

**AUTONOMY, LIBERALISM, AND ADVANCE CARE PLANNING**

by

**Sharon Ikonmidis**

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Graduate Department of Philosophy, Joint Centre for Bioethics  
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Doctor of Philosophy 1997

Sharon Ikonomidis

Department of Philosophy, Joint Centre for Bioethics, University of Toronto

## **ABSTRACT**

The justification for advance directives is typically grounded in the notion that they preserve, enhance and extend patient autonomy into future states of incompetency through active patient participation in decision making about end-of-life care. However, the weight given to autonomy has become questionable in the light of recent empirical studies revealing the significance of other important values of social justice, paternalism, and personal relationships that emerge in the decision-making process. Such findings, along with objections on theoretical grounds, suggest that the value of autonomy, perceived to be a defining feature of liberal philosophical theory, is an inappropriate model for advance care planning. From a philosophical perspective, I explore the meaning and role of the value of individual autonomy within contemporary liberal writings to determine (i) whether the liberal concept of autonomy is a purely individualistic concept and (ii) whether the concept of autonomy is overemphasized by liberals at the expense of other important values of social justice, paternalism, and personal relationships. As a result of this analysis, I challenge the claim that liberalism, being a theory defined strictly in terms of its emphasis on individual autonomy, is an

inappropriate framework in accounting for advance care planning. I suggest that liberalism is an indispensable component in a complete framework for advance care planning, but that it needs to be supplemented with theoretical models that explicitly focus on relevant values besides individual autonomy.

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## INTRODUCTION

Advance directives are documents that allow individuals to specify the type of medical interventions they want and do not want to receive, and the person(s) they want to make decisions on their behalf, in the event that they should become incapable of making treatment decisions themselves. An example of a generic advance directive form is the Centre for Bioethics Living Will (Appendix I) developed at the University of Toronto Joint Centre for Bioethics. The prevailing assumption underlying the use of advance directives is that these documents should be honoured since they respect, or at least aim to respect, the value of patient autonomy or self-determination.

The principle of autonomy is unquestionably valued in decisions to apply or forgo life-sustaining treatments. It entitles patients to make important decisions bearing on their own lives in the absence of paternalistic influence or intervention. Advance directives are arguably justified on the basis that they preserve and promote patient autonomy. These documents allow capable persons to make choices intended to influence the care they would receive should they lose the capacity to make their own treatment decisions. By enabling a competent person to "extend" his or her autonomous decision-making capacity into a future state in which this capacity no longer exists, an advance directive presumably gives a person some control over the end of his or her life.

Among the most cogent objections to the use of advance directives are those aimed directly at their primary justification, namely, the value of patient autonomy or self-determination. In what follows, I will examine the meaning and role of the modern

liberal concept of autonomy, and the liberal theoretical framework with which it is associated, with respect to the philosophical grounding of advance care planning.

After describing in chapter one advance directives and arguments for their use, chapter two outlines a critique of the concept of autonomy. I will consider two main criticisms that suggest that autonomy, and the liberal framework within which it is associated, is an insufficient value upon which to base advance care planning. First, critics of the liberal concept of autonomy argue that it is an impoverished or internally flawed concept. This criticism is directed at the essential meaning of autonomy - a meaning that has been allegedly misconceived by liberals insofar as it implies a misconception of the metaphysical nature of persons. Second, critics object that, regardless of whether it is an impoverished concept or not, autonomy is overemphasized by liberals at the expense of other important values. Although for reasons of clarity I have appealed largely to communitarianism as representative of the first criticism, and certain branches of feminism as representative of the second, the significant extent of overlap between the two is acknowledged.

The concept of autonomy that is criticized in the bioethics literature as a distinctly liberal moral imperative behind advance care planning requires clarification. Though it is often taken for granted by critics writing in the area of biomedical ethics that autonomy is *the* liberal value, this literature lacks an adequate account of what is meant by liberal autonomy. In the bioethics literature the value of individual autonomy is associated with liberal political philosophy. I will compare the references to autonomy in bioethics that relate to the criticisms examined in chapter two with modern liberal conceptions of the

term. The goal in chapter three is to establish a clarified sense of autonomy according to contemporary liberal writers' various conceptions of the term in order to demonstrate whether the liberal concept of autonomy is or is not impoverished in the way critics claim.

The second objection to liberal autonomy lies in the claim that its (over)emphasis entails the denial of other important values - particularly those of personal relationships, paternalistic decision making on behalf of patients, and social justice - that are social in nature. Chapter four addresses this claim from two empirical-based perspectives. The first is that of the patient or person engaged in advance care planning: Does the principle of autonomy account for the concerns people have who engage in the advance care planning process? Is it the primary value underlying the goals and motivations that people who complete advance directives have for completing them? There are two ongoing studies that, among other things, examine the adequacy of autonomy in the light of the actual experiences and attitudes of those who undertake advance care planning and thus provide data that is useful in the attempt to answer these questions.

The second perspective is that of the patient's loved ones and health care providers who assist in advance care planning and/or who act as substitute decision-makers after the patient has become incapable of his or her own decision making: Is autonomy the primary justification for honouring an advance directive? That is, should it be granted priority by those other than the patient who participate in decisions about end-of-life care? Must designated substitute decision-makers grant its authority under *all* circumstances? Case studies are offered which address the claim that patient autonomy

may be justifiably overridden when it conflicts with patient well-being and/or the well-being of those either involved directly in the care of the patient or indirectly affected by patient choices.

The objection that liberal autonomy is insufficient in accounting for the role other important values play in the process of advance care planning entails the assumption that the overemphasis of autonomy is an essential or defining aspect of liberalism. Following this assumption, it would seem that liberalism is an inappropriate framework for understanding values other than autonomy that may dominate the advance care planning process. Chapter five challenges this assumption in examining modern liberalism's weighing of autonomy. I attempt to defend the claim that even though autonomy has roots in liberal theory, liberalism is not simply a theory about autonomy. Liberals do not unequivocally hold autonomy to be a foundational value to be upheld at all individual and social costs. Liberals recognize the relative worth of autonomy vis-à-vis other important values.

In an attempt to further this point, I focus briefly on the extent to which contemporary liberals recognize and incorporate the values of social justice, paternalism in decision making for others, and personal relationships (including concern for the welfare of others) into their theoretical frameworks since these are the values that, according to the theoretical criticisms and empirical data considered above, emerge in the advance care planning process. I hope to show that modern liberalism, understood as a political theory based ultimately on a conception of justice as equality, and one that takes into account defensible instances of paternalism, is not necessarily an inappropriate

framework for understanding the aspects of advance care planning in which these values emerge.

What remains questionable, however, is the extent to which liberalism serves as a theory specifically of personal and private relationships. It may be reasonable to assume that the liberal concern for political and public relationships reflects a deeper agenda to protect the private choices and affairs of individuals. Yet the liberal writers considered here do not discuss the nature and value of personal relationships, *per se*, though they may seek to define a liberal account of the individual as situated or embedded in community and culture. Liberalism, though not necessarily an inappropriate framework for understanding advance care planning, may not be entirely adequate in accounting for the private aspects of this process. In conclusion, I suggest the supplementation, and not replacement, of liberalism with theoretical accounts that stress the value of personal relationships.

## CHAPTER ONE

### **Advance Directives and Autonomy**

Advance directives are instruments that allow individuals to specify the type of medical interventions they want and do not want to receive, and the person(s) they want to make decisions on their behalf, if or when they become incapable of making treatment decisions themselves. They may be formally documented, as in the case of living wills and durable powers of attorney for health care, or informally executed, as in the case of oral instructions, recollections of pertinent discussions, and medical record notes.<sup>1</sup>

There are two main types of formal advance directives: the "instruction directive" allows individuals to specify medical procedures they would want to receive or forgo upon losing the ability to make such decisions themselves and the "proxy directive" allows individuals to designate another person to make treatment decisions on their behalf should they lose their decision-making capacity.<sup>2</sup>

The use of advance directives arose out of a concern about the overtreatment of patients, particularly those at the end of their lives, and for needless prolonged end-of-life suffering.<sup>3</sup> Public support for advance directives has been demonstrated by surveys in

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<sup>1</sup> Teno, Nelson, and Lynn 1994.

<sup>2</sup> Meslin and Sutherland 1993.

<sup>3</sup> Wetle 1994.

both Canada<sup>4</sup> and the United States.<sup>5</sup> Professional endorsement of advance directives has been revealed in Canadian<sup>6</sup> and United States<sup>7</sup> surveys of physicians' attitudes. Moreover, in both Canada<sup>8</sup> and the United States,<sup>9</sup> patients themselves have demonstrated positive attitudes toward advance directives.

Legal support for the patient's right to opt for treatment withdrawal also exists in both countries. Since the 1976 United States case of Karen Quinlan<sup>10</sup>, the first public case involving treatment withdrawal from an incompetent patient, advance directives have been widely endorsed as model documents for advance care planning. This case set a precedent for the recognition of a patient's right to refuse life-sustaining treatment. This right is reflected in the laws most states now have, following the 1976 California Natural Death Act<sup>11</sup>, that recognize the use of advance directives, and in the 1990 decision of the United States Supreme Court in the Nancy Cruzan case<sup>12</sup>. The United States Patient

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<sup>4</sup> Molloy *et al.* 1991; Singer, Choudhry, and Armstrong 1993.

<sup>5</sup> Emanuel *et al.* 1991; Gamble, McDonald, and Lichstein 1991.

<sup>6</sup> Hughes and Singer 1992.

<sup>7</sup> Emanuel and Emanuel 1989, 261:3288; Davidson *et al.* 1989; Brunetti, Carperos, and Westlund 1991.

<sup>8</sup> Sam and Singer 1993.

<sup>9</sup> Emanuel *et al.* 1991; Gamble, McDonald, and Lichstein 1991.

<sup>10</sup> *Re Quinlan*, 70 NJ 10, 1976.

<sup>11</sup> *California Natural Death Act*, 1976, California Code of Health and Safety, S 7185-7195.

<sup>12</sup> *Cruzan v. Director*, Missouri Department of Health, 110 SCt 2841, 1990.

Self-Determination Act<sup>13</sup>, which became effective in December 1990, requires hospitals, nursing homes, and other patient care institutions to notify all patients upon admission of their right to refuse medical treatment, to ask whether patients have advance directives, and, if not, to provide written information about these documents.

In Canada, both case law and provincial legislation exist that support the use of advance directives. Two Ontario cases involving incapable patients, *Malette v. Shulman*<sup>14</sup> in 1990 and *Fleming v. Reid*<sup>15</sup> in 1991, have supported the patient's right to forgo life-sustaining treatment. In the former case, the physician in question was liable to pay damages for administering a blood transfusion to a Jehovah's witness who had on her person a card stating that she was never to receive a transfusion. In the latter case, the court disallowed provisions of the Mental Health Act which permitted therapy to be given to an incompetent patient despite his wishes, made when competent, not to receive therapy. Common law also supports the patient's directive to remove life-sustaining treatments. The 1992 Quebec case of *Nancy B. v. Hôtel-Dieu de Québec*<sup>16</sup> involving a capable patient supported the patient's directive to withdraw life-sustaining therapy. Moreover, in 1993, the Supreme Court of Canada did not honour a dying patient's

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<sup>13</sup> *Omnibus Budget Reconciliation Act*, United States Public Law, S 4206, 4751, October 26, 1990; p. 12638.

<sup>14</sup> *Malette v. Shulman*, 72 OR 2d 417, Ontario Court of Appeals, 1990.

<sup>15</sup> *Fleming v. Reid*, 4 OR 3d 74, Ontario, 1991.

<sup>16</sup> *Nancy B. v. Hôtel-Dieu de Québec*, et al., 86 DLR 4th 385, Québec, 1992.

request for a lethal injection in the case of Sue Rodriguez,<sup>17</sup> but did accept her right to forgo treatment.<sup>18</sup>

Provincial legislatures support the use of written advance directives. The provinces of Manitoba,<sup>19</sup> Ontario,<sup>20</sup> Quebec,<sup>21</sup> Nova Scotia,<sup>22</sup> and Newfoundland<sup>23</sup> have legislation in recognition of advance directives. British Columbia,<sup>24</sup> Alberta,<sup>25</sup> and Prince Edward Island have introduced similar legislation.<sup>26</sup> There is also support for written advance directive forms in policies of professional organizations such as The Canadian Medical Association.<sup>27</sup> Some hospitals and long-term facilities have policies regarding written advance directive forms.<sup>28</sup>

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<sup>17</sup> *Rodriguez v. Attorney General of British Columbia*, 7 WWR, 641 (SCC), 1993.

<sup>18</sup> Addison 1994.

<sup>19</sup> Health Care Directives and Consequential Amendments Act, SM, 1992, c.33.

<sup>20</sup> Health Care Consent Act, SO, 1992, c.31; Substitute Decisions Act, SO, 1992, c.30.

<sup>21</sup> Public Curator Act, SQ 1989, c.54.

<sup>22</sup> Medical Consent Act, RSNS 1989, c. 279.

<sup>23</sup> Advanced Health Care Directives Act, SN, 1995, c. A-4.1.

<sup>24</sup> Representation Agreement Act, SBC, 1993, c. 67. (not yet proclaimed)

<sup>25</sup> Personal Directives Act, SA, 1996. (not yet proclaimed)

<sup>26</sup> Consent to Treatment and Health Care Directives Act, c. 10 (Bill No. 43), 4th Session, 59th General Assembly, Province of Prince Edward Island, 45 Elizabeth II, 1996. (not yet proclaimed)

<sup>27</sup> CMA 1992.

<sup>28</sup> Rasooly *et al.* 1994; Choudry, Rasooly, and Singer 1994.

To date, the use of advance directives has been based on the assumption that these documents should be honoured since they respect, or at least aim to respect, the value of patient autonomy.<sup>29</sup> Autonomy, defined briefly in the bioethics literature, is "people's interest in making significant decisions about their lives for themselves and according to their own values or conception of a good life. It is by having our self-determination respected by others that we are able to exercise significant control over and responsibility for our lives".<sup>30</sup> Raanan Gillon defines autonomy as the "capacity to think, decide, and act (on the basis of such thought and decision) freely and independently".<sup>31</sup> According to Ezekiel J. Emanuel,

...defines the essential characteristic of human beings as their ability to conceive and pursue personal interpretations of the good. Self-determination is an elemental component of the ultimate human good and a meaningful human life.<sup>32</sup>

The principle of autonomy is unquestionably valued in decisions to apply or forgo life-sustaining treatments. Some argue that it "gives patients the right to reject or select

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<sup>29</sup> Kapp 1982; Eisendrath and Jonsen 1983; Davidson *et al.* 1989; Frankl, Oye, and Bellamy 1989; Emanuel and Emanuel 1989; Engelhardt, Jr. 1989; Orentlicher 1990; Cohen-Mansfield *et al.* 1991; Molloy *et al.* 1991; Emanuel *et al.* 1991; Brunetti, Carperos, and Westlund 1991; Danis *et al.* 1991; Schneiderman *et al.* 1992; Addison 1994.

<sup>30</sup> Brock 1994.

<sup>31</sup> Gillon 1985, 60.

<sup>32</sup> Emanuel 1987, 17(5):17.

among therapies and is central to life-support decisions, which can affect a patient's length and quality of survival"<sup>33</sup> or, more generally, that it entitles patients to make important decisions bearing on their own lives in the absence of paternalistic influence or intervention.

A major part of the public appeal of advance directives is that reliance on a patient's prior directive is consistent with widely shared values of personal autonomy since the patient is the principal party making the decisions<sup>34</sup>. As K.M. McIntyre writes,

The goal of the AD is to preserve patient autonomy. The purpose of an AD is to ensure that a health care decision that is made for patients who cannot make the decision for themselves is the one that patients would have made if they had been able to do so.<sup>35</sup>

In support of advance directives as means by which patient autonomy may be upheld, Chris Hackler and colleagues write,

Nowhere is the patient's right to self-determination more poignant than in the use of burdensome life-sustaining technologies. In recent years the medical profession has greatly increased its capacity to preserve and extend life. Although the new techniques often produce dramatic improvements in a patient's condition, they are sometimes accompanied by serious drawbacks. For example, life-sustaining

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<sup>33</sup> Frankl, Oye, and Bellamy 1989, 645.

<sup>34</sup> Dresser and Robertson 1989.

<sup>35</sup> McIntyre 1992, 2271.

technologies may prolong a patient's life but may also contribute to the dying patient's intense suffering. They may sustain indefinitely the life of a patient in a persistent vegetative state but offer no hope for recovery. Many believe that when the benefits of treatment are overshadowed by burdens imposed, treatment may ethically be withdrawn. Decisions to withdraw treatment are best made by patients themselves. All too often, however, at the time such a decision must be made, the patient has lost the capacity to request or to refuse burdensome but life-sustaining treatment.

Advance directives are important because through them one can extend self-determination into the future. They record choices made by competent persons intended to influence the care they receive should they lose the capacity to participate in treatment decisions directly.<sup>36</sup>

By enabling a competent person to "extend" his or her autonomous decision-making capacity into a future state in which this capacity no longer exists,<sup>37</sup> an advance directive presumably gives a person control over the end of his or her life.<sup>38</sup> Overall, advance directives may be viewed as a response to the public's desire for control over health care decisions that concern them.<sup>39</sup>

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<sup>36</sup> Hackler, Moseley, and Vawter 1989, 1-2.

<sup>37</sup> Hackler, Moseley, and Vawter 1989; Emanuel *et al.* 1991.

<sup>38</sup> Eisendrath and Jonsen 1983.

<sup>39</sup> Molloy *et al.* 1991.

## CHAPTER TWO

### **The Critique of Liberal Autonomy**

There are many arguments against the use of advance directives. Practically, advance directives have received wide criticism on the grounds that they are often difficult to interpret,<sup>1</sup> that they concentrate strictly on terminating treatment but not maintaining or providing treatment, that they apply only to terminally ill patients, that they are vague in characterizing the state a patient must be in before his or her advance directive may be implemented, that they are vague in delineating the types of medical interventions to be terminated,<sup>2</sup> and that when they are drafted in specific language, they cannot provide guidance for circumstances not anticipated when the advance directive was completed.<sup>3</sup> Moreover, they fail to take into account the fact that some terminally ill patients survive longer than predicted and may even recover, that what is today considered "extraordinary treatment" may tomorrow become standard procedure, and that extraordinary therapy may make a terminal illness less painful and distressing.<sup>4</sup>

People often complete advance directives without discussing them with their

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<sup>1</sup> Brett 1991.

<sup>2</sup> Emanuel and Emanuel 1990, 10-11.

<sup>3</sup> Orentlicher 1990.

<sup>4</sup> Kapp 1982.

physicians who may thus remain ignorant of their patients' wishes.<sup>5</sup> Furthermore, advance directives might end up restricting patients' autonomous choices by coercing individuals who have not completed one to submit to care they otherwise would not have wanted<sup>6</sup> - a "no-choice" default mechanism. Or, patients' choices might be restricted through psychological pressure from family and health care professionals to avail themselves of the opportunity to execute an advance directive<sup>7</sup>. Problems of compliance may also exist when advance directives are ignored or disregarded in clinical settings.<sup>8</sup> Practical problems with proxy directives include the potential disagreements between either the patient's wishes and the proxy's decision or between proxies where more than one has been designated,<sup>9</sup> and the problem for some patients of discerning the most appropriate proxy.<sup>10</sup>

Metaphysically, it has been claimed that the very process leading to patient incompetence destroys the conditions necessary for the patient's personal identity.<sup>11</sup> The objection is based on the widely held assumption that psychological continuity is a

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<sup>5</sup> Emanuel and Emanuel 1989, 3289.

<sup>6</sup> Meslin and Sutherland 1993, 198.

<sup>7</sup> Kapp 1982; Francis 1993.

<sup>8</sup> Danis *et al.* 1991; Dresser 1994.

<sup>9</sup> Emanuel and Emanuel 1989.

<sup>10</sup> Orentlicher 1990, 2366; Lambert, Gibson, and Nathanson 1990, 209.

<sup>11</sup> For a discussion of this claim see for example Buchanan 1988; Dresser 1989; Francis 1993; Kuczewski 1994.

necessary condition for personal identity: is the person who completed the advance directive the "same" person as the one now incompetent and to whom the directive applies?

Epistemologically, it may be claimed that desires expressed by the competent patient cannot be known with certainty to represent those the patient holds after becoming incompetent (assuming incompetent persons have wishes and desires at all).<sup>12</sup> Advance directives may pose a threat to incompetent patients because they either confuse the present interest of an incompetent patient with interests he or she had when competent, or because they privilege the competent person's interest in control and certainty over the incompetent patient's need for treatment.<sup>13</sup> Studies reveal the poor ability of spouses and physicians to predict accurately the preferences of patients.<sup>14</sup> Even where proxy decision-makers have had prior discussions with patients they may remain unclear about what the patient would have wanted in a particular unanticipated circumstance.<sup>15</sup> This problem could lead to error and abuse,<sup>16</sup> or inflexibility on the part of physicians who rigidly adhere to instruction and proxy directives.<sup>17</sup> Thus, the most important element in planning for mental incapacity may be the quality of communication among patients,

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<sup>12</sup> Meslin and Sutherland 1993.

<sup>13</sup> Robertson 1991.

<sup>14</sup> Bedell and Delbanco 1984; Uhlmann, Pearlman, and Cain 19988; Seckler *et al.* 1991.

<sup>15</sup> Emanuel and Emanuel 1989.

<sup>16</sup> Schneiderman and Arras 1985; Stone 1994.

<sup>17</sup> Francis 1993.

families, and health care providers to clarify to the greatest extent possible the patient's views about life, death, and medical treatment.<sup>18</sup>

Although there is considerable strength to some or all of the above arguments against the use of advance directives, they are not necessarily insuperable or fatal to advance directive implementation. Perhaps the most cogent objection to the use of advance directives is that aimed directly at their primary justification, namely, the value of patient autonomy or self-determination. In what follows, I will examine the role of modern liberalism along with its concept of autonomy in the philosophical grounding of advance care planning. I will consider two main criticisms that underlie the objection that autonomy, and the liberal framework within which it is conceived, is an insufficient value upon which to base advance care planning. First, critics of the liberal concept of autonomy argue that it is an impoverished or internally flawed concept. This criticism is directed at the essential meaning of autonomy; a meaning that has been allegedly misconceived by liberals insofar as it implies a misconception of the nature of persons. Second, critics object that, regardless of whether it is an impoverished concept or not, autonomy is overemphasized by liberals at the expense of other important values. Although for reasons of clarity I have appealed to communitarianism as representative of the first criticism, and feminism as representative of the second, the significant extent of overlap between the two is acknowledged.

### **Liberalism and the Impoverishment of Autonomy**

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<sup>18</sup> Brett 1991.

A major objection to the liberal concept of autonomy is that it implies a misconception of the self as, according to Joan Teno and colleagues, "a rational, independent agent, free to decide for himself how significant his ties to others should be."<sup>19</sup> To Hilde and James Lindemann Nelson, such a conception of self suggests that human beings are "disengaged, unencumbered"<sup>20</sup> or are, as Daniel Callahan puts it, "moral agents...essentially independent of each other and isolated...not social animals, but morally self-enclosed, self-encompassing animals."<sup>21</sup> It has been assumed that, granted an individual capacity for autonomous choice exists, liberal notions of autonomy that define freedom in terms of the ability to question the given limits of our social situation and roles suggest a self that exists in a void.<sup>22</sup>

An ethic of individual autonomy, if indeed impoverished in the way critics claim, cannot serve as a basis for advance care planning unless people engaged in the planning process do in fact make treatment decisions in a way that is entirely detached from the interests of others. Such an ethic is, to John Hardwig, isolating and destructive when applied to patients since it suggests that "patients make 'their own' treatment decisions on a self-regarding basis...[and since it] encourages each of us to see our lives as simply our own."<sup>23</sup> This, he argues, is mistaken since persons are essentially attached to the lives

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<sup>19</sup> Teno, Hill, and O'Connor 1994.

<sup>20</sup> Nelson and Nelson 1994, S20.

<sup>21</sup> Callahan 1984, 41.

<sup>22</sup> Kymlicka 1989b, 47.

<sup>23</sup> Hardwig 1990, 7.

of close others. Accordingly, autonomy cannot mean simply a person's right to choose for him or herself based on personal interests alone; the interests of those close to the patient (e.g., family) are essentially part of his or her own.

Along the same lines, communitarians have argued that the liberal concept of autonomy is deficient since it wrongly portrays the individual as essentially disconnected from the rest of the community and since it demands the denial of the priority of other, communal, values. According to Michael Sandel, the liberal autonomous self, as one able to question and revise convictions of the good life, is falsely represented as defined prior to its ends. But for Sandel, the self is constituted by its ends - ends that are not chosen but rather are discovered by virtue of our being embedded in some shared social context. As Kuczewski puts it, the self is not merely a product of the will but also cognitively determined in that preferences and values are discovered by the person in the process of interaction with the community.<sup>24</sup> It is impossible to conceive of ourselves as entirely separate from the purposes and ends characteristic of the communities within which we live. The individual, and hence individual capacity for choice, is structured in part by these ends and the roles he or she assumes with respect to the community.<sup>25</sup> The liberal self is thus understood by communitarians to be a sort of disembodied, or unencumbered being whose capacity for choice is highly exaggerated.

According to Sandel, a liberal account of autonomy ignores the self's essential embeddedness in communal practices such that the constitutive sense of community (and

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<sup>24</sup> Kuczewski 1994.

<sup>25</sup> Sandel 1984, 5-6.

communal ends) is ruled out. He writes, "On [this] view, a sense of community describes a possible aim of antecedently individuated selves, not an ingredient or constituent of their identity as such".<sup>26</sup> To Sandel, communal aims and values are not only affirmed by the members of the community but also define their very identity. We do not choose communal goals (as liberals assume); we discover our relationship to them. Community, for Sandel, is a constitutive conception insofar as it describes not just what we have as fellow citizens but also what we are; not a relationship we choose but an attachment we discover; not merely an attribute but a constituent of our identity.<sup>27</sup> He argues that "the relevant description of the self may embrace more than a single, individual human being, as when we attribute responsibility or affirm an obligation to a family or community or class or nation rather than to some particular human being."<sup>28</sup> Political arrangements, says Sandel, cannot be justified without reference to common purposes and ends, and personhood cannot be conceived without reference to our citizenship role.<sup>29</sup>

Similarly, for Alasdair MacIntyre, social identity is defined in terms of membership in social groups with which the individual identifies. To be a sister, or a member of this particular community, are not accidental characteristics, but rather substantiate the individual, serving in part to define her obligations and duties.

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<sup>26</sup> Sandel 1982, 64.

<sup>27</sup> Sandel 1982, 150.

<sup>28</sup> Sandel 1982, 62-63.

<sup>29</sup> Sandel 1984, 5.

"Without", writes MacIntyre, "... a place in the social order, a man would not only be incapable of receiving recognition and response from others; not only would others not know, but he would not himself know who he was."<sup>30</sup>

The individual, in MacIntyre's view, is identified and constituted by and through "those roles which bind the individual to communities in and through which alone specifically human goods are to be attained; I confront the world as a member of this family, this household, this clan, this tribe, this city, this nation, this kingdom. There is no 'I' apart from these."<sup>31</sup> Self-identity is thus partly defined by the community roles that one assumes. One is therefore never able to seek the good strictly *qua* individual, nor outside the context of a tradition, argues MacIntyre, since what it is to live the good life varies from concrete circumstance to circumstance: "we all approach our own circumstances as bearers of a particular social identity...what is good for me has to be good for one who inhabits these roles."<sup>32</sup>

Self-identity is always derived from a community story or "narrative" in which one is necessarily embedded. An individual's life is essentially narrative in that one cannot escape one's history or the past which makes us who we are (and, it might be added, the future that affects who we are). To know oneself as a social person is, MacIntyre argues, "to find oneself placed at a certain point on a journey with set goals; to move through life is to make progress - or to fail to make progress - toward a given

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<sup>30</sup> MacIntyre 1981, 132-134.

<sup>31</sup> MacIntyre 1981, 172.

<sup>32</sup> MacIntyre 1981, 220.

end."<sup>33</sup> Human action, which "has a basically historical character", is carried out with reference to goods defined in terms of an individual's specific characteristics. Since personhood has both individual and social aspects, the goods are defined in terms which are both particular and general: "We live out our lives, both individually and in our relationships with each other, in the light of certain conceptions of a possible shared future."<sup>34</sup> (For MacIntyre the "fact" of our social embeddedness does not entail that the self is condemned to accept the moral limitations set by the community. The search for the good life, he claims, can involve rejection of the role within which one finds oneself. He does not, however, explain how our ability to be separate - insofar as we can reject our roles - is to be reconciled with our "social embeddedness".)

The communitarian self is therefore defined by its social ties. Self-identity cannot be abstracted from one's community or social relationships. Whereas a purely autonomy-based philosophy takes the individual to be responsible for devising and questioning life plans, the communitarian perspective maintains that these issues should be dealt with by society at large - the fundamental communitarian question is not what a particular individual happens to prefer, but rather what his or her moral objectives ought to be.<sup>35</sup> Moreover, the communitarian concept of the self is "narrative", i.e., one partly constituted by a life story with a certain end, or *telos*;<sup>36</sup> and "intersubjective".<sup>37</sup>

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<sup>33</sup> MacIntyre 1981, 34.

<sup>34</sup> MacIntyre 1981, 215.

<sup>35</sup> Zwart 1993, 54.

<sup>36</sup> MacIntyre 1981.

Accordingly, the moral agent is not properly viewed in an atomistic, dislocated way, as is associated with liberal theory, but is rather situated in a moral community from which moral identity, substantial moral convictions, and a moral orientation are derived, and which provides the resources by means of which moral problems can be evaluated.<sup>38</sup>

Advance care planning may be based on a purely individualistic ethic only if patients make treatment decisions in a way that is essentially detached from the interests of others - a way that the communitarian view deems impossible. As Nelson and Nelson write,

There is a persistent tendency to regard treatment directives, durable powers of attorney for health care, and living wills as reflecting merely an 'underlying liberal value of neutrality' among conceptions of the good, whereas in fact they are complexly interwoven with a particular and quite substantial set of normative and metaphysical theories: an Enlightenment view of the unencumbered self, a self whose fulfillment rests in the satisfaction of preferences. Alternatively, we might see selves and their fulfillment in terms of constitutive social relationships...<sup>39</sup>

Given such a view, a purely individualistic ethic thus fails as a basis for advance care planning. As Jeffrey Blustein notes,

The patient is not...an atomic entity, a free and rational chooser of ends

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<sup>37</sup> Sandel 1982, chap. 1.

<sup>38</sup> Zwart 1993.

<sup>39</sup> Nelson and Nelson 1994, S20.

unencumbered by communal and other allegiances. On the contrary, his or her identity is constituted by family relationships, and he or she is united with other family members through common ends and mutual understanding. In these circumstances, the patient is too enmeshed in a network of relations to others to be properly singled out as the one to make treatment decisions.<sup>40</sup>

### **Liberalism and the Overemphasis of Autonomy**

The significance of the social embeddedness of the individual for self-identity highlights the fact that the principle of autonomy is one of several important moral values in personal decision making. Autonomy is not a moral absolute nor the sole source of moral guidance and thus may be justifiably overridden in some contexts.<sup>41</sup> Data suggest that "in caring for incapacitated patients, physicians balance respect for [previous] autonomy with other competing ethical principles in order to make what they believe are the wisest decisions" and that, moreover, this "raises the possibility that advance directives may on rare occasions pose an ethical and legal dilemma, because strict adherence to them precludes the opportunity to balance autonomy against other valuable ethical principles."<sup>42</sup> Communitarians have argued that the principle of individual autonomy promotes self-interest at the expense of other important values, particularly those of the community. Others insist that the emphasis on individual autonomy denies

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<sup>40</sup> Blustein 1993.

<sup>41</sup> Childress and Fletcher 1994.

<sup>42</sup> Danis *et al.* 1991, 887.

the importance of the values of paternalistic decision making, social justice, and personal relationships.

Along with the values of community, paternalism and social justice may also conflict with individual autonomous decision making and thus contribute to the reason why a purely individualistic ethic is an insufficient model upon which to base advance care planning. Though the principle of patient autonomy usually takes precedence over conflicting benevolent wishes of caregivers, patient autonomy may be overridden when caregivers' care for patients is based strictly on factors that contribute to their well-being. The principle of beneficence marks the foundation of the Western Hippocratic medical tradition and becomes relevant to advance care planning when the physician's perceptions of the patient's "good" come into conflict with the patient's expressed wishes.<sup>43</sup> For instance, paternalistic action is sometimes taken by caregivers in direct violation of patient autonomy, as when an advance directive specifying that the patient does not want sedatives or pain medications to be administered under any circumstances is not honoured.<sup>44</sup> Also, physicians are not obligated to comply with patient requests for treatment they believe is ill-advised, harmful, or futile<sup>45</sup> - treatment that the patient, when competent, may not have anticipated.

There also exists a potential conflict between principles of autonomy and justice where patients appear to have the right to claim whatever resources they want regardless

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<sup>43</sup> Schneiderman and Arras 1985.

<sup>44</sup> Danis *et al.* 1991; Mower and Baraff 1993.

<sup>45</sup> Danis 1994, S22.

of the impact of their decisions on their families or community.<sup>46</sup> Childress and Fletcher highlight the concern that focusing exclusively on individual autonomy may have a negative effect on community values or what is in the best interests of the community as a whole. For example, relaxing the societal and professional rules against euthanasia may represent a form of respect for patient autonomy. However, the community as a whole may not best be served by such a change - for example, would such a change promote or actually threaten patient autonomy under conditions of serious illness?<sup>47</sup>

John Hardwig defends the role of the patient's family as a matter of justice. He writes,

The requirements of justice and the needs of other patients must temper the claims of autonomous patients...in many cases family members have a greater interest than the patient in which treatment option is exercised. In such cases, the interests of family members often ought to *override* those of the patient...<sup>48</sup> To be part of a family is to be morally required to make decisions on the basis of thinking about what is best for all concerned, not simply what is best for yourself...<sup>49</sup>

Families often bear the effects of patient decision making due to their closeness and

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<sup>46</sup> Childress and Fletcher 1994.

<sup>47</sup> Childress and Fletcher 1994.

<sup>48</sup> Hardwig 1990, 5.

<sup>49</sup> Hardwig 1990, 6.

familiarity with the patient<sup>50</sup> or, as Hardwig puts it, the fundamental "connected interests"<sup>51</sup> of the lives of patients and the lives of those who are close to them. Hardwig defends families' rights to participate in the decision making process, whether or not the patient is inclined to consider such rights. To Hardwig, the interests of family members are not relevant simply because they are relevant to the patient, nor are they relevant because they are part of the patient's interests or values; they are relevant regardless of patient values.<sup>52</sup>

On a broader level, honouring a patient's advance directive could pose a threat to fairness in the allocation of health care resources. Dan Brock argues that advance directives asking for specific treatments may be overridden when a "just level" of care is exceeded and others are being denied resources.<sup>53</sup> Patient choice may also be limited when treatment is too costly, especially given that other health needs are not met,<sup>54</sup> or resources are scarce. Under a universal health care plan like that in Canada, the autonomy of patients who demand services that are not provided under the unified public plan could be restricted.<sup>55</sup> This may mean that patients do not have a legitimate claim

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<sup>50</sup> High 1994.

<sup>51</sup> Hardwig 1990, 5-6.

<sup>52</sup> Hardwig 1990.

<sup>53</sup> Brock 1991.

<sup>54</sup> Danis 1994.

<sup>55</sup> Powers 1992.

to treatment that is being withheld as part of a just rationing system.<sup>56</sup>

It is inappropriate to honour the right of the patient to choose without regard for the general effect of his or her choice on others. Adherence to the overriding value of autonomy runs against a principled way of limiting the medical services that ought to be guaranteed to individuals.<sup>57</sup> Even in Canada where the emphasis on universal access to health care services is based on collectivist principles that call for social responsibility for the basic welfare of its members,<sup>58</sup> a significant dilemma exists since the state both protects individual autonomy by providing for an individual's welfare and threatens it by making allocation dependent on the consent of the plurality.<sup>59</sup>

In a strictly autonomy-based context of decision making that puts patients and physicians in a one-to-one relationship, there may be no incentive for individual physicians to consider the broader impact of decision making.<sup>60</sup> In response to this problem, Norman Daniels proposes a "closed health care system" in which physicians can be the ideal advocate for particular patients and for all patients in general knowing that funds saved in denying care will be applied where needed within the system.<sup>61</sup> However, it is not clear how autonomy and justice are both served when patients'

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<sup>56</sup> Weber 1993.

<sup>57</sup> Emanuel 1993.

<sup>58</sup> Clark 1991.

<sup>59</sup> Weinberg 1988.

<sup>60</sup> Danis and Churchill 1991, 27.

<sup>61</sup> Daniels 1987.

requests for treatment conflict with those of other patients - what counts as a "better use" of services? The dilemma of how to balance individual and social interests is described by Marion Danis and Larry R. Churchill who write,

This devotion to the patient at hand, without a framework for incorporating or arbitrating among other values, seems too narrow. Good done within a narrow sphere of accepted responsibilities must be weighed against those responsibilities not assumed - the good forgone, the patients or population groups left untreated, or what economists call the "opportunity costs". It is ethically short-sighted to assume that other duties do not exist or are insignificant...The lack of an integrated framework has made it difficult to resolve conflicts between individual and societal perspectives at both a theoretical and a practical level. Ethical theory encourages the physician to act as the patient's advocate, to respect individual wishes, and to ignore cost. In practical terms, government agencies, employers, and institutions concerned about the rising cost of those decisions make regulations based largely on cost containment, rather than on patient preference or medical grounds, because there is no moral consensus about just distribution. Moral philosophers who have worried about equitable distribution rather than efficiency alone have not yet articulated how equity can be reconciled with a commitment to respect patient autonomy.<sup>62</sup>

According to Robert Veatch, it is a mistake to posit our commitment to autonomy in tension with our commitment to society. Rather, he describes the individual level at

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<sup>62</sup> Danis and Churchill 1991, 28.

which "our society has opted for an ethic that provides benefits within the constraints of respect for the individual's autonomy" and the social level at which "we need to opt for an ethic [of justice] that maximizes benefits within the constraints of the uniqueness of individuals as equals in their claim on social resources."<sup>63</sup> Autonomy, claims Veatch, is only applicable when the community is limited to an isolated patient exercising his or her will unbound by obligations to others. The point is put simply by Erich Loewy: social justice entails individual rights just as individual rights depend on the prior existence of social justice.<sup>64</sup>

The promotion of autonomy in advance care planning must be understood not as a guarantee that the patient will get whatever he or she wants, but rather as "the responsible use of freedom"<sup>65</sup> according to which the right course of action for the patient is not always one that promotes his or her own interests. This has recently been described as a "socially responsible" approach to advance directives according to which the patient is viewed as both citizen and consumer, and patient self-determination is understood in the context of "informed consent" rather than in the context of "consumer

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<sup>63</sup> Veatch 1984, 39.

<sup>64</sup> Loewy 1991.

<sup>65</sup> Hardwig, 1990. Hardwig's argument is fundamentally one from distributive justice: the effects of patients' decisions on their families entitle their families to a role in the decision-making process; justice demands familial involvement.

sovereignty".<sup>66</sup> A "citizen ethic" according to which the patient is viewed as a citizen with rights within health care along with duties to make judicious and proportionate choices has been proposed by Danis and Churchill.<sup>67</sup>

Advance care planning may be based on a purely individualistic ethic, as that attributed to liberalism, only if those engaged in the process make decisions in an entirely self-regarding way without affecting or being affected by the interests and welfare of others. However, given the importance of the interests of those other than the individual, it seems then that the formulation of acceptable health care policies requires compromises in which the principle of autonomy is important but not always decisive.<sup>68</sup>

James Lindemann Nelson argues that current "individualistic" medical practice neglects the important values of familial intimacy that arise out of personal relationships. He writes,

Both theoretical medical ethics as now most widely understood and medicine's own ethical tradition are ruggedly individualistic: the interests of the individual patient, in splendid isolation from her social context, are to a considerable extent privileged. To be sure, there are powerful reasons for this focus, rooted in our concern about defending the vulnerability and privacy of patients. Yet there is increasing reason to believe that this intensity of focus on patient interests -

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<sup>66</sup> Weber 1994. Patients may be concerned, for example, with the burden of the financial costs of treatment on family or society in general.

<sup>67</sup> Danis and Churchill 1991.

<sup>68</sup> Childress and Fletcher 1994.

considered as the interests of splendidly isolated individuals - reflects a kind of moral obtuseness, and that we would do better to design a system of medical decision making sensitive to a broader range of values.<sup>69</sup>

Intimate (familial) relationships are important, according to Nelson, not only because of their instrumental value in the successful pursuit of individualized conceptions of a good life, but also due to the "fundamentally nonconsequential character of their value."<sup>70</sup>

Families matter, he insists, because they entail relationships of love and loving someone entails a disposition to advance his or her interests beyond what would be consistent with advancing the general good.

Despite evidence that family choices are not always representative of patient wishes,<sup>71</sup> the importance of family has been argued to be at least as important as a "rigid devotion to the goal of patient autonomy".<sup>72</sup> Thomasma and Pellegrino defend the family's role in advance care decision making on the grounds that the family of the patient is "present" in the patient's own value system. They offer the following example:

Suppose the patient has expressed the wish not to prolong his life unduly because "he does not want to be a burden on his family". Not only has this value been formed from years of love and devotion, but it also points to the family as the beneficiary of the decision. Hence the family does have a role in this decision.

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<sup>69</sup> Nelson 1992, 7.

<sup>70</sup> Nelson 1992, 8.

<sup>71</sup> Seckler *et al.* 1991.

<sup>72</sup> Menikoff, Sachs, and Siegler 1992.

The family itself does not express the value. It acquires a presence through the patient's life preferences. Further, as a beneficiary of an expressed wish of the patient, the family can be seen as the object of a value the patient holds...As such, its presence cannot be ignored, especially if the family itself must help the physician interpret the meaning of "burdensomeness".<sup>73</sup>

Relational theorists have argued that an individualistic ethic, with its overemphasis on autonomy, demands the denial of the value of personal relationships which, they claim, are the condition for the very capacity of autonomy. According to these views, an individualistic ethic for those involved in the process of advance care planning is sufficient only insofar as treatment decisions are made by persons who are not only detached from all social or communal interests but from the interests of close ones as well.

The concern for the value of relationship ties is sometimes expressed by those who deny the traditional philosophical conception of autonomy dating back to Immanuel Kant's conception of rational self-rule and associated with "this era of liberal humanism, where 'private', individual choice is thought to be sacrosanct."<sup>74</sup> According to Susan Sherwin, this tradition views autonomy as "the instrument of agency for individuals who are perceived as separate, independent, and 'fully rational'."<sup>75</sup> Sherwin argues that people are not independent and their decision making does not always meet the norms

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<sup>73</sup> Thomasma and Pellegrino 1987, 287.

<sup>74</sup> Sherwin 1992, 203.

<sup>75</sup> Sherwin 1992, 137.

that define rationality:

Ethical models based on the image of ahistorical, self-sufficient, atom-like individuals are simply not credible to most women...most women experience the world as a complex web of interdependent relationships, where responsible caring for others is implicit in their moral lives. The abstract reasoning of morality that centers on the rights of independent agents is inadequate for the moral reality in which they live. Most women find that a different model for ethics is necessary<sup>76</sup>... The concept of autonomy carries too many associations of isolation and independence to capture feminist conceptions of agency.<sup>77</sup>

Echoing communitarian objections to the liberal concept of self, Jennifer Nedelsky rejects what she perceives to be the "liberal incarnation" of autonomy - an incarnation that she claims carries with it the individualism characteristic of Anglo-American liberalism and the American conception of rights as limits. In her words,

The now familiar critique by feminists and communitarians is that liberalism takes atomistic individuals as the basic units of political and legal theory and thus fails to recognize the inherently social nature of human beings...the notion of social context must take seriously its constitutive quality; social context cannot simply mean that individuals will, of course, encounter one another. It means, rather, that there are no human beings in the absence of relations with others. We take

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<sup>76</sup> Sherwin 1992, 47.

<sup>77</sup> Sherwin 1992, 156.

*our being* in part from those relations.<sup>78</sup>

The crucial point here is that not only are humans social insofar as they engage in relationships with others, but that personal identity is to a large extent constituted by one's interactions with others. Nedelsky argues that liberalism, which emphasizes individual autonomy and rights for the protection of individuals from state power, denies the reality of the centrality of relationships in constituting the self and thus implies that individuals exist in isolation from one another.

Nedelsky offers her own view of autonomy reconceived in terms of women's relationships to family, friends, and community. She writes,

If we ask ourselves what actually enables people to be autonomous, the answer is not isolation, but relationships - with parents, teachers, friends, loved ones - that provide the support and guidance necessary for the development and experience of autonomy...relatedness is not, as our tradition teaches, the antithesis of autonomy, but a literal precondition of autonomy, and interdependence a constant component of autonomy.<sup>79</sup>

Nedelsky thus views autonomy as a capacity that exists only in the context of social relations that support it.

Does Nedelsky's view therefore necessitate an abrogation of individual autonomy in the name of the interests of significant others? In response to conventional conflicts between collective goods and individual rights, Nedelsky writes,

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<sup>78</sup> Nedelsky 1989, 8,9. (emphasis added)

<sup>79</sup> Nedelsky 1989.

The autonomy I am talking about does remain an individual value, a value that takes its meaning from the recognition of (and respect for) the inherent individuality of each person. But it takes its meaning no less from the recognition that individuality cannot be conceived of in isolation from the social context in which that individuality comes into being. The value of autonomy will at some level be inseparable from the relations that make it possible; there will thus be a social component built into the meaning of autonomy...But the presence of a social component does not mean that the value cannot be threatened by collective choices; hence the continuing need to identify autonomy as a separate value...<sup>80</sup>

According to Jeffrey Blustein, although the individual is enmeshed in a network of relationships, the argument for family decision making applies only to families that are communities, i.e., whose members are harmonious and have common ends, and not to those that are "just collections of individuals whose lives affect each other in major ways."<sup>81</sup> It therefore fails as a framework for decision making when the patient does not belong to such a community. Individual rights therefore have an important place where community is lacking but, as Blustein argues,

...they are not just claims we fall back on in the unhappy situation where community is lacking or faltering. Additionally, they serve to secure recognition of the diverse values and ends that persist even in intact and well-functioning communities...Individual rights have an important place in community because the

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<sup>80</sup> Nedelsky 1989, 35-36.

<sup>81</sup> Blustein 1993, 9.

existence of community does not eradicate serious disagreement about ends, about the relationship between particular choices and shared ends, and so forth.<sup>82</sup>

This comment addresses a key issue of whether the freedom that is a necessary condition for the authentic expression of the (liberal) individual is compatible with the interdependence that comes with relatedness to other human beings. It has been rightly noted that maintaining a sense of autonomy need not be inconsistent with dependencies on others and that individuality need not entail independence in the strict sense of the term. (Social) dependencies do not conflict with autonomy if, as George Agich argues for example, individuals can still maintain a sufficiently adequate range of identifications to sustain their own sense of integrity and worth.<sup>83</sup>

The strand of feminism considered here does not demand the denial of patients' autonomous decision making. However, given a conception of autonomous choice as that essentially dependent upon the personal relationships within which one is engaged, a purely individualistic patient ethic, as that associated with liberalism, falls short as an adequate model for advance care planning.

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<sup>82</sup> Blustein 1993, 10.

<sup>83</sup> Agich 1990.

## CHAPTER THREE

### **The Liberal Concept of Autonomy**

The concept of autonomy criticized in the bioethics literature as a distinctly liberal moral imperative behind advance care planning requires clarification in order to understand the theoretical concerns and empirical findings that question the centrality of autonomy in advance care planning. Though it is often taken for granted by critics writing in the area of biomedical ethics that autonomy is *the* liberal value, there lacks in this literature an adequate account of what is meant by liberal autonomy.

In the bioethics literature the value of individual autonomy is largely associated with liberal political philosophy. I will compare the references to autonomy in bioethics that relate to the criticisms examined in chapter two with modern liberal conceptions of the term. It is worth noting that there is wide disagreement over the meaning and significance of the concept of individual autonomy within political philosophy and liberal theory in particular. Indeed, most liberals do not refer to "autonomy" at all but rather to what are clearly the related notions of liberty and freedom.<sup>1</sup> The goal in what follows is

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<sup>1</sup> Autonomy is not necessarily the *same* as freedom. John Christman takes these terms to refer to "separate, though complementary, properties of a person's life and action". Autonomy, as he views it, must be more than mere freedom from restraints: "What is primary in an analysis of autonomy is a special property of preference or belief *formation...*" (Christman 1991, 21:2,4).

to establish a general sense of autonomy according to contemporary liberal writers' various conceptions of the term in order to demonstrate whether the liberal concept of autonomy is or is not impoverished in the way critics claim.

It is well known that autonomy is derived literally from the Greek *autos* (self) and *nomos* (law or rule), an etymology that has led to wide usage of approximate synonyms such as "self-determination", "self-government", and "independence".<sup>2</sup> As explained by Gerald Dworkin, the term was first applied to the Greek city state: "A city had *autonomia* when its citizens made their own laws, as opposed to being under the control of some conquering power."<sup>3</sup> As a result of their frequent application to states and institutions, it is plausible, Joel Feinberg suggests, that "the original applications and denials of these notions were to states and that their attribution to individuals is derivative, in which case 'personal autonomy' is a political metaphor."<sup>4</sup> That autonomy is often interpreted in political terms is evident in the writings of contemporary liberal theorists. Liberal conceptions of autonomy and rights-language form the theoretical backdrop not only of much political theory, but also of much moral discourse.<sup>5</sup>

Roughly speaking, liberal conceptions of autonomy reveal an underlying concept understood in terms of self-government, self-determination, or a kind of self-ownership of values, beliefs, desires, and choices; in other words in terms of a life that is not "other-

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<sup>2</sup> Feinberg 1989, 27.

<sup>3</sup> Dworkin 1989, 57.

<sup>4</sup> Feinberg 1989, 28.

<sup>5</sup> Keenan 1990.

governed". Autonomy, therefore, is not mere *choice*, nor the capacity to choose. After all, one's choices may not be one's own - they may be the product of some form of external coercion or influence.

Feinberg identifies the closely related notions of the concept of autonomy that refer either to the capacity to govern oneself, to the actual condition of self-government and its associated virtues,<sup>6</sup> to an ideal of character derived from that conception, or to the sovereign authority (and corresponding right) to govern oneself. These notions, as Feinberg sees it, presuppose personal independence. He writes,

Note that corresponding to these senses of "autonomous" there are parallel senses of the term "independent": The *capacity* to support oneself, direct one's own life, and be finally responsible for one's own decisions; the *de facto condition* of self-sufficiency, which consists in the exercise of the appropriate capacities when the circumstances permit; the ideal of self-sufficiency; and the sense, applied mainly to political states, of *de jure sovereignty* and the right of self-determination.<sup>7</sup>

There is no reason to suppose that the conceptual core upon which these notions rest need be the *actual condition* of autonomy. For example, even if there were no such thing as personal autonomy - no such thing as an actual capacity to be self-governing -

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<sup>6</sup> Feinberg's list of virtues includes self-possession, distinct self-identity or individuality, authenticity in self-selection, self-creation or self-determination, self-legislation, moral authenticity, moral independence, integrity or self-fidelity, self-control or self-discipline, self-reliance, self-generation or initiative, and self-responsibility. Feinberg 1989, 31-43.

<sup>7</sup> Feinberg 1989, 28.

the ideal of virtue derived from the concept may exist in individuals' minds to factor significantly in the motivation behind and resulting structures of particular personal and public relationships. No juggling of the four related meanings of autonomy needs to be performed in order to grasp the overall idea Feinberg conveys that personal autonomy, as self-government, is a character trait of an independent self, whether such governance is potential, actual, or ideal and despite any moral conclusions that it may confer (such as moral rights) vis-à-vis another self or group.

In The Inner Citadel: Essays on Individual Autonomy,<sup>8</sup> John Christman attempts to offer a "sustained and focused treatment" of the modern liberal concept of autonomy. Overall, three liberal interpretations of the core concept of autonomy are identified in terms of rational willing, rank-ordered desires and personal identification, and historical formation.

### **Autonomy and the Rational Will**

The idea of an "independent self" is apparent in Kant's conception of autonomy defined as "the property [the will] has of being able to work independently of alien causes".<sup>9</sup> As Thomas E. Hill, Jr. describes it, this means that a rational (i.e., Kantian) agent is one who makes decisions that are not determined by causes independent of one's deliberation and choice.<sup>10</sup> Moreover, the agent must see himself or herself as acting

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<sup>8</sup> Christman 1989.

<sup>9</sup> Hill, Jr. 1989, 97.

<sup>10</sup> Hill, Jr. 1989, 91-105.

independently, i.e., "whatever the agent's *beliefs* about metaphysical determinism, one must *when deliberating* take the attitude that the choice itself is still 'up to oneself'.<sup>11</sup> For Kant, autonomy is a principal property of rational individuals that determines their ability to derive moral principles; autonomy is the basis of morality in his ethics. Yet this need not lead to the Kantian conclusion, as Hill states, that "in rational deliberation, one must not only take oneself to be able to choose and act without the choice having been causally determined by desire (or anything else), one must also take oneself to be able to act for the sake of ends other than the satisfaction of desire... In rational deliberation one cannot assume that what one will or must do is among those things for which one feels an antecedent desire".<sup>12</sup> To deny the Kantian conclusion is to deny that autonomy is a function, strictly speaking, of rational, impartial, and independent agents (despite Kant's insistence that autonomy is a property of the wills of virtually all human beings).

Though, according to Kant, desire cannot serve as a sufficient basis for purely autonomous choice regarding the moral law, it is not clear why individual desire, intuition, and the like do not factor in autonomous decisions (providing they are not the result of external manipulation). It may be easier to conceive of a process of rational deliberation as entailing, at least to a certain degree, autonomous behaviour. Desire, intuition, and the like seem more spontaneous since a personal deliberative process, if one exists at all, is often not evident. The most that can be said then is that we have no

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<sup>11</sup> Hill, Jr. 1989, 97.

<sup>12</sup> Hill, Jr. 1989, 98.

convincing explanation of how such behaviour can be autonomous, not that it is necessarily non-autonomous. Granted the possibility that a desire or other "non-rational" motivation for behaviour is not externally caused, then there are no grounds for assuming that it is non-autonomous since autonomy need not have to do with sufficient *reasons* for acting as much as it has to do with whether such actions are internally or externally caused.

Although, according to Hill, Kant's "most tortured effort [is to] avoid *assuming* that morality is necessarily rational and to give independent considerations for the belief that all reasons are not based on desires",<sup>13</sup> this does not exclude the possibility that desire-motivated action without apparent rational grounding may be compatible with personal autonomy. After all, as Gary Watson suggests, "Appetitively [as opposed to rationally] motivated activities may well constitute for a person the most worthwhile aspects of his life".<sup>14</sup> Susan Wolf's argument that autonomy (and responsibility) depends on an external condition of rationality, which includes the ability to know what one is doing, the ability to know that what one is doing is right or wrong, and having an accurate moral view, is thus problematic. Those we call "irrational" might know what they are doing in terms of consequences and those we call "rational" may not know right from wrong - sometimes the distinction is blurred. Furthermore, Wolf does not define an "accurate moral view".

In sum, autonomy may not depend on the existence of a rational, essentially

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<sup>13</sup> Hill, Jr. 1989, 104.

<sup>14</sup> Dworkin 1989, 115.

independent self. The autonomous individual may act on the basis of reasons and/or desires. But it may still be claimed that desire-motivated action is carried out by a "self" that must achieve independent ownership of its desires in order for such desires to be autonomous. This claim is further explored below.

### **Autonomy, Rank-Ordered Desires, and Personal Identification**

A second significant strand in liberal thought characterizes autonomy in terms of rank-ordered desires (or wants) and personal identification. Here, desires are a basis for autonomous action - the sort of action defined in individualistic and independent terms. Harry G. Frankfurt describes the free (autonomous) person as one who has second-order "volitions" to have her first-order desires move her to action.<sup>15</sup> Being free or autonomous on this account means not only being in a position to do what one wants, but also being able "to want what one wants". He writes,

Besides wanting and choosing and being moved *to do* this or that, men may also want to have (or not to have) certain desires and motives. They are capable of wanting to be different, in their preferences and purposes, from what they are. Many animals appear to have the capacity for what I shall call 'first-order desires'..., which are simply desires to do or not to do one thing or another. No animal other than man, however, appears to have the capacity for reflective self-evaluation that is manifested in the formation of second-order desires.<sup>16</sup>

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<sup>15</sup> Frankfurt 1989, 63-76.

<sup>16</sup> Frankfurt 1989, 64.

The notion of the will, for Frankfurt, is the notion of an "effective desire", or one that moves a person all the way to action. Furthermore, it is only in virtue of one's rational capacities that a person is capable of forming second-order volitions, i.e., "The structure of a person's will presupposes, accordingly, that he is a rational being."<sup>17</sup> Freedom of action, or the ability to translate first-order desires into actions - in other words to do what one wants - is not the same as freedom of the will which concerns the desires themselves, according to Frankfurt. One may be free to act on one's desires but those desires may be subject to manipulation. To be a free person in the full sense, one must also be able to *identify* with their first-order desires, i.e., they must be one's *own* desires. To have both freedom of action and freedom of will a person must be capable of governing her actions according to her first-order desires, and be capable of governing her first-order desires by her second-order desires.

Gerald Dworkin's "full formula for autonomy" also builds on the distinction between higher and lower desires and includes what he calls "authenticity" of lower-order desires with which one identifies, plus "procedural independence". He writes,

A person is autonomous if he identifies with his desires, goals, and values, and such identification is not itself influenced in ways which make the process of identification in some way alien to the individual. Spelling out the conditions of procedural independence involves distinguishing those ways of influencing people's reflective and critical faculties which subvert them from those which

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<sup>17</sup> Frankfurt 1989, 68.

promote and improve them.<sup>18</sup>

Unlike freedom which defines an act at a given time, autonomy for Dworkin can be assessed only over extended portions of a person's life. The reason for this lies in his claim that autonomy is defined as the higher-order approval of one's lower-order motivations. In other words, one must have a self-conception at a higher level than the level of one's immediate preferences.<sup>19</sup> Dworkin leaves open the question of whether such approval must be based on rational critical reflection.

Several critics have pointed out the problematic aspects of the above conceptions of autonomy. They claim, particularly in response to Frankfurt, that autonomy must entail more than merely having a higher-order desire that one has a lower-order desire; in addition, one's higher-order desires must be one's own. In other words, *identification* must occur at a higher level than that of lower-order desires. After all, it is possible that one can identify with lower-order desires but still be manipulated, for example, when secretly given an addicting drug.

Watson claims that according to Frankfurt's account, higher-order disapproval of a lower-order desire would amount to nothing more than a conflict of wants at both levels. What is needed, he argues, is an account of what relates one's volitions to "oneself" - how our volitions are our "own". In other words, a more detailed account of identification is needed to explain autonomous wants. For Watson, the motivational system of an individual (i.e., that set of considerations which move her to action) must

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<sup>18</sup> Dworkin 1989, 61.

<sup>19</sup> Hardin 1988.

coincide with her valuational system (i.e., judgments of what she ought to do given the circumstances): to be free one must be able to "get what one most wants" or "values".<sup>20</sup> Thus, unlike Frankfurt, Watson holds that the difference between free and unfree action is not grounded in the logical relative ordering of the desires from which these actions arise, but rather must relate to a difference in the quality of their source. Insofar as one's actions are governed by desires which are, in turn, governed by one's values or "valuational system", they are free actions. In short, Watson claims, "one cannot dissociate oneself from all normative judgments without forfeiting all standpoints and therewith one's identity as an agent."<sup>21</sup>

Along the same lines as Watson, Susan Wolf and Irving Thalberg argue that a person's higher-order desires should be consistent with her lower-order desires. She may approve and identify with her lower-order desires. According to these models, such a person is autonomous. However, as Wolf and Thalberg suppose, she may be a coerced or manipulated person whose choice of lifestyle and whose values are not ultimately her own (she may be brainwashed by a patriarchal society, for instance). In agreement with Watson, their criticisms highlight the need for an account of what relates one's volitions to "oneself", or an account of identification. Furthermore, they insist on an account of what relates the *values* that govern one's desires to oneself. In other words, what is needed is an account which allows the individual to assess whether or not her values are her own. As Thalberg notes, one cannot readily assume that our moral principles or

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<sup>20</sup> Watson 1989, 110.

<sup>21</sup> Watson 1989, 117.

values specify what we most want.<sup>22</sup>

Thalberg objects to the idea, which he attributes to Frankfurt and Dworkin, that "when you ascend to the second level, you discover the real person and what she or he really wants."<sup>23</sup> His own nonhierarchical account aims at an explanation of such wants. This raises the question of the standards appropriate for assessing whether a person's desires are ultimately hers to identify with and this brings us back to the notion of rationality or objective reasonableness - must an agent be rational to be autonomous as Susan Wolf argues? Or does the very idea of an objective or "external" condition of rationality to the requirements for autonomy conflict with the concept of self-government that autonomy is intended to express, as Christman suggests<sup>24</sup>?

Despite the differences between them, liberals who interpret the concept of autonomy in terms of rank-ordered desires and personal identification express a common concern for what might be called "desire-ownership" or the idea that one's desires, whether first-order, second-order, etc., must be one's own and not influenced or manipulated by external or "alien" causes. An account of identification with one's desires is called for by these writers in order to explain how one's desires, volitions, and/or values, relate to "oneself". Such an account does not presuppose a self that is *essentially independent* in an existential sense but it does presuppose a self that is the independent "owner" of desires that lead to action. Autonomy is thus regarded as a

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<sup>22</sup> Thalberg 1989, 134.

<sup>23</sup> Thalberg 1989, 130.

<sup>24</sup> Christman 1989.

property of desire-ownership that depends on the relationship between an individual and his or her preferences.

### **The Historical Conception of Autonomy**

Writing as a liberal, Christman maintains that the core concept of autonomy, or "political freedom", is intimately connected with the notion that desires and values are a genuine expression of self-governance. His own interpretation of the core concept of autonomy, however, focuses on how those desires and values came about. Autonomy, for Christman, is an essentially historical conception in that the conditions that must be met in order for desires to be autonomous are properties of the *formation* of, and not mere identification with, those desires.<sup>25</sup> He writes,

...we all know that no person is self-made in the sense of being a fully formed and intact "will" blossoming out of nowhere. Our values and preferences are explained by essential reference to a variety of influences that have come to bear on our development throughout our personal histories.<sup>26</sup>

He further adds that,

The key element of autonomy is, in my view, the agent's acceptance or rejection of the process of desire formation or the factors that give rise to that formation, *rather than the agent's identification with the desire itself.*<sup>27</sup>

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<sup>25</sup> Christman 1989, 9.

<sup>26</sup> Christman 1991, 1.

<sup>27</sup> Christman 1991, 2. (emphasis added)

Christman finds three main defects with Dworkin's "full formula for autonomy" that surround the condition of identification, the question of preference formation, and what Christman labels the "incompleteness problem". Both readings of the identification condition - either that identification is the simple acknowledgement of one's desires or that it also includes an evaluation of the having of one's desires - are problematic to Christman. On the first reading, identification with desires that are nevertheless the result of heteronomous processes appears to conflict with an intuitive sense of autonomy. This first reading is questionable given Dworkin's "procedural independence" as a stipulation of autonomous processes of identification. On the second reading, it would be conceptually impossible to have an autonomous desire of which one would not approve (suggesting that one's desires are always the right ones to have), not to mention the problem of how our (higher order) approvals or disapprovals are justified without leading to an infinite regress of higher and higher level justifications.

According to Christman, then, identification *per se* is not necessary but the problems it poses lead to the more relevant question of whether one's desires developed according to one's will. To avoid the infinite regress problem, our higher order desire(s) must be autonomous in a way that our lower order desire(s) are not. The lack of an account of how this is so is referred to by Christman as the "incompleteness problem". To be complete, such an account must include more than the information an agent has at a particular given time by which to evaluate her desires (she could unknowingly be "hypnotized to want strawberries" or have drug-induced desires). That is, the determination of autonomy, writes Christman, cannot occur simply by *structural* analysis

according to which a person's desires are determined to be autonomous, nor by taking a "time slice" of the person and asking her for an evaluation:

The problem here, I think, is just this "time slice" approach. What is suggested by the criticisms we have discussed...is that what is crucial in the determination of the autonomy of a desire is the manner in which the desire was *formed* - the conditions and factors that were relevant during the (perhaps lengthy) process of coming to have the value or desire. And these conditions may have little to do with how the agent evaluates the desire itself (*qua* desire).<sup>28</sup>

To determine whether an agent is autonomous, therefore, it is not necessary to determine what her evaluation of her desire is at a particular time. What matters, argues Christman, is that the agent considers the process of coming to have the desire. The conditions of autonomy must, then, "set out the conditions that determine the agent's 'participation' in this process of preference formation...[and] must attempt to capture this requirement: that the agent was in a position to resist the development of a desire and she did not."<sup>29</sup> This would appear analogous, and not contrary, to Dworkin's criterion of "procedural independence" which accompanies the criterion of authentic identification. Dworkin writes,

The condition [of identification]...cannot be the whole story of autonomy. For the second-order identifications a person makes, or the choice of the type of person he wants to be, may have itself been influenced by others in such a fashion that we

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<sup>28</sup> Christman 1991, 9-10.

<sup>29</sup> Christman 1991, 10-11.

do not view it as being his own. In this case his motivational structure is his, but not his own. I...call this a failure of procedural independence.<sup>30</sup>

Not entirely unlike Dworkin, then, Christman argues that a person is autonomous when in the position to be aware of the changes and development of her character and of why these changes come about. But he adds two further conditions of autonomy: that this awareness must enable her to resist or accept such changes (i) in a minimally rational manner and (ii) in a non-self-deceived manner. That is, she must be free of any influencing factors that would otherwise hinder such self-awareness. Preference changes must be the result, then, of deliberations "that do not involve inconsistencies, and, by implication, mistakes in logical inference;"<sup>31</sup> the explanation of a new desire must be "one which the agent is capable of considering and which is not patently inconsistent with some verifiably true description at another (deeper) level."<sup>32</sup> Although Christman insists that, in his account, the threat of regress is avoided since another level of desire is not appealed to to explain one's desire in question, these conditions raise the question of how "inconsistencies" or "mistakes in logical inference" are identified and defined. If rationality and adequate self-reflection are the two conditions necessary for autonomy then what are the criteria for these conditions?

In keeping with the core concept of autonomy as *self-government*, Christman argues for minimal internal conditions for rationality, such as consistency of beliefs and

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<sup>30</sup> Dworkin 1989, 61.

<sup>31</sup> Christman 1991, 12.

<sup>32</sup> Christman 1991, 13.

desires, as opposed to basing rationality on objective standards. The key requirement, he insists, is that the autonomous person not be guided by "manifestly inconsistent" desires or beliefs. Christman captures an important, perhaps intuitive, sense of the meaning of autonomy; namely, that

One is autonomous if one comes to have one's desires *and* beliefs in a manner which one accepts. If one desires a state of affairs by virtue of a belief which is not only false but is the result of distorted information given to one by some conniving manipulator, one is not autonomous just in case one views such conditions of belief formation as unacceptable...[one does not lack] autonomy *simply* because one's beliefs are false.<sup>33</sup>

Autonomy, for Christman, requires self-awareness or a lack of self-deception. Self-awareness demands that the agent realize when her beliefs are not manifestly inconsistent or irrational. When a person becomes incapable of making consistent and reflective judgments about her own set of desires by which she is moved to action - for instance when she suffers from certain kinds of psychopathologies - she is no longer autonomous.

What matters for autonomy, as Christman points out, is that the agent is not moved by desires whose genesis is outside of her control. How one comes to have desires and beliefs is in large part not self-determined but "whether I continue to act on them and fail to revise them", says Christman, "*is up to me.*"<sup>34</sup> It is therefore not the content of the preference itself that determines its autonomy. What Christman wants to

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<sup>33</sup> Christman 1991, 16.

<sup>34</sup> Christman 1991, 21.

see preserved and promoted in terms of individuals' autonomy is their ability to reflect on the manner they develop as persons and on the social and cultural conditions that shape that development through their life history.

### **Is the Liberal Concept of Autonomy Impoverished?**

Those who argue that an ethic of patient autonomy conceived in *purely* individualistic terms unrealistically portrays persons as fundamentally disconnected and isolated from others are not wrong. It is often *assumed*, however, that a liberal-based medical ethic is purely individualistic and suggests thus that patients make treatment decisions on a self-regarding basis and are essentially alone and isolated.<sup>35</sup> As explained above, theoretical objections that suggest liberal conceptions of autonomy are impoverished are based on the argument for a kind of situated self, or the demand for an explanation of persons that situates them within the broader community or society. Yet liberal interpretations do not demand an understanding of the self that denies its situation within a social or cultural context.

Christman describes the (liberal) self as "atomistic" and "independent" in that "the fulcrum of the determination of autonomy remains the point of view of the agent."<sup>36</sup> However, this is not to suggest, claims Christman, that the individual is able to dislocate herself from her social and historical context. Christman does not presuppose the "independent self" as one able to stand outside history in self-judgment. We are,

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<sup>35</sup> Hardwig 1990.

<sup>36</sup> Christman 1991, 24.

Christman agrees, able to judge ourselves only in the light of our social and cultural history and the manner in which it affects and shapes on our development as persons.

Although individuals may be atomistic and independent in the way that Christman describes, they are not atomistic and independent in the sense of being fundamentally or ultimately detached from others and their essential community, social and cultural ties. Critics who argue that the autonomy of liberalism is excessively abstract and centred solely on individual self-interests do not have a solid appreciation of liberal interpretations of this concept. Nothing in the writings of modern liberalism suggests that the individual is essentially independent in terms of being existentially isolated from all other human beings nor that no values other than those of the individual matter.

The "significant truth about ourselves," as Feinberg stresses, is that we are social animals. He writes,

No individual person selects "autonomously" his own genetic inheritance or early upbringing. No individual person selects his country, his language, his social community and traditions. No individual person invents afresh his tools, his technology, his public institutions and procedures. And yet to *be* a human being is to be a part of a community, to speak a language, to take one's place in an already functioning group way of life. We come into awareness of ourselves as part of ongoing social processes. Their fruits and instruments, precedents and records, wisdom and follies accumulate through the centuries and leave indelible marks on all the individuals who are a part of them. And all individuals *are* a part of these

social histories. We can no more select our historical epoch than we can select the country of our birth and our native tongue.

How do these truisms affect our thinking about personal autonomy? Very clearly they place *limits* on what the constituent virtues of autonomy can be. The human world does not and cannot consist of millions of separate sovereign "islands" each exercising his own autonomous choice about what, where, how, and when he shall be, each capable of surviving and flourishing, if he so chooses, in total independence of all the others, each free of any *need* for the others...It is impossible to think of human beings except as part of ongoing communities, defined by reciprocal bonds of obligation, common traditions, and institutions. Any conception of ideal human virtue must be consistent with this presupposition. What liberals have always rightly deplored has been the effects on individual character of social manipulation, the condition in which individuality is swallowed up by the collective mass, and persons are interchangeable parts in a great organic machine.<sup>37</sup>

Put simply by Blustein, thinking in liberal terms of autonomous choice does not demand a view of the individual as "atomistic, egoistic, and asocial" as critics claim:

It rests rather on a picture of the person as a separate being, with a distinctive personal point of view and an interest in being able securely to pursue his or her own conception of the good. This by itself entails neither that one's relationships to others are intrinsic to one's identity nor that one is only accidentally and

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<sup>37</sup> Feinberg 1989, 46-47.

externally related to others.<sup>38</sup>

To state, as communitarians do, that self-identity is defined *strictly* in terms of community ties is inadequate. It is important to note Marilyn Friedman's point that the project of self-definition cannot arise solely from communities in which we merely discover our immersion. It is communities that are *chosen* that help to define the individual: "The modern self may seek new communities whose norms and relationships stimulate and develop her identity and self-understanding more adequately than her unchosen community of origin, her original community of place."<sup>39</sup>

Friedman is correct in stating that our "communities of origin" do not necessarily constitute us as selves who agree or comply with the norms which unify those communities. We may not identify with the communities within which we find ourselves. For example, the feminist challenge to sex/gender arrangements upon which communities rest is an incentive to seek and choose new community norms and relationships. Communitarian thought must be developed beyond "its complacent regard for the communities in which we once found ourselves toward (and beyond) an awareness of the crucial importance of dislocated communities, communities of choice."<sup>40</sup>

Liberals recognize the extent to which communities can stifle individual autonomy. As noted by Sagoff, they reject "group essentialism" or the idea that one's membership in an ascriptive group is so central to one's identity that to distance oneself

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<sup>38</sup> Blustein 1993, 10-11.

<sup>39</sup> Friedman 1989, 289.

<sup>40</sup> Friedman 1989, 290.

from it or to impugn its norms and expectations is to be guilty of inauthenticity or treason. Individuals often belong to more than one group and should be free to work to change group norms they cannot accept.<sup>41</sup>

The liberal self is not therefore a sort of disembodied, or unencumbered being defined prior to its ends. This is a misinterpretation of the modern liberal notion of selfhood. Liberal conceptions of autonomy are therefore not impoverished in the way critics describe. As Will Kymlicka notes, what is central to the liberal view is not that we perceive ourselves to be prior to our ends but that we are understood prior to our ends in the sense that no end or goal is exempt from possible re-examination.<sup>42</sup> The liberal claim that we have an ability to detach ourselves from any particular social context does not mean that we can place ourselves in a situation in which there is no given communal practice. It means rather that nothing is "set in stone" for us; nothing is authoritative before our judgment of its value. We are never perceived as selves totally unencumbered by any ends - there are always some given ends - but there are no particular ends which must always be taken as given with the self. Moreover, not only can we question our values but we can even go further to reject them entirely, such as when we come to view them as worthless or degrading. Otherwise, argue liberals, we would ultimately be trapped by our attachments and thus never truly capable of questioning whether a given aim is worth pursuing or not. Consequently, the liberal notion of autonomy suggests that the self, though constituted by its ends, must therefore

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<sup>41</sup> Sagoff 1994.

<sup>42</sup> Kymlicka 1989.

play an important role in the construction of its own identity.

Contemporary liberal writings do *not* therefore indicate a necessary connection between 1) our independence in terms of having self-ownership of our own beliefs and values, identifying with our beliefs and values as being our own, and actively participating in the formation of our beliefs and values, and 2) our independence in terms of being selves that are essentially isolated and disconnected from each other and all historical context. Nevertheless, examination of modern liberal theory reveals that this connection is a spurious one which is unrepresentative of contemporary liberal thinking. The shared feature of the various liberal interpretations considered above reflects a concept of autonomy that refers to a self that is self-governed, free to act without external manipulation and coercion, and one whose desires, preferences, and values are identified as its own with an approval not only of its desires *per se*, but also of the manner by which its desires came about. This presupposes that the desires of free or autonomous individuals are subject to critical reflection, analysis and revision whether through some kind of higher-order desiring or through a kind of evaluative or rational judgment process.

Wolf is correct in stating that "We human beings...have the ability to step back from ourselves and decide whether we are the selves we want to be"<sup>43</sup> and because of this ability, she writes,

...although we may not be *metaphysically* responsible for ourselves - for, after all, we did not create ourselves from nothing - we are *morally* responsible for

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<sup>43</sup> Wolf 1989, 139-140.

ourselves, for we are able to understand and appreciate right and wrong, and to change our characters and our actions accordingly.<sup>44</sup>

Modern liberals do not suggest that we created our *moral* selves from nothing. To philosophers, this opens up a Pandora's box of issues around freedom and responsibility; these are issues not to be explored here. The point is that a notion of moral responsibility need not necessitate a purely independent self, and thereby a conception of personal autonomy based on purely independent selfhood, in the sense of a self conceived as essentially isolated and disconnected from all others and all historical context. The modern liberal ideal of the autonomous person is thus not impoverished as claimed and is accurately described as "that of an authentic individual whose self-determination is as complete as is consistent with the requirement that he is, of course, a member of a community".<sup>45</sup>

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<sup>44</sup> Wolf 1989, 147. (emphasis added)

<sup>45</sup> Feinberg 1989, 47.

## CHAPTER FOUR

### **Autonomy and Advance Care Planning**

In the context of advance care planning, Rebecca Dresser suggests that individual autonomy should not necessarily be the primary value underlying treatment decisions.

She writes,

Philosophers and others favoring the advance directive approach have contended that since autonomy is (and ought to be) assigned a high priority by most members of this society, it should carry the most weight in resolving decisions on medical treatment...[but] data suggest that the exercise of precedent autonomy might not be very important to most of the public. At least, not so important that they are willing to take the time and trouble to learn about directives and to complete a written directive...The key question is whether the minimal use of directives is attributable to technical and other unnecessary barriers now keeping people from doing what they would prefer to do, or to a more basic problem with directives, which is that directives do not "fit" the concerns and needs of real people.<sup>1</sup>

Such an empirical question is worth considering since, according to D.M. High, ...[it] may help to inform our theoretical and conceptual understandings of who we are as social beings and the values we exercise within the interdependencies that constitute primary units. Empirical data...could add further credibility to those

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<sup>1</sup> Dresser 1994, S3.

arguments that autonomy is a relational concept and that self-determinative decisions are at least social in nature. We may begin to realize that persons are neither atomistic creatures nor are their decisions merely individualistic, self-centred determinations.<sup>2</sup>

I have argued that the liberal notion of autonomy is not an impoverished one that suggests persons are atomistic, individualistic or self-centred in the way critics describe. The liberal notion of autonomy may still be challenged, however, insofar as its (over)emphasis entails the denial of other important values, particularly those of personal relationships, paternalistic decision making on behalf of patients, and social justice, that do not stem from expressed individual interests but rather are social in nature. What remains unanswered, then, is the question of the extent to which the principle of autonomy serves as a sufficient value upon which advance care planning may be based.

The claim that liberal autonomy is overemphasized at the expense of other important values may be dealt with from two perspectives. The first is that of the patient or person engaged in advance care planning: Does the principle of autonomy account for the concerns people have who engage in the advance care planning process? Is it the primary value underlying the goals and motivations that people who complete advance directives have for completing them? The second is that of the patient's loved ones and health care providers who assist in advance care planning and/or who act as substitute decision-makers after the patient has become incapable of his or her own decision making: Is autonomy the primary justification for honouring an advance directive? That

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<sup>2</sup> High 1994, S17.

is, should it be granted priority by those other than the patient who participate in decisions about end-of-life care? Must designated substitute decision-makers grant its authority under *all* circumstances? Given the theoretical objections to autonomy as a basis for advance directives considered above and the empirical facts about the role of autonomy in the advance care planning process to be considered below, it becomes clear that although the value of autonomy has an important and indeed necessary role to play in advance care planning, it is not sufficient by itself since other important values should and do sometimes accompany or override it in the process.

### **From the Perspective of the Patient: Empirical Data and a "New Model" of Advance Care Planning**

From the perspective of the patient, it becomes clear that advance care planning is a process in which the value of personal relationships accompanies or sometimes surpasses that of individual autonomy. Most subjects consult with a family member or close friend about preferences for treatment during a critical illness<sup>3</sup>. Two empirical studies conducted at the University of Toronto show that persons who participate in advance care planning consult with a family member or close friend about preferences for future treatment and that loved one's attitudes affect patients' own end-of-life decisions. Both suggest a new model of advance care planning. The so-called traditional model emphasizes individual autonomy, preparation for incapacity, written advance directive forms, and the patient-doctor relationship. In contrast, the new model emphasizes

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<sup>3</sup> Elpern, Yellen, and Burton 1993.

autonomy *and* personal relationships, preparation for death, the social and communicative aspects of advance care planning, and the patient's relationships with loved ones. The facts revealed by the ongoing studies suggest that, at least from the perspective of those engaged in advance care planning, the so-called traditional model of advance care planning, as one based in part on the principle of individual autonomy, is flawed.<sup>4</sup>

### *Study I Purpose*

A specific objective of the first ongoing study is to examine the acceptability of generic versus dialysis-specific advance directive forms. The study was designed to explore the phenomenon of advance care planning from the perspective of people on dialysis. In doing so, this study challenges the adequacy of the traditional model in the light of the actual experiences and attitudes of those who undertake advance care planning. Verbatim quotes that reflect the attitudes of patients toward advance care planning and, specifically, the role of autonomy within the process (rather than attitudes toward disease-specific forms) are my primary concern.

### *Study I Methods*

The qualitative study used semi-structured interviews among a volunteer sample of 48 patients receiving hemodialysis who had been exposed to an educational intervention regarding advance directives.

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<sup>4</sup> I am indebted to Douglas K. Martin for his original scholarship surrounding these studies.

### *Study I Results*

To date, the study has revealed that the overall goal of advance care planning was preparation for incapacity and/or death. Control of their own treatment decisions *and* relieving loved ones of the decision-making burden were identified by patients as the specific goals of advance care planning. Several participants hoped to achieve both of these specific goals. First, participants said that completing an advance directive would enable them to control their own treatment decisions (which tended toward limiting treatment to avoid prolonged suffering) should they become incapable. Verbatim quotes from two participants include the following:

The important thing to me is that I've seen many patients die here, and, you know, it's depressing...I've seen their condition and I don't want to be kept alive in this condition, you know, when I say kept alive it's like without hooked up to dialysis...so for that reason I wanted to be protected from that...protected from being in that situation. You know, where I'm lying there and everybody's trying to hook me up to everything and I can't say no to it and I can't explain to them what I want. So if this is done, then they'll know this is what I want.

and,

My understanding is that an individual should be able to...give directions about future medical treatment in the event that that individual becomes *non compos mentis* and names proxies or surrogates who will make decisions for the individual in the event that that individual is no longer able to make them.<sup>5</sup>

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<sup>5</sup> Singer *et al.* (manuscript submitted for review)

Persons planning their end-of-life care generally want to participate in decision making about matters that potentially affect them; they do not want health care providers, the hospital institution, or government authority to override their wishes. Thus, the liberal principle of autonomy is clearly an important value underlying advance care planning.

However, as also revealed in the empirical findings, other values also figure in the process. Control, though an important goal, was not always sought for its own sake. Concern with relieving others (namely, loved ones) of the burden of difficult substitute decision making about end-of-life care was cited as a second goal of advance care planning. As one participant stated,

I think it takes a lot of pressure off the family to decide; at that moment it's very hard, and to put them through...they're going through enough, and if they know the wishes of the person who is sick, then they should follow through and just do what they want, because they're the one that's going through it.

It gives them the right to take you off the treatment and also the decision is not up to my brother or my mother or my, you know, any relative...if a family member has to do it then it has to affect them mentally and emotionally...It would affect me emotionally. Did I do the right thing? It would just be a lot of extra pressure and personal torment.<sup>6</sup>

Advance directives were described as a means for providing information needed to help relieve the decision-making burden on loved ones who would be acting as substitute decision-makers. Also, by expressing treatment preferences for times of future

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<sup>6</sup> Singer *et al.* (manuscript submitted for review)

incompetency, whether through discussion or written advance directive forms, participants sought to mitigate the burden of care others would be forced to provide and the burden of having to be part of an unnecessarily prolonged dying process.

According to the study, the "traditional model" of advance care planning is based on the value of autonomy and entails the theoretical presumption that those engaged in the process are unconnected, unencumbered individuals motivated in a way detached from the interests of others. Yet most of the participants in the study involved others in their advance care planning process, with involvement of close loved ones, rather than health care providers, being of key importance. The choice of whom to involve in the planning process was determined by emotional closeness or intimacy and most often included spouses, children or parents and, for those without their own families, siblings or close friends.

Moreover, the disposition of the loved ones, as revealed by their reaction during the planning discussion, influenced the participants' own decisions. For example, one participant reported that,

Every time I spoke with my mom about it she said, 'Well, I don't think you need one of those, it's only for people that are really dying. It's just your kidneys don't function properly. You don't need to fill one of those out.' She avoided the subject most of the time. Even though I tried hard to make her understand why I want to have one, she just avoided the subject...He (dad) is the same.<sup>7</sup>

This participant did not overcome her family's resistance to advance care planning. In

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<sup>7</sup> Singer *et al.* (manuscript submitted for review)

contrast, with the emotional support and encouragement of those close to them, participants were more likely to proceed with advance care planning.

Along with its emphasis on the value of individual autonomy, the so-called traditional model of advance care planning is described in the study as one emphasizing written advance directive forms as opposed to verbally expressed instructions. Yet data reveal that advance directive forms are embedded within the social process of advance care planning and need not be the central or defining feature of the process. The advance care planning process follows a chronology, beginning informally, through personal and family experiences, sometimes years before the more explicit formal process of discussions or consideration of advance directive forms. Those individuals able to proceed with advance care planning often feel satisfied that they have achieved their advance care planning goals because they have gone through the process of preparing their proxies for substitute decision making, with or without the completion of written advance directives.

According to the study, the "traditional model" of advance care planning also emphasizes physician-patient relationships. Such an emphasis, however, fails to provide insight regarding the key importance of loved ones in the process of advance care planning. The data show that health care providers are not centrally involved. Participants said they prefer to involve loved ones in discussions about future care. There are two primary reasons for this. First, individuals consider their advance care planning to be a "private" matter, only to be discussed with intimate loved ones. Second, it is loved ones who will bear the burden of emotional torment and the burden of

substitute decision making should individuals become incompetent. Quotes from three participants include the following:

Q: Would you have the same discussions with your doctor or have you?

R: No...I don't think so...He's only a doctor. He's not a relative.<sup>8</sup>

and,

Q: Did you discuss it with your dialysis doctor as well?

R: No. No. That is something which I feel is a very private matter. I don't want to have too many people involved in that.<sup>9</sup>

and,

Q: Did you show it or talk to your dialysis nurses or doctor?

R: No...Well, what business is that of them? They can't help me. It's my business. And if it is so far that it has to be handled, my son will tell the nurses or the doctor what's going on.<sup>10</sup>

The authors concluded that the appropriate role of health care providers was initiating advance care planning discussions, directing patients to appropriate resources, providing pertinent information about health states and treatments, addressing any information needs that arise, reviewing the results of the process, including completed AD forms, to ensure the patient has understood the relevant information, and being involved in the outcome of advance care planning as substitute decision-makers after the patient becomes incapable.

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<sup>8</sup> Singer *et al.* (manuscript submitted for review)

<sup>9</sup> Singer *et al.* (manuscript submitted for review)

<sup>10</sup> Singer *et al.* (manuscript submitted for review)

### *Study II Purpose*

A specific goal of the second study is to examine participants' preferences for either a generic or HIV specific advance directive form. This study was designed to build on the findings of the first study by examining in further detail the factors of motivation and communication in advance care planning. Overall, this study, like the first, challenges the adequacy of the traditional model in the light of the actual experiences and attitudes of those who undertake advance care planning. Again, verbatim quotes that reflect the attitudes of patients toward advance care planning and, specifically, the role of autonomy within the process (rather than attitudes toward disease-specific forms) are my primary concern.

### *Study II Methods*

The qualitative study used semi-structured interviews among a volunteer sample of 140 patients with HIV who had been exposed to an educational intervention regarding advance directives.

### *Study II Results*

According to the participants in this study, as in the first, the main purpose for partaking in advance care planning was to be prepared, or to prepare others, for facing the circumstances of illness and death. Advance care planning was also regarded as a means of taking control of own's own health care. For example, one participant said that,

I think it's very important that I should do this because I want a say over what happens to me if I'm not able to make those decisions. Because I don't want other people making decisions for me. I should make my own decisions.<sup>11</sup>

The impetus for preparation in the form of advance care planning began, for many participants, in their experiences with illness or death (their own or that of another). By leading them to look into their own potential future, these experiences generated fear in many participants; this fear resulted in their desire for control in future care to prevent the deterioration and suffering they saw in others. As one participant stated,

I've had a few friends that have gone through what seemed to be a really painful way to leave this planet. And I think the main focus for me was: I have two children and I really wouldn't want them to go through it...I'd rather have them remember the good side and not that. For me, it was just an awful memory. It's like, I almost forgot about what the real person was like after visiting them for six months of their deterioration process. So, I figured out for me that, if there was some way around that, and then this Living Will thing came into play, where I thought maybe that could benefit, and possibly prevent some of this stuff, you know.<sup>12</sup>

The nature of the participant's relationships, with either with a partner, lover, spouse, or relative, also motivated many participants to pursue advance care planning. Participants wanted to prepare loved ones for the dying process with as little emotional

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<sup>11</sup> Martin *et al.* (manuscript submitted for review)

<sup>12</sup> Martin *et al.* (manuscript submitted for review)

burden as possible. A participant reported that,

Basically that I am interested in filling this document because I do not want to be... I don't want the burden of making these major decisions left in the hands of anybody, you know, including my son or my girlfriend. You know, it's not up to her, it is up to me. Because I know if she has her way, she would keep me alive even if, you know, I know the way she is and, ah... I don't think she would disobey, as a matter of fact, let me rephrase that, I know that she would not do anything that I would not ask her to do. But it would be very, very, very difficult for her...<sup>13</sup>

Also, participants with problematic relationships often feared unwelcome interference from uninformed family members and thus sought control in the decision-making process to secure the status of their preferred proxy. For example, a participant said that,

It's [advance directive] also, I think, a safeguard for them [partner or friend] as well because they're much closer to me than my family is, you know. My family is not from the city and I don't see them that often and I think, ahm, particularly my parents who do not know that I'm HIV positive at this point, may want to do things differently and I don't want there to be any sort of conflict between them and the rest of the people involved in my care, sort of thing... [parents] might want to, you know, put me on a respirator or something to prolong my life and that's something that I wouldn't want. And I think having that expressed in here will safeguard myself, you know, from that sort of situation. And it also, I think,

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<sup>13</sup> Martin *et al.* (manuscript submitted for review)

gives my lover and my proxies a sort of peace of mind too, you know. They've got something to back up their actions.<sup>14</sup>

For these participants, as for those in the first study, proxy selection was based on intimacy. Many participants felt a need to complete an advance directive form as a way of formally appointing a homosexual partner as proxy so that the authority and legal standing of the partner would be protected. Because proxies were chosen according to the criterion of intimacy, protecting proxies and relieving the burden on proxies through preparation were important features of the participants' advance care planning. As in the first study, communication with physicians was rare. More physicians were involved in advance care planning but almost exclusively for the purpose of providing information.

### *General Conclusions*

Given the theoretical objections to autonomy as a basis for advance directives and the empirical facts about the role of autonomy in the advance care planning process, it is clear that although the value of autonomy has an important and indeed necessary role to play in advance care planning, it is not a sufficient value since it does not account for the importance of personal relationships in the planning process. It is but one, albeit important, value that motivates people into bringing their advance care planning to completion, along with their concern for the impact of their decision making on significant others and the role their significant others are to play in the decision-making process. The data, though limited in terms of their contribution to an acceptable

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<sup>14</sup> Martin *et al.* (manuscript submitted for review)

normative framework for advance care planning, thus serve to verify empirically the overall claim that the principle of autonomy is not a sufficient value upon which to base this process.

### **From the Perspective of the Substitute Decision-Maker: Case Studies**

The question of the extent to which the liberal value of autonomy serves as a sufficient value upon which advance care planning may be based also relates to the perspective of those other than the patient: Is autonomy the primary justification for *honouring* advance directives? Should autonomy be granted priority by those other than the patient when decisions about end-of-life care remain to be made? Lambert and colleagues write,

Surrogate decision-making has...only lately...become prominent with respect to health care decisions. This may be due to several factors, including...[an] increased appreciation for the notion of maintaining patient autonomy to the fullest extent possible...As a result of this new-found respect for the patient's, as opposed to the physician's, values, surrogate medical decision-making has taken on real substance and import.<sup>15</sup>

Indeed, empirical evidence from physicians regarding attitudes towards advance directives reveals that of a variety of favourable arguments for honouring advance directives, those concerned with patient autonomy received the strongest support.<sup>16</sup> As Allen E.

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<sup>15</sup> Lambert, Gibson, and Nathanson 1990.

<sup>16</sup> Davidson *et al.* 1989; Hughes and Singer 1992.

Buchanan and Dan W. Brock write,

In the case of proxy advance directives, the same respect for self-determination that justifies the recognition of the authority of an advance directive in the first place suggests that the proxy ought (unless otherwise instructed) to attempt to make decisions according to the substituted judgment standard - choosing as the incompetent individual would choose in the circumstances were he or she competent.<sup>17</sup>

Following an advance directive, or exercising substituted judgment, can thus be viewed as a way of respecting individual autonomy or self-determination.<sup>18</sup>

However, one questionnaire examining the attitudes of physicians towards advance directives indicated that of those physicians who said that they had refused to follow directions in an advance directive, the following reasons were given: the family disagreed with the directive, the wording of the directive was considered inappropriate given the clinical situation, the patient was not terminally ill, the preferences expressed in the directive were not really understood by the patient and would be different if the patient were aware of the situation, and the preferences expressed were out of date.<sup>19</sup>

An empirical study that included the preferences of substitute decision-makers for life-sustaining care found that the effectiveness of written advance directives was limited by inattention to them and by decisions to place priority on considerations other than the

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<sup>17</sup> Buchanan and Brock 1989, 112.

<sup>18</sup> Buchanan and Brock 1989.

<sup>19</sup> Hughes and Singer 1992.

patient's autonomy. Though medical treatment was consistent with the patient's advance directive seventy-five percent of the time, failure to honour patient's wishes was attributed to the following reasons: the initial preference may have been too restrictive to allow care that was strongly believed to be appropriate, the treatment was not likely to afford benefit to the patient, the patients changed their minds, the family changed its mind, the families made choices that contradicted the patients' previously expressed wishes, and, the advance directives were not followed because providers were unaware of them.<sup>20</sup>

Further reasons for non-compliance by substitute decision-makers include the concern for the use of resources and restriction of medical costs.<sup>21</sup> Though developed primarily to ensure that patients' preferences guide the administration of their future care, advance planning may also be seen as a tool to limit care<sup>22</sup> not only for reasons based on what is in the best interests of the patient but also to provide an ethical approach to reducing health care costs.<sup>23</sup> The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) aimed to "improve end-of-life decision making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying."<sup>24</sup> In studying the effect of advance care planning on end-of-life care

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<sup>20</sup> Danis *et al.* 1991.

<sup>21</sup> Schneiderman *et al.* 1992.

<sup>22</sup> Levinsky 1996.

<sup>23</sup> Schneiderman *et al.* 1992.

<sup>24</sup> SUPPORT Principal Investigators 1995, 1591.

on the premise that "those who complete a living will generally intend to limit life-sustaining treatment,"<sup>25</sup> it found that the great majority of patients in the study, who were expected to die within six months, preferred vigorous treatment to extend life.<sup>26</sup> The study also revealed that the facilitation of advance care planning through nurse-patient communication did not reduce the use of hospital resources.<sup>27</sup>

Reasons for failing to honour a patient's advance directive lead to the question of whether designated substitute decision-makers must, regardless of the circumstances, grant patient autonomy overriding priority at the expense of other values and concerns that may arise. Practically speaking, all requests cannot and *should not* be honoured simply because they represent the autonomous wishes of the individual. Though the deleterious impact of physician denial upon patient autonomy has been documented in case analysis,<sup>28</sup> sometimes honouring patient autonomy can have a negative impact not only on the patient, but also on the patient's caregivers. The case studies that follow serve to highlight this claim in emphasizing other important values of paternalistic decision making and social justice that are rightfully taken into account by substitute decision-makers.

For example, patient autonomy may be justifiably overridden through paternalistic decision making when the family or caregiver is in a more appropriate position to

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<sup>25</sup> Teno *et al.* 1995.

<sup>26</sup> Teno *et al.* 1994.

<sup>27</sup> SUPPORT Principal Investigators, 1995.

<sup>28</sup> Meyers 1992.

represent the patient's best interests than the patient whose competency has become questionable. Care-givers are not necessarily morally obligated to act in ways that conflict with what they consider to be in the best interests of their patients. The following cases help to illustrate this claim.

[In the case of *Evans v. Bellevue Hospital*], an incompetent patient diagnosed with AIDS Related Complex had when competent executed a document stating that life-sustaining treatment should be foregone if he suffered from 'illness, disease or injury or experienced extreme mental deterioration, such that there is no reasonable expectation of recovering or regaining a meaningful quality of life'. He also had executed a power of attorney authorizing another individual to make all medical decisions on his behalf. The court case arose after physicians observed that the patient had multiple brain lesions, which they attributed to toxoplasmosis...The patient's proxy decision-maker asked physicians to withhold antibiotic treatment for the infection. They refused, arguing that the treatment was expected to produce recovery from toxoplasmosis and restore the patient's ability to communicate. The court authorized the treatment...<sup>29</sup>

and,

Person B believes both that life should be preserved to the maximum extent possible and that suffering is preordained and carries redemptive value in an afterlife. B prepares an advance directive in which all possible life-extending medical intervention is requested and all pain relief is rejected. At the time of the

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<sup>29</sup> Dresser and Robertson 1989.

preparation of the directive, B has a conversation with a physician in which the physician explicitly warns him that many terminal illnesses entail excruciating pain. Despite that admonition, B directs that all means to preserve life be utilized and that analgesics be omitted. Subsequently, B suffers from cancer, which both affects his brain, rendering him incompetent, and causes him to suffer excruciating pain. Further medical treatment such as radiation or chemotherapy will extend B's life but will not itself relieve the pain or cause any remission in which competence would return.<sup>30</sup>

In the case of *Evans v. Bellevue Hospital* it is not clear what the patient means by a "reasonable expectation of recovering or regaining a meaningful quality of life". But regardless of what the *patient* means, the *physicians* may be justified in applying their own interpretation of these terms in what they consider to be the best interests of the patient. It may be argued that Person B's request for maximum treatment with the exception of palliative care is justifiably overridden once he becomes incompetent and suffers excruciating pain since, when competent, he was not in the position to assess accurately the experiential phenomenon of the condition he now endures. And, most importantly, it may be argued, palliative care is in his best interests given the excruciating pain he suffers which analgesics can relieve.

The case of Margo is an interesting illustration of the possible conflict between individual autonomy and paternalistic decision making for the sake of what is (or appears to be) in the patient's current best interests. Described by medical student Andrew Firlik

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<sup>30</sup> Cantor 1993, 101.

who met and visited her daily during a gerontology elective, fifty-five-year-old Margo had Alzheimer's disease. Her apartment door was equipped with multiple locks to prevent her from leaving in the night, which she had done before. Says Firlik, "We usually found her a couple of days later when we learned of a police report describing a woman in a nightgown seen roaming Central Park. Bad things have happened during these excursions."<sup>31</sup> Margo's dementia was clearly evident. She claims to enjoy reading yet at any one time dozens of pages of her book at hand were dog-eared. She listened to the same songs over and over, each time as if anew. She claimed to know Firlik but never called him by name. In her art class for Alzheimer's patients, she typically painted the same picture - "a drawing of four circles, in soft rosy colors, one inside the other" - each day. Nevertheless, Firlik describes Margo as "undeniably one of the happiest people I have known. There is something graceful about the degeneration her mind is undergoing, leaving her carefree, always cheerful."<sup>32</sup>

In his recent discussion of Margo, Ronald Dworkin invites us to suppose that Margo had, when competent, executed an advance directive stating that if she should develop Alzheimer's disease she should not receive treatment for any other serious, life-threatening disease she might contract.<sup>33</sup> He then asks whether, in the light of her current condition, her prior wishes may justifiably be overridden. It would seem repugnant to deny Margo medical treatment as long as she is experiencing pleasure and

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<sup>31</sup> Firlik 1991, 201.

<sup>32</sup> Firlik 1991, 201.

<sup>33</sup> Dworkin 1993, 226.

happiness in life without any apparent harm to her well-being (the doors to her apartment have, after all, been securely locked and she is in no apparent physical or mental pain). As Dresser suggests, Margo's continued ability to participate in the life she is living furnishes a defensible basis for state limitations on the scope of her precedent autonomy.<sup>34</sup> Moral paternalism may therefore be justified when dementia patients have a quality of life comparable to Margo's.

Patient autonomy may be justifiably overridden when it conflicts not only with the perceived best interests of the patient but also with the welfare of those directly involved in the life of the patient, namely, caregivers and loved ones. The use of life-sustaining treatments in caring for a dying patient may be limited by internal constraints such as the physician's obligation to the norms of the profession and his or her own moral beliefs and by external legal constraints.<sup>35</sup> It may be ethical not to honour a patient's choice for treatment if doing so would seriously violate the moral or professional integrity of the treating physician; for example, doctors are not obligated to provide treatment that is clearly futile,<sup>36</sup> or non-beneficial, medically speaking. From a physician's standpoint, overriding patient autonomy as expressed in the terms of an advance directive may be based on the view that sound medical practice suggests otherwise or that the physician's conscientious scruples do not enable him or her to comply with what the patient (or

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<sup>34</sup> Dresser 1995, 37.

<sup>35</sup> Gould 1992.

<sup>36</sup> Brock 1991.

proxy) wants.<sup>37</sup> The following is a case example.

On 14 December 1989, Helga Wanglie, eighty-six, broke her hip when she slipped on a rug in her Minneapolis home. After the hip fracture was successfully treated at the Hennepin County Medical Center (HCMC) she was discharged to a nursing home. She was readmitted to HCMC on 1 January 1990 when she developed respiratory failure and was placed on a respirator. Over the next five months repeated attempts to wean Mrs. Wanglie from the respirator were unsuccessful. During this initial admission, Mrs. Wanglie was conscious, aware of her surroundings, could acknowledge pain and suffering, and could recognize her family.

The hospital was unable to wean Mrs. Wanglie from the respirator, and on 7 May 1990 she was transferred to another facility that specializes in the care of respirator-dependent patients. When further attempts were made to wean her from the respirator at the new facility, she experienced a cardiopulmonary arrest on 23 May. She was resuscitated and then transferred to another acute care hospital in St. Paul. She was now felt to have extremely severe and irreversible brain damage. Because of this dismal prognosis, a hospital ethics committee reviewed her case and doctors discussed with the family the possibility of limiting further life-sustaining treatment. However, the family resisted this idea and requested that Mrs. Wanglie be transferred back to HCMC, where they felt she had received excellent care.

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<sup>37</sup> Cantor 1993.

Since readmission to HCMC on 31 May 1990 the patient has been vigorously treated with continued respirator support, antibiotics for recurrent pneumonia, artificial feeding, and treatment for electrolyte and fluid imbalance. Initial diagnosis on readmission to HCMC was persistent vegetative state secondary to severe hypoxic-ischemic encephalopathy. Over the next several months repeated evaluations by the neurology and pulmonary medicine services confirmed the diagnosis of permanent unconsciousness (persistent vegetative state), and permanent respirator dependency because of chronic lung disease.

Because of her age, previously prolonged hospital stay at HCMC in early 1990, multiple medical complications, ultimately unsuccessful weaning from the respirator, and neurologic condition, the medical staff caring for Mrs. Wanglie viewed her prognosis as extraordinarily poor. They did not believe that the respirator could benefit her. However, the immediate family - her husband, daughter, and son - insisted that all forms of treatment be continued.<sup>38</sup>

This case poses a unique dilemma since, unlike in earlier right-to-die cases, it is the family who wants life-sustaining treatment to continue and the physicians who are arguing for the patient's right to die.<sup>39</sup> Since the patient had not expressed her preferences for treatment while competent, the family is assumed to act in accordance with what the patient would have wanted (the substituted judgment standard). Yet, it is arguable in this case that the family cannot demand that the physicians taking care of Helga Wanglie

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<sup>38</sup> Cranford 1991.

<sup>39</sup> Angell 1991.

continue to administer treatment that they consider contrary to what is in their patient's best medical interests. Insofar as the family's preference for treatment is reflective of Helga Wanglie's wishes (though it is not clear that their choice reflects Helga's wishes at all), patient autonomy *may* therefore be overridden.

According to Brock,<sup>40</sup> in treating patients very near death, physicians sometimes say that they are principally treating the family, not the patient. Treatment being provided may have very little effect one way or the other on the interests of the patient, but may have a great effect on the surviving family and how they are able to deal with the patient's dying and death. For example, stopping treatment might be very briefly delayed to help the family accept the patient's death. The following case describes a situation in which it is arguably justifiable to honour the family's decision regarding the patient over and above what the patient himself wants due to the potential violation of the family's welfare posed by the patient's wishes.

A 59-year-old male farmer was kicked in the back of the neck by a cow. He was found approximately 10 hours later and admitted to a hospital with diagnoses of exposure and a fractured neck with a spinal cord injury. He was fully conscious but unable to move his arms or legs and could not cough or take a deep breath. He was transferred to intensive care. Within a few hours edema of the spinal cord made ventilatory support necessary. The patient required ventilatory support for two weeks and then did well without the respirator. He gradually regained the ability to shrug his shoulders and to weakly flex his arms. He was transferred to

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<sup>40</sup> Brock 1991.

an intermediate care area after eight weeks in intensive care. Ten days later he was readmitted to intensive care for ventilatory support and treatment of pneumonia caused by inhaling food and stomach contents. He was weaned off the respirator after four weeks, and six weeks later was transferred to an intermediate care area.

This cycle was repeated two more times consuming a total of six months hospitalization and approximately \$375,000 - the limit of his hospitalization insurance. Further care would require selling stocks valued at \$100,000 and then the family farm. The patient, his wife, and three sons declared that no ventilatory support should be instituted. This desire of the patient was documented by physicians, nurses, a social worker and a member of the Hospital Pastoral Service. Three weeks later the patient again inhaled food and developed aspiration pneumonia and pulmonary insufficiency. He was readmitted to intensive care for treatment but refused mechanical ventilatory support. In spite of oxygen therapy and nursing care his pulmonary status deteriorated and he became hypoxic. Because of the lack of oxygen supply, his mental status deteriorated and he became progressively agitated and disoriented. He *then* requested mechanical ventilatory support but his sons insisted the patient's previous wish, stated when he was rational, be honored and that no support be provided although death would then be inevitable.<sup>41</sup>

This case illustrates a difficult situation to assess given the lack of knowledge about the

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<sup>41</sup> Feinberg 1986, 362-363.

family's true motivations. Nevertheless, assuming he is now incompetent to make a decision about treatment, the patient's family may have legitimate grounds for overriding his present "choice" based on significant threats to their own emotional and financial security.

These cases suggest that, from the perspective of the family, the denial of patients' autonomous choices may be defended by the family's own inability to cope with the patient's death or accept the terms of the patient's request(s)<sup>42</sup> and/or the potential threat to the welfare of the family or family member(s) the patient's wishes pose.

It may also be justifiable not to honour a patient's autonomous choice for treatment if doing so would seriously violate the moral and professional integrity of the hospital or institution within which the patient is situated. An example of the importance of "institutional welfare" lies in the case of a patient of a church-owned hospital:

Beverly Requena, a competent 55-year-old woman hospitalized with amyotrophic lateral sclerosis in a church-owned hospital, became dependent on a ventilator in April 1985. In July 1986 she stated that she would refuse tube feeding. The hospital administration objected, maintaining that food and fluids were fundamental forms of care, but arranged to transfer Requena to a nearby facility willing to honor her request. She refused the transfer, and the hospital sued to compel her to leave. The judge ruled that her wish to decline tube feeding must be honored by the hospital staff, who had voiced moral objections to this change

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<sup>42</sup> Cantor 1993.

in her treatment plan...<sup>43</sup>

It remains questionable whether there is such a thing as institutional conscience or valid institutional conscientious objections.<sup>44</sup> Nevertheless, it could be argued that based on a fundamental moral imperative of tolerance for the diversity of social and community values, including those of a religious nature, there is no moral obligation for those who work in an institution that is organized and representative of a particular community to be denied their values, beliefs and tenets. It would seem reasonable, then, that Requena accept the transfer in order that her wishes may be honoured. The hospital staff who identify with the religious creeds of the institution within which they work cannot be expected to treat patients in ways that violate their own sense of what is morally acceptable.

Individual patient autonomy may be justifiably overridden not only when honouring autonomy leads to a conflict with what is perceived to be in the best interests of the patient, the patient's family and/or caregivers, but also when it conflicts with the interests of the broader society. As Childress and Fletcher note, the limits on respect for autonomy are generally greater when agents request than when they refuse treatments. Only in rare cases, as in the case of Requena, would serious harm or injustice fall on others when patients refuse life-sustaining treatments. Yet when patients or their surrogates request treatments that are futile - futile in that they do not serve the best interests of the patient and may serve another patient better - there may be greater

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<sup>43</sup> Miles, Singer, and Siegler 1989.

<sup>44</sup> Cantor 1993.

justification for overriding the principle of autonomy.<sup>45</sup> The following case may serve as an example.

Mr. Smith has been admitted to the intensive care unit after being involved in a head-on collision. He is unconscious, has been intubated, and is on a ventilator. His prognosis, while certainly poor, is as yet questionable. After three days, Mrs. Smith requests that the ventilator be removed and that her husband be "allowed to die because he has suffered enough". She further indicates that she wants to donate his organs so that "some good may come out of this tragedy".

Despite all treatment, Mr. Smith has continued to deteriorate. He has suffered a cardiac arrest and has been resuscitated but has suffered anoxic brain damage. Examination shows that he is, in fact, brain dead. At this point, the bed is badly needed because another accident victim has come to the emergency room. Mrs. Smith, unfortunately, has changed her mind and opposes stopping therapy as well as organ donation.<sup>46</sup>

As a matter of justice, it is arguable that, even though keeping Mr. Smith's body alive may be a potential source of organ donation, Mrs. Smith's final request for the continuation of treatment is an unfair one compared with the need of others who are currently competing for Mr. Smith's bed. As in the case of Helga Wanglie, patient autonomy is justifiably overridden insofar as Mrs. Smith's choices are representative of her husband's otherwise autonomous wishes were he competent.

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<sup>45</sup> Childress and Fletcher 1994.

<sup>46</sup> Loewy 1991.

It is conceivable and perhaps mandatory as a matter of ethics that patient autonomy sometimes be overridden by values that do not stem from the expressed interests of the individual (or proxy). Even if all patient requests were honoured, it is not clear that they would be so strictly out of respect for patient autonomy. For example, in the face of scarce resources and an advance directive that requests that treatment be denied, it is not correct to say the advance directive will be honoured because the patient expressed a wish to forgo treatment; the patient's wish may be respected only as an indirect by-product of the decision (made by someone other than the patient) to deny treatment considered to be of better use elsewhere. In other words, the advance directive was "honoured" - in an empty sense of the word - because it happened to comply with the decision to deny treatment. Respect for the principle of autonomy may not always be a sufficient reason for honouring a patient's advance directive. It is thus unrealistic to assume that autonomy is always granted priority by substitute decision-makers even in those cases where the previously expressed wishes of the patient are consistent with final decisions about future treatment.

From the perspective of substitute decision-makers, patient autonomy may be overridden when paternalistic decision making is morally appropriate and/or when concerns of social justice or conflicts between what patients request and the health services that are available to them after they become incapable are rightfully taken into account. Advance care planning thus remains a mechanism for informed consent, but one "by which the patient's wishes can be evaluated and brought into line with the realistic

possibilities of medical care."<sup>47</sup>

Understood as a concept that is not impoverished in the way considered earlier, autonomy is recognized by critics to be an important moral principle for advance care planning along with other important principles. Respect for autonomy may be the primary reason that advance directives ought to be honoured. It is not desirable that autonomy be discarded altogether. Of course, critics do not argue that it should be. Rather, they oppose its ultimate moral authority. Their point is well taken that under certain conditions, autonomy is justifiably overridden by values of personal relationships, paternalism, and social justice that do not stem from the interests of the individual. Notwithstanding the importance of preserving and protecting the individual's role in the determination of those values, beliefs, choices and actions that are in some important defining sense his or her own, to overemphasize the liberal value of autonomy in advance care planning would be to demand the denial of broader concerns that might otherwise justifiably outweigh those of individuals. The liberal value of autonomy, though an integral aspect of the rationale behind advance care planning, is not a sufficient value to account for all of the concerns that underlie the actual process of advance care planning.

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<sup>47</sup> Levinsky 1996.

## **CHAPTER FIVE**

### **Autonomy and Contemporary Liberalism**

The theoretical criticisms and empirical data considered above suggest that, in the context of advance care planning, autonomy is an insufficient basis for decision making about end-of-life care. Thus, the objection to the liberal value of autonomy as an overemphasized defense of advance care planning has proven to be a reasonable one. However, this objection entails the assumption that the overemphasis of the liberal value of autonomy - the significance of individual autonomy as an ultimate overriding value - is an essential or defining aspect of liberalism. Following this assumption, it would seem then that liberalism is an inappropriate framework for understanding values other than individual autonomy that may dominate the advance care planning process.

I would like to suggest that such assumptions about liberalism, at least in its modern form, are invalid. Liberalism is commonly understood as the source of autonomy in the bioethics literature - an interpretation that all too often results in the wrongful equation of these terms. Though autonomy has roots in liberal theory, liberalism is not simply a theory about autonomy. Liberals do not unequivocally hold autonomy to be a foundational value to be upheld at all individual and social costs. Liberals recognize the relative worth of autonomy vis-à-vis other important values. In fact, liberals argue fundamentally about justice as a principle of equality without

necessarily assuming the overriding role of autonomy.<sup>1</sup>

In an attempt to further this point, I will focus briefly on the extent to which contemporary liberals recognize and incorporate the values of social justice, paternalism in decision making for others, and personal relationships (including concern for the welfare of others) into their theoretical frameworks since these are the values that, according to the theoretical criticisms and empirical data considered above, emerge in the advance care planning process. Liberalism, understood as a political theory based ultimately on a conception of justice as equality, and one that takes into account defensible instances of paternalism, is not necessarily an inappropriate framework for understanding the aspects of advance care planning in which these values emerge. What remains questionable, however, is the extent to which liberalism serves as a theory specifically of personal relationships.

It may be reasonable to assume that the liberal concern for political relationships reflects a deeper agenda to protect the private choices and affairs of individuals. Yet the liberal writers considered here do not discuss the nature and value of personal relationships, *per se*, though they may, as in the case of Kymlicka, seek to define a liberal account of the individual as situated or embedded in community and culture. Liberalism, though not necessarily an inappropriate framework for understanding advance care planning, may not be entirely adequate in accounting for the private aspects of this process. Therefore, the supplementation, and not replacement, of liberalism with theoretical accounts that stress the value of personal relationships is suggested.

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<sup>1</sup> See, for example, Kymlicka 1990; chapter 3.

## **Liberalism as a Theory of Justice**

The quest for fairness in the distribution of resources is a concern that is not unique to those who participate in advance care planning. However, it is a value that may motivate competent individuals in their decisions about future care and it may cause conflicts between competent individuals' wishes and the health services that are available to them once they become incompetent. Thus, it is important to understand what it means to contemporary liberals and the role it plays in liberal theory. As discussed above, critics accuse liberals of overemphasizing the value of individual autonomy at the expense of broader concerns such as the good of the greater community. The choice of a patient as expressed in an advance directive may be justifiably overridden when it constitutes a request for costly and/or scarce treatment that is of little or no benefit to the patient and would serve other patients better.

To critics, it may not be clear how liberal theory can account for the process of advance care planning when the interests of society outweigh those of the individual. They often assume that autonomy is the trump value within liberalism, leaving little or no room for an account of justice and equitable resource allocation. Yet this is simply not a valid assumption, at least for the majority of modern liberal writers. As Rosemarie Tong writes,

For classical liberals, the ideal state protects civil liberties (for example, property rights, voting rights, freedom of speech, freedom of religion, freedom of association) and, instead of interfering with the free market, simply provides all individuals with an equal opportunity to determine their own accumulations within

that market. For welfare liberals, in contrast, the ideal state focuses on economic justice rather than on civil liberties. As this more recent group of liberals sees it, individuals come to the market with differences based on initial advantage, inherent talent, and sheer luck. At times, these differences are so great that some individuals cannot take their fair share of what the market has to offer unless some adjustments are made to offset their liabilities. Due to this perceived state of affairs, welfare liberals call for such positive government intervention in the economy as legal services, school loans, food stamps, low-cost housing, Medicaid, Medicare, Social Security, and Aid to Families with Dependent Children so that the market does not perpetuate or otherwise solidify huge inequalities.<sup>2</sup>

In sum, the contemporary liberal objective may be stated as follows: If we are to treat people as equals, we must protect them in their possession of certain rights and liberties.<sup>3</sup> Of course much has been written within liberalism on the question of which rights and liberties these are, but that is not of immediate concern. Rather, the point is that the moral demand of liberal equality is held prior to that of the protection of our (individual) rights and freedoms.

In his recent work Political Liberalism<sup>4</sup>, John Rawls' "egalitarian (liberal political) conception of justice" entails two principles summarized as follows:

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<sup>2</sup> Tong 1989, 12.

<sup>3</sup> Kymlicka 1990, 50.

<sup>4</sup> Rawls 1993.

- a. Each person has an equal claim to a fully adequate scheme of equal basic rights and liberties, which scheme is compatible with the same scheme for all; and in this scheme the equal political liberties, and only those liberties, are to be guaranteed their fair value.
  
- b. Social and economic inequalities are to satisfy two conditions; first, they are to be attached to positions and offices open to all under conditions of fair equality of opportunity; and second, they are to be to the greatest benefit of the least advantaged members of society.<sup>5</sup>

According to Rawls, these two principles express an egalitarian form of liberalism that entails:

- a) the guarantee of the fair value of the political liberties...;
- b) fair...equality of opportunity;
- c) the so-called difference principle, which says that the social and economic inequalities attached to offices and positions are to be adjusted so that, whatever the level of inequalities, whether great or small, they are to the greatest benefit of the least advantaged members of society.<sup>6</sup>

Notwithstanding the problems of the theory that arise, as when the various goods (e.g., liberty and equality) being distributed according to the principle of justice conflict, justice as fairness understood in terms of an equal share of social goods (whether, e.g.,

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<sup>5</sup> Rawls 1993, 5-6.

<sup>6</sup> Rawls 1993, 6-7.

equal liberties, equal opportunities, or equal resources) remains the very crux of Rawls' liberalism. As Kymlicka points out, Rawls' "original position", from which principles of justice are chosen by those with hypothetical equal bargaining capacities, is supposed to represent equality between individuals as moral agents:

Rawls's argument is not, then, that a certain conception of equality is derived from the idea of a hypothetical contract...Rather, the hypothetical contract is a way of embodying a certain conception of equality, and a way of extracting the consequences of that conception for the just regulation of social institutions. By removing sources of bias and requiring unanimity, Rawls hopes to find a solution that is acceptable to everyone from a position of equality - i.e. that respects each person's claim to be treated as a free and equal being...the premiss of the argument is equality, not contract.<sup>7</sup>

Similarly, in A Matter of Principle<sup>8</sup>, Ronald Dworkin argues that a certain conception of equality is the central principle of liberalism. He does not accept the claim that liberals are committed fundamentally to economic growth, the government required to ensure this growth, and a conception of life in which growth is pursued for its own sake in the form of competition, individualism, and material pursuits.

Dworkin offers a list of what he takes in general to be the core set of political positions characteristic of liberalism:

In economic policy, liberals demand that inequalities of wealth be reduced through

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<sup>7</sup> Kymlicka 1990, 63.

<sup>8</sup> Dworkin 1985.

welfare and other forms of redistribution financed by progressive taxes. They believe that government should intervene in the economy to promote economic stability, to control inflation, to reduce unemployment, and to provide services that would not otherwise be provided, but they favor a pragmatic and selective intervention over a dramatic change from free enterprise to wholly collective decisions about investment, production, prices, and wages. They support racial equality and approve government intervention to secure it, through constraints on both public and private discrimination in education, housing and employment.

But they oppose other forms of collective regulation of individual decision: they oppose regulation of the content of political speech, even when such regulation might secure greater social order, and they oppose regulation of sexual literature and conduct, even when such regulation has considerable majoritarian support. They are suspicious of the criminal law and anxious to reduce the extension of its provisions to behavior whose morality is controversial, and they support procedural constraints and devices, like rules against the admissibility of confessions, that makes it more difficult to secure criminal convictions.<sup>9</sup>

It is mistaken, Dworkin claims, to assume that principles of liberty and equality make up the basis of liberal's core positions. Liberty and equality often conflict; the promotion of one may be at the expense of the other. But to Dworkin, equality is favoured more by liberals and the fact that it is is evident in the core set of liberal positions he describes. Fundamental liberties are valuable not in themselves but because

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<sup>9</sup> Dworkin 1985, 187.

of something else we value that they protect. Equality is taken to be the liberal ideal.

In the first, constitutive sense, equality according to Dworkin requires that government treat all citizens "as equals". Dworkin equates the question of what it means for government to treat its citizens as equals to the question of what it means for the government to treat its citizens as free, or independent, or as entitled to equal concern and respect. The conception of equality that liberalism takes as its constitutive political morality is, according to Dworkin, the idea that government must be neutral on "the question of the good life". That is, political decisions must be, as far as possible, independent of any particular conception of the good life, or of what gives life value. Since the citizens of a society differ in their conceptions, the government does not treat them as equals if it prefers one conception to another. Of course, this conception of equality assumes that the government *can* be neutral on the question of the good life.

In the second, derivative sense, equality requires that the government treat all citizens "equally" in the distribution of resources. Though liberals value equality in both senses of the term, it is by encompassing the derivative sense that liberals are distinguished from non-liberals.

According to Dworkin, it is through the two "familiar institutions" of our own (referring to the U.S.) political economy that the most egalitarian state constitution is possible. The first is the *economic market* for decisions about what goods shall be produced and how they shall be distributed. This institution is upheld under the specific condition that people differ only in preferences for goods and activities to avoid the anti-egalitarian consequences that otherwise would manifest. Dworkin recognizes, however,

that in the "real world" people do not differ only with respect to their preferences; they are unequal in terms of abilities and talents, inheritance, and special needs - inequalities that will have significant effects on the distribution a market economy will provide. The liberal conception of equality is thus problematic since it

requires an economic system that produces certain inequalities (those that reflect the true differential costs of goods and opportunities [such as inequality of monetary wealth as the consequence of the fact that some preferences are more expensive than others]) but not others (those that follow from differences in ability, inheritance, and so on). The market produces both the required and the forbidden inequalities, and there is no alternative system that can be relied upon to produce the former without the latter.<sup>10</sup>

The liberal finds the market defective because it allows what are considered to be morally irrelevant differences (such as talent) to affect distribution. Therefore, the liberal must argue, according to Dworkin's account, that those who have, say, less talent, have the right to some form of redistribution in the name of justice. Otherwise, economic growth may be rejected or curtailed as a strategy for securing equality. A scheme of welfare rights or socialism may be more effective and not contradictory to, as is often assumed by critics of liberalism, the liberal conception of equality.

The second "familiar institution" is *representative democracy* for collective decisions about what conduct shall be prohibited or regulated so that other conduct might be made possible or convenient. But, as Dworkin notes, here majority vote does not

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<sup>10</sup> Dworkin 1985, 195-196.

reflect the views of everyone and as such fails to secure the right of citizens to be treated as equals. As in the case of the first institution, representative democracy forces the liberal to argue for a scheme of civil rights whose effect will be to determine those political decisions that reflect strong external preferences (such as those of the majority) and to remove those decisions from majoritarian political institutions altogether. To relate to liberalism's core political principles, then, both institutions therefore require individual rights for the protection of equal concern and respect. This means that, as Kymlicka writes,

If [liberals] allow some kinds of inequality-producing economic freedoms, it is not because they believe in liberty as opposed to equality. Rather, they believe that such economic freedoms are needed to enforce their more general idea of equality itself.<sup>11</sup>

Liberalism's adherence to the value of individual autonomy does not therefore "run against a principled way of limiting the medical services that ought to be guaranteed to individuals" as suggested earlier. For example, a "closed health care system" of the sort mentioned above may be plausible, in which physicians are the ideal advocate for particular patients and for all patients in general knowing that funds saved in denying care will be applied where needed within the system. This would approach a "citizen ethic" for advance care planning or a "socially responsible" approach also mentioned above whereby patients are viewed as consumers *and* citizens and patient choices are considered in the context of "informed consent" rather than in the context of "consumer

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<sup>11</sup> Kymlicka 1990, 85.

sovereignty".

The concern for fair distribution in the allocation of scarce and/or costly resources may be a part of the overall goals of those engaged in advance care planning or it may cause conflicts between competent individuals' requests for treatment and the health services that are available to them once they become incapable of decision making. In general, liberalism is a political theory based on an egalitarian conception of justice. Liberal theory thus provides an account of the concerns for equitable resource allocation that those planning for their future care and their caregivers sometimes exhibit.

The incorporation of justice in resource allocation is not always a concern at the forefront of advance care planning. Individuals planning for their future care may be more concerned about the impact of their decisions on loved ones than they are about the impact on the broader patient population. Substitute decision-makers may be more concerned about what is in the best interests of patients they represent than they are about the motivations behind previously expressed patient wishes. What remains to be shown, then, is the extent to which liberalism accounts for paternalistic decision making which may justifiably override previously expressed individual wishes as in the cases of Evans, Person B, and Margo, and the extent to which it accounts for the importance of personal relationships that, as the empirical data suggests, emerge as a key motivation in the decisions individuals make in the process of advance care planning.

### **Liberalism and Paternalism**

If individual autonomy were indeed liberalism's trump value, then it would be

very difficult, if at all possible, for liberals to justify paternalistic acts. This poses a problem in defining a liberal account of advance care planning since substitute decision-makers are sometimes justified in treating incompetent patients paternalistically, as in the cases of Evans and Person B, when to honour a patient's wishes as expressed when he or she was competent would pose an unnecessary risk to his or her own welfare or to that of others.

Is contemporary liberalism able to account for the justification of paternalistic acts in advance care planning as suggested by these cases? As Kymlicka notes, liberals insist that in order to lead a good life "every competent adult be provided with a sphere of self-determination which must be respected by others"<sup>12</sup> and "For those who pass the threshold of age and mental competence, the right to be self-determining in the major decisions in life is inviolate."<sup>13</sup>

William Galston's problem with liberalism is not aimed specifically at the fact that it is based on an affirmative conception of individuality; that, he says, is inevitable.

Rather, as he writes,

...this conception is unnecessarily partial and partisan...it tends to exclude individuals and groups that do not place a high value on personal autonomy and revisable plans of life...there is...an understanding of individuality that is both more inclusive in practice and more consistent at the theoretical level with core liberal principles. This understanding focuses on the ability of diverse individuals

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<sup>12</sup> Kymlicka 1990, 100.

<sup>13</sup> Kymlicka 1990, 100.

within liberal societies to agree on the virtues needed to sustain such societies and to make the practice of these virtues effective in their lives...the human goods available in, or promoted by, liberal polities are capacious enough to evoke wide support from groups who otherwise agree on little else. The accommodation of diversity within a determinate but limited conception of liberal public purposes is a better foundation for liberal philosophy than is the promotion of rational reflection or personal autonomy.<sup>14</sup>

What is distinctive about liberalism to Galston is not the absence of a substantive conception of the good, but rather a reluctance to move from this conception to what he calls "full-blown public coercion" of individuals. (Where he draws the line between full-blown and thus presumably unacceptable coercion and that which is acceptable is unclear.) Liberalism (and its notion of neutrality which I will explore below), for Galston, is unjustified insofar as it necessitates the absolute lack of constraint by others in the pursuit of individual purposes, or insofar as it necessitates absolute "negative freedom."<sup>15</sup>

Galston argues that "we can accept paternalistic interventions in a range of circumstances without believing that this benevolent coercion contradicts [the liberal ideal of] equal respect for persons."<sup>16</sup> He claims that "the overlapping moral consensus required for full state neutrality is most unlikely to exist...neutralist noncoercion cannot

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<sup>14</sup> Galston 1993, 153-154.

<sup>15</sup> Galston 1993, 83.

<sup>16</sup> Galston 1993, 110.

be the liberal's only desideratum, because it is also necessary to come to some collective decision about the community's structure of liberty and distribution."<sup>17</sup> On Galston's account, modern liberalism is therefore a theory both minimal, in that it allows wide scope for free choice and diversity, and moral, in that it appeals to individual motivations other than self-interest.<sup>18</sup> Liberals thus allow for acts of paternalism - paternalistic acts may be justified in our relationships with children, the demented, the otherwise temporarily incapacitated, and even, under certain circumstances, in our relationships with competent adults who exhibit "weakness of will" in doing what is in their best interests<sup>19</sup>. As Kymlicka writes,

Certain acts of paternalism involving competent adults may be justified when we are faced with clear cases of weakness of will. For example, most people know that the gain in safety is well worth the effort of putting on a car seat-belt. Yet many people let momentary inconvenience override their reason. Mandatory seat-belt legislation helps overcome this weakness of will, by giving people an extra incentive to do something that they know they already have sufficient reason to do.<sup>20</sup>

Writing in the context of legal paternalism, Joel Feinberg calls attention to the distinction between "hard paternalism", which justifies the imposition of values and

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<sup>17</sup> Galston 1993, 110.

<sup>18</sup> Galston 1993, 118.

<sup>19</sup> Kymlicka 1990, 232 n.1.

<sup>20</sup> Kymlicka 1990, 232 n.1.

judgments on people "for their own good", and "soft paternalism" which

...holds that the state has the right to prevent self-regarding harmful conduct...*when but only when* that conduct is substantially nonvoluntary\*, or when temporary intervention is necessary to establish whether it is voluntary or not...the law's concern should not be with the wisdom, prudence, or dangerousness of [an individual's] choice, but rather with whether or not the choice is truly his. Its concern should be to help implement [the individual's] real choice, not to protect [him] from harm as such...<sup>21</sup>

Soft paternalism, argues Feinberg, is therefore a principle "in accord with the animating spirit of liberalism" since it permits interference in the (and only in the) absence of voluntariness or genuine consent. He offers the following example:

...if we see a normally calm person who we know has been experimenting with hard drugs go into a sudden frenzy and seize a butcher knife with the clear intention of cutting his own throat, then we do have the right to interfere. In so doing we will not be interfering with his real self or blocking his real will. That we may not do. But his drug-deluded self is *not* his "real self," and his frenzied desire is *not* his "real choice," so we may defend him against these threats to his autonomous self, which is quite another thing than throttling that autonomous self with external coercion. Interference on this ground is no more illiberal than

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<sup>21</sup> Feinberg 1986, 12. "A "nonvoluntary" act is one for which consent is "missing because the subject, being only an infant, or comatose, or insane, is incapable of giving his voluntary consent" (Feinberg 1986, 345).

interference to prevent him from harming or offending an unwilling second party.<sup>22</sup>

Other examples include an irreversibly comatose person, and a terminal patient "so maddened with pain that he cannot 'voluntarily' consent to die". A further example might be the 59-year-old farmer whose mental status had deteriorated due to a (requested) lack of oxygen supply. His request for ventilatory support after he became agitated and disoriented may not be voluntary nor representative of his "genuine" wishes expressed when clearly capable of making such decisions. Moreover, honouring his request would probably not be in his best interests given the likelihood of further suffering he will endure. Such persons cannot make their own choices and in which case, argues Feinberg, soft paternalists might agree with hard paternalists and opt for a scheme that permits proxies to appeal to the incompetent person's "own good" rather than his or her voluntary choice. Since "the being in question can make no choice of his own, benevolent intervention by another can hardly be an invasion of his autonomy."<sup>23</sup>

According to Feinberg, though, there is room for soft paternalism, but never hard paternalism, within liberal theory. Only hard paternalism "invades the realm of personal autonomy where each competent, responsible, adult human being should reign supreme."<sup>24</sup> Of course, it could be argued that soft paternalism is compatible with liberalism because it is not really paternalism at all since it applies to cases in which

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<sup>22</sup> Feinberg 1986, 14.

<sup>23</sup> Feinberg 1986, 346.

<sup>24</sup> Feinberg 1986, 25.

individuals are not autonomous anyway, and thus are incapable of their own decision making. Soft paternalism, however, is regarded as an "alternative, essentially liberal, rationale for most of what seems reasonable in paternalistic restrictions."<sup>25</sup>

The expressed preferences of Evans, Person B, and Margo (assuming she had executed an advance directive), are those representative of competent persons who are each capable of making their own decisions about matters that affect them. Evans was competent when he executed an advance care document. Person B was fully capable of preparing his advance directive. The case of Margo is based here on the assumption that she executed an advance directive when competent.

There are two ways in which liberalism may account for paternalism in the above cases. First, the choices of the patient when competent may not have been voluntarily made. Coercion and bias, whether from health care professional(s) and/or family members (who may, for instance, be anxiously awaiting relief from the emotional and financial burden of caring for their loved ones as perhaps the farmer's family experienced) may be reasons for nonvoluntary decision making. Paternalistic decision making may be acceptable under such circumstances to defend the patient, as Feinberg puts it, against threats to his or her autonomous self. Or, these may be interpreted as cases of what Kymlicka refers to as a "weakness of will".

Second, paternalistic decision making that overrides previously expressed preferences made when competent is arguably in the best interests of Evans and Person B who, had they foreseen their current condition, would not have expressed the wishes they

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<sup>25</sup> Feinberg 1986, 26.

did. On this interpretation, these are cases of what Feinberg might refer to as a blocked will. Of course this *assumes* that had they been able to predict and appreciate the nature of their current circumstances, these individuals would not have expressed the preferences for treatment that they in fact did.

The case of Margo (as elaborated by Ronald Dworkin) poses an interesting contrast to that of Evans and Person B. Margo, Evans and Person B might not have expressed the preferences for (lack of) treatment that they in fact did had they appreciated the potential harm such a decision would eventually pose to their well-being (in the case of Margo this applies if she were to contract a life-threatening disease, for example). Yet, where moral paternalism is justified in the cases of Evans and Person B due to the poor quality of life these patients experience, moral paternalism is justified in the case of Margo due to the quality of life she experiences as a conscious, albeit incompetent, person. It is acceptable to override the previously expressed wishes of Evans and person B because they now suffer. It is acceptable to override the previously expressed wishes of Margo because, not only does she not suffer at present, but she appears to have retained the capacities, such as the abilities to interact and communicate with others and experience pleasure and happiness, that are characteristic of conscious persons.<sup>26</sup>

Dworkin examines the question of what moral rights incompetent people such as Margo have or retain in the late stages of dementia and what is in their best interests.<sup>27</sup> Is there a conflict between a demented patient's best interest and her precedent autonomy

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<sup>26</sup> Dresser 1995.

<sup>27</sup> Dworkin 1993.

when competent? If so, then the view that Margo's present right to treatment in her best interests is sufficient to justify overriding her precedent autonomy is persuasive. Yet Dworkin insists that if Margo's precedent autonomy is not respected - "if we refuse to respect her past decisions, though made when she was competent, because they do not match her present, incompetent wishes"<sup>28</sup> - then her interests are violated.

For Dworkin, mentally incapacitated persons such as Margo do not have a right to make decisions for themselves that others would deem not in their best interests.<sup>29</sup> We might take the "evidentiary" view that maintains that we should respect the decisions that competent people make for themselves simply because each person knows what is in his or her own best interests better than anyone else. But this, says Dworkin, does not apply in the case of Margo since her dementia prevents her from any awareness of what is in her own best interests. He emphasizes, rather, the integrity rather than the welfare of the agent as justification for honouring her choices. He writes,

...the value of autonomy, on this view, derives from the capacity it protects: the capacity to express one's own character - values, commitments, convictions, and critical as well as experiential interests - in the life one leads. Recognizing an

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<sup>28</sup> Dworkin 1993, 228.

<sup>29</sup> One exception to this claim may be lie in reasons, other than autonomy, for allowing demented people to do as they wish: "For example, if they are prevented from doing as they wish, they may become so agitated that we do them more harm than good by opposing them, even though the decision they make is not itself in their interests." (Dworkin 1993, 222).

individual right of autonomy makes self-creation possible. It allows each of us to be responsible for shaping our lives according to our own coherent or incoherent - but, in any case, distinctive - personality. It allows us to lead our own lives rather than be led along them, so that each of us can be, to the extent a scheme of rights can make this possible, what we have made of ourselves.<sup>30</sup>

Does Margo have the general capacity to lead her life out of a distinctive sense of her own character, a sense of what is important to and for her? Does she, in Dworkin's language, have "the ability to act out of genuine preference or character or conviction or a sense of self"<sup>31</sup>? Dworkin claims that seriously demented patients (such as Margo) do not have this ability. Because their choices contradict one another, "reflecting no coherent sense of self and no discernable even short-term aims", then they do not have the capacity that autonomy otherwise protects.

Although Margo, as now demented, has no right to autonomy according to Dworkin, he maintains that she has a right to her precedent autonomy assuming it is expressed, say, in an advance directive. This right is not based on the evidentiary view - Margo could not judge what would be in her best interests in situations she could not predict - but rather on the integrity view that Dworkin offers. After all, he claims,

A competent person making a living will providing for his treatment if he becomes demented is making exactly the kind of judgment that autonomy, on the integrity view, most respects: a judgment about the overall shape of the kind of life he

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<sup>30</sup> Dworkin 1993, 224.

<sup>31</sup> Dworkin 1993, 225.

wants to have led.<sup>32</sup>

Not only should Margo's previous wishes be respected because no new choices by a person capable of autonomy have annulled them, but also because they are reflective of her "critical" interests. Such interests, claims Dworkin, give genuine meaning and coherent narrative structure to her particular life (as opposed to her "experiential" interests or things pursued simply because we like the experience of them - experiences we share with all sentient creatures). Margo's interest in "living her life in character" (according to her critical interests) includes an interest in controlling the circumstances in which others should permit her life as an Alzheimer patient to continue: limiting that control would in Dworkin's view be an unacceptable form of moral paternalism.

According to Dworkin, Margo as now incompetent has no right to have her wishes respected for reasons of autonomy. Thus, even if she seems happy and expresses a desire to live, her desire is invalidated by her prior wishes that reflect her genuine life values. When a demented patient's interests and her precedent autonomy when competent conflict, her precedent autonomy must reign based on the critical interests that give her life integrity. Even her present right to beneficence - a right that Dworkin grants incompetent persons - is not reason enough to ignore her precedent autonomy, "to make her happy now in spite of whatever she directed before."<sup>33</sup> In fact, claims Dworkin, Margo's prior wishes must be followed in order to do what is in her best interests since what is in her best interests relates not only to Margo as an incompetent

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<sup>32</sup> Dworkin 1993, 226.

<sup>33</sup> Dworkin 1993, 229.

person but to Margo when competent as well. If we are to treat Margo in a way that keeps her in a state she earlier specified that she did not want to be kept in - to honour Margo's present interests and desires - then, on Dworkin's account, we cannot claim to be acting for *her* sake at all.

Once we rule out that form of paternalism - once we accept that we must judge Margo's critical interests as she did when competent to do so - then the conflict between autonomy and beneficence seems to disappear. If Margo had asked not to be given medical care for life-threatening illnesses contracted after she had become demented, neither her right to autonomy *nor* her right to beneficence would give us grounds for denying that request, even if the demented Margo is enjoying her life. We cannot say that we would be showing compassion for Margo if we refused to do what she wanted when she was competent, because that would not be compassionate toward the whole person, the person who tragically became demented.<sup>34</sup>

According to Dresser,<sup>35</sup> Dworkin makes two questionable assumptions about Margo. First, he assumes (in supposing the existence of an advance directive) that her choices will originate in correct and complete information. But, if her choices are in fact based on incorrect information, as is often the case with patients' prior instructions, then there are arguably liberal grounds for interference with these choices. Soft paternalism permits interference in Margo's previously expressed wishes only in the absence of

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<sup>34</sup> Dworkin 1993, 231-232.

<sup>35</sup> Dresser 1995.

voluntariness or genuine consent, as in the case of the 59-year-old farmer. Furthermore, as argued with respect to the cases of Evans and Person B, had Margo predicted her current condition, she might not have documented the choices she did.

Second, Dworkin assumes that Margo the dementia patient is the same person who issued the earlier requests to die. Her critical interests persist, according to Dworkin, despite her current inability to appreciate them. But, insists Dresser, "substantial memory loss and other psychological changes may produce a new person..."<sup>36</sup> If Margo is not in fact the "same person" as she was prior to her dementia, then there are arguably liberal grounds for interference with her prior wishes since her prior wishes do not apply to the person who Margo now is. The past wishes of the woman who was once competent and autonomous are not violated through paternalistic decision making applied to the present incompetent and nonautonomous woman since that past woman no longer "exists". It is not thus illiberal to interfere with the past Margo's choices in the treatment and care of the present Margo's choices since they are different people.

Is there a way in which paternalistic decision making in the case of Margo may be justified from the perspective of Dworkin's otherwise anti-paternalistic liberalism? On the topic of abortion, Dworkin maintains that only conscious individuals can possess interests in not being harmed or destroyed. State interference in the lives of conscious individuals (such as sentient, viable fetuses) is justified based on its perceived legitimate role in protecting creatures capable of having interests of their own. As Dresser argues, Dworkin's analysis of abortion provides support for a policy in which the state acts to

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<sup>36</sup> Dresser 1995, 35.

protect the interests of conscious dementia patients like Margo who, though substantially impaired, "retains capacities for pleasure, enjoyment, interaction, relationships, and so forth."<sup>37</sup> Margo continues to partake in her life's activities - she reads and paints and interacts with other people, for example. Moreover, she *seems* happy living her life. But the fact that she is not unconscious in the way an early stage fetus is may provide a defensible basis for state limitations on the scope of her precedent autonomy, as well as on the choices others make on her behalf.<sup>38</sup> As Dresser argues,

...state restriction is justified when a systematic evaluation by clinicians and others involved in patient care produces agreement that a minimally intrusive life-sustaining intervention is likely to preserve the life of someone as contented and active as Margo.<sup>39</sup>

Thus, notwithstanding her dementia and the incompetence it entails, paternalistic decision making (for example in the form of palliative care should Margo contract a painful and terminal illness) may be justified in the case of Margo given her quality of life.

(Apparent) happiness is not the criterion for limitations on her prior directive. The criterion depends on the acceptability of classifying Margo as a conscious person with the capacities (which for Dresser are Margo's capacities for pleasure, relationships, and so forth) that accompany such consciousness.

From the perspective of liberalism, an argument might be made for decision

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<sup>37</sup> Dresser 1995.

<sup>38</sup> Dresser 1995.

<sup>39</sup> Dresser 1995, 37.

making that overrides the competently expressed preferences of persons on the basis that the interests of parties who are affected by such choices must be protected. For example, the requests of the farmer's family and Oliver Wanglie may be justifiably overridden for the sake of the interests of loved-ones and health care providers, respectively. Beverly Requena's preferences for treatment may be justifiably overridden with respect to the organized beliefs and values of the institution caring for her. And the requests of Mrs. Smith may be justifiably overridden for the sake of the interests of other patients. However, it is difficult to justify within liberalism a soft-paternalistic defense of overriding a patient's previously expressed voluntary, autonomous choice where that choice poses a threat to others since this does not have to do with the best interests of the patient.

Whether the existence of a "weak" or "blocked" will, there are justifiable grounds for (soft) paternalistic action within liberalism. Insofar as it incorporates a principle of (soft) paternalism, at least with respect to a soft-paternalistic defense of overriding a patient's previously expressed voluntary, autonomous choice where that choice now threatens her well-being, contemporary liberalism contributes to an account of justifiable paternalism within the process of advance care planning.

### **Liberalism and the Value of Personal Relationships**

It is implied by critics of the liberal value of autonomy that liberalism fails to account for the concerns and goals people who engage in advance care planning have that relate to the impact of their decision making on others or to the impact of others'

attitudes on their decision making. Autonomy and the concern for individual control is part of what motivates people into bringing their advance care planning to completion, along with their concern for the impact of their decision making on significant others and the role their significant others are to play in the decision-making process. It may be reasonable to assume that the liberal concern for political relationships reflects a deeper agenda to protect the private choices and affairs of individuals. Yet the liberal writers considered here do not discuss the nature and value of personal relationships, *per se*. Though they may portray the individual as situated or embedded in community and culture, the common concern of liberals has not been to provide an account of what is appropriate for relationships in the private (i.e., interpersonal as opposed to strictly domestic) realm. Private relationships, between, for example, physician-patient, patient-family member, physician-family member, have simply not been the liberal focus - the liberal priority being the public (i.e., socio-political) relationship between citizen and state.

It may be argued then that liberalism does not fail as a framework for understanding the value of personal relationships since it has never been its intention to serve in this capacity. As Charles Larmore insists, liberalism (with its ideal of state neutrality and "negative" conception of freedom) is best considered a political doctrine.<sup>40</sup> Nevertheless, as a political doctrine, modern liberalism may still bear on the importance of personal relationships. There are two ways in which it may do this. The first, already mentioned, is through its depiction of the social and communal aspects of

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<sup>40</sup> Larmore 1987.

personhood. The second is through its notion of "political neutrality" which is based primarily on the liberal values of equal respect and political noninterference. Both have relevance for a theoretical account of advance care planning, not in terms of the promotion of the value of personal relationships, but rather in terms of its preservation and protection.

The modern liberal notion of political neutrality is expressed in the view that the state should not reward or penalize particular conceptions of the good life but rather should provide a neutral framework within which different and potentially conflicting conceptions of the good can be chosen and pursued by its citizens. Not all liberals, however, are neutralists. Liberals Ronald Dworkin<sup>41</sup>, Charles Larmore<sup>42</sup>, Will Kymlicka<sup>43</sup> and John Rawls<sup>44</sup> hold that the essence of liberalism is its demand for neutral political concern for different ways of life and individual conceptions of what is good or valuable. Yet, liberals Joseph Raz<sup>45</sup> and William A. Galston<sup>46</sup> argue otherwise that the modern liberal state is committed to a distinct conception of the good such that state neutrality is neither possible nor obligatory.

Among those modern liberals who hold that the fundamental liberal principle must

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<sup>41</sup> Dworkin 1985.

<sup>42</sup> Larmore 1987.

<sup>43</sup> Kymlicka 1989a, 1989b.

<sup>44</sup> Rawls 1993.

<sup>45</sup> Raz 1986.

<sup>46</sup> Galston 1993.

be that of neutrality, or the view that the state should remain neutral toward different conceptions of the good life, Dworkin writes that "government must be neutral on what might be called the question of the good life."<sup>47</sup> That is, political decisions must strive to be independent of any particular view of what gives life value. According to Larmore, "political neutrality consists in a constraint on what factors can be invoked to justify a political decision. Such a decision can count as neutral only if it can be justified without appealing to the presumed intrinsic superiority of any particular conception of the good life".<sup>48</sup> As long as the condition of neutral justification is satisfied then state intervention is defensible. Kymlicka defines neutrality as the view that "the state should not reward or penalize particular conceptions of the good life, but, rather, should provide a neutral framework within which different and potentially conflicting conceptions of the good can be pursued."<sup>49</sup> For Rawls, the state action must satisfy "neutrality of aim in the sense that basic institutions and public policy are not to be designed to favor any particular comprehensive doctrine."<sup>50</sup>

Overall, state neutrality is defined by modern liberals in at least the four following ways<sup>51</sup> that may overlap. First, a neutral state may be defined as one that ensures for all its citizens an equal opportunity to pursue by their own choice their own conceptions

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<sup>47</sup> Dworkin 1985, 191.

<sup>48</sup> Larmore 1987, 44.

<sup>49</sup> Kymlicka 1989, 883.

<sup>50</sup> Rawls 1993, 194.

<sup>51</sup> Galston 1993, 100-101.

of the good, i.e., a *neutrality of opportunity*. Second, a neutral state may be regarded as one whose actions are not justified on the basis of any particular conception of the good rather than another (Larmore and perhaps Dworkin), i.e., a *neutrality of procedure*. Third, a neutral state is viewed as one that does not promote any conception of the good over another (Kymlicka and Rawls), i.e., a *neutrality of aim*. Fourth, a neutral state may be defined as one that does not act in such a way that makes it more likely that a citizen accept, pursue, or realize a particular conception of the good over another. Such a state is neutral if its principles, institutions, and policies do not favour certain ways of life over others, i.e., a *neutrality of outcome, effect, or influence*, which most neutral liberals (notably Larmore and Rawls) reject as being too unrealistic.

In general, modern liberal theorists in defense of state neutrality base their arguments on one of the following three claims.<sup>52</sup> The first is the claim that there is no rational basis for choosing among different conceptions of the good life. The second is the claim that diversity in moral outlooks is a basic fact of modern society and that public efforts to constrain it would be disrespectful of the fundamental equal worth of all citizens and their conceptions of the good. This claim is one of "equal respect". The third claim that may underlie arguments of neutrality is that even if a particular conception of the good life can be known to be true or false, it would be a breach of individual freedom for the state to impose this knowledge on its citizens. This claim is one of "negative freedom" or "political noninterference".

The first is an epistemological claim of scepticism or relativism about knowledge

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<sup>52</sup> Galston 1993, 82.

of the good that implies either that ignorance of the good suggests a kind of moral relativism which mandates tolerance which in turn mandates a neutral state, or that human beings must be treated as equals since there is no known reason to assume one individual's conception of the good is superior to that of another. This claim does not justify neutrality to most liberal theorists. Moreover, it does not speak to the question of the position of autonomy in relation to other values according to modern liberalism.

The second claim that may be appealed to in defense of state neutrality is that diversity in moral outlooks is a basic fact of modern society and that public efforts to constrain it would be morally unacceptable since to do so would constitute a violation of the fundamental equal concern and respect owed to all citizens. The notion of justice as equality, prior to autonomy, is the fundamental basis for this claim.

Dworkin, who holds that the principle of equality is constitutive of modern liberalism, bases his position on the fact that citizens differ in their conceptions of the good. Government fails to treat its citizens as equals when it prefers one conception over another. Therefore, given the fact of pluralism and dispute, government must be neutral among conceptions of the good to ensure that it treats its citizens with equal concern and respect.<sup>53</sup>

The liberal emphasis on the notion of equal respect for freedom of all individuals needed to pursue their own conceptions of the good life is also found in Larmore's liberalism. Freedom here refers strictly to "the right of the person not to face neutrally

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<sup>53</sup> Dworkin 1985, 191.

unjustifiable interference by the state."<sup>54</sup> As a political concern, freedom is thus understood negatively. Negative freedom, or autonomy, demands state neutrality. But surely neutrality would not be a moral demand rightly placed upon government if respect for autonomy were not regarded as a prior political value. Larmore resists this view arguing rather that moral theories, committed to overall "personal ideals", such as autonomy, are unsatisfactory appeals in defense of liberal neutrality since they are "rightly controversial" and thus anything but neutral in themselves.

The distinctive liberal notion for Larmore is that of state neutrality "understood as a response to the variety of conceptions of the good life."<sup>55</sup> Why though should the state remain neutral in the face of pluralism and dispute? On Larmore's account, the required neutral justification of political neutrality is based upon a "universal norm of rational dialogue" applied to political debates. Without exploring this concept here, what Larmore seems to be arguing is that neutrality is justified on the grounds that it leads to the resolution of political disputes through rational dialogue; dialogue that is important to engage in due to the "equal respect" we owe one another.

Rawls' political liberalism is not neutral insofar as it entails principles of justice that express a political conception of fairness for which there is an overlapping consensus or common ground despite the fundamental fact of social pluralism. That is, Rawls' theory of justice aims at public justification for its conception - a justification that begins with public intuitions about what is fair. The idea of the priority of right over good is an

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<sup>54</sup> Larmore 1987, 47.

<sup>55</sup> Larmore 1987, 43.

essential element in Rawls' liberalism. This idea is one associated historically with liberalism, namely, that a political conception of justice must affirm certain basic rights and liberties. For Rawls, when government takes certain steps to strengthen political virtues that are part of a reasonable conception of justice, it is "taking reasonable measures to strengthen the forms of thought and feeling that sustain fair social cooperation between its citizens regarded as free and equal."<sup>56</sup> Conceptions of the good are thus limited by the political conception of justice. Yet ideas of the good must be shared by all free and equal citizens and must not presuppose any particular comprehensive doctrine - a "neutrality of aim" as mentioned above. Social institutions and policies should not be designed to favour any one particular comprehensive doctrine of the good and it is respect for the notion of liberal equality that underlies this demand.

The third claim that may be appealed to in defense of state neutrality is that even if a particular conception of the good life can be known to be true or false (notwithstanding the fact of social diversity), it would be a breach of individual freedom for the state to impose this knowledge on its citizens. This is a claim of negative freedom, or political noninterference.

Critics of this underlying claim take it to mean that freely chosen individual error is always preferable to the coerced pursuit of the good. This, again, is the objection that liberalism necessarily overemphasizes the value of individual autonomy. Neutrality is justified, say critics, because, "it is the practical expression of this priority of freedom over the good". Freedom, or autonomy, thus appears to be the fundamental basis for this

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<sup>56</sup> Rawls 1993, 195.

claim. Yet even if this were the case, there is no reason to equate the (liberal) claim that state imposition would be a breach of individual freedom with the supposition that such freedom must automatically preclude considerations of broader, social goods. Modern liberalism entails a notion of autonomy, understood in terms of the neutrality debate, that is respectful of both individual and shared conceptions of the good.

Modern liberalism, according to Kymlicka, is distinct in its emphasis on state neutrality; a neutrality that is based on the preconditions that to be fulfilled one's life must be led from the "inside", free from coercion, according to one's own beliefs about the good and that one must be free to question those beliefs. Equal state treatment demands that each citizen be provided with the liberties needed to meet these preconditions. For Kymlicka, liberty is essential for the individual to distinguish a life worth pursuing from one not worth pursuing. Nevertheless, the state must be neutral not so that purely individualistic goals may be pursued, but to give citizens the opportunity to make their own autonomous and responsible choices with respect to their social context and communal attachments. Autonomy, he writes, is a fundamental moral power which gives people the capacity to pursue, reflect on, and revise their most deeply held beliefs about what is valuable.<sup>57</sup> Kymlicka's liberalism thus makes room for the importance of social and communal values while still incorporating and preserving the value of individual autonomy. "The real issue", he says, "is not whether individuals' values and autonomy need to be situated in social relations but whether the relevant relations are

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<sup>57</sup> Kymlicka 1989, 892.

necessarily or desirably political ones."<sup>58</sup> The relations that promote individual autonomy should not be determined according to state ideals about what is valuable for leading a good life.

On Kymlicka's account, contemporary liberal neutrality, while based on the liberal principle of autonomy, recognizes the necessity of having a secure cultural structure, i.e., a pluralistic social context. This is not to imply that autonomy is promoted only when judgments about the good are taken out of the political realm (into, say, the "cultural marketplace") but rather that autonomy is *not* promoted when the state uses coercive measures to establish these judgments. Liberal neutrality does not deny the social requirements of individual autonomy but it does demand that individuals be free to choose and form their associations and attachments with others. It challenges the claim that whatever is social must become the province of the political. Modern liberals insist on the importance of the distinction between society and state. Nevertheless, in keeping with the above response to the objection that modern liberalism overemphasizes the value of autonomy, liberal neutrality is not thus excessively individualistic in terms of its conception of the way that individuals evaluate and pursue their ends, i.e., in terms of individual autonomy.

I have explored three claims on which modern liberal defenders of state neutrality base their arguments: that there is no rational basis for choosing among different conceptions of the good life, that diversity in moral outlooks is a basic fact of modern society and that public efforts to constrain it would be disrespectful of the fundamental

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<sup>58</sup> Kymlicka 1989, 905.

equal worth of all citizens and their conceptions of the good, and that even if a particular conception of the good life can be known to be true or false, it would be a breach of individual freedom for the state to impose this knowledge on its citizens. The second and third of these claims emphasize the liberal values of equal respect and political noninterference, respectively, both of which have relevance for a theoretical account of advance care planning. Equal respect and noninterference, though perhaps not important in promoting the value of personal relationships, are essential in the preservation or protection of personal relationships, especially those that function within a broader political institution such as the hospital setting (though it may not be part of the state, *per se*). These liberal values may be essential in keeping personal relationships intact within a political institution that otherwise threatens their security.

Modern liberalism therefore does have something to contribute to an account of the value of personal relationships in advance care planning (depending on how far its notions of neutrality, equal respect, and the social and communal aspects of personhood are stretched). It remains, however, inadequate in accounting for the value of personal relationships, *per se*. That is, liberals do not focus explicitly on the value of personal relationships - the value of personal relationships is not one which defines or is an intrinsic aspect of liberal theory. A revised model for advance care planning must, however, account for the social aspects of personal selfhood and offer an explanation of the significance of important values other than that of individual autonomy that emerge in the decision-making process.

The "new model" of advance care planning described above is based on the fact

that most individuals engaged in the process do not choose to make decisions on their own in isolation from others but rather consult with a family member or close friend about preferences for treatment. Individuals prefer not to involve health care professionals or other "outsiders" when discussing and planning future health care because they consider their advance care planning to be a "private" matter only to be discussed with loved ones and/or because loved ones bear the emotional burden and the burden of substitute decision making when individuals become incompetent. Also, the disposition of loved ones or significant others influences the decisions of those engaged in advance care planning. Those with the emotional support and encouragement of significant others are more likely to proceed with the process than those lacking such support. Moreover, the impetus for preparation in the form of advance care planning begins either in individuals' experiences with illness (their own or that of another) or death of another, or in the nature of individuals' relationships with others. Liberal theory does not provide an explanation of *why* personal relationships are valued in the decision-making process; an explanation which an adequate account of advance care planning must offer. A required supplement to liberalism, then, as an account specifically of the importance of relationships in advance care planning, is a relationship ethic offered by "feminine theorists"<sup>59</sup> from within feminist theory.

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<sup>59</sup> See Sue Sherwin's *No Longer Patient* on the distinction between "feminine ethics" which "consists of observations of how the traditional approaches to ethics fail to fit the moral experiences and intuitions of women" (Sherwin 1992, 49) and "feminist ethics" which "derives from the explicitly political perspective of feminism, wherein the oppression of

Relational theorists argue that although appropriate to relationships between strangers and to purely professional relationships, autonomy is not appropriate to close, personal relationships.<sup>60</sup> In particular, autonomy, they claim, may be inappropriately emphasized when individuals are vulnerable due to illness and dependency on others. Such persons typify those for whom advance directives become useful.

The concern for the value of personal relationships is emphasized in a morality of care that challenges justice-based theories of moral development and judgment<sup>61</sup> (i.e., those associated with the liberal tradition) and theories of ethics and moral education<sup>62</sup> on the grounds that they fail to attend to the justice of the treatment of the sexes. As Susan Okin writes,

This phenomenon is undoubtedly due in part to the fact that Aristotle, whose theory of justice has been so influential, relegated women to a sphere of "household justice" - populated by persons who are not fundamentally equal to the free men who participate in political justice, but inferiors whose natural function is to serve those who are more fully human. The liberal tradition, despite its supposed foundation of individual rights and human equality, is more Aristotelian in this respect than is generally acknowledged. In one way or another, almost all

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women is seen to be morally and politically unacceptable" (*ibid*).

<sup>60</sup> Jennifer Nedelsky, who reconceives autonomy in terms of relationships as I mentioned earlier, is, along with other feminists, an exception to this pool of critics.

<sup>61</sup> Gilligan 1982.

<sup>62</sup> Noddings 1984.

liberal theorists have assumed that the "individual" who is the basic subject of the theories is the male head of a patriarchal household. Thus they have not usually considered applying the principles of justice to women or to relations between the sexes...mainstream contemporary theories of justice do not address the subject any better than those of the past...<sup>63</sup>

Such theories have therefore been criticized as "masculine" approaches to moral decision making and ethical analysis with little, if any, concern for the interests of women.<sup>64</sup>

Moreover, they are often viewed as the presumption of Western (liberal) medical ethics which "often relies on a lexical ordering of principles...or the context of justification for ethical decision making rather than the context within which such decision making takes place...or the kinds of reasons that are regarded appropriate to the making of moral judgments..."<sup>65</sup> Consequently, relational theorists have argued for the importance of context-based values such as that of personal relationships rather than what are perceived to be purely abstract, universal principles.

For example, Sara Fry, who writes in the area of nursing ethics, argues that a feminine medical ethic - an ethic of care "grounded within a moral-point-of-view of persons rather than any idealized conception of moral action, moral behaviour, or system of moral justification"<sup>66</sup> - is more appropriate as the foundation for theories of medical

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<sup>63</sup> Okin 1989.

<sup>64</sup> Fry 1992.

<sup>65</sup> Fry 1992, 94.

<sup>66</sup> Fry 1992, 94.

ethics than liberal values of justice and autonomy.

The difference between "traditional" theories of justice and an ethic of care is described by Betty Sichel who also writes in the area of medical ethics:

With a theory of universal and abstract principles, e.g., as articulated by Rawls, moral agents are not particular, concrete individuals with their own unique life histories, desires, and emotions. Further, neither these dimensions nor relationships with others, neither friendships nor community, should affect moral judgments. Instead, the moral agent is like a placemark, a variable in an algebraic equation, no better and no worse than any other person in that given moral situation. The criteria of deontological moral theory require that moral agents put themselves in the role of relevant others, all of whom should be given equivalent weight.

Women's moral language of response and caring starts from a very different perspective: Moral dilemmas are particular, unique situations in which all parties retain their individual identities, their life histories, emotions, feelings, and relationships. Caring and relationship occur between particular concrete individuals. Moral situations exist within a particular historical and sociological context; they are bound by time and place. Women's morality emphasizes concrete situations, networks of relationships, caring, interpersonal communication...and responsiveness.<sup>67</sup>

Largely stemming from Carol Gilligan's important work that challenges the male

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<sup>67</sup> Sichel 1992, 117-118.

notions of justice as the (superior) norm for all human moral development,<sup>68</sup> an ethic of care is often based on the assumption that women's and men's ways of thinking about moral issues differ significantly. As Okin (along with Gilligan herself) suggests, it may be that the differences can be explained in terms of roles that are socially determined and thus alterable. To assume otherwise may in fact be harmful to women. Okin writes,

There is certainly no evidence - nor could there be, in such a gender-structured society - for concluding that women are somehow naturally more inclined toward contextuality and away from universalism in their moral thinking, a false concept that unfortunately reinforces the old stereotypes that justify separate spheres.<sup>69</sup>

Whether or not Gilligan intended to make such generalizations about the possible distinct moralities of women and men, her literary examples and research, as Tong points out, lead one to generalize that "*men* focus on rights, claims, self-interested demands, strict duties and obligations, burdens, and limits on autonomy and that *women* focus on responsibilities to respond empathetically, to show concern in close relationships, and to nurture and give aid."<sup>70</sup>

Yet this problem with an ethic of care is not with the idea or practice of caring *per se*. Caring, understood as a feminine value, is not necessarily essential to women's and not men's nature, as Gilligan herself admits. The crux of the matter is that caring ought to be promoted in particular private relationships and, as many feminists argue, in

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<sup>68</sup> Gilligan 1982.

<sup>69</sup> Okin 1989, 15.

<sup>70</sup> Tong 1989, 166.

public ones as well. As highlighted by Fry and Sichel, the relevance of a caring-based ethical model for medical ethics is clear. In the area of advance care planning, an ethic of care is essential in accounting for the significance of personal relationships exhibited in the process. After all, a care ethic is not merely prescriptive - it also has explanatory power insofar as it defines moral dilemmas, such as decision making about future care, as particular, unique, and concrete situations in which individuals are engaged in networks of relationships, interpersonal communication and emotions shared by others.

A relationship ethic is more appropriate than liberalism as an account specifically of the value of personal relationships revealed in the process of advance care planning; after all, liberalism is fundamentally a political doctrine. But does this mean that, although fundamentally a political doctrine, modern liberalism cannot serve in this capacity at all? I have argued that liberalism, through its depiction of the social and communal aspects of personhood and its notion of political neutrality, bears on the significance of personal relationships in terms of their protection and preservation. Yet does this mean that modern liberal thinking must remain essentially detached from thinking of ourselves as essentially related to close others? Can it provide an account of why personal relationships have the significance they do in advance care planning? Liberal responses to critiques aimed at liberal feminism are attempts to answer these questions.

Feminist critics who separate themselves from liberal thinking have argued against liberal feminism in a way that suggests that liberal feminist theory, and its presumption of an ethic of justice, is incompatible with an ethic of care. Two prominent criticisms echo

those aimed at liberalism as described earlier. One is a socialist feminist critique of liberal feminism that comes from Alison Jaggar, writing in 1983, whose main criticism of liberal feminism is aimed at its conception of the self as an abstract rational and autonomous agent.<sup>71</sup> The other comes from Jean Bethke Elshtain who, writing in 1986, says of liberal feminists that "their emphasis on the priority of the individual over the community prevents people from coming together."<sup>72</sup> These criticisms are not surprising, given those against liberalism in general. What they imply specifically, though, is that liberal feminism (and thus liberalism more broadly considered) *precludes* the value placed on concrete, personal relationships that is integral to an ethic of care.

Okin, herself a liberal feminist, insists otherwise. She writes,

...I think the distinction between an [liberal Rawlsian] ethic of justice and an ethic of care has been overdrawn. The best theorizing about justice...has integral to it the notions of care and empathy, of thinking of the interests and well-being of others who may be very different from ourselves. It is, therefore, misleading to draw a dichotomy as though they were two contrasting ethics. The best theorizing about justice is not some abstract "view from nowhere," but results from the carefully attentive consideration of *everyone's* point of view. This means, of course, that the best theorizing about justice is not good enough if it does not, or cannot readily be adapted to, include women and their points of view as fully as

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<sup>71</sup> Tong 1989.

<sup>72</sup> Tong 1989, 32.

men and their points of view.<sup>73</sup>

...As Rawls himself says, the combination of conditions he imposes on them "forces each person in the original position to take the good of others into account." The parties can be presented as the "rational, mutually disinterested" agents characteristic of rational choice theory only because they do not know *which* self they will turn out to be. The veil of ignorance is such a demanding stipulation that it converts what would, without it, be self-interest into equal concern for others, including others who are very different from ourselves. Those in the original position cannot think from the position of *nobody*, as is suggested by those critics who then conclude that Rawls's theory depends upon a "disembodied" concept of the self. They must, rather, think from the perspective of *everybody*, in the sense of *each in turn*. To do this requires, at the very least, both strong empathy and a preparedness to listen carefully to the very different points of view of others.<sup>74</sup>

From the perspective of liberalism in general, rather than from that of liberal feminism, Kymlicka highlights the question of "whether there is a care-based approach to political questions that competes with justice, and, if there is, whether it is a superior approach."<sup>75</sup> Though the ethic of care deals with the responsibilities we take on in

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<sup>73</sup> Okin 1989, 15.

<sup>74</sup> Okin 1989, 100-101.

<sup>75</sup> Kymlicka 1990, 264.

virtue of engaging in particular private relationships, many feminists, Kymlicka says, argue that the care ethic has public significance and should be extended to public affairs.<sup>76</sup>

The challenges that a liberal conception of justice faces with respect to an ethic of care are taken on by Kymlicka in terms of three headings: moral capacities (i.e., developing moral dispositions rather than learning moral principles); moral reasoning (i.e., solving problems by seeking responses that are appropriate to the particular case rather than by seeking principles that have universal applicability), and moral concepts (namely, attending to responsibilities and relationships rather than attending to rights and fairness).<sup>77</sup>

Most contemporary theorists of justice, admits Kymlicka, concentrate more on determining correct principles than on explaining how individuals are to develop moral dispositions. Yet he argues that the justice ethic also requires these moral dispositions in order that general principles of justice are determined to be relevant to a situation, and to determine what those principles require. And, he continues,

Even if justice involves applying abstract principles, people will only develop an effective "sense of justice" if they learn a broad range of moral capacities, including the capacity for sympathetic and imaginative perception of the requirements of the particular situation.<sup>78</sup>

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<sup>76</sup> Kymlicka 1990, 264.

<sup>77</sup> Kymlicka 1990, 265.

<sup>78</sup> Kymlicka 1990, 266.

Many justice theorists, insists Kymlicka, recognize the role of the family in developing a sense of justice. For example, Rawls presents a view of how a sense of justice stems from the moral environment of the family. However, in agreement with Okin, Kymlicka recognizes that Rawls, along with other liberal thinkers, neglects the issue of the justice or injustice of the gendered family itself.

Moreover, Kymlicka argues that the kind of moral reasoning associated with an ethic of justice is not inconsistent with that of an ethic of care since in making moral decisions, individuals do not merely attend to the particularities of the situation. The process also entails identifying the particular features that are morally significant and sometimes resolving conflicts between the demands of those in a particular case - steps that necessitate appeal to a broader framework of normative principles.

Finally, Kymlicka challenges the perceived difference between the moral concepts of a care ethic approach and that of an ethic of justice. Care theorists, in stressing the connectiveness of all persons, are, as justice theorists, committed to a principle of universality (though this principle is not necessarily applied the same way by both theories). Also, an ethic of justice does not respond solely to people's common (abstract) humanity rather than our concrete differences with which an ethic of care is concerned. In keeping with Okin in referring to Rawls' theory as a feminist paradigm of justice-thinking he writes,

The fact that [on Rawls' account] people are asked to reason in abstraction from their own social position, natural talents, and personal preferences when thinking about others does not mean that they must ignore the particular preferences,

talents, and social position of others. And...Rawls insists that parties behind the original position must take these things into account...the effect of the veil [of ignorance] is that "it no longer matters to the [contractor in] the original position who, if anyone, occupies the position with him or what its occupants' interests are. What matters to him are the desires and goals of every *actual* member of his society, because the veil forces him to reason *as if he were any one of them*".<sup>79</sup>

Kymlicka also challenges the perceived difference between the moral concepts of a care ethic approach and that of an ethic of justice by arguing against the claim that justice reasoning focusses on concern for others in terms of respecting rights-claims, whereas care reasoning thinks of concern for others in terms of accepting responsibilities. The justice framework with the exception of the libertarian construal of rights as noninterference, he argues, emphasizes people's rights as rights that impose responsibilities on others. If a difference exists, then it lies, rather, in the tendency liberals have for preferring objective unfairness as the basis for moral claims as opposed to the care theorist's emphasis on subjective hurt. Yet Kymlicka insists that the emphasis on objective unfairness is legitimate only in certain contexts; namely, interactions between competent adults - a public context that is arguably separate from the private sphere of the morality of subjective hurt. This distinction has implications for moral responsibility:

For care theorists, the emphasis on objective unfairness sanctions an abdication of moral responsibility, because it limits our responsibility for others to claims of

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<sup>79</sup> Kymlicka 1990, 274.

unfairness, and thereby allows people to ignore avoidable suffering. For justice theorists, the emphasis on subjective hurts sanctions an abdication of moral responsibility, because it denies that the imprudent should pay for the costs of their choices, and thereby rewards those who are irresponsible, while penalizing those who act responsibly...The debate between care and justice, therefore, is not between responsibility and rights. On the contrary, responsibility is central to the justice ethic<sup>80</sup>

...But I cannot legitimately expect people to attend to all of my interests [as is the case when subjective hurts are taken to give rise to moral claims], for there are some interests which remain my own responsibility, and it would be wrong to expect others to forgo their good to attend to things which are my responsibility.<sup>81</sup>

The justice theorist's appeal to abstract rules to determine in advance the appropriate limits on our autonomy and moral responsibilities to others (fully context-sensitive decisions do not permit this kind of predictability) is not evidence that justice ignores our "distinct individuality", claims Kymlicka. He writes,

For the net result of this abstraction from particularity is to protect particularity more fully. The more our claims are dependent on context-sensitive calculations of everyone's particular desires, the more vulnerable our personal projects are to

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<sup>80</sup> Kymlicka 1990, 278.

<sup>81</sup> Kymlicka 1990, 277.

the shifting desires of others, and so the less we will be able to make long-term commitments. Meaningful autonomy requires predictability, and predictability requires some insulation from context-sensitivity. This still leaves the possibility that some [competent] people will have strong desires that are frustrated by the application of abstract rules. But...the justice ethic assumes that competent adults are capable of adjusting their ends in the light of public standards.<sup>82</sup>

Feminist critics who separate themselves from liberal thinking have argued against liberal feminism in a way that suggests that liberal feminist theory, and its presumption of an ethic of justice, is incompatible with an ethic of care. Yet, although a relationship ethic is more appropriate than liberalism in accounting for the value of personal relationships revealed in the process of advance care planning, this does not mean that modern liberalism as a political doctrine has nothing to contribute to the role of personal relationships in the planning process. Modern liberals do portray the individual as situated or embedded in community and culture. And, modern liberalism's doctrine of noninterference may be viewed as a way of preserving personal relationships in the process. Moreover, liberalism as a theory of justice is not entirely contradicted by an ethic of care which does clearly account for the role of personal relationships in advance care planning. Yet, though not necessarily detached from thinking of ourselves as essentially related to close others, liberalism, in lacking an account of *why* personal relationships are valued, remains insufficient in accounting for the extent of the concerns and goals people who engage in advance care planning have that relate to the impact of

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<sup>82</sup> Kymlicka 1990, 281.

their decision making on others or to the impact of others' attitudes on their decision making. Through its account of moral capacities, reasoning and conceptualizing, a relationship ethic as offered by feminism, defines the moral dilemmas of decision-making as particular and concrete situations in which persons are engaged in relationships with others.

The integration of both ethics as part of an overall theoretical framework for advance care planning is, however, most suitable. It has been argued that autonomy and relatedness are compatible concepts; rather than opposites they are associates and even co-dependents.<sup>83</sup> This seems to be supported by the empirical data of the studies considered above insofar as the concept of control serves the needs of relationships as relationships shape the need for control.<sup>84</sup> As Donna Hoopfer reminds us, each person is simultaneously separate from and connected to others. She writes,

A sense of justice and caring reflects this inherent duality of separateness and connection in the human condition. All of us are constituted by being in relation with others but each of us is a unique and separate human being from those who care for us. This way of seeing people acknowledges that care and justice are both equally needed in the moral life. Without a sense of justice, the individual moral worth of a person is not acknowledged; and without caring, the essential connection between the flourishing of individuals is not acknowledged. The coalition of caring and justice can be stronger in guiding ethical practice than

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<sup>83</sup> Berlin and Johnson 1989.

<sup>84</sup> Martin 1996.

either ethical concept can provide alone... An ethic based solely on caring, like an ethic based solely on justice, would result in incomplete moral responses.<sup>85</sup>

Modern liberal theory accounts for important aspects of advance care planning that capture respect for the inherent worth of each person who participates in the process. It also recognizes that autonomy is not a value with absolute overriding significance. Yet, though it serves to preserve and protect the value of personal relationships in advance care planning through its historical and social interpretation of the autonomous individual and its notion of political neutrality, a relationship ethic is more accurate than liberalism in accounting for the relational aspects of advance care planning. Thus, the supplementation of modern liberal theory with relational accounts that stress the value of personal relationships is warranted.

### **Is the Value of Autonomy Overemphasized by Liberals?**

The objection that the liberal value of autonomy is overemphasized in the theoretical grounding of advance care planning carries with it the assumption that such overemphasis characterizes liberalism. As shown above, values other than that of individual autonomy play a significant role in decision making about future care. Individual autonomy, though an important aspect of the rationale behind advance care planning, does not serve as a sufficient value for this process. Liberalism is faulty, critics have claimed, in promoting individual autonomy at the expense of other important values that take the concerns and welfare of others into account. However, liberalism, at

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<sup>85</sup> Hoopfer 1996, 6,7.

least in its contemporary form, does not necessitate the overriding significance of individual autonomy.

Modern liberalism is rightly understood as a political theory generally based on a conception of justice as equality. As such, it accounts for the concerns those planning for their future treatment may have for the effect of their decisions on the greater patient population and society-at-large and for decisions that override patient wishes for the sake of fairness in allocation of available health services. Moreover, it accounts for concerns for personal control in decision making and even acts of paternalism where personal choice is justifiably denied based on what is in the best interests of patients.

Such concerns are not contradicted by a liberal theoretical framework for advance care planning. Yet modern liberalism is insufficient in accounting for the importance of personal relationships in the process of advance care planning. Relational theory which pertains specifically to the value of personal relationships is a plausible complement to the liberal framework as a theoretical basis for advance care planning.

## CONCLUSION

The prevailing assumption underlying the use of advance directives is that these documents should be honoured since they respect, or at least aim to respect, the value of patient autonomy, or self-determination. By enabling a competent person to "extend" his or her autonomous decision-making capacity into a future state in which this capacity no longer exists, an advance directive presumably gives a person control over the end of his or her life. Among the most cogent objections to the use of advance directives are those aimed directly at their primary justification, namely, the value of patient autonomy or self-determination. In this thesis, I have examined the meaning and role of the modern liberal concept of autonomy, and the liberal theoretical framework with which it is associated, with respect to the philosophical grounding of advance care planning.

With respect to two main criticisms that underlie the objection that autonomy, and the liberal framework within which it is associated, is an insufficient value upon which to base advance care planning, I have tried to show that the liberal concept of autonomy is not an impoverished or internally flawed concept. As explained above, theoretical objections that suggest liberal conceptions of autonomy are impoverished are based on the argument for a kind of situated self, or the demand for an explanation of persons that situates them within the broader community or society.

The liberal autonomous self, however, is not atomistic and independent in the sense of being fundamentally or ultimately detached from its essential community, social

and cultural ties. It is not a disembodied, or unencumbered, being defined prior to its ends. This is a misinterpretation of the modern liberal notion of selfhood. The liberal claim that we have an ability to detach ourselves from any particular social context does not mean that we can place ourselves in a situation in which there is no given communal practice. It means rather that nothing is "set in stone" for us; nothing is authoritative before our judgment of its value. We are never perceived as selves totally unencumbered by any ends - there are always some given ends - but there are no particular ends which must always be taken as given with the self. Moreover, not only can we question our values but we can even go further to reject them entirely for instance when we come to view them as worthless or degrading. Yet liberal interpretations do not demand an understanding of the self that denies its embeddedness within society and culture.

The objection that the liberal value of autonomy is overemphasized in the theoretical grounding of advance care planning carries with it the assumption that such overemphasis characterizes liberalism. But this assumption is invalid. Liberals recognize the relative weight of autonomy with respect to other important values, concerns and goals. Charles Taylor argues that true freedom, or capacity for autonomous choice, is "situated" or set in a situation that gives content to our actions, and not something pursued strictly for its own sake without regard to projects and goals that are worth pursuing. As Kymlicka notes, modern liberalism does not contradict Taylor on this point. Liberals hold that it is precisely because our goals are so important that we should be able to revise and reject them if they become unfulfilling. Individual autonomy is not pursued for its own sake, but as a precondition for pursuing those projects and goals that

are valued for their own sake.<sup>86</sup>

Liberal ideals are not based fundamentally on the value of autonomy and, where autonomy does appear to be a fundamental ideal, it is not one that negates the importance of individuals' social attachments. While it aims to preserve the value of individual autonomy, modern liberalism, understood in terms of the neutrality debate, is respectful of both individual and shared conceptions of the good. It acknowledges that relationships, society, community, and culture constitute, to a large degree, self-identity. Of course relationships, society, community, and culture can be promoted and protected by legally enforced "collective rights". Contemporary liberalism does not deny this. Its task, however, in response to conventional debates between the value of collective goods versus individual rights is not to categorically confirm individual values over and above relationships or the collective but rather *to specify the appropriate sense in which individual values are to be preserved given the importance of other values.*

Though not all modern liberals are neutralists, or share the same understanding of the proper relationship between citizen and state, they do share the common, fundamental liberal concern for the preservation of the individual vis-à-vis "the crowd". Individual fulfillment depends on a sense of self-worth, and the liberal aim is to protect this sense of worth. Individual liberty, or autonomy, is a requirement of self-worth and fulfillment and is thus assumed by liberals (unlike, say, authoritarians) to be a human good. Modern liberal theories offer accounts of the ways in which the individual must be related to the state to be most effective in the protection of personal liberty. It is important to realize,

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<sup>86</sup> Kymlicka 1989b, 48.

therefore, that according to modern liberalism, autonomy is a political value attributed to the individual in relation to the governance of his or her broader society and culture. As Nedelsky points out, the presence of a social component of autonomy does not mean that the value cannot be threatened by collective choices and so there exists the continuing need to identify autonomy as a separate value. One role of modern liberalism is to respond to this need.

As empirical studies of advance care planning reveal, values other than that of individual autonomy play a significant role in decision making about future care. Moreover, case studies suggest that values that do not stem from the expressed wishes of the individual ought to override individual autonomy under certain circumstances. Autonomy, though an important aspect of the rationale behind advance care planning, does not serve as a sufficient value for this process. Liberalism is faulty, critics have claimed, in promoting individual autonomy at the expense of other important values that take the concerns and welfare of others into account. However, I have tried to demonstrate that liberalism, at least in its contemporary form, does not necessitate the overriding significance of individual autonomy.

Modern liberalism's concept of autonomy and its related interpretations are crucial for the theoretical explanation of the fact that persons engaged in advance care planning cite control of their own treatment decisions as a main planning incentive. Understood as a political theory generally based on a conception of justice as equality, modern liberalism accounts for the concerns those planning for their future treatment may have for the effect of their decisions on the greater patient population and society-at-large and

for decisions that override patient wishes for the sake of fairness in allocation of available health services. Modern liberalism also allows for acts of paternalism where personal choice is justifiably denied based on what is in the best interests of patients. Advance care planning, therefore, must not be based on an ethic that precludes the liberal value of autonomy.

Moreover, though it makes a limited contribution to the value of personal relationships in the process of advance care planning through its notions of political neutrality and equal respect, the liberal value of autonomy, and the liberal theoretical framework with which it is associated, is insufficient in accounting for the value of personal relationships that are a key element of advance care planning. I have argued, therefore, for the supplementation, and not replacement, of liberal theory with relational accounts of the more specific nature and value of personal relationships toward a theoretical basis for advance care planning.

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## **APPENDIX**

### **An Example of a Generic Advance Directive Form\***

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## **ABOUT THE CENTRE FOR BIOETHICS**

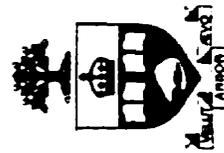
The University of Toronto Centre for Bioethics, established in 1989, is an interdisciplinary group of health care professionals, lawyers, philosophers, and others. The activities of the Centre include bioethics research, education, and consultation. This living will is a direct product of our research program. The Centre is funded entirely by research grants, private donations, and bequests. If you would like more copies of this living will, more information about the Centre, or information about making a donation to the Centre, please contact us at the address below. Private and corporate donations to the Centre are eligible for a charitable tax receipt. Proceeds from this living will are used to support further research on living wills at the Centre for Bioethics.

**UNIVERSITY OF TORONTO  
CENTRE FOR BIOETHICS**

# **LIVING WILL**

**CENTRE FOR BIOETHICS  
UNIVERSITY OF TORONTO**

88 College St.  
Toronto, ON M5G 1L4  
Tel. (416) 978-2709  
Fax. (416) 978-1911



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## PREFACE

The Centre for Bioethics Living Will was developed by Dr. Peter A. Singer. It is a guide to help you think about and express your wishes about future health and personal care decisions. The living will is not intended to be used in the absence of specific medical or legal advice. The Centre for Bioethics and Dr. Singer assume no liability for any reliance by any person on the information contained herein. The University of Toronto makes no representations regarding the technical quality, accuracy, or lawfulness of the material presented herein. If you have any suggestions for improving this living will, please send them to Dr. Singer at the Centre for Bioethics (see back page for his address).

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## Chapter 1

### Questions and Answers About Living Wills

#### WHAT IS A LIVING WILL?

A living will is a document containing your wishes about your future health care or personal care. You make a living will when you can understand treatment choices and appreciate their consequences (i.e., when you are "capable"). A living will only takes effect when you can no longer understand and appreciate treatment choices (i.e., when you are "incapable"). Living wills are also called "advance directives", "health care directives", and "powers of attorney for personal care". There are two parts to a living will: a *proxy directive* and an *instruction directive*.

#### WHAT IS A PROXY DIRECTIVE?

A *proxy directive* specifies *who* you want to make decisions on your behalf if you can no longer do so. The proxy should be someone you know and trust, such as a spouse, partner, family member, or close friend. This person should be capable of making health care and other personal care decisions and willing to be your proxy. Because the proxy is responsible for carrying out your wishes, **it is important that you discuss your wishes with your proxy**. Otherwise, it may be difficult for your proxy to guess what your wishes might be.

## WHAT TYPE OF LIVING WILL SHOULD I COMPLETE?

Because instruction and proxy directives are complementary, your living will should, if possible, contain both of these directives. However, if you do not have someone you trust to make decisions on your behalf, then you may want to complete only the instruction directive. If you find that making decisions for a possible future illness is too difficult, then you may want to complete only the proxy directive.

## WHAT ARE "PERSONAL CARE" DECISIONS?

Personal care decisions refer to decisions about those aspects of daily life that are necessary for maintaining your health and well-being. These include shelter, nutrition, hygiene, clothing, and safety. This living will allows you to state your wishes about these issues in a separate instruction directive.

You may name more than one person to act as your proxy, but you should state whether they should make decisions together as a group, or whether they should be given authority individually. In addition, you may want to indicate how disagreements between your proxies should be resolved, or you may want to name different proxies to make different decisions. Taking these steps can help to avoid conflict in case your proxies disagree about your treatments. You may want to say in your living will whether you would want your doctors to follow the treatment decisions of your proxy or your wishes as expressed in the instruction directive if these two appear to be in conflict.

## WHAT IS AN INSTRUCTION DIRECTIVE?

An *instruction directive* specifies *what* health care or other personal care choices you would want your proxy to make. This living will gives you information on which to base your health and personal care decisions. It also provides space for you to express, in your own terms, the values that should guide these decisions.

## HOW IS A LIVING WILL DIFFERENT FROM A PROPERTY WILL OR FINANCIAL POWER OF ATTORNEY?

A property will takes effect only after you have died, and directs how your property will be distributed among your heirs. A living will takes effect when you become incapable of making decisions for yourself. It contains your instructions regarding health care and other personal care decisions, and/or names someone to make these decisions on your behalf if you are no longer capable of doing so. A living will is also different than a financial power of attorney, which authorizes someone to make decisions regarding your finances and property, but not personal care.

## DO I NEED TO COMPLETE THE LIVING WILL WITH MY DOCTOR?

You should probably review your living will with your doctor. The doctor can ensure that you have understood the choices in the living will and tailor the instruction directive to your own health situation. For example, a person with chronic lung disease will want to focus primarily on whether to go on a ventilator (breathing machine) if he/she develops respiratory failure. A person with kidney failure receiving dialysis will want to focus primarily on the situations in which he/she would want dialysis to be continued or stopped.

## DO I NEED TO COMPLETE THE LIVING WILL WITH MY LAWYER?

You do not need a lawyer to complete your living will. However, some people might feel more comfortable if they review their living will with a lawyer. There are situations in which you should involve a lawyer in completing your living will: if your capacity to make a living will is likely to be challenged or if it is likely that there will be disagreement about treatment among your family or between your family and proxy. Many lawyers raise the topic of living wills when their clients are making out their property wills. A lawyer can also give you more specific and current information about the laws regarding living wills in your province, and ensure that your living will is legally valid.

## WHAT IF I CHANGE MY MIND ABOUT MY TREATMENT WISHES OR PROXY?

You can change your mind about your health care or other personal care decisions or your proxy at any time while you are still capable. If you change your mind, you should change your living will. Also, you should review your living will at regular intervals, such as once a year, and when there are important changes in your life - for example: if your medical condition changes, if you are admitted to hospital, if you marry or divorce, or if your proxy dies. If you change your living will, replace all copies of the old one with copies of the new one. You should destroy the old copies so they do not get mixed up with the new copies of your living will.

## WHAT SHOULD I DO WITH MY COMPLETED LIVING WILL?

Since a living will speaks for you when you are no longer able to speak for yourself, other people must know that it exists and where you keep the original. The cut-out card at the back of this booklet could be carried in your wallet. You should give copies of your living will to your proxy, doctor(s), lawyer (if you have involved one), and family members. If you review your wishes with these people and give them the opportunity to discuss your living will with you, they will be more likely to understand and be able to follow your wishes. Do not put your living will in your safety deposit box, since it will not be easy to gain access to it when needed. You should feel free to photocopy the Centre for Bioethics Living Will once you have completed it.

## WILL MY LIVING WILL BE FOLLOWED?

Yes, it should be followed. The Canadian Medical Association has endorsed a policy supporting living wills and most doctors favour them. In provinces with specific legislation, people may be legally required to follow your living will. However, there could be circumstances in which you would not want people to follow your living will – for example, if there is evidence that you have changed your mind but have not changed your living will, or if there has been a medical advance that you did not know about when you completed the forms. In your living will, you can say how much leeway you want to give your proxy in following your wishes.

## WHO SHOULD COMPLETE A LIVING WILL?

People who want to maintain control over their future health care and personal care should consider making a living will. However, to make a living will, you must consider the prospect of your own sickness and death. Some people might find this distressing. Each person should decide whether completing a living will is right for them. Remember, a person may choose to complete an instruction directive, a proxy directive, both, or perhaps neither.

## WHY SHOULD I COMPLETE A LIVING WILL?

If you don't, there might be conflict among family members about who should make decisions for you or what treatment should be given. Even if there is no conflict, it may be very difficult for your loved ones to make life-and-death decisions for you. A living will makes it easier on loved ones by reducing guilt feelings. If your loved ones feel they are making the decision you would have made, they will be less likely to blame themselves and feel guilty. If you haven't told anyone what you want, no one will know.

## Chapter 2

### Is A Living Will Legal In Canada?

The provinces of British Columbia, Manitoba, Nova Scotia, Ontario and Quebec have passed laws recognizing living wills. Some of the laws recognize proxy directives only, whereas others recognize both proxy and instruction directives.

In British Columbia, a new package of legislation has been passed and is expected to come into force in 1996. The laws will allow people to name a representative or temporary substitute decision-maker to make minor or major health care decisions on their behalf, as well as other decisions about personal care, legal, and financial matters. The laws will also allow people to give detailed instructions about any of these decisions.

The Manitoba law came into force on July 26, 1993. In Manitoba, a living will is called a "Health Care Directive". People who are 16 years of age or older are presumed capable to make a health care directive. The person appointed to be the proxy must be at least 18 years old. To be valid, a health care directive must be in writing, signed by the person making it, and dated. The health care directive does not need to be witnessed if the person making it can sign for him-herself. The legislation does not require that a particular form be used.

In Nova Scotia, the legislation permits a competent adult (i.e., a person of the age of majority) to authorize another person of the age of majority to give consent on his or her behalf in the future at any time when the person who gave the authorization is no longer capable of giving such consent.

The Ontario law was passed in 1992 and is expected to come into force in 1995. In Ontario, a living will is called a "power of attorney for personal care". A power of attorney for personal care must contain a proxy (known as the "attorney for personal care"), and may contain instructions. The document must meet certain technical requirements to be legally valid. The person making the power of attorney for personal care, as well as the person appointed to be the proxy, must be at least 16 years old. The following people cannot act as proxy: someone providing the person making the living will with health care, or residential, social, training, advocacy, or support services for pay (unless the person is a spouse, partner, or relative). The power of attorney for personal care must be witnessed by two people. The witnesses must have no reason to believe the person making it is incapable of giving a power of attorney for personal care. The following people cannot act as witnesses: the proxy; the spouse or partner of the patient or proxy; a child of the patient; anyone who him-herself has a legal guardian; and anyone who is less than 18 years old. After the person has become incapable, it is possible to validate a power of attorney for personal care through the Public Guardian

and Trustee. Once validated, changes to the document must be filed with the Office of the Public Guardian and Trustee. The legislation does not require that a particular form be used.

In Quebec, since April 15, 1990, a person may give a proxy directive termed a "mandate in advance of incapacity". The person giving the mandate (the mandator) may name another person (the mandatory) to act on his/her behalf when he/she becomes incapacitated. Section 11 of the Civil Code of Quebec, which came into force on January 1, 1994, refers to the mandate given by a person in anticipation of incapacity and confirms that it may include the power to accept or refuse care. This mandate given by an adult at least 18 years of age is made by notarial act or in the presence of two disinterested witnesses who attest to the fact that the person is competent. The mandate takes effect once the court verifies that the person has become incompetent and confirms the validity of the mandate. No particular form is specified in the law.

It is reasonable to expect that other provinces will pass laws about living wills in the future. There are also court cases in Canada that would support the use of living wills. As well, the Canadian Medical Association has endorsed a policy supporting the use of living wills.

## Chapter 3

# Information About Health Care Decisions

To make an **instruction directive** for health care decisions, you need to imagine yourself becoming very ill or nearing death. It is not easy to imagine these situations or to decide upon treatments for them. To help you with this, we describe in detail some health situations in which a living will might be needed, and the life-sustaining treatments that might be used. This information should help you to fill in the "grid" part of the instruction directive on page 27.

As you are considering these treatments, keep in mind that you may feel differently about them if you were actually in the situations described than you feel about them now. For all the situations, imagine you are in the situation, and that you need the treatment. Remember that the treatment can be long-term or short-term as described below.

## HEALTH SITUATIONS

### CURRENT HEALTH

This describes the way your health is now. The category of current health is included mainly for emergency purposes. That is, if you had a potentially reversible accident or illness that made you incapable today, the

way your health is now, what treatments would you want if you needed them? For example, if you had a heart attack and your heart stopped, would you want CPR (see below)? If you developed pneumonia and couldn't breathe on your own, would you want to go on a ventilator?

## STROKE

This means you would have damage to the brain causing permanent physical disability such as paralysis. You might also have trouble communicating because of impaired speech. Assume that these problems stay the same for the rest of your life. They do not get worse with time unless there is another injury to the brain, such as another stroke. Stroke can be described as follows.

**Mild:** You would have mild paralysis on one side of the body. You could walk with a cane or walker. You would be able to have meaningful conversations, but might have trouble finding words. You could carry out most routine daily activities, such as work and household duties, dressing, eating, bathing, and using the toilet. You would have bowel and bladder control. You could live at home with someone caring for you for a few hours each day.

**Moderate:** You would have moderate paralysis on one side of the body. You would be unable to walk and would need a wheelchair. You could carry out conversations, but you might not always make sense. You would need help with routine daily activities. You may have bowel and bladder control. You could live at

home with someone caring for you throughout the daytime; otherwise you would probably need to live in a nursing home.

**Severe:** You would have severe paralysis on one side of the body. You would be unable to walk, and would need to be in a chair or bed. You would not have meaningful conversations. You would be unable to carry out routine daily activities. You would need a feeding tube for nourishment. You would not have bowel or bladder control. You could live at home with someone caring for you all day and night; otherwise you would probably need to be cared for in a chronic care hospital.

## DEMENTIA

This means you would have a progressive and irreversible deterioration in brain function. You would be awake and aware but you would have trouble thinking clearly, recognizing people, and communicating. The most common cause of dementia is Alzheimer's disease. Dementia gradually gets worse over months or years. Dementia can be described as follows.

**Mild:** You could have meaningful conversations, but would be forgetful and have poor short-term memory. You could carry out most routine daily activities, such as work and household duties, dressing, eating, bathing, and using the toilet. You would have bowel and bladder control. You could live at home with someone caring for you for a few hours each day.

**Moderate:** You would not always recognize family and friends. You could carry out conversations but you might not always make sense. You would need help with routine daily activities. You may have bowel and bladder control. You could live at home with someone caring for you throughout the daytime; otherwise you would probably need to live in a nursing home.

**Severe:** You would not recognize family and friends, and would be unable to have meaningful conversations. You would be unable to carry out routine daily activities. You would need a feeding tube for nourishment. You would not have bowel and bladder control. You could live at home with someone caring for you all day and night; otherwise you would probably need to be cared for in a chronic care hospital.

**PERMANENT COMA**

This means you would be permanently unconscious. Permanent coma is usually caused by decreased blood flow to the brain for example, from the heart stopping. You would be unable to eat or drink and would need a feeding tube for nourishment. You would not have bowel or bladder control. You would need to be in bed, and you would never regain consciousness. You could live at home with someone caring for you all day and night; otherwise you would probably need to be cared for in a chronic care hospital.

**TERMINAL ILLNESS**

This means you would have an illness for which there is no known cure, such as some types of cancer. The time between diagnosis of a terminal illness and death varies considerably, but it is usually less than six months. One of the most common concerns for people diagnosed with a terminal illness is that they will have to suffer a great deal of pain. With proper pain management, however, this should usually not be the case.

**LIFE-SUSTAINING TREATMENTS**

In each of the health situations described above, you might need one or more of the following life-sustaining treatments.

**CARDIOPULMONARY RESUSCITATION (CPR)**

is used to try to restart the heart if it has stopped beating. CPR involves applying pressure and electrical shocks to the chest, assisted breathing with a respirator (breathing machine) through a tube inserted down the throat and into the lungs, and giving drugs through a needle into a vein. It is usually followed by unconsciousness and several days of treatment in an intensive care unit. Without CPR, immediate death is certain. On average when hospitalized patients are given CPR, it is successful at restarting the heart in about 41% of patients (41 patients out of 100). However, about 14% (14 patients out of 100) will live to be discharged from hospital. These figures vary greatly depending on the type and severity of the patient's illness. Patients whose hearts are

successfully restarted but who do not survive to hospital discharge spend several days in an intensive care unit before death. The chance that a person will live depends on the cause of the heart stopping and the seriousness of the person's other illnesses.

**VENTILATOR** (breathing machine) is used when a person cannot breathe; for example, because of emphysema or a serious pneumonia. A tube is put down the person's throat into the lungs. The ventilator is needed as long as the person's lungs are not working. Without the ventilator, a person with respiratory failure will probably die within minutes to hours. With the ventilator, the chance that a person will live depends on the cause of the respiratory failure, and the seriousness of the person's other illnesses.

**DIALYSIS** (kidney machine) replaces the normal functions of the kidney. Dialysis removes excess potassium, water, and other waste products from the blood. Without dialysis, the potassium in the blood would build up and cause the heart to stop. Dialysis is needed as long as the person's kidneys are not working. Without dialysis, a person with kidney failure will die within 7 to 14 days. With dialysis, the chance that a person will live depends on the cause of the kidney failure and the seriousness of the person's other illnesses.

**LIFE-SAVING SURGERY** may involve a wide range of procedures – for example, removal of an inflamed gall bladder or appendix. Without surgery, a person with a serious illness may die within hours to days. With

surgery, the chance that a person will live depends on why the person needed surgery and the seriousness of the person's other injuries or illnesses.

**BLOOD TRANSFUSION** refers to blood given through a needle inserted in a person's vein. A person who is bleeding very heavily from a car accident, a stomach ulcer, or during major surgery, needs a blood transfusion. Without a blood transfusion, a person who is bleeding very heavily will probably die within hours. With a blood transfusion, the chance that a person will live depends on the seriousness of the person's other injuries or illnesses.

**LIFE-SAVING ANTIBIOTICS** refers to the drugs needed to treat life-threatening infections; for example, pneumonia or meningitis. These drugs usually are given through a needle inserted in a person's vein. Without antibiotics, a person with a life-threatening infection will likely die in hours to days. With antibiotics, the chance that a person will live depends on the seriousness of the infection and the seriousness of the person's other illnesses.

**TUBE FEEDING** involves putting a tube into a person's stomach (through the nose, or through a small hole in the abdomen). A person who cannot eat (e.g., someone in a coma) needs a feeding tube. Without tube feeding, a person who cannot eat or drink will die within days to weeks. With tube feeding, the chance that a person will live depends on the seriousness of the person's other injuries or illnesses.

**Information About Personal Care Decisions**

In addition to decisions about health care, you can use your living will to record your wishes about other aspects of your personal care, such as shelter, nutrition, hygiene, clothing, and safety.

**SHELTER**

Decisions about shelter concern where you will live. These decisions arise most often when you cannot easily receive the care you need at home, or when it is felt that you are at risk of suffering harm if you continue to live at home. If you would need to, are you willing to go to a hospital or long-term care facility?

**NUTRITION**

Decisions about nutrition concern what types of food you will receive. For example, if you would prefer to be given a vegetarian diet, or if you would prefer a specific type of food according to your cultural or religious beliefs (such as Kosher food), you can indicate in your living will.

**HYGIENE**

Decisions about hygiene concern your personal cleanliness. For example, what would you like your caregivers to do if you refuse bathing?

**CLOTHING**

Decisions about clothing concern what types of clothing you want to wear. For example, there may be certain clothing that has cultural or religious significance such as yarmulkes or turbans.

**SAFETY**

Safety is a theme that runs through all of these other personal care decisions. Some decisions you might make about shelter, nutrition, hygiene, or clothing could put you "at risk" of suffering harm. In addition, safety may involve decisions about the use of restraints. How would you like your caregivers to balance your freedom to be "at risk" against your personal safety?

## Chapter 5

# The Centre for Bioethics Living Will

### INFORMATION ABOUT THE PERSON COMPLETING THIS LIVING WILL

I have read and understood all sections of this living will. All previous living wills made by me are to be disregarded, and this directive is to be followed according to my wishes stated here.

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## WITNESSES

We have witnessed the signature above and have no reason to believe the person making this living will is incapable of making a living will. [NOTE: The witnesses must be present together when the living will is signed by the person completing it.]

### WITNESS 1

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

### WITNESS 2

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

### PROXY DIRECTIVE

The proxy must follow the wishes of the person making the living will. In situations for which the person has not specified a wish the proxy would make the decision based on the person's best interests, taking into consideration the person's values and beliefs.

If you name more than one person to act as your proxy, you should say how they will make their decisions. There are three options.

First, you can have your proxies make decisions one at a time, in the order that you list them in your living will. If a particular proxy is unavailable, or has died, then the next proxy listed in your living will would make the necessary decisions on your behalf.

Second, you can say in your living will that you want your proxies to make decisions as a group. If you want your proxies to make decisions as a group, you should indicate how you would like disagreements between your proxies to be resolved.

Third, you can limit the authority of your proxies to make certain decisions. For example, you may have someone who you want to make decisions about your health care, and someone else to make other personal care decisions such as nutrition, clothing, hygiene or shelter.

You can also say how much leeway your proxy should have in interpreting your wishes.

In accordance with current standards of the province, I authorize the following person to make health care and other personal care decisions on my behalf if I am no longer capable of making them myself:

#### Proxy 1

Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Telephone: \_\_\_\_\_

If you want more than one person to be your proxy, add the additional name(s) below:

#### Proxy 2

Name: \_\_\_\_\_

Relationship: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Telephone: \_\_\_\_\_ 176

Proxy 3

Name: \_\_\_\_\_  
Relationship: \_\_\_\_\_  
Address: \_\_\_\_\_  
\_\_\_\_\_  
Telephone: \_\_\_\_\_

Proxy 4

Name: \_\_\_\_\_  
Relationship: \_\_\_\_\_  
Address: \_\_\_\_\_  
\_\_\_\_\_  
Telephone: \_\_\_\_\_

Do you want your proxies to make decisions individually (i.e., proxy 1 will make decisions if available; otherwise proxy 2 will make decisions etc.), or as a group?

- individually
- as a group

If you want your proxies to make decisions as a group, how do you want disagreements resolved?

- follow directions of proxy 1
- follow directions of the majority of my proxies

If you want particular proxies to make health care decisions, and others to make other personal care decisions, specify here:

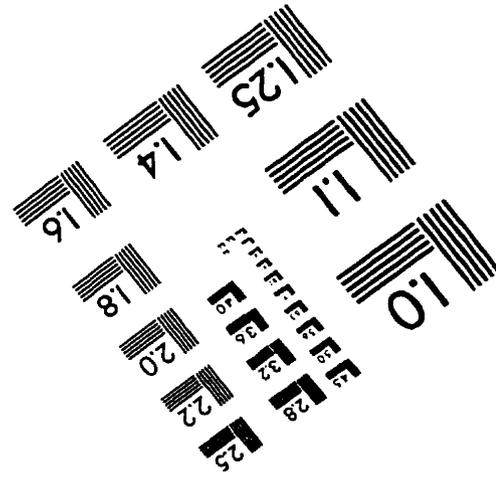
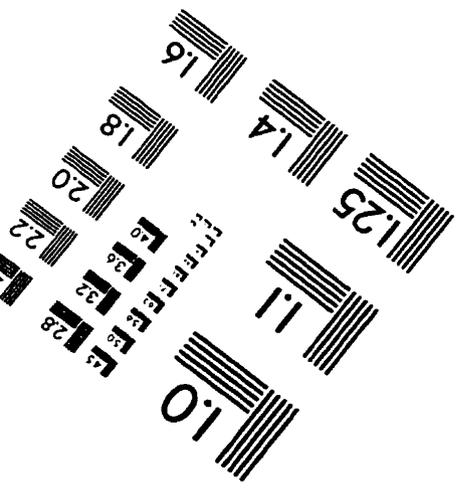
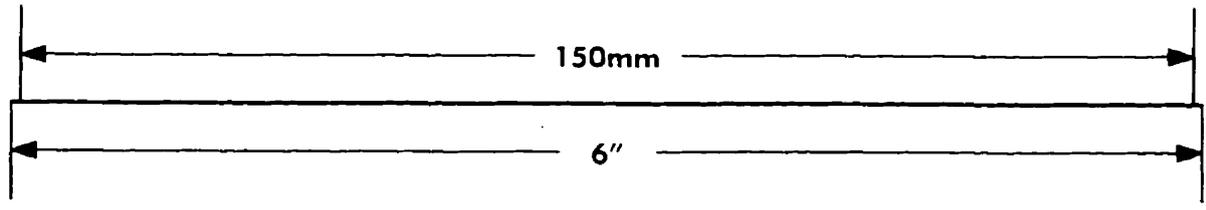
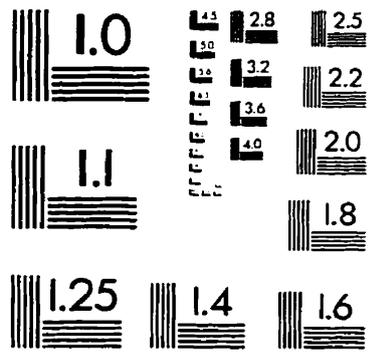
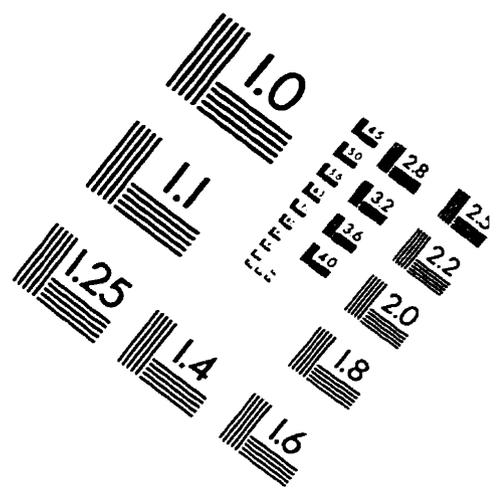
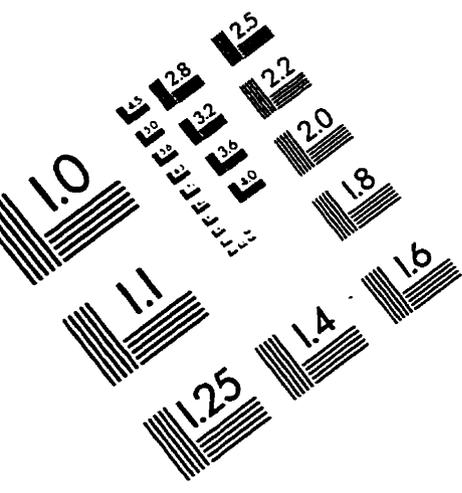
How much leeway do you want to give your proxies in interpreting your wishes? Specify here:







# IMAGE EVALUATION TEST TARGET (QA-3)



APPLIED IMAGE, Inc  
 1653 East Main Street  
 Rochester, NY 14609 USA  
 Phone: 716/482-0300  
 Fax: 716/288-5989

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