STILLBORN AUTONOMY: WHY THE REPRESENTATION AGREEMENT ACT OF BRITISH COLUMBIA FAILS AS ADVANCE DIRECTIVE LEGISLATION

by

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ABSTRACT

An advance directive is an instruction made by a competent person about his or her preferred health care choices, should the person become incapable to make treatment decisions. Legal recognition of advance directives has developed over the last half century in response to medical advances that can prolong the life of a patient who is no longer sentient, and who has decided to forego some or all treatment under such circumstances. Two types of directive have emerged in the law: an instructional directive, in which a person sets out treatment choices, and a proxy directive, which enables the person to appoint a proxy to make treatment decisions.

Development of the law has been impeded by fear that advance directives diminish regard for the sanctity of life and potentially authorize euthanasia or assisted suicide. In Canada, this fear explains the continued existence of outdated criminal law prohibitions and contributes to provincial advance directive legislation that is disharmonized and restrictive, in some provinces limiting personal choice about the type of advance directive that can be made. The British Columbia Representation Agreement Act (RAA) is an example of such restrictive legislation. The RAA imposes onerous execution requirements, is unduly complex and restricts choice of planning instrument.

Respect for patient autonomy requires that health care providers honour patients’ prospective treatment preferences. Capable persons must have ready access to a choice of health care planning instruments which can be easily executed. B.C. should implement advance directive legislation that meets the needs and respects the autonomy of B.C. citizens. The Criminal Code must be amended to eliminate physicians’ concern about potential criminal liability for following an advance directive. Advance directive legislation across Canada should be harmonized. Finally, health care providers should receive training on effective ways to communicate with patients about end-of-life treatment decisions to ensure that patients’ health care choices are known and respected.

1 Representation Agreement Act, RSBC 1996, c. 405.
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DEDICATION

For Dennis, Elizabeth and Graeme
who make everything worthwhile.

With thanks and love.
INTRODUCTION

1. Overview of Study

An advance directive is a statement of the maker’s wishes regarding acceptance or refusal of medical treatment, particularly life-sustaining medical treatment, in the event he or she becomes incapable to make personal health care decisions. Advance directives are typically made in writing but may be oral.\(^1\) Two primary forms of advance directive have developed in the law: the instructional advance directive and the proxy advance directive. The instructional advance directive, frequently called a “living will”, explains the maker’s preferences for future medical treatment in the event of incapacity. The proxy advance directive, frequently called a “durable power of attorney for health care”, specifies the person or persons who the maker appoints to make health care decisions on his or her behalf.\(^2\) Advance directives typically “spring” to legal life on the incapacity of the maker, although some directives may have immediate effect.\(^3\)

The advance directive evolved in response to people’s desire to have the ability to provide medical treatment instructions, particularly a preference to forego life-sustaining treatment, in the event of future incapacity.\(^4\) The legal foundation for the advance directive is the doctrine of consent to medical treatment.\(^5\) The advance directive is

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\(^2\) See Chapter One, below, for further discussion of the definitions of advance directives.

\(^3\) See Carol Krohm & Scott Summers, Advance Health Care Directives: A Handbook for Professionals, (Chicago: ABA Publishing, 2002) [Krohm & Summers, Advance Health Care Directives] (“Unless otherwise stated, the effectiveness of the powers might begin at the moment of signing and run until death. ...If desired, one may insert a future date for it to become effective, as well as a “sunset” date for expiration. A “springing” power may be appropriate.” at 16-17); See also Fay A. Rozovsky, Consent to Treatment: A Practical Guide, 3\(^{rd}\) ed., (Gaithersburg, Maryland: Aspen Publishers, Inc., 2000)[Rozovsky, Consent to Treatment] at 7:72.

\(^4\) Meisel & Cerminara, The Right to Die, supra note 1 at 7-9 – 7-10.

\(^5\) The legal foundation for the advance directive in the doctrine of consent to treatment is recognized in the U.S. in living will statutes and in case law. See e.g. Rasmussen v Fleming, 154 Ariz. 207, 741 P 2d. 674 (1987); In re Browning, 568 So. 2d. 4, 15 (Fla. 1990). In Canada, the advance directive is statutorily endorsed under various provincial laws, and in the courts by the case of Malette v Shulman, (1990), 67
ethically grounded on the principle that citizens have a fundamental right to individual autonomy and self-deliberation regarding personal treatment decisions.\(^6\) The concept of the advance directive is generally endorsed by the public and is accepted in principle by the medical profession.\(^7\) Nevertheless, most people do not make advance directives.\(^8\)

A number of reasons have been suggested to explain why capable adults do not make advance directives, including public discomfort discussing death\(^9\), physician unwillingness to relinquish control over medical treatment decisions\(^10\), and the inability or unwillingness of people to predict appropriate treatment choices for an uncertain medical future.\(^11\) All of these factors have some bearing on the relative failure of competent persons to embrace the advance directive as a tool for health care planning. This thesis argues, however, that it is the law which creates the greatest impediment to widespread use of the advance directive. Although it is evident that discussions about advance treatment planning between patients and physicians should be improved, to a large extent it is the limitations in advance directive and related legislation which cause the public and health care providers to avoid using the advance directive.

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\(^6\) Fleming v Reid, (1991), 82 D.L.R. (4th) 298 (Ont. C.A.) [Fleming] (fundamental right to prospectively refuse specific psychiatric treatment); and see Morgentaler v. the Queen (1988), [1988] 1 SCR 30; 44 D.L.R. (4th) 385 (S.C.C.) [Morgentaler]. In the U.S. this right is found within the constitutional liberty interest, but the individual right is subject to state-imposed limitations related to a state’s interest in preservation of life. See Cruzan v Director, Mo. Dept. of Health, 497 U.S. 261, (1990).

\(^7\) L. Emanuel et al., “Advance Directives for Medical Care: A Case for Greater Use”, (1991)324 N. Eng. J. Med. 889[Emanuel, “Advance Directives for Medical Care”]; K. Stelter et al., “Living Will Completion in Older Adults”, (1992)152 Archives of Internal Medicine 954. (See Chapter Two for further discussion of public and medical attitudes towards the advance directive.)


\(^10\) Krohm & Summers, Advance Health Care Directives, supra note 3 ("[a]n attending physician may disagree with either a directive or an agent (or both)" at 2); Rozovsky, Consent to Treatment, supra note 3 ("In many instances, a patient’s decision to refrain from treatment runs contrary to the culture, mores, beliefs, and training of health care professionals." at 7:1).

The central argument of this thesis is that many of the statutes that have been enacted to recognize the common law right of an individual to prospectively refuse medical treatment present significant barriers to completion of advance directives. This thesis argues that the motivation behind restrictive legislation is fear of euthanasia and concern for the protection and preservation of life. This thesis further argues that the advance directive legislation in British Columbia, (B.C.) the *Representation Agreement Act (RAA)*\(^\text{12}\), is an example of legislation that creates impediments to making an advance directive because the legislation is directed towards protection of individuals and preservation of life, rather than towards respect for individual autonomy to make personal end-of-life treatment choices. The restrictions and limitations of the *RAA* prevent B.C. citizens from easily preparing an advance directive that meets their individual health care planning needs and, consequently, the *RAA* fails as advance directive legislation.

Common law and statutory recognition of advance directives began in the United States (U.S.) during the 1970’s and progressed rapidly during the next two decades. By comparison, no Canadian province recognized an instructional advance directive [living will] until the Manitoba *Health Care Directives Act*\(^\text{13}\) came into force in 1993. Most legal and ethical consideration of advance directives emanates from the U.S. For that reason, many of the authors quoted and examples used in this thesis are American. This thesis argues, however, that public and legislative concerns about euthanasia and preservation of life have distorted development of Canadian advance directive legislation much as they have distorted development of the U.S. legislation, which has been especially influenced by the antipathy of right-to-life organizations towards advance directives.

Not all of the statutory restrictions in the legislation of the two countries are identical. For example, no Canadian province explicitly restricts the operation of an advance directive.

\(^{12}\) R.S.B.C. 1996, c. 405.
\(^{13}\) C.C.S.M. 1992, c. H27.
directive during pregnancy, where this restriction is commonplace in the U.S.\textsuperscript{14} However, half of the Canadian provinces do not recognize an instructional advance directive, effectively limiting the choice of Canadians in these provinces to the use of a proxy directive. This thesis argues that, whatever the benefits of a proxy directive, failure for legislatures to also recognize instructional advance directives or a combination of the two types of directive is a restriction on personal autonomy.

The next section sets out the arguments of this thesis respecting the limitations on personal autonomy that are created by restrictive advance directive legislation and the obligation of government to ensure that citizens are provided with legislation that enables them to direct their end-of-life treatment in accordance with their personal life values.

\textsuperscript{14} Meisel & Cerminara, \textit{The Right to Die}, supra note 1 at 7-91.
2. Thesis Arguments

The author of a leading text on the law of consent to treatment comments with regard to the "legislation in many states, including an array of advance directives"\(^{15}\) that:

\[\text{[notwithstanding the voluminous case law and legislative inroads in this area, the law surrounding the right to refuse treatment is far from settled. ... [T]he right to decline treatment needs clarification, with many states carving out their own requirements through case law and legislation.}\]^{16}\]

The various statutes which create a legislative platform for the advance directive frequently limit the use of the directive through narrow definitions and significant restrictions on its application.\(^{17}\) Many statutes include complex provisions, complicated documents, and onerous execution formalities that deter widespread use by the public.\(^{18}\) Some advance directive law, and in Canada the related criminal law, fails to adequately ensure legal protection against liability for health care providers who follow an advance directive.\(^{19}\) The statute may not offer a method for people to provide their specific treatment instructions; instead they can only appoint a proxy to make decisions on their behalf.\(^{20}\) The laws are not harmonized and do not share common definitions, creating uncertainty about their application.\(^{21}\) In a country, such as Canada, which purports to offer universal health care, this disharmony underlines the potential in the Canadian healthcare system for different treatment outcomes at the end of life depending upon a patient's province of residence.

\(^{15}\) Rozovsky, *Consent to Treatment*, *supra* note 3 at 7:2.
\(^{16}\) Ibid.
\(^{17}\) Meisel & Cerminara, *The Right to Die, supra* note 1 ("Some advance directive legislation imposes restrictions on the circumstances under which advance directives are effective and the types of decisions that can be made through an advance directive.") at 7-26.
\(^{18}\) Krohm & Summers, *Advance Health Care Directives, supra* note 3 ("Regrettably, some preprinted documents may be downright intimidating....[I]ndividuals may give up in exasperation...") at 58.
\(^{19}\) See for e.g., *Representation Agreement Act, [RAA]; supra* note 12, (B.C.); *Substitute Decisions Act, S.O. 1992, c. 30 (Ontario); Civil Code of Quebec, S.Q. 1991, c. 64. art. 11-25, 153, 256-297, 2130-2185 (Quebec); Medical Consent Act, R.S.N.S. 1989, c. 279, (Nova Scotia).
\(^{20}\) Ibid.
\(^{21}\) Meisel & Cerminara, *The Right to Die, supra* note 1 at 1-18 - 1-19; and see Chapter Four below, regarding disharmony in Canadian law.
Legal and ethical texts on the topic of advance directives acknowledge the disharmony in the laws, the complex execution requirements and the potential for an advance directive to be ineffective because of restrictive definitions that limit its application. The texts do not always attempt to explain, however, the motivation behind the restrictions, limitations and disharmony in advance directive statutes. This thesis argues that the limitations in advance directive laws are caused by fear that the statutes may authorize euthanasia or assisted suicide. The concept of the advance directive finds its fiercest opponents among supporters of the “right to life” who argue that respect for the sanctity of life obligates society to maintain people alive as long as possible, regardless of the quality of life or the personal choice of the individual.

Some of the statutory provisions that limit the application of advance directives are intended to prohibit a directive coming into force until a person is very close to death and to ensure that death results from underlying disease and not from any action on the part of a health care provider. Many U.S. advance directive statutes suspend a directive during pregnancy. These limitations reflect a belief that the state is correct to intervene with private decisions to refuse life-sustaining treatment in order to guard and preserve life because life, regardless of whether it is severely compromised, is sacred. This thesis proposes that the disharmony in advance directive laws is caused by the failure of different governments to agree on the amount of respect that should be accorded citizens to choose to refuse treatment at the end of their lives versus the degree to which the state should intervene to preserve life.

22 Olick, Taking Advance Directives Seriously, supra note 8 at 24.
23 See e.g Meisel & Cerminara, The Right to Die, supra note 1 at 7-90 – 7-91.
24 Alan D. Lieberson, Advance Medical Directives, (New York: Clark, Boardman, Callahan, 1992)[Lieberson, Advance Medical Directives] at 32.
27 Meisel & Cerminara, The Right to Die, supra note 1 at 7-91.
28 Ronald Dworkin, Life’s Dominion, An Argument about Abortion, Euthanasia, and Individual Freedom, (New York: Alfred A. Knopf, 1993) [Dworkin, Life’s Dominion] (“A state need not honor a living will if it has decided that allowing people to die is an insult to life’s sanctity.”) at 198.
Ronald Dworkin makes the following comments regarding the issue of state intervention into this most personal of decisions:

So the appeal to the sanctity of life raises here the same crucial political and constitutional issue that it raises about abortion. Once again the critical question is whether a decent society will choose coercion or responsibility, whether it will seek to impose a collective judgment on matters of the most profound spiritual character on everyone, or whether it will allow and ask its citizens to make the most central, personality-defining judgements about their own lives for themselves.²⁹

This thesis argues that governments have a legal and ethical obligation to enable citizens to make prospective decisions about their preferred end-of-life medical treatment through legislation that honours individual autonomy and respects personal life values that are central to a person’s identity and well-being. An advance directive that allows a person to stipulate treatment refusals for when he or she is no longer capable to consciously make such decisions is an attempt to offer that autonomy. However, advance directive legislation, although prevalent, remains conflicted about offering people sufficient autonomy to refuse life-sustaining treatment, and is often very restrictive in its application. The legislation should be drafted to ensure the directive will be effective in a broad range of circumstances. Choice should not be limited to either an instruction directive or a proxy; both should be offered, as well as a combination of the two.

This thesis argues that effective communication between physicians and patients respecting end-of-life treatment planning and the use of advance directives is undermined by social and medical reluctance to discuss death and dying. This thesis recommends that health care providers in Canada receive training to communicate with patients about advance health care planning in a manner that is sensitive to their patients’ preferences and needs.

²⁹ Ibid at 216.
This thesis maintains that the advance directive legislation in B.C., the *RAA*, is an example of restrictive legislation that has been drafted to protect and preserve life, rather than to offer individual autonomy. The *RAA* only offers B.C. citizens the option of designating a proxy for health care decisions; the legislation does not enable them to make a living will. The *RAA* imposes burdensome restrictions on the creation of an advance directive and the legislation is not harmonized with any other jurisdiction in Canada. (In fact, the *RAA* is particularly unusual in its form and creates an instrument that is flawed in its basic legal structure.) The *RAA* does not respect the rights of mature minors to make an advance directive. This thesis argues that new law is needed in B.C. to provide the citizens of the province with advance directive legislation that honours choice and respects individual autonomy.

Finally, this thesis argues that modern advance directive legislation should be uniformly implemented across Canada to ensure consistent end-of-life treatment for all Canadians regardless of their province of residence.
Chapter One discusses the two types of advance directive in greater detail, and describes the failure of the statutes and legal texts to offer clear definitions of them. This thesis argues that authors and legislative drafters struggle to define the advance directive because they are uncomfortable with its underlying subject matter. The balance of Chapter One reviews the history and legal development of the advance directive in the United States and Canada as described by the principal authors in the fields of law and ethics who write on the topic of advance directives.

Chapter Two examines social and medical discomfort with the topic of death and considers available information on the public desire to create an advance directive. This thesis argues that, while people, including doctors, still evidence a certain amount of reluctance to discuss end-of-life issues or, more specifically, the subject of death, progressively there is a desire for people to make their treatment wishes known. The research indicates that current methods of physician and patient communication on this topic are insufficient to meet people’s needs, and should be improved.

Chapter Three considers the current debate about the legitimacy of the instructional advance directive, or living will, and examines the underlying reasons for the criticism of the living will. This thesis argues that much of the criticism of the instructional advance

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30 Rozovsky, Consent to Treatment, supra note 3 ("It has taken the law a long time to come to grips with the notion of the right to refuse care.") at 7:92.
31 Olick, Taking Advance Directives Seriously, supra note 8 ([P]hysicians and other health care professionals often receive [advance directives] through the lens of a medical culture that remains wedded to the Hippocratic commitment ...and death is considered the ultimate failure." at xvi); AARP, “End of Life: Talking About your Final Wishes”, (“Death is a natural part of life - but for most of us, talking about it isn’t. Most people are uncomfortable talking, or even thinking, about what will happen when they or a loved one dies.”) online: <http://www.aarp.org/families/end_life/a2003-12-02-endoflife-finalwishes.html>; (last accessed November 27, 2005).
32 See for e.g. Emanuel, “Advance Directives for Medical Care”, supra note 7.
directive is based on fear of euthanasia and the philosophy of vitalism.\textsuperscript{34} The deficiencies of both living wills and proxy advance directives are discussed and the controversial subject of substitute decision-making is analyzed. This thesis argues that people should not be restricted from using either type of directive to meet their planning needs. This thesis further recommends that legislators ensure that individual rights to prospectively refuse treatment through a choice of advance directive are protected in legislation.

The fourth chapter examines the particular impediments to the success of advance directives in Canada that arise from Canadian law. This thesis argues that the outdated \textit{Criminal Code}\textsuperscript{35} provisions, the disharmonized provincial legislation and the dearth of relevant jurisprudence all contribute to the confusion in Canada about the legality of advance directives, and particularly the instructional advance directive. This thesis proposes that the laws must be amended to ensure that the legal rights of Canadians to govern their end-of-life treatment choices are respected.

Chapter Five analyzes the law in British Columbia in light of the findings in the foregoing chapters and concludes that it illustrates many of the restrictions on autonomy found in advance directive statutes. This thesis argues that the restrictions and limitations of the \textit{RAA} relative to its purpose as advance directive legislation are caused by an underlying fear of euthanasia and a desire to protect people from their own decisions as well as from the acts of others. The \textit{RAA} is paternalistic and does not respect the autonomy of the citizens of B.C. Consequently, this thesis argues that the \textit{RAA} fails as advance directive legislation.

\textsuperscript{34} "Vitalism" is a philosophical approach premised upon a rigid application of the sanctity of life principle. This topic is discussed in more detail in Chapter Three, below.

\textsuperscript{35} R.S.C. 1985, c. C-46 [\textit{Criminal Code}].

Chapter Six (the concluding chapter) sets out a list of elements that should be incorporated into new advance directive legislation in B.C. and also argues in favour of harmonized legislation in Canada. Some Canadian provincial advance directive legislation does reflect the ideals of good advance directive law. For example, the legislation in Manitoba offers its citizens a choice of either instructional, proxy or a combined form of advance directive, ensures easy access to the instruments, provides for simple execution formalities, and respects the rights of mature minors to refuse medical treatment. The legislation in Prince Edward Island adopts the flexible regime for respecting extra-provincially created advance directives recommended by the Uniform Law Commission of Canada. These statutes honour the principles of autonomy and self-determination that are the reason for creating the advance directive, and many of their provisions should be adopted across Canada. This thesis concludes that harmonized provincial legislation is essential in a country that offers universal health care.

Finally, this thesis recommends that further study be done to determine how best to enhance communication between health care providers and patients regarding end-of-life treatment planning. Such planning is unlikely to be completely effective in the absence of a suitable statutory regime. However, assuming that appropriate and necessary legislation can and will be implemented, it is essential that health care providers learn how best to approach the topic of advance care planning with their patients. Enhanced communication between health care providers and patients is necessary to ensure that patients' preferences for end-of-life treatment are understood and that the same priority is given to the goal of meeting those preferences as to all other aspects of quality health care.

37 Health Care Directives Act, supra note 13.
38 Consent to Treatment and Health Care Directives Act, S.P.E.I. 1996, c. 10.
4. Related Issues

This thesis does not analyze or discuss a number of issues that are closely related to the topic of advance directives, except to the extent that these issues touch on the subject of advance directives. Among these related issues are the following:

1. Capacity and incapacity: This thesis does not discuss the question of how capacity is assessed or how a determination of incapacity is made. For the purposes of this thesis, an advance directive made by a capable person that is intended to come into force on the maker’s incapacity becomes effective when a valid finding of incapacity has been determined by suitably trained professionals.

2. Futility: This thesis does not discuss the matter of futility, meaning the ability of the medical profession to pronounce a particular medical treatment futile and to unilaterally withhold it from a patient. For the purposes of this thesis, it is assumed that the maker of an advance directive cannot successfully insist on the provision of medical treatment which is deemed to be futile. The choice that can be made under an advance directive is to either accept or refuse medical treatment which has not been deemed futile. Typically, advance directives specifically relate to a decision to either accept or refuse various types of life-sustaining treatment.

3. Do Not Resuscitate (DNR) Orders: Closely connected to the issue of futility is the DNR order. Traditionally, a decision to place a DNR order has been within the sole discretion of the medical profession. That view is now being

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challenged; however, this thesis does not equate the DNR with an advance directive; nor does it discuss the appropriateness of the DNR as a treatment direction.

4. Euthanasia and Assisted Suicide: This thesis does not propose the decriminalization of euthanasia or assisted suicide. This thesis instead argues that cessation of life-sustaining medical treatment on the authority of an advance directive is different “in kind” from either euthanasia or assisted suicide.

Each of these topics represents a controversial issue. I do not review the legal history or current status of these issues except to the extent that they affect the interpretation of the law governing advance directives.

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\[41\] Ibid.
\[42\] Margaret Somerville, *Death Talk: The Case Against Euthanasia and Physician-Assisted Suicide*, (Montreal and Kingston: McGill-Queen’s University Press, 2001) (“I will not discuss here the rapidly evolving use of “advance directives” in decision-making...I argue that there is a difference in kind between euthanasia and these other situations.”) at 73.
CHAPTER ONE: THE ADVANCE DIRECTIVE

1. Introduction

The advance directive for medical treatment has been a difficult concept for society to embrace. In the last few decades, U.S. and Canadian courts have acknowledged the right of individuals to direct their medical treatment decisions even when they are no longer personally capable to provide contemporaneous instruction, although the extent of this right remains unsettled.\(^1\) Legislatures, medical practitioners and the public have struggled to agree on how such directions should be given and by whom. Consequently, two types of advance directive have emerged: the living will, constituting a direct instruction to health care providers, and the proxy, designating an individual to make treatment decisions on behalf of an incapable patient. Controversy has accompanied both types of advance directive. Some critics oppose either type and argue that decisions for incapable patients should be made on the basis of their best interests.\(^2\) Others argue vehemently in favour of the proxy advance directive in preference to the living will.\(^3\) There is little agreement in the literature on advance directives about the terminology that should be used to describe them. Advance directive legislation is similarly conflicted about the scope and authority of advance directives, particularly that of living wills.\(^4\)

Dramatic changes in medical technology created the need for advance directives. Increasingly, patients confirmed their prospective refusal to be kept alive but unaware for protracted periods on life-sustaining technology that was seen only to prolong the process

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\(^{2}\) See *e.g.* Rebecca S. Dresser and John A. Robertson, “Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach”, (1989) 17:3 Law, Medicine and Health Care 240.


\(^{4}\) See Chapter Three, below, for further discussion about the limited clinical relevance of living wills arising out of statutory limitations.
of dying. Such prospective treatment refusal was frequently confused with a request for euthanasia or assisted suicide, both of which are criminally prohibited in the U.S. and in Canada, and are typically morally repugnant to the public. Consequently, the concept of advance directives has been ardently opposed by special interest groups fearful of a culture approving involuntary euthanasia and by members of the “right to life” who believe that life must always be sustained regardless of the quality of life. This thesis argues that deference by legislators to special interest groups opposed to advance directives, including vitalist groups such as the “right to life” organizations, has impeded development of appropriate legislation and has clouded the public perception of the morality and legality of advance directives.

The failure of some Canadian provinces to endorse instructional advance directives [living wills] as legally binding documents is motivated by fear that advance directives might authorize euthanasia and assisted suicide. The failure of the Canadian Parliament to amend the Criminal Code to confirm that health care providers are not criminally liable for ethically following the terms of an advance directive reflects the same concern. The Canadian courts, however, have confirmed the validity of an instructional advance directive in the form of a blood refusal card and have also described the right to

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5 See e.g. Rasmussen v. Fleming, 154 Ariz. 207 at 211, 741 P.2d 674 (1987). (See note 48, infra, and accompanying text.)
8 Ibid (“Interest groups tried to keep the issue [of advance directives] off the [legislative] agenda by arguing that legislation was not needed and by linking living will laws to active euthanasia and other much broader - and sometimes bizarre - social concerns. ...[Advance directive laws] reflect demands from powerful groups for the most limited legislation possible) at 129.
10 Edward W. Keyserlingk, Sanctity of Life or Quality of Life in the Context of Ethics, Medicine and Law, A Study written for the Law Reform Commission of Canada (Ottawa: Minister of Supply and Services Canada, 1979); See also Law Reform Commission of Canada, Working Paper 28, Euthanasia, Aiding Suicide and Cessation of Treatment (Ottawa: Minister of Supply and Services Canada, 1982) [LRC, Working Paper 28]; Law Reform Commission of Canada, Report 20, Euthanasia, Aiding Suicide and Cessation of Treatment (Ottawa: Minister of Supply and Services Canada, 1983); Report of the Special Senate Committee on Euthanasia and Assisted Suicide, Of Life and Death (Ottawa: Minister of Supply and Services, 1995).
prospectively refuse treatment for mental disability to be fundamentally protected\textsuperscript{11} under the \textit{Canadian Charter of Rights and Freedoms}.\textsuperscript{12} Similarly, the Canadian Medical Association recognizes the ethical validity of instructional and proxy advance directives and advises physicians, under the CMA \textit{Code of Ethics}\textsuperscript{13}, to learn their patients' treatment preferences and to follow them whenever possible.\textsuperscript{14} It is clear that the relevant legislation, including many advance directives statutes and the Canadian \textit{Criminal Code}, is out of step with modern medical and legal ethics respecting advance directives, and must be revised.

This chapter reviews the multitude of definitions used to describe advance directives and examines the inability of the law and medicine to consistently and concisely define them. The balance of the chapter explains the ethical impetus for advance directives and sets out the legal development of advance directives in the U.S. and in Canada. This chapter concludes that advance directive legislation must meet social needs and must not impede personal freedoms. Restrictive legislation that limits personal choice and creates impediments to the exercise of individual autonomy in directing end-of-life treatment defeats the purpose of implementing advance directive legislation. Legislators must work actively to ensure that advance directive legislation respects individual rights to autonomy and self-determination so that citizens are able to make treatment choices at the end of life that accord with their personal life values.

\textsuperscript{11} \textit{Fleming v Reid} (1991), 82 D.L.R. (4\textsuperscript{th}) 298 (Ont. C.A.) \textit{[Fleming]}.  
\textsuperscript{12} Part I of the Constitution Act, 1982, being Schedule B of the Canada Act 1982 (U.K.), 1982, c.11 \textit{[Charter]}.  
\textsuperscript{14} \textit{Ibid} at ss. 27-28.
2. Definitions

Discussion about the proper form and content of a "living will" or an "advance directive", either instructional or proxy, depends upon a clear understanding of the meaning and the underlying ethical basis for the documents. However, texts and materials on these subjects rarely provide a precise definition of these terms, and the literature confuses both the terms and their meanings regularly. This inability of writers and legislators to precisely define advance directives reflects not only misunderstanding of the documents but also an underlying discomfort with their subject matter.\(^{15}\)

Inconsistency in terminology respecting advance directives leads health care providers to be cautious responding to them and consequently defeats their purpose.\(^{16}\)

*Black's Law Dictionary* provides the following definitions which imply that a written advance directive has a broader scope than a living will:

**advance directive.** 1. A durable power of attorney that takes effect upon one’s incompetency and designates a surrogate decision-maker for healthcare matters. SEE POWER OF ATTORNEY. 2. A legal document explaining one’s wishes about medical treatment if one becomes incompetent or unable to communicate. – Also termed *medical directive; physician’s directive; written directive*. Cf. LIVING WILL\(^{17}\)

**living will.** An instrument, signed with the formalities necessary for a will, by which a person states the intention to refuse medical treatment and to release healthcare providers from all liability if the person becomes both terminally ill and unable to communicate such a refusal. – Also termed declaration of a desire for a natural death; directive to physicians. Cf. ADVANCE DIRECTIVE.\(^{18}\)

\(^{15}\) Glick, *Policy Innovation, supra* note 7 at 16-20.


\(^{18}\) *Ibid*, s.v. “living will”.

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"Advance directive" is typically recommended as the preferable terminology to "living will" and is frequently found in medical ethics and health law textbooks.19 However, exact definitions of either "living will" or "advance directive" and its related terms are generally not found in the literature. In some texts "living will" is defined to be solely a written instructional advance directive20, in other materials as both an instructional advance directive and a proxy advance directive21 and occasionally as either one individually.22 For example, Professors Meisel and Cerminara [Meisel and Cerminara] state:

The term advance directive is used to denote several different things. Sometimes it designates the concept of anticipatory health care decisionmaking. At other times it refers to the content of an oral or written statement made by an individual (declarant) to become effective under stated conditions. The term can also refer to a vehicle for embodying such a statement, such as a living will or durable power of attorney.23

In their definition of a “living will” Meisel and Cerminara write:

Living wills are documents that give instructions to health care providers about particular kinds of medical care that individuals would or would not want to have to prolong life, and therefore are sometimes referred to as instruction directives. Sometimes the term living will is used to refer generically to all written advance directives, but the term should be used to refer to advance directives issue by a person for use in case of incapacity of the person.24


21 The 1997 living will materials issued by the Centre for Bioethics, University of Toronto, combined both concepts under the definition of a living will. The language of the Centre for Bioethics Living Will was updated in 2004. Where the former definition explained that there were two parts to a living will, an instruction and proxy directive, the revised version now separates the concepts of instructional and proxy advance directives, recommending that makers include both types of advance directive into their living will. Centre for Bioethics Living Will, © Dr. Peter Singer, 1993, reprinted by permission of the University of Toronto Centre for Bioethics September 1997; University of Toronto, Joint Centre for Bioethics, Living Will, online: University of Toronto <http://www.utoronto.ca/jcb/home/main.htm> (last accessed August 14, 2005); Hébert, Doing Right, Supra note 19, at 27.


23 Meisel & Cerminara, The Right to Die, supra note 20 at 7-8.
directives that give instructions and not to those that appoint an agent to make decisions for the declarant. ... A living will might be custom-drafted by or for the declarant, or it might be based on a form.\textsuperscript{24}

To define a Proxy Directive (which they also entitle Health Care Power of Attorney) they state:

Another form of advance health care planning entails the appointment of another person, referred to as a proxy, to make health care decisions in the event of future incapacity. ... A proxy directive is a statement by which one makes such a designation. It is usually contained in a written instrument, but could possibly be an oral statement. A number of other terms also are used to refer to such a written instrument, such as health care proxy, health care power of attorney, proxy directive, medical directive and durable power of attorney for health care.\textsuperscript{25}

The proxy (also entitled Agent or Attorney-in-fact) is defined by Meisel and Cerminara as the person on whom the proxy directive confers powers, although “...some advance directive statutes refer to this person as a surrogate, an agent, the holder of the power, or an attorney-in-fact, the latter two borrowing from conventional power-of-attorney terminology.”\textsuperscript{26}

In answer to the rhetorical question “What is an advance health care directive?” Krohm and Summers respond “Simply put, it’s a personal contingency plan (usually written) on how medical decisions are to be made in the event of decisional or communicative incapacity.”\textsuperscript{27} Their subsequent definitions are anything but simple. Where Meisel and Cerminara define the proxy as an agent, Krohm and Summers, define the proxy form as the health care power of attorney and the agent as a “deputy”. Living Wills are defined

\textsuperscript{24} Ibid, at 7-9 and 7-10
\textsuperscript{25} Ibid at 7-11
\textsuperscript{26} Ibid at 7-13; See also Terry J. Barnett, Living Wills and More: Everything You Need to Ensure that All Your Medical Wishes Are Followed, (New York: John Wiley & Sons, 1992) ("The law in Michigan calls an agent a “patient advocate,” ... and in West Virginia a “representative”,"") at 5.
as "Declarations" and the proxy is also defined as a durable health care power of attorney.

King makes little effort to define an advance directive in her text, offering instead a group of five model forms to "demonstrate both a core understanding of what advance directives are and some of the bewildering array of points and variations that have given rise to confusion about the legal, practical, and moral significance of different forms".28 Similarly, Lieberson documents the legal origins of the advance directive but provides no concise definition of the term.29

In 1988 George Alexander, former Dean of the Santa Clara Law School, described a durable power of attorney as a living will:

[A] living will is a document by which we create a power of attorney that is binding even when we are incapacitated. It is to be distinguished from a general power of attorney, which becomes ineffective when one becomes incompetent.30

If this type of living will was drafted to come into effect on the incapacity of its maker, Alexander described it as a "springing living will (or springing durable power of attorney)".31 Alexander recognized the potential for confusion by his adoption of the term "living will" for the durable power of attorney but explained that his document should not be confused with the traditional living will which was more appropriately called a "directive to physician".32 In Alexander's view, the latter document was governed by statutes and was very specifically limited in scope to discontinuing life support. He offered in his book a form that would meet the statutory requirements then effective in various states for durable powers of health care which he entitled "Durable Power of Attorney or Living Will".33 While Alexander's forms and his approach were

28 King, Making Sense, supra note 22 at 16-17.
29 Alan D. Lieberson, Advance Medical Directives, (New York: Clark, Boardman, Callahan, 1992)[Lieberson, Advance Medical Directives] at 37(ff, c.4).
31 Ibid at 51.
32 Ibid at 49.
33 Ibid at 50.
not followed, his confusion about the meaning of the term “living will” has continued to exist throughout the history of advance directives.

Advance directive statutes also use a wide variety of terms and definitions, but these are not uniform or consistent and vary significantly in substantive matters. Lieberson explains that:

provisions of LW [living will] statutes ... vary between jurisdictions thereby influencing the clinical applicability of an LW in the particular state. Unlike most other statutes, the definition of terms often limits the rights granted by the other provisions of the Act.

In a noted Canadian health law text, Barry Sneiderman calls an advance directive a “health care directive”, a living will an “instructional directive” and explains that a proxy under a proxy directive is “an agent (surrogate decision-maker)”. Mr. Sneiderman may have adopted the name “health care directive” from text adopted by the Uniform Law Conference of Canada which used this definition in its proposed model for adoption of foreign directives: “Advance Directives in Health Care: Recognition of foreign health care directives”.

Arguably, the term health care directive is a more comprehensive term than advance directive and is intended to include all health related personal care matters, such as housing or admission to a care facility, for incapable persons and not only decisions

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34 Glick, Policy Innovation, supra note 7 at 169; See also Lieberson, Advance Medical Directives, supra note 29 at c. 5ff (Living Will Statutes: Variable Provisions).
35 Lieberson, Advance Medical Directives, ibid at 67.
36 J Downie, T. Caulfield, C. Flood, eds., Canadian Health Law and Policy, 2 ed. (Canada: Butterworths, 2002).
38 Ibid.
39 Ibid.
dealing with medical treatment at the end of life. Some of the Canadian legislation, such as the Ontario Substitute Decisions Act [SDA]\(^{41}\) and the B.C. Representation Agreement Act [RAA]\(^{42}\) combine the concepts of an attorney for personal care with an advance directive proxy into one document. For example, the SDA defines personal care to include much more than solely health care. The relevant section of the SDA is as follows:

_Incapacity for personal care_

45. A person is incapable of personal care if the person is not able to understand information that is relevant to making a decision concerning his or her own health care, nutrition, shelter, clothing, hygiene or safety, or is not able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.\(^{43}\)

Manitoba is the only province that has adopted the exact term "health care directive" as the title of its advance directive legislation (although that exact name is not used in the legislative provisions). Despite its title, the Manitoba legislation does not speak to personal health care.\(^{44}\) A "Directive" under the Manitoba Health Care Directives Act [HCDA]\(^{45}\) may express the maker’s health care decisions or appoint a proxy; i.e., the HCDA acts as either an instructional or proxy advance directive in common with more typical advance directive legislation. In the Canadian advance directive legislation, the names used for advance directives vary significantly among the provinces, as do the definitions and other provisions.\(^{46}\)

The inconsistency among common law and statutory definitions and terminology for advance directives create confusion about their legal and ethical status. Melvin Urofsky

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41 S.O. 1992, c. 30 [SDA].
42 R.S.B.C. 1996, c. 405 [RAA].
43 Supra note 41 at s. 45.
44 The Health Care Directives Act, C.C.S.M. 1992, c. H27,[HCDA] (although HCDA does not define the term "health care directive"; instead, HCDA states; “ “directive” means a health care directive made in accordance with this Act, and includes a directive made before this Act comes into force;” at s. 1. Prince Edward Island also uses the name “health care directive” in the title of its advance directive legislation and as the subheading of Part III of the legislation, but does not include the name “health care directive” in the legislative provisions or in the definition of “directive”. See Consent to Treatment and Health Care Directives Act, R.S.P.E.I. 1988 c. C-17.2).
45 HCDA Ibid.
46 See Chapter Four below for discussion of the specific provisions in the Canadian legislation.
notes that “[b]ecause advance directives may take such a variety of forms, health care providers are understandably cautious in their response”. Public confusion and health care provider distrust about advance directives cause these instruments for personal end-of-life treatment decision-making to be misunderstood, little used and potentially disregarded.

Henry Glick’s research indicates that as the right to die emerged as a social and political issue, the diffusion of state legislation governing advance directives was a result of legislative attention to external interest group pressures. According to Glick:

> the content of many similar laws, policies and procedures varies in important ways, and they are likely to affect citizens differently according to where they live. ...[I]f states do not embrace a uniform policy ...[they may] ...create new twists on old policies that possibly are more effective in coping with social problems.

In the absence of universal agreement on the basic morality of the advance directive, individual jurisdictions will continue to create legislation that does not embrace uniform definitions or common provisions, and which is informed by the political interests of each jurisdiction.

The next section discusses the social and ethical impetus for the advance directive and the development of advance directive laws in the U.S. and Canada which attempt to interpret and meet the competing social goals of autonomy and preservation of life.

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47 Urofsky, *Letting Go*, supra note 16 at 135.
49 *Ibid* at 48.
3. Ethical and Legal Development of Advance Directives

3.1. Ethical Impetus for Advance Directives

Advance directives are a relatively new phenomenon in ethics and in law. Until the middle of the last century they were unnecessary. Advance directives became relevant after developments in medical technology and pharmacology enabled the medical profession to sustain people on various types of life support for extended periods. These advances in medical technology transformed the way people die in North America. Less than a century ago the vast majority of people died at home without medical treatment; today, nearly three-quarters of the population in the U.S. and in Canada die in hospital or in nursing homes. However, the life-sustaining technology that can artificially maintain failing hearts, lungs and kidneys through pacemakers, respirators and dialysis programs is also able to sustain for indefinite periods people who are completely incapable and no longer sentient. Chief Justice Frank Gordon of the Arizona Supreme Court eloquently described the problem that has arisen as a result of these medical advances.

Not long ago, the realms of life and death were delineated by a bright line. Now this line is blurred by wondrous advances in medical technology...[which]...has effectively created a twilight zone of suspended animation where death commences while life, in some form, continues. Some patients, however, want no part of a life sustained only by medical technology. Instead, they prefer a plan of medical treatment that allows nature to take its course and permits them to die with dignity. As more individuals assert their right to refuse medical treatment, more frequently do the disciplines of medicine, law, philosophy, technology, and religion collide. This interdisciplinary interplay raises many questions to which no single person or profession has all the answers.

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50 Lieberson, Advance Medical Directives, supra note 29 at iii – vii.
52 Rasmussen v. Fleming, supra note 5 at 678.
During this period, the medical and legal professions evidenced a growing acknowledgement that patients have the absolute right to direct their medical care.\textsuperscript{53} Medical ethics, which had long accepted the patient's right to refuse treatment,\textsuperscript{54} increasingly acknowledged that respect for autonomy requires health care providers to adhere to a patient's prospective decision to consent to or refuse medical treatment in the event of future incapacity.\textsuperscript{55} Robert Veatch explained the ethical position that had emerged by 1976 as follows:

It is an assault on human dignity to impose treatment on adults despite wishes they clearly and knowledgeably expressed while coherent and competent. They should not be regarded as children who have never made moral judgements of their own just because they have passed into a semiconscious or unconscious state.\textsuperscript{56}

Physicians relinquished their dominance over treatment decision-making grudgingly in view of their expertise.\textsuperscript{57} End-of-life medical cases continued to pit the power and authority of physicians to make decisions about treatment against the role of patients or their families.\textsuperscript{58} However, progressively the concept of patient autonomy prevailed, not as recognition that patients know what is best for them, but because patients are the sole arbiters of what matters to them.\textsuperscript{59}

Another significant change that took place in medical practice and medical ethics which created further impetus for advance directives was the growing acceptance that artificial nutrition and hydration constituted a form of medical treatment that could be refused by

\textsuperscript{53} Norman L. Cantor, \textit{Advance Directives and the Pursuit of Death with Dignity}, (Bloomington and Indianapolis: Indiana University Press, 1993) [Cantor, \textit{Advance Directives}] at 1.

\textsuperscript{54} \textit{Schloendorff v Society of New York Hospital}, 105 N.E. 92,93 (N.Y. 1914)[\textit{Schloendorff}].


\textsuperscript{56} Veatch, \textit{Death, Dying, and the Biological Revolution}, Ibid at 163.


\textsuperscript{58} King, \textit{Making Sense}, supra note 22 at 52.

patients. In 1992, the Council on Ethical and Judicial Affairs of the American Medical Association publicly acknowledged and endorsed the right of competent patients to forego life-sustaining treatment and rejected “the idea that it is never permissible to forego artificial nutrition and hydration” or that “there is an ethically significant distinction between withholding and withdrawing life-sustaining treatment.” 60 Consequently, health care providers increasingly accepted that people could specify their wish to forego life sustaining treatment, including life-sustaining nutrition and hydration, in the event of future incapacity.

The growing acceptance of patient autonomy as the touchstone for medical treatment decisions paired with the wish of many patients to decide in advance to forego aggressive treatment if they were to become permanently incapable raised questions for society that continue to be highly contentious. 61 Olick explains that “[b]eneath the surface of debate about advance directives is a shared disquiet with the ambiguity and uncertainty involved in end-of-life decisions.” 62

These dramatic changes in medicine and in medical ethics created ethical challenges for hospitals, doctors, and patients who sought advice to help them resolve difficult life and death questions. The earliest advisors to hospitals respecting end-of-life treatment cases were not physicians, lawyers or bioethicists, however; they were religious advisors. 63

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60 Council on Ethical and Judicial Affairs, American Medical Association, “E2.20 Withholding or Withdrawing Life-Sustaining Medical Treatment”, Issued March 1981 (former Opinion 2.11, “Terminal Illness”) and December 1984 (former Opinion 2.19 “Withholding or Withdrawing Life-Prolonging Medical Treatment: Patient’s Preferences”). In 1989, these Opinions were renumbered 2.20 and 2.21, respectively. Updated June 1994 based on the reports, “Decisions Near the End of Life” (1992) 267 JAMA, 2229 – 2233 and “Decisions to Forego Life-Sustaining Treatment for Incompetent Patients” both adopted June 1991 and updated June 1996. [In March 1981, the Council on Ethical and Judicial Affairs issued Opinion 2.11, “Terminal Illness”. The Opinion was renumbered 2.15 in 1984 and was deleted in 1986. In March 1986, the Council on Ethical and Judicial Affairs adopted its policy statement, “Withholding or Withdrawing Life-Prolonging Medical Treatment.” This statement was later included as Opinion 2.18 (1986), now Opinion 2.20.] Code of Medical Ethics, (Chicago: American Medical Association, 1998).


62 Olick, Taking Advance Directives Seriously, Ibid.

63 Lieberson, Advance Medical Directives, supra note 29 at iv.
schools to make decisions regarding whether to terminate life-sustaining treatment. Initial hospital decision-making for such cases is thus infused with modern Judeo-Christian attitudes about how and whether to end the life of a person being sustained on artificial life supports.64 The withdrawal of artificial nutrition and hydration, in particular, has attracted significant religious commentary and criticism.65 The ongoing debate about the morality of withholding artificial nutrition and hydration has been exacerbated for Catholics by a recent change in the position of the Catholic Church regarding whether such treatment is to be considered medically “extraordinary”. In 2004 the late Pope John Paul II advised:

I should particularly like to underline how the administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act. Its use, furthermore, should be considered, in principle, ordinary and proportionate, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.[emphasis in original]66

The opinion expressed by Pope John Paul II differs from that of Pope Pius XII who explained in 1957 that medical practitioners were not morally required to provide care that would be burdensome to patients. Pope Pius XII stated “...morally one is held to use only ordinary means ...”, but that extraordinary means (assumed at that date to include artificial water and food) could be foregone if fatal or terminal illness threatened.67

Although medicine and medical ethics were undergoing dramatic changes, the law was slower to address these changes. The next section considers development of the law governing advance directives.

64 Ibid.
66 Ibid at 2.
67 The Pope Speaks: Prolongation of Life (1957) 4 Osservatore Romano 393-8
3.2. Legal Development of Advance Directives

3.2.1. U.S. Legal Development

During this transformative period in medicine, legal scholars were pondering the type of document that could meet the needs of citizens to direct their future care. In 1969, Luis Kutner, a human rights attorney described as the “father of the living will” set out a proposal for the living will in which he argued that the patient’s right to refuse treatment should be extended beyond the point where the patient is no longer competent to consciously refuse treatment. Kutner offered a wide variety of titles to a document that would refuse consent to treatment in certain circumstances after the patient became incompetent, including “living will”, “declaration determining the termination of life”, “testament permitting death”, “declaration for bodily autonomy”, “declaration for ending treatment”, and “body trust”. Kutner couched the legality of the proposed document, as well as all of the proposed names, in terms of trust law, explaining the “living will is analogous to a revocable or conditional trust with the patient’s body as the res, the patient as the beneficiary and grantor, and the doctor and hospital as the trustees. The doctor is given authority to act as trustee of the patient’s body by virtue of the patient’s consent to treatment … the patient is free at any time to revoke the trust...”. Consequently, Kutner presumed the trust was founded upon the doctrine of consent to treatment. However, he was quite clear that the patient could not use a living will to authorize the commission of euthanasia on the grounds that, in keeping with the Law of Trusts, a living will could not violate public policy.

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68 Lieberson, Advance Medical Directives, supra note 29 (“...Luis Kutner, the father of the living will, introduced the concept.”) at 38; King, Making Sense, supra note 22 (“The term “living will” was coined in 1969 by Luis Kutner”) at 256 n2.


70 Ibid at 551.

71 Ibid at 552.

72 Ibid at 553.
In a subsequent article, Kutner abandoned the trust analogy and focused on the doctrine of consent to treatment and the right to self-determination as the legal and ethical foundations for the living will, explaining the basis of the Living Will to be informed consent, non-interference with liberty of action and the right of each individual to privacy. In a frequently quoted passage, he states:

The intelligent approach to life is that it is a beautiful phenomenon of sentient beauty encased in a fleeting vulnerable body. The individual must be free to elevate his personal life, exercise moral restraint, and determine his right of privacy.

At the time of Kutner’s proposal, U.S. common law had long recognized the patient’s right of self determination with respect to medical treatment. Justice Cardozo’s famous words in *Shloendorff v Society of New York Hospitals* that “Every human being of adult years and sound mind has a right to determine what shall be done with his own body…” were foundational to the doctrine and often repeated. Similarly, it was well accepted “in medical ethics in particular and bioethics in general that the competent adult patient has the final say in his or her own medical care”. Nevertheless, according to Leiberson, Kutner’s concept “increased fear that living will legislation was a step down the slippery slope to euthanasia and induced antagonism of right-to-life supporters. This fear remains.”

The first advance directive legislation was proposed in Florida in 1968 by Dr. Walter Sackett, a doctor elected to the Florida legislature. The highly contentious bill proposed not only to provide competent adults the means to determine medical treatment in the event of a terminal illness, but also the withholding of medical treatment for “hopelessly retarded wards of the state” if they contracted any illness including infections that, left

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74 Ibid at 41.
75 Supra note 54.
77 Lieberson, *Advance Medical Directives*, supra note 29 at 32.
78 Glick, *Policy Innovations*, supra note 7 at 104.
untreated, would lead to death.\textsuperscript{79} The proposals inflamed advocates for the disabled, the right to life groups and the Florida Catholic Conference (FCC) but the bill was so extreme that heavy lobbying against it was unnecessary and it died in house committee for three successive years.\textsuperscript{80} A revised living will bill that did not mention the mentally retarded and only provided advance directive rights to competent adults was approved by the Florida House Judiciary Committee and sent to the Senate in 1973. The bill died on the Senate Calendar with the FCC taking credit for lobbying the conservative Florida Senate members to defeat the bill.\textsuperscript{81}

After the defeat of the 1973 Florida proposal, the American Medical Association announced its opposition to living wills, encouraging traditional medical decision-making.\textsuperscript{82} Similar bills to the 1973 version were introduced in Florida but were defeated in the face of strong lobbying by the right to life and religious organizations who argued that the bill was the first step towards a program of eugenics. According to Henry Glick, the FCC characterized the proposals as “mercy killing and similar to Nazi policies on euthanasia for the mentally and physically deformed. Repeatedly, living wills were described as the “first step on the slippery slope to active euthanasia” for the elderly and “other unwanted groups”\textsuperscript{83}. Although the FCC was generally willing to consult and debate, some extreme right-to-life groups linked the bill to declining respect for life and predicted apocalyptic outcomes, including “the injection of birth control drugs into the nation’s water supplies, cannibalism which would result from using the bodies of those selected to die to feed the hungry, and more”\textsuperscript{84}

Concomitantly, Barry Keene, a California State Senator, introduced a similar bill to the California legislature in 1974 where it also was defeated. The California bill was introduced again in 1976 and on its passage the \textit{Natural Death Act}\textsuperscript{85} became the first

\textsuperscript{79} Ibid at 106.
\textsuperscript{80} Ibid.
\textsuperscript{81} Ibid at 107.
\textsuperscript{82} Ibid at 108.
\textsuperscript{83} Ibid.
\textsuperscript{84} Ibid.
\textsuperscript{85} California Health and Safety Code §§7185-7195 [NDA].
statute to grant immunity to health care providers who honoured advance directives. Glick suggests that the greater “diversity and liberalism” of California compared to Florida’s “greater homogeneity and conservatism” was a primary cause for the passage of the bill in that state.\(^{86}\) The public desire to have legal authority for advance directives was clearly apparent across the United States at that time, however, since forty-three states considered advance directive legislation within a year of the passage of the California legislation, and seven states passed bills.

Although Kutner and others had urged lawmakers to “generate adequate legal measure to permit a dignified death”, Lieberson believes that the premature emphasis on statutory advance directives was unfortunate in that, in his opinion, the common law is “more suited to defining individual rights which may be opposed by large constituents of voters”.\(^{87}\) He described the California *Natural Death Act* as having been “hastily drafted without common law precedents” and explains that its original weaknesses were nonetheless copied by other states, thus slowing the proper evolution of the statutes.\(^{88}\) Lieberson argues that the original drafting was driven by physicians’ fears of malpractice suits, as evidenced by the initial declaration, which states “…the legislature further finds that there exists considerable uncertainty in the medical and legal professions as to the legality of terminating the use of application of life sustaining procedures…”\(^{89}\)

The final words of the declaration enabled an adult to “…make a written directive instructing his physician to withhold or withdraw life-sustaining procedures in the event of a terminal condition”.\(^{90}\) The definition of “terminal condition” was interpreted to be a limiting provision which restricted the application of an advance directive to a condition in the patient where death was imminent regardless of whether life-sustaining procedures

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\(^{86}\) Glick, *Policy Innovations*, supra note 7 at 107

\(^{87}\) Lieberson, *Advance Medical Directives*, supra note 29 at 43.

\(^{88}\) Ibid at 44.

\(^{89}\) Ibid at 44-45.

\(^{90}\) Ibid at 45.
were utilized. Lieberson argues that such an interpretation defeated the very purpose of the advance directive.\textsuperscript{91}

Meisel and Cerminara suspect that "[r]ecognition of the difficulties inherent in living wills is probably responsible for the increased popularity of proxy directives."\textsuperscript{92} They point out that proxy directives can be exceptionally helpful when medical circumstances differ from those anticipated by the maker of an instructional advance directive and, in general, can provide greater flexibility for decision-making. But they also caution that:

\begin{quote}
there are pitfalls in proxy directives, too, the potentially most serious ones being that the proxy might act contrary to the patient’s wishes or have no idea what medical treatment the patient would have wanted. Although proxy directives are advantageous to health care professionals because they identify the patient’s surrogate decisionmaker, a proxy directive may merely shift the burden of the uncertainty concerning the patient’s wishes from health care professionals to the proxy.\textsuperscript{93}
\end{quote}

The preference for a proxy advance directive to an instructional advance directive can also be seen as a means of providing certain protections to the incapable patient. Protection of the patient rather than deference to patient autonomy was apparently the impetus behind the decision of New York State to implement legislation that solely recognizes a proxy advance directive.

In the 1980’s the State of New York considered and rejected the option of enacting living will legislation in favour of solely enacting proxy directive legislation. Beginning in 1985, a New York State Task Force [Task Force] sought information from hospitals, health care facilities and physicians in New York State on the degree to which they respected living wills. Finding that support for living wills was exceptionally low among these respondents, the Task Force recommended against enacting legislation that would

\textsuperscript{91} Ibid at 46.
\textsuperscript{92} Meisel & Cerminara, \textit{The Right to Die}, supra note 20 at 7-11.
\textsuperscript{93} Ibid at 7-12.
recognize a living will.\textsuperscript{94} It is interesting to consider the legal analysis carried out by the members of the Task Force in that it diverged from the growing emphasis on respect for personal autonomy in legal and medical ethics.

The Task Force effectively decided to rely on the common law legitimacy of living wills as evidence of the "clear and convincing proof" required by New York courts regarding a patient's wishes to forego life-sustaining treatment, and to recommend against formalizing that legitimacy in legislation.\textsuperscript{95} The Task Force Report includes an interesting Minority Report that emphasizes the importance of the concept of liberty advocated by John Stewart Mill in preference to the progressively more frequent adoption of the self-determinism doctrine espoused by Justice Cardozo in the famous \textit{Schloendorff}\textsuperscript{96} case.\textsuperscript{97} Invoking Mill’s argument that the principle of freedom cannot require that a person should be free not to be free, the Task Force Minority Report concluded that "[a] person cannot invoke a right to liberty as justification for being permitted to dispose of his own life."\textsuperscript{98}

Despite its acknowledgement that there was great interest among the people of New York for the ability to direct their treatment wishes,\textsuperscript{99} the Task Force was clearly influenced by opinions in favour of protection and preservation of life. They concluded that "the value of patient autonomy must be balanced with other important social concerns. In seeking to achieve this balance, society must move forward with caution and thoughtful concern."\textsuperscript{100} The Task Force concluded that "[t]he health care proxy has been widely recognized as the best vehicle to provide this protection and extend the individual's participation in health care decisions beyond the loss of decision-making capacity."\textsuperscript{101}

\textsuperscript{95} Ibid at 27.
\textsuperscript{96} Supra note 54.
\textsuperscript{97} New York Task Force, supra note 80 at 52-53.
\textsuperscript{98} Ibid at 53.
\textsuperscript{99} Ibid at 5-6.
\textsuperscript{100} Ibid at 40.
\textsuperscript{101} Ibid at 139.
Greater comfort with the proxy advance directive is reflected by its rapid enactment throughout the U.S. Meisel and Cerminara note that today “[a]ll states have enacted statues to provide an explicit basis for the issuance of proxy directives”. 102

Three uniform statutes have been drafted in the U.S. related to medical decision-making, but only one, the *Uniform Rights of the Terminally Ill Act* 103 [URTIA] which dealt solely with living wills, significantly affected advance directive legislation. 104 Meisel and Cerminara comment that:

> The URTIA is designed to be narrow in scope; its application is intended to be limited to instances involving life-prolonging treatment and patients who are in incurable and irreversible terminal conditions, who will soon die and who are unable to participate in treatment decisions. 105

The National Conference of Commissioners subsequently drafted new uniform legislation, the *Uniform Health Care Decisions Act* [UHCDA] 106, which is more comprehensive legislation, addressing the designation of proxies and of surrogates for individuals who do not appoint proxies. Although the UHCDA was intended to supplant the URTIA in those states which had implemented the former legislation, the UHCDA has only been implemented in a small number of states. 107

Medical professionals are regularly warned to be aware of the specific legal requirements in their jurisdiction to ensure that a directive is valid, leading to medical distrust of advance directives. 108 Provisions that vary between U.S. statutes frequently concern matters that are seen to be related to euthanasia, such as the withdrawal of artificial nutrition and hydration. Proxies are frequently held to trump living wills, presumably in

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105 Ibid at 7-55.
107 Meisel & Cerminara, *The Right to Die*, supra note 20 at 7-52
order to ensure that a directive to forego life-sustaining treatment is not rashly followed. For example, Krohm and Summers advise medical professionals to:

[n]ote well that some jurisdictions (Illinois and Missouri, for example) do not permit the withdrawal of artificial hydration and nutrition under the terms of a living will if such withdrawal (rather than the terminal condition itself) would be the cause of death. On the other hand, enabling legislation for powers or proxies in forty-one states, specifically authorize the agent to withhold sustenance. This issue is not addressed in Arkansas, California, the District of Columbia, Kansas, Massachusetts, Michigan, Montana, North Dakota, Rhode Island, and Wyoming. Refer to applicable statute. ... Be especially alert to possible overlaps and conflicts between living wills and durable health care powers or health care proxies. Some jurisdictions (for example, Alabama and Georgia) provide that both may be executed, with the power taking precedence if there is an agent available and ready to act.109

Brody et al comment that some states have begun to draw definitions of terminal and irreversible conditions more narrowly,110 reflecting greater state intervention to prevent death through cessation of treatment.

With respect to revocation, Brody et al explain that “[r]eflecting the state’s interest in preserving life, living will statutes also provide for revocation of the living will regardless of whether the patient’s revocation is competent”.111 Similarly, Krohm and Summers warn practitioners to “[b]e aware that powers and proxies are predicated on the most gossamer and fleeting of consents. ... If revoked, it is over – no matter how incongruous or implausible or inopportune or irrational the revocation may seem to be.”112

It is not within the scope of this thesis to consider all of the significant jurisprudence decided in the U.S. concerning advance directives. It is important, however, to comment on two cases which dramatically gripped the attention of the U.S. public and formulated

109 Ibid at 11.
110 Brody, Medical Ethics, supra note 76 at 268.
111 Ibid.
112 Krohm & Summers, Advance Health Care Directives, supra note 27 at 10.
legal doctrine respecting the correct balance to be drawn between patients' rights to refuse life-sustaining medical treatment and the state's interest in preserving life: *In re Quinlan* [*Quinlan*] and *Cruzan v Director, Mo. Dept. of Health* [*Cruzan*].

There are many similarities in the facts of the *Quinlan* and *Cruzan* cases. Both cases involved young women who had suffered an accident which caused them to fall into a diagnosed permanent vegetative state (PVS). In both cases, the parents of the young women brought actions to have life-sustaining treatment terminated. In neither case had the young women made a written advance directive.

*Quinlan*, a decision of the New Jersey Supreme Court, was the first reported appellate end-of-life case in the U.S. The *Quinlan* decision highlights the legal and ethical positions adopted by physicians and by States in 1976, the same year in which the California *Natural Death Act* was passed. The physicians argued that the decision to remove Karen Quinlan's respirator was "within the exclusive province of the medical profession". The State of New Jersey argued that there was no constitutional right to die and there was a compelling State interest in preserving life. The New Jersey Supreme Court recognized those competing interests, but held they were insufficient to outweigh the patient's constitutional right to refuse treatment. The court in *Quinlan* held that the constitutional right to refuse treatment is based on the right to privacy. The patient's constitutional privacy right to refuse treatment must be balanced, however, against the competing State interests in preserving life, preventing suicide and safeguarding the integrity of the medical profession, and "...the State's interest contra weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims."

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114 *Cruzan supra* note 1.
116 *NDA Supra* note 85.
118 *Supra* note 113 at 41.
The *Quinlan* case is particularly important for establishing the concept of “substituted judgement” as the basis for surrogate decision-making. According to Robert Olick, a clear message from *Quinlan* was that the ultimate decisional authority rests with the patient and family, rather than with the physician.\(^{119}\) Olick explains:

> [S]ubstituted judgement is widely and properly viewed as an autonomy-based doctrine because it gives the patient’s previously expressed wishes and values priority ranking in deciding for incompetent patients. A surrogate’s primary task is to ascertain and effectuate what the patient would want; best-interest assessments are supplementary and should be patient-centered and made from the patient’s point of view to the extent possible. *Quinlan*’s recognition of an incompetent patient’s autonomy-based right to refuse treatment, together with the court’s practical approach of looking to close family to reconstruct the patient’s prior expressions and values, planted the seeds for rapid evolution of the principle of prospective autonomy in end-of-life decisions.\(^{120}\)

Other authors describe the substituted judgement standard as “controversial”.\(^{121}\) Nancy King explains that “[t]here are obvious problems with using the substituted judgement standard ... [and] almost before the ink was dry on the *Quinlan* decision, courts and commentators began attempting to reformulate, rehabilitate, or replace it”.\(^{122}\) The issue of substitute decision-making is discussed in greater detail in Chapter Three, below.

The *Cruzan* case, decided in 1990, was the first end-of-life case to be decided by the U.S. Supreme Court. Nancy Cruzan’s parents, who were her court-appointed guardians, had reached the conclusion that Nancy would not want to remain alive in her PVS condition and asked to have the feeding tube that kept her alive disconnected. The State of Missouri argued that nutrition and hydration could not be removed from a terminally ill person unless there was “clear and convincing evidence” of that person’s authorization for such termination prior to his or her incapacity. The U.S. Supreme Court had to decide

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\(^{119}\) Olick, *Taking Advance Directives Seriously*, supra note 61 at 5.

\(^{120}\) *Ibid* at 7.

\(^{121}\) King, *Making Sense*, supra note 22 at 189.

\(^{122}\) *Ibid* at 191.
if the U.S. Constitution prohibited Missouri from requiring this standard of proof. The Court held that it did not: the Missouri requirement did not violate any hypothetical constitutional liberty interest. Meisel and Cerminara explain the precise finding in the Cruzan decision as follows:

The Court’s precise holding, grounded in the Fourteenth Amendment’s guarantee of liberty, rather than in the right of privacy, is narrow and simple: the Constitution permits a state to require the rendition of life-sustaining treatment to an incompetent patient unless there is clear and convincing evidence that the patient authorized the forgoing of the treatment prior to losing decisionmaking capacity.[footnotes omitted].

Ronald Dworkin comments about the Cruzan decision that, although the Supreme Court upheld the onerous Missouri requirement, “a majority of the justices, for the first time, recognized that competent people do have a constitutional right to direct that life support be withheld from them if they become permanently vegetative”. He notes that a number of U.S. states revised their laws after the Cruzan decision and every state now has some form of advance directive legislation honouring instructional advance directives, proxy advance directives or both. While a number of states require clear and convincing evidence of a patient’s preference to forego life-sustaining treatment before such treatment can be withheld, Meisel and Cerminara point out that the only other State apart from Missouri to require the identically stringent test of “clear and convincing” evidence that the patient personally authorized cessation of treatment is New York State.

Brody et al explain that

[i]n the aftermath of the Cruzan decision, Congress enacted the “Patient Self-Determination Act,” which became law in December 1999. The act provides that hospitals and nursing homes receiving federal funding...must have written policies and

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124 Dworkin, Life’s Dominion, supra note 59 at 188.
125 Ibid, and see Meisel & Cerminara, The Right to Die, supra note 20 at 7-7.
procedures explaining how adult patients will be given information about their decisionmaking rights upon admission to the facility [footnote amended].

The *Cruzan* case cannot be read expansively, however, to include a right to physician-assisted suicide. In the subsequent twin cases of *Washington v Glucksberg* and *Vacco v Quill*, the U.S. Supreme Court reversed claims from the second and ninth U.S. circuits that the "liberty interest recognized in *Cruzan* was based on personal autonomy" and held that there is a distinction between killing and letting die. The Court found no constitutional right to physician-assisted suicide but also found no constitutional barrier to the states creating such a right. Meisel and Cerminara find it "unlikely" that the *Glucksberg* and *Vacco* decisions will be the last word on this issue. However, Oregon is the only state to have implemented a statute to legalize physician-assisted suicide.

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128 Brody, *Medical Ethics*, supra note 76 at 266.
133 Brody, *Medical Ethics*, supra note 76 at 289.
135 *Death With Dignity Act*, Or.Rev. Stat. §§ 127.800 to 127.995 (The Oregon statute recently withstood legal attack from former Attorney General John Ashcroft who brought a petition in 2001 arguing that the prescription of narcotics by physicians to enable patients to commit suicide was in violation of the *Controlled Substances Act*, 1970, 21 U.S.C. §§ 801-904. In May 2004, the 9th Circuit Court of Appeals ruled in favour of the state legislation and found the Attorney General’s position wrongly interfered with state power over the regulation of medicine. In February 2005 the U.S. Supreme Court agreed to hear an appeal from the decision of the 9th Circuit Court of Appeals. The S.C. decision in *Gonzales v Oregon* is expected to be rendered in 2006. The Attorney General’s original petition argued that allowing physicians to provide aid-in-suicide was inconsistent with their role as healers.)
3.2.2. **Canadian Legal Development**

There is no question that consideration of advance directive legislation in Canada was greatly influenced by legislative examples from the U.S. The first proposal in Canada for advance directive legislation was an Ontario Bill introduced in 1977 entitled *An Act Respecting the Withholding or Withdrawal of Treatment Where Death is Inevitable*.\(^{136}\) This Bill, presented by a private Member, was closely modelled on the 1976 California *Natural Death Act*\(^{137}\) and included many of the same restrictions found in that legislation, such as suspension of the direction during pregnancy, the requirement for confirmation that the patient be “terminal” by two physicians, application only to legal adults and a limitation on the time period of its effect.\(^{138}\) The Ontario Government seriously considered enacting the 1977 Bill.\(^{139}\) On Second Reading the legislature approved the Bill by a sizeable majority but a provincial election intervened and terminated further consideration, so the Bill was not passed.\(^{140}\) Subsequent similar legislation was put forward but was not pursued by the Ontario Legislature because the Ontario Ministry of Health then announced the intention to draft its own legislation.\(^{141}\) However, advance directive legislation was not passed in Ontario until 1992 when the *Substitute Decisions*

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\(^{137}\) Supra note 85.

\(^{138}\) Similarly in Alberta, a member of the legislature tabled a private member’s Bill on three occasions, in 1977, 1978 and 1979, which was modelled on the California *Natural Death Act*. In common with the Ontario Bill, the proposed legislation in Alberta, which was not passed, would apply only to terminally ill patients and the living will required re-execution every five years to remain valid. It is clear that Alberta health care providers were interested in the implementation of living will legislation, however, since the Alberta Healthcare Association passed a resolution in 1990 calling for the introduction of living will legislation in the province. Alberta, Alberta Law Reform Commission, “Advance Directives and Substitute Decision-Making in Personal Health Care, Report for Discussion No. 11”, (Edmonton: Alberta Law Reform Institute, 1991) [Alberta, “Report No. 11"] at 28.

\(^{139}\) Dickens, *Right to Natural Death, supra* note 136 at 874.

\(^{140}\) Ibid; Another private member’s Bill modeled on the California Legislation, Bill 8, the *Natural Death Act*, was introduced to the Ontario Legislature in 1990 and received second reading on April 11, 1991, but further debate was deferred when the Government intervened with its own proposed legislation on May 27, 1991: see Ontario Hansard, June 20, 1991, at 2195; see also Dickens, *Right to Natural Death, supra* note 136 at 873.

\(^{141}\) Dickens, *Right to Natural Death, ibid.*
Act \(^{142}\) [SDA] was enacted. The SDA does not recognize instructional advance directives; the legislation only provides authority for proxy advance directives.

In his analysis of the 1977 Ontario Bill, Professor Dickens questioned whether the proposed legislation offered less, rather than more, protection to individuals than existed at common law.\(^{143}\) He concluded that the proposed legislation was unnecessary for legal purposes and might have the effect of shrinking patients’ common law rights.\(^{144}\) Professor Dickens’ opinion is similar to that offered by Professor Alan Lieberson, who opined in connection with U.S. advance directive legislation that the common law has a greater chance for ensuring respect for individual rights than does the typically narrowly drafted legislation.\(^{145}\)

Professor Dickens is not entirely opposed to the concept of advance directive legislation, however, in view of the non-legal benefits which might be achieved, “since an Act which does nothing more than declare present law would at least bring it more visibly to the attention of the public and especially of the medical and hospital communities.”\(^{146}\) Following his reasoning, advance directive legislation should, at the least, enshrine existing rights rather than limit them. Fortunately, the legislation that has been enacted in Canada since the first attempts in Ontario and Alberta in 1977 has avoided enshrining many of the most restrictive provisions prevalent in U.S. statutes, such as the narrow definition of “terminal condition” that must be met before the directive becomes effective. The Canadian legislation is not, however, without problems. Some of the limitations of the Canadian provincial advance directive legislation are discussed in more detail in Chapter Four below.


\(^{143}\) Dickens, *Right to Natural Death*, supra note 136 at 873.

\(^{144}\) Ibid, at 873-876.

\(^{145}\) Lieberson, *Advance Medical Directives*, supra note 29 at 44; and see supra note 87 and accompanying text.

\(^{146}\) Dickens, *Right to Natural Death*, Supra note 136 at 873.
Many of the Canadian provinces began to consider advance directive legislation, beginning in the late 1980's and early 1990's. The first advance directive legislation implemented in Canada was enacted in Nova Scotia in 1988 as the *Medical Consent Act*. It is possible that the Nova Scotia legislature was influenced by the 1987 New York Task Force Report, since the Nova Scotia *Medical Consent Act* only permits proxy advance directives, in common with New York. In its Report for Discussion No. 11 on Advance Directives, the Alberta Law Reform Institute noted:

> On third reading of the Bill in the Nova Scotia legislature, the official opposition indicated that it would not support the Bill, because though well intentioned it was “poorly drafted” and would probably be challenged successfully in the courts: see Nova Scotia Hansard, May 24, 1988, at 3934.

Despite subsequent recommendations of the Law Reform Commission of Nova Scotia to amend the legislation to include recognition of instructional advance directives and combination advance directives, no amendment has been made to the *Medical Consent Act* as of December, 2005.

During the early 1990's, the Law Reform Commissions of several provinces issued formal reports recommending advance directive legislation. At the date of writing, all of the Canadian provinces except New Brunswick have enacted some form of advance directive legislation, as has Yukon Territory. However, there is no equivalent to the U.S. model advance directive legislation in Canada. The Canadian provinces have not agreed upon uniform legislation. Consequently, the advance directive statutes in those provinces and territories which have enacted legislation use different terminology and include provisions that vary substantially from one another.

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147 See e.g. Alberta, “Report No. 11” supra note 138.
148 R.S.N.S. 1989, c. 279.
149 New York Task Force, supra note 94.
150 Alberta, “Report No. 11” supra note 138 at 33 fn 114.
153 See Chapter Four below for further discussion on the Canadian provincial advance directive legislation.
The law in Canada reflects, to a great degree, the same struggle between the competing interests of patient autonomy and the protection and preservation of life that is evident in the U.S. legislation. This struggle is depicted clearly in the B.C. legislation, the RAA, which is significantly different in form, and substantially more onerous in execution, than advance directive legislation in any other jurisdiction in the country. The B.C. RAA is innovative legislation that offers an unusual hybrid instrument for end-of-life planning that combines the concept of an enduring power of attorney for financial matters with a personal directive for health care and a proxy advance directive for consent to treatment. This proposed form of advance directive provided under the RAA fuses two types of future planning documents, leading to a legally confused result. The legislation was drafted to ensure protection for the vulnerable and creates such onerous legal hurdles that it effectively forestalls widespread understanding and acceptance.154 More than any other provincial advance directive legislation, the RAA reflects discomfort with the concept of the advance directive.155

However, other provinces similarly restrict choice, patently out of paternalistic concern for citizens. Ontario, in similar fashion to B.C., has adopted the legislative position that the appointment of a substitute decision maker is always preferable to enabling a maker to create an instructional advance directive. A document published by the Advocacy Centre for the Elderly for Ontario explains that:

There is no reference to “advance directives” or “living wills” in the Ontario legislation. ... For a written document to give authority to appoint a substitute decision maker ...the document MUST be a Power of Attorney for Personal Care and not just an “advance directive”.156

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155 See Chapter Five below for further discussion on the RAA.
Judith Wahl of the Advocacy Centre for the Elderly further explains that:

[I]t must be recognized that some people do not want to create an advance directive. It may not be culturally appropriate or fit into their personal system of beliefs. That is one of the reasons that the provincial legislation was drafted to ensure that everyone in the province had a substitute decision-maker. ...The health care professionals need not rely on paper documents like advance directive forms or struggle with trying to interpret a patient’s wishes, however drafted, however expressed. The hospital/facility cannot remove this freedom of expression nor override the role of the substitute in giving direction if the patient is not capable of giving or refusing consent to treatment.157

While it is true that hospitals in Ontario cannot remove freedom of expression for a substitute to interpret or convey a patient’s wishes, it is also true that the Ontario provisions deny a patient the freedom to simply document his or her wishes and expect those wishes to be followed without having to designate a proxy. Some people may have no close relation or friend to designate as a proxy, or may not want to designate a proxy, but in Ontario as in B.C., they have no choice but to do so if they wish to convey their preferred treatment instructions in the event of incapacity.

A major obstruction to development of advance directive law in Canada is the uncertainty created by Criminal Code158 provisions that apparently make health care practitioners criminally liable for terminating life-sustaining treatment on the instruction of an advance directive. Over the last three decades numerous recommendations have been made to the Federal Parliament to amend the Criminal Code to eliminate uncertainty over physician liability for following an advance directive. Unfortunately, all entreaties to federal Parliament to amend the Criminal Code have been unsuccessful, so that the uncertainty in Canada regarding the potential legal liability for health care providers who follow an advance directive remains extant.159 In view of Parliament’s failure to amend the Criminal Code, the Senate attempted to pass a bill to limit criminal liability for medical

157 Ibid at 10.
158 Criminal Code, supra note 9.
159 See Chapter Four below for further discussion regarding recommendations for Criminal Code amendment.
practitioners.\textsuperscript{160} Although the bill went to second reading in the Senate, it died on the Order Paper in 2000.

More than twenty years ago the Law Reform Commission of Canada argued that the mere fact that legal proceedings had not been brought against medical practitioners who had withheld or withdrawn treatment from dying patients should not be considered adequate comfort to the medical profession since “the present policy of not laying charges could change under the pressure of events”\textsuperscript{161} In their view “[t]he question is far too important and far too fundamental to be left in such a state of uncertainty”.\textsuperscript{162} Unfortunately, this state of uncertainty remains more than two decades later.

The common law governing advance directives in Canada has been greatly influenced by two cases, both delivered by the Ontario Court of Appeal. The first of these, the 1990 case of \textit{Malette v Shulman}\textsuperscript{163} is the hallmark of judicial recognition of advance directives in Canada. Mrs. Malette brought an action against a doctor who treated her while she was unconscious with life-threatening injuries, and who provided a life-saving blood transfusion, although the doctor was aware of a signed Jehovah’s Witness medical alert card in her purse refusing blood. Citing the U.S. decision of \textit{Schloendorff v. Society of New York Hospital}\textsuperscript{164} as the essential statement of the principle that no medical procedure can be undertaken without the patient’s consent, the Ontario Court of Appeal held that the patient’s right to refuse treatment, regardless of the outcome to her life or health, outweighed the state interest in preserving life and health and protecting the integrity of the medical profession. Although the court attempted to confine the decision to the facts of the case, and not to extend its application to an advance directive or living will, the

\textsuperscript{160} Canada, Bill S-2, \textit{An Act To Facilitate The Making Of Legitimate Medical Decisions Regarding Life-Sustaining Treatments And The Controlling of Pain}, 2\textsuperscript{nd} Sess., 36\textsuperscript{th} Parl., 1999 (1\textsuperscript{st} reading October 13, 1999).
\textsuperscript{162} \textit{Ibid}.
\textsuperscript{163} \textit{Malette, supra} note 1.
\textsuperscript{164} \textit{Schloendorff, supra} note 54.
The Malette case has subsequently been understood to confirm the legal status of advance directives in Canada.\textsuperscript{165} Barney Sneiderman explains:

After Shulman, \cite{Malette} it was generally accepted that, if a patient is legally allowed on religious grounds to refuse treatment that holds the promise of restoring his or her health, then the law as a matter of course would allow the refusal of life-prolonging treatment by a patient who had come to regard life as no longer worth living. Furthermore, although Shulman is a civil case, its holding would have the same implications in a criminal case because, after all, treating a patient against his or her will is not only the tort of battery but also the crime of assault.\textsuperscript{166}

The second case, Fleming \textit{v} Reid,\textsuperscript{167} examined whether the state was entitled to administer neuroleptic drugs in a non-emergency situation to involuntary incompetent psychiatric patients who previously, while competent, expressed the wish not to be treated with such drugs. The Ontario Court of Appeal again upheld the validity of the advance directive refusing treatment and decided that it would be a deprivation of security of the person, in violation of S. 7 of the \textit{Canadian Charter of Rights and Freedoms}\textsuperscript{168} [Charter], to impose treatment on incompetent patients that they had refused when competent. The Fleming case is a strong statement in Canadian law confirming the Charter rights of patients to have their advance directives, expressed while competent, upheld during a subsequent period of incapacity.

The Malette case was referred to approvingly in the Supreme Court of Canada (SCC) case of Rodriguez \textit{v} British Columbia (Attorney General),\textsuperscript{169} in which Sopinka, J. also referred to the previous SCC decision of Ciarlareillo \textit{v} Schacter,\textsuperscript{170} in explaining that both cases confirmed the right of patients to refuse treatment or to demand that it be withdrawn or discontinued, even if the withdrawal or refusal will result in death.\textsuperscript{171}

\begin{footnotes}
\item[\textsuperscript{165}] See Sneiderman [Decision-Making] \textit{supra} note 37 at 503.
\item[\textsuperscript{166}] \textit{Ibid.}
\item[\textsuperscript{167}] Fleming, \textit{supra} note 11.
\item[\textsuperscript{168}] Charter, \textit{supra} note 12.
\item[\textsuperscript{169}] Rodriguez, \textit{supra} note 1.
\item[\textsuperscript{170}] [1993] 2 S.C.R. 119.
\item[\textsuperscript{171}] Rodriguez, \textit{supra} note 1 at 598.
\end{footnotes}
These cases were instrumental in confirming the legal right of Canadians to have their prospective instructions for health care respected, regardless of the existence of statutory authority for advance directives. Prior to the issuance of the Malette and subsequent cases, the law was very unsettled. For example, a Joint Report of the Alberta Law Reform Institute and the Health Law Institute published in 1993 included as one section of the summary of the law in this area that:

3. It is generally assumed that an advance healthcare directive (often referred to as a “living will”) has no legal force in the absence of legislation, but recent case-law from Ontario* casts significant doubt on this assumption. The position under Alberta law remains uncertain. [* Footnote referring to the Malette and Fleming cases omitted.]

Prior case law in Canada had left uncertainty on this issue. For example, the decision of Procureur Général du Canada c. Hôpital Notre-Dame et Niemiec held that a prisoner who refused feeding by placing a metal wire in his throat did not have the right to have his treatment refusal respected and was rightfully subjected to force-feeding. A similar case in B.C., British Columbia (Attorney General) v. Astaforoff held the contrary result, finding that corrections authorities in B.C. “did not have a duty to forcibly feed a Doukhobor prisoner on a hunger strike even though she was likely to die without force-feeding”. Professor Jocelyn Downie suggests that the decisions in Malette, Fleming and especially Rodriguez resolve the confusion generated by these earlier cases and confirm “that there is a common law right for adults to refuse potentially life-sustaining treatment.”

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176 Ibid at 21.
A strong argument can be made that the SCC would uphold the legitimacy of an instructional advance directive as a fundamental right under Canadian law. For example, in the seminal case of *Morgentaler v The Queen*, Wilson, J. made the following comments:

"in a free and democratic society the conscience of the individual must be paramount to that of the state. Indeed, s. 2(a) makes it clear that this freedom belongs to each of us individually. "Freedom of conscience and religion" should be broadly construed to extend to conscientiously-held beliefs, whether grounded in religion or in a secular morality and the terms "conscience" and "religion" should not be treated as tautologous if capable of independent, although related, meaning. The state here is endorsing one conscientiously-held view at the expense of another. It is denying freedom of conscience to some, treating them as means to an end, depriving them of their "essential humanity"."¹⁷⁷

However, the SCC has not yet directly considered a case involving the termination of life-sustaining treatment from an incompetent patient despite the reference to *Malette* in the *Rodriguez* case. In particular, the SCC has not considered specifically the legal authority of a living will in a jurisdiction that does not statutorily recognize living wills, such as British Columbia. Also, it is instructive to remember that the SCC determined in *Rodriguez* that the state's interest in preserving life outweighed the *Charter* S. 7 security interests of a dying patient to request assisted suicide. One can conclude that the jurisprudence in Canada respecting advance directives is sparse and the law remains less than perfectly clear.

¹⁷⁷ *Morgentaler*, supra note 5 at 37 (cited to SCR).
4. Conclusions

Advance directives are still a developing legal concept. Some scholars continue to question the basic morality of advance directives\textsuperscript{178} while others argue that they should be limited to authorizing others to speak on behalf of the maker.\textsuperscript{179} Although it seems advance directives have a solid foundation in the doctrine of consent to treatment, in fact the legislation supporting advance directives remains confused and ambiguous and reflects uncertainty about their morality. Meisel and Cerminara advise that the legal status of advance directives continues to be clarified by legislative and judicial developments “in the context of somewhat murky legal origins”.\textsuperscript{180} The overtly restrictive approach taken in much of the advance directive legislation works against their widespread use for future health care planning.

During the last decade, debate has increased about the proper form of advance directives, with some scholars arguing that instructional advance directives, or living wills, have “failed” and should be abandoned in favour of recognizing only proxy directives.\textsuperscript{181} This opinion is reflected in Canadian legislation, such as the RAA and SDA which do not entitle citizens to create instructional advance directives. The debate respecting why instructional advance directives do not constitute a legitimate method for directing future health care choices is analyzed in Chapter Three, below. This thesis argues that instructional advance directives are legally and ethically sound and should be honoured, whether alone or in combination with a proxy directive.

In 1995, a committee of the Canadian Senate held extensive hearings which included consideration of the subject of advance directives. The Special Committee of the Senate on Euthanasia and Assisted Suicide (the Special Committee) heard testimony from

\begin{thebibliography}{181}

\bibitem{179} Fagerlin & Schneider, Enough, \textit{supra} note 3.
\bibitem{180} Meisel & Cerminara, \textit{The Right to Die}, \textit{supra} note 20 at 7-26.
\bibitem{181} Fagerlin & Schneider, Enough, \textit{supra} note 3.
\end{thebibliography}
numerous parties concerning their support for advance directives. In its 1995 Report\textsuperscript{182}, the Special Committee confirmed general endorsement for the concept of the advance directive, including the instructional advance directive, among health care providers and recommended that legislation be implemented in the provinces. The Special Committee quoted the comments of Dr. Elizabeth Latimer, a palliative care specialist:

"Most witnesses agreed that advance directives should be legally binding in all provinces and medical staff should be required to defer to patients' wishes, expressed through valid advance directives. Dr. Latimer, for example, supported this view:

\emph{I would be in favour of people having the option to decide about their treatment which can be conveyed in a living will, in terms of what sort of treatment they would like to have toward the end of life. In other words, they may choose not to have certain kinds of therapies which prolong their life. They should have the right, or the option to be able to choose.} [italics original]

Latimer 4:10\textsuperscript{183}

In the subsequent follow-up report to the recommendations of the Special Committee, published in 2000 by the Subcommittee to update “Of Life and Death”, the Senate Subcommittee retreated from its earlier endorsement of advance directives, accepting concern that advance directives relied too greatly on the concept of personal autonomy.\textsuperscript{184} The comments of the Committee are as follows:

\textbf{5. Advance Directives}

Witnesses stressed that advance directives, whether instruction directives (telling the physician what types of treatment the patient does or does not want) or proxy directives (designating a certain person to make the patient's medical decisions), should not

\textsuperscript{182} Canada, Parliament, Senate Special Committee on Euthanasia and Assisted Suicide, \emph{Of Life and Death – Final Report}, (Ottawa: The Special Committee, 1995), online: \texttt{<www.parl.gc.ca/english/senate/com-e/euth-e/rep-e/lad-e.htm>}

\textsuperscript{183} Ibid, c. V Withholding and Withdrawal of Life-Sustaining Treatment, Points of Views of Witnesses at 4:10.

\textsuperscript{184} Canada, Subcommittee to update “Of Life and Death” of the Standing Senate Committee on Social Affairs, Science and Technology “Final Report, Quality End-Of-Life Care: The Right of Every Canadian”, Online: \texttt{<http://www.parl.gc.ca - Quality End-of- Life Care., June 2000> (Chair: The Honourable Sharon Carstairs).}
be viewed as purely legal documents. Whether people give too little or too much detail in their advance directives, there may well be interpretation problems, with physicians and family members sometimes disagreeing on the meaning. Most people do not update their advance directives, and family members may feel that a dated advance directive does not reflect the patient's current thinking. Sometimes medical staff may not be aware that an advance directive exists, although witnesses recommended the use of a wallet-sized card or bracelet to signal the existence of an advance directive.

Most of these problems are associated with the traditional view of advance directives as based on the principle of the patient's autonomy, and the witnesses noted that advance directives are now best seen as part of a planning and communication process that helps people prepare for death in the context of their loved ones. The preparation of an advance care directive can facilitate discussions between people and their family, and provide guidance and support for substitute decision-makers who must make the difficult decisions regarding life-sustaining treatment. If loved ones and medical professionals have engaged in a process of serious communication, the problems associated with the interpretation and application of advance directives are much less likely to arise. The passage to death is eased, the level of comfort rises, and the burden of care is lightened for the substitute decision maker. 185

The words of the Subcommittee comment on the need for improved communication between patients, families and physicians. The need for such improvement is not disputed. However, Canadian law should not return the role of decision-maker for medical treatment decisions to physicians and family members; this would be a return to paternalistic attitudes that have no place in the modern legal doctrine of consent to treatment. The comments of the Subcommittee suggest that advance directives are best seen as solely “guidance and support for substitute decision-makers who must make the difficult decisions regarding life-sustaining treatment”. Canadian law argues that the role

185 Ibid at “B. Achieving Quality End-of-Life Care, 5. Advance Directives".
of decision-maker for end-of-life treatment decisions belongs to the patient in accordance with the principles of respect for autonomy and self-deliberation.

Advance directives touch on one of the most difficult issues that people ever face: the end of their own life or that of someone they love. It is not surprising that physicians, legal scholars and legislators have struggled to decide on the correct approach to take in practice and in legislation. Despite general agreement that personal autonomy and the right to self-determination are critically important values, families and professionals feel torn by the desire to preserve life even where there is no hope of a patient’s recovery. Progressively, however, there is acceptance among medical practitioners and members of the public that respect for individual dignity and personal autonomy requires that people be entitled to make their own choices respecting the treatment they wish to accept in the event of their permanent incapacity with the comfort of knowing that their choices will be honoured. The legislation must not create a barrier to this necessary personal freedom.

According to Roger Cotterrell, “orderly social engineering through law requires that interests be balanced in a rational and consistent manner”. Cotterrell adopts the American legal scholar Roscoe Pound’s philosophy in arguing that the values applied by law in resolving competing claims are invariably specific to a legal system and society in which they arise. Social values change, but the legislation changes only slowly as new doctrine gradually alters the scheme of interests. Cotterrell explains that the “enduring problem of regulation in the modern state ... is to bridge this gap between the local moral conditions ... and the uniform society-wide system of state-created law”.

The gap between advance directive legislation and social moral conditions can be overcome by acknowledgement that the laws must respect autonomy. Jocelyn Downie

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187 Ibid.
188 Glick, Policy Innovation, supra note 7 (“It is common for governments to move in small steps rather than in giant leaps, especially regarding controversial issues.”) at 215.
189 Cotterrell, Sociology of La, supra note 186 at 79.
argues that “the Canadian legal system almost always resolves internal conflict [among cherished moral values] by holding that autonomy takes precedence over life”. In her opinion, protection of the vulnerable is not a separate value from autonomy and the two values are not dichotomous. In fact, protection of the vulnerable is an outcome of respect for autonomy. Legislators who defend restrictive advance directive legislation on the grounds that it will work to protect the vulnerable fail to recognize that respect for autonomy necessarily entails protection of and respect for the dignity of the vulnerable.

Existing advance directive legislation creates confusion among the public and scepticism towards advance directives in the medical profession. The battle between those who work to implement legislation that offers wide powers of personal choice and their counterparts who fight to protect and preserve all life for religious, cultural and political reasons may perpetuate the existence of this conflicted and inharmonious legislation that creates such confusion and scepticism. If, however, courts and legislators understand the reasons for the conflict and consciously work to create certainty in the law by defending legal rights to autonomy and self-deliberation, then public and medical attitudes and understanding about advance directives may change.

The next chapter considers current public and medical attitudes about advance directives.

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190 Downie, Dying Justice, supra note 175 at 49.
191 Ibid.
CHAPTER TWO: SHADING OUR EYES: Social and Medical Barriers to Advance Directives

1. Introduction

"Death, and the sun, can’t be look’d at steadily.”

La Rochefoucauld, from the *Maximes*, 1665\(^1\)

Nearly four centuries have passed since the 6\(^{th}\) Duc de La Rochefoucauld wrote his famous *Réflexions, ou sentences et maximes morales*. North American society, however, including members of the medical profession, continues to shade its eyes not only to the fact of death, but especially to the mode of dying in the 21\(^{st}\) century. Numerous authors who write about advance directives comment on the increasing unwillingness of the current generation to acknowledge death. For example, Krohm and Summers state:

American culture has been characterized by some as death-denying if not altogether death-defying. ...Additionally, rituals of death and dying were largely “sanitized” during the twentieth century: the sad reality of an individual’s passing was often stripped from community (and familial) consciousness. In other words – death has become distasteful. Discussions of death are taboo.\(^2\)

Regarding the medical approach to death, Desmond Manderson suggests that:

[...]he terminally ill may be subjected to an unwittingly ruthless medical culture, committed to the prolongation of life. Yet we have become alienated from the process of death and dying in terms of social and psychological practices: both are sanitised from view, banished from the hearth of the nuclear family.\(^3\)

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The majority of people living in North America today (>75%) will die in a hospital or a nursing home and the majority of the people who die in a hospital (70%) will do so after a decision has been made to terminate or forego life sustaining treatment. For the most part, this decision will have been made after the patient has become incompetent. In only a small number of cases (no more than 20%) the decision to terminate or forego life-sustaining treatment will be made because the patient has left an advance directive.

Studies of older adults’ preferences respecting end-of-life treatment indicate that many people in this demographic category would prefer to forego aggressive interventions, such as cardiopulmonary resuscitation (CPR), dialysis or placement on a respirator, at the end of life. As explained in Chapter One, American and Canadian courts have long acknowledged the legal right of patients to make such choices about their medical treatment. Although the law regarding advance directives is still developing in Canada, it is arguable that Canadian patients have a fundamental right to prospectively consent to or refuse treatment regardless of the risk to their health or life. Increasingly, the medical profession recognizes the advance directive as a way to provide this fundamental right to patients who have lost capacity to give contemporaneous instruction. Numerous

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6 Ibid at xiii.
7 Ibid at xv.
9 Schloendorff v Society of New York Hospital, 105 N.E. 92, 93 (N.Y. 1914).
medical texts recommend advance directives for improving end of life care. Authors of one guide to advance directives, both of whom are physicians, advise that they have witnessed many cases where an instructional or proxy advance directive has spared families from sorrow and saved patients from medical hardship, and they have also seen the lack of an advance directive to cause anguish and needless suffering. Yet most people do not write advance directives.

This chapter examines the public reluctance to draft advance directives and the hesitancy of the medical profession to embrace advance directives. This chapter argues that, despite social reticence to discuss death, people typically have definite preferences respecting their treatment choices at the end of life and generally approve the concept of formalizing their choices in an advance directive. However, the current methods of communication between patients and doctors are not conducive to formalizing a patient’s wishes in an advance directive. This thesis argues that patient and physician communication regarding end-of-life treatment choices must be improved. Physicians and other health care providers must respect the autonomy of patients to direct their own medical care in accordance with their personal wishes through conversations that elicit patients’ choices. Improved communication by physicians and other health care providers about end-of-life treatment decisions will help patients to develop useful advance directives that diminish their anxiety about incapability, improve their care at the end of life and provide greater comfort to their loved ones that their wishes and decisions have been honoured.

15 Olick, Taking Advance Directives Seriously, supra note 5 (“Most of us do not write advance directives; over the years, an estimated 5-20 percent of us have actually done so (most observers would put the figure at closer to 20 percent today).”) at xv - xvii.
2. Completion of Advance Directives

Dr. Bernard Lo explains that "[m]any patients fear that they will lose control over care if their decision-making capacity is impaired and that medical intervention will be imposed on them against their wishes."\(^{18}\) He commends the advance directive to patients as a means for "allowing their preferences and values to guide care even when they can no longer make informed decisions."\(^{19}\) In view of such obvious benefits, why do so few people write advance directives? Krohm and Summers express bewilderment about this question, listing the various factors that have been considered potentially responsible for the failure of the public to embrace the advance directive: "Why? Aversion? Fatalism? Fear? Ignorance? Intimidation? Disgust? Sloth? Procrastination? Lousy Marketing? Cultural Issues? All of the Above?"\(^{20}\)

Despite the many accolades given advance directives for improving end-of-life treatment planning, most people do not write advance directives.\(^{21}\) Despite the plethora of advertisements for workshops, seminars, training sessions, books and pamphlets, all designed to help people draft them and the state and federal legislation enacted in acknowledgement of their clear benefit, it is estimated that only one-third of the population of people admitted to hospital in the United States, and one-fifth of the U.S. population as a whole, have prepared advance directives.\(^{22}\)

In an attempt to improve public awareness of advance directives the U.S. federal government enacted the *Patient Self Determination Act* [PSDA]\(^{23}\) which requires every federally funded health care facility to bring to the attention of newly admitted patients

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\(^{19}\) Ibid.


\(^{21}\) Olick, *Taking Advance Directives Seriously, supra* note 5 ("Despite their featured place in strategies for decision making in behalf of incompetent patients, advance directives to refuse treatment have fallen far short of widely shared expectations. Most of us do not write advance directives...") at xv.

\(^{22}\) Ibid at xv - xviii.

\(^{23}\) 42 USCA §1395 cc (1992) [PSDA].
the existence of state law concerning advance directives, and to offer assistance with
drafting the documents. Significant educational resources are directed in the U.S towards
explaining the benefit of preparing advance directives to the general public, yet the
numbers of advance directives has increased only marginally in the U.S. since the
implementation of the *PSDA* in 1991.\(^{24}\) Although all 50 states and the District of
Columbia have enacted advance directive legislation in one form or another, and every
US hospital federally funded for Medicare or Medicaid is required to provide incoming
patients with information respecting their state’s advance directives,\(^{25}\) no more than 20% of
the US population has prepared them.\(^{26}\)

An even smaller number of Canadians is estimated to have prepared advance directives\(^{27}\)
which may reflect the fact that only half of the Canadian provinces have passed
legislation recognizing an instructional advance directive.\(^{28}\) A March 2005 article in the
Globe and Mail newspaper exhorting readers to prepare a living will (or instructional
advance directive) stated that fewer than 14 per cent, or one in seven Canadians, has
written an advance directive, although no source was provided for that statistic.\(^{29}\) A
report prepared by Robert Brown for the Institute for Insurance and Pension Research in
2003, however, reported that no actual Canadian statistic on the number of advance
directives or living wills was available at the date of his report, presumably reflecting the
fact that Canadian hospitals do not maintain accurate data on this issue.\(^{30}\)

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\(^{24}\) Cindy Westley & Linda Briggs, “Using the Stages of Change Model to Improve Communications About
at 5-6.

\(^{25}\) *PSDA* supra note 17.

\(^{26}\) E. Emanuel et al, “How Well is the Patient Self Determination Act Working? An early assessment”,

Canadian Medical Association Journal 1689 [Singer, “Bioethics for clinicians”] [“...only 12% of Ontarians
and 10% of Canadians have completed an advance directive form.”].

\(^{28}\) British Columbia, Ontario, Quebec, and Nova Scotia only recognize proxy directives and New
Brunswick has not, to date, enacted legislation for advance directives of any kind. However, instructional
advance directives have been recognized under the common law in Canada since 1990. (See *Malette supra*
ote 10). See Chapter Four below for discussion of the advance directive legislation in the Canadian
provinces.


\(^{30}\) Robert L. Brown, “Further Analysis of Future Canadian Health Care Costs”, Institute of Insurance and
The Brown report comments on the fact that implementation of the PSDA in the U.S. led to an increase in the number of patients completing the documents but no comparable legislation exists in Canada.\(^{31}\) The report explains “[w]hile Advance Directives (also called Living Wills) can exist in Canada, there is no legislative pressure for hospitals to promote the concept of the Advance Directive as exists under the PSDA in the United States.”\(^{32}\)

Thomas Mappes suggests a variety of reasons why so few people have living wills. He argues that typically people prefer not to think about death and therefore avoid the subject of planning for their own death.\(^{33}\) Cultural and religious beliefs may affect how people perceive the concept of planning for death, in some cases creating reluctance to discuss death openly.\(^{34}\) Additionally, Mappes speculates that many people find the concept of drafting a living will to be intimidating.\(^{35}\) He also accepts the argument made by Joanne Lynn that many people are satisfied to leave end-of-life decision making in the hands of a supportive family.\(^{36}\) It is probable that all of these factors contribute to the fact that such a small number of advance directives are written, notwithstanding their reputed benefits. This thesis argues, however, that a more significant impediment to completion of advance directives is the difficulty that members of the medical profession have in communicating with their patients about end-of-life planning. Bernard Lo explains “[currently], discussions about advance directives are problematical. … A detailed analysis of doctor-patient conversations about advance directives found serious problems. [footnote omitted].\(^{37}\)

\(^{31}\) Ibid (“the introduction of the legislation [PSDA] resulted in an increase in the prevalence of Advance Directives (from 25 percent in 1990 to 34 percent in 1992). Obviously, no similar data exist for Canada.” at 11).
\(^{32}\) Ibid at 7.
\(^{34}\) Ibid at 360; see also Krohm & Summers, Advance Health Care Directives, supra note 2 at 53.
\(^{35}\) Ibid.
\(^{37}\) Lo, Resolving Ethical Dilemmas, supra note 18 at 99.
George Annas argues that “[i]f we really want to enable patients in hospitals to have their pain properly treated and to exercise their right to refuse treatment near the end of life, we must have much stronger prevention methods and establish much more effective patient-centered interventions.”

Annas further states:

There are real problems with the way Americans die, ...Americans consistently say they want to die at home, with friends and family, quickly and without pain. Instead most Americans die in the hospital, surrounded by strangers and in varying degrees of pain. There are many reasons for this (including denial on the part of dying patients), but I think the most important one is that patient rights are not taken seriously during life and therefore they are not likely to be taken seriously just before death.

The empirical evidence of social attitudes towards advance directives discloses that people are generally interested in and willing to discuss their end-of-life treatment choices, and consider this an extremely important issue, despite their discomfort discussing death. However, studies also show that the medical profession is uncomfortable discussing death or embarking on end-of-life planning discussions with patients.

Arthur Caplan writes that “clinicians, despite their support for the concept of living wills and other forms of advance directives, are deeply sceptical that such documents can really be effective in guiding the course of health care.”

Although the evidence indicates that health care providers typically consider advance directives beneficial for end of life decision-making, it is not clear that the advance planning materials or the training provided to health care practitioners provide them with the communication tools necessary to embark on end-of-life planning discussions with their...
patients. Philip Kleespies writes that “if we focus on meaningful discussion and communication about end-of-life issues, ... than patients may be far more likely to understand that it can be relevant for them.”

It seems apparent that more understanding is needed respecting how members of the public, and particularly patients who live with compromised health, approach end-of-life decision-making. Kleespie states: “[t]he quality of communication about advance directives is an area that has not been examined very thoroughly.” If health care providers do not recognize and respect public attitudes and patient preferences about advance health care planning and ensure that the communication tools they use to promote advance directives are sensitive to the needs of the population they serve, advance planning will not be embraced by the public, despite its benefits for enhancing end-of-life care.

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44 Ibid.
46 Caplan, If I were a rich man could I buy a pancreas? supra note 42 ("The greatest challenge in maintaining and enhancing autonomy for anyone receiving healthcare, be they elderly or not, is figuring out exactly what sorts of information would help identify their ends.") at 276-277.
3. Public Interest in Discussing Advance Directives

Authors of the Robert Wood Johnson study *Means to a Better End: a Report on Dying in America Today* [*Means to a Better End*] state “Americans have successfully avoided the unpleasant topic of death and dying for two or three generations.”47 A community-wide research study conducted by the Partnership for Improving End-of-Life Care48 (Care Study) corroborates this statement regarding public attitudes to discussion of death and dying.

Care Study results confirmed that 89% of respondents were either “not very comfortable” or “not comfortable at all” talking about death although 70% of respondents had experienced a death of someone close in the last five years and 60% thought it would be worse than death not to be able to communicate their end-of-life wishes to their families. Although 70% of respondents did not want artificial nutrition and 61% rejected artificial hydration, only 5% had discussed their wishes for end-of-life care with their primary physician. 43% of the Care Study respondents thought the physician should be the party to initiate discussion on the topic. An Ipsos Reid study conducted in December 2003 concluded that the majority of Canadians are also very interested in discussing end-of-life care with physicians and family members.49

Dr. Bernard Lo explains that the rationale for doctors to discuss advance directives with their patients is the prevalence of patient interest in having conversations about end-of-life treatment.50 He extrapolates from a number of studies to explain that between 59%

48 The University of South Dakota School of Medicine and Health Sciences, Department of Neurosciences, Susan L. Schrader, (Project Coordinator) “Dying to Know”, Partnership for Improving End-of-Life Care, 2004, online: <http://www.usd.edu-USD-Dying to Know - Community Assessment 2004>.
49 Ipsos Reid, “Hospice Palliative Care Study”, conducted December 9 to 11, 2003, a survey based on a sample size of 1055 Canadians (results considered to be accurate to within ±3 percentage points 19 times out of 20 had the entire Canadian population been polled) conducted by Ipsos-Reid and commissioned by the Canadian Hospice and Palliative Care Association and GlaxoSmithKline Inc., (Cited in *Still Not There - Quality End of Life Care: A Progress Report* June 2005, (Senator Carstairs) Online: <http://sen.parl.gc.ca>.
and 85% of outpatients “want to talk with their physicians about life-sustaining interventions before a clinical crisis occurs” although “fewer than 6% have done so.”

Such conversations are apparently very helpful for patients who subsequently feel “in control, relieved, or cared for” as a result of having had them. Philip Hébert similarly notes that “[a]pparently most patients are willing to discuss advance directives and can be encouraged to do so by supportive staff” [footnotes omitted].

A study of seniors’ views regarding life-sustaining treatment completed by Carol Baer concluded that, despite considerable legislative development and increasing public interest in advance directives, “little has been accomplished with regard to actual documentation of treatment preferences”. Baer focused her research on patients’ preferences for life-sustaining technologies since she found that little substantive research had been completed on that subject. She concludes that the elderly population has significant preferences that can be comprehensively assessed. Two findings of her survey were the statistically higher proportion of elderly in the study group who had signed advance directives and the fact that the group who had signed advance directives indicated a lesser interest in receiving prolonged life-sustaining technologies. Baer notes that the study recipients clearly demonstrated a desire to protect themselves from an aggressive level of care.

A Canadian research study conducted by Bowman et al concluded that the quality of end-of-life care is often unsatisfactory, particularly with regard to the limited use of palliative treatments and the application of burdensome or overly aggressive treatment.

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51 Ibid.
52 Ibid at 99.
55 Ibid at 63.
A study of quality end-of-life care based on patients' perspectives by Singer et al,\textsuperscript{57} found that patients indicate significant preferences for the ability to avoid inappropriate prolongation of dying, to achieve a sense of control, and to relieve the burden on loved ones and consider these important factors for their comfort at the end of life.

A study respecting preferences for care at the end of life conducted by the Agency for Healthcare Research and Quality\textsuperscript{58} examined patient preferences for treatment based on health status, invasiveness, length of treatment and prognosis using data primarily collected from research with patients with chronic disease and from physicians. The study indicated that age influenced perceptions of hypothetical health states as being better or worse than death, with a greater proportion of younger adults (66\%) perceiving permanent coma as worse than death, although the same proportion of younger and older age groups rated dementia as being worse than death. The study participants, all of whom were patients, were more willing to accept life sustaining treatment for states considered better than death and were least likely to want CPR if they were in a permanent coma.\textsuperscript{59} Similarly, a study by Donald Patrick et al concluded that “[p]rospective life-sustaining treatment preferences show high convergent validity. For most persons, treatment preferences are grounded in a consistent belief system.”\textsuperscript{60}

High numbers of people philosophically agree with the concept of the advance directive.\textsuperscript{61} However, much of the investigation of public attitudes has focussed on the views of the elderly and chronically ill, so little is yet known of the attitudes of younger


\textsuperscript{59} Ibid at 5.

\textsuperscript{60} Donald L. Patrick, et al, “Validation of Preferences for Life Sustaining Treatment: implications for advance care planning”, (1997) 127 Annals of Internal Medicine 509. (The authors also commented with respect to the benefits of discussion about patient advance care choices that: “Advance care planning in clinical practice helps patients think through and communicate preferences for life-sustaining treatments.” at 510.)

\textsuperscript{61} Emanuel, “Advance Directives – A Case for Greater Use”, supra note 16; see also K Stelter et al., “Living Will Completion in Older Adults”, (1992)152 Archives of Internal Medicine 954.
generations or healthier groups. Some researchers report that many people respond well to discussions about advance directives and would like their physicians to raise the subject and another found that patients who completed advance directives were less anxious as a result. A study by Singer et al found that patients preferred to engage loved ones in advance care planning.

Dr. Bernard Lo explains that "[p]atients want discussions to occur earlier than physicians do: earlier in the natural history of disease, and earlier in the patient-physician relationship [footnote omitted]. Elisabeth Macdonald and Katherine Murphy similarly state:

[p]atients increasingly want doctors to take account of their preferences and to involve them in choice of treatment and management of their condition. Many patients now want to play a part in their own care.

Westley and Briggs agree that the discussion about [advance directives] should take place while people are still healthy, or early in the disease process, with the primary care provider and/or other person specially trained to discuss treatment goals and future medical care planning.

Some ethnic groups are not comfortable discussing advance directives. This is especially true of some Asian cultures which encourage extended families to make decisions about a family member’s care. Bernard Lo comments that

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62 Krohm & Summers, Advance Health Care Directives, supra note 2 at 46.
63 Bernard Lo, G. McLeod & G. Saika, “Patient Attitudes to Discussing Life-Sustaining Treatment” (1986) 146 Archives of Internal Medicine 1613.
65 Singer “Patients’ Perspectives”, supra note 57.
66 Lo, Resolving Ethical Dilemmas, supra note 18 at 100.
69 Carol Levine, ed., “Are Some Advance Directives Too Risky for Patients”, Taking Sides: Clashing Views on Controversial Bioethical Issues, 10th ed. (Guildford, Connecticut: McGraw-Hill/Dushkin, 2004) (“Advance directives have more appeal to European Americans. African Americans had less knowledge about them, despite a positive view towards them, while Mexican and Korean Americans both held negative attitudes towards the concept.”) at 76.
[i]n some cultures, advance directives are undesirable. For example, many traditional Chinese patients believe that talking about future illness will anger the ghosts, who then will make the illness occur or cause bad luck. Such reluctance to discuss future plans needs to be respected.\(^{71}\)

Kerry Bowman and Edwin Hui agree that a document founded on the principles of autonomy and self-determination may not be suitable to a number of cultures that are significantly represented in Canada, such as the Chinese community. Bowman and Hui describe their findings as follows:

Many of the assumptions implicit in a Western autonomy-based approach to bioethical deliberation may not be shared by Chinese Canadians. In traditional Chinese culture, greater social and moral meaning rests in the interdependence of family and community, which overrides self-determination.\(^{72}\)

Krohm and Summers similarly comment that:

intricate family relationships in [some] cultures give rise to different approaches and responsibilities for care of the sick and dying. For example, end-of-life decision-making may be assumed (according to tradition or custom) by family members; a terminally ill individual may be effectively insulated from health care choices. This is because speaking of death in front of an ill patient may be seen as disrespectful.\(^{73}\)

Some preliminary work indicates that culturally sensitive interventions to educate ethnic groups are effective in increasing receptivity to the concept of advance directives.\(^{74}\) The *Means to a Better End* study concluded that different cultures have unique needs, wishes and views respecting death and dying and that “ethnicity is strongly related to attitudes to and personal wishes for the use of life support”.\(^{75}\)

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\(^{71}\) Lo, *Resolving Ethical Dilemmas*, supra note 18 at 100.


\(^{73}\) Krohm & Summers, *Advance Health Care Directives*, supra note 2 at 53.


Means to a Better End similarly found an increasing recognition of the importance of spirituality in the care of dying people. The report concluded, based on relevant studies, that patients want physicians to ask them about their spiritual beliefs.\(^{76}\) In fact, seriously ill patients and their family rate spirituality as among the most important issues and concerns that they would like to discuss when planning for the end of life.\(^{77}\)

Although the public is not entirely comfortable discussing death and dying, these studies show that people have strong opinions and personal preferences respecting their end-of-life medical treatment, particularly respecting life-sustaining technologies. The studies indicate that many people are interested in discussing end-of-life treatment issues and consider such discussions extremely important. Although the majority of the population has not completed an advance directive, most people approve the concept and would welcome a discussion about them with their family and with their doctor.

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4. Medical Community Barriers to Completion of Advance Directives

Do not go gentle into that good night,
Old age should burn and rave at close of day;
Rage, rage against the dying of the light.

Dylan Thomas

Whether it is because of training or disposition, medical practitioners appear to “rage against the dying of the light” more than many of their patients. Robert Olick is deeply disquieted that more than 25 years after the *Quinlan* case, “dying patients’ wishes often do not direct care near the end of life, even when patients’ intentions and plans are put to writing in an advance directive”.

Olick argues that physicians tend not to respect advance directives because they cling to paternalistic ideas regarding patient care. Hall, Bobinski and Orentlicher agree with Olick’s opinion that physicians fail to recognize or frequently override advance directives, commenting as follows:

Although courts have clearly and emphatically recognized that end-of-life decisions should be based on patient preferences and values, empirical studies indicate that it is the physician’s preferences and values that seem to drive decisions regarding the withdrawal of life-sustaining medical treatment. David Orentlicher, *The Limitations Of Legislation*, 53 Md. L. Rev. 1255, 1280-1288 (1994). In one study, after nursing home residents completed living wills, researchers followed the residents to determine whether subsequent medical decisions were consistent with them. The researchers found that physicians overrode the living wills 25 percent of the time. Marion Danis et al., *A Prospective Study of Advance Directives for Life Sustaining Care*, 324 New England J. Med. 882 (1991). While a 75 percent agreement may seem good, the study suggests that physicians overrode the patient’s preferences the majority of the time when there was a disagreement between the patient’s choice and the physician’s preferences.

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79 Olick, *Taking Advance Directives Seriously, supra* note 5 at ix
The *Means to a Better End* Report includes a case study entitled: "Doctors fear end-of-life decisions, too." The oncologist in the case hesitates to confirm to his patient that death is imminent and that any treatments offered to treat the patient’s cancer will not be effective to forestall death. Alexander Capron describes the tendency for medical science to turn away from the subject of death as follows:

In recent years, death has become more public in the physical sense of occurring increasingly in hospitals or other health care facilities, which today are the site of about eighty percent of all deaths. Yet while this factual shift to public deaths was occurring, death as a concept became private, almost shameful in the world as we construct it verbally. Perhaps because death remained the ultimate reminder of the failure of medicine, it came to be regarded as not a fit subject for the biomedical sciences.

Health Care Providers or, more particularly, physicians still appear to be equivocal in their support of advance directives. Advance directives are typically described in a positive light by both patients and physicians and are considered helpful information for medical authorities. However, the benefit of preparing an advance directive remains uncertain, because physicians and medical facilities frequently argue that the documents are too vague to give necessary guidance on end-of-life decisions. Dan Brock warns of the difficulty in assuming physicians can provide patients with "the facts about treatment alternatives in a value-neutral form" and suggests that shared decision making between physicians and patients requires "a more delicate balancing." Brock argues that physicians must be advocates for their patients’ well-being but also must be prepared to

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84 Singer et al, “Bioethics for clinicians” supra note 27.
87 *Ibid* at 77.
respect their patients’ self-determination, regardless of whether they agree with the patient’s choice.\textsuperscript{88}

Krohm and Summers surmise that doctors disagree with the concept of an advance directive since it potentially conflicts with the “Do No Harm” rubric of the Hippocratic Oath, and therefore fail to discuss them with patients as a planning option.\textsuperscript{89} They also acknowledge that some individuals, including patients and health care providers hold personal or spiritual convictions that maintain life is precious and must be preserved and maintained irrespective of physical or financial cost...[and] [o]thers construe advance directives as either a ruse or charade for euthanasia or as a form of subterfuge to ... deny care for the enfeebled, the elderly, and the physically disabled or mentally incapacitated. Accordingly, some may think the entire concept of directives repugnant and may reject them categorically.\textsuperscript{90}

The SUPPORT\textsuperscript{91} study on advance care planning found that advance directives placed in a patient’s medical charts often did not guide medical decision-making beyond naming a proxy or documenting general preferences in a standard living will, and even specific instructions were not followed at least 50% of the time. The principal investigators of the SUPPORT study concluded that care for the elderly ill needs to be significantly improved, particularly in the areas of planning and the use of aggressive care near death.\textsuperscript{92}

The SUPPORT study conducted interviews with patients, patient surrogates, and physicians to determine the effect of advance directives over a four year period both

\textsuperscript{88} \textit{Ibid.}

\textsuperscript{89} Krohm & Summers, \textit{Advance Health Care Directives supra} note 2 at 5. (Krohm & Summers also quote N. Wengler et al, “Physicians Understanding of Patient Resuscitation Preferences: Insights and Clinical Implications” (2000) 48 Journal of the American Geriatrics Society 544, who suggest that physicians may feel obligated to perform life sustaining measures despite the directive, at 8, n.5.)

\textsuperscript{90} \textit{Ibid} at 53.


\textsuperscript{92} \textit{Ibid.}
before and after the implementation of the *PSDA*. The researchers concluded that the existence of, or creation of, an advance directive by hospitalized patients during the study period had little effect on communication between the doctor and the patient regarding the advance directive and did not affect physician decision-making about end-of-life care. Joan Teno, a principal investigator of the SUPPORT study, subsequently recommended that more rigorous clinical attention and research studies be undertaken to develop a better understanding of end-of-life preferences and that research should be conducted to consider not only empirical but normative theory with regard to these questions. The study group concluded that work should be done to improve practice patterns.

Some of the reluctance of physicians to embark on discussions about advance directives may be lack of familiarity with the documents. In view of the low numbers of advance directives completed by the general public, physicians and other health care providers have little experience in reading and interpreting advance directives. Doukas and Reichel explain that recent research indicates “physicians can benefit from having more information about [advance directives] and more experience with their use. It also appears that physicians too often wait for patients to bring the subject up.” The ongoing lack of experience in using advance directives may hinder many physicians from attempting to initiate conversations about them with patients.

Studies indicate that the conversations that physicians have with their patients about advance directives may not provide sufficient information to ensure that patients are making informed choices. For example, “[e]ven after discussions with physicians, only 33% of patients know that patients on a ventilator cannot talk, and about one-half believe that ventilators are oxygen tanks or that ventilated people are always comatose. ...Similarly, patients have serious misunderstandings about cardiopulmonary

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Although physicians frequently criticize advance directives for using vague language and broad terminology, an analysis of doctor-physician conversations about advance directives showed that “[t]ypically, physicians used vague language, asking patients what they would want if they were “very, very sick” or “had something that was very serious.” Doctors rarely tried to define such terms or ascertain how patients interpreted them.”

The authors of a study conducted in Glasgow, Scotland, on the willingness of physicians to adhere to the strict terms of an instructional advance directive concluded that the documents are open to widely varying interpretation. Some of this variability is related to the ambiguity of the directive’s terminology whereas some is related to the willingness of health professionals to make subjective value judgments concerning quality of life.

The Scottish physicians were presented with a hypothetical case of an elderly patient in a care facility suffering from severe Alzheimer’s disease who had contracted pneumonia. The patient had signed an advance directive many years earlier when she was competent stating that treatment, including antibiotics, for a life threatening disease should be withheld if she had been previously diagnosed with an underlying degenerative disease (including Alzheimer’s disease). The majority of the physicians responded that they would treat the patient for pneumonia, notwithstanding the advance directive, because they felt her quality of life was sufficiently high that she would not have wanted the advance directive to be adhered to. The reaction of the Scottish physicians is to override an advance directive on the grounds that the patient’s current best interests appear to conflict with the strict terms of the written instruction.

96 Lo, Resolving Ethical Dilemmas, supra note 18 at 97.  
97 Ibid at 99.  
Canadian courts have commented on the relative positions of the patient and the physician with regard to instructions about treatment. In the Ontario Court of Appeal case of *Malette v Shulman*, which upheld the validity of a written advance instruction in the form of a card refusing a blood transfusion, Robins, J.A. considered the competing interests of the patient, the medical profession, and the state and made the following comments:

Safeguarding the integrity of the medical profession is patently a legitimate state interest worthy of protection. However, I do not agree that this interest can serve to limit a patient’s right to refuse blood transfusions. I recognize, of course, that the choice between violating a patient’s private convictions and accepting her decision is hardly an easy one for members of a profession dedicated to aiding the injured and preserving life. The patient’s right to determine her own medical treatment is, however, paramount to what might otherwise be the doctor’s obligation to provide needed medical care. The doctor is bound in law by the patient’s choice even though that choice may be contrary to the mandates of his own conscience and professional judgement. If patient choice were subservient to conscientious medical judgement, the right of the patient to determine her own treatment, and the doctrine of informed consent, would be rendered meaningless.

Changes adopted by the Canadian Medical Association (CMA) over the last dozen years to their joint policy statements indicate that Canadian physicians are increasingly more positive about the benefits of advance directives. The CMA now supports the use of advance directives in all of its current Codes and Statements. The CMA *Code of Ethics* and related policies advise physicians to assist their patients in a consultative capacity in preparing an advance directive, if a patient requests such assistance. Pursuant to the CMA *Code of Ethics*, physicians are also directed to “Recognize your patient’s wishes about the initiation, continuation or cessation of life-sustaining treatment” and to “Respect the intentions of an incompetent patient as they were expressed (e.g. through a

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99 Malette, supra note 10.
101 CMA Code of Ethics, supra note 12.
valid advance directive or proxy designation) before the patient became incompetent."102

Similarly, The CMA Joint Statement on Resuscitative Interventions states “When a person is incompetent, treatment decisions must be based on his or her wishes [which] may be found in an advance directive… .103
5. Conclusions

The studies reviewed in this chapter confirm that patients want to discuss advance care planning with physicians and family. They would like such discussions to take their personal cultural and religious concerns into consideration to ensure those matters are respected as part of the planning process. Progressively medical facilities confirm that end-of-life care is enhanced where the patient’s goals are known and recorded and where the health care providers can use this guidance to meet the needs of an incompetent and dying patient and his or her family. The authors of a text on clinical practice explain:

It is the physician’s responsibility to help the patient anticipate and prepare for the future. The patient’s primary care physician should ask the patient about his values and preferences regarding life, death, and end-of-life choices. These conversations should be documented in the chart and, where appropriate, should be shared with family members and close friends. The physician should also encourage the patient to consider writing an advance directive and assigning someone as durable Power of Attorney for Health Care.  

The authors of the SUPPORT study concluded that “the effectiveness of [advance directives] could have been improved and enhanced substantially. [The research findings] attest to the need to recast [advance directives] from the formal, legal process of signing a document to a more dynamic process of communication and negotiation about the goals of care, which we ... have called “advance care planning.”

Bernard Lo agrees that physicians should try to understand the patient’s “general values and preferences” and should use “open-ended questions ...to elicit the patient’s perspective.”

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106 Lo, Resolving Ethical Dilemmas, supra note 18 at 100.
In terms of establishing dialogue with patients, it is not clear that doctors and other health care providers have the communication tools necessary to assist individuals with planning or drafting advance directives. Although brochures have been created both in the US and in Canada, little guidance has been offered to health care providers to assist with developing dialogue. Westley and Briggs recommend that health care providers adopt a behaviour change model to assist patients with developing a meaningful document that meets the patient’s needs. This process would include providing a script for health care providers to help direct their conversations respecting advance care planning.

Dr. Bernard Lo recommends that physicians start the planning process by raising the topic with patients who are not ““terminal” or in a progressively downhill course, but also those with serious chronic illness like congestive heart failure, whose course is not so predictable”. Lo and Steinbrook suggest that state laws should make it possible for patients to simply tell their physicians their preferences and who they would like the doctor to consult should they become incapable. These authors argue that the communication process is more critical than the legal form and that “physicians need to develop effective communication skills to discuss advance directives with patients”.

The inescapable conclusion of these studies on patient and health care providers’ attitudes to discussions of death and advance care planning is that communication must be improved. People are willing to embark on these discussions to make sure that their choices are known. Health care providers must ensure that the necessary conversations take place. It is no longer suitable to shade our eyes from the topic of death when it can be prolonged nearly indefinitely, despite a poor quality of life. The health care system must ensure that patients’ rights to autonomous decision-making at the end of life are not merely statements but are effectively brought into the process of health care planning.

108 Ibid at 9.
109 Lo, Resolving Ethical Dilemmas, supra note 18 at 99-100.
110 Lo & Steinbrook, “Resuscitating Advance Directives”, supra note 17 at 1504.
111 Ibid at 1505.
The next chapter considers the relative advantages and weaknesses of the two types of advance directive, the living will and proxy directive, as tools for health care planning and examines the reasons for their limitations.
CHAPTER THREE: HAS THE LIVING WILL FAILED? A Prognosis for the Living Will

1. Introduction

Historically, Church and State ideologies have militated against indulgence of certain aspects of autonomous control over our physical selves. ... Despite the rapid development of rights discourse, the ethical and legal debate ... is enmeshed by this heavy inheritance, locked into endless shadow-boxing between the corners of sanctity and autonomy.¹

In a controversial article published in 2004, entitled “Enough: The Failure of the Living Will”, ² [“Enough”] Angela Fagerlin and Carl Schneider [Fagerlin and Schneider] maintain that “[t]he living will has failed, and it is time to say so”.³ “Enough” was widely quoted in the mainstream news, with many editorials and columnists commenting, based on the article, that the living will [instructional advance directive] may not be the best planning option for end-of-life treatment decisions.⁴ The primary criticism that Fagerlin and Schneider make about the living will is that it is not used. The authors argue that the living will fails because people fail to make a living will. This thesis argues that some of the criticisms of the living will outlined in “Enough” are based on a philosophy of vitalism that is antipathetic to the living will.

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³ Ibid at 30.
⁴ See e.g. E.J. Mundell, “Value of Living Wills Under Fire: Bucking Conventional Wisdom, Studies Suggest They Don’t Work”, HON News, (May 18, 2004) (“Living wills fail on many counts, she [Fagerlin] and Schneider claim. First of all, despite years of advocacy, the vast majority of individuals do not complete an advanced directive. Many just procrastinate, Fagerlin said, while others "think that living wills are for the infirm or elderly."" at ¶8)online:< http://www.hon.ch/News/HSN/518982.html>; “Study: Living Wills Not Always Helpful”, The News-Herald, (July 11, 2004), (Southgate, Ml.) (“What they found was provocative: The documents designed to help people choose the treatments they would like when dying fail to meet five key criteria for success. Worse, the evidence suggests they don’t work.” at ¶3 Online < http://www.thenewsherald.com/>; Laura Meckler, “Living Wills: A Good Idea Not Often Implemented.” Contra Costa Times (Ca.) (Nov. 28, 2004) (“...the reality is, too often they don’t really work.”) Online: http://www.contracostatimes.com >
Fagerlin and Schneider do not propose that people should be left without a statutory option for end-of-life medical treatment decision-making. They recommend the proxy advance directive, or durable power of attorney for health care, as the better and perhaps the only option. Fagerlin and Schneider argue that, in light of its failure to achieve the goals of end-of-life treatment planning, the living will should be abandoned and replaced with a durable power of attorney or health care proxy. In their view, “patients should be told about powers of attorney ... since surrogates know more at the time of the decision than patients can know in advance.”

The proxy advance directive, however, can also be criticized. The proxy may choose treatment contrary to the expressed wishes of the principal. There is the potential for conflict of interest to exist, such as where a proxy acts precipitously to terminate life-sustaining treatment for financial or other motives. Meisel and Cerminara state that “there is an inherent conflict of interest in the theory of surrogate decisionmaking.”

Notwithstanding the potential problems with proxy advance directives, some jurisdictions have adopted the position espoused by Fagerlin and Schneider so completely that they do not provide the option of a living will to their citizens. In British Columbia, for example, people are entitled to create a representation agreement, which is a type of proxy advance directive, under the Representation Agreement Act [RAA] The statute does not recognize a living will. Similarly, Ontario does not statutorily recognize living wills. These jurisdictions have decided that, without exception, people are better off to appoint a substitute to make decisions on their behalf in the event of their incapacity. Therefore, there is no statutorily approved option for citizens to provide direct instructions to health

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5 Fagerlin & Schneider, “Enough” supra note 2 at 39.
6 Ibid at 39.
8 R.S.B.C. 1996, c. 405 [RAA].
9 Substitute Decisions Act, S.O. 1992, c. 30 [SDA]. Similarly, Quebec, Nova Scotia and Yukon Territory do not provide the option of living wills to citizens of those provinces in their advance directive legislation. See Chapter Four below for further discussion of the Canadian advance directive legislation.
care providers regarding their decision to forego life-sustaining treatment under certain circumstances. Citizens in these provinces must designate a proxy to give instructions.

Chapter Two concluded that a majority of people would like to discuss and confirm their choices for end-of-life treatment with family and physicians. However, not every patient has family. Some people may never have formed a family. Some patients may have lost their family members and close friends or may not want to place the role of decisionmaker on others. Also, some people feel strongly that their personal directions to physicians should be respected without deference to another person and may wish such instructions to remain a confidential matter between patient and physician. The last chapter concluded that good communication between patients and their physicians should result in documentation which can guide health care providers in the event of a patient’s incapacity.

This chapter examines the legal and ethical issues underlying the criticism of living wills and considers the difficulties associated with decision-making by both the instructional advance directive [living will] and by the proxy advance directive. This thesis argues that the criticism of living wills by authors such as Fagerlin and Schneider, Professor Rebecca Dresser and others is premised, to some extent, upon a vitalist philosophy that rejects the concept of personal autonomy to direct the termination of life-sustaining treatment. “Vitalism” is a philosophical approach premised upon a rigid application of the sanctity

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10 Robert S. Olick, *Taking Advance Directives Seriously: Prospective Autonomy and Decisions near the End of Life*, (Washington, D.C.: Georgetown University Press, 2001) [Olick, *Taking Advance Directives Seriously*] (“For people who believe that the written document *ipso facto* stands for clear and convincing evidence, there is no need to look further than the document itself; the need to do so is considered to diminish the directive’s probative value.”) at 166. Also, patients under Canadian law are entitled to have their treatment decisions and their discussions with their physicians maintained in confidence, and are not required to confide these instructions to a third party. See note 80 infra and accompanying text below for case law and further discussion of this issue.

of life principle. Special interest groups in the U.S. have successfully lobbied for living will legislation that incorporates a vitalist philosophy and, as a consequence, vitalism is pervasive in U.S. living will statutes. In Canada, deference to vitalism has resulted in many provinces failing to implement legislation that recognizes living wills.

This thesis also argues that the use of a proxy directive may not be more successful, and may be less successful, than a living will in resolving “hard cases”. Two recent legal cases, one American and one Canadian, involving termination of treatment are used to illustrate this argument. In light of the problems associated with decision-making pursuant to either instructional or proxy advance directives, an advance directive that combines aspects of both types of directive may be the most beneficial instrument for future medical treatment planning.

This thesis argues that a patient should have the choice to either prepare written instructions (preferably after discussing treatment options with their physician) appoint a proxy, prepare a combination of both or do nothing at all. No one should have to create

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13 Henry R. Glick, The Right to Die: Policy Innovation and Its Consequences, (New York: Columbia University Press, 1992) [Glick, Policy Innovation] (“[V]arious state and local right to life organizations oppose living will laws …[and] these groups also generally refuse to compromise on living will legislation.”) at 22.

14 See supra note 9.


16 Schindler v Schiavo (In re Schiavo) 780 So.2d 176 (Fla. Dist. Ct. App. 2d Dist. 2001), reh’g denied (Feb.22,2001), review denied by: Schindler v Schiavo, 789 So.2d 348 (Fla. 2001) (Schiavo I); remanded by: Schindler v Schiavo (In re Schiavo), 792 So.2d 551 (Fla, Dist. Ct. App. 2d Dist. 2001) (Schiavo II); appeal after remand at, remanded by: Schindler v Schiavo, 800 So.2d 640, (Fla. Dist. Ct. App. 2d Dist. 2001) (Schiavo III), review denied by: In re Schiavo v Schindler, 816 So.2d 127 (Fla. 2002); Appeal after remand, remanded by Schindler v Schiavo (In re Schiavo) 851 So.2d 182 (Fla. Dist. Ct. App. 2d Dist.), review denied, 855 So.2d 621 (Fla. 2003) (Schiavo IV); Bush v Schiavo, 871 So. 2d. 1012, aff’d 885 So.2d 321(Fla. 2004) (Schiavo V); reh’g en banc denied by Schiavo ex rel. Schindler v. Schiavo, 404 F.3d 1270 (11th Cir. Fla. 2005) [Schiavo].

an advance directive in order to receive the highest quality of health care, but all people
should have the right to create an advance directive that suits their personal needs.

Some people may not wish to make an advance directive; a decision whether to make a
directive must be their prerogative. If citizens do wish to make an advance directive,
governments should ensure that each type of directive, both instructional and proxy, as
well as a combination of both types, is statutorily recognized in a regulatory scheme
designed to provide citizens autonomy to carry out future health care planning in a way
that meets their personal needs and wishes.

18 Carl E. Schneider, The Practice of Autonomy: Patients, Doctors and Medical Decisions (New York:
Oxford University Press, 1998) ("...many people have strong reasons for not wanting to grasp the nettle of
autonomy.") at 42.
2. The Debate About the Living Will

In 1992, Peter Singer et al. asked the question "Are advance directives an advance?" and answered it somewhat tentatively as follows:

We believe they are. However, as we realized and as will become apparent when advance directives are more broadly used, they contain many limitations. Having identified and addressed some of these limitations, we hope that the introduction of advance directives in Canada will proceed with due caution.¹⁹

It appears that many Canadian legislators followed the advice to proceed with due caution. At the time of publication of the article by Singer, et al.,²⁰ no living will legislation existed in Canada. Nova Scotia²¹ and Quebec²² had enacted legislation recognizing proxy directives but no other province had enacted advance directive legislation of any kind. Subsequent to publication of the article by Singer et al., seven more provinces and the Yukon Territory²³ have enacted advance directive legislation, but legislators have been exceedingly cautious. In B.C.²⁴, Ontario²⁵ and the Yukon Territory, the legislation only recognizes proxy directives. Therefore, in Canada, only the five provinces of Alberta,²⁶ Saskatchewan,²⁷ Manitoba²⁸, Prince Edward Island²⁹ and Newfoundland³⁰ recognize living wills in their advance directive legislation.³¹

In the dozen years that have passed since Singer's article was published, the benefits of creating an advance directive, and particularly a living will, have become progressively

²⁰ Ibid.
²¹ Medical Consent Act, R.S.N.S. 1989, c. 279.
²³ Care Consent Act, S.Y. 2003, c.21 Schedule B (c.i.f. May 2005).
²⁵ SDA supra note 9.
²⁶ Personal Directives Act, S.A. 1996, c. P-4.03.
²⁷ The Health Care Directives and Substitute Health Care Decision Makers Act, S.S. 1997, c.H-0.001.
²⁹ Consent to Treatment and Health Care Directives Act, S.P.E.I. 1996, c. 10.
³¹ See Chapter Four below for further discussion of the Canadian advance directive legislation.
more contentious. Arguments about the benefits of all advance directives, but especially living wills, continue unabated notwithstanding the proliferation of enabling legislation throughout the United States, Canada and in foreign jurisdictions, as well as the apparent validation of advance directives in the courts and their endorsement by many authors in the biomedical ethical community.

The controversy respecting the benefits of living wills is particularly evident in the United States where the problems associated with their use have become the subject of heated argument in the biomedical ethical literature and a matter of discussion and debate at the President's Council on Bioethics in 2004. However, even the most vehemently expressed objections to instructional advance directives are curiously ambivalent. For example, Fagerlin and Schneider argue that "...living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results, and should be abandoned". Notwithstanding this objection to living wills they also state "[w]e do not propose the elimination of living wills. We can imagine recommending them to patients whose medical situation is plain, whose crisis is imminent, whose preferences are specific, strong and delineable, and who have special reasons to prescribe their care".

32 Alaska passed the Health Care Decision Act, Ala. Stat. §§13.52.101 to .395, (eff. Jan. 2005) modernizing its advance directive legislation to include instructional or proxy advance directives as well as combination forms. All of the U.S. States have advance directive legislation of some form.  
33 For e.g. the English Mental Incapacity Act (2005, C.9) was passed in April 2005, to have application in England and Wales, after 15 rancorous years of debate and argument that the legislation was a first step towards the legalization of euthanasia. The legislation gives legal recognition to both instructional and proxy advance directives. For further comment on the Mental Incapacity Act, see text below.  
35 See e.g. Robert S. Olick, Taking Advance Directives Seriously, supra note 10.  
36 See e.g., Fagerlin & Schneider, "Enough", supra note 2.  
38 Fagerlin & Schneider, "Enough", supra note 2 at 30-31.
It appears that the recommended abandonment of the "policy" respecting living wills by Fagerlin and Schneider means that only a select group of patients, rather than the general public, should make living wills. Similarly, Professor Rebecca Dresser states "In my view, reliance on advance treatment choice is misguided and morally troubling". In another article she asks:

Why are directives preferable to other possible approaches to end-of-life decisionmaking for incompetent patients? Why are they preferable to, for example, an approach that permits close relatives or friends to decide how aggressively to treat such patients, after consultation with caregivers and within a range of choices deemed acceptable by courts, legislators, and other institutions involved in establishing normative standards in our society?  

Nevertheless, despite these comments (which display little concern for patient autonomy), and despite Professor Dresser's arguments to the President's Council on Biomedical Ethics in April 2004 outlining the numerous problems associated with using living wills, she admitted to the Council members that she had an advance directive herself, and in fact "a pretty specific one because I think it's a prudential thing to do. It gives your family members more authority in the hospital; that is if you can wave this piece of paper, the doctors are more likely to pay attention to you." Her description of her personal directive as being "pretty specific" implies that it is either an instructional advance directive or that she has left specific treatment instructions in a proxy advance directive.

Fagerlin and Schneider accuse the law of imposing living wills on the populace despite the evident failure of living wills to achieve their intended purpose. They blame the law for continuing to recommend that people in the U.S. make living wills or, worse yet, for

40 Rebecca Dresser, "Advance Directives: Implications for Policy", supra note 11 at S2.
41 President's Council, supra note 37 at Transcripts April 2, 2004, Session 6.
implying that living wills must be made, through State advance directive legislation and such federal policies as the Patient Self Determination Act [PSDA]. The PSDA requires federally funded hospitals and nursing homes in the U.S. to advise patients about the state advance directive legislation, to provide patients with information regarding their right to make an advance directive and to create policies and procedures to ensure internal compliance with this requirement, although medical care cannot be conditional upon the patient creating an advance directive. Fagerlin and Schneider argue that living wills are costly both to individuals and to U.S. society generally because of the compliance costs related to the federal PSDA.

Fagerlin and Schneider argue that the benefit of a proxy is that the proxy will know the exact circumstances that exist at the time decisions respecting life-sustaining treatment are necessary and therefore will be better able to make the right decisions. They assert that a major problem with the living will is the inability for people to prospectively determine what medical treatment they might need and what the best choice might be for them respecting life-sustaining treatment in the event of their incapability. These authors argue that people are better off leaving such decisions in the hands of loved ones who will make the best decision.

Fagerlin and Schneider list a variety of problems inherent to living wills: people do not know and cannot articulate what they will want in terms of future medical treatment, so they do not draft living wills; people are generally satisfied to delegate future treatment decisions to family or physicians, and so they do not need to draft living wills; people who do draft living wills do not present them to medical authorities or the documents cannot be located; and surrogate decision makers, typically family members, impose their own wishes instead of ensuring compliance with the prior expressed wishes of their loved ones.

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42 Fagerlin & Schneider, “Enough”, supra note 2 at 31-32.
43 42 USCA §1395 cc (1992) [PSDA]
44 Fagerlin & Schneider, “Enough”, supra note 2 at 38.
45 Ibid.
one, making the living will irrelevant. For all of these reasons, these authors argue, the living will fails.

Commentators such as Dresser and Schneider argue that proxy advance directives will avoid the problems common to living wills, including physicians' fear of liability if they follow an instruction directive.47 Alan Lieberson agrees that physicians continue to fear that they may be subject to legal reprisals if treatment is based upon instruction from an incompetent person's living will and therefore believe that litigation will be avoided if family members have consented to the decision to terminate treatment.48 These reasons all explain that proxy directives were developed because living wills were inadequate to meet patients' and physicians' needs. However, it is also arguable that the living will was rendered inadequate because of legislation that frequently made a living will inapplicable or provided insufficient legal protection for physicians who followed a living will.

In “Enough”, Fagerlin and Schneider consider the evidence that people do not make living wills but they do not examine the law, apart from criticizing the bureaucratic red tape imposed by the PSDA, to determine if the legislation also may be to blame for public reticence to make living wills. In particular, Fagerlin and Schneider do not examine living will statutes for deficiencies that contribute to the failure of the living will to be an effective advance planning mechanism. This thesis argues that deficiencies in living will statutes, including the narrowly worded legislation in many U.S. statutes and the failure of many Canadian provincial statutes to recognize living wills, are a significant cause for the failure of people to make living wills and for the failure of health care providers to follow them. Limitations and restrictions in advance directive legislation, as well as much of the criticism of living wills, frequently reflect a vitalist philosophy that seeks to protect and preserve life, regardless of quality of life.

47 Supra note 11; Ibid at 37.
In a 1993 text on advance directives, Norman Cantor explains that the “legislative hesitancy to endorse full-blown autonomy in the context of future-oriented terminal medical decisions also stemmed from political pressure. State legislative processes have commonly been impacted by a variety of interest groups (including religious groups and right-to-life organizations).” 49 Henry Glick agrees with this view stating that “Judges have generally expanded patient’s rights to control their own treatment while conservative legislators and interest groups seek to limit it”. 50

Some authors are sceptical that durable powers of attorney or health care proxies are sufficient to overcome all the problems that arise for families and physicians trying to resolve the complex questions relating to termination of a patient’s treatment. Fay Rozovsky explains:

Durable powers of attorney and healthcare proxy laws are not without problems. A designated decision maker may be unwilling or unable to fulfill the responsibilities of the patient’s surrogate. Ambiguity surrounding the scope of authority vested in the power of attorney also may prove problematic. Strict interpretation of a statute vesting the power of attorney with authority to consent to treatment may not include the power to withdraw consent to treatment. [emphasis original; footnote omitted]. 51

Henry Glick advises that “At first glance it seems that [proxy directives], which transfer decision making to another person sometime in the future, solve the problem of implementing the right to refuse treatment. But proxies in many states will find legal restrictions ...”. 52 Glick explains that in some states “right to life groups have been able to attach restrictions [on proxies] identical to those found in many living will laws”. 53

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50 Glick, Policy Innovation, supra note 13 at 119.
52 Glick, Policy Innovation, supra note 13 at 203.
53 Ibid.
An analysis of the two types of directives reveals that there are limitations to each, and that a combination of both types of directive may offer the greatest benefits to people who wish to maintain autonomous control over end-of-life treatment decisions.

3. Limitations of Living Wills

3.1. Statutory Restrictions

There is general agreement in the literature on advance directives that living wills fail to resolve all of the difficult questions that arise regarding medical treatment for incapable people nearing the end of life. To a great extent this is because the statutes restrict living wills from becoming effective under many relevant circumstances. For example, many living wills become effective only after “the attending physician determines that the declarant is in a “terminal condition” defined as “an incurable and irreversible condition, that, without the administration of life-sustaining treatment, will, in the opinion of the attending physicians, result in death in a relatively short time.” Therefore, the decision as to when a directive becomes effective is left to the physician, who may feel uncomfortable to activate it. Also, the patient’s condition may meet the criteria of constituting an incurable and irreversible condition that creates total incapacity, but the prognosis may not necessarily result in death “in a relatively short time”, so that the living will will not come into force although the maker of the directive intended to avoid treatment under this very circumstance.


55 Meisel & Cerminara, The Right to Die, supra note 7 at 7-55 citing 1989 Uniform Rights of the Terminally Ill Act 9B U.L.A. 609 § 1(9); See also Terry J. Barnett, Living Wills and More: Everything You Need To Ensure That All Your Medical Wishes Are Followed (New York: John Wiley & Sons, 1992) [Barnett, Living Wills] (“Many laws consider a condition not to be terminal whenever death can be delayed by life-sustaining treatment. Limitations of this kind can be misused to justify imposing life support on almost everyone who will eventually die from a chronic illness.”)at 6-7.
Alan Lieberson argues that the common law is more supportive of living wills than is the enabling legislation because of the legislative attempts to carefully avoid any form of permission for euthanasia or assisted suicide. These legislative measures narrowly limit the applicability of advance directives. Similarly, attempts to prevent the possibility of family coercion behind the drafting of an advance directive may adversely affect the frequency of execution of the documents. He argues that where the legislation is overly restrictive and the advance directive rarely meets the rules for implementation, there is a growing chance that it will simply be ignored.

Meisel and Cerminara explain that, despite some statutory modernization, restrictions within the statutes continue to limit the effectiveness of instructional advance directives. For example, in addition to requiring that a patient be terminally ill or permanently unconscious for a living will to be implemented, a few U.S. statutes require a waiting period between the diagnosis of a terminal condition and implementation of the directive. A substantial number of U.S. statutes limit the operation of the advance directive if the declarant is pregnant. Norman Cantor agrees that the legislation creates “significant obstacles to the widespread use of living-will type instruments”.

Suspension of a living will during the pregnancy of the declarant, a term found in the majority of U.S. living will statutes, reflects the underlying philosophy of the majority of groups who oppose living will laws. Opponents of living will legislation typically represent religious and right to life organizations that promote a philosophy of vitalism. In the U.S. context, Glick explains that “...state Catholic conferences universally are the most prominent interest groups affecting living will laws” [and] “the Catholic church was able to prevent the enactment of living will laws in most of the states for many

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56 Lieberson, *Advance Medical Directives*, supra note 48 at 32.
57 Ibid at 33.
58 Ibid.
59 Meisel & Cerminara, *The Right to Die*, supra note 7 at 7-79.
60 Ibid, citing for e.g. Colo. Rev. Stat. § 15-18-104(3).
61 Ibid, citing for e.g. Ala. Code § 22-8A-4(e), at 7-91.
62 Cantor, *Advance Directives*, supra note 49 at 34.
63 Glick, *Policy Innovation*, supra note 13 at 195.
years". However, as court cases increasingly recognized patients’ rights and legislation appeared more likely, Glick explains that “Catholic strategies changed toward producing limited laws, which also are counterweights and alternatives to liberal court decisions.”

The Law Reform Commission of Canada explained in a 1982 report that for supporters of vitalism:

...human life is an absolute value in itself and every effort must always be made not only to preserve it but to prolong it and hence to combat death with all available means. Considerations as to the quality of life become secondary and even unimportant. Life in the quantitative sense must be saved, maintained and prolonged because it represents a value in itself.

The Commission noted at that date that “vitalism has found some support within ...the medical profession [since] [t]he first and traditional role of medicine has always been to save lives, and to try to prolong life by combating disease and death”. However, while medical training may still teach physicians that the success or failure of medicine “is measured by the quality, strength and aggressiveness of the struggle waged” [to combat death] and “an aggressive struggle represents excellence in the practice of the art of medicine”, increasingly over the last several decades the medical profession has accepted the view that patients have the right to refuse life-sustaining treatment, that advance directives should be respected and that palliative care is a significant part of good medical practice. Norman Cantor stated in a 1987 text on medical ethics that

“[o]ver the last twenty years, more and more physicians have acknowledged that “palliative” care (aimed at making the patient comfortable but not prolonging his existence) is an acceptable

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64 Ibid at 202.
65 Ibid.
67 Ibid.
68 Ibid.
69 Canadian Medical Association Code of Ethics (Update 2004) www.cma.ca/index.cfm (reviewed at July 17, 2005) [CMA Code of Ethics]; see also, D.L. Hughes & P.A. Singer, “Family Physicians’ Attitudes Toward Advance Directives” (1992) 146 Canadian Medical Association Journal 1937 which indicated widespread support for advance directives in a 1992 survey of 1,000 Ontario family physicians, although the physicians rarely discussed advance directives with their patients. Current medical attitudes towards advance directives are discussed in more detail in Chapter Two, above.
approach in many terminal cases ... [and] the whole doctrine of informed consent is grounded on the premise that a physician’s judgement is subservient to a patient’s right to self-determination”.  

Although the Canadian medical profession no longer endorses a vitalist position, many groups in Canada remain opposed to the right of individuals to prospectively refuse life-sustaining treatment, recommending that such decisions should be left to supportive families. For example, in a March 2005 advance care planning seminar, Judith Wahl, a lawyer who acts for the Advocacy Centre for the Elderly of Ontario, explained frequently in her presentation to a group of B.C. health care providers that they should be suspicious of written instructions because a person might have “changed their mind”. She advised that a four year old instructional advance directive may no longer represent the patient’s current wishes and should not be considered binding, since the person might have “changed their mind several times” in that four year period.

The scepticism that documents refusing treatment are true expressions of a patient’s current wishes reflects fear that a patient may have changed their mind about the decision to refuse life sustaining treatment but failed to document the change and thus be subject to involuntary euthanasia. Meisel and Cerminara note that the New York Court of Appeals has “been especially plagued by this fear, and consequently, it has insisted upon a standard requiring a “clear expression of a present intention to forego” the treatment in question” [emphasis original to quote]. This issue was considered by the Florida Supreme Court in the case of In re Browning. The Court rejected the argument raised

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71 See CMA Code of Ethics, supra note 69 (recommending that physicians follow advance directives) at ss. 27-28.
72 British Columbia, Fraser Health Authority, Advance Care Planning: A Canadian Perspective for Physicians and Other Health Care Providers, Live Seminar, March 11, 2005, Auditorium B, Riverview Hospital, Coquitlam, B.C., VHS TC Burn Transfers of betacamSP originals, (Surrey: FraserHealth Planning and Systems Development for End-Of-Life Care, 2005).
73 Ibid at VHS Tape 1.
74 Ibid at 4-30 quoting In re Westchester County Med. Ctr. (O’Connor), 531 N.E. 2d 607, 614 (N.Y. 1988) (Hancock, J. concurring) (emphasis added) at 619.
75 568 So. 2d 4, 15 (Fla. 1990).
by the state that the patient may have changed her mind after issuing an advance
directive, finding that even a failure to act constitutes a choice.\textsuperscript{76}

The concern expressed by the New York Court of Appeals is consistent with the position
adopted by the New York Task Force\textsuperscript{77} which recommended against statutory provision
for living wills in that state. The New York Court of Appeals appears to be similarly
concerned with protecting the state's interest in the preservation of life in preference to
ensuring respect for patient autonomy. The argument articulated by Ms. Wahl reflects
this same concern about preservation of life. The apparent belief is that a proxy directive
will provide protection and assurance that a patient's best interests will be considered
before life supporting measures are terminated.

A failure to respect the prospective instruction of a capable patient to withhold treatment
during a future period of incapability appears to be contrary to Canadian law. In the case
of \textit{Fleming v Reid}\textsuperscript{78} the Ontario Court of Appeal considered the issue of whether an
instruction made when a person was capable should be followed during a subsequent
period of incapability. Robins, J.A. delivered the following reasoning:

\begin{quote}
A patient, in anticipation of circumstances wherein he or she may
be unconscious or otherwise incapacitated and thus unable to
contemporaneously express his or her wishes about a particular
form of medical treatment, may specify in advance his or her
refusal to consent to the proposed treatment. A doctor is not free
to disregard such advance instructions, even in an emergency. The
patient's right to forgo treatment, in the absence of some
overriding societal interest, is paramount to the doctor's obligation
to provide medical care. This right must be honoured, even
though the treatment may be beneficial or necessary to preserve
the patient's life or health, and regardless of how ill-advised the
patient's decision may appear to others.\textsuperscript{79}
\end{quote}

\begin{footnotes}
\footnotetext{76}{Meisel \& Cerminara, \textit{The Right to Die}, supra note 7 (citing \textit{In re Browning}; the \textit{Browning} case is
discussed below in connection with the decision of the Florida courts respecting the \textit{Schiavo} cases) at 4-31.}
\footnotetext{77}{See discussion about the New York Task Force in Chapter One \textit{supra} note 94 ff and accompanying text.}
\footnotetext{78}{(1991), 82 D.L.R. (4\textsuperscript{th}) 298 (Ont. C.A.) [Fleming].}
\footnotetext{79}{\textit{Ibid} at 310.}
\end{footnotes}
This decision counters the proposal that a person’s medical instructions, which were drafted when the person was capable, should be considered suspect since the person may have subsequently changed his or her mind. If a person has gone to the trouble of creating health care instructions, this effort should be evidence of their determination to have their wishes respected. People may subsequently change their minds and can therefore change their instructions. If instructions have not been amended, then the instructions should be considered evidence of the patient’s directions. The law should respect a person’s decision to create, amend and discard instructions as a reflection of respect for personal autonomy. Pursuant to Fleming v Reid, every Canadian is entitled to have their previously offered instructions for health care treatment respected.

In addition, people may consider their personal health care decisions to be a private matter between themselves and their physician, and may not wish to discuss them with any person apart from their physician. This privacy right must be respected under Canadian law.80

3.2. Living Wills Are Not Clinically Relevant

A significant criticism of living wills, mentioned not only by Fagerlin and Schneider, but by other authors who write about living wills, is that the documents frequently fail to achieve clinical relevance. Alan Lieberson agrees that one of the most likely reasons for the limited use of living wills in clinical practice is the “lack of clinical relevance of those documents that are written”.81 Some authors maintain that the underwhelming response of the public to the opportunity to exercise their “prospective autonomy” by creating an advance directive is primarily a reflection of the inattention paid to advance care planning

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80 Canadian physicians have a legal duty of confidentiality with respect to a patient’s health information: Halls v Mitchell, [1928] S.C.R. 125, as well as a fiduciary obligation to maintain patient health information in confidence: McInerney v MacDonald, [1992] 2 S.C.R. 138, in addition to any statutory obligations of confidentiality under provincial privacy statutes.

81 Lieberson, Advance Medical Directives, supra note 48 at 125.
by physicians.\textsuperscript{82} However, physicians' inattention to advance directives can be blamed on the law for several reasons. The lack of clinical relevance is frequently a direct result of the limited scope for operation of the directive under the legislation. Lieberson comments with respect to the earliest legislation that “[p]assage of the Natural Death Act led almost ten percent of Californians to write an LW [living will] the first year. Physician support was overwhelming, but LWs seldom influenced clinical care. Considering the wording of the Act, this is not surprising.”\textsuperscript{83}

Robert Olick comments critically on the “special conditions” and “burdensome requirements” imposed under various state advance directive statutes\textsuperscript{84}, noting especially the requirements in some states that “clear and convincing evidence” be produced in order for artificial nutrition and hydration to be terminated.\textsuperscript{85} He points out that while some statutes expressly preserve patients’ common law rights:

\begin{quote}
[t]here can be a large gap, however, between the niceties of legal interpretation and the daily practice of medicine. Statutory limitations on the right to refuse treatment through an advance directive often are taken literally by health care professionals and (sadly) attorneys who advise them. Too often, health care professionals believe the myth that anything the law does not expressly permit it therefore prohibits. Moreover, health care professionals often believe that statutory law is more important than case law and are more familiar with statutes addressing an area of medical practice than with individual cases. Collectively, these factors can create a climate of reluctance (if not hostility) to honor more expansive instruments.\textsuperscript{86}
\end{quote}

Olick also cites the SUPPORT study\textsuperscript{87} which found that physicians felt little or no obligation to honour an advance directive and tended to follow the advance directive only

\begin{footnotes}
\textsuperscript{83} Lieberson, \textit{Advance Medical Directives}, supra note 48 at 53.
\textsuperscript{84} Olick, \textit{Taking Advance Directives Seriously}, supra note 10 at 24.
\textsuperscript{85} \textit{Ibid}, \textit{e.g.} Nebraska and Oklahoma and, especially, Ohio which requires that the decision to terminate hydration and nutrition be ordered by a probate court.
\textsuperscript{86} \textit{Ibid} at 25.
\textsuperscript{87} Joan Teno et al, “Do Advance Directives Provide Instructions that Direct Care? SUPPORT Investigators, Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment”, (1997) 45:4
\end{footnotes}
in those cases where the directive confirmed their own judgement about what would be best for the patient. However, Joan Teno and colleagues, authors of the SUPPORT study, found no evidence “that a physician unilaterally decided to ignore or disregard an [advance directive]”. Rather, according to Teno et al, there was “a complex interaction of three themes”. [First,] “the contents of [living wills] were vague and difficult to apply to current clinical situations.” [Second,] “patients were not seen as ‘absolutely and hopelessly ill’ and thus, it was never the time to invoke the [living will].” [Third,] “family members or the surrogate designated in a [advance directive] were not available, were ineffectual, or were overwhelmed with their own concerns and did not effectively advocate for the patient.” Fagerlin et al also suggest that “surrogates may be guided by either their own treatment preferences or an urgent desire to keep their beloved alive.”

Olick agrees that ambiguity created by the law leads to confusion about the legality of advance directives in clinical practice. Although the law appears to impose “a prima facie duty to follow the directive” ... “the state of affairs in clinical practice reveals considerable confusion”. Olick goes on to explain: “Extant law is palpably ambivalent about the legal weight of advance directives and has failed to articulate a consistent message to guide clinicians”.

Norman Cantor explains how the statutory restrictions lead to clinical irrelevance of living wills as follows:

[the] principal flaw stems from provisions in many living-will laws significantly qualifying the circumstances in which

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Journal of the American Geriatric Society 519. [Teno, “SUPPORT Study”] (The SUPPORT study, which was conducted in five teaching hospitals in the United States and involved more than 9,000 patients, concluded that the existence of an advance directive made little difference to the end-of-life treatment that a patient received from health care providers.).

88 Olick, Taking Advance Directives Seriously, supra note 10 at 27.
89 Teno, “SUPPORT Study”, supra note 87 at 519-20.
90 Ibid at 513-518.
92 Ibid.
93 Ibid.
94 Ibid.
legislative endorsement is accorded to implementation of advance
instructions. Because such legislation appears to limit the scope
of a declarant's autonomy (in contrast to the broad common-law
acceptance of prospective autonomy), it threatens to have a
negative impact on the responsiveness of health care providers to
living-will type instruments. Statutory restrictions may well
cause health-care providers to have hesitations about the legal
effect of certain living-will instructions. The providers' risk-
aversive tendencies would then prompt irresolution and thus
hamper the implementation of advance instructions.

Cantor identifies the reason for such limitations, citing George Alexander's comment that
living will statutes tend to be "riddled with restrictions presumably attributable to
excessive caution," and further explains that:

[Despite the considerable potential of living-will type laws, major
disappointments must be noted regarding the bulk of such
legislation to date. ... First, the legislation in most jurisdictions is
seriously flawed. The state political processes have clearly been
impacted by a variety of interest groups: health-care providers,
religious groups, and right-to-life organizations, as well as
patients' rights advocates. The result has been serious limitations
on the circumstances in which state legislatures have given their
endorsement to the implementation of living wills.]

3.3. Failure To Ensure Complete Immunity To Physicians

Meisel and Cerminara explain that concern about physician liability has been an
important motivating force in the development of the law respecting advance directives.
Physicians are concerned both about foregoing treatment and about providing treatment
when family members wish it to be stopped although, historically, prosecutions of
physicians in connection with their decision to follow an advance directive are
"exceedingly rare" and are resolved in the clinical, rather than the judicial, setting.

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95 Cantor, Advance Directives supra note 49 at 35.
96 Ibid at 181 fn 14, citing George J. Alexander, "Time for a New Law on Health Care Advance
97 Ibid at 34.
98 Meisel & Cerminara, The Right to Die, supra note 7 at 1-9.
99 Ibid at 1-11.
Canadian law creates fear of liability for physicians who fail to carry out every potential life-sustaining treatment when family members demand such measures, notwithstanding the previously expressed wishes of an incapable person, through a failure to offer explicit immunity to health care providers under federal or provincial legislation.\textsuperscript{100}

Dr. Glenn Greiner described the practical issue in a 1991 article:

> What I want to do is try to explain why, in many instances, the individual’s decisions are not followed.

In the first place, I think there is a large fear of the law. As a medical student recently put it to me when we were discussing a case in which I thought treatment had gone on too long, “Nobody ever got sued for overtreating.” Reforming the law to make it crystal clear that patients do have the right to refuse treatment—even life saving treatment—would go a considerable way in relieving that fear.\textsuperscript{101}

Lieberson deplores the failure to integrate common law concepts into statutory living wills, stating “[t]his failure to extend the immunity possible through statutory law in pace with common law developments has been a major failing of living wills statutes, which only require interested and courageous legislators to reverse.”\textsuperscript{102}

### 3.4. Statutory Impediments to Public Use of Living Wills

Robert Olick explains that “[living will] legislation … has been marked by substantive and procedural limitations on the scope of permissible patient choice.”\textsuperscript{103} He notes that many early statutes excluded artificially provided fluids and nutrition from the range of life-sustaining procedures that could be refused, although many state laws have been amended since the \textit{Cruzan}\textsuperscript{104} decision to allow patients the right to also refuse feeding

\textsuperscript{100}See Chapter Four for a discussion of the failure of Canadian federal and provincial legislation to provide criminal and civil immunity to physicians who comply with advance directives.


\textsuperscript{102}Lieberson, \textit{Advance Medical Directives, supra} note 48 at 140

\textsuperscript{103}Olick, \textit{Taking Advance Directives Seriously, supra} note 10 at 23.

\textsuperscript{104}\textit{Cruzan V Director, Mo. Dept of Health}, 497 U.S.261 (1990) [\textit{Cruzan}];
Although most living will statutes preserve common law and constitutional rights, living will legislation is often so narrowly drafted that it creates uncertainty about the legitimacy of advance directives. Importantly, living will legislation imposes no penalty on physicians for failing to respect an advance directive: the documents are rights without remedies.

Regarding the absence of remedies, Olick states that there is no “teeth of enforceability” with respect to advance directives. He notes that the usual maxim that ‘for every right there is a remedy’ does not seem to apply in the case of advance directives. Consequently, physicians have been led to believe that there is little or no price to pay for failing to adhere to a patient’s advance directive.

Although the judiciary appears to view advance directives as dispositive, neither courts nor legislators have attributed to such documents traditional contract notions of breach and remedy. ... Even decisions validating claims of battery (the initial basis for the doctrine of informed consent) have severely limited monetary recovery to nominal damages.

Krohm and Summers agree with Olick’s assessment, asserting: “Directives are rights without remedies. There are almost no jurisdictions which include statutory remedies for breach.” The absence of a legal remedy for failure to follow an advance directive may reflect a vitalist philosophical position that, since life is sacred, there can never be a penalty associated with prolonging life.

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107 *Ibid* at 28-29.
108 *Ibid*.
111 Note, however, the thesis argued by Edward Keyserlingk, that “in some circumstances to initiate treatment or prolong or postpone death can reasonably be seen as non-beneficial to the patient. One such circumstance is excruciating, intractable and prolonged pain and suffering.” [emphasis original] Edward W. Keyserlingk, *Sanctity of Life or Quality of Life in the Context of Ethics, Medicine and Law*, A Study written for the Law Reform Commission of Canada (Ottawa: Minister of Supply and Services Canada, 1979) at 60.
3.5. Use of Vague Terminology and Statutory Complexity

Fagerlin and Schneider argue that patients do not know, or cannot articulate, what they want in terms of future treatment; hence, advance directives are too vague, general, specific or unclear to be of any use and consequently they are not followed. The living will is often criticized for using vague terminology that requires interpretation and qualification. The use of the expressions “terminal condition”, “extraordinary measures” and “unusual or heroic means” are mentioned by some authors as examples of such vague terminology. Norman Cantor explains that “[t]erms such as “heroic” or “extraordinary” are too often used in instruction directives to describe types of unwanted medical intervention. The terms have no commonly understood content and serve only to confuse”. However, the vague language used in living wills, especially the earliest documents, reflects living will legislation. For example, many living will statutes were drafted with the limitation that the person be in a “terminal condition” before the living will would be effective. If, however, living wills used the exact language set out in the statute they were held to be vague. Cantor explains that:

[the sample living wills sometimes provided within living will statutes are even more problematic. In the first place, they commonly state that the patient must be in a “terminal condition” as defined in the particular statute. ...Such a limitation may well be inconsistent with a typical declarant’s wish to avoid a prolonged, highly debilitated existence or a protracted period of decline associated with degenerative diseases.]

Living will legislation is replete with unnecessary complexity, rendering it inaccessible to many people. Krohm and Summers note that advance directives can be intimidating because they are inordinately technical and full of jargon. Often the documents are unnecessarily complex and lack “readability”. Additionally, cost can be a barrier to

112 Fagerlin & Schneider, “Enough”, supra note 2 at 34 -35.
113 Cantor, Advance Directives, supra note 49 at 57.
114 Ibid.
115 Ibid at 58; See also Barnett, Living Wills, supra note 55 (“Terminal condition limitations undermine the basic reasons people make health-care planning documents: to avoid prolonging their dying.”) at 7.
116 Krohm & Summers, Advance Health Care Directives, supra note 54 at 57
completion, especially if the documents are seen to be complex. These authors argue that advance directives should not be costly to implement since they ought to be clear and straightforward for people to understand and execute.\(^ {117}\) Nancy King agrees that most state statutory advance directive documents “contain their own barriers to execution” including the time required to understand and complete them owing to their complexity.\(^ {118}\)

In many U.S. jurisdictions\(^ {119}\) and in some Canadian jurisdictions\(^ {120}\), directives must be witnessed or notarized or both. Krohm and Summers point out that it may be difficult to assemble witnesses to attend before a notary.\(^ {121}\) These authors also note that most U.S. advance directive statutes require the writer to be 18 years old\(^ {122}\) which therefore denies mature minors their rights to consent to or refuse medical treatment.\(^ {123}\)

### 3.6. Incompetent Revocation

Significant problems have been identified in connection with the typical requirement in the statutes that the currently expressed wishes of a patient, regardless of their diagnosed incompetence, must be respected by a substitute decision maker or a physician in preference to the patient’s previously expressed wishes in an advance directive.\(^ {124}\) This concern has been described by Thomas Mappes as the “problem of incompetent

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\(^{117}\) \textit{Ibid.}


\(^{119}\) \textit{e.g.} Arizona, California, Hawaii.

\(^{120}\) \textit{e.g.} B.C., which requires that a lawyer review a representation agreement (proxy advance directive).

\(^{121}\) Krohm & Summers, \textit{Advance Health Care Directives}, supra note 54 at 59. (This can be especially true if the patient is in hospital.)

\(^{122}\) Alabama and Nebraska specify 19; similarly in B.C. the writer, representative and witnesses all must be 19 years old.

\(^{123}\) Krohm & Summers, \textit{Advance Health Care Directives}, supra note 54 at 62.

revocation” and is closely related to the “past wishes versus present interests problem.”

Mappes explains that state living-will statutes ordinarily provide for a patient—whether competent or incompetent—to revoke a living will at any time. Thus the system essentially gives priority to the present wishes of the incompetent patient over the past wishes of the previously competent patient.

3.7. Summary of Statutory Limitations

Roger Cotterrell proposes that “perhaps the most obvious characteristic of law... in Western societies is its isolation [and separation] from other aspects of life”. He argues that, to many people, the law is an intimidating profession centred on an obscure body of knowledge. Further, most people will seek to avoid the law since legal experience is “thought to exist in a different realm from social experience.” Therefore, the use of the law to change behaviour or to serve as a vehicle for social goals will be avoided if “cloaked in a legal mantle”. The legal mantle cloaking living will legislation causes people to avoid drafting instructional advance directives, despite a desire to provide prospective instructions.

Cotterrell argues that law can provide the institutional framework to exert influence for societal change, but must exhibit a number of characteristics in order to do so. He adopts the seven conditions under which law can “effectively influence behaviour and perhaps attitudes” described by William Evan as a framework for his discussion. Among these seven conditions are that enforcement agents must be committed to the behaviour required by the law and that positive sanctions must be as important as negative ones. “Laws ... which seek positive societal changes of major proportions must rely as much

127 Ibid.
128 Ibid.
on education and persuasion as on negative sanctions.” In addition, Cotterrell explains that effective protection must be provided for the rights of those who would suffer as a result of evasion or violation of the law.

Cotterrell’s arguments must be taken into consideration by drafters of advance directive statutes if they intend the legislation to encourage people to plan for end-of-life care. The foregoing examination of advance directive legislation reveals that it fails to meet these necessary elements of legislation which is intended to encourage a particular social behaviour. As a consequence of the multitude of statutory limitations common to the legislation, advance directive laws are a primary cause of the widespread failure of people to create, or doctors to respect, living wills.

3.8. Moral Objections to Living Wills: Precommitment

Closely related to the concern that people may change their minds about their decision to refuse life-sustaining medical treatment is the concern that earlier capable selves should not have the right to choose treatment for an altered, incapable self. Some authors question whether individuals should have the moral authority to precommit their later selves in ways their later selves may reject. Professor Charles Weijer, is also concerned about the fact that living wills “are limited by our inability to fully anticipate future medical circumstances.” Rebecca Dresser argues that “precommitment” is a dubious concept in bioethics on the grounds that the present self should not have the

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130 Ibid (quoting William K. Muir, “Under What Circumstances Can We Bring About Attitude Change?” (1967), reprinted in Grossman, Law and Change (“If an individual is induced, not compelled, to act in a certain way, he will search for information to support his commitment.”) at 51.)


ability to bind the future incapable self.  

(One of her arguments includes the concern, discussed above, that a person may have changed their wishes, but failed to update their advance directive.) Dresser proposes that a competent person drafting an advance directive may not have the same interests and wishes as the incompetent person they become as a result of some degenerative disease, such as Alzheimer’s disease. The incompetent Alzheimer’s patient may have a relatively satisfactory life, although not the life that his or her former self would have wanted, and may not wish to reject all forms of life-sustaining treatment. She argues that people today fear “that physicians will forego treatment too early, at a point when life-sustaining measures offer a meaningful chance for survival.” Dresser argues that physicians and others have a legal duty “to protect incompetent patients from harm” and she recommends that advance directives be overridden in favour of external determination of the patient’s best interests.

Ben Rich explains that this reaction is an endorsement of the “personal identity theory” offered by philosopher Derek Parfit, which suggests that the earlier capable person and the later incapable person are, in fact, two different persons with different interests. Rich disagrees, adopting Ronald Dworkin’s view that the former capable person has future critical interests which can be harmed if her or his earlier capable wishes are not respected. Rich argues that executing an advance directive is the exercise of “prospective autonomy” or “the process of infusing narrative unity into the life of a person.” In his view, arguments that a written advance directive should be ignored when it conflicts with what are considered the current best interests of an incapable patient dismiss the critical importance of respecting the person’s prospective autonomy.

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133 See generally Dresser, “Precommitment” supra note 39.
134 Ibid at 1834-1835.
135 Ibid at 1845.
136 Ibid at 1846.
137 See Rich, “Personhood” supra note 82.
138 Ronald Dworkin, Life’s Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom, (New York: Alfred A. Knopf, 1993) [Dworkin, Life’s Dominion] (“[M]ost people think that they have what I shall call critical interests that it does make their life genuinely better to satisfy, interests they would be mistaken, and genuinely worse off, if they did not recognize.”) at 201 ff.
139 Rich, “Personhood” supra note 82 at 616.
Ronald Dworkin describes this concept as recognizing the “critical interests” that define our vision of ourselves, thus acknowledging our dignity as human beings. He states: “A person’s right to be treated with dignity . . . is the right that others acknowledge his genuine critical interests”. Dworkin argues that a seriously demented person retains his critical interests because what happens to him in his demented condition affects his life as a whole. Adopting Dworkin’s argument, our agreement to respect an individual’s personal sense of dignity, their personal critical interests, is a greater acknowledgement of the sanctity of their life than a benevolently intended failure to respect their wishes.

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140 Dworkin, *Life’s Dominion*, supra note 138 at 236.  
4. Limitations of Proxy Advance Directives

Many academics explain that proxy directives developed to resolve the inadequacies of the instructional advance directive or living will. There are advantages to the appointment of a proxy, particularly the fact that health care providers can discuss proposed treatment decisions with the proxy, but there are disadvantages as well. The proxy directive, in common with the instructional directive is limited by some statutory restrictions and limitations, and the concept of substitute decision making is subject to extensive criticism. Additionally, conflict of interest is a potential problem.

4.1. Statutory Limitations

In some jurisdictions, such as Missouri and New York, the courts have determined that evidence of a patient’s express prior instruction may be necessary to provide the clear and convincing evidence necessary under the statute for termination of nutrition and hydration. Authorization of a proxy may be insufficient in these states to direct the termination of hydration and nutrition, notwithstanding the finding of the U.S. Supreme Court that the provision of nutrition and hydration constitute medical treatment. Proxy directives are also subject to the same types of statutory requirements for execution described above for living wills. These statutory requirements make the materials difficult to understand and the burdensome execution formalities work against completion of proxy directives.

142 See for e.g. King, Making Sense, supra note 118 ("Good-faith engagement with a patient's wishes by means of an advance directive is always challenging; indeed, this accounts for the ever-increasing popularity of proxy directives, which give caregivers a designated person to work things through with.") at 184; Meisel & Cerminara, The Right to Die, supra note 7 ("Recognition of the difficulties inherent in living wills is probably responsible for the increase popularity of proxy directives.") at 7-11.
143 Meisel & Cerminara, The Right to Die, supra note 7 at 2-9.
144 See Cruzan, supra note 104; In Re Westchester County Med. Ctr. On behalf of O'Connor, 531 N.E. 2d 607 (N.Y. 1988); and see Rozovsky, Consent to Treatment, supra note 51 at 7:51 ff.
145 Cruzan supra note 104 (The Court's position on this issue was most forcefully stated by Justice O'Connor in her concurring judgment: " The liberty guaranteed by the Due Process Clause must protect, if it protects anything, an individual's deeply personal decision to reject medical treatment, including the artificial delivery of food and water" at 289.)
146 See text at 3.5 above.
4.2. **Substitute Decision Making**

A complex and contentious issue that arises in connection with the proxy advance directive is the basis of decision-making for the now incapable person. The ability of a substitute to effectively and legitimately “speak” for an incapable person is among the most ethically challenging controversies associated with proxy advance directives. The proxy for decision-making typically is directed to act as a “substitute decision-maker” for the person who has appointed them under a health care proxy. In the role of a substitute decision-maker, the proxy must attempt to make the decision the person would have made. Progressively, the “subjective standard” for substitute decision-making, meaning the decision the incapable person would have individually made, and not the decision that most people would make, is considered to be the preferred standard. Where the proxy has no knowledge of the decision the person would have made, and is unsure of the person’s personal values, then the proxy typically is directed to make a decision in the “best interests” of the person. Robert Olick comments that:

> [t]he substantive standard of choosing as the patient would has been the most controverted and troublesome aspect in life-and-death litigation. The primary reason is that implementing this standard and determining whether to authorize the surrogate to direct forgoing of life support can become a thorny evidentiary question. Couched against the law’s time-honoured presumption in favour of life, the burden of proof that the patient would refuse life support rests with the surrogate.

4.2.1. **Substituted Judgement Standard**

The substituted judgement standard was first used in connection with the withdrawal of life-sustaining treatment in the decision of *In re Quinlan* when the court “imagined a transient moment of lucidity for Ms. Quinlan in order to convey the nature of the decision...
that a proxy would be asked to make.” The overtly fictional nature of substituted judgement “reached its full flower” in the 1977 decision of Superintendent of Belchertown State School v. Saikewicz when the “transient moment of lucidity became a complete, rather than just a partial, fiction,” since Joseph Saikewicz had never been competent. Nancy King wonders if the court in Saikewicz was concerned that a reversion to a strictly best interests test for a never-competent person might invariably lead to a determination in favour of preserving life “because personal values come strongly into play in end-of-life decision making.”

4.2.2. Subjective vs. Objective Standard

The standard used for substituted decision-making can vary from the highly subjective standard, i.e. the exact decision that the patient previously chose, to the more objective substituted standard, based upon the decision that the patient would likely have made, based upon his or her known values. Meisel and Cerminara explain that the “subjective” substituted judgement standard requires the substitute to be guided by the now incompetent patient’s actual wishes. That is, the substitute should ensure that the decision made to forgo life-sustaining treatment is made “based on the instructions the patient actually gave before losing decisionmaking capacity” [italics original]. “[U]nder this standard, life-sustaining treatment may be withdrawn or withheld only if the patient himself authorized the forgoing of treatment prior to losing decisionmaking capacity …[rather than] as the substituted judgment standard permits, his or her probable wishes.” Unless a patient has created a living will or some other document, or has given explicit instructions to a proxy, meeting the test of the subjective standard for substituted judgement is very difficult.

150 King, Making Sense, supra note 118 at 190.
151 Ibid.
153 King, Making Sense, supra note 118 at 190.
154 Ibid at 191.
155 Meisel & Cerminara, The Right to Die, supra note 7 at 4-28.
156 Ibid at 4-29.
Three reasons are given for preferring a subjective standard for substitute decision making. The first is that the subjective standard respects patient autonomy, in that the patient’s actual instructions are followed as though the patient was competent. The second reason is that the standard ensures that substitutes do not impose their own preferences into the decision. The third reason is the fear that a patient may have changed his or her mind about the decision to refuse life sustaining treatment and not articulated or documented this change. Therefore, the standard effectively requires evidence of the patient’s wishes immediately prior to his or her losing capacity.

The result of such an exacting standard as required under the subjective test creates serious problems: only those people who have thought to create a living will may have their wishes fulfilled, assuming an objection is not sustained that they may have changed their minds prior to becoming incompetent. In his dissenting opinion in the Cruzan decision, Mr. Justice Brennan raised the fact that such a stringent evidentiary test will not serve the public well in light of the fact that only a small part of the population writes an advance directive.

Although the subjective standard is too exacting to be practical, the objective substituted standard is problematic as well. The substituted judgement standard is frequently criticized for the fact that it is based upon a fiction. For example, Professors Tom Beauchamp and James Childress explain:

The standard of substituted judgment is, at best, a weak autonomy standard. ...[t]he basic premise of the substituted judgment standard rests on a fiction. An incompetent person cannot literally be said to have the right to make medical decisions if that right can only be exercised by other competent persons.

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157 Ibid at 4-29 – 4-31.
158 See supra note 74 ff and accompanying text above for discussion of the issue of undocumented change of mind.
159 Cruzan, supra note 104, (Brennan, J., dissenting) (“Too few people execute living wills or equivalently formal directives for such an evidentiary rule to ensure adequately that the wishes of incompetent persons will be honoured.”); See also Meisel & Cerminara, The Right to Die, supra note 7 at 4-32.
Beauchamp and Childress argue that previously competent patients who have autonomously expressed their preferences in an oral or written directive should be treated under the pure autonomy standard but, where the person’s wishes are unknown, a surrogate should make decisions for the person in their best interests. That is, Beauchamp and Childress collapse the concept of surrogate decision-making into only two options. The proxy must follow the previously expressed wishes of the now incapable person or, if the person’s wishes are unknown, the proxy must act in the best interests of the person despite the acknowledged shortcomings of the best interests approach.\textsuperscript{161}

4.2.3. Best Interests Standard

However, the “best interests” standard is also subject to controversy, particularly when applied to a person in a PVS state. In the English case of \textit{Airedale NHS Trust v Bland},\textsuperscript{162} regarding the application to terminate life supporting medical treatment for Anthony Bland, a young man who had fallen into a PVS state after a trampling incident had deprived him of oxygen, the Judges of the House of Lords “continued applying the best interests test but now with a significant degree of self-admitted contradiction” [in view of their observations that] “the PVS patient had no interests whatsoever”.\textsuperscript{163} Lord Mustill mused in the \textit{Bland} decision:

What other considerations could make it better for him to die now rather than later? None that we can now measure, for of death we know nothing. The distressing truth must be shirked in that the proposed conduct is not in the best interests of A. Bland, for he has no best interests of any kind.\textsuperscript{164}

In her discussion of the difficulty in using a best interests standard for PVS patients, Nancy King similarly describes:

\textsuperscript{161} \textit{Ibid} at 103.
\textsuperscript{162} [1993] 1 All E. R 821 \textit{[Bland]}.
\textsuperscript{163} Manderson, \textit{Courting Death, supra} note 1 at 185.
\textsuperscript{164} \textit{Bland supra} note 162 at 894.
the problems of attempting categorical best interests determinations by addressing a specific condition in which the patient is said by definition to have no current interests on which a best interests determination may be based. The problem of ascertaining the patient’s best interest under other circumstances continues ... 165

Beauchamp and Childress also comment on the potential failing of the best interests determination, stating “[u]nfortunately, the best interests standard has sometimes been interpreted as highly malleable, thereby permitting values that are irrelevant to the patient’s benefits or burdens”. 166

4.3. Conflict of Interest

Meisel and Cerminara note that conflicts of interest “almost always exist in decisionmaking about life-sustaining treatment”. 167 The conflicts can be financial in nature, such as when a surrogate “stands to gain financially by the patient’s death [footnote omitted]” 168 or emotional, such as by “a wish to end a tremendous emotional strain on his own or other family members’ lives caused by the patient’s illness [footnote omitted]”. 169 They comment that family members may also be motivated by guilt or by denial, causing them to consciously or unconsciously “err on the side of administering treatment”. 170

There are also practical issues that hinder the effectiveness of proxy directives. Krohm and Summers advise that

[c]onflict with and among families may present the most challenging obstacle to implementation of a directive. During a health care crisis, latent hostilities may accelerate into venal and

165 King, Making Sense, supra note 118 at 188.
166 Beauchamp and Childress, Principles, supra note 160 at 103.
167 Meisel & Cerminara, The Right to Die, supra note 7 at 3-96.
168 Ibid at 3-98 citing Cruzan, supra note 104 (Stevens, J. dissenting) (“trial court’s findings make it clear that the parents’ request had no economic motivation”) at 333.
169 Ibid at 3-100, citing Cruzan, supra note 104 generally.
170 Ibid.
vicious arguments, leading family members to challenge the validity of a directive or the authority of a designated agent or proxy. 171

Another problem that Krohm and Summers identify is the difficulty of resolving conflicts among family members or friends of the patient who may all serve as substitute decision makers. Where the attending physician identifies one person as the primary substitute decision-maker, conflicts may arise among the remaining potential candidates. 172

171 Krohm & Summers, Advance Health Care Directives, supra note 54 at 106.
172 Ibid at 101.
5. Summary of Limitations Comparison

This analysis indicates that there are limitations to both types of advance directive. Consequently, some authors argue that the most advantageous approach is to combine a living will with a durable power of attorney for health care or, in other words, create a single advance directive that both gives instructions regarding preferences for medical treatment in the event of incapacity and appoints a proxy.\(^{173}\)

This thesis argues that respect for autonomy requires governments to ensure citizens have a choice of instrument with which to plan end of life treatment and that such choice should include the option of creating an instruction advance directive, a proxy advance directive or a combination of the two. The latter option would enable health care providers to act on the instructions if they are clear and pertinent but, in the event the instructions are inapplicable to the particular circumstances or seem otherwise inappropriate for the now incapable patient, the health care providers can consult with the proxy to seek appropriate consent to treatment.

The next section considers two controversial cases where a decision to terminate life-sustaining treatment was legally contested by family members. This thesis argues that neither type of advance directive will completely satisfy the concern of relations who refuse to accept the death of a beloved member of the family or the philosophical opposition held by members of the right to life to termination of life support.

\(^{173}\) See e.g. Meisel & Cerminara, *The Right to Die*, *supra* note 7 at 7-14.
6. Resolving Hard Cases

6.1. Two Hard Cases

1. In re Schiavo

The tragic case of In Re Schiavo [Schiavo] made headline news for more than a year, both for its heart-wrenching drama and for the astonishing array of political manoeuvres it provoked. Terri Schiavo [Terri] became comatose at age 28 and remained that way for more than 14 years. Numerous neurological assessments diagnosed her to be in a permanent vegetative state (PVS) with no reasonable hope of recovery. Unable to swallow on her own, Terri was tube fed continuously. She did not leave written instructions respecting her choice of health care if she were ever in such a situation, but she had told her husband and friends that she would not want to be kept alive on life support indefinitely.

After Terri had remained in a PVS state for more than eight years, and every effort at rehabilitation had proven hopeless, her husband Michael began legal steps to follow her previously expressed wishes not to remain on life support indefinitely and to have the feeding tube removed. Under the Florida scheme for guardianship appointment, Michael was named her guardian and was statutorily empowered to direct her health care. Aware that his strongly Catholic parents-in-law, the Schindlers, were fiercely opposed to removal of their daughter’s life supports, Michael went to Guardianship Court for direction on the matter. After reviewing the testimony of five neurologists and numerous witnesses, the Guardianship Court held that Terri would not have wanted to remain in her PVS state and ordered removal of the feeding tube.

The Guardianship Court in Schiavo considered and followed the landmark Florida case of In re Browning [Browning] in which the Florida Supreme Court confirmed that an incapacitated person has the same privacy right to refuse life supporting treatment as a

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174 Schiavo supra note 16
175 Ibid, Schiavo 1.
176 Supra note 75.
person with capacity and that no significant legal distinction exists between various artificial means of life support. *Browning* held that a surrogate must adopt the concept of substituted decision-making so as to make the decision that the patient would choose, and asserted that the individual’s right of privacy and self-determination is not served if the substitute makes a decision which the family, state or public opinion preferred.

Reviewing all of the evidence in the *Schiavo* case, the Guardianship Court found that Terri’s preferred decision would be to remove the life supporting feeding tube.

The ability to refuse life-sustaining nutrition and hydration is statutorily recognized under the Florida advance care statute.\(^{177}\) The relevant provisions are as follows:

765.101 (10) "Life-prolonging procedure" means any medical procedure, treatment, or intervention, including artificially provided sustenance and hydration, which sustains, restores, or supplants a spontaneous vital function. The term does not include the administration of medication or performance of medical procedure, when such medication or procedure is deemed necessary to provide comfort care or to alleviate pain.

765.102 (3) The Legislature recognizes that for some the administration of life-prolonging medical procedures may result in only a precarious and burdensome existence. In order to ensure that the rights and intentions of a person may be respected even after he or she is no longer able to participate actively in decisions concerning himself or herself, and to encourage communication among such patient, his or her family, and his or her physician, the Legislature declares that the laws of this state recognize the right of a competent adult to make an advance directive instructing his or her physician to provide, withhold, or withdraw life-prolonging procedures, or to designate another to make the treatment decision for him or her in the event that such person should become incapacitated and unable to personally direct his or her medical care.

Terri’s parents’ legal battle to keep the feeding tube implanted sparked a public outcry with fierce debate on both sides of the issue. Florida and federal courts unfailingly upheld the decision of the Guardianship Court that Terri would not want to live on

\(^{177}\) Flo. Stat. § 765 [Health Care Advance Directives].
continuous life support and consistently approved the removal of the feeding tube. Politicians at both the state\textsuperscript{178} and federal\textsuperscript{179} level intervened to assuage the vociferous outcry from the strongly conservative and religious right to keep Terri alive on life support. After all judicial and political avenues of intervention had been unsuccessfully pursued by Terri’s parents,\textsuperscript{180} and her feeding tube had been disconnected, Terri passed away on March 31 of 2005.

Many news articles that commented on the Schiavo case observed that Terri, in her PVS state, did the general public a service by highlighting the benefit of preparing an advance directive to guide family and medical staff in the event of future incapacity.\textsuperscript{181} These commentators imply that the case could have been resolved more easily if Terri had provided some tangible form of clear and convincing evidence, \textit{i.e.} written evidence, that she did not wish to remain alive indefinitely on life support. It is arguable, however, that neither a living will nor a proxy would have resolved the Schiavo case to the satisfaction

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\textsuperscript{180} The US District Court for the Middle District of Florida, Tampa Division, denied injunctive relief on March 25, 2005 in a chambers application (\textit{Schiavo ex rel. Schindler v. Schiavo supra} note 179). (Among the arguments brought by the Schindlers was the claim, based on the \textit{Cruzan} decision (\textit{supra} note 104), that due process of the 14\textsuperscript{th} amendment requires decisions to remove hydration and nutrition to be supported by clear and convincing evidence that the patient would have made the same decision. The Chambers Judge held that “…the Supreme Court in \textit{Cruzan} did not mandate application of the heightened clear and convincing evidence standard. The question before the \textit{Cruzan} court was whether the state’s application of the heightened evidentiary standard overburdened the patient’s right to refuse medical treatment, not whether it adequately protected the patient’s right to life.” James D. Whittemore, U.S. D.J. at 1167.)

\textsuperscript{181} See for e.g. “High court won't rule on feeding tube case” Editorial, \textit{DailySouthtown [of Illinois]}, 25 January, 2005 ("Terri Schiavo’s loved ones have been fighting tooth and nail in court … That’s because she left no written instructions...The Terri Schiavo case is the best argument we’ve heard for having a living will, stating whether an individual wants extraordinary steps to be taken to extend his or her life.") online: <www.dailysouthtown.com/southtown/dsedit/x26-ed1.htm> ; Karen Hanna, "More seek info on end-of-life directives." \textit{The Herald-Mail} (of Mi.) 28 March, 2005 ("The national exposure of the Terri Schiavo case has resonated with people locally, prompting some to seek information about end-of-life directives, a spokesman for Maryland Attorney General J. Joseph Curran said last week.") online: <http://www.herald-mail.com>.
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of Terri’s parents or to the right to life organizations that lobbied to maintain her feeding tube in place. Arguably, a living will would have provided greater certainty about Terri Schiavo’s personal wishes respecting her preferences for medical treatment in the event she became permanently incapacitated. Nevertheless, the analysis in Section 3 above indicates that vitalists will not necessarily accept written instructions as authoritative and might have protested that Terri had “changed her mind”, as in fact her parents did with regard to testimony about her statements made while she was capable. Carl Schneider quotes the court-appointed guardian ad litem as noting that the Schindlers “stated that even if Theresa [Terri] had executed a formal, written living will, they would have fought to have it voided because they did not believe it was consistent with their and her beliefs.” 182

Professors Rebecca Dresser and Carl Schneider both say an instructional advance directive, or living will, would not have helped in the Schiavo case. 183 It is probable that a living will would not have been sufficient evidence of Terri’s instructions to satisfy the family or the right to life groups who lobbied to keep Terri’s feeding tube implanted, since their objections were based on vitalism. The argument made by authors such as Dresser and Schneider that a living will would not be successful in resolving these cases is because the primary objections to the living will are premised on a philosophy of vitalism.

Would a proxy advance directive appointing Michael Schiavo as Terri’s proxy to provide health care instructions, as provided for under the Florida Statute, 184 have helped to resolve this case? In fact, Michael was appointed Terri’s legal guardian to make health care decisions for Terri by the Florida probate court. 185 Michael Schiavo’s argument that he was acting in accordance with what he perceived to be Terri’s wishes, as confirmed

184 Flo. Stat. § 765.102 (3)
185 Schiavo I supra note 16.
and directed by the Florida probate court, did not assuage the wrath of the family or the objections of the right to life lobbyists.

2. *Jantzen v Jantzen*\(^{186}\)

A similar, albeit not so dramatic, case occurred in Ontario in 2002. In *Jantzen v Jantzen* [*Jantzen*], the wife of a 43 year old man who was diagnosed in a PVS with no reasonable hope of recovery was taken to court by his sister after the wife agreed to medical recommendations that life supports be terminated for her husband. Mrs. Jantzen was the appropriate legal substitute to provide consent or refusal to treatment on behalf of her husband under S. 20(1) of the Ontario *Health Care Consent Act*.\(^{187}\) Mrs. Jantzen and her own sister provided evidence that Mr. Jantzen has expressed that wish not to be maintained on life supports in the event he became incapable. Mrs. Jantzen initially had postponed removal of her husband’s life support in recognition of the anguish his siblings felt about its removal, but was eventually determined not to leave her husband on artificial life support indefinitely. Mr. Jantzen’s sister asked the court to name her guardian of her brother in order to maintain his life supports in place. The sister asked to be named guardian despite the fact that her brother had been happily married for 12 years and there was no reason to suspect his wife did not have her brother’s best interests at heart in accepting the medical recommendation to terminate life supports. The Ontario Superior Court of Justice found that ongoing medical treatment would not improve Mr. Jantzen’s medical condition or his quality of life and would be contrary to his previously expressed wishes. Aitken, J. appointed Mr. Jantzen’s wife to be guardian of her husband, and also asked in his judgement that Mr. Jantzen’s siblings offer the same high degree of compassion to Mrs. Jantzen that she had afforded them. The siblings did not appeal the decision and Mr. Jantzen’s life supports were subsequently removed. He died shortly thereafter.

\(^{186}\) *Jantzen*, supra note 17.

\(^{187}\) S.O. 1996, c. 2.
6.2. Euthanasia and Sanctity of Life Arguments

The Schiavo and Jantzen tragedies are examples of cases in which the logical surrogate was appointed under the law to make health care decisions for an incapacitated person who left no direct instruction regarding end of life treatment choices. The appointment as surrogate was no less legitimate than a proxy advance directive. Despite the legitimacy of their appointment, in both cases the surrogate had to face a court battle to carry out what they perceived to be the decision their loved one would have chosen. These court battles may not have been avoided even if the individuals had left explicit instructions about their choices because the objections to removal of life-sustaining medical treatment are based on a fear of euthanasia.

Michael Schiavo did not make the decision to refuse ongoing life supports for his wife. The Guardianship Court of Pinellas County accepted the responsibility to make a substituted decision on behalf of Terri Schiavo regarding her ongoing consent to medical treatment.\(^{188}\) It was little reported by the press that the decision to remove Terri Shiavo’s feeding tube was made by the Guardianship Court, and not by her husband. Much of the diatribe in the special interest press (including religious and right to life newsletters) was directed squarely against Michael Schiavo, although a number of articles also attacked the Appeal Courts for striking down state and federal attempts to overturn the decision of the Guardianship Court.

LifeSiteNews.com, an on-line religious newsletter representing the views of the strongly conservative Catholic community, lamented the judicial finding that “Terri’s Law”\(^{189}\) was

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\(^{188}\) Schiavo I, supra note 16; see also Schindler v Schiavo (In re Schiavo) 30 Fla. L. Weekly D 743 (Fla. Dist. Ct. App. 2d. Dist. Mar. 16, 2005) (“The trial court’s decision does not give Mrs. Schiavo’s legal guardian the option of leaving the life-prolonging procedures in place. No matter who the guardian is, the guardian is required to obey the court order because the court, and not the guardian, has determined the decision that Mrs. Schiavo herself would make.” at 2-3 per Altenbernd, C.J.)

\(^{189}\) Terri’s Law, supra note 178.
unconstitutional, “giving her husband the green light to euthanasize (sic) her”\textsuperscript{190} Later editorials labelled the action “euthanasia” of a “disabled woman” and described the case as “reminiscent of German eugenics in 1933”\textsuperscript{191} Tellingly, the title of one editorial was “The Terri Schiavo Case -Generation X’s Roe v Wade”\textsuperscript{192} This article makes a strong connection between advance directives and abortion, stating:

“In the name of medical privacy and personal choice, a quarter of our generation found itself butchered in the womb. Abortion has claimed more lives among our generation than the combined effort of AIDS, drugs and gang violence.

Yet our blood has not satiated the culture of death. In the name of medical privacy and personal choice, the culture of death now seeks the blood of our elderly, our disabled, and our terminally ill. Like Roe v Wade, the execution of Terri Schindler-Schiavo (sic) is a defining moment in the culture war. It sets a precedent whereby our society no longer judges our elderly, our disabled, and our terminally ill as fully human\textsuperscript{193}

Similar reporting accompanied the introduction in the English House of Parliament of the Mental Capacity Bill\textsuperscript{194} proposing legislation recognizing instructional and proxy advance directives in England and Wales. The BBC news reported that “Some Christian groups say it could mean doctors withholding food and fluids,”... “Christian groups have said the bill would allow euthanasia through the “back door” and that the Christian Medical Fellowship argued against the bill, stating; “Patients (could) make unwise and hasty advance decisions to refuse food and fluids without being properly informed”\textsuperscript{195}

\textsuperscript{190} “U.S. Supreme Court Refuses to Hear Schiavo Appeal” LifeSiteNews.com (25 January 2005) online: <http://www.lifesite.net/ldn/2005/jan/05012501.html> (The article quoted Ken Connor, attorney for Governor Bush as stating: “The effect of this decision is that Terri Schiavo will die of starvation and dehydration as the result of a judicial death warrant.”).


\textsuperscript{192} Ibid.

\textsuperscript{193} Ibid.

\textsuperscript{194} Subsequently enacted as the Mental Incapacity Act, supra note 33.

These comments do not merely represent the voice of the politically far right, the righteously religious and the right-to-life groups. The same concerns emerge from writers such as Carl Schneider and Rebecca Dresser. Schneider (who apparently misunderstands the significance of the *Cruzan* decision) notes with concern that “the Supreme Court came within one vote of holding that incompetent patients have a constitutional right to refuse life-sustaining treatment.” [emphasis original]\(^{196}\) The dissenters, he argues, effectively free surrogate decision makers to “…decide for themselves whether patients should live. It takes a keen eye to detect the difference between this and involuntary euthanasia, the traditional bottom of the slippery slope.”\(^{197}\)

Schneider then draws a comparison between the *Schiavo* decision and *Roe v Wade*.\(^{198}\) Both cases, he argues, describe an assumption by the courts of social policy development that should be allowed to occur in the political arena. Schneider refers to the “failure of the living will and the limits of surrogate judgement”\(^{199}\), quoting Dresser as authority for this description, and states that we are compelled to consider a best interests test for “those incompetent patients for whom no one speaks.”\(^{200}\) Dresser advises that we have a “duty” to take more than a patient’s subjective position into consideration in making substituted decisions about medical treatment for the patient; we also have the “duty to protect vulnerable incapacitated individuals, reflected in the *parens patriae* doctrine. The antidiscrimination provisions of our disability laws are also relevant.”\(^{201}\)

Dresser does not explain why a legal right founded on autonomy such as the advance directive should succumb to benevolent paternalism. Neither author explains why concrete evidence of a patient’s treatment choice is less, rather than more, helpful in

\(^{197}\) *Ibid*.
\(^{198}\) 410 U.S. 113 (1973).
\(^{199}\) Schneider, “Hard Cases”, *supra* note 15 at 27.
\(^{200}\) *Ibid*.
\(^{201}\) Dresser, “Schiavo’s Legacy”, *supra* note 184 at 21.
arriving at a conclusion regarding whether the patient would choose to refuse life-sustaining treatment. 202

Ronald Dworkin argues that benevolent paternalism, with regard to end-of-life decision making, is based on a presumption that life is not only precious but sacred, and it should always be preserved. 203 Dworkin explains that this presumption adopts the argument that we merely inhabit our bodies, and the decision to terminate our lives rests with a higher deity or a power greater than ourselves.

Dworkin responds to this argument by proposing that it is not life itself which is sacred, but the way that life’s sanctity should be understood; that is, in terms of our whole lives.

Someone who thinks his own life would go worse if he lingered near death on a dozen machines for weeks or stayed biologically alive for years as a vegetable believes that he is showing more respect for the human contribution to the sanctity of his life if he makes arrangements in advance to avoid that, and that others show more respect for his life if they avoid it for him. 204

202 But see Timothy E. Quill, “Terri Schiavo – A Tragedy Compounded” (2005)352:16 New Eng. J. Med. 1630 at 1633 [Quill, “Terri Schiavo”]. Although doctors such as Timothy Quill argue that we should “listen carefully to the patient’s voice” to decide what the patient’s choice would be, it is unlikely that either a living will or a proxy directive will be sufficient to satisfy those members of society who will never accept the right of a patient to autonomously choose to refuse life-sustaining medical treatment. 203 Dworkin, Life’s Dominion, supra note 138 at 214. 204 Ibid at 216.
7. Conclusion: The Prognosis For Living Wills

Instructional and proxy advance directives are both attempts by capable individuals to govern future medical treatment decision-making according to personal values. Both types of directive can help to reduce stress for families and can direct health care providers with difficult medical treatment decisions but, as discussed in this chapter, instructional advance directives generate passionate moral debate. To a great extent, this debate is a reflection of societal fear associated with euthanasia.

Living will legislation in the U.S. is often so restrictive that the documents are not useful or used. Legislation in Canada frequently does not recognize instructional advance directives. Both of these limitations on the use of living wills exemplify a social fear that living wills may make helpless or vulnerable individuals subject to cruel and unnecessary withdrawal of medical treatment or purposeful euthanasia. The presence of a proxy, it is hoped, will offer protection from such an eventuality. As shown in the cases of Schiavo and Jantzen, however, the presence of a proxy (in both cases, a court appointed proxy) may not resolve anxiety about a decision to terminate life support. This is particularly true where family and special interest groups espouse vitalist philosophy that rejects the concept of autonomy to direct cessation of life-supporting medical treatment.

Many people, however, do not adhere to the philosophy of vitalism adopted by the strongly religious and the right to life organizations. Many people want to form their own decisions about their end-of-life treatment and want to know that their personal choices about treatment will be followed. Many people consider it advantageous to discuss these matters with physicians and family members and document their choices.205 A document indicating a patient's preferences will help to guide health care providers in

205 See Chapter Two, above, for discussion of current social preferences about making advance directives.
the event of the patient’s incapacity. Under Canadian law\textsuperscript{206} and Canadian medical ethics,\textsuperscript{207} such documents should be followed.

The deficiencies of living wills have been imposed on the documents to a great extent. It is probable that instruction directives will become more useful and used as the medical profession and the general public feel more confidence that the documents are not only legitimate but ethical and beneficial additions to a patient’s medical chart. Canadian law progressively embraces patient autonomy as the guiding tenet for treatment decisions. Medical ethics statements progressively adopt the position that patient’s previously expressed wishes regarding end-of-life treatment choices should be ‘respected’.\textsuperscript{208} Advance directives statutes increasingly provide for both instructional and proxy decision making.\textsuperscript{209}

The criticisms that living wills are unhelpful and unnecessary are founded on a moral argument which has to do with preserving and protecting life, and stems from a fear that allowing individuals to dictate their ends will lead to a society that disrespects life.\textsuperscript{210} Despite the evidence that living wills are encouraged by the legal framework in the U.S.\textsuperscript{211} and by healthcare providers, there remains a strong element of discomfort with their use owing to external pressure from vitalist sources. Legislators should not allow this pressure to limit the rights of citizens to direct their end-of-life treatment. To do so is a restriction of rights and personal freedoms that are recognized under the law.

Timothy Quill underlines the benefit of documentation in his commentary on the Schiavo case even as he expresses regret that it was necessary for the case to be resolved in the courts. He asks:

\textsuperscript{206} See Malette, supra note 34; Fleming supra note 78.
\textsuperscript{207} See e.g. CMA Code of Ethics supra note 69.
\textsuperscript{208} Ibid at ss. 27-28.
\textsuperscript{209} See e.g. Alaska Health Care Decision Act, supra note 32 (the previous state advance directive legislation was modernized to legalize both instructional and proxy directives); Manitoba Health Care Directives Act, C.C.S.M. 1992, c. H27, (which recognizes both instructional and proxy advance directives).
\textsuperscript{210} See Dworkin, Life’s Dominion, supra note 138 at 214.
\textsuperscript{211} See for e.g. PSDA, supra note 43.
So what was known about Terri Schiavo’s wishes and values? *Since she unfortunately left no written advance directive*, the next step would be to meet with her closest family members and try to understand what she would have wanted under these medical circumstances if she could have spoken for herself... (emphasis added).\(^{212}\)

There is little doubt, even among those who disparage the use of living wills, that the documents can reflect the real wishes and choices of their authors. Establishing the patient’s wishes for future care will progressively be seen as an important element in the medical charts of patients as the medical community and the general population more readily acknowledge patient autonomy as the guiding principle in medical care and treatment.

The prognosis for the instructional advance directive is a positive one; the documents increasingly will be regarded as valuable and necessary patient information both by health care providers and by the public. Legislation should provide the public with a choice of directive, including instructional, proxy or a combined form in order to ensure that citizens have the broadest range of options with which to express their wishes and assert their right of autonomy.

The next chapter will examine legal impediments to the widespread understanding and use of advance directives in Canada.

\(^{212}\) Quill, “Terri Schiavo” *supra* note 202 at 1631.
CHAPTER FOUR: ADVANCE DIRECTIVES IN CANADA: Legal Status, Legal Problems, Legal Prospects

1. Introduction

There is confusion in Canada about the legality of advance directives, and especially about the legality of instructional advance directives or 'living wills'. The reason for this confusion is not immediately obvious since the legal status of advance directives is arguably quite certain. Canadian common law acknowledges instructional advance directives as legal directions that bind health care providers. Advance directives represent fundamental rights pursuant to s. 7 of the Canadian Charter of Rights and Freedoms [Charter]. Many of the Canadian provinces have enacted legislation setting out statutory schemes for both instructional and proxy advance directives. The Code of Ethics of the Canadian Medical Association instructs physicians to follow advance directives.

In light of such legal certainty, there should be no confusion as to whether advance directives or living wills are “legal”. Nevertheless, as detailed below, books, news reports, medical websites and articles respecting advance directives, and living wills in particular, frequently question the legitimacy of the documents. This chapter attempts to uncover the reasons for the confusion about the legitimacy of advance directives by examining the Criminal Code provisions relevant to health care providers who follow

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2 See Fleming, Ibid.
advance directives, the provincial advance directive legislation, and judicial interpretation of the legal status of advance directives in Canada.

This thesis argues that Canadian law creates confusion about the legality of living wills and uncertainty about the morality of advance directives generally. The outdated provisions of the Criminal Code and the disharmonized and often limited provincial advance directive legislation both work to create this uncertainty. The relative paucity of case law leaves the common law position indefinite. An analysis of the Canadian law respecting the advance directive indicates that, however certain the concept is in law and in ethics, the actual legal position of the living will and proxy directive is unsettled, leaving the Canadian public confused about the legality of the documents for end-of-life treatment planning.
2. Legal Status

In her text on Powers of Attorney, M. Jasmine Sweatman advises her readers: "Remember, the common law does not generally recognize advance directives relating to future medical treatment with some exemptions (for example, in *Malette v Shulman* the court accepted the "no blood" card found in Mrs. Malette's purse.)[footnote omitted]"\(^6\)

In fact, the *Malette v Shulman* \(^7\) case is generally considered to be "a persuasive precedent in favour of ...recognition [of instructional advance directives] as a matter of common law."\(^8\) However, Ms. Sweatman's position regarding the status of advance directives under the law is not uncommon.

The confusion regarding the legality of instructional advance directives, or living wills, is especially evident in British Columbia where the scheme for advance directives is found in the *Representation Agreement Act (RAA)* \(^9\). For example, a CTV news story reported online on March 29, 2005 regarding the case of Terri Schiavo entitled "Living Will" states: "The bitter legal battle in Terri Schiavo's case might have been avoided if Terri Schiavo had made a living will. But here in BC, a living will isn't legally binding. ..."\(^10\) The reporter, Dr. Rhonda Low, repeats this assertion again in the report, stating: "A living will is not legally binding in BC. Instead, there's the representation agreement, which came into effect in 2000."\(^11\) She quotes lawyer Hugh McLellan who comments on the BC legislation as follows: "The choice of representative is probably the most important decision one can make," says McLellan.\(^12\)

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\(^7\) *Supra* note 1.
\(^9\) RSBC 1996, c. 405 [RAA]
\(^12\) *Ibid.*
Further in her report, in response to the rhetorical question: "Can you just write down your wishes on a piece of paper and have it witnessed?", Low explains:

You could do that and this is what some have called a living will, but these are only legally binding in an emergency such as for Jehovah Witnesses who do not want to receive blood products. Unfortunately, most people who are terminally ill are not in this kind of situation and this type of document would not hold up in court.\(^{13}\)

The reporter is mistaken in this assertion. The common law rights of a patient to have his or her health care instructions followed in an urgent or emergency situation are statutorily prescribed in the *Health Care (Consent) and Care Facility (Admission) Act (HCCA)*\(^{14}\) of British Columbia, which states:

12.1 A health care provider must not provide health care under section 12 if the health care provider has reasonable grounds to believe that the person, while capable and after attaining 19 years of age, expressed an instruction or wish applicable to the circumstances to refuse consent to the health care.

In addition, on a reading of the Canadian case law since *Malette v Shulman*\(^{15}\), (which involved an instructional advance directive made by a Jehovah’s Witness) it is clear that the narrow interpretation expressed in the article above is an incorrect statement of the common law. Yet this view is not uncommonly held. A similar news report on CBC News Indepth entitled “Indepth:Wills, Living Wills, FAQs”, asked the rhetorical question: “Are living wills legal in Canada?” and incorrectly responded: “Actually, the phrase “living will” is not a legal term in Canada. But it is used to describe the legal directives each province sanctions that deal with your medical care wishes should you be unable to communicate them”.\(^{16}\)

\(^{13}\) *Ibid.*

\(^{14}\) RSBC 1996, c. 181, s.12.1 as am. by *Health Care (Consent) and Care Facility (Admission) Amendment Act*, 2002, SBC c-46, s.3 (“No emergency health care contrary to wishes”).

\(^{15}\) *Supra* note 1, See e.g., *Fleming and Rodriguez, supra* note 1.

The website of the British Columbia Vancouver General Hospital Health and Sciences Centre asks the same question about advance directives, but answers only indirectly and, to some extent, incorrectly as follows:

**Is the Advance Directive a legal document?**

- An Advance Directive is part of the Representation Agreement Act passed in British Columbia in 1993. The new law is not yet in effect. The Representation Agreement can include financial, legal and health decisions.
- Even though the Representation Agreement Act is not yet the law, your Advance Directive can become part of your health record. Your physicians will consider your wishes when determining treatment.  

The webpage of the Resource Centre for the Representation Agreement Act (of British Columbia) [RARC] states:

A living will fits within the Representation Agreement.

...  
2. If you already have an existing living will, you can give it *full legal effect* and broader scope by making a Representation Agreement. [emphasis added]  

It is not clear what the RARC authors mean by the term “full legal effect” since a living will must be respected by health care providers in accordance with the legislation and the common law.

The apprehensiveness exhibited in the RARC and Vancouver General Hospital materials to accord full legal authority to a living will may reflect a reticence to honour a document that will have the effect of hastening the death of the maker. Alternatively, health care providers may be uncertain of the legality of acting solely on the basis of an instructional advance directive. For example, several Canadian provinces have enacted legislation that

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17 British Columbia, Vancouver Coastal Health Authority, “What is an Advance Directive (Living Will)?” *Advance Directives (Living Wills)* (Vancouver: Vancouver Coastal Health Authority, 2002), online: &lt;http://www.vanhosp.bc.ca/html/pros_cpu_renal_advance.html&gt;, Last accessed November 27, 2005 [apparently the website has not been updated to reflect the fact that the RAA has been enacted].  
18 British Columbia, Representation Agreement Resource Centre, Centre for Quality of Life Planning, &lt;http://www.rarc.ca/textual/info-gen/living-will.html&gt; (last accessed November 27, 2005).
allows a person to appoint a proxy for future health care decisions in the event of their future incapacity, but does not recognize instructional advance directives\textsuperscript{19}.

The drafters of such proscriptive legislation may be motivated by the intent to prevent any act that could be construed as euthanasia\textsuperscript{20}. In a 1987 text, Professor Gilbert Sharpe, then Legal Counsel to the Ontario Ministry of Health, expressed a decidedly negative opinion about living wills, wondering whether they might “sanction unconscious, self-destructive impulses in people” and represent “another escapist system in a world looking for easy answers to the human dilemma?”\textsuperscript{21} Professor Sharpe worried that Canadian society had spent insufficient time establishing a consensus about the sanctity of life and the degree to which society has a moral obligation to override an individual’s choice to die.\textsuperscript{22} He suggested that “[t]hese issues ought to be resolved before lawyers are required to grapple with them in the courts, and before over-zealous legislators foist an impractical solution on us all.”\textsuperscript{23} In view of Professor Sharpe’s position within the Ontario Ministry of Health in 1987, it is perhaps not surprising that the province of Ontario subsequently passed substitute decision-making legislation in 1992\textsuperscript{24} “after many years of study”\textsuperscript{25} that does not recognize instructional advance directives. “There are no references to advance directives and living wills in the \textit{Substitute Decisions Act}, 1992, it only refers to powers of attorney for personal care and “wishes”.”\textsuperscript{26}

The Ontario example supports the argument made by Professor Bernard Dickens in his discussion of advance directive legislation, that “...the issues of suicide and euthanasia

\textsuperscript{21} Ibid.
\textsuperscript{22} Ibid.
\textsuperscript{23} Ibid.
\textsuperscript{24} Supra note 19 (in force April 3, 1995).
\textsuperscript{26} Sweatman, \textit{Powers of Attorney}, supra note 6 at 101.
may distort the appearance of the legislation”. However, in Professor Dickens’ view “[s]uicide and natural death stand in contrast rather than comparison to each other, and, similarly, euthanasia in the sense of active steps to end life before its natural termination would appear distinguishable”. 28

Professor Dickens’ position is also adopted by Professor Margaret Somerville, who argues that there is a “difference in kind” between euthanasia and advance directives. Although Professor Somerville argues ardently against the legalization of assisted suicide and euthanasia, she firmly believes in the right of individuals to draft and depend on the validity of advance directives. She states:

Competent adults must have the right to refuse treatment, in particular, life-support treatment, including artificial hydration and nutrition. They have the right to be offered any treatment necessary to relieve pain, moreover, even if it could shorten life.” 30

Almost everyone agrees that competent people should be able to refuse treatment – when necessary through advance directives (living wills or durable powers of attorney) – and that, when it is impossible to know someone’s wishes, there is no legal or moral obligation to continue medically futile treatment. Likewise, almost everyone agrees that people have the right to adequate pain-relief treatment, even if it could or would shorten life, if this is necessary to relieve pain. Where we disagree is whether physician-assisted suicide and euthanasia should be legalized. 31

A review of the cases indicates that the Canadian common law progressively acknowledges the absolute right of individuals to direct their personal medical treatment but the relevant legislation, including the federal Criminal Code and the provincial advance directive laws, remains mired in the confusion between voluntary passive euthanasia and advance directives. Professor Somerville muses: “Often, euthanasia is

28 Ibid.
30 Ibid, at 102.
31 Ibid at 143.
32 R.S.C. 1985, c. C-46 (Criminal Code)
confused with respecting refusals of life-sustaining treatment. Is that intentional? As she explains, voluntary passive euthanasia is a beneficently bestowed act to end the suffering of another. Following an advance directive represents respecting the previously expressed autonomous self-direction of an individual concerning his or her preferred medical treatment, particularly at the end of life. The former is forbidden under the Criminal Code; the latter is endorsed by the Canadian courts. The Criminal Code and various examples of the provincial advance directive legislation do not sufficiently recognize the difference between these two acts. Consequently, the law is unclear and confusing, and results in the type of misunderstanding depicted in the publications above.

The anxiety caused by this confusion was discussed at length during the hearings held by the Special Committee of the Senate on Euthanasia and Assisted Suicide (the Special Committee). The Special Committee heard poignant testimony from many of Canada’s most respected scholars and experts in the fields of medicine, law and biomedical ethics. Witnesses despaired of the failure of our political, legal and medical systems to resolve the difficult moral and ethical questions faced daily by dying patients, their families and their health care providers relating to end-of-life treatment. The Special Committee acknowledged that Witnesses were unable to agree on correct terminology for end-of-life treatment practices. There was disagreement, for example, on the meaning of expressions such as “euthanasia”. The Special Committee explained:

For instance, most witnesses argued that acts of withholding or withdrawing a life-support system are fundamentally distinct from acts of euthanasia because, in their view, withholding or withdrawing life saving treatment is, in effect, allowing natural death to occur; while an act of euthanasia is the cause of death. Other witnesses argued that withholding and withdrawing actions

33 Somerville, Death Talk supra note 29 at 34 (Professor Somerville notes that the media frequently confused the refusal of life-supporting treatment by a young quadriplegic woman with euthanasia in the case of Nancy B v Hôtel Dieu de Québec (1992), 86 D.L.R. (4th) 385 (Que. Sup. Ct.).
34 Ibid at 32-33.
35 See supra note 1.
are forms of euthanasia because, morally, these are as active as lethal injections.\textsuperscript{37}

The following excerpt from the testimony of Dr. Paul V. Adams of Manitoba Physicians for Life before the Special Committee confirms that confusion exists respecting the ethical difference between withholding or withdrawing life-supporting treatment and euthanasia:

There is an essential difference between causing one to die, which is euthanasia, helping one to die, which would be assisted suicide, and allowing natural death to occur, which I referred to as withholding or withdrawing treatment. Frequently, there is confusion regarding the third category, that is, allowing natural death to occur when death is inevitable, and there is no clinical or ethical reason to intervene. This is not euthanasia. ... \textsuperscript{38}

The Honourable Allan Rock, Minister of Justice and Attorney General of Canada testified before the Special Committee regarding the administration of palliative pain relief in quantities that might cause death that,

\textit{despite} the fact that there is little doubt that this practice is legal, ... there seems to be some confusion within the medical profession, and the public in general, as to what is legally permissible in this regard. ...\textit{Many} would like the law in the area to be clearly set out and simplified and there is support for greater clarification of the issue.\textsuperscript{39}

The following section examines the implications of the \textit{Criminal Code} provisions relevant to health care providers who follow advance directives.

\textsuperscript{37} \textit{Ibid} online at Chapter II, Introduction.
\textsuperscript{38} \textit{Ibid}, online at 18:40, (Manitoba Physicians for Life).
3. Legal Problems

3.1. The Canadian Criminal Law

On a plain reading, the Criminal Code “appears to preclude respecting an individual’s refusal of potentially life-sustaining treatment.”\(^{40}\) In her book, Dying Justice: A Case for Decriminalizing Euthanasia and Assisted Suicide in Canada, Professor Jocelyn Downie analyzes Criminal Code ss. 215 (1) and (2), 216, 217, 219(1) and (2), 220, and 222(5) which all fall under “Part VIII, Offences Against the Person and Reputation”\(^{41}\) relating to Duties Tending to Preservation of Life. She finds that all of these sections indicate that withholding or withdrawing life-sustaining treatment constitute criminal offences, potentially including criminal negligence, criminal negligence causing death, and/or culpable homicide. From her plain reading of the Criminal Code, Professor Downie concludes “[t]hat much is clear.”\(^{42}\)

The withdrawal of life-sustaining treatment is often accompanied by palliative pain relief, such as heavy doses of morphine, in order to ensure that the patient does not suffer pain as a result of the cessation of treatment.\(^{43}\) Medical practitioners are aware that such palliative pain relief may, in itself, hasten death.\(^{44}\) Once again, a plain reading of ss. 219, 220, 222 and 229 of the Criminal Code “supports the proposition that the law prohibits at least some provision of potentially life-shortening palliative treatment.”\(^{45}\) However, the seemingly plain meaning of the Criminal Code does not accord in any way with the manner in which the courts have handled such cases. After reviewing three cases concerning the administration of pain relief in doses that greatly exceeded amounts necessary to control pain, Professor Downie explains: “[d]espite the potential for criminal

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\(^{40}\) Downie, Dying Justice, supra note 8 at 15.
\(^{41}\) Ibid at 16-18.
\(^{42}\) Ibid at 17.
\(^{44}\) Ibid.
\(^{45}\) Downie, Dying Justice, supra note 8 at 30.
charges, no charges have ever been laid for the provision of potentially life-shortening palliative treatment.\textsuperscript{46}

Professor Downie does not analyze \textit{Criminal Code} s. 245 in detail, although that section also indicates that the administration of palliative pain relief in sufficient quantity to bring about the death of a person is a criminal offence, (Administering Noxious Thing) as well as constituting possible homicide. The section reads as follows:

\begin{quote}
245. Every one who administers or causes to be administered to any person or causes any person to take poison or any other destructive or noxious thing is guilty of an indictable offence and liable  
\begin{enumerate}
\item To imprisonment for a term not exceeding fourteen years, if he intends thereby to endanger the life of or to cause bodily harm to that person; or
\item To imprisonment for a term not exceeding two years, if he intends thereby to aggrieve or annoy that person.
\end{enumerate}
\end{quote}

Various cases where a care provider has administered potassium chloride have resulted in charges under \textit{Criminal Code} s. 245, but the courts have generally held that health care providers should not be incarcerated for taking such action to relieve suffering.\textsuperscript{47}

Presumably charges have been laid for administration of potassium chloride but not for administration of lethal doses of morphine because the former is seen as medication intended to kill where the latter could be considered pain relief. This distinction is made by the prosecution notwithstanding that the care provider administering the large dose or doses of morphine does so with knowledge that the medication is likely to quickly bring about the death of the patient. There is evidence that crown prosecutors enforcing a s. 245 charge against a health care provider who has administered potassium chloride to

\textsuperscript{46} \textit{Ibid} at 30-31 (The cases involved Dr. Thomas Perry who gave a lethal injection of morphine to his dying father; Dr. Peter Graaf who ordered repeated doses of morphine and valium for two dying patients, and a coroner's inquiry into the case of fifteen deaths of severely handicapped children in Ontario.)

\textsuperscript{47} See, e.g. \textit{R. v. Mataya} (unreported Ontario Court of Justice, August 24, 1992) before Wren J. sitting without a jury, in which a nurse who administered potassium chloride and pled guilty under s. 245 was given a suspended sentence and placed on probation for 3 years); \textit{R. v. de la Rocha}, (unreported 2 April 1993) Ontario Court, (Timmins, Ontario,) (Ont. Gen. Div.), in which the crown withdrew second degree murder charges against a doctor who administered potassium chloride, allowing him to plead guilty to s. 245. The court determined that custody was inappropriate and directed a 3 year probation order with no conditions).
relieve suffering feel torn by the evident discrepancy in the way such cases are handled under the Criminal Code. For example, Mr. David Thomas, the prosecutor who handled the de la Rocha case\textsuperscript{48}, testified before the Special Committee\textsuperscript{49} to this effect. Mr Thomas explained:

I have to confess that I had a great deal of difficulty with the case. As one who has prosecuted what I will call real killers - child killers, sex slayers, thrill killers - I had a very hard time casting Dr. de le Rocha (sic) in the same sinister light as these other types of men. I knew that if I was having that problem, surely to goodness a jury would be similarly situated when it came time to decide if is he a murderer.\textsuperscript{50}

In both the De la Rocha and Mataya cases\textsuperscript{51} potassium chloride was administered to patients who were in distress, choking and gasping subsequent to the removal of life-sustaining treatment. Care providers are left in the dreadful position that if they ethically follow an advance directive to withdraw treatment, but the withdrawal of treatment causes the patient to become physically distressed, they are very limited in the steps they can take to relieve the patient’s suffering. If they take active measures to end the patient’s suffering, they may be subject to criminal prosecution.

Professor Downie turns to the Rodriguez \textsuperscript{52}case for more guidance on this issue, noting that Justice Sopinka, “for a majority of five of the Supreme Court of Canada, implies that potentially life-shortening palliative treatment is not illegal.”\textsuperscript{53} She quotes Justice Sopinka as follows on this point:

The administration of drugs designed for pain control in dosages which the physician knows will hasten death constitutes active

\textsuperscript{48} supra note 47.

\textsuperscript{49} Senate Report, Of Life and Death supra note 36 (Proceedings of the Senate Special Committee, 12 December 1994, Issue #29).

\textsuperscript{50} See also R. v Latimer, 1995 S.J. No. 402 (Sask. C.A.) (Mr. Thomas’ comments to the Senate Special Committee, \textit{ibid}, were cited by Bayda, C.J.S.) at ¶129.

\textsuperscript{51} Supra note 47. See also Downie, Dying Justice, supra note 8 at 43. Professor Downie notes that the Criminal Code is “Clearly...being tempered by the exercise of prosecutorial discretion.”

\textsuperscript{52} Rodriguez supra note 1.

\textsuperscript{53} Downie, Dying Justice supra note 8 at 31.
contribution to death by any standard. However, the distinction drawn here is one based upon intention – in any case of palliative care the intention is to ease pain, which has the effect of hastening death ... In my view, distinctions based upon intent are important, and in fact, form the bases of our criminal law. While factually the distinction may, at times, be difficult to draw, legally it is clear.  

Professor Downie argues that the distinction Justice Sopinka makes between intent to ease pain and intent to hasten death is unsustainable. Her argument is primarily drawn in support of the legalization of euthanasia and assisted suicide, and does not focus on the subject of advance directives. Nevertheless, her argument is equally applicable in the context of the withdrawal of life-sustaining treatment pursuant to an advance directive. The physician who withdraws life-sustaining treatment does so in full knowledge that the action will hasten death. Under Canadian law, commitment of a criminal offence requires both intent to commit the offence and the actual undertaking of the criminal act; that is, the “mens rea and actus reus must exist pari passu”. A physician or other health care provider who follows an advance directive to withdraw or withhold life-sustaining treatment carries out the act (the actus reus) with full knowledge that death will ensue and with intent to cause death (the mens rea). Such acts occur regularly but are not criminally prosecuted.

Professor Somerville argues that the failure to prosecute cases of withdrawal or withholding of treatment that causes death is based on a “fine line between having the intention of allowing someone to die and having the intention of causing someone to die.” She describes this line as a “marker event” and explains:

The marker event for distinguishing euthanasia from other medical interventions at the end of life is a mens rea (state of mind) of a primary intention to cause death and an actus reus ...

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54 Ibid (quoting Rodriguez supra note 1 at 607).
55 Ibid at 93.
57 Ferguson, Choice in Treatment, supra note 43 at 63.
58 Somerville, Death Talk, supra note 29 at 29.
(conduct) of an act or omission that causes someone else’s death.\textsuperscript{59}

Arguably, this line is too finely drawn. All of the requirements for prosecution are evident where life is ended through cessation of treatment or an overdose of palliative pain relief. However, since the criminal law is out of step with accepted medical ethics and with the common law, particularly in the case where health care providers follow an advance directive, prosecutors do not pursue charges.

Professor Gerry Ferguson explained in a 1988 article that the Canadian public is generally ignorant of the fact that decisions to administer or withhold medical treatment necessary for the prolongation of life are made daily in Canadian hospitals.\textsuperscript{60} These decisions are made notwithstanding that they could be considered criminal acts under the current provisions of the \textit{Criminal Code} because the people making them consider them to be medically and ethically correct.\textsuperscript{61} Accordingly, he argues,

\begin{quote}
[w]ith the threat of illegality and criminality hanging over them, it is not surprising that the medical profession remains silent. Unfortunately, because of their silence, the ethical, social and legal implications of these life and death decisions escape[s deleted] public debate, scrutiny and resolution.
\end{quote}

Another complication related to potential criminal liability of health care providers is the combined federal and provincial responsibility for making and upholding the criminal law. While the power to make laws in relation to criminal law falls to the federal Parliament pursuant to 91(27) of the \textit{Constitution Act}, policing and prosecution of \textit{Criminal Code} offences fall to the provinces pursuant to s. 92(14) of the \textit{Constitution Act}.\textsuperscript{62} Consequently, enforcement of the \textit{Criminal Code} provisions is directed to the provinces. Funston and Meehan explain that because of the joint federal and provincial responsibility for prosecution of criminal offences, the criminal law is “...not as

\begin{footnotesize}
\textsuperscript{59} Ibid
\textsuperscript{60} Ferguson, Choice in Treatment \textit{supra} note 43 at 63.
\textsuperscript{61} \textit{Ibid}.
\end{footnotesize}
centralized as other fields of federal legislative power...". This division of power entitles provinces to create individual provincial policies respecting how they will prosecute cases involving advance directives.

An example of such an individual provincial policy is the policy adopted by the Criminal Justice Branch of the B.C. Ministry of the Attorney General in 1993 [the B.C. Policy] described by Professor Robert Gordon in his text on the Representation Agreement Act. The B.C. Policy is intended to guide Crown Counsel regarding the laying of charges where “a person, motivated by compassion for the deceased, participated in causing a death.” The B.C. Policy states that decisions will be made on a case by case basis and suggests that prosecution be pursued only where there is a substantial likelihood of conviction and the public interest requires a prosecution. Gordon cites the policy as follows:

Two types of medical treatment are identified as *not* being subject to criminal prosecution. These are,

a) “palliative care”, defined as the administration of “medication or other treatment to a terminally ill patient with the intention of relieving pain or suffering even though this may hasten death” by a qualified medical practitioner or a person acting under the practitioner’s general supervision, and,

b) “withholding or withdrawing treatment” defined as “discontinuing or not intervening with medical procedures to prolong life beyond its natural length” by a qualified medical practitioner with consent given by the patient, or by someone else acting on the patient’s behalf.

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63 *Ibid*
65 The B.C. Policy *supra* note 64.
66 Gordon, *Annotated RAA, supra* note 64 at 98.
On the other hand, two sets of circumstances are identified as possibly requiring a decision, on a case by case basis: active euthanasia and assisted suicide.\cite{67}

In making a decision to prosecute, Crown Counsel must consider the "provable intention of the person involved" and "any evidence whether the deceased, if able to do so, would have requested the withholding or withdrawing of treatment".\cite{68}

The Criminal Code creates confusion about advance directives for many reasons. An additional factor is the failure of the Criminal Code to provide a definition of "death". Although health care providers may be charged with criminal negligence causing death, "nowhere in the Code, nor in any other federal legislation, is the term "death" defined."\cite{69}

In view of the enlarged definition of death in the last few decades, (recognition of "brain death" was adopted by the Canadian Medical Association in 1968)\cite{70} the failure to define death for criminal law purposes is a significant omission in relation to the provision of health care and, more particularly, in charges relating to withholding or withdrawal of medical treatment.

In common with administration of the Criminal Code, however, constitutional responsibility related to death is not entirely federal. The provinces have jurisdiction to enact legislation relating to death for civil and property rights matters, such as certification of death or organ transplantation. Therefore, the provinces have the right to legislate a definition of death for their province, although Manitoba is the only province to date that has taken the step of enacting a definition of death.\cite{71}

Professor Ferguson doubts that any Canadian Court "would convict a health care professional of murder or manslaughter for switching off a respirator on a person who had been medically determined to be brain dead"\cite{72} even though the Criminal Code does

\begin{itemize}
\item \cite{67} Ibid at 99.
\item \cite{68} Ibid.
\item Sharp Law & Medicine supra note 20 at 306
\item \cite{69} Ibid at 297
\item \cite{70} The Vital Statistics Act, C.C.S.M. c. V60, s.2.
\item \cite{71} Ferguson, Choice in Treatment, supra note 43 at 66.
\end{itemize}
not expressly recognize brain death as a definition of death. Once again, however, this means that law enforcement officers simply ignore the strict terms of the Criminal Code.

It is trite to say that the Criminal Code should be amended to exempt health care providers who withdraw or withhold life-sustaining treatment in compliance with an advance directive or who administer palliative care that causes death, since this amendment has been recommended many times. The Law Reform Commission of Canada (LRC) has strongly recommended such amendment to Parliament on several occasions, to no avail. For example, in its 1982 Working Paper 28, in addition to recommending retention of the criminal prohibition against euthanasia, the LRC suggested the following amendment to the Criminal Code regarding end-of-life medical treatment:

The Commission therefore suggests the addition to the Criminal Code of the following texts:

1. *Nothing in sections 14, 45, 198 and 199 of the Criminal Code shall be interpreted as requiring a physician*
   a. to continue to administer or to undertake medical treatment against the clearly expressed wishes of the person for whom such treatment is intended;
   b. to continue to administer or to undertake medical treatment, when such treatment is medically useless and is not in the best interests of the person for whom it is intended, except in accordance with the clearly expressed wishes of this person.

2. *Nothing in sections 14, 45, 198 and 199 of the Criminal Code shall be interpreted as preventing a physician from undertaking or ceasing to administer palliative care and measures intended to eliminate or to relieve the suffering of a person for the sole reason that such care or measures are likely to shorten the life expectancy of this person.*

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The LRC did not recommend that Canada adopt an act equivalent to the California Natural Death Act\textsuperscript{74} based on the "already-established rule" that there should be no duty on physicians to initiate or maintain treatment when it is useless to do so.\textsuperscript{75} The LRC recommended that the Criminal Code should recognize this common law principle as well as the principle that a competent person has the right to refuse treatment or to demand that it be withdrawn. However, the LRC stopped short of recommending that an advance directive be upheld in every case, and instead suggested that family and physicians consider an incapable person's prior wishes, as well as the best interests of the incapable person, as determined by the physician and family or, if necessary, the courts.\textsuperscript{76}

One year subsequent to the issue of Working Paper 28, the LRC produced Report 20 based upon consultation with "members of the public, the legal profession and representatives of the health sciences."\textsuperscript{77} The LRC confirmed that any law reform must be based on "the protection of life as a fundamental value", while recommending that "the patient's autonomy and right to self-determination...should be explicitly affirmed in law."\textsuperscript{78} The LRC further argued that reform to the Criminal Code should

acknowledge that human life should be considered not only from the "quantitative" perspective, but also from the "qualitative" perspective. When patients freely choose to refuse treatment, their choice is often based upon quality-of-life considerations. In the Commission's view such considerations should be respected.\textsuperscript{79}

In acknowledging the importance of "quality-of-life" considerations to criminal law reform respecting cessation of treatment, the Commission adopted the 1979 recommendation on this issue made by Professor Edward W. Keyserlingk, Coordinator of the Protection of Life Project, and author of the seminal report, Sanctity of Life or Quality

\textsuperscript{74} California Health and Safety Code §§ 7185-7195 (The LRC was referring to the California Natural Death Act of 1976).
\textsuperscript{75} Supra note 73 at 69.
\textsuperscript{76} Ibid at 73.
\textsuperscript{78} Ibid at 11-12.
\textsuperscript{79} Ibid at 12.
of Life in the Context of Ethics, Medicine and Law, a study written for the Law Reform Commission of Canada. In his thoughtful review of the religious and philosophical origins of the concept of "sanctity of life" that supports the presumption in favour of life (which is a foundational concept in the Canadian Criminal Code\textsuperscript{81}), Professor Keyserlingk concludes that the sanctity of life principle tests and finds its content in rules which focus on quality of life factors.\textsuperscript{82} His analysis of the religious and secular views in Canadian society respecting the concept of the sanctity of life permeates both LRC Working Paper 28 and Report 20 and ultimately influenced the proposals made by the LRC for revision to the Criminal Code.

In Report 20, the LRC modified the position it adopted in Working Paper 28, particularly with respect to the decision-making power of physicians. The LRC confirmed most of its previous recommendations for change to the Criminal Code but it deleted the proposed requirement that physicians be required to continue or cease treatment in accordance with the express wishes of the patient. The amended recommendation was worded as follows:

199.1 Nothing in ss 14, 45, 198, 199 ad 229 shall be interpreted as requiring a physician,
(a) ...
(b) to continue to administer or undertake medical treatment, when such treatment has become therapeutically useless in the circumstances and is not in the best interests of the person for whom it is intended.
(c) Nothing in sections 14, 45, 198, 199 and 229 shall be interpreted as preventing a physician from undertaking or obliging him to cease administering appropriate palliative care intended to eliminate or to relieve the suffering of a person, for the sole reason that such care or measures are likely to shorten the life expectancy of this person.\textsuperscript{83}

\textsuperscript{80} Edward W. Keyserlingk, Sanctity of Life or Quality of Life in the Context of Ethics, Medicine and Law, A Study written for the Law Reform Commission of Canada (Ottawa: Minister of Supply and Services Canada, 1979).
\textsuperscript{81} LRC Report 20 supra note 77 at 11.
\textsuperscript{82} Supra note 80 at 47.
\textsuperscript{83} Ibid at 32-34. (Criminal Code s.229 was renumbered s.245 in the 1985 amendments. See supra note 73)
It appears that the medical profession may have had a strong hand in drafting the 1983 proposed amendments given the extended authority offered to physicians in the LRC Report 20 recommendations. In Report 20 the LRC retreated from its earlier position that the courts be involved in resolving disputes about continuation of life-sustaining treatment for incompetent patients where agreement could not be reached between family and physicians. The LRC effectively directed the decision to physicians, stating that it "recommended that the decision be primarily medical in nature, believing that there is no ideal solution and that, all things considered, this option remains the least unsatisfactory." The LRC opined that:

...since it is physicians who normally bear the onerous burden of possible criminal liability, it is only fair to clarify for their sake the rather ambiguous provisions of the Criminal Code. ... 

The Commission therefore recommends that a physician should not incur any criminal liability if he decides to discontinue or not initiate treatment for an incompetent person, when that treatment is no longer therapeutically useful and is not in the person’s best interest. (bolding original)

Even though the recommendations in Report 20 appear to have been endorsed by the legal and medical professions, as well as by some "members of the public," the proposed revisions to the Criminal Code were not pursued by Parliament.

In 1987 the LRC made another attempt to persuade the Government to amend the Criminal Code provisions respecting cessation of treatment when it issued Report 31 on Recodifying Criminal Law. In the introduction to this major work, the LRC stated that the existing Criminal Code "uses archaic language", "contains gaps", "includes obsolete provisions" and "fails to address some serious current problems.

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84 Ibid at 26.
85 Ibid at 27-28
86 Supra note 77 and accompanying text.
88 Ibid at 1.
its previous work in Working Paper 28 and Report 20 for the proposed draft, but revised the earlier recommendations, making the text simpler and briefer. Unfortunately, Report 31 still did not propose a definition of death. However, the proposals did include legal immunity for cessation of life-sustaining treatment in accordance with withdrawal of consent to treatment. The proposed Criminal Code section 6(2) states:

(2) No person is criminally liable for an omission to provide or continue medical treatment that is therapeutically useless or medical treatment for which consent is expressly refused or withdrawn.

Although the Government initially announced its intention to introduce a new Criminal Code after the publication of LRC Report 31, the report was not acted on by Parliament. Four years following the publication of LRC Report 31, two Private Member’s Bills attempted to stir Parliament to action. In March, and again in May, 1991, Parliament was presented with a Private Member’s Bill to amend the Criminal Code to offer protection to medical professionals who follow an advance directive. The first died on the Order Paper and, although the second progressed to a second reading and was referred to Legislative Committee, the second Bill died when the Committee Adjourned.

After hearing extensive testimony from the medical and legal community, the Senate Special Committee concluded that amendment to the Criminal Code was necessary. The Special Committee made the following recommendations in its report:

1995 Recommendations

- The Criminal Code be amended to clarify the practice of providing treatment for the purpose of alleviating suffering that may shorten life.

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89 Ferguson, Choice in Treatment, supra note 43 at 71.
The Criminal Code be amended and necessary legislation be enacted in order to explicitly recognize and to clarify the circumstances in which the withholding and withdrawal of life-sustaining treatment is legally acceptable.\textsuperscript{92}

Subsequent to the Special Committee report,\textsuperscript{93} the Senate proposed three Bills to Parliament recommending amendment to the Criminal Code.\textsuperscript{94} None of these were successful.

Despite these valiant efforts by the LRC, the Special Committee, and private members of Parliament to modernize and clarify the Criminal Code provisions regarding life-sustaining treatment, the Criminal Code has not been amended.

Academics are dismayed by the inaction of Parliament in this matter. Professor Ferguson states:

\begin{quote}
Canadian law is outdated and uncertain in regard to many decisions to administer or withhold medical treatment. It is important that these laws be reconsidered in light of the modern realities of medical technology. For example, a new legal definition of death seems necessary when equipment exists that can keep the heart and lungs functioning indefinitely. The legal duty to treat needs clarification ... \textsuperscript{95}
\end{quote}

It may be that the Members of Parliament fear that any amendment to the Criminal Code respecting cessation of medical treatment or the requirement for health care providers to respect advance directives will arouse public concern that they are attempting to decriminalize euthanasia and physician-assisted suicide. However, although the politicians may be disinclined to embark on that debate, there is evidence that the public

\textsuperscript{92} Supra note 36
\textsuperscript{93} Ibid
\textsuperscript{94} Canada, Bill S-13, \textit{An Act to amend the Criminal Code, (protection of health care providers)}, 2\textsuperscript{nd} Sess., 35\textsuperscript{th} Parl., 1996, (1\textsuperscript{st} reading November 27, 1996); Canada, Bill S-29, \textit{An Act to amend the Criminal Code(Protection of Patients and Health Care Providers)}, 1\textsuperscript{st} Sess., 36\textsuperscript{th} Parl., 1997-98-99, (1\textsuperscript{st} reading April 29, 1999). Canada, Bill S-2, \textit{An Act to facilitate the making of legitimate medical decisions regarding life-sustaining treatments and the controlling of pain}, 2\textsuperscript{nd} Sess., 36\textsuperscript{th} Parl., 1999 (1\textsuperscript{st} reading October 13, 1999).
\textsuperscript{95} Ferguson, Choice in Treatment, supra note 43, at 70.
is interested in pursuing it. For example, an editorial opinion printed in the Globe and Mail in August, 2005, expressed the following view:

Canada has not really faced up to the issue [of physician-assisted suicide]. One reason the Supreme Court of Canada narrowly rejected the claim by Sue Rodriguez, a patient with Lou Gehrig’s disease, that she had a right to assisted suicide was that it did not want to pre-empt a national debate it felt belonged first of all in Parliament. But Parliament has offered little discussion of the matter since that 1993 ruling. Meanwhile, a British Columbia jury expressed the views of many Canadians last year in refusing to convict an accused in a case of assisted suicide. [footnotes added]

The same opinion might be said of advance directives: a national debate has not taken place, but logically ought to be encouraged. Whatever Parliament’s reasons for failing to address the obsolete provisions of the Criminal Code, the outcome is unsuitable. The common law regarding advance directives has moved beyond the criminal law provisions, forcing physicians and prosecutors to simply ignore the Criminal Code. The Canadian Medical Association (CMA) advises its members, as a matter of medical ethics, to

27. Ascertain wherever possible and recognize your patient’s wishes about the initiation, continuation or cessation of life-sustaining treatment.
28. Respect the intentions of an incompetent patient as they were expressed (e.g., through a valid advance directive or proxy designation) before the patient became incompetent.

The CMA, jointly with the Canadian Healthcare Association, Canadian Nurses Association and the Catholic Healthcare Association of Canada, advises members that

...every effort must be made to ensure that health care decisions are consistent with [a patient’s] known preferences. These preferences may be found in an advance directive or may have been communicated orally. In jurisdictions where the issue of decision-making concerning care and medical treatment for

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96 Rodriguez supra note 1.
98 CMA Code of Ethics, supra note 5.
incompetent persons is specifically addressed in law, the requirements of that legislation should be met.99

The medical organizations offer such directions to their members despite the language of the Criminal Code which, under a strict reading, implies that health care providers may be subject to prosecution for following these ethical guidelines. Prosecutors do not pursue the strict wording of the Criminal Code.100 Academics101 and judges102 contort the meaning of “intent” within the Criminal Code in order to explain the difference between intentionally ending a life through cessation of treatment or palliative treatment using morphine, and intentionally ending a life through palliative treatment using potassium chloride. In fact, the provisions of the Criminal Code respecting end-of-life medical treatment are, for the most part, ignored. Through ignoring the relevant Criminal Code provisions, the health care providers, prosecutors and jurists uphold the principles of patient autonomy and the sanctity of life, defined in accordance with “quality” of life; however, none of them uphold the principle of respect for the law. It cannot be beneficial for Canada to maintain criminal laws that are not respected for ethical reasons. To do so brings the law into disrepute.

It seems obvious that the Criminal Code must be amended. However, despite the various efforts described above to amend the Criminal Code to eliminate the potential for criminal liability where health care providers act on an advance directive, the federal Parliament has failed to change the obsolete legislation. Consequently, physicians “remain exposed to all the risks of criminal responsibility…”.103

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100 See supra note 54.
101 See Somerville, Death Talk, supra note 29.
102 See Rodriguez, supra note 1.
103 Sharpe, Law & Medicine, supra note 20 at 310.
3.2. The Provincial Legislation

The third edition of a text on Canadian biomedical ethics published in 2005 includes the following comment about the status of advance directive legislation in Canada:

All Canadian provinces and territories have passed or are in the process of passing laws that validate the legal status of advance directives, that stipulate the specific form that they should take, and that outline the procedures that would have to be followed for recording them.\(^{104}\)

The editor of the text places particular importance on this last item, noting that advance directives are of little assistance “if they are not part of the patients’ records and therefore are inaccessible to the professionals who are looking after the patients.”\(^{105}\)

A review of the advance directive legislation across the country indicates that the above summary is an optimistic but inaccurate description of the current legislation. No Canadian jurisdiction stipulates the form an advance directive should take or mandates procedures that should be followed for recording them. The laws of Saskatchewan\(^ {106}\), Manitoba\(^ {107}\), Ontario\(^ {108}\), Prince Edward Island\(^ {109}\) and Yukon\(^ {110}\) specifically state that no mandatory form of advance directive is required, that any prescribed form included in the legislation is to be considered an example only and that use of it is not mandatory. The remaining jurisdictions which have enacted legislation simply do not prescribe a mandatory form. The originally proposed provisions of the B.C. \textit{RAA} required mandatory registration\(^ {111}\), but the sections of the \textit{RAA} requiring registration of representation agreements (a form of proxy advance directive) were not brought into force when most of the \textit{RAA} was brought into force in 2000 and there is no indication that

\(^{104}\) Eike-Henner W. Kluge, ed., \textit{Readings in Biomedical Ethics: A Canadian Focus}, 3\textsuperscript{rd} ed. (Toronto: Pearson Prentice Hall, 2005) [Kluge, \textit{Biomedical Ethics}] at 199.

\(^{105}\) Ibid at 200.

\(^{106}\) \textit{Supra} note 4 at s. 10.

\(^{107}\) \textit{Supra} note 4 at s. 11.

\(^{108}\) \textit{Supra} note 19 at s. 46(8).

\(^{109}\) \textit{Supra} note 4 at 21(3).

\(^{109}\) \textit{Supra} note 19 at s. 36.

\(^{111}\) \textit{Supra} note 9 at s. 14 (not in force).
the province intends to enact these provisions. No other province or territory has proposed a mandatory registry for advance directives.

In 1995, at the time that the Special Committee of the Senate completed its extensive hearings and issued its Report, only three Canadian provinces had enacted advance directive legislation\textsuperscript{112} and only one of these, Manitoba, had enacted legislation that recognized both instructional and proxy advance directives. Two additional provinces had passed, but not brought into force, advance directive legislation that only recognized proxy advance directives,\textsuperscript{113} and one province, Alberta, was contemplating legislation that would recognize both instructional and proxy advance directives.\textsuperscript{114} Testimony provided to the Special Committee suggested that provincial advance directive legislation could assist in resolving some of the ethical and legal concerns faced by families and health care providers for patients nearing the end of life:

> The legitimacy of the advance directive as enshrined in the provincial legislation will address some of the problems regarding treatment decisions, such as the withholding of treatment if a person's wishes are known prior to his or her becoming ill. In accordance with the advance directive, treatment or non-treatment will respect the individual's wishes and ensure that these wishes are respected in the event that the person is not able to express his or her own views. Many of the difficult situations and eventualities that arise at the end of life could be prevented if this legislation were available across the country and advance directives became widespread.\textsuperscript{115}

The Special Committee concluded, based upon the testimony from the legal, medical and biomedical ethical communities that provincial advance directive legislation would benefit society. Members of the academic community had suggested that advance directive legislation might guarantee equal access to certain types of medical treatment, standardize instruction and proxy forms across the country and promote awareness of

\textsuperscript{112} Nova Scotia, supra note 19, Quebec, supra note 19 and Manitoba, supra note 4.

\textsuperscript{113} B.C., supra note 9, and Ontario, supra note 19.


\textsuperscript{115} Supra note 36 at 32.57 (Chapman).
patients' rights. Accordingly, the Special Committee included the following recommendations in its report:

The Committee recommends those provinces and territories that do not have advance directive legislation adopt such legislation.

The Committee recommends the provinces and territories establish a protocol to recognize advance directives executed in other provinces and territories.

Ten years later, in 2005, only three Canadian jurisdictions do not have advance directive legislation in force including New Brunswick, Nunavut and the Northwest Territories. The Uniform Law Conference of Canada, which considered the topic of advance directives at its 1992 Conference, published a model statute regarding recognition of foreign health care directives in 1996 (the Model Act). It would appear that significant progress has been made towards meeting the recommendations of the Special Committee. However, on closer examination of the legislation, it seems more likely that the goals of the Special Committee will not be met by the existing provincial advance directive legislation.

Inter-jurisdictional reciprocity provisions, for example, are either not in force or are not addressed in six of the provinces which have enacted advance directive legislation. Only the province of Prince Edward Island has incorporated the Model Act into the PEI advance directive legislation. Only five of the ten jurisdictions with advance directive legislation recognize instructional advance directives, although the common law recognizes them and the medical community acknowledges their existence and

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116 See for e.g. Jocelyn Downie, ““Where There is a Will, There May Be a Better Way”: Legislating Advance Directives”, (1992) Health L. C. 73 [Downie, Where There is a Will] at 78.
117 Senate Report, Of Life and Death, supra Note 36 at Recommendations: Chapter V Advance Directives.
118 New Brunswick amended the Infirm Persons Act, R.S.N.B. 1973, c I-8 in 2000 by c.45 s.6, to add provisions regarding the appointment of Attorney for Personal Care. Personal Care is not defined. The Attorney owes the same legal obligations towards the principal as a Committee (Infirm Persons Act s. 42). The Infirm Persons Act does not speak to health care or the ability to consent to the withholding or withdrawal of medical treatment.
120 See list of provinces supra note 4.
importance. In a June 2000 Report to Parliament on the status of recommendations made in its 1995 Report Of Life and Death, a Subcommittee to update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology (the Subcommittee) commented on the difficulty in achieving the initial goals described in the 1995 Report:

There has been no coordinated attempt to establish reciprocal arrangements allowing the implementation of advance directives executed in another province or territory. One difficulty is that some provinces do not have both types of directives: an instruction directive, which sets out the medical treatment desired, and a proxy directive, which says who should make decisions in the event of incompetency. It would be difficult for a province with only proxy directives to implement an instruction directive.

The Subcommittee also described “new concerns” arising about the advance directive legislation which suggest a societal fear of involuntary euthanasia occurring accidentally because a patient “has changed his or her mind” or, alternatively, “their family may feel” this to be the case. The Subcommittee explained:

While advance directives continue to receive widespread support, some new concerns have arisen. For example, advance directives, if not updated regularly, may be implemented after a patient has changed his or her mind. Alternatively, family members may feel that a change in position has occurred. The health care team, or even the family, may not be aware of the advance directive. An emergency situation may arise in which the application of the health care directive is not clear, or emergency medical personnel, such as ambulance drivers, may have a legal duty to revive the patient. A public education and information campaign might alleviate these potential problems. There are several examples of good educational packages prepared by senior citizen groups.

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121 CMA Code of Ethics, supra note 5.
123 Senate Report, Of Life and Death, supra note 36.
124 Supra note 122 at Sec.E. “Advance Directives”, ¶ 5.
125 Ibid, ¶ 3.
The Subcommittee did not suggest explicit changes to the provincial legislation apart from recommending that "the federal government, in collaboration with the provinces, develop a national strategy for end-of-life care". It is not clear if such collaboration has the potential to enhance the existing provincial legislation.

The provincial advance directive legislation that has been enacted varies across the country in terminology and in substantive matters, derogating from the presumed goal of uniform understanding and application of advance directives in Canada. An advance directive is referred to in the provincial legislative schemes by various names, including "representation agreement" (British Columbia), "personal directive" (Alberta), "health care directive" (Manitoba), "power of attorney for personal care" (Ontario), "mandate given in anticipation of... incapacity" (Quebec), "directive" (Prince Edward Island), "authorization to give consent" (Nova Scotia) and "advance health care directive" (Newfoundland).

The legislation differs from province to province with respect to the definition and scope of advance directives, requirements respecting who is entitled to act as a surrogate for the patient, requirements for witnessing the document, procedures for activating the advance directive, and so on. There is little consistency in the definition of an advance directive

127 Supra note 9 at s.1.
128 Supra note 4 at s. 1(k).
129 Supra note 4 at s. 1
130 Supra note 19 at s. 46 (Powers of attorney for personal care were recommended by a Provincial Advisory Committee. The Committee stated in its final report: "With respect to medical and psychiatric treatment, the power could serve what has become known as a “living will”. The dignity of the individual would be maintained with minimal state involvement." “Final Report of the Advisory Committee on Substitute Decision Making for Mentally Incapable Persons”, Chair Stephen V. Fram, Q.C. (Toronto: The Advisory Committee on Substitute Decision Making for Mentally Incapable Persons, 1988) at 137. Cited by Jasmine Sweatman, Guide to Powers of Attorney, supra note 6 at 97.)
131 Supra note 19 at art. 2130.
132 Supra note 4 at 1(e)
133 Supra note 19 at s.2.
134 Supra note 4 at s. 2(a).
135 Dalhousie University maintains a website with information respecting the provincial advance directive legislation entitled the “End of Life Project” [EOL]. The EOL website features a link to a “Reading Room” which includes a PDF document entitled “A Summary of Canadian Legislation Concerning Advance Directives, Last Updated March 2005”. This document is a helpful summary of the relevant provincial
or what the legal characteristics of an advance directive are across the country. Arguably, this inconsistency and the resulting confusion respecting terms and provisions cause advance directives to be misunderstood, distrusted and little used.

A significant factor affecting and delaying the development of provincial advance directive legislation in Canada is that, unlike the situation in the United States, the provincial governments have no power to grant immunity from criminal liability to health care providers who follow an advance directive.\textsuperscript{136} In Canada, the constitutional responsibility for enacting criminal law is strictly federal, whereas the US constitutional division of powers enables state legislatures to provide immunity from both civil and criminal actions to health care providers who follow an advance directive. The provincial governments are limited to providing legal protection from civil liability to health care providers who act on an advance directive.

However, not all of the provinces have enacted advance directive legislation which provides statutory immunity even from civil actions to health care providers who follow an advance directive. Only four of the provincial advance directive Acts clearly provide protection from liability for a care provider who follows an advance directive. The B.C. \textit{RAA},\textsuperscript{137} for example, only provides immunity to representatives and monitors, and not to health care providers who act on an advance directive.\textsuperscript{138} (The \textit{RAA} is a system for legislation, although it is not complete or accurate, and should not be considered a definitive source. For example, the information on the \textit{RAA} under the heading “Finding of Incapacity” states:

\begin{itemize}
  \item s.15(1): an RA [Representation Agreement] becomes effective on the date it is registered
  \item unless the RA provides that it, or a provision of it, becomes effective later
  \item a) when the representative receives an assessment report under s.5 of the \textit{Adult Guardianship Act} indicating the adult is incapable
  \item b) when an event occurs
\end{itemize}

All of this information is incorrect. The proposed registration requirement pursuant to \textit{RAA} s. 14 (not s. 15) has not been proclaimed in force and, similarly, \textit{RAA} s. 15 1(a) has not been proclaimed in force. Despite the inaccuracies on the website, the EOL is a useful compendium of resource materials and information. \textit{"The End of Life Project Health Law Institute • Dalhousie University" Online: http://as01.ucis.dal.ca/dhl/cmp_welcome/default.cfm}; EOL Project report “Advance Directives - A Summary of Canadian Legislation” Online: http://as01.ucis.dal.ca/dhl/cmp_documents/documents/AD_quick_guide (Updated March 2005).pdf; accessed September 15, 2005.

\textsuperscript{136} Sharpe, \textit{Law & Medicine supra} note 20 at 306.
\textsuperscript{137} [\textit{RAA}]\textsuperscript{supra} note 9.
\textsuperscript{138} \textit{Ibid}, ss. 23, 25.
appointing proxies to make health care decisions). The *Health Care (Consent) and Care Facility (Admission) Act* of B.C.\(^{139}\) provides immunity to health care providers who act in good faith and use reasonable care\(^{140}\) and entitles them to rely on “someone’s authority to give, refuse or revoke consent to health care”.\(^{141}\) However, there is no specific immunity for health care providers under either of these Acts for civil actions brought in connection with a decision to withhold or withdraw life-sustaining treatment in accordance with an advance directive. It is also notable that the limited protection offered to health care providers for following an advance directive falls under separate legislation from the *RAA* which purports to provide adults with the power to make advance directives.

The requirement to look to separate legislation for health care provider protection is also found in Ontario where the *Substitute Decisions Act*,\(^{142}\) which enables adults to complete a “Power of Attorney for Personal Care” (a form of proxy advance directive), does not address the issue of immunity for health care providers. The only protection from liability offered under the *Substitute Decisions Act* is to volunteers who may be appointed by the Public Trustee and Guardian to provide advice under the Act.\(^{143}\) Health care providers must look to the *Health Care Consent Act*\(^{144}\) for comfort that they have protection against liability from civil actions where they act in good faith in following an advance directive. Since legislative immunity for their actions is located in different legislation than the *Substitute Decisions Act*, health care providers may be sceptical that it offers real protection to them if they follow an advance directive.

Some provinces, such as Saskatchewan\(^{145}\), Manitoba\(^{146}\), Prince Edward Island\(^{147}\) and Newfoundland\(^{148}\) clearly provide protection from liability for health care providers in the

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139 RSBC 1996 c. 181  
140 Ibid, s.33(1) (No action may be brought or continued against a person for any act or omission in the performance of a duty or the exercise of a power or function under this Act if the person has acted in good faith and used reasonable care.)  
141 Ibid, s. 33(2)(b).  
142 Supra note 19.  
143 Ibid at s. 87 (1).  
144 S.O. 1996, c. 2 (Schedule A) s 29.  
145 Supra note 4 at s. 22.  
146 Supra note 4 at s. 22.  
147 Supra note 4 at s. 18.
advance directive legislation, but the Acts of some provinces do not address the issue at all, such as those in Quebec and Nova Scotia. The Alberta legislation is obscure but appears to offer protection, assuming a health care provider is defined to be a "service provider" and the health care falls within the definition of "personal service."\textsuperscript{149}

The Canadian \textit{Criminal Code}, as currently worded, potentially imposes criminal liability on health care providers who follow an advance directive. Some of the provincial advance directive Acts do not provide protection from civil liability to health care providers. Cooperation between federal and provincial government is necessary in order to provide health care providers complete immunity from both criminal and civil liability.\textsuperscript{150} While such cooperation may be tacit, it is not express. The resulting legislative vacuum creates a disconcerting potential in some Canadian jurisdictions for both criminal and civil liability to be imposed on a health care provider who follows an advance directive to withhold or withdraw treatment.

In summary, the provincial advance directive Acts do not achieve many of the goals that the legislation was intended to meet. The lack of uniformity in the legislation works against inter-jurisdictional recognition, despite the goal of uniform country-wide medical treatment. The lack of harmony in the legislation also prevents widespread knowledge and understanding of advance directives. The failure of some provinces to recognize instructional advance directives leaves citizens in those provinces with the mistaken impression that their written wishes in a living will are "illegal" and may not be recognized by health care providers. The failure of several provinces to implement civil immunity for health care providers in their legislation leaves them uncertain about the risks they face in following an advance directive. The provincial advance directive legislation does nothing to minimize the confusion about the legality of instructional advance directives in Canada.

\textsuperscript{148} Supra note 4 at s. 19.
\textsuperscript{149} Supra note 4 at s. 28.
\textsuperscript{150} Sharpe, Law & Medicine, supra note 20 at 306-307.
3.3. The Jurisprudence

Descriptions of the legal status of advance directives in Canada typically refer to the Ontario Court of Appeal decision in *Malette v Shulman* [*Malette*]151 as authority for the principle that a physician must defer to the express wishes of a formerly competent patient as set out in an advance directive.152 Professor Kluge describes *Malette* as “a landmark case” holding that an instructional advance directive that “is specific to the situation in question and is unambiguous and requires no interpretation … must be followed”.153 The *Malette* case is referred to “approvingly”154 in *Rodriguez*,155 and was the basis for the subsequent Ontario Court of Appeal decision in *Fleming v Reid* [*Fleming*]156 which confirmed a Charter right to refuse treatment through an advance directive. The jurisprudence appears “[a]t first glance”157 to support the legal, moral and constitutional authority of the advance directive, until the case law is analyzed closely.

Although the *Malette* decision is considered foundational to the legality of the advance directive under the Canadian common law, Professor Downie points out that the Court of Appeal “explicitly rejected the extension of the reasoning in this case to cases involving patients who have been diagnosed as terminally or incurably ill or patients in a persistent vegetative state.”158 Robins, J.A. also “emphasized” that the court was not concerned with the case of a patient who rejected medical treatment through an “advance directive” or “living will”:

I should emphasize that in deciding this case the court is not called upon to consider the law that may be applicable to the many situations in which objection may be taken to the use or continued use of medical treatment to save or prolong a

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151 *Malette*, supra note 1.
153 Kluge, Biomedical Ethics, supra note 104 at 200.
155 *Supra* note 1
156 *Supra* note 1
157 See Downie, Dying Justice, supra note 8 at 157 n. 19.
158 *Ibid*; see also, Downie, Where There is a Will, supra note 116 at 75.
patient's life. The court's role, especially in a matter as sensitive as this, is limited to resolving the issues raised by the facts presented in this particular case. On these facts, we are not concerned with a patient who has been diagnosed as terminally ill or incurably ill who seeks by way of advance directive or 'living will' to reject medical treatment so that she may die with dignity; neither are we concerned with a patient in an irreversibly vegetative state whose family seeks to withdraw medical treatment in order to end her life; nor is this a case in which an otherwise healthy patient wishes for some reason or other to terminate her life. There is no element of suicide or euthanasia in this case." 159

Therefore, although subsequent courts have extrapolated from the language in *Malette v Shulman* the legal foundation for the advance directive under Canadian common law, the Court of Appeal made it abundantly clear that it did not intend its opinion to extend to the concept of the advance directive for end-of-life treatment. In fact, the next Ontario Court of Appeal decision to refer to the *Malette v Shulman* case, *Wijngaarden v. Tzalalis* 160, held that a hospital was correct not to follow the blood transfusion refusal card of a Jehovah's Witness on the ground that the injured patient, who was not consistently competent to give or refuse consent to treatment, might no longer hold the same position regarding blood transfusion that was set out on the blood refusal card.

Some authors refer to the "approving" 161 language in *Rodriguez* to infer that the Supreme Court of Canada accepts the binding effect of the instructional advance directive. However, in his discussion of the *Malette v Shulman* case in *Rodriguez*, Sopinka J. does not extend the autonomy principle beyond the right of a competent adult to refuse consent to medical treatment, a concept well accepted in the Canadian jurisprudence. 162 Sopinka, J., also refers to the *Cruzan* 163 decision of the U.S. Supreme Court, but never states that the reasoning in *Cruzan* is also the law in Canada:

159 *Malette, supra* note 1 at 428.
160 [1992] 11 O.R. (3d) 779 (C.A.) (Note that the Hamilton General Hospital confirmed that it would follow the direction given by the patient as soon as she became competent to provide consent or refusal of treatment).
161 See for e.g. *supra* note 154.
163 *Cruzan v Director, Mo. Dept. of Health*, 497 U.S. 261, (1990) (cited as: *Cruzan v. Director, Missouri Health Department* (1990), 111 L. Ed. 2d 224.)
Canadian courts have recognized a common law right of patients to refuse consent to medical treatment, or to demand that treatment, once commenced, be withdrawn or discontinued (Ciarlariello v. Schacter, [1993] 2 S.C.R. 119). This right has been specifically recognized to exist even if the withdrawal from or refusal of treatment may result in death (Nancy B. v. Hôtel-Dieu de Québec (1992), 86 D.L.R. (4th) 385 (Que. S.C.); and Malette v. Shulman (1990), 72 O.R. (2d) 417 (C.A.)). The United States Supreme Court has also recently recognized that the right to refuse life-sustaining medical treatment is an aspect of the liberty interest protected by the Fourteenth Amendment in Cruzan v. Director, Missouri Health Department (1990), 111 L. Ed. 2d 224. However, that Court also enunciated the view that when a patient was unconscious and thus unable to express her own views, the state was justified in requiring compelling evidence that withdrawal of treatment was in fact what the patient would have requested had she been competent.  

While the Malette case is referred to favourably by Sopinka, J., the Rodriguez decision cannot be taken to be a clear affirmation of the legal authority of advance directives for end-of-life treatment in Canada.

The common law right to express wishes in an advance directive is stated more clearly in the subsequent Ontario Court of Appeal case of Fleming.  

The facts of the case, however, are not concerned with an advance directive for end-of-life treatment but rather with a patient suffering from mental illness who had, during a prior period of competency, expressed a wish to forego a certain type of psychiatric treatment. While the fact pattern is not precisely on point; nevertheless, the language of the Court of Appeal is quite compelling. Once again Robins, J.A. spoke for the Court of Appeal, stating:

A patient, in anticipation of circumstances wherein he or she may be unconscious or otherwise incapacitated and thus unable to contemporaneously express his or her wishes about a particular form of medical treatment, may specify in advance his or her refusal to consent to the proposed treatment. A doctor is not free to disregard such advance instructions, even in an emergency. The patient's right to forgo treatment, in the absence of some

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164 Rodriguez, supra note 1 at ¶156.
165 Supra note 1.
overriding societal interest, is paramount to the doctor's obligation to provide medical care. This right must be honoured, even though the treatment may be beneficial or necessary to preserve the patient's life or health, and regardless of how ill-advised the patient's decision may appear to others.\textsuperscript{166}

The next case to absolutely confirm the legal status of advance directives under the common law is \textit{A.M. v. Benes [Benes]}\textsuperscript{167}, a case of the Ontario Court of Justice which, unfortunately for the jurisprudence regarding advance directives, was reversed on appeal. In common with \textit{Fleming}, the \textit{Benes} case involved a patient suffering from mental illness but the case particularly related to the role of a substitute decision maker. The words of Sutherland J., explaining the common law "bedrock position"\textsuperscript{168} respecting advance directives, are interesting for their fervent defense of the legal concept:

The case law requires that where the patient is incapable of consenting to, or refusing to consent to, a proposed treatment, the patient's prior capable wishes applicable to the circumstances, if known, are to be given effect to. That point is strongly and clearly made in \textit{Malette v. Shulman}.\textsuperscript{169}

...  

It is to be noted that \textit{Malette v. Shulman} states the common law position. Its conclusions are not based on statute or Charter, and it is binding upon me and upon the Board. It did not involve a substitute decision maker. The decision expresses the common law bedrock position as to the individual's right to control what is done to his or her body. The decision in \textit{Fleming v. Reid} (1991), 4 O.R. (3d) 74, introduces the constitutional dimension, giving that, right a constitutionally entrenched position under, and subject to, the provisions of s. 7 of the Charter.\textsuperscript{170}

The Ontario Court of Appeal\textsuperscript{171} reversed the Court of Justice decision in \textit{Benes} without referring to the \textit{Malette} decision.

\textsuperscript{166} \textit{Ibid} at 310.
\textsuperscript{168} \textit{Ibid} at 671.
\textsuperscript{169} \textit{Ibid} at 670.
\textsuperscript{170} \textit{Ibid} at 671.
\textsuperscript{171} \textit{A.M. v. Benes} (1999)\textsuperscript{180} D.L.R.4\textsuperscript{th} 72; 46 O.R. (3d) 271(C.A.), rev'g (1998)\textsuperscript{166} D.L.R. 4\textsuperscript{th} 658 (Ont. Gen. Div.).
While the jurisprudence favours the common law legality of the advance directive, including the instructional advance directive, or living will, the cases do not offer the "bedrock position" that Sutherland, J. described. Arguably, the strongest case defending the legality of the advance directive is *Fleming v Reid*, which does not involve a directive for end-of-life treatment. It is now possible to understand why Ms. Sweatman admonishes her readers to "remember" that "the common law does not generally recognize advance directives relating to future medical treatment...." The legality of advance directives under the common law is not nearly so certain as one might wish.

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172 Supra note 168.
4. Legal Prospects

The Canadian law regarding advance directives is not clear. The Criminal Code implies that following an advance directive is a criminal act, potentially constituting homicide. Not all of the provincial acts recognize instructional advance directives and many do not grant health care providers immunity for following an advance directive. The case law concerning advance directives is sparse and generally not precisely on point to the primary purpose of advance directives: making prior decisions or stating wishes respecting end-of-life medical treatment.

Recommendations to politicians to amend the legislative deficiencies have been made by many august bodies, including the Law Reform Commission of Canada, the Special Committee and Subcommittee of the Senate, and various groups from the legal and health communities, without success. In light of the failure of elected officials to make the recommended and necessary changes, some of these groups now act independently of the political structures to achieve the benefits proposed from the use of advance directives. For example, the Canadian Bar Association wrote in September 2003 directly to the Canadian Medical Association recommending that the CMA Code of Ethics be widened to ensure physicians take into consideration oral advance directives that may have been offered to someone other than a proxy and also honour "statements committed to writing but not translated into a "legally valid advance directive", in order to follow as much as possible the prior intentions of the patient expressed while competent.

However, independent bodies can only achieve limited success when attempting to act within the boundaries of outdated, narrow and insufficient legislation. Parliament and the provincial legislatures must act on the various recommendations for change if the goals of advance directives for improving end-of-life care are to be met. If the legislators adopt the position propounded by Professors Dickens and Somerville, and by the Special Committee of the Senate, that advance directives and euthanasia are "different in

174 Supra note 5.
175 Letter from Fiona Bergin, Chair, Canadian Bar Association Health Law Section, to John R. Williams, Director of Ethics, Canadian Medical Association, 18 September 2003.
kind”¹⁷⁶, then they can meet the concerns of those objectors who fear that authorizing autonomous decision-making will lead to a regime that pursues euthanasia against its vulnerable citizens.

Politicians have an obligation to make the recommended amendments to the *Criminal Code* and to implement modern provincial advance directive legislation that recognizes both instructional and proxy directives or a combination of the two. It is only right for our political bodies to act on behalf of those people who want authority to direct their treatment choices in whatever manner suits their needs, because their voices are stilled at a time when they need their instructions to be heard the loudest.

The next chapter examines the provisions of the *RAA* to explain why the statute fails as effective advance directive legislation for the citizens of British Columbia.

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CHAPTER FIVE: THE REPRESENTATION AGREEMENT ACT

1. Introduction

This chapter describes the current debate about advance directive legislation in B.C. The B.C. Representation Agreement Act\(^1\) (RAA) is an unusual form of advance directive legislation that solely recognizes proxy directives. Various groups, including members of the medical and legal communities, argue that the RAA is ineffective as advance directive legislation and should be replaced with new personal planning legislation that offers B.C. citizens greater choice and requires minimal execution formalities. The drafters of the RAA and various organizations particularly representing the disabled community argue that the RAA should be maintained as the sole advance directive legislation in B.C.

This chapter reviews the history and purpose of the RAA to explain the unusual emphasis on protection of vulnerable individuals found in the legislation. The chapter then examines how the RAA operates as a statutory vehicle for advance directives, including a review of the relationship between the RAA and the Health Care (Consent) and Care Facility (Admission) Act [HCCA]\(^2\) and an analysis of the legislative provisions. This thesis argues that the RAA was drafted with the primary purpose of protecting vulnerable individuals while extending their autonomy over daily living matters. The legislation emphasizes preservation of life and creates barriers to the use of advance directives. This thesis argues that the drafters of the RAA were influenced by vitalism\(^3\) and, consequently, the legislation displays discomfort with and antipathy towards the use of an advance directive to refuse life-sustaining medical treatment.

This thesis does not analyze the proposed replacement of enduring powers of attorney with representation agreements. The proposed repeal of s. 8 of the Power of Attorney Act

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\(^1\) R.S.B.C. 1996, c. 405 [RAA].
\(^2\) R.S.B.C. 1996, c. 181 [HCCA].
\(^3\) See Chapter Three note 12 and accompanying text for discussion on the topic of vitalism.
was thoroughly examined and cogently argued by Dr. Albert McClean who recommended retaining s. 8 POA enduring powers of attorney in his 2002 report [the McClean Report]. This thesis also does not address the usefulness of a s. 7 Representation Agreement for assisting persons who have diminished capacity with meeting their everyday living needs with dignity and autonomy. A s. 7 Representation Agreement may serve that purpose as intended. This thesis solely considers the issue of why the RAA fails as effective advance directive legislation.

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4 R.S.B.C. 1996, c.370 [POA].
2. The Debate about Advance Directive Legislation in B.C.

The Executive Director of the Representation Agreement Resource Centre [RARC] presented a paper [the RARC paper] in November 2004 entitled: “The Representation Agreement Act: B.C.’s “Living Will” Legislation.” The title of the RARC paper is inaccurate because the RAA does not recognize living wills [instructional advance directives]; the legislation only recognizes proxy directives. The RARC paper acknowledges this fact in a heading which states: “1. Representation Agreements are a Proxy-Type of Directive”.

The title of the RARC paper also contradicts the content, which is highly critical of living wills. The author explains that “[e]mpirical and anecdotal evidence demonstrates that instructional directives alone do not work and may be harmful.” The RARC paper notes that “[s]ome [B.C.] health authorities have signalled their intent to produce and promote standard forms for instructional advance care directives”. The author asks “Why this push from the Ministry of Health and health authorities?” and suggests that the health authorities are motivated to offer instructional advance directives in the hope that “resources can be saved.”

The author quotes Angela Fagerlin and Carl Schneider, [Fagerlin and Schneider] co-authors of “Enough: The Failure of the Living Will”, as authority for the assertion that

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7 Ibid at 7.1.4.
8 Ibid at 7.1.6.
9 Ibid (“The Vancouver Island Health Authority (VIHA) is the furthest along. VIHA received a grant of over $700,000.00 (2003?) (sic) from the federal government primary health care initiative. They contracted with William Molloy, an Ontario physician, to use/modify a B.C. edition of his book Let Me Decide. Fraser Health Authority is also considering implementing Molloy’s material but is probably waiting for VIHA to work out “the bugs.” [Footnote omitted]”) at 7.1.8.
10 Ibid.
11 Ibid.

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living wills “fail to achieve [the] goal” of self-determination and should be abandoned in favour of the proxy directive. As discussed in Chapter Three above, Fagerlin & Schneider are derisive of the concept of the living will.\footnote{Taylor, “The RAA”, supra note 6 at 7.1.7.}

The RARC paper illustrates the debate in B.C. about the need for new advance directive legislation. Ardent supporters of the \textit{RAA}, such as the Executive Director of RARC, argue that written instructions “do not account for changes in …the patient’s mind”\footnote{See Chapter Three note 12 and accompanying text. Schneider is similarly concerned about a proxy decision to withdraw life-sustaining treatment. See Carl E. Schneider, “Hard Cases and the Politics of Righteousness” (2005) 35: 3 Hastings Center Report 24 (“It takes a keen eye to detect the difference between [a substituted decision to withdraw life-sustaining treatment] and involuntary euthanasia, the traditional bottom of the slippery slope.” at 27).} and warn that the public is “generally unaware of how health care resources are allocated or rationed.”\footnote{Taylor, “The RAA”, supra note 6 at 7.1.6.} By comparison, some of the health authorities\footnote{Ibid.} and the Ministry of Health\footnote{See supra note 9.} have proposed that B.C. citizens would benefit from legislation that recognizes living wills and proxy directives as well as a combination of these forms. The authors and supporters of the \textit{RAA} are unlikely to acknowledge the potential benefits of living will legislation, however, since they believe that the many “safeguards” of the \textit{RAA} help to protect and preserve the lives of vulnerable individuals.\footnote{British Columbia, Ministry of the Attorney General, “Personal Planning Legislation: Government’s Response to McClean Report, Ministry of Attorney General”, (Victoria: Ministry of the Attorney General, Policy, Planning and Legislation Branch, 2004) Online: posted March 2004 at <http://www.ag.gov.bc.ca/legislation/guardianship/response.pdf.> [Ministry Proposal].}

The \textit{RAA} was drafted with the laudable goal of providing as much autonomy as possible to vulnerable persons who have diminished capacity to direct their daily lives. People with intellectual disabilities who have never had contractual capacity are enabled under

\footnote{13 Taylor, “The RAA”, supra note 6 at 7.1.7.}
\footnote{14 See Chapter Three note 12 and accompanying text. Schneider is similarly concerned about a proxy decision to withdraw life-sustaining treatment. See Carl E. Schneider, “Hard Cases and the Politics of Righteousness” (2005) 35: 3 Hastings Center Report 24 (“It takes a keen eye to detect the difference between [a substituted decision to withdraw life-sustaining treatment] and involuntary euthanasia, the traditional bottom of the slippery slope.” at 27).}
\footnote{15 Taylor, “The RAA”, supra note 6 at 7.1.6.}
\footnote{16 Ibid.}
\footnote{17 See supra note 9.}
\footnote{18 See Robert Gordon, \textit{The 2002 Annotated British Columbian Representation Agreement Act, Adult Guardianship Act and Related Statutes}, (Scarborough: Carswell, Thompson Canada Limited, 2001) [Gordon, \textit{Representation Agreement Act}] (“The Representation Agreement Act attempts to create safeguards …” at 12; “[there are] a variety of safeguards found throughout the Act” at 21; “[t]his subsection [9(2)] provides an important safeguard” at 29); See Taylor, “The RAA”, supra note 6 (“Representation Agreements have the potential to …avoid the ethical conflict that exists when those who are ‘offering’ the health care are the same parties producing the directive form” at 7.1.8.).}
the RAA to appoint a person or persons to assist them with decision-making for their daily living needs. The RAA incorporates many safeguards to ensure that this vulnerable population is protected.

The RAA statutorily provides for two types of agreement [a “Representation Agreement”] under the legislation: a section 7 (sometimes called “standard” or “limited powers”) Representation Agreement and a section 9 (sometimes called “enhanced” or “general powers”) Representation Agreement. The two types of Representation Agreement are distinguished in terms of the capacity required to enter into them and the power granted to the representative. A s. 7 Representation Agreement can be created by adults with diminished intellectual capacity and provides fewer powers to the representative. For example, a s. 7 Representation Agreement does not allow the representative to refuse consent to “life-supporting” medical treatment for the adult; only a s. 9 Representation Agreement provides this power to the representative.

Only adults with contractual capacity can create a s. 9 Representation Agreement. The s. 9 Representation Agreement can be both a current and an enduring power of attorney for financial and for personal care and also a proxy advance directive for capable adults. This thesis is concerned only with s. 9 Representation Agreements.

This chapter examines the many criticisms that can be made about the RAA as a statutory vehicle for advance directives. The RAA limits the choice provided to B.C. citizens for advance health care planning to a type of proxy advance directive and does not recognize an instructional advance directive [living will]. The RAA potentially imposes conflicting

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21 RAA, supra note 1 (“S.7 (2.1) A representative may not be authorized under this section to help make, or make on the adult’s behalf, a decision to refuse life-supporting care or treatment.”)
22 Ibid (“S.9 (1) In a representation agreement, an adult may also authorize his or her representative to do any or all of the following: ...(c) refuse consent to specified kinds of health care, including life-supporting care or treatment.”).
23 RAA (“s. 10. Test of Incapability for other provisions – An adult may authorize a representative to do any or all of the things referred to in section 9 unless the adult is incapable of understanding the nature of the authority and the effect of giving it to the representative.”).
obligations on a representative. The RAA imposes unusual and burdensome certification requirements for legal consultation and extensive witnessing of a Representation Agreement. The latter requirements reflect the importance to the drafters of providing safeguards for vulnerable individuals, but they create barriers to executing the document as an advance directive.

The onerous and unusual provisions of the RAA limit extra-provincial recognition of Representation Agreements or B.C. recognition of foreign advance directives because they are vastly different from comparable legislation in the rest of Canada. Even the name of the document is unusual. The name “Representation Agreement” is as uncommon among advance directive documents as is the multi-purpose nature of the legislation: no other Canadian (or U.S.) jurisdiction has named an advance directive for health care a “Representation Agreement”. Consequently, the purpose of the Representation Agreement as an advance directive is obscured to the general public and to the medical profession.

As a result of such deficiencies, the RAA fails to serve the needs of B.C. citizens for end-of-life decision making. The failure of the RAA to meet the needs of the majority of citizens in B.C. for future health care planning is ironic because, despite its principal goal of providing autonomy, as advance directive legislation the RAA is paternalistic and fails to respect individual autonomy for end-of-life decision-making.

As discussed in the previous chapters, a capable patient has a legal right to consent to, or refuse, medical treatment, including life supporting treatment. Although the law is still developing in Canada, the case of Malette v Shulman indicates that an incapable person’s instructional advance directive which sets out his or her preferred treatment

24 Note, however, that in West Virginia the person appointed under a Medical Power of Attorney is named the “Representative” of the Principal. (W.V. Code Ch. 16. Public Health, Art. 30 (a)).
choices in the event of such incapacity should be honoured as well. Arguably, Canadian citizens retain the right to have their medical treatment decisions carried out subsequent to their loss of capacity as a matter of fundamental justice. The legality and the morality of the advance directive rest on the same principle expressed by the Supreme Court of Canada (SCC) regarding competent patients in *Ciarlariello v Schacter* that:

> [e]veryone has the right to decide what is to be done to one’s own body. This includes the right to be free from medical treatment to which the individual does not consent. This concept of autonomy is fundamental to the common law and is the basis for the requirement that disclosure be made to a patient. This duty ... does no more than recognize every individual's basic right to make decisions concerning his or her own body.

In the *Ciarlariello* case, the SCC considered the rights of capable, rather than incapable, patients to dictate their treatment choices. This thesis argues that the rights described in *Ciarlariello* do not evaporate when a patient becomes incapable if the patient has been given the opportunity to express personal medical treatment decisions in advance in a way that suits their personal choices.

B.C. does not provide its citizens with the opportunity to express their wishes through accessible advance directive legislation that offers choice. This thesis argues that the restrictions and limitations of the *RAA* inhibit the choice of B.C. citizens to express their treatment decisions in the event of future incapacity in accordance with their personal life values and, therefore, the *RAA* fails as effective advance directive legislation.

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29 *Ciarlariello v Schacter*, *supra* note 25 at 135.
3. History and Purposes of the *Representation Agreement Act*

3.1. The Report “HOW CAN WE HELP?”

The *RAA* was “drafted primarily from the recommendations of the Joint Working Committee on Adult Guardianship”\(^\text{30}\) which were set out in a discussion draft and final report issued during 1992 [Report].\(^\text{31}\) The Committee’s principal goal was to modernize legislation affecting dependent adults.\(^\text{32}\) The Report focused on the need for vulnerable individuals to have a strong network of personal support in order for them to exercise autonomy.\(^\text{33}\)

Having suffered under antiquated legislation respecting dependent adults\(^\text{34}\), the Committee advocated for legislative change that would meet the needs of “key constituencies (e.g. the intellectually disabled, the mentally ill and seniors)”.\(^\text{35}\) The Committee took notice, as well, of the apparent inadequacy of laws respecting consent to health care and the need for codification of “new and popular ideas such as planning documents, [including] living wills and advance health care directives of both the proxy and instructional type”.\(^\text{36}\)

\(^{30}\) Gordon, *Representation Agreement Act* supra note 19 at 2.  
\(^{31}\) British Columbia, Joint Working Committee, with equal representation from government (Interministry Committee on Issues Affecting Dependent Adults) and community (the Project to Review Adult Guardianship) *HOW CAN WE HELP? A New Look at Self-Determination, Interdependence Substitute Decision Making and Guardianship in B.C. A Report Providing Recommendations for Legislation and Policy*, (Victoria: Interministry Committee on Issues Affecting Dependent Adults; Project to Review Adult Guardianship 1992) [The Report].  
\(^{32}\) *Ibid* (“The focus of this report is the reform of legislation ... affecting the support, assistance and protection of British Columbians who find it difficult to care for themselves...”) at 2.  
\(^{33}\) *Ibid* at 7. For example, the Report recommended establishment of programs, such as ‘circle of friends’, mini-boards or Ulysses Agreement committees to help people with intellectual or mental disabilities to have community support. (A “Ulysses” agreement provides that a person’s instructions which were made when the person was competent should be followed notwithstanding objections the person makes during a subsequent period of incompetence. Ulysses agreements are sometimes used by people who suffer intermittent periods of mental disability.)  
\(^{34}\) *Ibid* (The Report described the existing legislation as tending to reflect “a Victorian philosophy of benign paternalistic intervention.” at 3).  
\(^{35}\) Gordon, *Representation Agreement Act* supra note 19 at 4.  
\(^{36}\) Gordon, *Representation Agreement Act* supra note 19 at 4 -5.
The Committee prepared an initial discussion paper [Paper]\(^{37}\) inviting public comment on the proposals. The Paper is almost entirely focused on protecting the rights and the safety of vulnerable persons and is devoid of analysis of advance directives or consideration of advance directive legislation in any other jurisdiction. Advance directives are described as "informal agreements" in the Paper. Although the Committee members may have discussed these matters, review of the common law concerning advance directives is noticeably absent from the Paper,\(^{38}\) as is discussion of the doctrine of consent to treatment, withdrawal or withholding of treatment, and related end-of-life issues. Similarly, the Paper does not take notice of any of the published proposals for advance directive legislation under consideration in the other provinces at that time.\(^{39}\)

The Report did not vary significantly from the Paper and, in common with the Paper, contains no analysis of the law respecting advance directives or any consideration of advance directive legislation of other jurisdictions. The drafters of the Report did not include any consideration of whether mature minors should be able to implement advance directives in light of their common law rights to consent to, or refuse, treatment. Nor did the drafters consider whether the recommended regime for execution, amendment or revocation of documents should be different for advance directives than for documents primarily intended to meet the daily living needs of vulnerable adults. The drafters did not include discussion of the different legal foundations for enduring powers of attorney

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\(^{38}\)No comment is made, for example, of whether the case of Malette, supra note 27, had any implication for the legal status of living wills in Canada.

and advance directives or consider whether these potentially created different types of legal obligations for representatives. Almost no material in the Report discusses the use of a Representation Agreement as an advance directive. The drafters were principally concerned with legal guardianship issues and protection of the vulnerable.

It is instructive to review the provisions of the Report, not only because the recommendations set out in the Report were largely incorporated into the RAA, but also because the Report describes the intent and purposes behind the RAA provisions.

3.2. Proposed Purposes Of The Representation Agreement Act

The dominant theme of the Report was prevention of abuse. The Report was infused with concern about the potential “abuse, neglect or self-neglect of some older adults or people with disabilities or illnesses who are living in their own homes or those of relatives, or who reside in care facilities”. An Appendix clarifies that the Report resulted from an initial review of Adult Guardianship and that all of the analysis and recommendations reflect the interest in protecting the rights of vulnerable people. One of the consultants to the process explained that the RAA “attempts to create safeguards in response to concerns about the use of enduring powers of attorney as instruments of financial abuse, particularly amongst older people.”

Chapter 3 of the Report set out a recommendation to expand a Power of Attorney to include health and personal care to “provide a pre-planning mechanism which is easily understood and arranged yet includes safeguards necessary to prevent abuse.” A Representation Agreement was proposed as a method to “allow the adult to voluntarily select and empower one or more people to assist, support, act or make decisions on her behalf” in personal and health care matters, in addition to legal and financial decisions.

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40 The Report supra note 31 at 3.
41 Gordon, Representation Agreement Act, supra note 19 at 12.
42 The Report supra note 31 at 17.
43 Ibid.
With regard to decision-making under a Representation Agreement, the Report included an explanation that the adult would “share” the right to make decisions with the representative.\(^{44}\) The effect of such shared decision-making would be to enable third parties to act on a decision made by a representative, even when the adult disputed the decision.

In addition to its role as a power of attorney, the drafters intended a Representation Agreement to “recognize the general concepts found in the range of informal agreements, such as personal support networks, “living wills”, advance directives, health care proxies, Ulysses Agreements\(^{45}\) and psychiatric wills”.\(^{46}\)

The Report contained no sample form but set out in detail the committee’s recommendation for signing and witnessing of Representation Agreements. The committee recommended such a cautious approach to execution that these provisions were specifically not followed by other Canadian jurisdictions that subsequently considered implementing advance directive legislation on the grounds that they are onerous.\(^{47}\) Not only would the spouse, partner, child or parent of a representative be prohibited from witnessing an agreement, also prohibited were any employees, managers or agents of the representative. A breach of the witnessing restriction would render an agreement subject to court ordered cancellation. The drafters did not propose separate minimal requirements for persons with common law contractual capacity to create a streamlined advance directive.

\(^{44}\) *Ibid* at 19.

\(^{45}\) See *supra* note 33 for a definition of a Ulysses Agreement.

\(^{46}\) The Report *supra* note 31 at 18.

\(^{47}\) For example, Alberta, Alberta Law Reform Institute and The Health Law Institute, *Advance Directives and Substitute Decision-Making in Personal Health Care*; (Edmonton: Alberta Law Reform Institute, 1993) (Chair: Professor Gerald Robertson) states: “It should be noted, however, that the legal requirements and formalities surrounding the proposed Representation Agreement are much more onerous than those recommended in our Report for Discussion” at 13. Similarly, the Nova Scotia Law Reform Commission recommended against adopting restrictions respecting who could act as a witness such as those in the RAA on the grounds that “reforms should make it easier for people to make directives.” Nova Scotia, Law Reform Commission of Nova Scotia, *Living Wills in Nova Scotia*, (Halifax: Law Reform Commission of Nova Scotia, 1994) at 25.
The Report recommended that an adult making the Representation Agreement be allowed to choose an adult person or the Office of the Public Guardian and Trustee [OPGT] as representative. The Report also recommended a monitor be chosen to oversee the activities of the representative and that if no monitor was chosen, the OPTG would automatically be appointed a monitor. The assumption throughout is that an adult needs assistance to initiate, negotiate and implement a Representation Agreement and that subsequent oversight is necessary.

Much of the Report was written in casual language which makes the suggested terminology open to broad interpretation. Activities of daily living, including matters such as where the adult would reside, and financial management were described as “routine” and fell within the powers, authority and duties of the representative. This casual terminology was incorporated into the proposed legislation, leading to immediate criticism from the legal community. One lawyer opined that the proposed RAA was “…an illustration of how ideology without clarity … is not sufficient. The Act is unnecessarily complicated and rigid, and it creates a variety of problems for the people of British Columbia.”

The drafters of the Report anticipated that modification and revocation of Representation Agreements as well as the appointment or disqualification of representatives had potential to raise concern about abuse and so protections were added in each case. Notably, the drafters of the Report recommended that where a representative turned to the court for

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49 Ibid at 22.
50 See for e.g. (RAA s. 7(1) (b)). It appears that creating a simple description of “routine management of the adult’s financial affairs” proved to be a difficult task: a non-exhaustive definition of this section set out in the RAA regulation is two pages long. Arguably, a decision regarding residency is anything but routine where it involves moving an elderly person from a much loved home into a care facility, and there may not be any such thing as “routine dental work” for a severely disabled person.
51 See e.g. Magnusson, “Criticism of the RAA”, supra note 20.
52 Ibid at 517.
direction on how to proceed under a Representation Agreement, the court must follow a “best interests” determination and make a decision “in the best interests of the adult.” 53

The Report recommended that a Representation Agreement not be effective unless registered with a proposed Representation Agreement Registry. This proposal elicited so much disagreement and argument respecting privacy and cost that the registry has never been brought into existence. Similarly, provisions respecting recognition of extra provincial advance directives have never been implemented, possibly because the proposed sections required the documents to be registered.

Although the majority of the material in the Report was concerned with the role of the representative as an assistant with the “routine” daily living activities of the adult, and little related to health care, the last section of Chapter 3 specifically referenced the need for education to “dispel uncertainties and to ensure the agreements are respected in practice, particularly with respect to hospitals and care facilities.” 54

The RAA began to attract criticism before and immediately after it was promulgated because of its complexity and lack of clarity. 55 The legal community was particularly concerned about the proposed elimination of the enduring power of attorney, since it is considered to be a highly useful planning tool for many people.

53 The Report supra note 31 at 23. (The obligation for a representative to consider the best interests of the adult arises in the legislation, even in relation to the use of a s. 9 Representation Agreement as an advance directive. See note 77 ff infra and accompanying text.)

54 The Report, supra note 31 at 30.

55 See e.g. Magnusson, “Criticism of the RAA”, supra note 20; Fiona Hunter, “Representation Agreements: Formality Issues”, Continuing Legal Education Society of British Columbia, [Hunter, “Formality Issues”] online: <http://www.cle.bc.ca/CLE/Analysis/Collection/01-5031401-fomalityissues.htm>, Posted August 21, 2001, Accessed July 11, 2005 (“There has been a certain amount of frustration in...drafting and executing a validly binding agreement.” at 1); R. Trevor Todd, “Representation Agreements: Review and Critique”, online: <http://www.milneselkirk.com > Accessed July 11, 2005 (“The goal and intent of the legislation is laudable, but a number of concerns and discrepancies have yet to be “ironed out.”” at p. 2); Johnston Franklin Lawyers, “An Introduction to Representation Agreements”, online:<http://www.jlf.ca/practiceareas/willestates/estate7.shtml> Accessed June 16, 2005 (“The changes [RAA] were designed to provide greater protection for people unable to make their own decisions. The result is less choice and more formality.”) at p.1.
3.3. Enactment and Proposed Amendment of the Representation Agreement Act

The RAA was passed in 1993 as one of a package of acts collectively referred to as the “Adult Guardianship Legislation”.\(^{56}\) The package of legislation was controversial; consequently, its enactment was delayed for seven years. The RAA was enacted, though only in part, in 2000. After its partial enactment in 2000, the RAA was extensively amended by the Adult Guardianship Statutes Amendment Act\(^{57}\) in 2001. Subsequent legal and medical community reaction, described below, indicate that the RAA has been unsuccessful in meeting public and health care provider needs for suitable advance directive legislation.

In 2001, less than one year after the partial enactment of the RAA, the Ministry of the Attorney General commissioned Dr. A. J. McClean, Q.C., to conduct a review of Representation Agreements and enduring powers of attorney. The review was requested, among other reasons, because of concerns expressed by members of the public, and particularly the legal community, about the proposed repeal and replacement of s. 8 of the POA with Representation Agreements.\(^{58}\) Drafters of the RAA intended that a Representation Agreement would be used in place of a typical enduring power of attorney. To minimize concerns about the potential loss of the enduring power of attorney, the Government did not immediately repeal s. 8 of the POA, and asked Dr. McClean to consider which of the documents would best serve the needs of B.C. citizens to plan for personal financial matters in the event of incapacity. Dr. McClean was not asked to comment on the use of a s. 9 Representation Agreement as an advance directive.

\(^{56}\) Included in this group of Acts was the HCCA, supra note 2, the Adult Guardianship Act R.S.B.C. 1996, c.6 and the Public Guardian and Trustee Act R.S.B.C. 1996, c.383. The transition of the Patients Property Act [R.S.B.C. 1996, c. 349] to the Adult Guardianship Act has not been implemented to date. (The Public Guardian published a report in 2004 arguing that the proposed legislation should be modernized once again before it is enacted. See Jay Chalke, “Modernizing The Legal Framework For Long Term Substitute Decision Making” Elder Law, (Vancouver: Continuing Legal Education Society of B.C., 2004) at 3.1) [Chalke, “Modernizing the Legal Framework”].

\(^{57}\) S.B.C. 2001, c.2.

\(^{58}\) POA supra note 4. POA s.8 provides statutory authority for enduring powers of attorney.
The McClean Report⁵⁹ recommended that the s. 8 POA enduring power of attorney be adopted as the sole legislative vehicle for delegating financial management in the event of incapacity.⁶⁰ The McClean Report also indicated that the RAA created unnecessary complications and legal hurdles for capable adults with respect to use of a Representation Agreement as a power of attorney.⁶¹ In response to the McClean Report the Ministry of the Attorney General for British Columbia immediately issued a Bulletin⁶² accepting the McClean Report recommendations.

The Ministry subsequently proposed the terms for new Personal Planning Legislation [the Ministry Proposal]⁶³ in March 2004. The proposed legislation would simplify and standardize the drafting of Representation Agreements and would also enable the separate creation of instructional and proxy advance directives for health care.⁶⁴ The Ministry Proposal suggested “the removal of unnecessary execution, monitoring and reporting provisions”, elimination of the requirements for legal advice and assistance to create a Representation Agreement and “the development of model Representation Agreements, advance care directives and enduring powers of attorney for inclusion in the regulations.”⁶⁵ The Ministry Proposal stated “There is a recognized need for simplifying and streamlining personal planning.”⁶⁶

The reaction from community organizations⁶⁷ involved with the initial drafting of the RAA was vehement opposition to any legislative amendment and emphatic support for the existing RAA from some of the original proponents of the legislation, particularly those

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⁵⁹ McClean Report, supra note 5.
⁶⁰ Ibid at 32-34.
⁶¹ Ibid.
⁶³ Ministry Proposal, supra note 18.
⁶⁴ Ibid at 2.
⁶⁵ Ibid.
⁶⁶ Ibid at 3.
⁶⁷ See McClean Report supra note 5 at 18-19 for a list of community organizations in favour of abolition of the POA.
representing the disabled community. A response to the Ministry Proposal issued by the RARC stated that Ministry of Health support for separate advance directive legislation created a “serious ethical conflict” because it suggested that the Ministry was primarily interested in saving dollars on health care.68

Some seniors groups similarly imputed a sinister motive to the proposal to implement advance care directives. One editorial suggested that the proposal indicated intent on the part of the Ministry to ration health care:

The new proposed act would enshrine an advance care directive outside a Representation Agreement. This would mean that advance directives would exist without a proxy (representative) and would be useless. Enshrining the idea of supported decision-making in the Representation Agreement Act has done what the current attorney general, Geoff Plant, predicted in 1999 that it would. It enabled "aging adults and other persons of limited capacity - to plan, to maintain and to assign authority over decision-making in their lives.

What then is the motivation for eliminating the Representation Agreement Act? There is no evidence that the problems identified with advance directives have disappeared. If anything, there is a growing consensus among health care professionals, especially those in palliative care, that best practice requires a representative who is chosen in advance by the patient. Health professionals do not rely on written directives because of their concerns about the staleness of documents and the real intent of the individual.

The Ministry of Health and health authorities are behind the promotion of advance directives outside the representation agreement. This appears to be a serious ethical conflict when the ministry behind the promotion of advance directives is also responsible for providing health services. There must be several

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arms' lengths between the service provider and advance directives or it will be seen to be a method of rationing health care. 69

Special interest groups responded so vehemently and emotionally to the proposed changes70 that the government retreated from all effort to proceed with change.71

Many health care providers in British Columbia have been actively seeking legislative recognition of instructional as well as proxy advance care directives. In the absence of such advance directive legislation, and disappointed by the decision not to proceed with the proposed Personal Planning legislation, two major health authorities in British Columbia, have embarked on projects to design forms and materials to assist their patients with drafting advance directives.72 The two health authorities are not acting in unison and have chosen to base their materials on different drafting concepts.73 Neither health authority is using the RAA as a guide for creating an advance directive, nor are they directing patients to prepare Representation Agreements to meet their needs.


70 The Coalition to Save the Representation Agreement Act, Public Bulletin and Attachment, ““Urgent Community Alert: Save the Representation Agreement Act” and “Backgrounder on Representation Agreements” (10 April 2004) Online: Posted April 10, 2004 at: <http://www.povnet.org> (The “Backgrounder on Representation Agreements” states: The current proposal by government to eliminate the Representation Agreement Act ignores the reason the Alzheimer Society of BC and the BC Association for Community Living initiated reform of adult guardianship and personal planning legislation in 1989. ... The proposed changes will once again make us ALL vulnerable to guardianship and control.).

71 British Columbia, Legislative Assembly, Hansard, Vol. 25, No. 12, 5th Session, 37th Parliament (13 May, 2004) at 11098 ¶1440 (Hon Geoff Plant) (“Government has sat down, done its homework and listened to what we've heard, and we have decided to maintain the status quo. Accordingly, we will not be pursuing any further reforms in this area.”).

72 The Fraser Health Authority (representing the largest Canadian health authority measured by population) and the Vancouver Island Health Authority have both embarked on projects to create instructional advance directives for patients. See also Taylor, “The RAA” supra note 6.

73 The Vancouver Island Health Authority contracted Wm. Molloy to modify his materials for British Columbia: Wm. Molloy, Let Me Decide, 6th ed. (Troy, Ont.: Newgrange Press, 2000). The Fraser Health Authority (FHA) has adopted and modified materials prepared by the Gunderson Lutheran Medical Foundation: Gunderson Lutheran, Respecting Choices® online: http://www.gundluth.org/web/ptcare/eolprograms.nsf, last accessed November 27, 2005. The FHA version is called “My Voice”.
These two health authorities have been encouraged to work on their respective advance directive projects by a federal government primary health care initiative and by the Provincial Ministry of Health.\textsuperscript{74} The College of Physicians and Surgeons of British Columbia (CPSBC) endorses the position that both instructional and proxy directives should be respected by physicians. In 2005 the CPSBC removed a previous policy for end-of-life care from its online Policy Manual for Physicians and adopted the Canadian Medical Association \textit{Code of Ethics} which endorses both instructional and proxy advance directives.\textsuperscript{75} Consequently at least two B.C. health authorities and the CPSBC are developing or have adopted policy that is not consistent with the \textit{RAA}. It seems evident that legislative action is necessary to address this need for clarity in B.C.

The next section describes the limitations and restrictions of the \textit{RAA} as advance directive legislation. Although the \textit{RAA} is a relatively short statute, interpreting it is not

\textsuperscript{74} See Taylor, "The \textit{RAA}" \textit{supra} note 6 at 7.1.8 and see \textit{supra} note 9 for discussion of these two initiatives.  
\textsuperscript{75} The B.C. College of Physicians and Surgeons website states: "The College has adopted the Canadian Medical Association Code of Ethics (Update 2004)" (See Canadian Medical Association \textit{Code of Ethics} (Update 2004) www.cma.ca/index.cfm (reviewed at July 17, 2005) which recommends that physicians respect instructional or proxy advance directives at ss. 27-28) B.C.C.P.S. Resource Manual for Physicians, online: https://www.cpsbc.ca- College of Physicians and Surgeons of B.C. - Welcome to the College. The previous policy statement on the CPSBC online Policy Manual, Policy E-2 "End of Life Treatment Decisions" dated June 1995, provided an interesting opinion regarding living wills. The Policy stated:

\begin{enumerate}
\item \textbf{Living Wills}
These are not legally binding in Canada; in fact, the Law Reform Commission rejected legalizing them. (They believed it would risk the reversal of the already established rule in Canada that there should be no duty to initiate or maintain treatment when it is useless to do so. The Living Will approach begins from the opposite principle, since it requires the patient's wishes to be formally expressed in writing in order to allow the physician not to prolong the patient's agony and death. They remarked that this approach may be arguable in the context and legal systems of California and other states, but it was not an arguable reform for Canada.)

Lack of precision and specificity, questions of interpretation, outdated, etc., are all factors complicating the use of the Living Will. Nonetheless, such a document, carefully prepared and updated at regular intervals, can prove invaluable to health-caregivers in communicating patients' wishes at a later date when they may be incapable of doing so.

\textit{[Note: This policy statement no longer resides on the CPSBC on-line Policy Manual, but is available from the CPSBC.]}
straightforward because it must be read together with the *HCCA* to understand the role of the representative. The relationship of these two pieces of legislation creates confusion because of the conflicting obligations imposed on a substitute decision maker under each act. The other legal limitations of the *RAA*, including the restriction to a proxy directive, the restrictions on the actions of the representative, the onerous execution formalities and the restriction on the rights of minors to execute an advance directive are analyzed in greater detail.
4. Limitations of the Representation Agreement Act

4.1. The Problematic Relationship of the Representation Agreement Act to the Health Care (Consent) and Care Facility (Admission) Act

The RAA must be read together with the Health Care Consent and Care Facility (Admission) Act (HCCA) to understand the obligations of a representative under a Representation Agreement. The two pieces of legislation are interwoven but the duties of the representative to fulfill the terms of an advance directive, particularly where the directive requests that life-sustaining treatment be withdrawn, are unclear when read in conjunction with the HCCA.

Various provisions of the RAA refer the reader to the HCCA definitions and obligations. Similarly, the HCCA refers to the obligations of representatives under the RAA. For example, s.1 of the RAA defines health care as follows:

1. Definitions – In this Act:

   “health care” has the same meaning as in the Health Care (Consent) and Care Facility (Admission) Act;

“Health Care” is defined, in part, under the HCCA as follows:

"health care" means anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other purpose related to health, and includes
(a) a series or sequence of similar treatments or care administered to an adult over a period of time for a particular health problem, ...

Therefore, the definition of health care set out in the HCCA is embedded in the first purpose of the RAA, which states as follows:

s. 2. Purpose of this Act - The purpose of the Act is to provide a mechanism
(a) to allow adults to arrange in advance how, when and by whom, decisions about their health care, personal care or financial affairs or about other matters will be made if they become incapable of making decisions independently, and ...

When a Representation Agreement acts as an advance directive, the representative is enabled under the RAA to, inter alia:

9. (1) ...

(b) give consent, in the circumstances specified in the agreement, to specified kinds of health care, even though the adult is refusing to give consent at the time the health care is provided;

(c) refuse consent to specified kinds of health care, including life supporting care or treatment;

(d) give consent to specified kinds of health care, including one or more of the kinds of health care prescribed under section 34(2)(f) of the Health Care (Consent) and Care Facility (Admission) Act.

In carrying out the obligations described in s. 9(1)(c), the representative must act in accordance with the “Duties of Representatives” set out in Section 16 of the RAA. This section lists, inter alia, the following duties:

16. Duties of representative

(5) On application by a representative, the court may exempt the representative from the duty under subsection (3) to comply with any instructions or wishes the adult expressed while he or she was capable.

(7) Section 19(3) of the Health Care (Consent) and Care Facility (Admission) Act applies when a representative makes health care decisions on behalf of an adult.

Therefore, a representative acting in accordance with RAA s. 9(1) (c) in carrying out the terms of an advance directive is required, under RAA s. 16(7) to comply with s.19(3) of the HCCA which sets out the duties of a temporary substitute decision maker (TSDM)

\footnote{RAA supra note 1 at s.2.}
chosen to give or refuse substitute consent to health care. S. 19(3) of the HCCA lists the factors that a TDSM must take into consideration when making the decision to give or refuse substitute consent. Pursuant to s. 19(3), the TDSM must consider whether it is in the adult’s best interests (emphasis added) to give or refuse substitute consent. Section 19(3) of the HCCA reads as follows:

19 (1) A person chosen under section 16 to give or refuse substitute consent to health care for an adult must

(3) When deciding whether it is in the adult's best interests to give, refuse or revoke substitute consent, the person chosen under section 16 must consider

(a) the adult's current wishes,
(b) whether the adult's condition or well-being is likely to be improved by the proposed health care,
(c) whether the adult's condition or well-being is likely to improve without the proposed health care,
(d) whether the benefit the adult is expected to obtain from the proposed health care is greater than the risk of harm, and
(e) whether a less restrictive or less intrusive form of health care would be as beneficial as the proposed health care.

Therefore, pursuant to s. 16(7) of the RAA which sets out the duties of a representative when making a health care decision, the representative must be guided by s. 19(3) of the HCCA and must take the adult’s best interests into consideration when deliberating whether to consent to or refuse treatment. None of the options listed in HCCA s. 19(3) require the representative to consider the adult’s previous directions. Rather than withdrawal of treatment, HCCA s. 19(3) directs a representative to consider whether a less restrictive or intrusive form of treatment might be equally beneficial to the patient.

Curiously, the list of potential TSDMs set out in S. 16 of the HCCA from which a health care provider must choose a substitute decision maker does not include representatives, but only family members. On the other hand, the family members who are listed under s. 16 as TSDM (the adult’s spouse, child, parent, sibling or anyone else related by birth or adoption to the adult) may not give substituted consent to the highly invasive and controversial kinds of health care listed in the HCCA regulation (HCCA s. 18; B.C. Reg 20/2000 – Health Care Consent Regulation s.5), whereas a representative may do so(RAA S. 9(1)(d) ). These types of health care include, inter alia, abortion, electroconvulsive therapy, psychosurgery, removal of tissue from a living human body for implantation in another human body for medical education or
(In fact, pursuant to RAA s. 16(5) the representative can also ask a court to exempt him or her from the duty to comply with the previously expressed wishes of the adult which, pursuant to the stringent requirements of RAA s. 9(2), were made when the adult was certified to be capable.)

The HCCA does not expressly include a plan to withdraw or withhold treatment as part of the definition of health care, although it might be argued that the definition is sufficiently broad to include it. The HCCA provides the alternate right, however, being the right to “select a particular form of available health care on any grounds, including moral or religious grounds.” It is not clear if this provision overrides the apparent power of physicians to place DNR orders on a patient’s chart in cases of futility. Canadian courts have suggested that the appropriate forum to make this decision is in the legislature, rather than in the courtroom, but the drafters of the HCCA did not specifically address the question.

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79 Manitoba, Manitoba Law Reform Commission, Withholding or Withdrawing Life Sustaining Medical Treatment, (Winnipeg, Queen’s Printer, 2003) (“British Columbia’s Health Care (Consent) and Care Facility (Admission) Act requires consent to “health care” which does not expressly include a plan to withdraw or withhold treatment, although the definition may be broad enough to include it.” at 47).

80 HCCA s. 4(b)

81 See Sawatsky v Riverview Health Centre Inc. (1998), 167 D.L.R. (4th) 359 (Man. Q.B.) But see also Scardon v Hawryluck, 69 O.R. (3d) 700 [2004] O.J. No 300 (OSC) in which Cullity, J. overturned a decision of the Ontario Consent and Capacity Board to withdraw treatment from a dying (but not comatose) patient in accordance with a physician’s recommendations. The court held that even insufficiently expressed wishes of the patient should be taken into consideration in deciding upon the patient’s best interests when making a decision to withdraw treatment (in this case the patient’s substitutes refused withdrawal) at ¶55. It is possible that this decision was influenced by the presence of counsel for the Euthanasia Prevention Coalition of Ontario at the hearing.

82 In Re London Health Sciences Centre Inc. v K. (R.) (Litigation Guardian of) (1997)152 D.L.R. (4th) 724 (Ont. Gen. Div.) (“If what is being sought is a declaration that a physician has the legal right in these circumstances to withdraw life support from R.K., I am not at all certain that is a declaration a court should make. Questions such as this, involving as they do complex moral, ethical, religious, and legal issues are best dealt with in a multicultural society by Parliament rather than the courts. They lie essentially within the purview of the legislative branch of government, whose function is to decide upon and enumerate policy, and not within that of the judicial branch.” at 734); but see also Airedale N.H.S. Trust v Bland [1993] 1 All E.R. 821 (H.L.), which recommended that decisions to withdraw or terminate life sustaining treatment should be subject to review and endorsement by the court.

83 See Jocelyn Downie, “Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment: A Violation of Dignity Under the Law in Canada”, (2004) 20:3 Journal of Palliative Care, 143 (According to Professor Downie, “There is no clear direction on this issue to be gleaned from legislation” at 144.)
4.2. Restriction to Proxy Advance Directive

In 2002, Professor Stephan Salzberg prepared a report for the B.C. Law Institute setting out the terms of reference for a proposed study on the HCCA. Although his report was focused on the HCCA, Professor Salzberg found it necessary to review the legislation interrelated with the HCCA, including the RAA. He described the scheme for advance directives under the RAA as follows:

*British Columbia's Representation Agreement Act,* also in force as of February 28, 2000, provides only for proxy advance directives. Capable adults may, in a Representation Agreement, only specify a person whom the adult wishes to have binding and sole authority, subject to certain checks, to decide whether to give, refuse or revoke consent to health care. While the capable adult may give written instructions as to the desired substance of those decisions, either in the Representation Agreement itself or in some other document or instrument, formal or otherwise, those instructions do not have legally binding force.

Professor Salzberg suggested that the legislators might wish to consider amending the RAA to provide for instructional advance directives on the grounds that providing greater autonomy in decision-making options may encourage people to write advance directives.

After reviewing three Canadian unilateral withholding court cases: *Child and Family Services (Manitoba) v R.L.,* (1997) 123, Man R. (2d) 135 (C.A.), *Sawatzky v Riverview Health Centre Inc.* (1998), (supra note 81), and *Re London Health Sciences Centre v K. (R.)* (supra note 82), Professor Downie concludes that there is no moral defence for unilateral imposition of DNR orders by physicians.) at 149.


85 Ibid.

86 Ibid (“...One question that might usefully be considered ... is whether presumptive priority should be given to certain forms of expression in determining the adult's instructions or wishes expressed while capable. One possibility that might be considered would be instructions or wishes expressed in Representation Agreements. ... Consideration might also be given to the introduction of legally binding "living wills" in British Columbia, either in conjunction with or independent of proxy directives.”) at B.
Professor Salzberg was not asked to directly comment on the suitability of the \textit{RAA} as advance directive legislation. Therefore, he limited his comments to a suggestion that greater autonomy might be provided to B.C. citizens if they had the option of choosing the type of advance directive with which they were most comfortable.

As argued in Chapter Three above, legislation restricting citizens to have only the option of a proxy directive and failing to allow the option of either an instructional advance directive or a combined instructional and proxy directive, restricts the autonomy of the person making the advance directive. There are many reasons why a proxy advance directive may not be the most suitable option for an individual.\footnote{Robert Olick notes that on occasion the proxy will find the burdens of decision simply overwhelming; will deviate so radically from the terms of an instruction directive as to fail in his or her fiduciary responsibilities; or will, in unusual cases, exhibit a palpable breach of trust.} Robert Olick notes that

> on occasion the proxy will find the burdens of decision simply overwhelming; will deviate so radically from the terms of an instruction directive as to fail in his or her fiduciary responsibilities; or will, in unusual cases, exhibit a palpable breach of trust.\footnote{Tom Beauchamp and James Childress argue that the substituted judgement standard is ethical only if it “respects previous autonomous choices.” They conclude that substituted judgement should be abandoned altogether and that a pure autonomy standard should be used “whenever explicit prior autonomous judgements are identifiable.”\footnote{Professor Salzberg adopts a similar position, stating:}

> The next hierarchical criterion, the adult's known beliefs and values, represents an even less reliable basis for making a decision consistent with one that the adult would make himself or herself. …It may even, in certain cases, be dangerous, in light of

\begin{itemize}
\item \textbf{Issue IIIb}: “What difficulties exist in practice in ascertaining the instructions or wishes the adult expressed while capable and are there ways to ameliorate those difficulties through legislation?”. \footnote{For example, the individual may not have close family or friends, or they may not wish to impose the burden of choice on family members or family members may not be located nearby.}
\item \cite{Olick2001} Robert S. Olick, \textit{Taking Advance Directives Seriously: Prospective Autonomy and Decisions near the End of Life}, (Washington, D.C.: Georgetown University Press, 2001) \cite{Olick2001} at 111.
\item \cite{BeauchampChildress2001} Tom L. Beauchamp & James F. Childress, \textit{Principles of Biomedical Ethics}, 5th ed., (New York: Oxford University Press, 2001) \cite{BeauchampChildress2001} at 100.
\item \textit{Ibid.}
\end{itemize}
the elusive nature of "known beliefs and values," to allow them to be the sole criterion for health care decisions that may bear upon life or death.\(^91\)

Similarly, Ronald Dworkin states that since “beneficiary and fiduciary may take a different view of the former’s best interests, the right of beneficence differs from the right to autonomy … and may in some circumstances conflict with it.”\(^92\) Dworkin explains that the unwillingness to act on an autonomous direction for the cessation of life-supporting treatment is caused by the view that terminating a life, regardless of the quality of that life, is an affront to the sanctity of all life.\(^93\)

Advocates of proxy advance directives believe the presence of a proxy provides the protection that someone who cares about the patient has assessed the situation and has made a decision for the patient in the patient’s best interests.\(^94\) This is a beneficent but paternalistic approach to end-of-life decision-making, unless the patient specifically directed that another person should make the decision on his or her behalf. Also, as Cullity, J. explained in the Ontario decision of Scardoni v Hawryluk,\(^95\) proxy decision makers may find it exceedingly difficult to withdraw treatment where the specific wishes of the patient are unclear, even when doctors recommend that treatment plan.

Neither the How Can We Help Paper nor the Report includes any discussion of whether instructional advance directives should be recognized. Nor do they include explanation of why or how the decision was made to solely adopt proxy advance directives in the legislation. Professor Gordon describes public interest in legislation providing for both

\(^{91}\) Salzberg, *Health Care Decisions*, supra note 84 at 3. Issue CIII. Does the notion of the adult’s known beliefs and values and the role that they play in substitute health care decision making require clarification?


\(^{95}\) (2004) 69 O.R. (3d) 700 (“Substitute decisions that are increasingly required by advances in medical science and technology can be agonizing when they concern a withdrawal, or withholding, of treatment that may prolong the life of a close relative.” ) at ¶1.
instructional and proxy advance directives\textsuperscript{96} although this alternative was never recommended or implemented. He notes, however, that Representation Agreements may \textit{not} be the "most effective and least intrusive way of meeting an adult's needs" and assumes that the HCCA legislation "is intended to allow families to make substitute decisions for their members, when needed, and with a minimum of fuss." \textsuperscript{97} The purpose of the HCCA hierarchy for TSDMs, however, is to enable the appointment of a substitute decision-maker where the patient \textit{has not made} an advance directive. By assuming the HCCA will take precedence, the autonomy of the decision-maker is ignored and the power to make decisions is directed to family members.

Professor Gordon's text reflects a lack of understanding of the legal status of advance directives. Professor Gordon states: "Representation Agreements encompass a variety of so-called pre-planning documents that have widespread, popular and professional support but no clear statutory or common law foundation. These include living wills, advance medical directives, psychiatric wills, health care proxies and Ulysses agreements." \textsuperscript{98} At the date this comment was published in 2001,\textsuperscript{99} instructional advance directives had been statutorily recognized in many Canadian jurisdictions\textsuperscript{100} and recognized under the common law of Canada for over ten years.\textsuperscript{101} Certainly, a clear statutory foundation existed for instructional and proxy advance directives at the date that the RAA was enacted in 2000, and arguably a common law foundation for living wills existed as well. Therefore, either the statement is simply erroneous or the author intended to minimize the legal significance of instructional advance directives as documents providing autonomy to capable adults.

\begin{footnotes}
\item[96] Gordon, \textit{Representation Agreement Act} supra note 19 at 4.
\item[97] \textit{Ibid} at 6.
\item[98] \textit{Ibid}, at 11
\item[99] \textit{Ibid} at ii.
\item[101] \textit{Malette} supra note 27; \textit{Fleming} supra note 28.
\end{footnotes}
4.3. Restriction on Actions of the Representative

In addition to limiting the type of advance directive to a proxy directive under the *RAA*, the legislation further appears to limit the ability of representatives to revoke consent to health care.

Professor Salzberg notes that the *RAA*:

... in section 9(c) provides that an adult, in a representation agreement made while capable, may authorize a representative to refuse consent to "specified kinds of health care, including life-supporting care or treatment." No mention is made of revocation of consent. Is this an oversight, similar to other possible oversights in the HCCF Act, the *Adult Guardianship Act* and the *Representation Agreement Act*, or, given the similarity of each on this point, was there an intention to exclude revocation of consent and, if so, why?\(^{102}\)

There is no discussion in the Paper,\(^{103}\) the Report,\(^{104}\) or in Professor Gordon's book to provide specific guidance as to the drafters' intentions respecting revocation of consent.

Professor Salzberg also examines the broader authority offered to temporary substitute decision makers (TSDM) under *HCCA* s. 18(2) which enables a TDSM to refuse substitute consent to health care necessary to preserve life. The section reads as follows:

18(2) A person chosen under section 16 has authority to refuse substitute consent to health care necessary to preserve life, but only if there is substantial agreement among the health care providers caring for the adult that

\(^{102}\) *Salzberg, Health Care Decisions*, supra note 84 at D. Issue IIId: "What role should best interests determinations play, particularly with respect to decisions to refuse or revoke substitute consent to health care necessary to preserve life (substitute decision making at the end of life)? 2. Inclusion of Revocation of Consent."

\(^{103}\) Paper *supra* note 37.

\(^{104}\) Report *supra* note 31.
(a) the decision to refuse substitute consent is medically appropriate, and
(b) the person has made the decision in accordance with section 19(1) and (2)(a).

_HCCA_ sections 19(1) and (2)(a) require the TDSM to follow any instructions the adult made while capable. Professor Salzberg questions whether the narrow wording of _RAA_ s. 9(3) means that:

an adult cannot give a representative, designated personally by the adult, authority to refuse consent to health care necessary to preserve life generally, even though surrogate decision makers appointed under the _Adult Guardianship Act_, appointed by the court, and the HCCF Act [HCCA], selected from a list set out in the statute, have that authority? This would appear to be an inconsistency of some consequence, contrary to the emphasis on personal autonomy of the adult that undergirds all of the related statutes. [footnote omitted] 105

Interestingly, the TSDM is not required under _HCCA_ s. 18(2) (b) to act pursuant to _HCCA_ s. 19(3) when making a decision to refuse substitute consent to health care necessary to preserve life. Compliance with _HCCA_ s. 19(3) would require the TDSM to take the adult’s _best interests_ into consideration when making a decision to refuse life-sustaining treatment. The failure of _HCCA_ s. 18(2) (b) to include reference to s. 19(3) may reflect a belief that it is _never_ in the adult’s best interests to have life-sustaining treatment withdrawn or withheld.

4.4. _Onerous Execution Requirements_

The execution requirements for a s. 9 Representation Agreement are substantially more onerous than those found in advance directive legislation in any other jurisdiction in the country. This was particularly the case prior to enactment of the 50 amendments

105 Salzberg, _Health Care Decision, supra_ note 84 at E. Issue IIIe: “Is there a need to define, or further refine, the concept of “health care necessary to preserve life” as it is used in section 18(2) of the HCCF Act?”. 193
contained in the Adult Guardianship Statutes Amendment Act\textsuperscript{106} which simplified the original execution requirements significantly. In a 2001 paper for Continuing Legal Education,\textsuperscript{107} Fiona Hunter discussed the original requirements and described a certain amount of frustration in [executing a validly binding agreement], both for the lawyer and the client. The amount of paper and signing requirements sometimes seem overwhelming.

In a s. 9 Representation Agreement appointing one representative with no monitor, the client (adult) will sign once, the representative will sign twice, the lawyer will sign a consultation certificate, the two witnesses will each sign four times,\textsuperscript{108} and the form is dated 15 times.\textsuperscript{109} If the Representation Agreement is to be used for transferring land, the lawyer will sign and date one additional certificate. The agreement is not valid until all signatures are affixed. The document will usually be ten pages long [footnotes added].\textsuperscript{110}

Although the above-noted execution requirements were simplified, the number of persons' signatures needed to validly execute a s. 9 Representation Agreement is still significant. Ms. Hunter notes that “a representation agreement appointing only one representative and no monitor that required 12 signatures before the amendments will require only 6 signatures.”\textsuperscript{111}

Not only must the Representation Agreement be signed and witnessed, the lawyer, representative, witness(es) and monitor, if any, all must sign certificates.\textsuperscript{112} Although witnesses need not be present together and may sign in counterpart, an agreement is not valid unless all signatures and certificates are executed.\textsuperscript{113}

\begin{footnotes}
\item[106] Supra note 57.
\item[107] Hunter, “Formality Issues”, supra note 55.
\item[108] Including: once for witnessing each of the adult's and the representative's signature, and then again on two certificates.
\item[109] Including: dating the agreement; dating the signatures of the adult and the representative; inserting the agreement date to the certificate signed by the representative; inserting the agreement date to the certificates signed dating the certificates; and dating each of the certificates.
\item[111] Ibid, at Part II Changes to Execution Requirements, ¶7.
\item[112] RAA s. 13 (1.1)(b).
\item[113] RAA s 13 (1.1).
\end{footnotes}
In addition to the number of signatures required on multiple documents in order to execute a Representation Agreement, there are unusually large restrictions on the people who may witness a Representation Agreement. The relevant sections are as follows:

(5) None of the following may witness the signing of a representation agreement by or on behalf of the adult:
   (a) anyone named in the agreement as a representative or alternate representative;
   (b) a spouse, child or parent of anyone named in the agreement as a representative or alternate representative;
   (c) an employee or agent of a person named in the agreement as a representative or alternate representative;
   (d) anyone under 19 years of age;
   (e) anyone who does not understand the type of communications used by the adult who wants to be represented.

(6) A witness must complete a certificate in the prescribed form.

A s. 9 Representation Agreement is intended to allow persons with full capacity to create an advance directive. Pursuant to the RAA, only adults who are capable of understanding the “nature of the authority and the effect of giving it to the representative”\textsuperscript{114} are able to enter into a s. 9 Representation Agreement. Notwithstanding that the adult is required to be fully capable under the RAA, a s. 9 agreement is not effective unless the adult has consulted with a B.C. lawyer\textsuperscript{115} who then certifies that the terms of the Representation Agreement were explained to the adult and that he or she appeared to understand the nature of the authority given to his/her representative(s) and the effect of such authority.\textsuperscript{116}

Gordon explains that the more stringent “test of incapability” for s. 9 Representation Agreements is prudent in view of the “high risk that is usually associated with the areas...”

\textsuperscript{114} \textit{RAA supra} note 1 at s. 10
\textsuperscript{115} \textit{RAA} s. 9(2)(a)(i) “a member of the Law Society of British Columbia” or \textit{RAA} s. 9(2)(a)(ii) “anyone who belongs to a prescribed class of persons”. No prescribed class of persons in addition to lawyers has been designated under the \textit{RAA} as at October 2005.
\textsuperscript{116} \textit{RAA} s. 9(2) (b); \textit{RAA} Form 2 – Consultation Certificate.
of decision making mentioned in s. 9"\textsuperscript{117} and that the level of capability expected of a person executing a s.9 agreement is "basically the same as the test of contractual capacity."\textsuperscript{118}

It is interesting to compare the annotated comments in the Final Report of the Manitoba Law Reform Commission on Self-Determination in Health Care regarding execution requirements for advance directives under the proposed Manitoba legislation\textsuperscript{119} with those of Professor Gordon respecting execution of a S. 9 Representation Agreement. The Manitoba report states:

> In order to make health care directives as simple and accessible as possible, the execution requirements are very minimal. Health care directives need only be in writing and be signed by the maker. Persons unable to sign for themselves are given the same opportunity to make a health care directive through the use of a substitute signer; however, a witness for the substitute signer is required as a safeguard against fraud and forgery.\textsuperscript{120}

In contrast, Professor Gordon writes of the \textit{RAA} ss. 9 and 10:

> Sections 9 and 10 provide for an adult to either add \textit{more complex and controversial areas of decision making} to a Representation Agreement that contains the standard provisions, or to create an agreement containing only one or more of the matters mentioned in subsec.(1). The adult must be capable of making such an agreement and must consult with one of the individuals mentioned in subsec. (2). Section 10 sets out a test of incapability that is more stringent than the test found in s. 8. ...(emphasis added)\textsuperscript{121}

\textbf{Section 9, subsection (2)}

\textit{This section provides an important safeguard.} Before making an agreement with a representative that authorizes decision making in one of the areas mentioned in s. 9, the adult must consult with either a legal practitioner or someone belonging to the class of

\textsuperscript{117} Gordon, \textit{Representation Agreement Act supra} note 19 at 29.
\textsuperscript{118} \textit{Ibid} at 30.
\textsuperscript{119} Report #74 \textit{supra} note 39.
\textsuperscript{120} \textit{Ibid} at 29.
\textsuperscript{121} Gordon, \textit{Representation Agreement Act supra} Note 19 at 27.
persons prescribed in the Representation Agreement Regulation. (emphasis added)\textsuperscript{122}

\textbf{Section 10}

\textit{The high risk that is usually associated with the areas of decision making mentioned in s. 9 makes it prudent for an adult who creates an agreement containing such provisions to be subject to a test of incapability that is more stringent than the test of incapability for the standard provisions.} (emphasis added)\textsuperscript{123}

The onerous execution and elaborate consultation requirements under the \textit{RAA} create a barrier which has been purposefully imposed to \textit{protect} the makers of s. 9 agreements from the \textit{high risk} involved in preparing an advance directive, despite the requirement that the maker be \textit{fully capable}. The requirements create cost and complexity for capable adults and reflect unnecessary paternalism. The restriction on ready access to clear, easily executed documents in B.C. creates unfairness to the citizens of the province relative to the situation of other Canadians and denies them autonomy.

\textbf{4.5. Restriction On Mature Minors Making Advance Directives}

The \textit{RAA} requires anyone having anything at all to do with a Representation Agreement to be an adult; a designation statutorily defined to be 19 years of age in British Columbia.\textsuperscript{124} The person making the Representation Agreement\textsuperscript{125}, the representative(s)\textsuperscript{126}, the witnesses\textsuperscript{127} and presumably the lawyer or “person who belongs to a prescribed class of persons” with whom the person making the agreement is required to consult\textsuperscript{128} must all be adults. The effect is not merely to create a cautious regime – this requirement is arguably a violation of people’s legal rights in British Columbia.

\begin{footnotesize}
\textsuperscript{122} \textit{Ibid}, at 29.
\textsuperscript{123} \textit{Ibid.}
\textsuperscript{124} \textit{Age of Majority Act} RSBC 1996 c. 7.
\textsuperscript{125} \textit{RAA} (s. 4).
\textsuperscript{126} \textit{RAA} (s. 5 (1) (a) and s. 6 (1)).
\textsuperscript{127} \textit{RAA} (s. 13(5) (d)).
\textsuperscript{128} \textit{RAA} (s. 9(2)).
\end{footnotesize}
Under the Canadian common law, mature minors are recognized as having capacity to give or to withhold consent to treatment. By restricting mature minors from being able to make a legal advance directive, the RAA ignores their legitimate common law right to ensure their personal treatment choices are respected.

This restriction on the rights of minors to consent or refuse consent to health care is mirrored in the HCCA which is also applicable to adults. The HCCA requires that persons entitled to consent to treatment under the legislation be adults notwithstanding that Canadian law presumes persons 16 years of age and older to have capacity to consent to or to refuse health care, and notwithstanding the statutory right for minors to consent to treatment in British Columbia pursuant to s. 17 of the Infants Act. The section states:

(2) Subject to subsection (3), an infant may consent to health care whether or not that health care would, in the absence of consent, constitute a trespass to the infant's person, and if an infant provides that consent, the consent is effective and it is not necessary to obtain a consent to the health care from the infant's parent or guardian.

(3) A request for or consent, agreement or acquiescence to health care by an infant does not constitute consent to the health care for the purposes of subsection (2) unless the health care provider providing the health care

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129 Walker (Litigation Guardian of) v Region 2 Hospital Corp. (1994), 116 D.L.R. (4th) 477 (N.B.C.A.) [Walker]. Also, various provincial statutory regimes respecting consent to health care, including those in Ontario and New Brunswick, recognize mature minors as having capacity to consent to or refuse medical treatment. Similarly, advance directive legislation in some of the other jurisdictions in Canada presumes that mature minors (16 years and older) have capacity to create an advance directive. See e.g. Health Care Directives Act C.C.S.M. 1992, c. H27 at s. 4(2); Consent to Treatment and Health Care Directives Act, S.P.E.I. 1996, c. 10 at s. 20(1); Advance Health Care Directives and the Appointment of Substitute Decision Makers Act, S.N. 1995, c. A-4.1 at s.7(b).

130 See Ney v Canada (Attorney General) (1993) 102 D.L.R. (4th) 136, (1993) 79 B.C.L.R. (2d) 47 (S.C.) [Ney] (This description of the common law was accepted by Huddart, J. in Ney notwithstanding her comment that “neither the common law nor the statute interferes with the parens patriae jurisdiction of the court, which may override a minor’s refusal to consent to treatment that is in the minor’s best interests.” at 146.) See also Jocelyn Downie, Dying Justice: A Case for Decriminalizing Euthanasia and Assisted Suicide in Canada, (Toronto: University of Toronto Press, 2004) [Downie, Dying Justice] (in which the author argues that the parens patriae jurisdiction does not apply to mature minors) at 80-84.

131 HCCA supra note 2 at ss. 3 & 4.

132 RSBC 1996 c. 223.
(a) has explained to the infant and has been satisfied that the infant understands the nature and consequences and the reasonably foreseeable benefits and risks of the health care, and 
(b) has made reasonable efforts to determine and has concluded that the health care is in the infant's best interests.

Gordon notes that s. 17 of the *Infants Act* does not specifically provide for an infant to refuse consent to treatment, however, the *Infants Act* may be interpreted to provide both the right to consent and the right to refuse treatment.

The constitutionality of s. 17 (formerly s. 16) was reviewed by Huddart, J. in *Ney v Canada (Attorney General)*, [*Ney*] who found the ability of mature minors to give consent to treatment under the *Infants Act* was consistent with the Canadian common law position, but did not address the issue of whether mature minors had the ability to refuse treatment. In fact, she argued that the court retains *parens patriae* jurisdiction to override a decision of a mature minor to refuse treatment where the court determines the treatment would be in the best interests of the child. Two subsequent cases, *Walker (Litigation Guardian of) v Region 2 Hospital Corp.* and *Van Mol (Guardian ad litem of) v Ashmore* did find that a child has a right to refuse treatment, although the recent case of *S.J.B. (Litigation Guardian of) v BC (Director of Child, Family and Community Service)* [*S.J.B.*] held that the *Child, Family and Community Services Act* overrides a child’s right to refuse treatment. The *S.J.B.* case involved the refusal of a 14 year old girl, a member of the Jehovah’s Witness religious sect, to a potentially life-saving blood transfusion. The court acknowledged the common law right of mature minors to both

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134 *Ney supra* note 130.
135 Ibid.
136 *Walker supra* note 129.
137 (1999) 168 D.L.R. (4th) 637 (B.C.C.A.) (*Van Mole* was a medical malpractice case which held that a 16 year old could consent to or refuse treatment.)
138 (2005)42 B.C.L.R. (4th) 32; B.C.J. 836 (B.C.S.C.) (“In my view, quite contrary to the appellants' submissions, the Courts have repeatedly held that the legislature has the power to protect the life of a child who is endangered by his or her own refusal to accept necessary medical treatment, which power is not in any way constrained by the common law limits placed upon the *parens patriae* powers of a court of inherent jurisdiction.” per Boyd, J. at ¶ 70).
139 R.S.B.C. 1996, c. 46.

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consent to or refuse treatment, but held, following *Ney*, that this right did not override the *parens patrie* jurisdiction of the courts. Although the courts maintain the *parens patrie* jurisdiction, the common law rights of mature minors to both consent to or refuse medical treatment are affirmed by these judgements.

**4.6. Conflicting Roles of the Representative under the Common Law**

In the s. 9 Representation Agreement, the drafters intended to create a single document that could act as a current and an enduring power of attorney for both financial and health matters and also as a proxy advance directive. This combined purpose creates an essential flaw in the legal foundation of a Representation Agreement since the legal obligation of the representative is different for each of the two purposes.

The legal foundation for a power of attorney is the law of agency. The power of attorney document is an agency agreement which has been reduced to writing. Under the law of agency, the attorney must act in the donor’s best interests, as determined by the agent.

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140 Gordon, *Representation Agreement Act supra* note 19 (“Although the Act dispenses with enduring powers of attorney, the concept is not abandoned.” ... “Like powers of attorney, Representation Agreements are documents that create an agency relationship between a donor and the donee (or representative) and the common law of agency applies.”) at 12. “Section 16 sets out a list of duties [some of which] reflect well-established duties drawn from the common law of agency and of trusts. ... A representative is an agent of the adult. A representative is not a trustee, although he or she is in a fiduciary relationship with the adult.”) at 39). (Gordon, one of the drafters of both the report and the *RAA* explains, however, that additional safeguards set out in the *RAA*, beyond those in the *POA*, were necessary to resolve concerns about the use of powers of attorney as instruments of financial abuse. See *supra* note 19 at 12.); See also M. Jasmine Sweatman, *Guide to Powers of Attorney*, (Aurora: Canada Law Book, 2002) [Sweatman, *Powers of Attorney*] (Ms. Sweatman argues that the power of attorney to manage the affairs of an incapable person can be seen as a positive good (in her view a paternalistic attitude) or as a necessary evil, because it represents intervention. She adopts the belief that unnecessary intervention should be avoided, thereby respecting individual freedoms.) at 23.

141 See *RAA* s. 9 *supra* note 1.


At common law, the power of attorney ended on the incapacity of the donor, and therefore “ceased to operate at the very moment the donor wished and needed it to operate.” Consequently, at the instigation of several provincial law reform commissions during the 1970’s, the Uniform Law Conference of Canada recommended statutory reform to specifically provide for an enduring power of attorney that would continue to be valid after the incapacity of the donor. “Legislation based on the Uniform Act was enacted in British Columbia in 1979.” Although “the enduring power of attorney is a creature of statute … [i]ts predecessor was the common law power of attorney” so the agent is subject to the same obligations under both types of powers to act in the best interest of the donor.

The legal foundation for an advance directive is the doctrine of consent to treatment. Under the doctrine of consent to treatment, a proxy decision maker must use substitute decision-making to carry out the principal’s previously expressed wishes. Only if the wishes or the values of the principal are unknown should the substitute consider the best interests of the principal. Under RAA s. 9, the adult may specify the kinds of health care that he or she wishes to consent to or refuse. Pursuant to the common law provisions governing proxy decision-makers, the representative is required to comply with the wishes that the adult made while competent.

an agent of the donor, an attorney is in a position of trust and is viewed by the law as having a fiduciary duty to the donor.” at 1).
Since the Representation Agreement is intended to be both a power of attorney and a proxy directive, a potential conflict is created for the representative. Where the Representation Agreement acts as a proxy advance directive, the representative must act as a substitute decision-maker but since the representative is also an agent of the adult, he or she must act in the best interest of the donor. The melding of two types of legal instruments that impose different legal obligations on a representative creates uncertainty about the legal role of the representative.\(^\text{154}\)

By imposing fiduciary obligations on a representative, the \textit{RAA} fails to provide adults who use the documents as advance directives with complete autonomy, since the representative arguably has an obligation to act in what he or she believes to be the best interests of the adult rather than in accordance with the direction of the adult. This obligation is also borne out in the relationship between the \textit{RAA} and \textit{HCCA} in the requirement of representatives acting under \textit{RAA} 9(3) to turn to \textit{HCCA} 19(3) and consider the best interests of the adult.\(^\text{155}\)

\section*{4.7. Summary}

The confusion in a Representation Agreement of fiduciary obligations with the obligations of substitute decision-making, compounded by the legislative direction to representatives to act in the best interests of the adult who has given the advance directive, results in the autonomy of the adult being infringed. Additionally, both the \textit{RAA} and the \textit{HCCA} deny mature minors their legitimate rights to make contemporaneous and future health care treatment decisions, thereby failing to respect the autonomy of this

\begin{footnotesize}
\begin{itemize}
\item[(\textsuperscript{155})] See discussion of this issue at text in s. 4.1 above.
\end{itemize}
\end{footnotesize}
The RAA denies autonomy to B.C. citizens through its overzealous concern that people be protected from themselves as well as others. The onerous and burdensome execution formalities of the RAA are an example of this concern. The next section will consider the reasons for this zeal to circumscribe the power of individuals to make advance directives.

5. Ethical Analysis of the RAA

5.1. Paternalistic Concern For Safety

The RAA is widely viewed as legislation providing safety for vulnerable persons, particularly the disabled. For example, in Macdonald Estate v B.C. (Public Guardian and Trustee)157 Prowse, J.A. described the RAA as follows:

In 1993, four interrelated pieces of legislation dealing with adult guardianship were introduced and passed: the Adult Guardianship Act, the Representation Agreement Act, the Public Guardian and Trustee Act and the Health Care (Consent) and Care Facility (Admission) Act. A primary purpose of those Acts was to reform the previous treatment of disabled adults under then existing legislation, including the PPA. The goal was to move toward less institutionalization of disabled adults and to provide them with more options for controlling their own lives than had been available to them under prior legislation.158

The acceptance of the RAA as legislation necessary for protection of the disabled has created an assumption, particularly among members of the government responsible for adult guardianship, that protection of the public is generally necessary with respect to the creation of advance directives.

In 2000, Dulcie McCallum provided a report159 on Section 9 Representation Agreements with General Powers to Jay Chalke, Public Guardian and Trustee for B.C. Ms. McCallum had been asked by the Public Guardian to prepare a report “regarding who, if anyone, should be designated as a class of persons prescribed by Regulation to be a

158 Ibid at ¶49.
consultant for the purpose of s. 9". Although the terms of reference for the report were restricted to S. 9 agreements which, by statute, can only be made by capable people, Ms. McCallum titled one chapter of her report: “Safety is the Primary Public Interest Issue” (bolding original). She states:

“It is in the public interest to ensure that the prescribed consultants are in a position to provide maximum safeguards to protect those relying on their services. Most importantly, each member of the prescribed class must be committed to prevention of harm, to avoid any breach of their fiduciary duty to the donor and to ensure the sanctity and validity of the agreement upon which third parties will rely.”

Ms. McCallum did not question whether people should have the ability to write s. 9 advance directives with less legal restriction than those envisioned by the RAA. To the contrary, she recommended that the Public Guardian prepare rules or guidelines for all prescribed s. 9 consultants that would detail the circumstances under which a referral should be made to a third party for advice prior to completing a s. 9 Representation Agreement. In view of the “serious consequences for the adult” contemplated by s. 9 agreements, which “give rise to ethical and spiritual questions” Ms. McCallum suggested that “Spiritual and religious leaders” be included on the list of third party resources, as well as inter alia social workers, health care practitioners and capability assessors.

In 2004, the Public Guardian and Trustee (PGT) issued a discussion paper regarding modernizing the legal framework for court and statutory guardianships which assumed that the recommendations set out in the McClean Report for amendment to the RAA

160 Ibid at 10. (Ms. McCallum recommended that notaries public be included as persons designated for the purposes of s. 9(2) (a) (ii), which recommendation was adopted by the Attorney General. However, although legislation governing notaries was amended to enable notaries to be RAA s. 9 Consultants, the RAA regulation was not similarly amended to name notaries as persons entitled to act as Consultants for s. 9 agreements. Therefore, the only persons entitled to act as s. 9 Consultants under the RAA are lawyers who are members of the B.C. Law Society (s.9(2)(a)(i)).
161 Ibid at 44.
162 Ibid at 35.
163 Chalke, “Modernizing the Legal Framework” supra note 56.
would be enacted by the Attorney General. This assumption is offered without criticism; therefore, presumably, the PGT endorsed the recommendations in the McClean report. Those recommendations, had they been enacted, would have provided greater flexibility to capable adults for financial planning. The PGT does not, in the 2004 report, offer recommendation for similarly enhanced flexibility to capable adults for making advance directives.

Although the amendments recommended in the McClean Report were not implemented by the Attorney General, the B.C. Court of Appeal has opined that the greater detail set out in the RAA does not necessarily benefit the public. As stated by Saunders, J.A., in Goodrich v The Queen in right of British Columbia et al [indexed as Parnall (Attorney of) v. British Columbia (Registrar of Land Titles)]\textsuperscript{164} in considering whether the legislature intended to exclude a power of attorney which is limited in scope in order to achieve the donor’s purposes:

Nor do I view the scheme of the Representation Act as contrary to this view. That Act provides for a new instrument, the Representation Agreement, and being new it contains detail far beyond that of the Power of Attorney Act. As Professor McClean describes, the simplicity, and consequent availability, of powers of attorney are the reason they have such utility to members of the public. Mere absence of detail as is found in a subsequently drafted statute is not a basis, in my view, for supporting a narrow interpretation.\textsuperscript{165}

\textbf{5.2. Moral Discomfort With Advance Directives}

The comments set out in the McCallum report regarding the need for people to seek advice from professional and religious community advisors prior to completing an advance directive are reflective of the general discomfort many people in the community feel towards the completion of advance directives. Ms. McCallum suggests that

\textsuperscript{165} Ibid at ¶29.
consultants not only encourage clients to refer to community resources for advice about their decisions but satisfy themselves “that the donor has sought out information from other sources or declines to do so” although a referral to a community resource would not be mandatory. She contemplates, however, that:

a donor may discuss the termination of treatment with his or her priest or rabbi, doctor, hospital or community social worker, senior citizen counsellor and/or nurse. In giving binding instructions to a representative through a Representation Agreement with General Powers, the donor is making a decision in advance. Talking to those same resources serves to make the donor’s choices informed ones.\(^{166}\)

While decisions set out in an advance directive are clearly very important, and may indeed be among the most important decisions that people make respecting their health care, it is not clear that a person’s decision should be subject to scrutiny to determine if the person has received sufficient counsel prior to making the decision. The missing element from Ms. McCallum’s report is any consideration of whether the RAA regime requiring people to attend before a ‘consultant’ of any kind, whether a lawyer, notary, or other prescribed class of person, who will then want to satisfy themselves that the client has received sufficient counsel prior to making the advance directive, is an infringement on the autonomy of the individual.

It seems clear from his annotations that Professor Gordon is not comfortable with the concept of an advance directive being used to refuse all medical treatment. He presumes that, at a minimum, palliative medical treatment will still be provided to a dying patient. For example, Professor Gordon explains that a Representation Agreement drafted to be an advance directive would allow an adult to authorize a representative to refuse consent to medical treatment and to give consent, for example, to palliative care only, thereby allowing a medical condition to run its natural course and for the

\(^{166}\)McCallum Report supra Note 158 at 35.
adult to “die with dignity”. This is often referred to as “passive euthanasia”. 167

In explaining the implication of anyone finding “instructions or wishes scribbled on a notepad” 168 made by a person who has executed a s. 9 agreement, Professor Gordon states:

they should arguably, be recognized as more recent directions overriding those found in the agreement. This is particularly important if the new directions reflect a fundamental shift in the adult’s beliefs and values. For example, if an adult’s most recent instructions indicate that the person believes firmly in the sanctity of life and wishes to be kept alive at all costs, these should override an earlier written instruction to terminate any and all life support treatment and allow the adult to “die with dignity”. In a cases (sic) of uncertainty, representatives should seek the guidance of the court, or seek and follow the advice of the Public Guardian and Trustee .... Subsection [16] (5) might also apply where an earlier written instruction has been rendered an absurdity by unexpected events or where it is not consistent with changes in medical knowledge or technology and good medical practice. 169

Professor Gordon does not contemplate the situation where a person’s later writing might absolutely refuse medical treatment. He does not consider whether the individual might not want to have their advance directive overridden because of a change in medical knowledge. He is quite comfortable directing that recent instructions which potentially were made when the person had become incapable should override earlier instructions given when the person was capable, in particular if the “most recent instructions indicate that the person believes firmly in the sanctity of life and wishes to be kept alive at all costs.” 170

The RAA drafters’ concerns about cessation of life-sustaining treatment are revealed by comparing the general latitude given to representatives under a s. 7 agreement (the type

167 Gordon, Representation Agreement Act note 19 at 28.
168 Ibid at 40.
169 Ibid.
170 Ibid.
of agreement entered into by adults who may have limited capacity) with one of the few constraints imposed on representatives under a s. 7 agreement. A s. 7 representative has broad authority to authorize health care, including major health care as defined in the *HCCA*, to make investments and obtain legal services for the adult. One of the few restrictions imposed on a S. 7 representative is set out in S. 7(2.1):

S. 7(2.1) A representative may not be authorized under this section to help make, or to make on the adult’s behalf, a decision to refuse life-supporting care or treatment.

It appears from his annotations to the *RAA* that Professor Gordon would not be comfortable following a direction to remove life support that may hasten death. He and his fellow drafters ensured that the *RAA* would not allow citizens to create such directions simply or easily. They provided in the legislative language the ability for a representative to evade the strict terms of an advance directive to refuse or revoke consent to life sustaining technology. The *RAA* is morally drafted to protect life and is not legally drafted to protect autonomy.
6. Conclusion

New advance directive legislation is necessary for B.C. The population of the province is aging rapidly and the number of seniors living in B.C. is growing at a faster rate than in any other province in Canada. According to a study on seniors completed by the B.C. Provincial Ministry of Health in 2004, in the ten years between 1991 and 2001, “the median age in British Columbia increased 3.7 years, from 34.7 years of age to 38.4 years of age, [which] is higher than the national average of 37.6 years of age.” In the same period “the number of seniors age 80 and over soared from 87,065 to 134,175. This was a 54 percent increase and the highest level of growth amongst all provinces.”

Seniors now make up about 13.3 percent of the B.C. population and it is estimated that by 2031 seniors will make up 24 percent of the population. The following chart illustrates the projected growth of seniors as a percentage of the population based on data from 1971 through 2001:

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171 British Columbia, A Profile of Seniors in British Columbia, Children's, Women's and Seniors' Health, Population Health and Wellness, (Victoria: Ministry of Health Services, 2004). (Statistics Canada information is used in this study with the permission of the Minister of Industry, as Minister responsible for Statistics Canada.).

172 Ibid at 7.

173 Ibid.

174 Ibid at 9.
Although advance care directives are not only of importance to seniors,\textsuperscript{175} nevertheless, these statistics highlight the need for legislation that provides suitable options for end-of-life decision-making for a group that has a profound interest in the topic and a need for suitable resources.

This growing sector of the population will increasingly demand the ability to conduct future health care planning in a straightforward and convenient fashion. The \textit{RAA} was not drafted for the purpose of providing the citizens of B.C. with accessible advance directive legislation that is straightforward or convenient. The drafters of the \textit{RAA} incorporated the concept of advance directives into the \textit{RAA} as a secondary purpose to the main objectives of the legislation.

The drafters of the \textit{RAA} were primarily concerned with protecting vulnerable people from harm. Their concern about protecting individuals emanates from the reports upon which the \textit{RAA} was based. The drafters wanted to protect vulnerable people not only from others but even from themselves. To ensure this protection for the vulnerable, many careful limitations and restrictions have been placed within the \textit{RAA}. However, by establishing such strict limitations and restrictions on the rights of individuals to direct their end-of-life treatment decisions, the \textit{RAA} is virtually inaccessible for the purpose of advance treatment planning.

The \textit{RAA} is not only flawed because it is so restrictive, although the restrictions in the legislation could be construed as a limitation on Constitutional rights; the legislation is also fundamentally conceptually flawed. The dual requirements imposed on a s. 9 representative faced with upholding an advance directive requesting withdrawal of life sustaining treatment cannot be reconciled under the \textit{RAA}. The representative under common law should make a decision the adult chose or would have chosen whereas,

\textsuperscript{175} It is instructive to remember that the most well known U.S. cases highlighting the potential benefit of advance directives, those involving Karen Quinlan, Nancy Cruzan and Terri Schiavo, all involved relatively young people. See Chapter 1 notes 113 & 114 and accompanying text, above, and Chapter 3 note 174 and accompanying text above for discussion of these cases.
under the *RAA*, the representative is arguably directed to act in the adult's best interests. The former decision respects the autonomy of the adult to make a treatment decision that may or may not be in his best interests, as defined by others. The latter decision is the one that the representative believes to be in the best interests of the adult. This fundamental flaw is sufficient to invalidate the function of the *RAA* as advance directive legislation.

Numerous flaws of the legislation, including the failure to offer choice to capable adults to have their instructional advance directives honoured without the presence of a proxy, failure to recognize the rights of mature minors, and the onerous barriers to execution, similarly render the legislation unsuitable as advance planning legislation for British Columbia. It is necessary and critical that new advance directive legislation be implemented in order to provide the citizens of the province with the opportunity to exercise their legal and ethical rights to autonomy over their end-of-life decision-making.

The next chapter summarizes the analysis and conclusions of this thesis and recommends legislative amendments and practical changes that might help to achieve the goals of autonomous end-of-life treatment planning in B.C.
CHAPTER SIX: CONCLUSION

1. Introduction

The previous chapters considered the background to and the purpose for the development of advance directive legislation and then examined the effectiveness of the legislation in carrying out that purpose. Although advance directive legislation is commonplace, advance directives are little used. When the legislation and related laws are analyzed, it becomes clear that the legislation is itself an impediment to the success of advance directives. Much of the legislation is flawed because it is drafted restrictively and paternalistically and therefore fails to respect the goals of individual autonomy and self-determination that are foundational to the advance directive. The motivation for paternalistic drafting is fear: fear that people will bring death upon themselves and fear that death may be inflicted upon them against their wishes. The legislation is frequently riddled with limitations and restrictions both to protect people from themselves and to protect them from others. The problem of paternalistic legislation is depicted in the Representation Agreement Act (RAA)\(^1\) of British Columbia which incorporates many requirements that limit the accessibility and usefulness of the legislation. Consequently, the RAA fails as effective advance directive legislation.

The following section will summarize the results of the analysis contained in the previous chapters and explain the inferences that can be drawn from that analysis. The next section will recommend how this information can be used to draft advance directive legislation that will be beneficial to the people of British Columbia and will meet the goal of providing citizens with autonomy and self-determination for end-of-life decision-making. The final section sets out proposals for further research that might be carried out to ensure that the goals of advance directive legislation are met.

\(^1\) RSBC 1996, c. 405 [RAA]
2. Summary

The transformation of medicine during the last century has created a concomitant need for people to make decisions about a matter that was rarely an issue fifty years ago: whether to refuse medical treatment that has the power to keep them alive. Common law recognition of and legislation governing advance directives developed over the last half century in response to astonishing medical developments. Advances in medical technology and pharmacology enable physicians to prolong the life of a patient who is no longer sentient, and who has no prognosis for recovery, for an indefinite period. The technology is remarkable, but may be intrusive\(^2\) and does not necessarily preserve personal dignity. As noted by the Manitoba Law Commission:

> Individuals who once faced quick and certain death can now be kept alive for considerable periods of time. Many fear that they will languish for months or even years, perhaps in a vegetative state, unable to control their medical treatment. They fear that they will be subjected to procedures which may save their lives, but reduce or destroy the quality of that life. The fear of loss of control over their medical fate is coming to equal, and perhaps even surpass, people’s fear of death itself.\(^3\)

Some people anticipate that they would refuse treatment if they were in such circumstances and desire a legitimate way to voice their decision.

During this same period the courts have increasingly confirmed that respect for individual autonomy enables competent people to refuse medical treatment, regardless of the consequences to their health or even their life. The right to refuse medical treatment is now firmly enshrined in both American\(^4\) and Canadian\(^5\) law. The issue that remains

\(^2\) *Cruzan v Director, Mo. Dept. of Health*, 497 U.S. 261 (1990) [*Cruzan*] (O'Connor, J., concurring: "Whether or not the techniques used to pass food and water into the patient's alimentary tract are termed "medical treatment," it is clear they all involve some degree of intrusion and restraint." at 288).

\(^3\) Manitoba, Manitoba Law Reform Commission, "Self-Determination in Health Care (Living Wills and Health Care Proxies)" Report \#74 (Winnipeg: Queen's Printer, 1991) [Report \#74] at 3.


unclear and frequently contentious both in medicine and under the law is the legal ability for competent people to make decisions in advance to forego medical treatment in the event of their future incapacity. The two cases in Canadian law which argue strongly in favour of recognizing advance directives are *Malette v Shulman* [*Malette*]6 and *Fleming v Reid* [*Fleming*]. 7 Both cases speak to the importance of respecting individual autonomy over personal medical treatment decisions.

Advance directives evolved as a way to provide people autonomy to direct their treatment choices at the end of life. The two types of advance directives that have developed in law, the instructional directive and the proxy directive, reflect the need for individuals to have different options for future health care planning. Some people are content to leave treatment choices to family or friends in the belief that their loved ones will know how they would choose to be treated and will make the right choice. 8 Others prefer to set their specific choices out in writing in order to relieve family or friends of the need to make final treatment decisions. 9 Some experts in the health care field recommend that people create a combination of both forms which sets out their treatment wishes but also appoints a proxy to make decisions in the event that their instructions are inappropriate to the circumstances. 10

Choice is not readily available under the law, however, either in the U.S. or in Canada. The legislation governing instructional advance directives in many U.S. states is so restrictive and limited in scope that the instruments are frequently rendered useless. Some jurisdictions, including many Canadian provinces, fail to offer citizens a choice of possible planning options. Contrary to the legal position endorsed by the Ontario Court of Appeal in *Malette* and *Fleming*, individuals in these jurisdictions are offered no power

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to independently direct their treatment decisions, but must act through a proxy. Execution requirements for either type of advance directive are often complex, onerous and costly, rendering them inaccessible to the general public. The legislation does not always provide protection from legal liability for health care providers who follow an advance directive, leading to medical reticence to recommend them to patients.

This thesis argues that respect for individual autonomy obligates governments to pass legislation that offers a choice of advance directive options, imposes minimal restrictions on their application, imposes minimal execution formalities, and offers comfort to health care providers that they are legally protected if they follow an advance directive. The steps that have been taken in the last fifteen years to enact advance directive legislation are, in many Canadian jurisdictions and particularly in British Columbia, insufficient to meet these goals. More change is needed.

2.1. Public and Medical Reticence

The majority of Canadians have not written an advance directive. The public is typically reticent to engage in discussions about death and dying although there is growing evidence that people would like more opportunity to discuss and confirm end-of-life treatment choices. The medical profession, however, continues to register discomfort with advance directives. Even some medical ethics texts instructing medical professionals about advance directives express discomfort with the concept that a patient

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has the power to refuse treatment.15 All of these factors have worked against common acceptance and use of advance directives. The Canadian Medical Association, however, now acknowledges the ethical imperative for physicians to follow advance directives.16

Medical training should include education about end-of-life decision-making. Health care providers should be encouraged to learn about advance directives and trained to communicate effectively and sensitively with patients about their patients’ end-of-life treatment choices.

2.2. Euthanasia and Sanctity of Life Arguments

Meeting the goal of honouring autonomy through advance directives has proven difficult. Although a written expression of a person’s treatment choices may be able to provide the ‘clear and convincing evidence’ of an individual’s treatment choice, as required by some U.S. states before an advance directive can be followed,17 there is ongoing criticism of instructional advance directives.18 Debate about the “failure”19 of instructional advance directives to properly direct future care and the recommendation that this type of advance directive be discarded as a legislative option may arise from the ominous issue that overhangs the subject of advance directives: fear of euthanasia. Fear that advance directives represent the first step on the ‘slippery slope’ to a culture that imposes

17 See Cruzan, supra note 2 (Holding that the United States Constitution did not forbid Missouri to require under the applicable Missouri Living Will statute, (Mo. Rev. Stat. § 459.010 et seq.(1986) ) that evidence of an incompetent's wishes as to the withdrawal of life-sustaining treatment be proved by clear and convincing evidence) at 269-285.
19 Ibid at 30.
euthanasia on vulnerable citizens evokes fear and revulsion. Promotion of the proxy directive to the exclusion of instruction directives may be based on a belief that supervision by a proxy will ensure that a person is not subject to euthanasia and is protected from premature cessation of treatment against his or her wishes.

Analysis of both proxy and instructional advance directives reveals that there are limitations to each. As discussed in Chapter Three, below, there has been significant public criticism of living wills, but many academics are similarly critical of the ethical foundation of substitute decision-making, arguing that it favours paternalism over autonomy.

A major obstacle to widespread use of advance directives is the perceived difficulty of separating the practice of withdrawing or withholding treatment from an incapable person, even when done in accordance with his or her prior direction, from the practices of euthanasia or assisted suicide. The overlaps and similarities between these practices raise concern that advance directives will diminish society’s respect for the sanctity of life. The organizations that respond the most vocally and vehemently against decisions to withhold or withdraw medical treatment are frequently representatives from special interest groups associated with the ‘right to life’ or the anti-abortion movement.

Religious organizations and proponents of the right to life lobbied successfully for incorporation into the first U.S. advance directive legislation, the California Natural Death Act (NDA), of many restrictions on the scope and application of advance directives. A number of states subsequently enacted legislation based upon the NDA and, consequently, many of the U.S. advance directive statutes contain narrow definitions.

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that limit the situations under which an advance directive is effective. Meisel and Cerminara comment:

Most existing advance directive legislation restricts the operation of advance directives to situations in which a patient is either in a “terminal condition” or “permanently unconscious”. These provisions can severely limit the usefulness of advance directives and can place serious roadblocks in the way of individuals who wish to have treatment forgone when they become severely demented, which may or may not qualify as a “terminal condition,” depending on statutory definitions and on the progress of the particular individual’s illness.23

These special interest groups continue to protest removal of life-sustaining treatment on the basis of oral advance directives, most recently in the case of the removal of a feeding tube from Terri Schiavo in Florida.24 Passion is particularly inflamed in connection with the cessation of artificial hydration and nutrition, an issue which has been exacerbated by a 2004 statement from the late Pope John Paul II that such treatment should always be considered comfort care rather than medical treatment,25 notwithstanding agreement in the medical community that artificial nutrition and hydration constitutes medical treatment.26

It is perhaps not coincidental that all three of the oral advance directive cases in the U.S. that have evoked enormous publicity and controversy have involved young women since

24 See discussion of the Schiavo case above, in Chapter Three.
26 Council on Ethical and Judicial Affairs, AMA, Code of Medical Ethics: Current Opinions with Annotations § E-2.20 (current as at 2005). Online: American Medical Association <ama-assn.org – policyfinder > accessed September 11, 2005 (“Life-sustaining treatment is any treatment that serves to prolong life without reversing the underlying medical condition. Life-sustaining treatment may include, but is not limited to, mechanical ventilation, renal dialysis, chemotherapy, antibiotics, and artificial nutrition and hydration. There is no ethical distinction between withdrawing and withholding life-sustaining treatment.”).
some restrictions in advance directive legislation are patently connected with the issue of anti-abortion, such as the suspension of an advance directive during pregnancy. This restriction of rights is commonly found in the U.S. advance directive legislation, but does not exist in any of the Canadian provincial advance directive legislation. It is highly unlikely that suspension of advance directive rights during pregnancy would withstand a constitutional challenge in Canada, and arguably it is subject to constitutional attack in the U. S. as well.

Canadian legislators must bear in mind the Canadian guarantee of personal liberty under the Canadian Charter of Rights and Freedoms which arguably demands that advance directive legislation ensure broad scope for decision-making. As explained by Madam Justice Wilson in Morgentaler v The Queen, the right to liberty "guarantees to each individual a degree of personal autonomy over important decisions intimately affecting their private lives" [and] "state enforced medical or surgical treatment...[is]an obvious invasion of physical integrity". Individual rights to make personal medical decisions prospectively should be enshrined in legislation that offers this broad scope for decision-making and that ensures the guarantee of personal autonomy provided to Canadians under the Charter.

28 Meisel & Cerminara, The Right to Die, supra note 23 at 7-91.
29 Morgentaler v. the Queen (1988),44 D.L.R. (4th) 385 (S.C.C.) [Morgentaler]; See also Winnipeg Child and Family Services v. G. (D.F.) [1997] 3 S.C.R. 925, S.C.J. No. 96 (QL) in which McLachlin J., writing for the majority, found that the fetus has no rights under Canadian law, the parens patriae power of the court does not extend to the fetus, and the court cannot place a pregnant woman in mandatory treatment without her consent, as this would infringe the woman's fundamental liberties.
30 Meisel & Cerminara, The Right to Die, supra note 23 at 7-93 (“Provisions limiting the rights of pregnant declarants raise serious constitutional issues.”).
32 Morgentaler supra note 29.
33 Ibid at 490.
2.3. Criminal and Civil Liability

Although training medical professionals about advance directives is necessary and would be beneficial, concern about following advance directives is understandable for Canadian health care providers in light of outdated Canadian criminal law provisions that, on a plain reading, impose criminal liability on them for ethically following an advance directive. While there has been little prosecution imposed on health care providers who follow advance directives, the antiquated legislation fails to offer comfort that the decision to honour an advance directive is legally correct. As Professor Downie points out:

[W]hen the case law, common law, and provincial legislation conflict or say nothing on these questions, criminal liability for withholding or withdrawal of potentially life-sustaining treatment remains possible and chills the practice of medicine.

For many years, Parliament has failed to respond to repeated recommendations to amend the Criminal Code to modernize these outdated provisions. Parliament’s inaction may be motivated by concern that the proposed amendments will evoke public fear that euthanasia and assisted suicide are being legalized. Parliament fails to fulfil its obligation to the Canadian public through its unwillingness to modernize the outdated provisions of the Criminal Code. It is important that elected representatives legislatively

36 Ibid at 35.
37 Ibid at 17.
39 See discussion at Chapter 4 above.
40 A recent Private Member’s Bill indicates an ongoing interest in exempting assisted suicide from the provisions of the Criminal Code. See Canada, Bill C-407, An Act to amend the Criminal Code (right to die with dignity), 1st Sess., 38th Parl., 2005 (debated at 2nd reading October 31, 2005), (which would “amend the Criminal Code to allow any person, under certain conditions, to aid a person close to death or suffering from a debilitating illness to die with dignity if the person has expressed the free and informed wish to die.”) This debate remains contentious in Parliament, however, in light of an earlier Private Member’s Bill promoting a position endorsing sanctity of life. See Canada, Bill C-307, An Act to amend the Criminal Code to prevent health care practitioners from being coerced into taking part in medical procedures that offend the practitioner’s religion or belief that human life is inviolable, 1st Sess. 38th Parl., (1st reading Dec. 3, 2004).
confirm the difference between honouring autonomy to refuse life-sustaining treatment prospectively and legalizing the practices of euthanasia and assisted suicide. The Criminal Code should be amended to eliminate physicians’ concern about potential liability for following an advance directive.

Additionally, some Canadian provincial advance directive legislation offers no protection from civil liability to health care providers who follow an advance directive. Confirmation of immunity from civil liability for health care providers who act in good faith in following an advance directive is a significant purpose for enacting the provincial advance directive legislation. All provinces should ensure that their advance directive legislation is amended to incorporate civil immunity for health care providers.

2.4. Disharmonized Provincial Legislation

During the early 1990’s, the Law Commissions of some Canadian provinces examined the issue of whether their respective provincial laws should provide competent individuals with the right to make advance directives and, if so, what form the directives should take. One of the most comprehensive and thoughtful of the provincial analyses was completed by the Manitoba Law Reform Commission, which issued recommendations for advance directive legislation in Report #74. The authors drafted proposed legislation that stated in its preamble:

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43 Supra note 3.
WHEREAS Manitoba law recognizes the right of every competent person to consent, refuse to consent or withdraw consent to his or her health care;

AND WHEREAS this right should also be respected after individuals are no longer able to participate in their health care decisions; 44

... 45

The authors provided the following annotation to the proposed legislation:

The preamble is intended to set out the basic philosophy that underlies the Act: the control which an individual has over his or her health care after losing competence should be as close as possible to the control which he or she would have had if still competent. The balance of the Act flows from this essential principle. [italics original] 45

The Manitoba Law Reform Commission concluded that provisions which limit the scope of advance directives, such as suspension during pregnancy, or effectiveness only when the patient is diagnosed to be “terminal”, will also limit the usefulness of the documents, and so recommended against such restrictions. 46 Although the Manitoba Health Care Directives Act 47 does not track the precise language used in the proposed draft, the basic philosophy set out in Report # 74 is still obvious in the Health Care Directives Act and contributes to the legal and ethical soundness of the Manitoba advance directive legislation.

Not all of the provinces carried out the same extensive analysis of the law as did Manitoba. Some provincial legislatures were beset by the fears that have hindered development of liberal advance directive laws in the U.S. Some of the provincial legislation authorizing advance directives has been “distorted” 48 by concerns that advance directives may diminish regard for the sanctity of life and potentially authorize euthanasia or assisted suicide.

44 Report #74 supra note 3 at 25.
45 Ibid.
46 Report #74 supra note 3 at 4.
To alleviate these concerns, some of the legislation has been drafted restrictively, often limiting personal choice about the type of advance directive that can be made.\(^{49}\) Onerous execution formalities that make it difficult for people to create advance directives also act as a restriction to their accessibility. The caution offered by Professor Keyserlingk in 1979 that restrictive legislation might offer fewer rather than more rights than exist at common law is, in some jurisdictions, borne out.\(^{50}\)

### 2.5. The Example of the Representation Agreement Act

The legislation in British Columbia is an example of such restrictive legislation. The RAA limits the choice of advance directive to a proxy directive, called a “representation agreement” under the legislation. The execution requirements under the RAA are unduly onerous, including a requirement that individuals must consult with a lawyer in order to execute a valid representation agreement. The RAA restricts mature minors from creating a representation agreement, in violation of their common law rights to consent to or refuse health care. The legislation does not recognize advance directives from foreign jurisdictions and is itself so unusual that representation agreements cannot be readily recognized in foreign jurisdictions.

The RAA fails to serve the needs of British Columbians for advance directive legislation. Legally capable B.C. citizens should have the choice to use an instructional or a proxy advance directive, or a combination of both. Execution requirements should be simple. The RAA should be harmonized to the greatest extent possible with modern advance directive legislation in other provincial jurisdictions. However, the current legislation is too complex and arcane to simply amend. B.C. needs advance directive legislation that

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\(^{49}\) e.g. Substitute Decisions Act, S.O. 1992, c. 30 (Ontario), Medical Consent Act, R.S.N.S. 1989, c. 279, (Nova Scotia) RAA, supra note 1 (B.C.).

\(^{50}\) See Edward W. Keyserlingk, Sanctity of Life or Quality of Life in the Context of Ethics, Medicine and Law, A Study written for the Law Reform Commission of Canada (Ottawa: Minister of Supply and Services Canada, 1979) at 180.
will uphold the principles of personal autonomy and self-determination that are foundational to the concept of the advance directive. To meet the needs of B.C. citizens, new advance directive legislation should be enacted.
3. Recommendations for Legislative Change

3.1. Uniformity

The law presently accepts that individuals can control their current medical treatment. It is reasonable and consistent that, to the extent possible, individuals should have the same control over their future medical treatment. Just as they can now consent to treatment, refuse treatment or choose one treatment over another, they should be able to do the same in respect to future care. Just as the principle of self-determination guides the law in respect to current medical care, so should the principle of self-determination guide the law in respect to future medical care.\textsuperscript{51}

The principle set out above should be consistently enshrined in legislation by all of the provinces so that prospective control over end-of-life treatment decision-making is consistent and harmonized among the provinces. The best approach would be for provinces to agree upon and adopt uniform legislation governing advance directives. This approach would be consistent with the principles of universal medical care that are intrinsic to the Canadian health care system.

Among the five criteria of the \textit{Canada Health Act (CHA)}\textsuperscript{52} required to secure funding for hospital-provided health care are universality, accessibility and portability. The preamble to the \textit{CHA} states, \textit{inter alia},

\begin{quote}
\- that future improvements in health will require the cooperative partnership of governments, health professionals, voluntary organizations and individual Canadians:
\- that continued access to quality health care without financial or other barriers will be critical to maintaining and improving the health and well-being of Canadians.\textsuperscript{53}
\end{quote}

\textsuperscript{51} Report \#74, \textit{supra} note 3 at 4.
\textsuperscript{52} R.S.C. 1985, c. C-6.
\textsuperscript{53} \textit{Ibid} at preamble.
Presumably, the purpose of these criteria is to encourage, to the greatest extent possible, equal access to equivalent health care for all Canadian residents regardless of where in Canada such services are accessed in order to maintain and improve the health of Canadians. Without commenting on the degree to which these criteria are successfully met,\(^5^4\) it is appropriate to extrapolate from them the principle that there should be a uniform approach to advance directive legislation across the country. It is ethical and logical under the Medicare system that Canadians should expect identical respect for their treatment wishes at the end-of-life, regardless of their province of residence. Similarly, there should be uniform recognition of extra-provincial advance directives. This uniformity is necessary to provide all Canadians with equal access to equivalent treatment at the end of their lives.

The 1995 Special Senate Committee Report on Euthanasia and Assisted Suicide\(^5^5\) included a recommendation that advance directive legislation should be enacted in all Canadian jurisdictions and that such legislation should include a protocol to recognize advance directives made in other provinces and territories.\(^5^6\) The subsequent report on the progress made towards achieving the recommendations of the Special Senate Committee\(^5^7\) moved away substantially from the initial confidence in the benefits of advance directives, apparently swayed by testimony of the potential danger inherent in an advance directive that has not been updated.

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\(^5^4\) For a discussion on that issue, see Colleen M. Flood, “The Anatomy of Medicare”, in J. Downie, T. Caulfield, C. Flood, eds., Canadian Health Law and Policy, 2 ed. (Canada: Butterworths, 2002) 1 at 19-32.

\(^5^5\) Canada, Parliament, Senate Special Committee on Euthanasia and Assisted Suicide, Of Life and Death – Final Report, (Ottawa: The Special Committee, 1995) [Senate Report, Of Life and Death], online: <www.parl.gc.ca/english/senate/com-e/euth-e/rep-e/lad-e.htm>

\(^5^6\) Ibid, at Recommendations Chapter V: Advance Directives

Although the advance directive substantiates a legal right, the committee seemed convinced that they should not be thought of as “purely legal documents”.\textsuperscript{58} The Committee explained concerns that advance directives have the power to prematurely bring about death because a dying patient may have failed to update his or her instructions. The Committee seemed willing to set aside “the traditional view of advance directives as based on the principle of the patient's autonomy” in favour of finding “that advance directives are now best seen as part of a planning and communication process that helps people prepare for death in the context of their loved ones”\textsuperscript{59}.

Adoption of this finding as a model for end-of-life decision-making represents a return to paternalistic attitudes to medical care, where the family and the physician, rather than the patient, have control over decision-making. The intention is benevolent: that any decision would be made in the best interests of the patient. However, this model potentially deprives patients of personal autonomy to make their own treatment decisions.

People should never be forced to write an instructional advance directive or assign a proxy. Those who wish to leave medical decision-making to family and physicians, or who want to develop a consensus with their family on treatment decisions, should always be able to do so. But the legislative option of expressing treatment decisions in advance or naming a proxy to convey them must be made available to those who wish to make their own decisions. It is not appropriate to limit personal freedoms for fear that individuals may harm themselves, unless the implications of that harm do an injustice to the rest of society.

Unfortunately, the Committee offered no new recommendations for comprehensive and consistent advance directive legislation to be implemented. Therefore, the chances for establishing uniformity are greatly diminished.

\textsuperscript{58} Ibid at B. Achieving Quality End of Life Care 5. Advance Directives
\textsuperscript{59} Ibid.
3.2. **Advance Directive Legislation in British Columbia**

The Ministry of the Attorney General for British Columbia proposed new advance planning legislation in 2004 [the Ministry Proposal].\(^{60}\) The Ministry Proposal contained the following four provisions:

- That advance care directives must be in writing, dated and signed by the maker in front of two witnesses. The exception to this would be where the advance care directive is signed in front of a lawyer or notary, in which case there need not be another witness.
- An advanced care directive would contain a statement that the maker acknowledges that no third party will be involved in giving or refusing consent when the directive is in effect.
- The adult would be able to make a combined advance care directive and representation agreement, specifying wishes that must be respected in certain medical situations, while noting that in all other medical situations, the representative will make the decision.
- Where there are reasonable grounds to question the validity of an advance care directive, a procedure would be triggered, which would ensure that the person is given medically appropriate health care until any questions regarding the person’s wishes are resolved.\(^ {61}\)

All of the above proposals are beneficial components of advance directive legislation. In addition, advance directive legislation that honours autonomy and respects personal rights to self-determination will include the following aspects:

1. The definition of “health care” or “health care decision” should be broad in scope and not so limited that the advance directive frequently will not apply to the situation.

2. A directive should be in writing, although execution requirements should be simple, in keeping with or even simpler than the first bullet set out above in the Ministry Proposal.

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\(^{61}\) Ibid at 6.
3. Both types of advance directives should be available as options to individuals, as well as a combined directive.

4. Any capable person should be entitled to execute an advance directive, including mature minors.

5. Persons should be presumed capable unless there are reasonable grounds to show that they are incapable to make an advanced directive.

6. Advance directives should be invoked when a patient loses capacity to make treatment decisions. If the patient regains capacity, the directive should be suspended and treatment decisions should be made directly by the patient.

7. The effect of the treatment decision should have the same effect as a decision made by the patient when capable, subject to resolution of any reasonable concern that the advance directive is not valid.

8. An advance directive should be revocable in writing, orally, or through destruction of the original by the maker.

9. The proxy should act in accordance with the wishes of the maker or, if such wishes are unknown, in accordance with the maker’s known values or, if the maker’s values are unknown, in accordance with the maker’s best interests.

10. There should be no mandatory form of advance directive, although government should provide an example form for ease of use.

11. Advance directives should provide immunity from liability to health care providers and to a proxy who acts in good faith and in accordance with the advance directive.

12. Advance directive legislation should not derogate from any rights that a person has at common law and no presumption should arise because a person has not created an advance directive.

13. Advance Directive legislation should recognize extra-provincial directives that comply either with the provincial legislation or with the legislation of the provincial jurisdiction where the person is habitually resident.
4. Recommendations for Further Research

The conclusion reached in Chapter Two of this thesis is that communication about advance care planning must be improved between patients, families and health care providers. People are willing to enter into these discussions and want to make their choices known. Medical and other health care professionals must find a way to ensure that people have the opportunity to express their wishes. The 1995 Senate Report *Of life and Death*\textsuperscript{62} concluded that Canadians, including federal and provincial governments and the educational community need to collaborate on ways to increase education and training of all professionals involved in end-of-life care partly to improve communication.\textsuperscript{63} This training should ensure health care professionals are familiar with and comfortable discussing advance directives and carrying out end-of-life planning with patients.

It is still not clear, however, how best to engage society in this planning process. Medical professionals need communication tools for raising the issue of advance care planning and need training on how to offer sympathetic and sensitive advice to patients who seek assistance making decisions. Research should be done to learn social and medical preferences respecting preferred communication methods for end-of-life planning.

Uniform advance directive legislation is clearly suitable in a federation that provides universal health care. The Uniform Law Conference of Canada (ULCC) should embark on a project to recommend uniform provincial advance directive legislation. The ULCC should not be deterred by concerns that Canadians need to be protected from their own decisions. Canada is a country that endorses personal liberty and freedom of choice. Canadian legislation should reflect those principles.

\textsuperscript{62} Senate Report, *Of Life and Death*, supra note 55.
\textsuperscript{63} *Ibid*, Recommendation 6.
5. Conclusion

And death shall have no dominion.

Dylan Thomas⁶⁴

A century ago the legal right to choose or refuse medical treatment had not been established. Much has changed over the last century. The right of patients to be the arbiters of their own medical treatment decisions is now firmly embedded in the law. Progressively, the law recognizes that patients’ authority to direct their treatment decisions should not cease upon incapability, if their treatment preferences have been expressed in advance. Respect for patient autonomy and self-determination demands that such treatment preferences be honoured.

B.C. enacted the RAA with the intent to provide, among other things, an instrument for advance care planning. The RAA, however, does not meet the ideals of advance directive legislation. The RAA limits personal choice of planning instrument, imposes burdensome restrictions on execution, and fails to provide many of the essential elements of good advance directive legislation. The RAA was drafted with a primary goal of protecting people and preserving life. Despite its good intentions, the RAA creates a paternalistic regime for advance care planning and does not meet its purported goal of respecting individual autonomy. For these reasons, the RAA fails as advance directive legislation. New advance directive legislation is needed in B.C.

It is incumbent on the lawmakers to ensure that patients have the ability to make their treatment preferences known. People should have a choice of planning instrument that suits their needs, that is easily accessible and that is simple to execute. Advance directive

legislation should incorporate the ideals of patient autonomy and self-determination. Upholding the ideals of autonomy and self-determination ultimately enhances our respect for the dignity and worth of all individuals, including the most vulnerable among us.

Ronald Dworkin expresses beautifully why it is life and not death which holds dominion when laws strive to ensure freedom:

...if people retain the self-consciousness and self-respect that is the greatest achievement of our species, they will let neither science nor nature simply take its course, but will struggle to express, in the laws they make as citizens and the choices they make as people, the best understanding they can reach of why human life is sacred, and of the proper place of freedom in its dominion.65

1. PRIMARY SOURCES

CANADIAN LEGISLATION


*Age of Majority Act* R.S.B.C. 1996, c. 7.


Canada, Bill C-307, An Act to amend the Criminal Code to prevent health care practitioners from being coerced into taking part in medical procedures that offend the practitioner's religion or belief that human life is inviolable, 1st Sess. 38th Parl., (1st reading Dec. 3, 2004).


Care Consent Act, S.Y. 2003, c.21 Schedule B.


Consent to Treatment and Health Care Directives Act, S.P.E.I. 1996, c. 10.

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