Out-of-Hospital Cardiac Arrest in Elderly Patients" (1992) 21:10 *Annals Emerg. Med.* 1179 at 1181; M.S. Eisenberg, A. Hallstrom & L. Bergner, "Long-term Survival After Out-of-Hospital Cardiac Arrest" (1982) 306 *N. Eng. J. Med.* 1340.

<sup>5</sup> For descriptions of the clinical outcomes of some of the most common forms of life support and the effects both on patients' mental and physical functioning and psychological outcomes and on patients' families and caregivers, see *Life-Sustaining Technologies*, *supra* note 1, c. 5-9.

persistent vegetative state<sup>6</sup> or who are barely conscious<sup>7</sup> for extended periods of time—as much as twenty to thirty years.<sup>8</sup> More and more, however, questions are being raised as to whether this is a desirable end. To many people, medicine's ability to maintain existence under such conditions is a mixed blessing, or no blessing at all.

Doctors and other health care workers, family members, hospitals, and long-term care institutions have all been grappling for years with questions about when life support should be provided, to whom, for how long, and the basis on which such decisions should be made. Medical knowledge and technology are evolving so rapidly, however, that the law often trails behind technological developments. Many of the legal issues entailed in withholding and withdrawing life support have never been considered by Canadian courts, although they have come before courts elsewhere, particularly in the United States.<sup>9</sup> It seems only a matter of time—and not much time, at that—before

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<sup>6</sup> See *Cruzan v. Director, Missouri Department of Health* 110 S. Ct. 2841 at 2845, note 1 (1990) [hereinafter *Cruzan*], Renquist J.: "Persistent vegetative state" refers generally to "a condition in which the person exhibits motor reflexes, but evinces no indication of significant cognitive function." The condition has been described as follows in S. Martyn & H. Bourguignon "Coming to Terms with Death" (1991) 42 *Hastings L.J.* 817 at 819, note 7:

Patients in a persistent vegetative state (pvs) can breathe, digest food, and eliminate waste. They can open and close their eyes, suggesting periods of sleep and waking. They can move their eyes and manifest other reflex responses to external stimuli, such as coughing, gagging or moving their limbs. But these patients, though occasionally appearing to give conscious responses do not feel pain or sense their surroundings. They have irretrievably lost consciousness.

See also President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research, *Deciding to Forego Life-Sustaining Treatment* (Washington, D.C.: U.S. Government Printing Office, 1983) at 174-81 [hereinafter President's Commission].

<sup>7</sup> The term "barely conscious" is used by commentators to describe individuals who "cannot initiate purposeful activity, whose experiences are limited to physical sensations, and whose medical prognosis holds no reasonable chance of improvement ... they lack the cognitive capacity to interact with others and to appreciate being alive." R. Dresser & J.A. Robertson, "Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach" (1989) 17 *Law, Medicine and Health Care* 234 at 242. See also N.K. Rhoden, "Litigating Life and Death" (1988) 102 *Harv. L. Rev.* 375 at 403.

<sup>8</sup> *Cruzan*, *supra* note 6 at 2845, note 1. As Brennan, J. noted in his dissenting judgment in *Cruzan* at 2863: "medical technology has effectively created a twilight zone of suspended animation where death commences while life, in some form, continues." See also Stevens J. (dissenting) at 2883 on the "alarming" ability we now have to perpetuate human existence through a highly invasive "merger" of body and machine.

<sup>9</sup> See, for example, *Cruzan*, *supra* note 6, in which the court considered an application by the patient's parents to have artificial nutrition and hydration withdrawn from their daughter, a young woman who had been in a persistent vegetative state for a number of years following an automobile accident.

questions about whether and when to withhold or withdraw life support will increasingly confront our courts as well.<sup>10</sup> The heightened profile of this issue among health care workers and the general public,<sup>11</sup> the recent spate of legislative activity making provision for living wills and durable powers of attorney,<sup>12</sup> the American example of resorting to litigation as one means of resolving these questions,<sup>13</sup> the rise of advocacy groups for the disabled and the elderly,<sup>14</sup> and pressure on and by provincial and federal governments to restrain burgeoning health care costs all provide the impetus that will result in these matters being taken to court. Whether it will be for judicial imprimatur or sanction remains to be seen.

This article examines whether life support can legally be withheld or withdrawn from adults, and if so, in what circumstances and subject to what limitations. It analyzes the situation of both competent and incompetent patients. Because there is so little law on point, it is

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<sup>10</sup> Indeed, the first such cases have now done so. See *Rodriguez v. B.C. (A.G.)*, [1993] 3 S.C.R. 519 [hereinafter *Rodriguez*]; *Nancy B. v. Hotel Dieu de Québec* (1992), 86 D.L.R. (4th) 385 (Que. S.C.) [hereinafter *Nancy B.*]. See also *Manoir de la Pointe Bleue (1978) Inc. v. Corbeil*, [1992] R.J.Q. 712 (C.S.) [hereinafter *Corbeil*].

<sup>11</sup> As an indication of public interest, the Hemlock Society's *Final Exit*, a guide instructing terminally ill patients on how to commit suicide or find assistance to do so topped the *New York Times* bestseller list when it was released and quickly sold out in Canada. See "Suicide Book a Best Seller" *The [Toronto] Globe and Mail* (13 August 1991) C3; "The Recipe for Suicide in a How-To Manual" *The Globe and Mail* (15 August 1991) A14.

<sup>12</sup> See, for example, Nova Scotia's *Consent to Medical Treatment and Consequential Amendments Act*, R.S.N.S. 1989, c. 279 and Manitoba's *Health Care Directives Act*, S.M. 1992, c.33. In Ontario, the *Substitute Decisions Act* S.O. 1992, c. 30 and the companion *Advocacy Act*, S.O. 1992, c. 26 and *Consent to Treatment Act*, S.O. 1992, c. 31 passed third reading in the legislature in December, 1992. It is not anticipated that these statutes will be proclaimed in force until sometime in 1994, in order to allow time to develop the necessary administrative framework.

<sup>13</sup> See *Cruzan*, *supra* note 6 at 2888, note 21, Stevens J. listing many of the state court decisions that have considered aspects of this issue.

<sup>14</sup> For example, an advocacy group for the disabled was instrumental in focusing an inquest into the deaths of developmentally handicapped children at the Christopher Robin Home in Ontario on the general issue of "comfort care" orders when such children develop other illnesses. See "'Comfort Care' an Inquest Issue" *The [Toronto] Globe & Mail* (16 May 1991) A2; "Group Criticizes Care for Disabled" *The Globe & Mail* (13 May 1991) A6; *People First of Ontario v. Bennett* (1991), 5 O.R. (3d) 609 (Div. Ct.); *rev'd* on other grounds *People First of Ontario v. Porter* (1992), 6 O.R. (3rd) 289 (C.A.) (public interest advocacy group granted standing at inquest on basis of its direct interest in potential jury recommendations with respect to future preventable matters). In Quebec, the Canadian Association for Community Living sought unsuccessfully to have a provincial investigation into the hospital death of an infant with Down's syndrome, who required an operation to correct an intestinal blockage and from whom artificial nutrition and hydration were withheld. "Whitewash of Infant's Death by Starvation at Montreal Children's Hospital Complete" (1990) 4 Can. H. R. Advoc. 4.

less of a commentary on decided cases than an attempt to combine the reasoning and principles underlying the few existing and analogous cases with an appreciation of the moral, legal, and practical issues raised by withholding and withdrawing life support. I use that base to suggest the approach Canadian courts are likely to and should take.

Where competence is not an issue, both law and modern medicine espouse a great normative commitment to the patient as an independent, rational individual able to make free, informed choices with respect to medical care. The requirement of obtaining the patient's informed consent prior to treatment flows from that model. The model itself has, however, been subject to cogent criticism, as I outline. Nonetheless, given the countervailing forces in physician-patient relations and in the health care system more generally, and given that in the end, it is the patient who must bear the direct consequences of treatment decisions, I argue that it is most appropriate for the legal system to continue to centre on the primacy of autonomy and self-determination. However, I suggest that while courts are increasingly willing to give effect to the treatment choices of competent patients even where that decision might seem unwise, there are limits on a patient's right of self-determination, limits shaped in part by the court's ability to understand and accept the patient's reasons for refusing treatment and the gravity of the consequences that will follow.

Decision making when the patient is incompetent poses many more problems. A number of provinces have passed or proposed legislation giving legal effect to various forms of advance directives. Devices such as living wills and durable powers of attorney for health care are in keeping with the emphasis on patient self-determination and autonomy that pervades current thinking on medical care. Despite practical, legal, and philosophical difficulties, advance directives will be useful to provide some welcome certitude in individuals' capacity to control future care should incompetence intervene, at least for those (likely few in number) who are both sanguine and resourceful enough to execute them.

When the patient has never been competent or gave no clear indication of treatment preferences while competent, determinations about the use or continuation of life support become immensely more difficult. Each of the two legal standards that have evolved for terminating treatment in the United States and (to a lesser extent) in the United Kingdom—the substituted judgment and best interests tests—can be problematic. This is in part because the language used in some of the decisions implementing a substituted judgment standard makes too strong a claim for the process and its results. Courts have



asserted that they are acting on the (now incompetent) patient's choice in situations where they obviously could not be, as no such "choice" could actually have been made or identified. The Supreme Court of Canada rejected the substituted judgment standard in another context: the sterilization of a mentally incompetent young woman.<sup>15</sup> Nonetheless, I will still argue that where there is reliable evidence of the patient's prior competent views respecting the use of life-sustaining treatment, these ought to govern later decision-makers. A substituted judgment standard best effectuates that underlying principle.

As medical technology advances and the population continues to age, there will be increasing numbers of incompetent patients for whom a substituted judgment is not possible. Many will lack any close associates who would be able or willing to "speak" for them. For these patients, the best interests test remains. It poses its own problems, stemming in part from unarticulated underlying judicial assumptions about the task of identifying "the good" for a particular patient. Judgments will rightly be rooted in caution. However, existing jurisprudence in analogous areas suggests a tendency on the part of courts to require treatment unless the patient is suffering severe pain that cannot be alleviated. One can understand a court being reluctant to go beyond a factor with respect to which there is a broad consensus in society that treatment ought not to be continued. I argue that it is possible to develop a more encompassing series of considerations to ground decisions about life support than the single criterion of the presence or absence of pain. Such a standard would be based on a concern with maintaining and respecting the patient's dignity and humanity and with preserving humaneness in treatment. It could include the element of pain and suffering without doing injustice to those patients for whom the presence or absence of pain is either insignificant or ought not be the controlling value.

My focus in this article is on examining principles that could potentially guide decision making in this area, particularly when the patient is incompetent. Consequently, there are a number of other aspects of the general topic which are only touched on tangentially, such as the choice of primary decision-makers when the patient is decisionally incapable and the appropriate standard of proof. A consideration of the issues raised by the allocation of scarce medical resources and other such

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<sup>15</sup> *Eve v. Mrs. E* (1987), 31 D.L.R. (4th) 2 (S.C.C.) [hereinafter *Eve*].

“macro-level” questions is also beyond the scope of the article.<sup>16</sup> Rather, it tracks the individuated approach a court would take in determining whether and how a decision can be made to dispense with life-saving or life-prolonging treatment. It is written at a time in the development of the law in this area when it cannot be more than a preliminary effort—part description, part prediction, and part prescription.

## II. COMPETENT PATIENTS AND DECISIONS ABOUT LIFE SUPPORT

Respect for the integrity and autonomy of the individual is solidly grounded in the common law,<sup>17</sup> and Canadian courts, borrowing from their counterparts in the United States, have often reiterated their acceptance of the proposition that “[e]very human being of adult years and sound mind has the right to determine what shall be done with his own body.”<sup>18</sup> In fact, until the recent proclamation of the *Charter of Rights and Freedoms*,<sup>19</sup> this was the only basis on which one could claim a right to self-determination or personal inviolability in medical treatment decisions, and in many instances, it may still be.<sup>20</sup> From this

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<sup>16</sup> The social perception of costs and of the weight to be accorded various factors in decision making inevitably changes depending on the format of the decision. One key variable is whether the decision involves an identifiable subject (should *this* patient be provided with this particular treatment) or is made on an aggregated, statistical basis (how much of this type of treatment should be made available). This point is explored in more detail by Calabresi & Bobbitt, *supra* note 2, examining different countries' responses in developing policies regarding access to dialysis at a time when the scarcity and high cost of resources made treatment of chronic renal failure largely unavailable.

<sup>17</sup> For an early reference to this proposition, see for example, *Marshall v. Curry* (1933), 3 D.L.R. 260 (N.S.S.C.); more recently, see *Hopp v. Lepp*, [1980] 2 S.C.R. 192 [hereinafter *Hopp*]; *Reibl v. Hughes* (1980), 114 D.L.R. (3d) 1 (S.C.C.) [hereinafter *Reibl*]; *Ciarlariello v. Schachter*, [1993] 2 S.C.R. 119.

<sup>18</sup> *Schloendorff v. Society of New York Hospital*, 105 N.E. 92 at 93, Cardozo J. (N.Y. 1914). In the Canadian context, see, for example, *Reibl*, *ibid.* at 10.

<sup>19</sup> *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11 [hereinafter *Charter*].

<sup>20</sup> In a recent decision, *Fleming v. Reid* (1991), 4 O.R. (3d) 74 (C.A.) [hereinafter *Fleming*], the Ontario Court of Appeal held that patients could assert *Charter* rights in connection with decisions regarding medical treatment, but in the limited context of considering the constitutionality of certain provisions of the *Mental Health Act*, R.S.O. 1980, c. 262 [hereinafter *Mental Health Act*] regulating the provision of non-consensual psychiatric treatment. See also *Rodriguez*, *supra* note 10 (considering whether criminal prohibition on assisting suicide breached *Charter* rights of applicant who was terminally ill and wished such assistance). While a detailed consideration of the

fundamental proposition has grown the requirement that health-care providers obtain the informed consent of a patient prior to treatment. Briefly, the following prerequisites must be established for a consent to be "informed":

- i) the patient has the capacity to reason and make judgments (*i.e.*, is competent);
- ii) the decision is made voluntarily and without coercion; and
- iii) the patient has a clear understanding of the material risks and benefits of non-treatment and of the treatment alternatives, as well as of the disease or condition and his or her prognosis.<sup>21</sup>

It goes without saying that the patient must be able to communicate consent or refusal in some fashion.

While an in-depth critique of this model or a critical comparison of its requirements with what routinely happens between a physician and a patient is beyond the scope of this article, it is worth noting that what is actually accepted as fulfilling this model may differ greatly from the process one might assume occurs. An awareness of the discrepancies between theory and practice can affect one's assessment of the extent to which the doctrine of informed consent actually advances the core underlying value of individual autonomy or requires a real exercise in self-determination. Jay Katz, an American psychiatrist and legal academic, has argued cogently that what now seems to pass muster as disclosure and consent in physician-patient interactions is largely oriented by physicians towards convincing patients to accept their recommendations. He comments that:

[s]ince the promulgation of the informed consent doctrine ... physicians have of necessity become more aware of their new obligations to talk with patients about recommended treatments. Yet, by and large any disclosures have been limited to informing patients about the risks and benefits of proposed treatments, not about alternatives, and surely not about the certainties and uncertainties inherent in most treatment options. Most importantly, conversations with patients are not conducted in the spirit of inviting patients to share with their physicians the burdens of decision. Without such a commitment, dialogue is reduced to a monologue.<sup>22</sup>

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application of the *Charter* to decisions to withdraw life support is beyond the scope of this paper, it should be noted that the *Charter* may not apply to decisions regarding medical treatment where the presence of government action is not so obvious. See *Retail, Wholesale and Department Store Union v. Dolphin Delivery Ltd.* (1986), 33 D.L.R. (4th) 174 (S.C.C.) [hereinafter *Dolphin Delivery*]; *McKinney v. University of Guelph*, [1990] 3 S.C.R. 229; *Stoffman v. Vancouver General Hospital*, [1990] 3 S.C.R. 483.

<sup>21</sup> Hopp and Reibl, *supra* note 17.

<sup>22</sup> J. Katz, *The Silent World of Doctor and Patient* (New York: Free Press, 1984) at 26. See also R. Fox, *The Sociology of Medicine* (Englewood Cliffs, N.J.: Prentice Hall, 1989) at 248-52 and references cited therein. For comments to the same effect in the Canadian context, see B. Dickens, "The Life of One's Days and the Days of One's Life" (1986-1987) 51 Sask. L.R. 1 at 12.

He also adds that:

the court's emphasis on specific disclosures, particularly of material risks, reinforces the traditional passive mode of patients' interaction with their doctors. Risk information, like everything else patients need to know, can become meaningful to patients only if they are viewed as active participants in decision making.<sup>23</sup>

Additionally, work in disciplines other than law suggests that a patient's decisions regarding treatment may be profoundly influenced by the language used to explain the various therapies, even though the same information is given.<sup>24</sup> Language can be determinative in ways we do not intuitively anticipate, and its influence on the patient's decisions may go unrecognized.

Finally, the model of the patient as a rational, independent "choice-maker" giving a voluntary consent to treatment has been criticized at a much more profound level as fundamentally flawed. Robert Burt argues that despite the great normative commitment to the model of separate selves evident in both law and modern medicine, the boundaries of self are not so impermeable as is assumed, particularly where an ill patient is concerned. He regards this model as facilitating an abdication of responsibility to the patient by decision-makers, be they doctors or judges, and argues that there cannot and should not be absolute role allocation resulting in a regime of "patient rule" that presents the competent patient as the sole choice-maker and the

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<sup>23</sup> Katz, *ibid.* at 78. For responses to Katz, see (1987) 9 W. N. Eng. L. J. Katz's observations would seem to be equally applicable in Canada. A 1984 study indicated that, despite the Supreme Court of Canada's 1980 decision in *Reibl*, *supra* note 17, significantly altering the law regarding informed consent, surgeons aware of the decision and its importance had not altered their practices relative to the disclosure of risks to patients. Among factors guiding physician risk disclosure, a great many physicians still ranked their own view of a patient's best interests well ahead of the fact that the patient would probably regard the risk as relevant to his or her decision to undergo the treatment. See G.B. Robertson, "Informed Consent in Canada: An Empirical Study" (1984) 22 Osgoode Hall L.J. 139. More recent evidence suggests that physicians are spending more time with patients discussing the risks and benefits of treatment, largely because of fear of potential liability. However, as the author of the study notes, "increased quantity of interactive time does not guarantee the quality of discourse and critical information exchange." See B. Dickens, "The Effects of Legal Liability on Health Care Providers" in *Report of the Federal/Provincial/Territorial Review on Liability and Compensation Issues in Health Care* (Chair: J.R.S. Prichard), *Liability and Compensation in Health Care*, vol. 2, Appendix B (Ottawa: 1990) at 51.

<sup>24</sup> See B.J. McNeil *et al.*, "On Elicitation of Preferences for Alternative Therapies" (1982) 306 New Eng. J. Med. 1259-62. The authors note the discrepancies in patients' treatment choice when the treatment is spoken of in terms of one's percentage chances of living rather than one's chances of dying with that particular therapy. For similar findings relative to the significance of the language used in the context of competent patients' decisions regarding Do Not Resuscitate Orders, see D. Murphy, "Do Not Resuscitate Orders: Time For Re-appraisal in Long-Term-Care Institutions" (1988) 260 J. Am. Med. Assoc. 2098 at 2099.

physician and judge as “choice-less”—able only to implement the patient’s choice.<sup>25</sup> Doing so, he argues, ignores the multiple meanings of, and motivations for, a patient’s acceptance or refusal of treatment.<sup>26</sup>

Much of the discussion that will follow relative to the withdrawal of life support is premised not only on the primacy of individual self-determination and autonomy in decision making with regard to medical treatment (from which the doctrine of informed consent flows), but also on the implicit assumption that for competent patients at least, informed self-determination in refusing or consenting to treatment can and does occur. As I have indicated, critics of the doctrine have argued persuasively that this model may be far from descriptive of what in fact takes place between a doctor and patient. This does not mean, however, that we should therefore dispense with the emphasis on self-determination found in cases considering the withdrawal of life support. It does caution us to take with a grain of salt the claims in many of the cases to be reviewed that the patient has made an informed, considered, uncoerced decision to refuse life-sustaining treatment. This is particularly so in the instance of an incompetent patient, where that “decision” is filtered through (and some would say, inevitably distorted by) the extra layer of a surrogate.

Returning now to the formal, legal model, it would seem to follow that a competent patient has the right to refuse medical treatment at will, regardless of whether the treatment would be life-sustaining or whether death is imminent or not, and regardless of motive. However, our courts have not always applied that principle so single-mindedly to the exclusion of the rights and interests of others, especially when to do so would support a patient’s choice to decline *life-saving* medical care—that is, in support of one whose choice will or may result in death. Other principles and interests compete, and sometimes prevail. For instance, a patient’s pregnancy, the presence of dependent children, and the state’s interest in and obligation to preserve life have on occasion

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<sup>25</sup> R. Burt, *Taking Care of Strangers: The Rule of Law in Doctor-Patient Relations* (New York: Free Press, 1979) at 117-18 and at 136. Burt also rejects the converse, a regime of “doctor [or judge] rule.” *Ibid.*

<sup>26</sup> See especially *ibid.* at 1-21 and at 121-23, recounting the experience of a severely burned patient, who repeatedly asked that treatment for his burns cease so he could die, and exploring the patient’s reasons for rejecting treatment. The patient was treated despite his objections, and went on to enrol in and successfully complete law school. Burt concludes that whether the patient’s choice was ultimately or solely other-directed or self-directed, it was very much influenced by his interaction with those around him.

been held to outweigh an individual's right to refuse life-saving treatment or care.<sup>27</sup>

By way of example, in a 1984 decision, *Procureur Général du Canada v. Hôpital Notre Dame et Niemiec*,<sup>28</sup> the Quebec Superior Court authorized the applicant hospital to feed in whatever manner necessary and to treat surgically a competent adult detained pending deportation who had swallowed a piece of wire and refused all medical treatment, stating that he preferred death to a return to his own country. The court indicated that it would not allow Niemiec to invoke the principle of the inviolability of his person to support his refusal of treatment. Since, in the court's view, that principle is aimed at the protection and preservation of life, it could not be applied to do the opposite—that is, in support of a wish for self-destruction.<sup>29</sup> Niemiec's right to self-determination was subject to certain limits. Thus, although it occurs rarely, courts have overridden a competent adult's refusal of treatment, and not just in what might be considered the "easy" cases where the interests of children and the state's obligations by virtue of its *parens patriae* power over them are clearly implicated in the adult's decision. Indeed, one Canadian commentator suggested that competent patients

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<sup>27</sup> Courts in the United States, too, have recognized a right in the competent patient to refuse medical treatment without which he or she would surely die. However, American courts in the past often grounded their acceptance of an individual's right to refuse treatment on a constitutional right to privacy in addition to or instead of a common law right to self-determination. In *Cruzan*, *supra* note 6 at 2851 and note 7, the United States Supreme Court accepted without deciding that competent patients have a right to refuse treatment, analyzing the right as a constitutionally protected Fourteenth Amendment liberty interest rather than as part of a generalized right to privacy. Historically, privacy has not been constitutionally protected in Canada, and the limits on the relatively new *Charter* guarantees of life, liberty, and security of the person are still being developed. At this point, it is unclear whether Canadian courts will interpret the *Charter* to include constitutional rights equivalent in effect to those recognized in the United States in this area, and, if so, the limits to which they will be subject and the contexts in which they will apply. Given the constitutional underpinning to many of the American decisions, it cannot be assumed that they are automatically transferable to the Canadian situation. In the United Kingdom, courts have also upheld patients' common law right to refuse even life-sustaining treatment (see, for example, *Airedale N.H.S. Trust v. Bland*, [1993] 2 W.L.R. 359 at 367-8 (H.L.), Lord Goff [hereinafter *Airedale Trust*]; *In Re T. (Adult: Refusal of Treatment)*, [1992] 3 W.L.R. 782), but reserve the right to overrule the decision (see, for example, *In Re S. (Adult: Refusal of Treatment)*, [1992] 3 W.L.R. 806: court ordered a caesarian section that patient had refused on religious grounds where physicians believed both mother and child would die otherwise).

<sup>28</sup> (1984), C.S. 426 [hereinafter *Niemiec*].

<sup>29</sup> *Ibid.* at 427. Margaret Somerville notes that effectively, this "invokes an 'abuse of rights' doctrine, which is more explicit in civilian, than in common law, legal systems." M. Somerville, "Refusal of Medical Treatment in 'Captive' Circumstances" (1985) 63 Can. Bar Rev. 59 at 81, note 79. Echoes of the same view are evident in the judgement of Sopinka J. in *Rodriguez*, *supra* note 10, in commenting on the interpretation of the right to "life, liberty and security of the person" guaranteed by s. 7 of the *Charter*.

who are hospitalized or institutionalized may be subject to something akin to a "rescue right" in health professionals, such that a patient's avoidable death while under the charge of a hospital need not be tolerated. In the result, a curable patient would have no right to refuse ordinary treatment prolonging life, at least while hospitalized.<sup>30</sup> This position has been rejected in later judicial decisions.<sup>31</sup> Thus, while the current common law rule may be summarized as the Law Reform Commission of Canada has done—that is, a competent patient is the absolute master of decisions regarding his or her own body<sup>32</sup>—courts, at least one commentator and even some provisions of the *Criminal Code*<sup>33</sup> would suggest that competent patients are not necessarily master of their own death as well their life.

Although refusal of life-prolonging or life-saving treatment by a competent patient is not without legal difficulties, the principle of autonomy that implicitly underpins a decision to honour such a refusal is gaining ascendancy in this area. In the writer's view, this tendency is both reinforced by, and a logical extension of, the increasing weight accorded the patient's right to know and decide expressed in the concept of informed consent to treatment. Several decisions are indicative of the courts' growing emphasis on the principle of self-determination. In *Attorney General of B.C. v. Astaforoff*,<sup>34</sup> it was held that prison officials were under no statutory duty to force-feed a competent prisoner who chose to remain in prison on a hunger strike although free to leave on parole. The prisoner, an elderly Doukhobor woman, had indicated that she did not wish any measures taken to save her, even when she became unconscious. Although the judge in the first instance acknowledged the court's moral and legal duty to preserve the sanctity of life, he went on to hold that that duty did not extend to requiring the necessities of life to be forced on an unwilling recipient. The prisoner's wishes were to be

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<sup>30</sup> B. Dickens, "The Right to Natural Death" (1981) 26 McGill L.J. 847 at 851, 861 and at 876.

<sup>31</sup> See, for example, *Malette v. Shulman* (1990), 72 O.R. (2d) 417 (C.A.), aff'g. (1987), 63 O.R. (2d) 243 (H.C.) [hereinafter *Malette*], discussed *infra* notes 37-52 and accompanying text; and *Rodriguez*, *supra* note 10.

<sup>32</sup> Law Reform Commission of Canada, "Euthanasia, Aiding Suicide, and the Cessation of Treatment" (Working Paper 28) (Hull, Que.: Supply and Services Canada, 1982) at 55-56.

<sup>33</sup> R.S.C. 1985, c. 46 [hereinafter *Criminal Code*]. See, for example, ss. 14, 215, 219, and 241.

<sup>34</sup> [1983] 6 W.W.R. 322 (B.C.S.C.); aff'd. [1984] 4 W.W.R. 385 (B.C.C.A.) [hereinafter *Astaforoff*]. See also *Burke v. Government of Prince Edward Island* (1991), 292 A.P.R. 356 (P.E.I.S.C.), in which MacDonald C.J. dismissed the application of a prisoner awaiting trial on a murder charge for a declaration that he had a *Charter* right not to be force-fed and to refuse medical treatment. The court noted, however, that its decision did not mean the respondent had a right to force-feed the applicant, adding that if it did so, it would run the risk of incurring liability.

respected.<sup>35</sup> The decision was affirmed on appeal. Questions as to whether such a duty existed at common law rather than by statute and whether a duty would arise if the prisoner became unconscious or otherwise incompetent and unable to withdraw from the care and custody of prison authorities were specifically left open. Logically, though, ignoring her refusal of food at that point would seem to be an absolute negation of her right of refusal and a violation of her person and her right of bodily control, provided one was sure the refusal was informed, voluntary, and still current, at least up to the onset of incapacity. It may be that the different approaches taken in *Niemiec* and *Astaforoff* can be explained by the fact that the former concerned the hospital's power to take such action, while the latter considered only whether prison officials were under a duty to do so. It also seems to have been of significance that in *Astaforoff*, the prisoner was free to leave the institution on parole if she chose, while in *Niemiec*, he had to remain incarcerated in the custody of the state until deported, arguably both altering and strengthening the state's interest in the preservation of his life.<sup>36</sup>

In a 1990 decision, *Malette v. Shulman*,<sup>37</sup> the Ontario Court of Appeal affirmed that a refusal of blood transfusions by a Jehovah's Witness made while competent must be honoured by a physician treating her during a later period of incompetence following an automobile accident. The refusal was evidenced by an undated, signed card bearing that message, which she carried with her, and was reliably confirmed by a close family member as having been voluntarily made and as still expressing the patient's wishes. Mr. Justice Robins writing for the court characterized the card as the patient's "standing orders," giving notice of her "firm religious conviction" in "the only practical way

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<sup>35</sup> *Ibid.* at 326-27. From the aftermath of the case, it appears that the prisoner's wishes were respected with less ambivalence in the abstract (the judicial context) than in practice. The prisoner was fed by a physician who volunteered his services "on humanitarian grounds" when prison medical officers refused to do so without the prisoner's consent. During a subsequent hunger strike, Mrs. Astaforoff was tube-fed for three days, but not after she refused further feedings. Ultimately, she was granted a conditional pardon and released. See E. Carroll, "Forced Feeding of Prisoners: Mary Astaforoff, A Case In Point" (1983) 4 Health L. Can. 85 at 86.

<sup>36</sup> For a fuller discussion of *Niemiec* and a suggested distinction between cognitive and emotional competence, see Somerville, *supra* note 29. For a U.S. example, see *Commissioner of Correction v. Myers*, 399 N.E.2d 452 (Mass. 1979), where it was held that the state's interest in orderly prison administration outweighed any privacy interest of a prisoner who had inconsistently (and, it was argued, manipulatively) refused dialysis.

<sup>37</sup> *Supra* note 31.



open to her.”<sup>38</sup> Thus, the patient’s directions expressed while competent were held to have followed her through and to govern in a later period of incompetence, even though the evidence established that had blood been withheld, she might very likely have died.<sup>39</sup> The patient’s right to self-determination transcended any general interest of the state in preserving life and the specific interest of the treating physician in acting expeditiously so as to save her life in the midst of what must have seemed at the time to be a very uncertain situation, both factually and legally.<sup>40</sup>

In the course of its decision, the court clearly identified the rights to self-determination and bodily integrity as the controlling values in the doctor-patient relationship, stating that:

the right to determine what shall be done with one’s own body is a fundamental right in our society. The concepts inherent in this right are the bedrock upon which the principles of self-determination and individual autonomy are based.<sup>41</sup>

On the subject of the state’s countervailing interest in preserving life and the sanctity of life, the court proceeded on the basis that preserving “life” meant more than maintaining physical existence, asserting that doing so at the expense of individual free choice and self-determination “can only lessen, and not enhance, the value of life.”<sup>42</sup> Seemingly, then, the state’s interest is to be given a content that takes into account the patient’s own values as to how one’s life is to be lived. With that understanding, the interests of the individual and the state in life—and particularly, in this patient’s life—are not opposed, but complementary.

While the court made several strong statements supporting a patient’s right to refuse medical treatment for any reason, even if the decision “is generally regarded as foolhardy,”<sup>43</sup> it was also careful to note on a number of occasions that, in this case, the refusal was based on the patient’s religious values as a Jehovah’s Witness.<sup>44</sup> The court characterized her refusal of transfusions as choosing to assure her chances of eternal salvation in accordance with the tenets of her faith,

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<sup>38</sup> *Ibid.* at 431.

<sup>39</sup> *Ibid.* at 421.

<sup>40</sup> *Ibid.* at 429-30.

<sup>41</sup> *Ibid.* at 432.

<sup>42</sup> *Ibid.* at 430.

<sup>43</sup> *Ibid.* at 426 and at 424.

<sup>44</sup> *Ibid.* at 426 and at 428.

rather than as choosing death.<sup>45</sup> One is left wondering whether the weight the court accorded the right to self-determination in *Malette* was affected by its own ability to identify with the patient's reason for refusing treatment—her religious values. As the trial judge noted in a passage of his judgment that was quoted by the Ontario Court of Appeal:

However sacred life may be ... certain aspects of life are properly held to be more important than life itself. Such proud and honourable motivations are long entrenched in society ... refusal of medical treatment *on religious grounds* is such a value.<sup>46</sup> [emphasis added]

The situation was expressly distinguished from “suicide” or “euthanasia,”<sup>47</sup> words heavily freighted with unfavourable connotations in both our legal system and in society more generally. The court went on to state that:

The patient manifestly made the decision on the basis of her religious convictions. It is not for the doctor to second-guess the reasonableness of the decision *or to pass judgment on the religious principles which motivated it*.<sup>48</sup> [emphasis added].

In the court's eyes, this patient had an acceptable motivation for refusing treatment. The extent to which that became key rather than the patient's unadorned right to determine what medical treatment she would receive (even to the point of choosing an avoidable death) is unclear. While the court did affirm that the state has a “strong interest” in preserving life, which may in some circumstances override the individual's right to self-determination, it left those circumstances largely unspecified.<sup>49</sup>

From a pragmatic point of view, if the acceptability of the patient's motive for refusing life-sustaining treatment has been incorporated into this area of the law—that is, if treatment must be refused for a “good” reason—this imposes a nearly impossible task on medical personnel, particularly when working under the pressures generated by an emergency. They must be able to recognize not only that this patient's refusal of treatment can be relied upon, but also that it

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<sup>45</sup> *Ibid.* at 428 and at 432-33. While this is frequently the reasoning employed when Jehovah's Witnesses refuse transfusions, the characterization of that choice is certainly not the only one it could reasonably bear.

<sup>46</sup> *Ibid.* at 422.

<sup>47</sup> *Ibid.* at 428.

<sup>48</sup> *Ibid.* at 432.

<sup>49</sup> *Ibid.* at 429.

was made for a reason with respect to which a sufficient social consensus currently exists to justify honouring it. One can understand a court being hesitant to give patients *carte blanche* to refuse all medical treatment in all circumstances. Still, this does not seem to be the way to go about balancing respect for the patient's autonomy with the state's legitimate interests in preserving life and respect for the sanctity of life and in maintaining the integrity of the health professions.<sup>50</sup>

The decisions in *Malette* and *Niemiec* provide an interesting contrast in reasoning as well as in result. In *Niemiec*, the Quebec Superior Court expressed little sympathy for the reason the person concerned refused treatment, namely, that death was preferable to returning to his own country. In *Malette*, both the trial and the appellate courts seemed able to empathize strongly with and therefore respect the plaintiff's reason: religious commitment. In the former case, the court found the patient's refusal of treatment directly antithetical to the principle of the inviolability of the person, which it interpreted as an instrumental principle aimed at the protection and preservation of life. In the latter, the court held that treating the patient in the face of her refusal violated her rights of self-determination and bodily integrity, thereby diminishing the value of her life.<sup>51</sup> In *Malette*, the patient's life and limits on the steps taken to preserve it were assessed against the backdrop of her own value system—a value system the court and society at large could accept. In *Niemiec*, the court assessed the person's express wish to die rather than be returned to his own country against a generalized value system that prizes continued life as an absolute good, and found the patient's wishes less persuasive; the preservation of life prevailed as the controlling value.<sup>52</sup>

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<sup>50</sup> For a physician's viewpoint on difficulties with the level of uncertainty sanctioned by *Malette* regarding an incompetent patient's prior wishes to forego life-sustaining treatment, see P.A. Singer & F.H. Lowy, "Refusal of Life-sustaining Treatment, the *Malette* Case, and Decision-making Under Uncertainty" (1991) 24 *Annals R.C.P.S.C.* 401. For comments on the difficulty of the task facing judges "called to patients' bedsides and required to make life or death decisions," see *In Re A.C.*, 573 A.2d 1237 [hereinafter *Re A.C.*] at 1237, note 2 and at 1248 (D.C. App. 1990). The task facing treating physicians is much more difficult, particularly in an emergency situation. They must not only make such decisions but also attend to the patient at the same time. *Post hoc* evaluation of health care providers' decisions as though they were made on the same basis and in the same time frame as judicial decisions is unrealistic. Unlike judges, health care providers often do not have the liberty to, or the luxury of, reserving their decisions.

<sup>51</sup> *Niemiec*, *supra* note 28 at 427; *Malette*, *supra* note 31 at 430.

<sup>52</sup> It must also be recognized that *Niemiec* was decided while the crisis was on-going—the person concerned might still have died—while *Malette* was decided after the fact, when the patient had recovered, albeit with permanent injuries. The very different viewpoints, which foresight and hindsight must have given the decisionmakers, cannot be discounted. In this regard, see *In Re A.C.*,

One year after *Malette*, in another decision authored by Mr. Justice Robins, the Ontario Court of Appeal again affirmed a patient's right to refuse medical treatment. In *Fleming v. Reid*,<sup>53</sup> two involuntary patients being held pursuant to Lieutenant Governor's warrants had, while competent, refused treatment with neuroleptic drugs for their schizophrenia. Each had made his refusal known to the Official Guardian, whom each had appointed his substitute decision maker should he later become incompetent, as provided in governing legislation, the *Mental Health Act*.<sup>54</sup> When the patients became incompetent, their attending physician took the matter to a review board seeking authorization to administer the drugs. The statute provided that the review board had to make its determination only on the basis of the patients' best interests, thus excluding a consideration of their earlier, competent refusal of the drugs. The board authorized treatment and the patients appealed, alleging a violation of their rights under section 7 of the *Charter*.<sup>55</sup>

The court held that the statutory provisions depriving involuntary patients of any right to have their prior competent decisions about psychiatric treatment control or even be considered in a later period of incompetence breached the patients' right to security of the person under section 7 of the *Charter*.<sup>56</sup> The breach could not be justified under section 1 of the *Charter* and, hence, the impugned statutory provisions could not stand. In an interesting development, the court explicitly melded the patients' common law rights in consent-to-treatment cases with the rights guaranteed under section 7 of the *Charter*.

The common law right to bodily integrity and personal autonomy is so entrenched in the traditions of our law as to be ranked as fundamental and deserving of the highest order of protection. This right forms an essential part of an individual's security of the person and must be included in the liberty interests protected by s. 7. Indeed, in my view the common law right to determine what shall be done with one's own body and the

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*supra* note 50 at 1237, note 2 and at 1248 (D.C. App. 1990) vacating a lower court's order that a caesarian section be performed on a terminally ill woman—but after the fact. Both mother and child had died shortly after the operation. The appellate court expressed reservations that judges “called to patients’ bedsides and called on to make quick decisions on matters of life and death” could ever “realistically frame principled and useful responses to the legal dilemma with which they are being confronted.”

<sup>53</sup> *Supra* note 20.

<sup>54</sup> *Supra* note 20.

<sup>55</sup> *Supra* note 19.

<sup>56</sup> *Fleming, supra* note 20.

constitutional right to security of the person, both of which are founded on the belief in the dignity and autonomy of each individual, can be treated as co-extensive.<sup>57</sup>

Thus, at least where the necessary element of government action is present,<sup>58</sup> a patient's common law right to refuse treatment is now recognized as having the extra weight of constitutional status behind it as well.

In *Fleming*, the patient's right to refuse medical treatment was, if anything, stated even more strongly than in *Malette*:

With very limited exceptions, every person's body is considered inviolate, and, accordingly, every competent adult has the right to be free from unwanted medical treatment. The fact that serious risks or consequences may result from a refusal of medical treatment does not vitiate the right of medical self-determination ... It is the patient, not the doctor, who ultimately must decide if treatment—any treatment—is to be administered.<sup>59</sup>

Neither the court's affirmation of the patients' right to refuse treatment nor its recognition of the force and effect of a patient's advance instructions respecting his or her future care was tied to, or contingent on, the patient having "good" reasons for the decision, as was arguably the case in *Malette*.

At the same time, though, the court did set out in detail the serious side effects potentially associated with the use of neuroleptic drugs, emphasising the extremely intrusive nature of the treatment.<sup>60</sup> After reading the list of complications, one is left with the distinct impression that a reasonable person might well choose to live with the symptoms of the mental illness rather than to risk the side effects of the drugs. There was no explicit link drawn in the judgment between the court's support for the patients' right to refuse treatment and the existence of rationally supportable, "good" reasons for the refusal—reasons which the court and anyone else could find credible. Nor was there any indication that these reasons must actually have formed the basis of the patients' decisions. Indeed, the court said it did not matter that the patients' decisions may seem "ill-advised."<sup>61</sup> Yet, if patients really do have a near-absolute right to refuse medical treatment regardless of motivation, one wonders why the description of the drugs' dangers was included in the judgment at all; there was no similar

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<sup>57</sup> *Ibid.* at 88.

<sup>58</sup> See cases cited *supra* note 20 (applicability of the *Charter* to medical treatment decisions).

<sup>59</sup> *Fleming*, *supra* note 20 at 85.

<sup>60</sup> *Ibid.* at 84-85 and at 88.

<sup>61</sup> *Ibid.* at 86 and at 91.

description of the serious effects of the illness on these patients.<sup>62</sup> The judgment in *Fleming*, then, does not entirely answer the questions *Malette* raised respecting limits on the rights of competent patients to refuse treatment.

*Fleming* involved the non-consensual administration of psychiatric treatment. In that sense, it could be said to be distinguishable from cases involving the withholding or withdrawal of life support, as the refusal of treatment being considered was not life-threatening. Yet a patient's right to make decisions regarding medical treatment and the pre-eminent place accorded that right in legal analysis should not differ just because the treatment proposed could be life-saving. Indeed, the court in *Fleming* seems to have meant to speak more at large:

The patient's right to forego treatment, in the absence of some overriding societal interest ... must be honoured, even though the treatment may be beneficial or necessary to preserve the patient's life or health.<sup>63</sup> [emphasis added]

There is good reason to hold to a paradigm of decision making that affirms the competent patient's control in questions of life support. The doctor-patient relationship is marked by a strong imbalance of power, an imbalance that flows from disparities in knowledge and access to resources, as well as from the physical, emotional, and psychological toll taken by being ill and in need of medical assistance.<sup>64</sup> Physicians commonly and with the best of intentions seek to guide their patients toward particular treatment decisions.<sup>65</sup> In doing so, they exert a very strong influence. However, the solution a physician views as optimal may be narrowly focused on relieving a particular set of symptoms, regardless of side effects and regardless of inability to cure the underlying diseases or disabling conditions.<sup>66</sup> It is the patient who experiences the illness, its treatment, and its repercussions. In short, it is

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<sup>62</sup> For a contrasting, contemporaneous decision, see *Institut Phillippe Pinel de Montréal v. Blais* (1991), R.J.Q. 1969 (Que. S.C.) authorizing treatment for an involuntary patient detained pursuant to a Lieutenant Governor's warrant who refused all treatment. In her decision, Lebel J. detailed the effects schizophrenia had on the patient, seemingly largely to establish that he had never been competent to refuse treatment.

<sup>63</sup> *Supra* note 20 at 86.

<sup>64</sup> On the nature of the doctor-patient relationship, see *Norberg v. Wynrib*, [1992] 2 S.C.R. 226.

<sup>65</sup> See Katz, *supra* note 22; and Dickens, *supra* note 22. Canadian courts, too, have recognized physicians' influence on patients' choices of treatment. See, for example, *Bucknam v. Kostick* (1983), 3 D.L.R. (4th) 99 at 112 (Ont. H.C.); *aff'd.* (1986), 55 O.R. (2d) 187 (C.A.).

<sup>66</sup> *Life-Sustaining Technologies*, *supra* note 1 at 25; Rhoden, *supra* note 7 at 428, note 227 and at 430.

the patient who has to live (or not) with the decision. As such, it is the patient who should be the one to ultimately determine whether to undergo treatment, even where the treatment would be life-sustaining. Strong support from the legal system for a patient's right to self-determination in this area will go some way toward compensating for the powerful forces built into the very structure of our health care delivery system that tend to take health care decisions away from the patient. Increasingly, courts are providing that support.

Most recently, Nancy B., a competent young woman permanently disabled by Guillain Barré syndrome, commenced proceedings in the Quebec Superior Court seeking an injunction requiring the hospital in which she was a patient, its staff, and her physician to refrain from administering treatment without her consent and to stop treatment in progress at her request.<sup>67</sup> Specifically, she wished to be removed from the ventilator which sustained her life, but she was physically incapable of doing so herself. The suit was not contested by either the defendant hospital or her physician, who had been added to the proceedings as a third party. Both, however, were concerned for their potential criminal liability if they acceded to the patient's request. Hence, they required some form of judicial imprimatur before they would act. All parties, including the intervener, the Attorney General for Quebec, agreed that pursuant to Quebec's *Civil Code*, no one could be made to undergo care without his or her consent.<sup>68</sup> The Quebec Superior Court held that the respirator was a form of medical treatment to which the Code applied, and that, having initially consented to the treatment, the patient was entitled to request that it be stopped.<sup>69</sup>

The court then turned to consider the effect of the *Criminal Code*. While recognizing that if read technically and entirely in the abstract some sections of the *Code* might be applicable to the actions of one who removed Nancy B. from the ventilator,<sup>70</sup> the court concluded that the practical ramifications of such an interpretation were such that it could not have been Parliament's intent. Any other result would be "absurd."<sup>71</sup> Rather, the federal and provincial legislation ought to be read together as a coherent whole. In that light, the behaviour of a

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<sup>67</sup> *Nancy B.*, *supra* note 10.

<sup>68</sup> *Ibid.* at 389-90.

<sup>69</sup> *Ibid.* at 392.

<sup>70</sup> See, for example, *Criminal Code*, *supra* note 33, ss. 217, 219, 241.

<sup>71</sup> *Nancy B.*, *supra* note 10 at 393.

physician who "interrupts the respiratory support of a patient, at the patient's informed request, in order to let nature take its course" would not attract criminal liability.<sup>72</sup> In the result, the court made an order permitting Nancy B.'s physician to stop respiratory support when the patient so requested, and to ask the hospital for any necessary assistance "so that everything takes place in a manner respecting the dignity of the plaintiff."<sup>73</sup> The order was not to take effect until the expiry of the period within which an appeal could be commenced. Nancy B. remained firm in her decision, was removed from the ventilator, and died shortly thereafter.

A few weeks after this decision, in *Manoir de la Pointe Bleue (1978) Inc. v. Corbeil*,<sup>74</sup> Mr. Justice Rouleau of the Quebec Superior Court granted the petition of a long-term care institution for a declaration that it must neither administer treatment nor transfer a patient elsewhere without consent when the patient had executed a legal directive requesting that he be allowed to die by starvation. The patient was a competent thirty-five-year-old man, married with two young children, who had been permanently paralysed from the neck down following an accident with an all-terrain vehicle in 1990. At the time of

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<sup>72</sup> *Ibid.* at 394.

<sup>73</sup> *Ibid.* at 395. The permissive phrasing of the order is noteworthy. It raises questions as to the result if physicians, hospital staff, or the hospital had been unwilling to assist. The extent to which courts can or will require hospitals and medical personnel to implement non-treatment decisions has been touched on by courts in other jurisdictions. In the United States, see *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 at 304 and at 306 (Cal.App. 2 Dist. 1986) (a competent patient's right to self-determination as to her own medical treatment—removal of nasogastric tube—must be paramount to the interests of the hospital and doctors in continuing her care, nor may they deny her relief from pain and suffering should she exercise that right); *Bartling v. Superior Court of California*, 163 Cal. App.3d 186 (Cal. C.A. 1984); and *Bartling v. Glendale Adventist Medical Center*, 184 Cal. App.3d 961 (Cal. C.A. 1986). See also *Re Jobes*, 529 A.2d 434 [hereinafter *Jobes*] at 450 (N.J.S.C. 1987), and *In re Requena*, 517 A.2d 886 (N.J. Super. Ct. 1986) to the same effect. But see *Brophy v. New England Sinai Hospital*, 497 N.E.2d 626 [hereinafter *Brophy*] at 639-40 (Mass. S.J.C., 1986) (where substituted judgment of patient in a persistent vegetative state is to cease artificial feeding and hydration, hospital could refuse to remove or clamp G-tube where hospital is willing to assist in a transfer of the patient to a suitable facility or home and hospital asserts a breach of its ethical integrity, as there is substantial disagreement in the medical community over the appropriate course of action. Medical professionals in these circumstances are not to be compelled to take "active measures contrary to their view of their ethical duty toward their patients.") In the United Kingdom, see *Re J. (A Minor: Child in Care: Medical Treatment)*, [1992] 4 All E.R. 614 (C.A.) [hereinafter *Re J.*] (a court will not require a medical practitioner or health authority to adopt a course of treatment that in the *bona fide* clinical judgment of the practitioner concerned is contraindicated as not being in the best interests of the patient—in that case, repeated ventilation and other "intensive" measures to prolong the life of a severely handicapped infant with an unalterably short life expectancy).

<sup>74</sup> *Supra* note 10.



writing this article, the patient had not asked that the directive be put into effect.<sup>75</sup>

*Nancy B.* and *Corbeil* strongly support a patient's right to self-determination in medical treatment, even when the patient's decision will result in an otherwise avoidable death and the assistance of a third party will be required to effectuate the decision (to remove *Nancy B.* from the ventilator or to ease any suffering *Robert Corbeil* might experience). Both, however, were based on Quebec's *Civil Code*, which provides as follows:

*Art. 19.* The human person is inviolable. No one may cause harm to the person of another without his consent or without being authorized by law to do so.

*Art. 19.1.* No person may be made to undergo care of any nature, whether for examination, specimen taking, removal of tissue, treatment or any other act, except with his consent.

Where the person concerned is unable to consent to or refuse care, a person authorized by law or by mandate shall replace him.<sup>76</sup>

Despite their basis in civil law, these decisions nonetheless should not be considered to be limited in effect only to Quebec. The *Civil Code's* statement of the inviolability of the individual and the need to obtain his or her consent to treatment and care are essentially identical to the right to autonomy and bodily integrity and the requirement of obtaining the patient's informed consent to medical treatment recognized at common law.<sup>77</sup> Consequently, *Nancy B.'s* and *Corbeil's* affirmation of the patient's right to determine the medical treatment he or she will receive is as applicable in the rest of Canada as it is in Quebec.

Given that the Quebec Superior Court recognized a competent patient's right to refuse consent to even life-saving treatment in *Nancy B.* and *Corbeil*, one must ask whether its earlier decision in *Niemiec*<sup>78</sup> has now been effectively overruled. After all, that was the very right *Niemiec* asserted when he refused treatment for the wire he had swallowed and opposed the hospital's application for judicial authorization to treat and force-feed him. Indeed, Rouleau, J. suggested in *Corbeil* that Article 19.1 of the *Civil Code*, which came into force 15

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<sup>75</sup> (1992) 8 *Humane Med.* 303.

<sup>76</sup> Arts. 19, 19.1 C.C.Q. Article 19.1 came into effect in 1990. See *Corbeil*, *supra* note 10.

<sup>77</sup> See, for example, *Fleming*, *supra* note 20 at 88. Indeed, *Nancy B.* was cited with approval by the Supreme Court of Canada in *Rodriguez*, *supra* note 10 (a British Columbia case).

<sup>78</sup> *Supra* note 28.

April 1990, would be dispositive of a like case today.<sup>79</sup> The cases are distinguishable, however. The operative forces in *Nancy B.* were much more like those in *Malette*<sup>80</sup> than *Niemiec*. As in *Malette*, the court in *Nancy B.* was clearly able to empathize with the patient and her plight—in Dufour, J.’s words, Nancy B. was “literally tied to her hospital bed,” with no hope of cure or even any improvement in her condition.<sup>81</sup> As her mother testified, for her daughter, “[i]t’s no longer liveable.”<sup>82</sup> In those circumstances, the court was prepared to accept both the patient’s assessment of her life<sup>83</sup> and her choice.

The same is true of the decision in *Corbeil*. Once again, the court was careful to ascertain that, for this patient, the circumstances of his life were insupportable.<sup>84</sup> Although noting that no one can judge another’s quality of life, Robert Corbeil’s situation and choice obviously engaged the court’s sympathy. Rouleau, J. cited with approval an earlier decision of the Quebec Superior Court, *Re Goyette*:

L’état doit préserver la vie humaine, mais si, malgré ces soins, la vie devient inhumaine, c’est la dignité de la personne qui doit l’emporter sur l’intérêt de l’état. L’art. 12 de la charte canadienne des droits permet alors à la personne de dire que tout traitement qu’on veut lui administrer est ‘cruel’ et elle peut le refuser. Mais le test de la disparition de la dignité de vie doit être objectif.<sup>85</sup> [emphasis added]

He added that:

[I]e cas Robert Corbeil est sûrement aussi grave. Dans ces circonstances, la décision à prendre doit aller dans le sens de la primauté du respect de la volonté de l’intimé de mettre fin à ses jours.<sup>86</sup> [emphasis added]

Whether the patient’s choice of an avoidable death is to be accepted at face value in all circumstances remains an unanswered question. Given the state’s interest in the protection and preservation of life, will a court

<sup>79</sup> *Corbeil*, *supra* note 10. However, Dufour, J. in *Nancy B.*, *supra* note 10 at 389, pointed out that the legal duty to obtain consent to treatment existed in Quebec prior to the addition of s. 19.1 to the Code. See also *Couture-Jacquet v. Montreal Children’s Hospital* (1986), 28 (D.L.R.) (4th) 22 (Que. C.A.) [hereinafter *Couture-Jacquet*] at 31, Chevalier J.

<sup>80</sup> *Supra* note 29.

<sup>81</sup> *Nancy B.*, *supra* note 10 at 387.

<sup>82</sup> *Ibid.* at 388.

<sup>83</sup> Although this remains unspoken, it is implicit in the judgment.

<sup>84</sup> *Corbeil*, *supra* note 10.

<sup>85</sup> *Ibid.* at 719, citing *Re Goyette: Centre de Services Sociaux du Montréal*, [1983] C.S. 429 at 436 [hereinafter *Goyette*].

<sup>86</sup> *Corbeil*, *ibid.*

always abide by the patient's evaluation or, as *Goyette* suggested, will the decision be subject to a preliminary test of the disappearance of human dignity, objectively determined, that is, evaluated from an outside standpoint? *Corbeil* did not require the court to answer this question, for, as Rouleau J. noted, he was proceeding on the basis that it could reasonably be concluded that Robert Corbeil's life had passed that point.<sup>87</sup>

These cases, then, do not test the limits of a patient's right to make decisions about medical treatment when the course chosen will result in an avoidable death. Niemiec presented just such a challenge in refusing treatment for harm he had done to himself. Unlike Nancy B. and Robert Corbeil, his lifespan would not otherwise be curtailed in duration or quality if he were treated (at least in the court's assessment, if not his own). The court in *Nancy B.*, just as in *Malette*, was careful to distinguish this patient's decision to decline life-sustaining medical treatment from an attempt to commit suicide; death for Nancy B. would be "the result, primarily, of the underlying disease, and not the result of a self-inflicted injury."<sup>88</sup> By way of contrast, Niemiec's refusal of treatment was characterized as a wish for self-destruction. The court concluded that allowing him to assert the inviolability of his person in these circumstances would subvert the legislative purpose underlying that principle.<sup>89</sup> Based on that view of Niemiec's decision, it would also arguably fall outside the protection afforded by the freedom of conscience and religion guaranteed by the *Charter*<sup>90</sup> even if that term is read broadly to include a secular, conscientious morality.<sup>91</sup> The Court in *Niemiec* would not have been prepared to accept his choice as either conscientious or expressive of a particular morality.

The suggestion remains after *Malette*, *Fleming*, *Nancy B.*, and *Corbeil* that a patient's right to self-determination is subject to greater restriction than would at first seem apparent from a reading of these judgments. Choices to refuse life-sustaining treatment may be scrutinized with a view to assessing the degree of congruence with generally acceptable motivations and values. This limitation is not

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<sup>87</sup> *Ibid.*

<sup>88</sup> *Nancy B.*, *supra* note 10 at 393, quoting with approval from an American decision, *Re Conroy*, 486 A.2d 1209 (N.J.S.C. 1985) [hereinafter *Conroy*]; see also *Malette*, *supra* note 31 at 428.

<sup>89</sup> *Niemiec*, *supra* note 28 at 427.

<sup>90</sup> *Supra* note 19, s. 2 (a).

<sup>91</sup> See Wilson J. (concurring) in *Morgentaler v. R.*, [1988] 1 S.C.R. 30 [hereinafter *Morgentaler*] at 178-79 on the breadth of s. 2(a) of the *Charter*.

express, but arises by implication from the careful factual basis laid in each of these judgments. Motives are, of course, open to differing interpretations. One can see that the manner in which a court characterizes the patient's reasons for refusing treatment—the generosity of its reading—could become very significant. For instance, if the court in *Niemiec* had been prepared to see the refusal of treatment as an act of political protest, perhaps the result would have been different. Religious freedom (*Malette*), preservation of one's bodily and mental integrity (*Fleming*), and relief from a permanent state of almost complete physical immobility and dependence on others (*Nancy B.* and *Corbeil*) have all proven to be examples of acceptable motivations, although they by no means constitute an exhaustive list. The parameters of any limitations on patients' right to refuse life-sustaining treatment remain to be mapped more clearly.

One obvious limitation is to be taken from sections 14 and 241 of the *Criminal Code* (which vitiate the effect of consent to one's own death and prohibit assisting in suicide, respectively<sup>92</sup>) and the decision of the Supreme Court of Canada in *Rodriguez v. British Columbia (Attorney-General)* affirming that while Sue Rodriguez, who suffered from amyotrophic lateral sclerosis, had the right to refuse even life-sustaining treatment, she did not have a right at common law or under the *Charter* to assistance in bringing about her own death.<sup>93</sup> The Court maintained the distinction between refusing treatment, which is permissible and can be effectuated even where the result will be death, and assisting in taking a life, which is not. The interest of the state in preserving life and protecting the vulnerable outweighs the individual interest in autonomy in the latter but not the former. At first glance, the difference between

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<sup>92</sup> *Criminal Code*, *supra* note 33.

<sup>93</sup> *Supra* note 10. The decision was made by the narrowest of margins—five judges in the majority and four dissenting. The dissenting judges were variously of the view that the impugned section of the *Criminal Code* violated the applicant's right to liberty or security of the person under s. 7 of the *Charter* or that the law breached her equality rights under s. 15 of the *Charter*, discriminating against her on the basis of physical disability. The dissenting judges would have recognized that Sue Rodriguez had not only a right to take her own life but also a right to "assistance under proper circumstances." *Ibid.* at 566. These would include testing for decisional capacity, time-limited certification by a physician with respect to the applicant's condition, state of mind, and a number of other matters, advance notice to the coroner, and the presence of a physician, although the act taking her life would have to be her own—in other words, "unassisted." *Ibid.* For a suggestion from another discipline that where an individual wants to end his own life, the "humane response is a presumption that he or she is suffering from a treatable mental illness (i.e. with impaired judgment) until proven otherwise (reversing the normal presumption of competence)," see F. Lowy, a psychiatrist and Director of the Centre for Bioethics at the University of Toronto, "What Kind of Life? What Kind of Death? The Sue Rodriguez Case" Canadian Bar Association—Ontario and Medical-Legal Society of Toronto, Tape S-92-707 (14 May 1993).

the two situations seems apparent and the distinction a salutary one to maintain—the right to self-determination has to do with making decisions about one's own health care, not having oneself killed. Society does not condone killing; the extent of societal disapprobation of killing is such that it is appropriately expressed through criminal sanctions. That argument is convincing in the abstract. However, the difference between what will constitute assisting a patient to refuse treatment and assisting that patient to die is not so obvious in practice. In *Nancy B.*, for instance, the actions of third persons removing the patient from the ventilator were characterized as the former.<sup>94</sup> They could equally well have been characterized as the latter, since the result that would follow (and indeed, was intended) was obvious to all, and that result was death.<sup>95</sup> Nonetheless, whether always logically defensible or not, the difference in the legal consequences of the two is clear.

To summarize, where the patient is competent, courts appear increasingly willing to give effect to the familiar proposition that common law medical treatment cases cite and recite: every human being of adult years and sound mind has the right to determine what shall be done with his or her own body. This principle is not applied in every instance, nor without ambivalence. The strength of courts' commitment to the underlying values—which they most often identify as autonomy, self-determination and bodily integrity—wavers, particularly if the court has difficulty accepting the reason for refusing treatment. Other principles and interests compete, and sometimes prevail. But for the most part, where the patient is competent, the theme of self-determination predominates.<sup>96</sup> And so it should, given the countervailing forces in our health care system and in the dynamics of physician-patient relationships, and even more importantly, given that it is the patient who has to live with and through decisions about whether to undergo treatment.

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<sup>94</sup> *Supra* note 10 at 392.

<sup>95</sup> See J. Fletcher, "The Courts and Euthanasia" (1987/88) 15 *Law, Med. & Health Care* 223 at 224-25.

<sup>96</sup> This seems true where there is no judicial intervention as well. For example, in Alberta recently, a woman left paralysed and in intractable pain after being shot requested the removal of a life-sustaining respirator and the hospital complied. She died shortly thereafter. "Shot by Spouse, Woman Asks to Die" *The Globe & Mail* (3 August 1991) A2. Other hospitals and health care workers are not so sanguine about their own potential liability in such a situation. See *Nancy B.* and *Corbeil*, *supra* note 10.

### III. DEFINITIONS OF DEATH: WHEN IS THERE A DECISION TO BE MADE?

One might expect there to be general agreement on the minimal point beyond which life support need not be continued, that being when death has occurred. Yet in Canada, it is not absolutely clear that the legal and medical definitions of death coincide,<sup>97</sup> thus complicating the consideration of when there is any decision to be made about suspending the use of life support or about the identity of appropriate decision-makers. Whatever the definition of death, determining that it has occurred is still a medical judgment and consequently, remains in the hands of physicians.<sup>98</sup> After the fact, however, the law may have something different to say about when death occurred and may even recognize several different times of death.<sup>99</sup> The traditional legal definition of death considers it to be an event occurring at an identifiable point in time, generally when heartbeat and respiration cease. Most physicians, however, now believe that it is more accurate to view death as a process, or alternatively, that death may manifest itself in various ways and is certainly not limited to a situation where the heart has stopped functioning. In medicine, then, brain death has assumed greater importance in determining when life has ceased.

A number of organizations, particularly in the United States, have developed criteria for establishing when brain death has

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<sup>97</sup> L. Kushnir, "Bridging the Gap: The Discrepancy Between Medical and Legal Definitions of Death" (1976) 34 U.T. Fac. L. Rev. 199. See also B. Dickens, "Legal Evolution of the Concept of Brain Death" (1985) 2 Transplantation Today 60.

<sup>98</sup> But see M. Burgess, "Law and Ethics: Opportunistic Infections of Medical Practice?" (1988) 3 Can. J. L. S. 265 and 269, pointing out that definitions of death have moral, cultural, and religious, as well as medical aspects. Currently, we have given this determination entirely over to physicians. Burgess suggests that widespread adoption of the "brain death criterion" once transplants became feasible represents one more example of the medical profession successfully pressuring society to accept expedient technical solutions without resolving underlying moral, cultural, and religious differences. Robert Veatch concludes that "[p]lacing responsibility on the individual physician or the profession as a whole for deciding what the definition of death should be is the result of inadequate analysis." While physicians have special skills to determine whether particular bodily functions have ceased, they have no particular expertise to select a particular philosophical or theological concept of death. See R. Veatch, *Death, Dying and the Biological Revolution: The Last Quest for Responsibility*, rev'd. ed. (New York: Yale U. Press, 1989) at 48.

<sup>99</sup> As one commentator noted regarding the laws governing transplantation in the early 1980s, "[t]he legislatures of the English-speaking provinces have embarked upon a path of balkanization of the human body," as "the definition of death ... varies depending upon which particular organ is to be transplanted." B. Freedman, "By Good Appliance Recovered: New Reflections on Organ Transplantation and the Definition of Death in Canada" (1982) 3 Health L. Can. 3.

occurred.<sup>100</sup> The Canadian Medical Association has clearly accepted the concept of brain death as an ethically valid basis for defining death.<sup>101</sup> The Law Reform Commission of Canada has recommended that legislation be passed recognizing that “a person is dead when an irreversible cessation of all that person’s brain functions has occurred.”<sup>102</sup> At present, however, Manitoba is the only province to expressly recognize brain death as an acceptable criterion for the determination of death.<sup>103</sup> Even legislation the various provinces have developed to deal with organ transplants sidesteps the issue by omitting to ascribe a meaning to the concept of death or to indicate how to determine whether it has occurred. In Ontario, for instance, section 7 of the *Human Tissue Gift Act* provides: “For the purposes of a *post mortem* transplant, the fact of death shall be determined by at least two physicians in accordance with accepted medical practice.”<sup>104</sup>

Canadian case law gives little guidance as to whether brain death can be equated with death, particularly as most of the cases concerned with determining when death occurred have arisen in the very different context of establishing entitlement to insurance proceeds or bequests under a will.<sup>105</sup> One of the very few Canadian judgments to consider this issue is the dissenting opinion in *R. v. Kitching and Adams*,<sup>106</sup> a 1976 decision of the Manitoba Court of Appeal. The defendants, who had

<sup>100</sup> The first and most prominent of these American definitions was the “Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death” (1968) 205 J. Am. Med. Assoc. 85.

<sup>101</sup> Canadian Medical Association, “A C.M.A. Position—Guidelines for the Definition of Brain Death” (1987) 136 Can. Med. Assoc. J. 200 A-B.

<sup>102</sup> Law Reform Commission of Canada, *Criteria for the Determination of Death* (Report No. 15) (Ottawa: Supply and Services Canada, 1981) at 25. The determination would be made on the basis of prolonged absence of spontaneous circulatory and respiratory functions, or, when this is impossible because of the use of artificial means of support, by any means recognized by the ordinary standards of current medical practice.

<sup>103</sup> Vital Statistics Act, R.S.M. 1987, c. V-60, s. 2 provides: “For all purposes within the legislative competence of the Legislature of Manitoba, the death of a person takes place at the time at which irreversible cessation of all that person’s brain functions occurs.”

<sup>104</sup> *Human Tissue Gift Act*, R.S.O. 1990, c. H.20, s. 7. Other provincial legislation regulating organ transplants contains similar provisions. See, for example, *Human Tissue Act*, R.S.N. 1990, c. H.15, s. 9(1); *Human Tissue Act*, R.S.B.C. 1979, c. 187, s. 7; *Human Tissue Gift Act*, R.S.N.S. 1989, c.215, s. 8; *Human Tissue Gift Act*, R.S.P.E.I. 1988 c. H-13, s. 7(1); *Human Tissue Gift Act*, R.S.A. 1980, c.H-12, s. 7; *Human Tissue Gift Act*, R.S.S. 1978, c.H-15, s. 8(1); *Human Tissue Gift Act*, R.S.Y.T. 1986, c. 89, s. 7.

<sup>105</sup> See, for example, *Re Warwicker v. Toronto General Trust Corp.* (1936), 3 D.L.R. 368 (Ont. S.C.).

<sup>106</sup>[1976] 6 W.W.R. 697.

caused the deceased's original head injuries, asserted that the real cause of death was the acts of the physicians in removing the deceased's kidneys for transplant purposes and, thereafter, in stopping the respirator. The Crown responded that the deceased was already dead by that time, as brain death had been established. Upon canvassing the various criteria proposed for establishing the occurrence of brain death, the dissenting judge held the view that there was not a broad enough consensus among physicians to be able to determine when brain death had occurred, but that the issue was not essential to the resolution of the case.<sup>107</sup> His comments in this regard were not adopted by the majority, who simply noted that the deceased was maintained on a respirator to preserve his organs, not his life, but did not consider the defendant's argument in detail.<sup>108</sup>

In a more recent decision of the British Columbia Supreme Court, *R. v. Green*,<sup>109</sup> Mr. Justice Wood also relied on the traditional definition of death—that is, death does not occur until the cessation of all vital functions, including the heart. In that case, it was necessary to determine whether the accused (who admitted shooting the deceased after the deceased had already been shot by someone else) could be found guilty of murder. Each shot taken individually would have been fatal, in that the damage to the respiratory centre of the brain was so significant that respiration would have ceased. However, the evidence also showed that the heart would continue beating for three to five minutes after the first shot, during which time the accused also shot the deceased. The court had to determine at what point death occurred—with the extensive brain damage caused by the first shot, or some minutes later, after the victim had been shot by the accused and his heart stopped beating. The court ultimately concluded that while brain death may be a suitable legal standard in medical and civil law contexts, it was impractical to apply in criminal law. In reaching this conclusion, the court seemed largely motivated by what it regarded as the impossible burden this would place on the Crown to prove when death had occurred. This would itself seem to be a misreading of the medical understanding of death. Brain death is only one of the clinical criteria physicians commonly employ to determine whether death has occurred; it does not necessarily exclude other clinical criteria. Either brain criteria or heart and lung criteria can, as appropriate, be taken as

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<sup>107</sup> *Ibid.* at 711-14, O'Sullivan J.A.

<sup>108</sup> *Ibid.* at 701, Matas J.A.

<sup>109</sup> (1988), 43 C.C.C. (3d) 413 (B.C.S.C.).



indicators of death, in the sense of irreversible destruction of whole brain function.

Current medical knowledge and, indeed, unchallenged medical practice so overwhelmingly support the conclusion that brain death can be equated with death that Canadian courts can be expected to acknowledge this to be so, certainly in the context of decisions about life support. Such a result would be consistent with the direction taken by courts in the United Kingdom and the United States.<sup>110</sup> This conclusion finds support in the provinces' willingness to afford legal recognition to "accepted medical practice" in determining when death has occurred evidenced by the legislation governing transplants.<sup>111</sup> Although criminal liability is determined by federal law, not provincial legislation, it is almost impossible to imagine that a physician would be prosecuted criminally for acts or omissions that are legal provincially. While the risk of this occurring remains a theoretical possibility, the weight of legal and medical authority leads to no other sensible conclusion than that brain dead patients need not be maintained on life support mechanisms, and that no liability would attach as a result of a physician suspending life support from a patient determined to be brain dead in accordance with currently accepted medical practice.

Beyond that, however, physicians, families, hospital ethics committees, and courts are faced with quandaries arising from the

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<sup>110</sup> In the United Kingdom, this issue would appear to be resolved such that, at least in the context of criminal proceedings, courts are prepared to acknowledge that where the victim of a crime is considered dead by accepted medical criteria (i.e., brain death has occurred), life support can be withdrawn without breaking the chain of causation between the original injury necessitating the use of life support and the death. See *Finlayson v. H.M. Advocate* (1978), Solic. Law Times, Notes 60 and *R. v. Malcherek*; *R. v. Steel*, [1981] 2 All E.R. 422 (C.A.).

In *Malcherek*, Lord Lane, C.J., specifically noted at 429 that:

[w]hatever the strict logic of the matter may be, it is perhaps somewhat bizarre to suggest ... that where a doctor tries his conscientious best to save the life of a patient brought to hospital in extremis, skilfully using sophisticated methods, drugs and machinery to do so, but fails in his attempt and therefore discontinues treatment, he can be said to have caused the death of the patient.

Although the court made it clear it was not passing judgment on whether the confirmatory tests for brain death represented a satisfactory code of practice, implicit in Lord Lane's statement must be a recognition and acknowledgment that "death" can be defined as brain death determined in accordance with accepted medical practice. It is not that the state absents itself from any role in defining death, but rather, that the state has limited its intervention to deciding that some other profession shall decide, by leaving what the court chooses to characterize as a clinical decision in the hands of clinicians.

<sup>111</sup> *Supra* note 99.

increasingly multiple meanings of death,<sup>112</sup> and with difficult questions about the extent to which contentious expansions of our understanding of when death has occurred ought to be applied in decisions about life support. The Law Reform Commission of Canada recommended that the law should clearly state that a physician acts legally in deciding to terminate or not to initiate “treatment which is useless or which no longer offers reasonable hope, unless the patient has expressed his wishes to the contrary.”<sup>113</sup> One must ask, “reasonable hope” of what?

This question remains as an unexplored sub-text to the preceding discussion. It does require attention both in the context of defining death and more generally in decision making about life support. What minimum must a patient meet before there is a point to determining his or her best interests or what the patient’s decision regarding the use of

<sup>112</sup> See S. Goldberg, “The Changing Face of Death: Computers, Consciousness and Nancy Cruzan” (1990) 43 Stan. L.R. 659 at 665-81 (tracing the move from a whole brain definition of death to the development in the United States of a legal and medical “consensus” that those who are “permanently deprived of self-awareness by cessation of higher brain functioning” can be allowed to die, and noting that some ethicists now distinguish the capacity for social interaction rather than mere consciousness as crucial in determining whether life support need be continued). See also *Delio v. Westchester County Medical Center*, 516 N.Y.S.2d 677 (S.C.A.D. 1987) [hereinafter *Delio*] (accepting concept of neocortical or “higher brain” death). In a New Zealand decision, *Auckland Area Health Board v. Attorney-General*, [1993] 1 N.Z.L.R. 235 [hereinafter *Auckland Area Health Board*] at 245 (H.C.), an application by a patient’s doctors and hospital seeking court approval for the removal of a ventilator from a man suffering from an extreme form of Guillain Barré syndrome who was unable to communicate in any way, Thomas J. commented on:

[t]he problem ... when life passes into death but obscurely ... the process of living can become the process of dying. This is the plight of the irreversibly doomed patient. Maintained by mechanical means they exist suspended in a state of moribund inanimation. Whether a body devoid of a mind or, as in the case of Mr. L. a brain destitute of a body, does not matter in any sensible way. In their chronic and persistent vegetative condition they lack self-awareness or awareness of the surroundings in any cognitive sense. They are the ‘living dead’.

He did not mean by that expression that he considered the patient dead in the legal sense, but that his decision turned on his conclusion that the ventilator was being used to defer death rather than sustain life because the difference between brain death and this patients’ state is “a matter of medical description.” *Ibid.* at 246. Distinguishing between treatment that sustains life and that which defers death is likely to be a difficult if not impossible line to draw in many instances. In Canada, an Alberta Provincial Court judge committed foster parents to stand trial on charges of second degree murder with respect to their foster child who was in a permanent coma and arguably showed no evidence of higher brain activity. The child had not suffered whole brain death. The Crown ultimately chose to proceed to trial only on a charge of aggravated assault. See *Lawyer’s Weekly* (14 January 1992) 14; *The National* (February 1992) 3; telephone conversation with D. Abbey, counsel to the accused (6 July 1992). The decision would appear to be an isolated departure from the general requirement of whole brain death in the criminal law context.

<sup>113</sup> *Supra* note 32 at 55-56. See also British Columbia Royal Commission on Health Care and Costs, *Closer to Home* (Victoria: Crown Publications, 1991) Vol. 2 at C-182-85 [hereinafter *Closer to Home*].

life support would have been? Is it physical existence alone, or some level of cognitive, sapient life<sup>114</sup> or an appreciation or awareness of one's environment and ability to interact?<sup>115</sup> While it is beyond the scope of this article to consider the question in detail, it is suggested that as a practical matter, Canadian courts will not go beyond very accepted, very conventional medical opinion in defining death in the context of life support issues. In Canada currently, that would mean death would be equated with whole brain death.<sup>116</sup> Life support could be withdrawn without question then. As we have seen, however, much more problematic determinations must be made when the patient does not meet that definition of brain death but is nonetheless in a severely compromised position, for instance, in a persistent vegetative state or barely conscious. Given that we can expect courts to take a very cautious approach overall in this area, it follows that their analysis of when death has occurred will be conservative as well. Certainly at this point, where the patient evidences some brain activity a court confronted with the question of whether or not to sanction the withholding or withdrawal of life support will not begin by adopting an expansive definition of death. In those circumstances, the question will be whether or not the patient should be maintained with life support staving off the underlying disease or condition, not whether the patient's existence as a person has ended, although he or she still exists as a human being, as some writers have suggested.<sup>117</sup>

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<sup>114</sup> This factor was emphasized in *Re C*, [1989] 2 All E.R. 783 at 787 (C.A.), but as a means of judging quality or experience of life for this patient, not in terms of whether the patient did not exist as a human being. In *Auckland Area Health Board*, *supra* note 112, the court relied on the patient's lack of self-awareness and awareness of his surroundings "in any cognitive sense" to support its conclusion that he was one of the "living dead" for whom life support only deferred death but could not be regarded as sustaining life.

<sup>115</sup> A criterion suggested by Goldberg, *supra* note 112; Rhoden, *supra* note 7 at 399-401 and at 442; A. Buchanan & D. Brock, *Deciding for Others: The Ethics of Surrogate Decision-Making* (Cambridge: Cambridge U. Press, 1989) at 194-99.

<sup>116</sup> The Law Reform Commission of Canada's recent report, *Procurement and Transfer of Human Tissues and Organs* (Working Paper 66) (Hull, Que.: Supply and Services Canada, 1992) at 95-102 implicitly confirms this conclusion in its recommendation that death *not* be re-defined such that anencephalic newborns (who are born missing a major portion of the brain, skull, and scalp and who cannot survive) be deemed brain dead to enable early organ transplants.

<sup>117</sup> See, for example, Buchanan & Brock, *supra* note 115 at 127-32.

#### IV. DECISION MAKING FOR INCOMPETENT PATIENTS

There is a growing commitment to honouring a competent patient's refusal of medical treatment, even when that treatment would be life-saving or life-prolonging, on the basis that the patient's autonomy—the right to determine for oneself what shall be done with one's body—is paramount. However, the principles to be applied in decision making when the patient is incompetent are much less clear. This is particularly so where the incompetent patient is in a persistent vegetative state or barely conscious but is not facing imminent death as long as life-support is continued. Because of the indications in *Malette* and *Fleming*, that patients' instructions about future care should prevail or at least be given great weight in treatment decisions,<sup>118</sup> the situation of patients with advance directives will be analyzed separately from those without.

##### A. *Patients With Advance Directives*

###### 1. Introduction

Legislation providing for advance directives attempts to structure an opportunity for competent individuals to exercise their right of self-determination with respect to future medical treatment decisions that must be made after the onset of incompetence. Subject to differing conditions and limitations, a person while competent can make a living will leaving instructions refusing or choosing life-support or other specified therapies, or can execute a durable power of attorney for health care appointing someone to make such decisions on his or her behalf should the individual later become incompetent, or some combination of the two. Nova Scotia recently formalized the effect to be given to a patient's prior competent appointment of a substitute decisionmaker in medical matters.<sup>119</sup> Quebec has made provision for appointment of a health care attorney as well.<sup>120</sup> Manitoba legislation now enables a patient to leave instructions with respect to treatment

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<sup>118</sup> *Supra* note 31 at 431 and *Fleming, supra* note 20 at 85-86.

<sup>119</sup> *Consent to Medical Treatment and Consequential Amendments Act, supra* note 12.

<sup>120</sup> *Quebec Civil Code, Art. 19.1* (enacted Bill 125, 1990).

after the onset of incompetence.<sup>121</sup> More wide-ranging legislation has been passed in Ontario, although at the time of writing, it has not yet been proclaimed in force.<sup>122</sup> Legislation in this area was recently introduced in British Columbia and is expected shortly in Alberta.<sup>123</sup> Advance directives have been sanctioned in many American states for some time. In a move that began in California in 1976, most states have passed legislation recognizing advance directives, such that there are now many variations on natural death acts, durable powers of attorney for health care, and family consent laws. The latter empower specified others to decide health care matters even absent an advance directive.<sup>124</sup> Federal legislation in the United States that became effective in 1992 contains explicit provisions to ensure that Medicare providers encourage and honour advance directives by requiring them to be routinely offered to patients, although prohibiting the facility from providing medical care conditional on the existence of an advance directive having been made.<sup>125</sup>

## 2. Difficulties in practice

Even where legislation is in place, however, practical and legal difficulties remain. The first and most obvious is that relatively few people execute living wills or durable powers of attorney, even in jurisdictions where they have had statutory recognition for some time.<sup>126</sup> Secondly, the legislation is generally drafted in such a way that the advance directive only becomes operative in quite restricted situations—most often, not until the patient is suffering from a terminal illness or death is otherwise imminent. This excludes whole categories of

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<sup>121</sup> See *Health Care Directives Act*, *supra* note 12.

<sup>122</sup> See *Substitute Decisions Act*, *Advocacy Act*, and *Consent to Treatment Act*, *supra* note 12.

<sup>123</sup> In British Columbia, see Bill 51, *Health Care (Consent) and Care Facility (Admission) Act*, 2d Sess., 35th Parl., British Columbia, 1993; Bill 49, *Adult Guardianship Act*, 2d Sess., 35th Parl., British Columbia, 1993; and Bill 48, *Representation Agreement Act*, 2d Sess., 35th Parl., British Columbia, 1993.

<sup>124</sup> See J. Areen, "Advance Directives Under State Law and Judicial Decisions" (1991) 19 *Law, Med. & Health Care* 91 at 93-97, summarizing relevant state laws as at October 1990. See also G. J. Alexander, "Time for a New Law on Health Care Advance Directives" (1991) 42 *Hastings L. J.* 755.

<sup>125</sup> Alexander, *ibid.* at 770-71, citing Pub. L. No. 101-508, 104 Stat. 1388 (1990).

<sup>126</sup> In the United States, it is estimated that only 15 per cent of the population have done so. See Areen, *supra* note 124 at 92.

conditions for which people might wish to specify that treatment be withheld—for instance, the onset of a persistent vegetative state, or a curable disease where the patient is suffering from an underlying, *incurable* malady or irremediable degeneration.<sup>127</sup> Such provisions also leave the physician in the position of gatekeeper, since classifying an illness as “terminal” or death as “imminent” is very much a medical judgment, and one that is frequently not made, at least not explicitly, or not communicated.<sup>128</sup> It is also difficult to have sufficient prescience to anticipate the variety of conditions from which one might suffer, the modalities of treatment that might be available and the range of prognoses that might hold in order to draft a living will or guidelines for a substitute decisionmaker in terms sufficiently clear and precise as to be meaningful or binding.<sup>129</sup>

Finally, the existence of legislation authorizing advance directives can itself be a two-edged sword, even though its aim is generally to make it easier for people to refuse treatment. The decision of the Supreme Court of Missouri in *Cruzan* is instructive in this regard.<sup>130</sup> There, the state had passed living will legislation, which the court held embodied a state policy strongly favouring life. Predictably enough, Nancy Cruzan, a young woman in her mid-twenties, had not made a living will. She was left in a persistent vegetative state following an automobile accident. After a number of years, her parents sought court approval for the withdrawal of artificial nutrition and hydration. In a decision affirmed on appeal to the United States Supreme Court, it was held that, absent compliance with the formalities required under the statute, “no person can assume that choice [to have life support

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<sup>127</sup> See *Evans v. Bellevue Hospital* (28 July 1987) [unpublished], referred to in N.Y.L.J. (28 July 1987) 11 [hereinafter *Evans*].

<sup>128</sup> See *Life-Sustaining Technologies*, *supra* note 1 at 7, noting that most dying patients have never been declared terminally ill.

<sup>129</sup> See, for example, *Evans*, *supra* note 127. An incompetent patient with AIDS Related Complex had when still competent executed a document stating that life-sustaining treatment should be withheld if his condition became such that he had no reasonable expectation of recovery or regaining a meaningful quality of life. He had also executed a power of attorney for health care. The patient developed toxoplasmosis, an infection resulting in brain lesions. The patient's health care decisionmaker asked that antibiotic treatment be withheld. The patient's physicians refused, as they were of the view that treatment could cure the infection and restore the patient's ability to communicate. The court to which the dispute was referred authorized treatment on the ground that the document's reference to “meaningful quality of life” was too ambiguous to sanction non-treatment and that, while the patient had no hope of recovery from AIDS, he could recover from toxoplasmosis, if treated.

<sup>130</sup> *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo.banc 1988) [hereinafter *Cruzan (Mo. S.C.)*] at 419-20, *aff'd.*, *Cruzan*, *supra* note 6.

withdrawn] for an incompetent.”<sup>131</sup> On that basis, the court concluded it was justified in imposing a very high standard of proof of the patient’s own choice regarding the use of life support on those seeking to have it withdrawn.<sup>132</sup> Seemingly, then, having life support withdrawn can be even more difficult where a formal regime for advance directives has been established than where there is no such legislation. In *Cruzan*, the fact that a statutory system existed acted as a dead hand on the decision-making process.<sup>133</sup>

### 3. Difficulties in analysis—the advance directive as a competent/incompetent hybrid

Entirely apart from their practical shortcomings, advance directives raise more profound ethical questions as well. It is difficult to know whether to analyze them in relation to competent or incompetent patients, for although advance directives only become operative after the patient has become incompetent, they are an expression of the patient’s instructions made at an earlier time, while competent. Laws regarding advance directives do not treat the onset of incompetence as a change of any moment except for the limited purpose of triggering the advance directive. Yet the loss of decisional capacity that is a necessary prerequisite to the advance directive becoming operative is itself obviously a change with significant consequences. It is that assumption in the law that the individual is and remains “all of a piece” regardless of the intervening change in decisional capacity that has been challenged by some philosophers and bio-medical ethicists. They criticize the lack of clarity among supporters of advance directives as to whose instructions are being honoured and whose interests are being served: is it the

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<sup>131</sup> *Ibid.* at 425 and quoted in *Cruzan*, *supra* note 6 at 2846.

<sup>132</sup> For comments on the standard of proof courts impose in this type of case, see Rhoden, *supra* note 7, and G. Annas, “When Procedures Limit Rights: From Quinlan to Conroy” (1985) *Hastings Center Report* 24. Interestingly, after the United States Supreme Court released its decision in *Cruzan*, the patient’s parents returned to the Probate Court, asking it to consider new evidence. The state Attorney General withdrew from the case, claiming the state had no further role once its law had been clarified. The judge ruled that the new evidence now met the state’s evidentiary standard and gave permission for the discontinuance of artificial feeding. Nancy Cruzan died 12 days later. See Martyn & Bourguignon, *supra* note 6 at 819, and note 8.

<sup>133</sup> But see *In Re Gardner*, 534 A.2d 947 at 952 and note 3 (Me. S.J.C. 1987), where the court held that state living will legislation, which prohibited the inclusion of instructions to discontinue artificial nutrition and hydration in an advance directive, did not affect the patient’s common law right to refuse medical treatment, exercisable through a competent intermediary. On the basis of that right, the court held that the incompetent patient’s artificial feeding could be withdrawn.

present interests of the incompetent individual, or the past interests and choices of the competent individual?

Briefly, those who criticize unquestioning reliance on advance directives argue that the very process that activates the advance directive—the onset of incompetence—can and often does bring with it such a significant break in the patient's psychological continuity or in the conditions of the patient's physical existence or both, that the advance directive ought no longer apply. It is said that the advance directive is overtaken by events and, as a result, loses its moral authority as a basis on which to make treatment decisions.<sup>134</sup> This position is generally based on one or both of the following arguments. The more obvious claim is that what a person regarded as desirable or essential while competent or healthy may change drastically in ways that cannot be foreseen when the person becomes incompetent or seriously ill. Matters that were of deep concern may become of little moment and vice versa. Hence, it is said that the advance directive may be irrelevant to the patient's current needs and interests.<sup>135</sup> Some commentators also make the more radical claim that the discontinuity between the patient's state before and after the onset of incompetence can be so great in some instances that the patient is quite literally not the same "self" as the person who executed the advance directive in the first place. It follows from this argument that the "earlier" competent self would have no moral authority to determine what is to happen to another self, that is, to the individual who remains after the onset of incompetence. Hence, the advance directive executed by the prior competent self need not be honoured.<sup>136</sup>

This conception of the person and personality is entirely oriented to the present. As one critic has responded, it means one views the person concerned "only in a highly restricted slice in time,"<sup>137</sup> a time

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<sup>134</sup> For exponents of this view, see for example, Dresser & Robertson, *supra* note 7 at 236, drawing on the work of British philosopher Derek Parfit, who argues that a person's life ought most accurately be viewed as a series of successive selves.

<sup>135</sup> *Ibid.* This point is also made even relative to competent patients. See, for example, *Life Sustaining Technologies*, *supra* note 1 at 24 and 238, noting that many health professionals are skeptical about advance directives not only because most lay persons have difficulty understanding the details of their condition and the treatment options, but also because the gulf between hypothetical and actual situations is so wide. Using the example of the "terrifying ... experience of severe breathing difficulty," one doctor commented, "patients who think they don't want to be ventilated change their mind when they are choking to death." *Ibid.* at 428-29.

<sup>136</sup> See Dresser & Robertson, *supra* note 7 at 236. For rebuttals, see Rhoden, *supra* note 7 at 411-12; and Buchanan & Brock, *supra* note 115 at 154-60.

<sup>137</sup> Rhoden, *supra* note 7 at 411-12.



when only very limited interests may remain to the patient—perhaps only physical sensations, if that. Ignoring an advance directive as arguably not speaking to the patient's current interests after incompetence intervenes is an approach that discounts much of what a person was and valued in his or her life. It does not seem appropriate to judge treatment options for once-competent patients only from the truncated perspective of their current state.

#### 4. The case for advance directives

Strong arguments can be made that advance directives do facilitate self-determination, both immediately and in the longer term. First, they allow an individual working within the framework of his or her own value system to set the parameters of the medical conditions under which he or she is willing to continue with life-sustaining treatment, at least in instances where the individual's future has already been severely circumscribed by the realities of failing health. Secondly, advance directives also foster the individual's well-being, both in the more immediate sense that being in control of one's fate at least in this way enhances one's peace of mind and sense of security and, looking to the future, in the sense that advance directives can ensure protection from overzealous medical interventions. It is paradoxical that advance directives enhance well-being in these ways, since promoting well-being—acting “for the patient's own good”—is often characterized as a paternalistic rival to autonomy in guiding medical treatment decisions. Thirdly, while it may be a fair comment that advance directives cannot always address all possibilities in sufficient detail to definitively determine treatment decisions, they can still indicate the fundamental approach to be adopted and the boundaries of what is appropriate for the person concerned. And finally, it has been suggested that advance directives allow one to “do good” for others as well as oneself, in the sense of enabling an individual to relieve the emotional and financial burden of extreme illness on family and friends by decreeing an endpoint to continued treatment.<sup>138</sup>

In any event, despite arguments among ethicists and the practical difficulties outlined, as a practical matter, it is not likely that our courts will dismiss lightly advance instructions regarding treatment. The current strong support for individual self-determination evident in many

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<sup>138</sup> See Buchanan & Brock, *supra* note 115 at 98.

areas of the law,<sup>139</sup> the decisions in *Malette* and *Fleming* recognizing that even informal advance instructions are useful as a means of giving effect to the highly prized value of patient autonomy, and legislation recently passed and pending that sanctions living wills, durable powers of attorney, and other forms of advance directives all indicate that they will be taken very seriously indeed by the courts.

## 5. Formal requirements for advance directives

The decisions in *Malette* and *Fleming* would suggest that directions respecting future care or the identity of designated decision-makers need not have been expressed in any particular manner in order to govern decisions made after the onset of incompetence, although that may change if legislation is passed formalizing the status of particular types of advance directives.<sup>140</sup> In *Malette*, the patient made her refusal of treatment known by means of a signed, undated card to that effect. In *Fleming*, the patients appointed the Official Guardian as their substitute decisionmaker and advised that office of their refusal of neuroleptic drugs. However, it may be that the ready acceptance of the means employed to communicate refusal of future treatment in these two cases was the result of long-standing customary usage in the first instance and the statutory status accorded the refusal in the second. In *Malette*, the court commented that both the religious belief of Jehovah's Witnesses regarding blood transfusions and the use of a card to transmit that information to others were well known, certainly among health care providers.<sup>141</sup> In *Fleming*, the patients had followed the system for advance refusal of psychiatric treatment that was mandated by statute;

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<sup>139</sup> See, for example, *R. v. Swain* (1991), 63 C.C.C. (3d) 481 (S.C.C.) [hereinafter *Swain*] at 505 (principles of fundamental justice in s. 7 of the *Charter* contemplate a criminal justice system founded on respect for the autonomy and dignity of human beings; therefore, it is for the accused to determine whether to waive defence of insanity); *Rodriguez*, *supra* note 10; *Morgentaler*, *supra* note 91 (at 56, Dickson and Lamer JJ. conclude that state interference with bodily integrity and serious state-imposed psychological stress constitutes a breach of security of the person guaranteed by s. 7 of the *Charter*, at least in the criminal law context; *Ibid.* at 166 and at 171 (Wilson J. indicates that the right to "liberty" contained in s. 7 guarantees an individual a degree of personal autonomy over important decisions intimately affecting his or her private life, including a woman's decision regarding abortion); and *Fleming*, *supra* note 20 at 88 (melding common law right to self-determination and constitutional right to security of the person in context of medical treatment decisions).

<sup>140</sup> See discussion of the effect of living will legislation on the decision in *Cruzan*, *supra* notes 130-33 and accompanying text.

<sup>141</sup> *Supra* note 31 at 433-34.

whatever the system's shortcomings,<sup>142</sup> once the patients had done so, they had done enough.

Given the very high value courts consistently place on self-determination in medical treatment decisions, one can anticipate that judicial recognition of even informal advance instructions will be extended beyond these limited circumstances. Still, in choosing to honour advance directives, courts must bear in mind that they are "not a cost-free empowerment of persons to control their medical future"; and they can result in the death of incompetent persons who retain significant interests in continued life.<sup>143</sup> Accordingly, while no particular format need be followed in making one's wishes regarding future care known, both *Malette* and *Fleming* indicate quite properly that the weight to be accorded to any such directions ought to depend on a number of factors, focusing on evidence probative of whether the written or oral instructions accurately reflect the patient's intentional, freely given directions (at least up to the onset of incompetence), and on their applicability to the patient's present circumstances.<sup>144</sup>

## B. *Patients Without Advance Directives*

### 1. The choice of decision-makers

This article is chiefly concerned with examining whether life support can lawfully be withheld or withdrawn from patients who are not brain dead, and if so, the test to be applied in making this decision. However, the type of decision-making process—the identity of the decisionmaker and the standard of proof to be met—must also be taken

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<sup>142</sup> Referenced obliquely in the decision itself. *Supra* note 20 at 94.

<sup>143</sup> *Dresser & Robertson*, *supra* note 7 at 237.

<sup>144</sup> *Malette*, *supra* note 31 at 434-35; see also *Fleming*, *supra* note 20 at 94, remarking on the different weights that might reasonably be accorded different types of communication. The Ontario Court of Appeal recently refused to overturn the order of a lower court allowing blood transfusions to be administered to an adult woman Jehovah's Witness following an automobile accident. She carried a card in her purse refusing blood, but unlike *Malette*, her husband and fifteen-year-old son testified she had told them she would not refuse a transfusion if her life were at risk. The judge hearing the application in the first instance concluded that the written instructions might not reflect the patient's actual current wishes and the appellate court held that it could not overturn that conclusion as it did not have access to the evidence (transcripts were not yet available when the appeal was heard, three days after the initial application). See *Wijngaarden v. Tzalis* (1992), 11 O.R. (3d) 779 (C.A.); "Jehovah's Witness can be given blood, court rules" *The Globe and Mail* (29 October 1992) A16.

into account in any consideration of these issues, as the process can greatly affect the outcome in a particular case. By way of example, in *Cruzan*, the patient's parents (who were her court-appointed guardians), her physicians, and even her court-appointed guardian *ad litem* all supported an end to her artificial feeding and hydration.<sup>145</sup> Had the decision been left to any or all of them, the matter would have ended there, with a determination that artificial feeding cease. The guardian *ad litem* appealed from the initial Probate Court decision, despite his agreement that it was in the patient's best interests, only because he felt it was his responsibility to the patient to "pursue this matter to the highest court in the state,"<sup>146</sup> that is, because of his perception of his role in a necessarily adversarial process. Introduction of a formally adversarial advocate for the patient, intervention by the state Attorney-General,<sup>147</sup> and moving to an appellate court changed both the type of decision being made (turning it into a contest over permissible evidentiary standards), and most significantly, reversed the outcome, since both the state Supreme Court and the United States Supreme Court refused to authorize the withdrawal of life support. The decision-making process made all the difference.<sup>148</sup> It is beyond the scope of this article to canvass exhaustively the ramifications of various types of decision-making processes that present as possibilities when the patient is incompetent. Nonetheless, it is important to bear in mind that whatever paradigm is ultimately chosen will have its own (perhaps decisive) effect on the outcome. It may be that in the end, the model of decision-making settled upon will be more significant than the standard to be applied to guide decision-makers.

In thinking about the identity of the primary decision-makers, one cannot lose sight of the broader framework within which these decisions are made. Whether or not the decision is that of a court or some other obviously governmental body or the patient's family or physician, government control is always present. Most obviously and

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<sup>145</sup> *Cruzan*, *supra* note 6 at 2853, note 9.

<sup>146</sup> *Ibid.* at 2853, note 9 and *Cruzan (Mo. S.C.)*, *supra* note 130 at 410. Before the United States Supreme Court, *Cruzan's* guardian filed a brief urging reversal of the Missouri Supreme Court's decision.

<sup>147</sup> Possibly in furtherance of a pro-life, anti-abortion agenda. See G. Annas, "The Long Dying of Nancy Cruzan" (1991) 19 *Law Med. & Health Care* 52 at 56.

<sup>148</sup> Although not ultimately, when the Attorney General withdrew from participation in the case. At that point, the Probate Court judge determined that on the basis of the new evidence introduced, the state's "clear and convincing evidence" standard had been met. See Martyn & Bourguignon, *supra* note 6.

most bluntly, the power of the state may well be brought to bear on those involved in the decision-making process after the fact through criminal, civil, and professional disciplinary proceedings. But even where the state's presence is not so apparent, it will have intervened already through its initial decisions allocating power over medical treatment decisions, defining the kind of substantive and procedural governances that it will impose on the individuals involved, and articulating norms. As Martha Minow has perceptively commented, it is a mistake to think that state intervention can ever be avoided in decisions such as these.<sup>149</sup> I do not use the concept of state intervention here to argue that all these decisions are manifestations of government action and therefore subject to the *Charter*,<sup>150</sup> but rather, to point out

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<sup>149</sup> M. Minow, "Beyond State Intervention in the Family: Baby Jane Doe" (1985) 18 U. Mich. J.L. Reform 933 at 951-52. Minow's observation as to the pervasiveness of state involvement was accepted by Handler J. in his concurring judgment in *Jobes*, *supra* note 73 at 461, and forms part of his justification for judicial intervention in decisions of this nature.

<sup>150</sup> On the meaning of "government" and "government action" in the *Charter*, see cases cited *supra* note 20. *Charter* issues were raised in *Eve*, *supra* note 15 at 36, a case concerning medical treatment and an incompetent person, but in the court's view, its duty to do what it considers to be in the incompetent person's best interests "must not ... be transformed so as to create a duty obliging the court, at the behest of a third party, to make a choice between two alleged constitutional rights—the right to procreate or not to procreate." Consequently, other than a brief reference at 35 to s. 7 protecting against "laws or other state action," the Court put *Charter* considerations aside. Although it is beyond the scope of this article to explore, one can still argue that the *Charter* would apply to non-governmental bodies and private individuals if acting pursuant to a statutory scheme, as in *Fleming*, *supra* note 21, and to courts making decisions about life support. See P. Peppin, "Justice and Care: Mental Disability and Sterilization Decisions" (1989-90) Can. H.R. Yrbk. 65 at 99-104 (courts exercising their *parens patriae* jurisdiction act as "government" within the meaning of s. 32 of the *Charter* since in doing so, they represent the sovereign). Recent cases suggest one need not make so fine a distinction in courts' functions as Peppin proposes. See *R. v. Swain*, *supra* note 139 at 502 (where the *Charter* is generally applicable to the litigation—in that case, criminal proceedings—it applies to judge made common law rules as well as to statutes and regulations); and *R. v. Rahey*, [1987] 1 S.C.R. 588 (The *Charter* right to trial within a reasonable time was breached where a trial judge adjourned defendant's application for a directed verdict twenty times and took eleven months to reach a decision. Writing one of the four concurring opinions, La Forest J. (with McIntyre J.) noted that "the courts, as custodians of the principles enshrined in the *Charter*, must themselves be subject to *Charter* scrutiny in the administration of their duties." *Ibid.* at 633). The strongest support can be taken from *B.C.G.E.U. v. B.C.*, [1988] 2 S.C.R. 214 (A court-ordered injunction prohibiting picketing of courts by government employees on lawful strike abridged *Charter* right to freedom of expression but was justified under s. 1. The *Charter* applied as the court was acting on its own motion and not at the instance of a private party; the court's motivation "... is entirely 'public' in nature rather than 'private'." *Ibid.* at 243, Dickson C.J., with whom Lamer, Wilson, La Forest, and L'Heureux-Dubé JJ. concurred. McIntyre J. also agreed that the *Charter* applied, but did not find a violation of the *Charter* right to freedom of expression) Generally on this topic, see P. Hogg, *Constitutional Law of Canada*, 3rd ed. (Toronto: Carswell, 1992) c. 34. It has also been suggested that in any event, even if a particular *Charter* right was not meant to apply in a medical context, it nonetheless shows implicitly the respect which the law has for self-determination. See *Corbeil*, *supra* note 10 at 209, Rouleau J. quoting with approval from J.-L.

that the question of the appropriateness of judicial involvement is not the stark one of whether to structure state intervention into personal matters or not; the state is already involved in myriad ways.

This is not to say that since the state is always involved, judicial approval need or ought always be sought prior to withdrawing life support from an incompetent patient. Such a response would in many instances be both unnecessarily cumbersome and would skew the decision-making process in potentially undesirable ways. Nor is it to say that the form of state intervention does not matter. As Minow points out, the state's decisions as to the allocation of power (even if "decided" only by default, by silence) are not neutral; they have their own effect on the results.<sup>151</sup> This would be true of increasing or formalizing judicial involvement in advance of a decision to withdraw life support as well. The commencement of court proceedings typically presents a sharp and often unwelcome departure from the preceding decision-making processes. For a graphic illustration of the power that underlies state determinations regarding the locus of decision-making authority and the type of decision-making process, we need only look to the decision in *Cruzan*. There, introducing a formal adversarial process changed the decision making from a contextualized inquiry into the patient's circumstances to an abstract debate about permissible evidentiary standards. The issue became a procedural one, although clearly with a significant substantive content, as it supported a substantive determination diametrically opposed to the considered judgment of all those more closely involved with the patient.<sup>152</sup>

Conversely, keeping courts out of the decision-making process is not to be understood as the state having carved out a boundary limiting state intervention in, for instance, families and personal autonomy. Rather, it simply indicates the different substantive and procedural governances of the family or the individual which the state has undertaken<sup>153</sup>—for instance, through allocating power to the attending physician, hospital prognosis committee, ethicists, or other government officials. These allocations of power to particular mechanisms and

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Baudouin, *Justice Beyond Orwell* (Montreal: Yvon Blais Inc., 1985). More generally, the Supreme Court of Canada has held that even where no reliance is placed on any specific provision of the *Charter*, "the values embodied in the *Charter* must be given preference over an interpretation which would run contrary to them." See *Hills v. Canada (A.G.)*, [1988] 1 S.C.R. 513 at 558, L'Heureux-Dubé J., citing and relying on *Dolphin Delivery*, *supra* note 20; and *Manitoba (A.G.) v. Metropolitan Stores Ltd.*, [1987] 1 S.C.R. 110.

<sup>151</sup> *Supra* note 149 at 952.

<sup>152</sup> See P. Brest, "The Substance of Process" (1981) 42 Ohio State L. Rev. 131.

<sup>153</sup> Minow, *supra* note 149 at 952.

participants are no more neutral than leaving decision making to the courts, and will also affect results.

Whether there should be judicial involvement in these decisions at all in the normal course and, if so, what role the legal system should play remain unanswered questions. We can predict with reasonable certainty that these are not decisions Canadian courts are likely to leave entirely to individual physicians, family members, or hospital ethics committees, particularly where there is disagreement over the appropriate course of action. In *Eve*, one of the Supreme Court of Canada's few recent decisions concerning medical intervention and a decisionally incapable person, the Court somewhat cryptically staked out this territory as at least potentially suitable for judicial intervention.<sup>154</sup> Although it was dealing with a different issue—the proposed sterilization of an incompetent young woman—it specifically raised and left open the question whether courts should permit the removal of life-sustaining equipment, obviously viewing this as an area in which court approval may be required. One can expect that, given the courts' *parens patriae* power, they will be vigilant to ensure that the rights and interests of those who are incompetent are protected (at least in those instances in which someone brings the matter to court).

What few comments there are from lower courts seem to indicate they are of two minds with respect to their role. On the one hand, there is the very activist role unnecessarily (and therefore possibly more pointedly) claimed by the Quebec Superior Court for judges in questions of life or death in *Institut Phillippe Pinel de Montréal v. Dion*.<sup>155</sup> That case granted an application by a psychiatric institution for a declaration that it had the authority to force an inmate being held under a Lieutenant Governor's warrant to undergo drug therapy and psychiatric treatment for his schizophrenia. The court considered the judiciary to have a non-delegable duty to determine such questions. The judge seemed to go out of his way to reject "any attempt to shift the ultimate decision making responsibility away from the duly established court ... to any committee, panel or group [*i.e.*, physicians or ethics committees]."<sup>156</sup> Although it was faced with a very different issue, thus

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<sup>154</sup> *Supra* note 15 at 29. However, by the time of the British Columbia Court of Appeal's decision just over five years later in *Rodriguez v. B.C. (A.G.)*, [1993] 3 W.W.R. 553 at 571, McEachern C.J. simply assumed that courts allow the withdrawal of life support from persons who are incompetent where that is seen as medically appropriate.

<sup>155</sup> (1983), 2 D.L.R. (4th) 234 (Que. S.C.) [hereinafter *Dion*].

<sup>156</sup> *Ibid.* at 242, quoting from the American case, *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d. 417 at 434 (Mass. 1977) [hereinafter *Saikewicz*].

making this particular reference unnecessary to support its decision, the court nonetheless quoted with approval from an American decision, *Superintendent of Belchertown State School v. Saikewicz*, which considered whether to authorize chemotherapy for an incompetent long-term adult resident of a state school who was suffering from leukaemia and who had no relatives interested in taking part in the decision:

We do not view the judicial resolution of this most difficult and awesome question—whether potentially life-prolonging treatment should be withheld from a person incapable of making his own decision—as constituting a ‘gratuitous encroachment’ on the domain of medical expertise. Rather, such questions of life and death seem to us to require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created. Achieving this ideal is our responsibility ... and is not to be entrusted to any other group purporting to represent the single ‘morality and conscience of our society’ no matter how highly motivated or impressively constituted.<sup>157</sup>

In the end result, the American court did not authorize the chemotherapy; the Quebec court authorized the hospital to treat.<sup>158</sup>

In contrast, the British Columbia Court of Appeal in *Astaforoff*<sup>159</sup> expressed chagrin that the question of whether prison officials had a duty to force-feed Mary Astaforoff had been brought before it at all. It characterized the case as primarily a dispute between the federal and provincial governments and chided them for not taking steps to avoid the impasse without involving the courts. The Saskatchewan Provincial Court in *Re Minister of Social Services and P.*<sup>160</sup> seemed to be of the view that a parental decision refusing a life-saving transplant operation for their child was not properly the concern of either the judicial or the child protection branches of the state, *provided* it met the baseline of falling within the bounds of current medical opinion and social mores. Of the physicians called as witnesses, only one insisted that a transplant was the treatment of choice; the others were of the view that given the burdens and risks associated with the operation and its aftermath, either decision—to seek a transplant or not—was

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<sup>157</sup> *Saikewicz*, *ibid.* at 435.

<sup>158</sup> Courts in the United States are divided in their decisions as to the need for court authorization prior to withdrawing life support, and the statement relied on in *Dion* should not be taken as a definitive statement of the American position. In Massachusetts, *In the Matter of Spring*, 399 N.E.2d 493 (Mass. App. 1979) marked the beginning of the withdrawal from the strong role *Saikewicz* staked out for courts in that state. More recently, see *Brophy*, *supra* note 73. For discussion of the situation in the United States more generally, see notes 165-69 and accompanying text.

<sup>159</sup> *Supra* note 34 at 389-90.

<sup>160</sup> (1990), 69 D.L.R. (4th) 134 [hereinafter *Re P.*].



acceptable. However, in *Couture-Jacquet*,<sup>161</sup> the Quebec Court of Appeal upheld a parent's refusal of a repetition of chemotherapy for her child in the face of physicians' recommendations to the contrary and the hospital's application for authorization to treat. In *N.B. (Minister of Health and Community Services) v. R.B. and S.B.*,<sup>162</sup> the New Brunswick Court of Queen's Bench granted the Minister temporary custody of a ten-year-old severely mentally retarded and neurologically handicapped child and authorized medical treatment (antibiotics for meningitis and an accompanying infection in the area of a shunt). Her parents had objected to the treatment, and, as in *Re P.*, there was a difference of opinion among physicians as to whether she should be treated. In this case, though, the court in a very brief judgment held that a decision not to treat would constitute discrimination against the child on the basis of her disability and hence, would be contrary to the *Charter*. Even if further medical treatment prolonged her suffering, it would also prolong her life, and "[t]hat life, however low its quality, is her right."<sup>163</sup> It seems, then, that there is not as yet consensus even among courts as to their proper role or the appropriate role for the other participants in the decision-making process when the patient is incompetent.

Nor will provisions to be found in some provincial legislation to the effect that parents, guardians, or next of kin can consent to surgical operations, diagnostic tests, or medical treatment or procedures on behalf of persons unable to give consent themselves necessarily suffice to remove these issues from the purview of the courts.<sup>164</sup> The Supreme Court of Canada has held that the purpose of such regulations is not to define the rights of individuals, but rather, to provide for the governing of hospitals so as to protect them from civil liability.<sup>165</sup> The Court added that these regulations were not intended to and do not provide a system

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<sup>161</sup> *Supra* note 79. The small chance of success the treatment offered and the very great suffering and physical damage it would surely cause were significant in the court's decision to put an end to the well-intentioned therapeutic relentlessness of the medical establishment.

<sup>162</sup> (1990), 106 N.B. (2d) 206 (Q.B.) [hereinafter *R.B. and S.B.*].

<sup>163</sup> *Ibid.* at 211.

<sup>164</sup> See, for example, O. Reg. 965/90, ss. 25 (1)(c), 26 (2)(c), made under the *Public Hospitals Act*, R.S.O. 1990, c.P.40. Nova Scotia, Quebec, Prince Edward Island, Saskatchewan, and New Brunswick have also made provision for substitute consent by next of kin if the patient is in need of immediate treatment; in Alberta, a guardian must be appointed. See Alberta Law Reform Institute, *Advance Directives and Substitute Decision-Making in Personal Health Care* (Report for Discussion No. 11) (Edmonton, November 1991) at 7-8 and 21-22.

<sup>165</sup> *Eve, supra* note 15 at 13. One would expect the analysis would differ where the legislation is obviously intended to have this effect, as is the case with the new wave of legislation in Ontario and other provinces. See *supra* note 12.

for the determination of human rights, which are primarily at issue in decisions such as these. The courts' silence in this area to date, then, merely indicates that the issue has not yet come squarely before them for determination. For all the reasons outlined at the outset of this article—continued technological advances, increased public awareness, legislative activity, interest group involvement, financial pressures on the health care system, and uncertainty as to standards among health care providers—we can expect that courts will be confronted with questions surrounding the provision of life-support to incompetent patients in the near future.<sup>166</sup>

Despite the longer American history of judicial involvement in this area, the judicial procedure when a decision is to be made as to whether life support can be terminated, and indeed, the appropriateness of judicial involvement at all, are not settled in the United States either.<sup>167</sup> Madam Justice O'Connor in her concurring judgment in *Cruzan* summarized the state of the law in that country when she noted that there is no national consensus on these matters and that consequently, they are most appropriately left to the "laboratories" of the individual states.<sup>168</sup>

One theme that does emerge very frequently in the American decisions is the repeated expression of the view that an adversarial judicial proceeding is not the appropriate institutional setting in which to resolve these issues. The American courts frequently urge that legislative guidelines be established, a sentiment that is echoed by judges

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<sup>166</sup> Relative to competent patients, see *Nancy B. Corbeil*, and Rodriguez, *supra* note 10.

<sup>167</sup> To take just a few examples, in New Jersey, see *In the Matter of Quinlan*, 355 A.2d 658 (N.J.S.C. 1976) [hereinafter *Quinlan*] (dispensing with the need for court approval of a decision to withdraw a patient from a respirator if there is concurrence among the guardian, family, attending physician, and a hospital prognosis committee); and *Conroy*, *supra* note 88 (developing a procedure when decisions were to be made regarding the termination of life-support systems for nursing home patients, requiring a guardian and intervention by what might loosely be termed a government ombudsman for the elderly, effectively shifting the decision making in part to an administrative branch of the state); in New York, see *Dello*, *supra* note 112 (anticipating regular judicial intervention to determine these matters); in California, see *Barber v. Superior Court of California*, 195 Cal. Rptr. 484 (Cal. App. 1983) [hereinafter *Barber*] (holding that the decision may be made by a surrogate with the advice of the patient's physician and that there need not be a court-appointed guardian); in Washington, see *In the Matter of Guardianship of Hamlin*, 689 P.2d 1372 (Cal. App. 1984) [hereinafter *Hamlin*] (recognizing that varying degrees of procedural safeguards may be necessary to protect against abuse, depending primarily on the incompetent patient's family situation. Safeguards range from agreement among the patient's family or court-appointed guardian, the attending physician, and the hospital prognosis committee through to a requirement of judicial approval).

<sup>168</sup> *Cruzan*, *supra* note 6 at 2859.

in the United Kingdom.<sup>169</sup> This sense of institutional inadequacy and maladaptation may in part underlie the frequent court-developed formalization of a role for prognosis committees, ombudsmen for the elderly, and others who can assist in reaching what becomes a collective judgment. The aim is presumably not only to share and ease the responsibility,<sup>170</sup> but also to make it a more widely informed and hence, better judgment.<sup>171</sup>

## 2. Existing guidance principles in decision making

We have seen that where the patient is competent, courts increasingly support his or her right to self-determination in medical treatment decisions. When a patient becomes decisionally incapable but has left advance instructions regarding medical care, *Malette* and *Fleming* indicate that those instructions will be honoured.<sup>172</sup> The approach courts will take in determining whether life support can be withheld or withdrawn is much less clear when considering the situation of a never-competent patient or someone once-competent who left no clear instructions about the use of life support. Difficulties in decision making are exacerbated when the patient is not facing imminent death so long as life support is continued. In jurisdictions where the issue has been considered by courts and commentators, two major models of decision

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<sup>169</sup> See, for example, *In the Matter of Farrell*, 529 A.2d 404 [hereinafter *Farrell*] at 407 (N.J.S.C. 1987); *Satz v. Perlmutter* 379 So.2d 359 at 360 (Fla. 1980). But see *In the Matter of the Conservatorship of Torres*, 357 N.W.2d 332 [hereinafter *Torres*] at 341 (Min. S.C. 1984) where three judges joined in a concurring opinion expressing the view that life support ought not be withdrawn from an incompetent patient without prior judicial approval even when there is unanimity among physician, family, and hospital ethics committee. In the United Kingdom, see *Airedale Trust*, *supra* note 27 at 392, Lord Mustill.

<sup>170</sup> A suggestion made in R. Mnookin, "Two Puzzles" (1984) *Ariz. St. L.J.* 667 at 683.

<sup>171</sup> This is clearly the view of Handler J. in *Jobes*, *supra* note 73 at 460; see also *Auckland Area Health Board*, *supra* note 112 at 255, and the reliance placed on guidelines developed by the national medical association in *Airedale Trust*, *supra* note 27. See for example, Lord Goff at 373-76. The tendency on the part of courts to encourage a wider involvement in the decision-making process has been attacked as a dangerous delegation of courts' immunity-granting authority that will encourage an abdication of the responsibility owed to the incompetent patient by health care providers, the patient's family, and ultimately, the state. See Burt, *supra* note 25 at 165-73; Annas, *supra* note 132 at 26. Veatch, *supra* note 98 at 143-48, sounds a somewhat different cautionary note respecting reliance on decision making by ethics committees with respect to a particular patient. He is concerned that such committees are "essentially private groups, appointed through private channels" with "no publicly authorized operating rules." *Ibid.* at 145. As such, they lack a publicly accepted authority to make such decisions or rules and procedures for doing so.

<sup>172</sup> *Malette*, *supra* note 31 and *Fleming*, *supra* note 20.

making have emerged, one based on a concept of substituted judgment and the other on the patient's best interests. When surrogate decision-makers formulate a substituted judgment, they try to establish as accurately as possible what decision the patient would make if he or she were competent to do so but could take into account the reality of his or her own incapacity as a factor in the decision.<sup>173</sup> If the determination is to be made on the basis of the patient's best interests, the surrogate decisionmaker assesses the patient's needs and the risks and advantages of the medical intervention to determine the net burdens and benefits the patient will derive from life with and without the treatment.<sup>174</sup> Both decision making models will be examined in greater detail.

### 3. Substituted judgment: the American experience

Questions surrounding the standard to be applied in decisions regarding life support and incompetent patients have been explored most fully in the United States. For that reason, it is helpful to review and analyze developments of the law in that country.<sup>175</sup> Ever since the well-known case allowing Karen Quinlan's removal from a respirator in 1976,<sup>176</sup> American courts have authorized termination of life support in certain situations, and have confirmed that doing so would not result in criminal or civil liability. They have differed among themselves, however, on the basis for the decision when the patient is incompetent—is it to be made in the best interests of the patient, or is it to be based on a concept of substituted judgment or surrogate consent exercised on behalf of the patient? The dominant approach since the decision in *Quinlan* has been the substituted judgment standard,<sup>177</sup>

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<sup>173</sup> President's Commission, *supra* note 6 at 132; see, for example, *Jobes*, *supra* note 73 at 444-45; *In Re Estate of Longeway*, 549 N.E.2d 292 [hereinafter *Longeway*] at 299-300 (Ill. 1989).

<sup>174</sup> Presidents' Commission, *ibid.* at 135; for applications of this model, see *Torres*, *supra* note 169; *Rasmussen v. Fleming*, 741 P.2d 674 (Ariz. S.C. 1987) [hereinafter *Rasmussen*]; and *Re C*, *supra* note 114.

<sup>175</sup> Familiarity with American jurisprudence in this area is also important because, as the British Columbia Royal Commission on Health Care and Costs notes, Canadian physicians tend to act as though the law in Canada is the same as the United States even, though this may not be the case. See *Closer to Home*, *supra* note 113 at C-184.

<sup>176</sup> *Quinlan*, *supra* note 167.

<sup>177</sup> See, for example, *Longeway*, *supra* note 173; *Conroy*, *supra* note 88; *Jobes*, *supra* note 73; *Barber*, *supra* note 167 at 491-92; *In the Matter of Hier*, 464 N.E.2d 959 (Mass. App. 1984); *Re A.C.*, *supra* note 50 at 1249-51 (applying substituted judgment test regarding a caesarian section to be performed on a terminally ill woman).

essentially attempting to effectuate for incompetent patients the same rights competent patients have to choose and refuse medical treatment, albeit through arrangements by which those rights are exercised for the incompetent individual by others. Where there is not acceptable evidence that the patient expressed any explicit intent, then many courts have allowed a proxy decisionmaker to base the determination on the patient's relevant values and preferences expressed when competent.<sup>178</sup> Each of these tests is considered to result in a determination of the (now-incompetent) *patient's* intent, and the exercise of the *patient's* right to refuse life-sustaining treatment.<sup>179</sup> The standard of proof of the patient's choice varies among the different courts that have considered these matters,<sup>180</sup> but the general analytical approach remains consistent.

The substituted judgment standard has been severely criticized.<sup>181</sup> At times, the efforts American courts engage in to imagine incompetent individuals as they were or would be if competent, as well as to deduce what the individuals' decisions *were* respecting life support, degenerate into unconvincing contortions. This is particularly so when courts attempt to apply this analysis to patients who were never competent and so could never have made the decision themselves,<sup>182</sup> or

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<sup>178</sup> The substituted judgment test was commented on extensively in *Conroy, ibid.* at 1229-30, and was developed further in *Jobes, ibid.* at 445. Sometimes, courts appear to elide analyses of a proxy acting on an expressed choice and one acting on a perceived preference. See for example, *In the Matter of Peter*, 529 A.2d 419 (N.J. 1987) [hereinafter *Peter*] and *Jobes*, *supra* note 73, where the New Jersey Supreme Court permitted the guardians of patients in a persistent vegetative state to have the patients' life support withdrawn even without clear and convincing evidence of the patients' intent, on the basis of the guardians' best judgment as to what the patients would have wanted. The court still characterised this exercise as "extrapolat[ing] the patient's choice." See *Jobes, ibid.* at 444.

<sup>179</sup> See, for example, the language used in *Longeway, supra* note 173 at 300 to describe the analytical process and its results.

<sup>180</sup> Indeed, the appropriate standard of proof was the issue that confronted the United States Supreme Court in *Cruzan, supra* note 6. As Justice O'Connor noted in her concurring opinion at 2859, there is no "national consensus" in the United States as to the best solution to these difficult questions. That being the case, in her view, these matters are better left to individual states to resolve.

<sup>181</sup> For example, *Rhoden, supra* note 7 at 386; and *Dresser & Robertson, supra* note 7 at 234-35 and at 238-39.

<sup>182</sup> A particularly striking example of this can be seen in *Saikewicz, supra* note 156, where the court purported to express the "choice" to refuse treatment of a profoundly retarded long-term resident of a state hospital who was suffering from leukaemia. The court decided that he should not undergo chemotherapy even though most competent people suffering from the disease would choose to do so. It based its decision both on the limitations of the treatment and the patient's inability to understand and therefore tolerate the pain associated with treatment. The reasoning (although not necessarily the result) has been roundly criticized by both commentators and courts in the United States. See, for example, *In Re Storar*, 420 N.E.2d 64 (N.Y. 1981); and A. Buchanan,

to patients about whom there is no reliable evidence from which to form a picture of the individual's value system and treatment preferences. Invoking the justification that the judicial decision merely elucidates the "patient's choice" is just not credible in these circumstances. Consequently, for the most part now, where the patient's intent relative to the use of life support cannot be determined,<sup>183</sup> or where a statute so directs,<sup>184</sup> American courts have adopted a best interests approach to determine the course of treatment to be followed. In applying that standard, courts do factor in quality of life considerations, although they commonly disavow any such characterization of their reasoning.<sup>185</sup> Quality of life is considered not in the sense of measuring the utility or worth of this person's life compared to others, but rather in the sense of trying to comprehend what life is like for the particular patient.<sup>186</sup> Courts weigh what they are told of the patient's character, lifestyle and preferences, the invasiveness of particular treatment, and whether the treatment is proportionate in terms of the benefit to be gained as against the burden caused to reach a conclusion as to this patient's best interests. One can see that the inquiries in which courts engage to determine patients' best interests and formulate appropriate substituted judgments may approach each other very closely, if not conflate.

#### 4. Evaluating the substituted judgment standard

The American approach seems to reflect a concentration on individual rights and equality common in many areas of American law, attempting to effectuate for incompetent patients the same right competent patients have to refuse treatment. The primacy given the right of the individual to decide how his or her fate is to be acted out, the juxtaposition of the individual against the state (the latter being aligned with the full panoply of medical technology), and the "win"—the

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"Medical Paternalism or Legal Imperialism: Not the Only Alternatives for Handling *Saikewicz*-Type Cases" 5 Am. J. Law and Medicine 97.

<sup>183</sup> As in *Rasmussen*, *supra* note 174 at 689.

<sup>184</sup> See, for example, *Torres*, *supra* note 169, interpreting a conservatorship statute; see also *Hanlin*, *supra* note 167.

<sup>185</sup> See, for example, *Brophy*, *supra* note 73 at 635.

<sup>186</sup> See for example, *Rasmussen*, *supra* note 174 at 689; *Torres*, *supra* note 169 at 338-39. In the United Kingdom, the House of Lords has indicated that if the personality of the patient is relevant to the application of the best interests test, it may be taken into account, although where the patient is in a persistent vegetative state it is difficult to see how knowing about the patient's personality can assist, other than to comfort the patient's relatives with the thought that he or she would not have wanted to live; *Airedale Trust*, *supra* note 27 at 375, Lord Goff

vindication of the individual's rights—perceived when a court allows life support to be withdrawn, all evidence this tilt. Given Americans' almost forty-year history of a very activist use of the constitutional right to equal protection in many different contexts, the underlying theme of recognizing and effecting equality in the ability to decide for oneself that is implicit although not usually explored in these decisions<sup>187</sup> must resonate with American courts and the wider society as correct—so obviously correct that it can be taken for granted.

An analytical approach recognizing that incompetent patients have rights when decisions are made about their lives, that they are “similarly situated” to competent patients requiring life support (to use the classic American formulation triggering the Equal Protection Clause),<sup>188</sup> and that incompetent patients have the same right that competent persons take for granted—the right to make and carry out decisions, even if through intermediaries<sup>189</sup>—is appealing. This is especially so as society becomes increasingly sensitive to the multitude of unacceptable ways in which incompetent persons (and disabled persons generally, whether competent or not) are treated paternalistically and often needlessly as not “like us,” as distanced from the competent decision-makers in the mainstream of society. The concept that the decisionmaker is expressing the patient's choice emphasized in these cases can also help in easing feelings of responsibility, guilt, and anguish over difficult, painful decisions, as well as give some direction to the decision-making process. Additionally, it enables courts to address their sense of discomfort, inappropriateness, and incompetence at being called on to make these decisions by transferring responsibility for the decision back to someone perceived to be better situated to decide,

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<sup>187</sup> Some American courts have considered the applicability of the Equal Protection Clause in this context. See, for example, the concurring judgment of Scalia, J. in *Cruzan*, *supra* note 6 at 2863, basing his conclusion that there are limits on the extent to which an individual can be required to preserve his own life on the Equal Protection Clause, while at the same time paradoxically insisting that the American Constitution has “nothing to say” on this subject. See also *Rasmussen*, *supra* note 174 at 686, quoting with approval from *Eichner v. Dillon*, 426 N.Y.S. 2d 517 at 542-3, *aff'd* 438 N.Y.S. 2d 266, cert. denied 102 S. Ct. 309 (Ct.App. 1981), where it was held that competent and incompetent patients have a right to equal treatment both in the content and the exercise of the right to refuse medical treatment.

<sup>188</sup> See J. Tussman & J. ten Broek, “The Equal Protection of the Laws” (1948) 37 Cal. L. Rev. 341.

<sup>189</sup> American cases seem to take for granted not only that incompetent patients retain a right of self-determination relative to the use of life-support, but also that they have an additional right to an effective means to assert that choice even if indirectly, at least when there is someone who will act on the patient's behalf to arrange to have life support withdrawn. See, for example, *Rasmussen*, *supra* note 174 at 686.

generally a family member or friend with closer ties to, and more intimate knowledge of, the patient.<sup>190</sup> The court can thus present its task and its decision as preserving an area of autonomy and privacy for the patient's family or close friends acting with medical advice, and can claim rather disingenuously that it is not presuming to make the decision itself, but merely deciding whether to sanction it.<sup>191</sup>

The American approach, beginning as it does with solid respect for the patient's autonomy and right to self-determination, has much to commend it. A number of the cases show, however, that it can become highly problematic when applied in practice. This is particularly evident when the person concerned never could or did clearly express his or her wishes relative to the medical intervention in question, or when, as is frequently the case with elderly long-term residents of a nursing home or other chronic care institution, the patient lacks the close family or friends through whom he or she could "speak." Despite this criticism, when limited to appropriate circumstances where there is reliable evidence, a substituted judgment standard can be a valuable way to approach issues surrounding the provision of life support. It is underpinned by the same core idea as advance directives, and responds to many of the same concerns. Both seek to ensure to the greatest extent possible that decisions about the use of life support are grounded in and express the patients' own wishes and values. Doing so advances concepts of autonomy, dignity, and self-determination, values to which our courts and society more generally are currently highly committed, especially in matters of bodily and personal integrity.<sup>192</sup> Thus, even where one cannot reach the sometimes imaginative heights of being able to identify the patient's explicit "choice" relative to life support, as long as the patient's preferences can be reliably ascertained, a substituted

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<sup>190</sup> The sentiment that courts are not the appropriate forum for making such decisions is repeatedly expressed in these decisions. See, for example, *Farrell, supra* note 169 at 407, where the court reiterated its earlier statement that the legislature is the proper branch to set guidelines in this area. See also *Barber, supra* note 167 at 486, commenting on charges of murder and conspiracy to commit murder laid against a physician who, at the family's request, withdrew artificial nutrition and hydration from a patient in a persistent vegetative state. Noting the legislature's failure to adequately address the legal and moral considerations the case raised, Compton J. referenced an earlier decision in which a court had pointedly observed, "[P]rosecution of a lawsuit is a poor way to design a motor vehicle." He added, "By analogy it appears to us that a murder prosecution is a poor way to design an ethical and moral code for physicians who are faced with decisions concerning the use of costly and extraordinary 'life support' equipment."

<sup>191</sup> See, for example, *Jobes, supra* note 73 at 436-37. For a critical assessment of courts' delegation of what has been called their "immunity-granting authority," see Burt, *supra* note 25 at 170-71 and Annas, *supra* note 132 at 24 and at 26.

<sup>192</sup> See cases cited *supra* note 139.



judgment standard is the approach that most accords respect to the patient as a whole person and is most consistent with our societal emphasis on self-determination and autonomy.

##### 5. The best interests test

Even though a few Canadian cases have made reference to *Quinlan* and some of the decisions that have followed in the United States,<sup>193</sup> considerable caution must be exercised in relying on American jurisprudence in this area. The Supreme Court of Canada in *Eve* considered and firmly rejected the American substituted judgment test, although in a very different context—the non-therapeutic sterilization of a mentally incompetent young adult for purposes of contraception. The Court characterized it as “fiction” and “sophistry” to suggest that its choice or anyone else’s could be that of the incompetent person, adding that what he or she would do is sheer speculation.<sup>194</sup> Rather, it settled on a best interests test to decide questions of medical intervention, at least when the person concerned has always been decisionally incapable. A different analysis might be accepted in the case of a patient who has become incapacitated but, while still competent, clearly rejected the idea of life support. This is particularly so given the emphasis on self-determination evident in judicial decisions since the passage of the *Charter*. However, at least for the never-competent patient and the once-competent patient whose wishes cannot be reliably discerned, the decision will be based on the patient’s best interests.<sup>195</sup>

It still remains to infuse that standard with content. How should a court, or for that matter, any decisionmaker determine whether discontinuing life support is in a patient’s best interests? Although considering a very different type of medical intervention, the Court in *Eve* gave some idea of its view of the nature of the task, acknowledging that a goal of determining best interests provides a less than precise standard and shapes a less than workable inquiry. The Court quoted with approval from an American decision, *Re Guardianship of Eberhardy*:

No one who has dealt with this standard [*i.e.*, ‘best interests’] has expressed complete satisfaction with it. It is not an objective test, and it is not intended to be. The substantial

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<sup>193</sup> See, for example, *Goyette*, *supra* note 85 at 431; *Dion*, *supra* note 155.

<sup>194</sup> *Eve*, *supra* note 15 at 35. See also *Airedale Trust*, *supra* note 27 at 395.

<sup>195</sup> This is also the test adopted in the United Kingdom (see *Airedale Trust*, *ibid.* at 370 and at 375) and New Zealand (see *Auckland Area Health Board*, *supra* note 112 at 252).

workability of the test rests upon the informed fact-finding and wise exercise of discretion by trial courts engendered by long experience with the standard.<sup>196</sup>

In seeming contradiction, the court in *Eberhardy* then expressed doubts as to the ability of the judiciary to properly discharge this task at all, particularly in the absence of "well thought-out policy determinations reflecting the interests of society, as well as of the person."<sup>197</sup> A court has the unenviable task of assessing the needs, risks, benefits, and burdens for the affected person from an external stance. Then, knowing it has only part of the picture and with little other guidance as to the content with which to infuse the standard, it must decide.

Legal commentators and some American and English courts have tried to establish a framework for that decision making. Originally, a distinction was posited between ordinary and extraordinary treatment, with the characterization determined not only by the treatment itself but by the patient's clinical prognosis with and without that treatment, such that extraordinary treatment could be rejected by or withheld from a patient in a terminal condition, but ordinary treatment must be provided.<sup>198</sup> That distinction has now been largely rejected as unworkably indeterminate, as it is not a classification on which consensus is possible either medically or in society at large.<sup>199</sup> More recently, it has been suggested that the decision to initiate or continue life support should be based on a determination as to whether the treatment is proportionate or disproportionate in terms of the benefit to be gained as against the burden caused.<sup>200</sup> Conclusions are largely dependent on the patient's prognosis—how long the treatment will extend life and under what conditions.<sup>201</sup>

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<sup>196</sup> *Eve*, *supra* note 15 at 33, quoting *Re Guardianship of Eberhardy*, 294 N.W.2d 540 (Wis.App. 1980).

<sup>197</sup> *Ibid.*

<sup>198</sup> See, for example, *Quinlan*, *supra* note 167 at 355, where the distinction was drawn from largely Catholic theological roots (the Quinlans themselves were Catholic). The distinction is commonly found in other religious and secular traditions as well; see *Burt*, *supra* note 25 at 162-63. See also *Dickens*, *supra* note 30 at 855-59.

<sup>199</sup> President's Commission, *supra* note 6 at 82-89; *Closer to Home*, *supra* note 113 at C-180-1.

<sup>200</sup> For applications of this guidance principle, see, for example, *Barber*, *supra* note 167 at 491-92; *Conroy*, *supra* note 88 at 1232; *Goyette*, *supra* note 85; *Re C*, *supra* note 114 at 784-87. But see *Airedale Trust*, *supra* note 27 at 371-72, Lord Goff, pointing out that when the patient is in a persistent vegetative state, there is no weighing to be performed, as the permanently unconscious patient can feel nothing and there is no prospect of improvement in the patient's condition.

<sup>201</sup> Another manner of phrasing the analysis that runs through some American decisions is the suggestion of a sliding balance between the interests of the individual and those of the state, such that as the patient's prognosis dims and the invasiveness and burden of the procedures proposed

The House of Lords in its 1993 decision, *Airedale Trust* concluded unanimously (although in five separate judgments) that where the patient is in a persistent vegetative state and there is no hope of any improvement in his condition, then life-prolonging treatment (artificial nutrition and hydration and antibiotic therapy) is neither appropriate nor required because it is useless.<sup>202</sup> It follows, then, that preserving biologic existence is not a required goal of medical treatment.<sup>203</sup> The permanent and complete loss of any level of cognitive sapient life justifies ending life support. While one could not say that the patient's best interests lay in ending life, neither could it be said that his interests were served by continuing treatment. Indeed, some of the judges went so far as to suggest that once it has been determined that the treatment is not in the patient's best interests, then doctors not only have no duty but no right to continue with it and that doing so could constitute battery and trespass to the person of the patient.<sup>204</sup> It follows from this analysis that irreversible unconsciousness shifts the framework of the decision making. It makes no sense to base treatment decisions for a patient in a persistent vegetative state on his or her best interests, because his or her interests are "null."<sup>205</sup> The judgment is carefully limited to patients lacking all consciousness and without any prospect of any recovery. As

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increases, the weight to be accorded to the individual's right to decline treatment must increase and that accorded to the state's interest in preserving life, decrease. See, for example, *Quinlan*, *supra* note 167 at 664; and *Brophy*, *supra* note 73 at 635. For a critical view of this approach, see A. Capron, "Borrowed Lessons: The Role of Ethical Distinctions in Framing Law on Life-Sustaining Treatment" (1984) *Ariz. State L.J.* 647 at 648-55. The point has also been made that where the patient is in a persistent vegetative state, he or she has no current interests and does not experience benefits or burdens, making this paradigm inapplicable. See *Peter*, *supra* note 178 at 425; *Airedale Trust*, *supra* note 27 at 361, Lord Keith and at 398, Lord Mustill.

<sup>202</sup> *Supra*, note 27 at 371-72, Lord Goff. See also *Auckland Area Health Board*, *supra* note 112 at 245 to the same effect, although with respect to almost the converse situation: "a brain destitute of a body," rather than "a body devoid of a mind."

<sup>203</sup> The Court did not mean by this that human beings can necessarily be reduced to physical existence and "that combination of manifold characteristics which we call a personality," or to deny that the human condition may also comprise a "distinct spiritual essence," but rather, to accept that in arriving at its decision, it can only proceed on the basis of "what we do know." We cannot know whether there is such a spiritual essence distinct from both body and personality, nor whether it perishes with death or transcends it. On the basis of what is known, the Court concluded that the patient's best interests no longer demanded continuance of his present care and treatment. *Ibid.* at 400, Lord Mustill.

<sup>204</sup> *Ibid.* at 379, Lord Lowry and at 385, Lord Browne-Wilkinson.

<sup>205</sup> *Ibid.* at 400, Lord Mustill and at 361, Lord Keith. Some of the judges do, however, continue to use the rubric of "best interests," although in connection with the patient's interests in continuing rather than in discontinuing treatment. The focus, then, is on weighing the patient's interests in the alternative to withdrawal of life support, continued life, rather than the patient's interests in ending the treatment.

Lord Mustill noted, "I might not decide the same ... where the glimmerings of awareness may give the patient an interest which cannot be regarded as null."<sup>206</sup>

## 6. Evaluating the best interests standard

None of these tests, though, tell us how the particular calculus settled upon is to be worked out. How does one weigh the burdens and benefits? What scale does one use? It is clear from the judgments that at least in terms of overtly acknowledged values, the only interests to be considered are those of the patient, not the interests of his or her family or friends, or those charged with the patient's care, or society at large.<sup>207</sup> Some critics of the best interests model have asserted, however, that despite courts' statements to the contrary, other directed considerations are already taken into account in decision making. They argue that courts and other influential bodies allow such factors to shape non-treatment decisions by introducing these considerations as part of the assessment of the burdens treatment imposes on the patient, all the while formally denying that the interests of others have any role to play in that determination.<sup>208</sup> Others respond that to omit these factors completely is to conceive of the patient as an entirely self-centered person with no thought or care for the burden on others. It is argued

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<sup>206</sup> *Ibid.* at 400.

<sup>207</sup> *Eve*, *supra* note 15 at 29. In the United Kingdom, however, the Court of Appeal recently explicitly confirmed that local health authorities can take the gravity of the patient's condition and the prognosis into account in allocating scarce medical resources. *Re J.*, *supra* note 73. It must be borne in mind, however, that limits on health care are much more prevalent, open, and accepted in the United Kingdom than in Canada, leading to different perceptions and expectations of the health care system; see R. Baker, "The Inevitability of Health Care Rationing: A Case Study of Rationing in the British National Health Service," in M.A. Strosberg, *et al.*, *Rationing America's Medical Care: The Oregon Plan and Beyond* (Washington, D.C.: Brookings Institution, 1992) at 208-30. However, see *Airedale Trust*, *supra* note 27 at 397, Lord Mustill, noting that the interests of others—the "best interests of the community"—is an issue for Parliament, not the courts.

<sup>208</sup> See, for example, Dresser & Robertson, *supra* note 7 at 239. For examples of analyses suggesting burdens on others as an appropriate consideration in determining the burden of continued treatment on the patient, see, for example, *Brophy*, *supra* note 73 at 635-36; *Cruzan*, *supra* note 6 at 2869, Brennan J. and at 2890, Stevens J. (dissenting) (patient's interest in not having her family's happy memories of her destroyed should be taken into account); more generally, see Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* (New York: The Hastings Center, 1987) at 26-27 (burdens on patients in persistent vegetative state include financial cost and emotional strain on loved ones); "The Appleton International Conference: Developing Guidelines for Decisions to Forego Life-Prolonging Medical Treatment" (1992) 18 (S) *J. Med. Ethics* 1 (in determining a patient's best interests, most persons ordinarily would want *inter alia* to avoid being a severe burden on others).

that such an analysis is itself neither desirable nor realistic, particularly if one recognizes the importance of bearing in mind the whole person in decision making, both before and after the onset of incompetence.<sup>209</sup>

The traditional best interests test has also been criticized for the narrowness of the circumstances in which non-treatment is permissible, which sometimes seem to have been limited to situations where treatment would cause or could not alleviate active, irremediable harm to the patient. In light of this, it has been suggested that, rather than framing the analysis in terms of whether death would be better for this patient than the *harm* of continued existence and treatment,<sup>210</sup> one should rather judge whether, from the incompetent patient's current perspective, his or her continued existence is a sufficient *good* to the patient to justify further treatment (a "current interests" test) or whether continued treatment is in the patient's interests.<sup>211</sup> Changing the focus of the question asked from the harm of continued life to the good that would come from continued life or treatment makes sense if the patient is in a persistent vegetative state. By definition, such patients no longer experience anything, and in that sense, they are neither harmed nor helped by continued treatment (except in the highly theoretical eventuality that a cure for their condition is eventually discovered).<sup>212</sup> The difficulty with the change in analytical framework suggested is one of limits. Patients who are barely conscious may not be so different from patients in a persistent vegetative state.<sup>213</sup> When the patient retains some degree of consciousness, our fundamental inability to take the perspective of an incompetent person in so profoundly compromised a condition remains. Whether we ask about the harm of continued treatment or the good of continued existence, where the patient still retains some consciousness but is in a severely disabled state and we lack any reliable basis for a substituted judgment, we cannot know what life is

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<sup>209</sup> Burt, *supra* note 25 at 151-52.

<sup>210</sup> The approach taken, for instance, in *Dawson*, discussed *infra* notes 228-30 and accompanying text.

<sup>211</sup> As to the former, see Dresser & Robertson, *supra* note 7 at 240-42. As to the latter, see *Airedale Trust*, *supra* note 27 at 398, Lord Mustill and at 371, Lord Goff.

<sup>212</sup> Peter, *supra* note 178; and *Airedale Trust*, *supra* note 27 at 398, Lord Mustill: "The distressing truth which must not be shirked is that the proposed conduct is not in the best interest of Anthony Bland, for he has no best interests of any kind."

<sup>213</sup> Rhoden, *supra* note 7 at 397. This conclusion is supported by the decision in *Auckland Area Health Board*, *supra* note 112, characterizing and treating patients cut off from contact with their own bodies or their environment in the same fashion. An absence of response, as when the patient is in a persistent vegetative state, is equated with a patient whose responses are largely absent, but are also (to some unknowable extent) entirely inaccessible.

like for that patient. We cannot truly take the patient's perspective. All our inferences, imagination, empathy—and in the end, our conclusions—are from the standpoint of we who are competent.<sup>214</sup> Pretending we are doing otherwise only obscures the awesomely difficult decision to be made. It is essential to acknowledge forthrightly both the standpoint and its limitations—the gaps it leaves.<sup>215</sup>

One of the most frequent criticisms levelled against a best interests test is that it assumes there are identifiable, societally shared criteria, or to put it another way, that a broad social understanding exists by which to determine not only what is of benefit to a patient and what is a burden, but also when that burden is excessive.<sup>216</sup> The response of many is that there “is no consensus in society about how the value of a life is affected by loss of higher brain function, severe physical deterioration, or unrelievable extreme pain.”<sup>217</sup> Buchanan and Brock point out that any assessment of the patient's best interests must be based on an underlying value system—a conception of what constitutes “the good” for the patient (and in life more generally). They identify three broad, widely recognized theories of well-being that both compete and overlap:

1. hedonist theories, which focus on the person having conscious experiences of a specified, positive sort;

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<sup>214</sup> As an oncologist noted poignantly in C.B. Wong & J. Swazey, eds., *Dilemmas of Dying Policies and Procedures for Decisions Not to Treat* (Boston: G.K. Hall Medical Publishers, 1981) at 192-93, in the end, decisions regarding incompetent terminally ill patients are always made by the “winners”—the healthy.

<sup>215</sup> The difficulties in determining the current interests of an incompetent patient with only minimal awareness are acknowledged at least implicitly by the proponents of this model themselves when, in giving content to their standard, they suggest that where patients suffer from certain conditions, such as severe and intractable pain or the onset of a persistent vegetative state, treatment need not be provided if the families so request. Their criterion for inclusion on the list of conditions for which continued treatment is elective, though, is that relative to which “wide consensus already exists [that] ... certain states of being are not in a patient's interest,” Dresser & Robertson, *supra* note 7 at 241. The judgment they rely on, then, is the very one they themselves reject (*ibid.* at 238)—that of competent people, speaking from their own perspectives about what constitutes a life that one would not want to continue.

<sup>216</sup> See, for example, E.J. Emanuel, “A Communal Vision of Care for Incompetent Patients” (1987) 17 *Hastings Center Report* 15 at 16.

<sup>217</sup> L. Tribe, *American Constitutional Law*, 2d ed. (Mineola: Foundation Press, 1988) at 1369. See also *Jobes*, *supra* note 73 at 457-58, Handler, J. (concurring); and *Airedale Trust*, *supra* note 27 at 381-82, Lord Browne-Wilkinson. A graphic illustration of this point can be found in J. Berger & A.S. Berger, eds., *To Die or Not to Die* (New York: Praeger, 1990), drawing together perspectives on this issue from different countries, cultures, and religions.

2. preference or desire satisfaction theories, where “the good” for a person is equated with having his or her desires or preferences satisfied to the maximum extent possible over a lifetime; and
3. objective list theories, that hold some things to be good or bad for a person independent of whether the person prefers them or will have positive, conscious experiences of them.<sup>218</sup>

Decisions about the treatment choice that is in the patient’s best interests generally neither articulate the underlying choice as to the values on which the determination is made, nor justify that choice over other possibilities. Still, those underlying assumptions as to what constitutes “the good” (and its absence) must be present.<sup>219</sup> Some decisions are underpinned by a hedonistic theory of the good—avoiding pain is all the court safely feels it can say is in the patient’s best interests.<sup>220</sup> In other cases, courts have incorporated into their assessment of the patient’s best interests whatever could be gleaned of what the patient would have wanted, an approach oriented by a preference satisfaction view of “the good.”<sup>221</sup> Those who would argue that there is value in preserving physical existence even when the patient can no longer experience it or might actively not want it would be basing their conclusion on a “list” of what is good for the person and for society more generally.<sup>222</sup>

Not only does this observation regarding the lack of social consensus undermine the legitimacy of a judicial decision purporting to identify the

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<sup>218</sup> Buchanan & Brock, *supra* note 115 at 31-33. There are, of course, a number of other classification systems that have been proposed.

<sup>219</sup> As Wilson, J. noted in her concurring judgment in *Morgentaler*, *supra* note 91 at 166: “The idea of human dignity finds expression in almost every right and freedom guaranteed in the *Charter*. Individuals are afforded the right to choose their own religion and their own philosophy of life, the right to choose with whom they will associate and how they will express themselves, the right to choose where they will live and what occupation they will pursue. These are all examples of the basic theory underlying the *Charter*, namely that the state will respect choices made by individuals and to the greatest extent possible, will avoid subordinating these choices to any one conception of the good life.” When a best interests test is employed, *some* vision of the good life must be chosen for and imposed on another.

<sup>220</sup> See, for example, *Conroy*, *supra* note 88 at 1243; for criticism see *ibid.* at 1247-49, Handler J. (concurring); in the United Kingdom, see *Re B*, [1981] 1 W.L.R. 1421 at 1422 (C.A.).

<sup>221</sup> See, for example, *Rasmussen*, *supra* note 174 and *Torres*, *supra* note 169.

<sup>222</sup> See, for example, J. Bopp & D. Avila, “Perspectives on *Cruzan*: The Sirens’ Lure of Invented Consent: A Critique of Autonomy-Based Surrogate Decision-Making for Legally-Incapacitated Older Persons” (1991) 42 *Hastings L.J.* 779; see also J.J. McCartney, “Right to Die: Perspectives from Catholic and Jewish Traditions,” in Berger & Berger, eds., *supra* note 217 at 22, commenting on the belief of some Catholic theologians that remaining alive is never rightly regarded as a burden.

patient's best interests, in real terms it also means that the patient's best interests as the patient or his or her community would perceive them may well not be the values informing the judgment. There will always be a line-drawing problem, and it is exacerbated by this plurality of views in society. Indeed, the intensity of the debate on this subject itself illustrates the diversity of deeplyheld views.<sup>223</sup> Nor is this concern vitiated by always leaning in favour of preserving life, of treating. One may undervalue the life of an individual who cannot speak for himself; on the other hand, one may also in unconscious and well-meaning cruelty greatly underestimate the extent of the suffering and deprivations experienced.<sup>224</sup> Further, trying to make decisions purely on the basis of "medical need" ignores the fact that concepts of medical need presuppose a value judgment about the desirability of treatment.<sup>225</sup> Thus, even though the cases often reference values "long recognized" by society or "ranking high in our scale of values" <sup>226</sup> or universally shared, in a pluralistic society the best interests approach necessarily entails

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<sup>223</sup> Compare, for example, G. Grant, "The Language of Euthanasia," in G. Grant, *Technology and Justice* (Notre Dame: University of Notre Dame Press, 1986) at 103-17, arguing strongly for the sanctity of life as the pre-eminent value; and J.E. Magnet & E.W. Kluge, *Withholding Treatment from Defective Newborn Children* (Que.: Brown Legal Publ., 1986), arguing equally strongly that judgments as to the quality of life must inform these decisions and that euthanasia can be justified when that quality is not acceptable according to standards of due discernment.

<sup>224</sup> See Minow, *supra* note 149 at 961. See also M. Somerville, "Pain and Suffering in Medicine and Law" (1986) 36 U.T.L.J. 286 at 314 on relief of pain and suffering for incompetent patients: "[t]here may in such cases be a brutal disregard for, and contravention of the feelings of the person who cannot think but can still feel, that is, who can experience emotionally." Her comments would seem equally applicable to the use of life support or life-prolonging treatment for incompetent individuals.

<sup>225</sup> In *Airedale Trust*, *supra* note 27, the House of Lords indicated physicians were the appropriate decisionmakers with respect to the best interests of a patient in a persistent vegetative state, provided they acted in accordance with a "responsible body of professional opinion." Families were to be consulted but ought not be able to dictate to doctors; see, for example Lord Goff at 373-74 (for a contrary view, see Lord Mustill at 399). On judgments of "medical need" see generally D. Callahan, "Terminating Treatment: Age as a Standard" (1987) 17 Hastings Center Report 21 at 24. See also N. Cantor, *The Legal Frontiers of Death and Dying* (Bloomington: Indiana University Press, 1987) at 54, noting that all medical decisions are infused with quality of life considerations, although competent patients at least have the prerogative of making these value judgments for themselves. Rhoden, *supra* note 7 at 430 suggests that the medical profession is prone to reductionist presuppositions about what amounts to a "benefit" to the patient, based on a "body-part-repair" orientation. For a decision sensitive to the need to take psychological, emotional, and social as well as medical considerations into account, see *Re P.*, *supra* note 160 at 142.

<sup>226</sup> See, for example, *Eve*, *supra* note 15 at 34 for use of this characterization relative to "the importance of maintaining the physical integrity of a human being." In the context of life-sustaining treatment, see *Re P.*, *ibid.* at 143.



imposing what may in fact be highly contested societal values on the incompetent patient.

#### 7. The best interests test applied

Although there are no Canadian cases directly on point, the withdrawal or withholding of other types of potentially life-prolonging medical treatment has been considered. Comments made in those cases may indicate the analysis likely to be applied to this issue. On review, they do raise a concern that in those instances when courts are involved in life-support decisions for incompetent patients, they will go to the other extreme from American courts and adopt something very close to a vitalist position, almost always valuing the preservation of life above all. The concern arises because in analogous cases where the withdrawal or withholding of other types of potentially life-prolonging medical treatment has been considered, it seems that the only factor that could mitigate against continuing to treat would be severe, intractable pain and suffering. Pain, however, can frequently be controlled, removing it as an operative factor in the decision making.

For instance, in two decisions in Quebec and Ontario, courts upheld parents' refusal of chemotherapy for their children suffering from cancer.<sup>227</sup> In both cases, the evidence established that the proposed treatment would be extremely intrusive and painful, had injurious side-effects, and could only marginally improve chances for recovery, which were very poor in any event. On the other hand, in *Re Superintendent of Child and Family Services and Dawson*,<sup>228</sup> surgical intervention to replace a shunt in an institutionalized severely handicapped hydrocephalic child was authorized by the British Columbia Supreme Court over the opposition of the parents. The evidence in that case established that the operation would assure the continuation of the child's life, characterized by the court as relatively happy and not evidencing pain or suffering, and that if the operation were not performed, the child might well suffer further deterioration,

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<sup>227</sup> *Couture-Jacquet*, *supra* note 79; *Re L.D.K.: Children's Aid Society of Metropolitan Toronto v. K. and K.* (1986), 48 R.F.L. (2d) 164 (Ont. Prov. Ct.).

<sup>228</sup> (1983), 145 D.L.R. (3d) 610 (B.C.S.C.), *rev'g.* (sub nom. *Re S.D.*) 42 B.C.L.R. 153 (Prov. Ct.) [hereinafter *Dawson*]. See also *Goyette*, *supra* note 85, authorizing a life-saving operation for a child with Down's Syndrome over the parents' objection, and *R.B. and S.B.*, *supra* note 162, authorizing treatment for meningitis for a severely mentally retarded and neurologically handicapped ten-year-old child over the parents' objection that the child would never have any quality of life.

pain and distress, but would not necessarily die. The court distinguished the situation before it from that of a terminally ill patient and the question of whether there is a “right to die,” and explicitly recognized that there may be instances where the child’s future will so certainly be full of such pain and suffering that the court might reach a different conclusion with respect to life-prolonging interventions.<sup>229</sup> Extreme and intractable pain was the only factor the judge explicitly noted might meet what she called the “most coercive” standard that would justify withholding treatment.<sup>230</sup>

These decisions all concerned patients who were conscious, interacting with others at some level, and connected with their surroundings. Further, all three decisions concerned children, who could not have developed a stable value system from which to identify preferences. The presence or absence of pain and whether it could be controlled were obviously significant factors in the patients’ lives. And in the first two decisions, it is a fair conclusion that the treatment would most likely have staved off death for only a limited period of time at best, if at all. The courts were not faced with the situation of a barely conscious patient or one in a persistent vegetative state, where the patient’s ability to feel anything is non-existent or highly questionable but where life could still be maintained for years. It may be that a court confronting that type of situation would not exclude considerations other than pain from its inquiries so absolutely.

Still, it would seem from these cases that our courts would regard it as appropriate that life support seldom, and only in extreme circumstances be withdrawn from incompetent patients. One need only look to the very strong emphasis in *Dawson* on “the laws of our society

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<sup>229</sup> *Dawson*, *ibid.* at 620 and at 623.

<sup>230</sup> *Ibid.* at 620 and at 623. It would follow from this comment that in the face of pain of that nature and degree, the judge would be “choiceless”; the fact that there is a decision—a choice—being made is obscured by the characterization of pain as a “coercive,” choice-removing factor. This characterization of severe pain itself is, of course, dependent on one’s underlying choice as to what constitutes “the good” for a patient.

For a different, more encompassing sensibility, see *Re P.*, *supra* note 160 at 156 and at 143, where parents’ refusal of a liver transplant for their child was upheld in the face of the government’s application to have the child declared in need of protection so that the operation could be authorized. While the child’s chances of survival with the transplant were good and death was certain and imminent without it, the court noted that the child would always suffer serious side effects, some of which were themselves potentially life-threatening, that the decision necessarily involved not just medical considerations but important psychological, social, and emotional components as well, and most importantly in the court’s view, that the parents’ decision was “made totally within the bounds of current medical practice” and “did not depart” from values society expects from parents of a terminally ill child.

[being] structured to preserve, protect and maintain human life [such] that in the exercise of our inherent jurisdiction this court could not sanction the termination of a life except for the most coercive reasons,<sup>231</sup> an emphasis that is echoed in *Niemiec*,<sup>232</sup> or, although in a very different context, the Supreme Court of Canada's choice in *Eve* of "the importance of maintaining the physical integrity of a human being"<sup>233</sup> as the controlling value from among several others and its hesitation to exercise its *parens patriae* jurisdiction to approve a contentious step that would be irreversible.<sup>234</sup> The tenor of these comments lends support to the conclusion that, at least relative to non-comatose, never-competent patients and once-competent patients who never clearly expressed their wishes relative to the use or continuation of life-sustaining medical interventions and who are not obviously near the end of a process of dying (itself a contentious and slippery term), courts may at least initially lean in favour of preserving life except in circumstances of certain, intractable pain.<sup>235</sup> While one can analyze this result in terms of avoiding quality of life decisions for which there is no consensus, or refusing to condone euthanasia, or avoiding a slippery slope of incrementally more morally questionable decisions, at bottom it is based on a sense that, as one judge put it, "the life of this [person] ... is so imponderable that it would be wrong for her to be condemned to die."<sup>236</sup> Judges confronted with questions about foregoing life-sustaining treatment will be keenly aware of their inability to know, their inability to find facts of the type and in the ways they are used to relying

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<sup>231</sup> *Dawson*, *supra* note 228 at 620.

<sup>232</sup> *Supra* note 28 at 427.

<sup>233</sup> *Eve*, *supra* note 15 at 34.

<sup>234</sup> *Ibid.* at 32-33.

<sup>235</sup> The presence of ongoing, intractable pain combined with a poor prognosis was key in the two decisions confirming parents' decisions not to force their children to undergo chemotherapy; *supra* note 209. Relative to the considerations to be taken into account when a child is "... so damaged as to have negligible use of its facilities," see *In Re J*, [1990] 3 All E.R. 930 at 944-45, Taylor L.J. He posited discontinuing treatment only as an alternative to a pain-filled existence or one in which the patient must be so heavily sedated as to lose consciousness in order to control pain. Neither of the other two judges were so categorical. But see *R.B. and S.B.*, *supra* note 162, where the court held that a child must be treated to prolong her life, even if doing so prolonged her suffering. The judgment is very brief and neither describes the child's condition or prospects in any detail nor expands on what is meant by "suffering." As such, it cannot be reliably factored into this analysis. It is likely that the non-invasive, minimal, routine nature of the treatment in question—antibiotic therapy—significantly affected the outcome as well.

<sup>236</sup> *Re B*, *supra* note 220, quoted with approval in *Dawson*, *supra* note 228 at 623. For critical comment on this choice of words, which has been termed "more emotive than accurate," see *In Re J*, *ibid.* at 942, Balcombe L.J. and at 944, Taylor L.J.

on as trustworthy in a traditional adversarial proceeding. They will be aware of the lack of a social consensus—a conventional morality—with respect to many of these questions. Most of all, they will know that if a court sanctions discontinuing life support, in all likelihood, that decision will shortly be irreversible. Taking all these factors together, the result is likely to be judgments rooted in caution that only rarely authorize an irrevocable step of this nature.

#### 8. Towards a theory of decision making

At the same time, these cases also recognize that there must be some weighing of the burden to the patient against the benefit possible or likely from the treatment—in other words, a quality of life assessment, but within the patient's own frame of reference. Thus, in *Dawson*, the court, quoting with approval from the decision of the English Court of Appeal in *Re B*, recognized that there might be circumstances in which “the life of this child is demonstrably going to be so awful” that a life-saving operation need not be performed.<sup>237</sup> It would seem from this observation and the cases where treatment was not ordered that Canadian courts are not committed to a firmly vitalist position no matter what the cost to the individual. The position is not one, then, that privileges the value of physical *existence* above all others; there is a recognition that it is not always necessary or in the patient's best interests to treat at all costs and with all measures available.<sup>238</sup>

It is likely that the judges in *Dawson* and in *Re B*, sensitive to criticisms of a “quality of life” approach, singled out pain and suffering because the judges felt able to identify confidently these factors as mitigating against continuing life within a broad, albeit not universal societal agreement at the time and given the circumstances of these patients.<sup>239</sup> But these decisions do not mean that pain and suffering are

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<sup>237</sup> *Supra* note 220 at 623. More recently in England, see *Re C*, *supra* note 114, relative to limits on treatment for a terminally ill child. See also *In Re J*, *supra* note 235 (an extremely physically and mentally handicapped child who was not terminally ill need not be placed on a ventilator again should the need arise. The decision was based on both the child's medical prognosis with and without the life support and an assessment of what the child's experience of life would be like with and without the treatment.) *Re J*, *supra* note 73 is to the same effect.

<sup>238</sup> The decision in *Malette*, *supra* note 31 at 430 lends support to this conclusion as well in its recognition that preserving the patient's life must be evaluated against the backdrop of her own values.

<sup>239</sup> For a similar comment in the American context, see *Jobes*, *supra* note 73 at 458, Handler J. at note 12.

the only factors that might persuade a court to authorize an end to life support. Even if the notion of "pain and suffering" is read broadly to include elements of mental and emotional suffering as well as pure physical sensation (an interpretation the phrase legitimately and sensibly bears), that does not seem exhaustive of what might make a life "so awful" that non-existence is the better alternative, to use the *Dawson* court's baseline.<sup>240</sup> There are many patients in extreme circumstances maintained on life support to whom a test hinging on the presence or absence of pain is simply not applicable. Patients in a persistent vegetative state, for example, do not experience pain—or anything else.<sup>241</sup> For these patients and for others, too, when pain is the only factor that is "enough," it "eclipses a whole cluster of other human values that have a proper place in the subtle weighing that will ultimately determine how a life should end."<sup>242</sup> Among the factors that an exclusive pain requirement negates might be a strong personal disapproval of artificially extended existence at the end of life, an abhorrence of dependence on others, a high valuation of personal privacy and dignity, and an ideal of bodily integrity rather than simply prolonging life.<sup>243</sup>

We live in a pluralistic society; we are not often going to be able to claim universal consensus. There *are* grave dangers of abuse in deciding to let a life end. At the same time, the question of withdrawing life support can be better and more sensitively addressed than by identifying only one example of what is intolerable, such as severe pain. We can begin to develop a more encompassing standard or series of considerations, motivated by a recognition that the life of one in a dire condition need not be perpetuated where to do so entails destroying the patient's dignity and denigrating his or her humanity.<sup>244</sup> For these

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<sup>240</sup> *Dawson*, *supra* note 228 at 623. The English Court of Appeal seems to take something of the same approach in its decisions; see *Re C*, *supra* note 114 at 979; and *In Re J*, *supra* note 235 at 938, Donaldson L.J. and at 945, Taylor L.J.

<sup>241</sup> *Peter*, *supra* note 178 at 425; and *Airedale Trust*, *supra* note 27 at 375, Lord Goff, at 361, Lord Keith, and at 398, Lord Mustill. Further, the line between those in a persistent vegetative state and those who are barely conscious is often not all that clear; see *Rhoden*, *supra* note 7 at 397.

<sup>242</sup> *Conroy*, *supra* note 88 at 1247, Handler J. See also Emanuel, *supra* note 216, contrasting the hedonistic conception of an acceptable existence for incompetent patients (using pain and pain alone as the standard of definition for benefits and burdens), with other possible standards—physical existence (vitalist), affective (human interaction), autonomy, and utilitarianism (collective pain and pleasure).

<sup>243</sup> Various American judges have given some indication of the range of factors that might be important to a patient in the decision-making. See, for example, *Conroy*, *supra* note 88 at 1248, Barber, *supra* note 167 at 493; and *Jobes*, *supra* note 73 at 462, Pollock J.

<sup>244</sup> An approach suggested in *Jobes*, *ibid.* at 459, Handler J.

patients, even if not otherwise near death, *that* fate can be “so awful” that non-existence is the better alternative. The organizing principles in the decision-making process, then, would be concepts of human dignity and personal integrity that are contextualized to inform the consideration of the patient’s particular circumstances—for instance, long-term constant and extensive handling of the insensate body of a patient who has essentially no hope of recovery.<sup>245</sup> The decision would not be a purely medical judgment consigned to health care professionals (even though expressed through the medium of a court), nor would it be entirely legalistic; rather, it must be recognized as a social and moral one as well.

This is a standard that could co-exist with the Supreme Court of Canada’s recognition in *Eve* of the primacy of the value of preserving physical integrity, not just physical existence. Protecting personal integrity (physical and mental) advances the core value of human dignity. It is a standard that can encompass the element of pain and suffering singled out in *Dawson*, without excluding many patients for whom this factor would be irrelevant or insignificant—for instance, the Karen Quinlans of the world. As with any standard, this one, too, calls for an infusion of content and a drawing of lines on the basis of moral judgments and social consensus on subjects relative to which strong arguments have been made that there cannot be universal agreement in modern society. While that observation is accurate in an absolute sense, in many instances, one can attain an accurate sense of general social mores—a shared notion of human dignity that can inform decisions as to how we and others should be treated. The impossibility of complete consensus will continue to require that courts err on the side of caution in this area—the dangers of cruel, unthinking misjudgments are real. I would still argue that when the *realities* of medical intervention for an incompetent individual have become such as to offend the sensibilities of a strong majority of people, when both humaneness in treatment and human dignity are gone or greatly eroded as a result of medical interventions,<sup>246</sup> we can say and our courts, if called on, should say, “enough.”

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<sup>245</sup> An example drawn from *Conroy*, *supra* note 88 at 1250, Handler J. (dissenting).

<sup>246</sup> For a critical view, see Dresser & Robertson, *supra* note 7 at 238, arguing that the “offence,” if there is any, is to competent observers and their concepts of dignified and respectful treatment, but not necessarily to the gravely debilitated patient. In the end, though, they too rely on the judgments of “competent observers.” See discussion of their proposed “current interests” test, *supra* note 216.

By attempting to articulate a guiding principle to underlie and support the significance accorded particular factors affecting the patient, such as pain, the analysis is of necessity taken up a level of abstraction. The standard is then open to the criticism that it lacks concrete, determinate meaning, that it offers little more than pious generalities. If the concepts of human dignity, integrity, and humaneness in treatment were only considered in the abstract and in isolation, that criticism could be telling. When these principles are applied to the patient's reality, however, they can usefully guide the inquiry. When specifics are considered, severe and intractable pain fits, as does the example of the extremes of constant and extensive handling and manipulation of an irrevocably declining patient's insensate body. There will be others as well. Unless a purely vitalist posture is adopted in all cases—and there is little support for that extreme a position—one will never be able to achieve a precise set of rules. At least, though, one will know something of what to look for, and why. It may be that the best we can do is not a rule book but a touchstone, itself firmly planted in the realities of the patient's particular situation.

