

DECISIONMAKING AT THE END OF LIFE: PATIENTS WITH ALZHEIMER'S OR OTHER DEMENTIAS

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Patients with dementia present difficult issues for health-care decisionmaking. This article addresses the moral and legal issues posed by end of life decisionmaking for such patients. In general, the ethical goals of care are to assure that patients' choices are respected and that patients' best interests are protected. These goals may not always recommend the same decisions about care, however, and there is controversy about how they should be balanced when they conflict. In addition, the law may not always further these goals, nor be as helpful as it could be in resolving conflicts between them.

In the bioethics literature, respect for patients' autonomy is generally taken to be the more weighty value. In the literature about dementia, however, this priority has been questioned. Some commentators have argued that, given the immense personal changes involved in the development of dementia, the best interests of a now-demented patient ought to take precedence over the choices of the previously-competent person. This article begins with issues raised by the value of autonomy, then turns to questions about the patient's interests, and finally discusses the resolution of conflicts between the two. The first section considers the patient's own participation in decisionmaking about care, emphasizing the importance of preserving present autonomy to the extent possible.¹ The second section discusses precedent autonomy and the mechanisms by which it may be fostered, such as living wills and special

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¹ See *infra* notes 7-46 and accompanying text.

powers of attorney for health care.² The third section examines arguments undermining the authority of precedent autonomy, including empirical data about the instability of preferences and the significance of radical alterations in personality.³ The fourth section takes up accounts of how to assess the best interests of patients with dementia, including hedonic accounts, preference accounts, and theories of objective interests.⁴ The final section defends a balance between precedent autonomy and best interests, arguing that as expressions of prior choice become clearer, they should bear the greater weight; correspondingly, when there are very strong interest based considerations that involve the patient's present experiences, they should prevail over less clear indications of prior choice.⁵

Because patients with dementia experience a more-or-less drawn-out downhill course, they present a variety of problems in end-of-life care. One problem is that it is not even clear what counts as "end-of-life care" for such patients. Although one study indicates a 53% mortality within six months for patients with dementia and pneumonia, and a 55% mortality within six months for patients with dementia and hip fracture, such patients with dementia may not meet the criteria for invocation of state advance directive statutes which require that a patient either be terminally ill in a narrow sense or permanently comatose.⁶ The scope of this article therefore includes decisions along what may be an extended course of care, rather than merely decisions at an apparent end point, such as DNAR ("do not attempt resuscitation") orders. Some of these decisions involve illnesses not associated directly with the dementia: cancer, diabetes, hypertension. Others involve conditions that are more direct manifestations of the dementia, such as malnutrition and the inability to take food orally, or pneumonia.

² See *infra* notes 47-128 and accompanying text.

³ See *infra* notes 129-70 and accompanying text.

⁴ See *infra* notes 171-219 and accompanying text.

⁵ See *infra* notes 220 and accompanying text.

⁶ R. Sean Morrison & Albert L. Siu, *Survival in End-Stage Dementia Following Acute Illness*, 284 JAMA 47, 50-51 (2000).

I. DECISIONMAKING ABOUT CARE: THE PATIENT'S OWN ROLE

Patients have the moral and legal right to make their own health-care decisions, to the extent that they are able to do so. This right applies to all patients, whether or not they have been diagnosed with dementia. The Ethics and Humanities Subcommittee of the American Academy of Neurology reminds physicians of the importance of trying to maintain the patient's ability to participate in decisions about care: "Neurologists may unintentionally depersonalize demented patients because subconsciously they may equate the loss of intellect with the loss of personhood Neurologists should optimize the therapeutic benefit of the patient-physician relationship by striving to maintain respect for the patient and recognizing and avoiding depersonalization behavior."⁷ This section takes up two forms of patient participation: making their own decisions directly, and creating advance directives to be used when they are no longer able to participate themselves.

A. DIRECT PARTICIPATION BY THE PATIENT IN DECISIONS ABOUT CARE

A diagnosis of dementia does not preclude a patient's ability to participate directly in decisions about her care. There are, however, characteristic issues that are likely to arise with respect to the decisionmaking capacities of patients with dementia, such as loss of cognitive faculties, memory failures, communication difficulties, frailty, and dependency. This section first sets out the appropriate framework to be used in deciding whether a patient has the capacity to participate in decisions, and then takes up the significance of these special problems.

First, a brief note about the medical issues involved in managing patients with dementia for maximum participation in health-care decisionmaking. Patients near the end of a downhill course of dementia almost certainly cannot participate in health-care decisionmaking and cannot be enabled to do so through medical

⁷ Am. Acad. of Neurology, Ethics and Humanities Subcomm., *Ethical Issues in the Management of the Demented Patient*, 46 *NEUROLOGY* 1180, 1180-83 (1996) [hereinafter Am. Acad. of Neurology].

management. Nonetheless, the reminder is in order that medical management itself may affect the cognitive and communicative abilities of patients.⁸ This reminder is perhaps especially in order in light of data that significant percentages of physicians may equate a diagnosis of dementia with incompetence.⁹ Medical choices can be arranged so as to help patients meet the standards set out below. Examples include treating depression, treating co-morbidities that affect cognition such as hypertension or diabetes, correcting deficits in sight or hearing, and ensuring proper nutrition.¹⁰ In some cases, difficult moral choices may be faced when there are conflicts between apparently optimal therapeutic management and efforts to enable the patient to participate in decisions; adjustment of medication to control agitation or pain is an example. Nonetheless, at a minimum autonomy requires acknowledging such conflicts and attempting to minimize them.

1. *Capacities and Legal Competence.* The terminology of "capacity/incapacity" and "competence/incompetence" is an initial source of confusion in discussions of the patient's participation in health-care decisionmaking. Strictly speaking, "competence/incompetence" are legal standards; "capacity/incapacity" refer to facts about the patient's abilities. "Incompetence" is a legal status: incompetent persons lack the legal power to make the range of decisions for which they have been declared incompetent. In its formal sense, a finding of incompetence requires a judicial determination. Without such a determination, patients are presumed competent; that is, are presumed to have the legal power to make their own decisions with respect to health care or any other matters. The terms "capacity" and "incapacity" refer to the patient's actual abilities. Incapacity indicates a medical or psychological judgment about what a person can or cannot do. Determinations of legal competence rest on such factual judgments about capacities. Capacities can fluctuate from moment to moment; competence is an ongoing status, subject of course to judicial revision. Terminology in

⁸ *Id.*

⁹ Seena Fazel et al., *Dementia, Intelligence, and the Competence to Complete Advance Directives*, 354 LANCET 48 (1999).

¹⁰ Am. Acad. of Neurology, *supra* note 7, at 1180-83.

this area is not always clear, however, and "competence/incompetence" and "capacity/incapacity" may be used interchangeably. Moreover, patients are frequently regarded as incompetent without a formal judicial determination, when their loss of capacities is undisputed; and courts encourage such informal judgments.¹¹ At times, this terminological confusion can be problematic, as when legal structures are set up with the goal of avoiding the need for a judicial determination of incompetence when a patient lacks decisionmaking capacity, but the terminology used in the structures is "competence/incompetence."¹²

Standards about the capacities which are relevant to a patient's making his or her own health-care decisions are linked to the moral value of protecting autonomy. Autonomy, as generally understood, means patients' ability to choose for themselves in accord with their own values.¹³ If patients are unable to make reasoned choices, or to communicate the choices they have made, they can no longer manifest autonomy directly and autonomy can no longer be protected for them by honoring their present choices. Accordingly, patients should have at least the following capacities in order to participate in their health-care decisions: a basic understanding of their condition, the choice(s) they face, and the alternatives available to them and their likely outcomes; the ability to articulate their values to a rudimentary extent; and the ability to link chosen alternatives to their values in a reasoned way. When patients lack these capacities and are likely to continue to do so for an extended period, a legal determination of incompetence may be needed and appropriate.

In addition to respect for autonomy, the patient's best interest is also a value in decisionmaking about care. In recognition of this value, some commentators suggest setting the standard for legal competence with both autonomy and the patient's best interests in

¹¹ *Wendland v. Wendland*, 93 Cal. Rptr. 2d 550 (Cal. Ct. App. 2000), *review granted and opinion superseded by*, *In re Conservatorship of Wendland*, 2 P.3d 1065 (Cal. 2000); *In re Conservatorship of Drabick*, 245 Cal. Rptr. 840, 844 (Cal. Ct. App. 1988).

¹² ALAN D. LIEBERSON, *ADVANCE MEDICAL DIRECTIVES* (1992 & Supp. 2000); ALAN MEISEL, *THE RIGHT TO DIE* (2d ed. 1995 & Supp. 2000).

¹³ *But see* Agnieszka Jaworska, *Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value*, 28 PHIL. & PUB. AFF. 105 (1999) (defining "autonomy" as "capacity to value").

mind. Buchanan & Brock¹⁴ argue that where the risks of a particular choice are high and irreversible, and where the chosen alternative appears to be clearly against the patient's best interests, the standard for competence should be set high.¹⁵ On the other hand, where risks are low and the patients' choices appear to be in accord with their interests, the bar for competence should be lowered, allowing more limited abilities of understanding and articulation. Their example of a risky choice against interests is refusal of surgery for a simple appendectomy when there is no apparent explanation for the refusal in the patient's own values. A decision to withdraw or withhold treatment, when death is a risk, may meet these criteria, provided it is clearly against the patient's best interests. But a decision to treat when the result would be significant discomfort or morbidity and little prolongation of life, or prolongation of life with limited quality, also might be against the patient's interests.¹⁶ Even on such a risk-related standard for competence, death is not the only, or always the worst, evil.

Risk-related standards for competence have been criticized severely. Wicclair points out that they have not been accepted legally.¹⁷ Perhaps this failure is judicious, in light of other difficulties Wicclair identifies, that the risk-related standard is both asymmetrical and normative. The asymmetry is that on the risk-related standard, a patient might be both competent and incompetent with respect to the same choice situation: competent to choose the course of action that is not regarded as risky, but not competent to choose the course of action that is. In the example of the appendectomy above, a patient who can meet a lower standard might be competent to choose the surgery, but not competent to refuse. Wicclair contends that this standard builds judgments about the content of decisions into determinations of competence and thus is implicitly normative.¹⁸ He voices the particular concern that it

¹⁴ ALLEN E. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* (1989).

¹⁵ James F. Drane, *The Many Faces of Competency*, 15 *HASTINGS CENTER REP.*, Apr. 1985, at 17-21.

¹⁶ *Id.*

¹⁷ Mark Wicclair, *Patient Decision-Making Capacity and Risk*, 5 *BIOETHICS* 91 (1991).

¹⁸ *Id.*

may lead health-care providers to be overly willing to judge a patient competent who agrees with therapeutic recommendations.¹⁹ Wicclair concludes instead that when decisions are riskier, we should be more careful in assessing competence, but should not change standards for competence themselves, either at the high or at the low end.²⁰ In a subsequent contribution to the debate, Wilks argues that the risk-related standard is not content based in the sense that it relies on the outcome of the decision, but that asymmetries of competence are appropriate when decisions are more complex.²¹ Brock replies that if the goal of a judgment of legal competence is to transfer the power to decide from the patient to a surrogate, it is appropriate to build both respect for autonomy and concern for the patient's interests into a determination of competence.²² As a practical matter, however, risk-related standards have not found their way into judicial determinations of incompetence.

Adjudications of incompetence determine legal status and transfer decisionmaking power from the patient to a surrogate appointed for that purpose. For health-care decisions, such determinations are infrequent; resort to them is most likely when there is disagreement about the appropriate course of action or concern about its legal ramifications, as there was in early cases authorizing discontinuation of ventilator support or medically-provided nutrition.²³ In the leading text about end of life decisionmaking, Meisel describes approvingly the fact that most difficult health-care decisions about incompetent patients are made without resort to the courts.²⁴ At the same time, Meisel notes continuing reluctance on the part of physicians to discontinue life-sustaining treatment without judicial authorization. The ironic

¹⁹ *Id.*

²⁰ *Id.*

²¹ Ian Wilks, *The Debate Over Risk-Related Standards of Competence*, 11 *BIOETHICS* 416 (1997). *Contra* Gita S. Cale, *Continuing the Debate Over Risk-Related Standards of Competence*, 13 *BIOETHICS* 131 (1999).

²² See generally Dan W. Brock, *Decisionmaking Competence and Risk*, 5 *BIOETHICS* 105 (1991); Dan W. Brock, *Trumping Advance Directives*, 21 *HASTINGS CENTER REP.*, Sept.-Oct. 1991, at S5-S6.

²³ MEISEL, *supra* note 12, at 164; *In re Conservatorship of Drabick*, 245 Cal. Rptr. 840 (Cal. Ct. App. 1988).

²⁴ MEISEL, *supra* note 12, at 164.

result may be inappropriate decisions to continue care, with as much or more frequency as inappropriate decisions to discontinue care.

Because they deprive the patient of a fundamental liberty, adjudications of incompetence require a high burden of proof, that of clear and convincing evidence, and they must be narrowly tailored to the patient's situation. Guardianships are thus often structured for limited purposes, such as health-care decisionmaking. In determining the need for guardianship, courts have been moving away from a focus on incapacities generally, to more specific consideration of whether patients lack the capacities outlined above to make reasoned decisions for their care. Meisel states forcefully the difference between assessments of these capacities and disagreement with a patient's apparent decision to refuse treatment: "It is essential . . . to distinguish refusal of treatment as a triggering factor from refusal of treatment as evidence (or worse, the equivalent) of incompetence."²⁵ Assessments of such a loss of capacity are factual judgments, relying on testimony from those who have assessed or worked with the patient. Law in at least one state, however, does not require a formal investigation for a determination of incompetence "if there is clear and convincing evidence from a physician that the person . . . suffers from . . . fourth stage Alzheimer's disease."²⁶

2. *Special Problems in Applying Standards of Competence to Patients with Dementia.* Cognitive deficits of patients with dementia may affect all of the capacities involved in making reasoned decisionmaking about health care. Patients may have limited cognitive abilities to understand information, to formulate the abstractions involved in having values, and to engage in decisionmaking processes. These impairments are not, however, predictably uniform among patients. They will also vary in their significance for particular decisions, depending on the complexity of the decision at stake. Commentators, therefore, stress that judgments of the capacity of a patient with Alzheimer's to participate in care decisions must be assessed on a situation-by-situation

²⁵ *Id.* at 120-21.

²⁶ UTAH CODE ANN. § 75-5-303(4)(a) (2000).

basis.²⁷ In addition to generally diminished capacity, several more specific problems are also likely to be encountered in patients with dementia.

Alzheimer's patients are likely to evidence difficulties with short-term memory. They may be unable, for example, to remember a recent conversation about a health-care decision. Thus a conversation about a treatment decision that occurred on one day may have been forgotten by the next. Such memory impairments, however, do not entail that a patient is incapable of making health-care decisions. Fellows argues that the fact that a memory impaired patient forgets earlier decisions should not undermine a judgment of capacity, so long as there is stability in the conclusions reached.²⁸ On Fellows' view, if the patient, thinking through the problem apparently anew, reaches the same conclusion that she did earlier, a judgment of capacity might be justified. The problem in such a case would be whether the patient is able to understand her condition and its significance and to formulate values; the loss of memory of a time-limited conversational event would not show conclusively the absence of such other capacities.²⁹

Depression is another source of difficulty in assessing the capacities of patients with dementia. Depression is a somewhat common correlate of dementia, one that may be difficult to diagnose.³⁰ Depression may affect cognition as well as affect. Depressed patients may be unable or unwilling to express values, or to process information in accord with their values. An important factor in attempting to foster the capacities of patients with dementia, therefore, is assessing and treating depression. The fact of depression, however, does not itself indicate incapacity; it is just one among the many factors that may affect the patient's ability to engage in reasoned decisionmaking.

Patients with dementia, moreover, may experience difficulties in communication that do not fully reflect their underlying abilities to

²⁷ Lesley K. Fellows, *Competency and Consent in Dementia*, 46 J. AM. GERIATRICS SOC'Y 922, 923 (1998).

²⁸ *Id.*

²⁹ See generally Jaworska, *supra* note 13.

³⁰ See generally Thomas B. Mackenzie et al., *Differences Between Patient and Family Assessments of Depression in Alzheimer's Disease*, 146 AM. J. PSYCHIATRY 1174 (1989).

make choices and express their wishes. Linguistic disturbances such as the inability to remember words are a common manifestation of Alzheimer's dementia. The relatively fast-paced rhythm of ordinary conversation is another difficulty. Recent research suggests that patients with early and mid-stage Alzheimer's demonstrate more understanding than is frequently believed.³¹ Methods for improving communication with demented patients have been developed, such as slowing down the speed of conversations and introducing methods of conversational control.³²

Frailty and resulting dependency are another set of problems encountered when patients have dementia. Patients who are physically frail may evidence fluctuating capacities to participate in decisionmaking. Efforts should be made to enable them to be consulted at times when they are most lucid and most physically able. Physical frailty, coupled with the cognitive deficits of dementia, may lead to significant dependency. In such circumstances, it is important to be especially sensitive to the risks of suggestibility and coercion.³³ When decisions must be made, the tendency may be to bypass any participation by the patient at all, in the erroneous equation of dementia and incapacity.³⁴ Even when patients are consulted, however, it is important to ascertain whether the choices expressed are the patients' own, rather than choices pressed upon them by care-givers or expressed in the effort to please care-givers. One reported trial court decision explored the possibility that a grandson had exerted undue influence on his grandmother's refusal of a tracheostomy, but concluded that she had decisionmaking capacity and that he had only made his views known to her and had not overreached for financial gain.³⁵ Cultural factors or gender roles may also be evident when patients assume attitudes of deference.

In sum, a diagnosis of dementia by itself does not preclude meeting standards of legal competence. To be sure, patients with

³¹ See generally MALCOLM GOLDSMITH, HEARING THE VOICE OF PEOPLE WITH DEMENTIA: OPPORTUNITIES AND OBSTACLES (1996).

³² *Id.*

³³ Fellows, *supra* note 27.

³⁴ Fazel et al., *supra* note 9.

³⁵ *Blackman v. New York City Health & Hosps. Corp.*, 660 N.Y.S.2d 643, 649 (Sup. Ct. 1997) (finding that clear and convincing evidence standard inapplicable when patient has decisionmaking capacity).

severe dementia are unlikely to meet these standards, but patients with early or mid-stage dementia might. Capacity should be assessed on a case-by-case basis, taking into account the patient's abilities to understand and reason in the context of the decision at stake.

B. CREATING ADVANCE DIRECTIVES

A related issue, but one not identical to decisionmaking about care itself, is whether patients with dementia have the legal power to create advance directives. The statutory standard for the power to make advance directives may differ from the standard for competence to make health-care decisions. It is possible for a patient to have the legal capacity to create an advance directive but to have been adjudicated incompetent for the purposes of making his or her own health-care decisions. It is also possible for the patient to have the legal power to make an advance directive that will come into play immediately by its terms in virtue of the patient's evident incapacity to make health-care decisions themselves.³⁶ One recent British study concluded that twenty percent of patients with early dementia were able to express reasoned treatment preferences with respect to clinical vignettes and that these capacities varied with intelligence.³⁷

The common standard for creating an advance directive is testamentary capacity. The Uniform Rights of the Terminally Ill Act Section 2, for example, provides that "[a]n individual of sound mind and [18] or more years of age" may make an advance directive,³⁸ and many state statutes use comparable language. "Of sound mind" is the standard language for testamentary capacity, borrowed from probate codes and used in advance directive statutes without definition or further explanation.

The streamlined Uniform Health-Care Decisions Act Section 2,³⁹ on the other hand, simply provides (without explanation) that "an

³⁶ LIEBERSON, *supra* note 12, at 735.

³⁷ Fazel et al., *supra* note 9.

³⁸ 9B U.L.A. 175 (Supp. 2000).

³⁹ See generally Charles P. Sabatino, *The New Uniform Health Care Decisions Act: Paving a Health Care Decisions Superhighway?*, 53 MD. L. REV. 1238 (1994).

adult” can give advance instructions for health-care decisions by means of a range of advance directives.⁴⁰ There are state advance directive statutes that do not use the language of probate; Oregon, for example, provides that a capable adult may execute a power of attorney for health care or a living will, but also provides no further explanation of its standard.⁴¹ Maine, in adopting the Uniform Health-Care Decisions Act, provided that the declarant must have capacity in a defined sense:

‘Capacity’ means the ability to have a basic understanding of the diagnosed condition and to understand the significant benefits, risks and alternatives to the proposed health care and the consequences of foregoing the proposed treatment, the ability to make and communicate a health care decision and the ability to understand the consequences of designating an agent or surrogate to make health-care decisions.⁴²

“Testamentary capacity” requires that the testator be able to identify the natural objects of her bounty and their relationships to him, to recall the nature and extent of his property, and to dispose of his property understandingly. A determination of legal incompetence in other respects and the appointment of a guardian or a conservator for financial matters does not preclude testamentary capacity, if the testator meets these standards.⁴³

There are clear analogies for advance directives to these standards for testamentary capacity. If a patient can understand the concept of a living will, the possibility of death, and the significance of turning down life-sustaining care, he would seem to have the capacity to make a living will. It is even more likely that a patient

⁴⁰ 9 U.L.A. 315 (Supp. 1999).

⁴¹ OR. REV. STAT. § 127.510(1) (1991) (providing for “not incapable” adult execution).

⁴² ME. REV. STAT. ANN. tit. 18, § 5-801(c) (West 1998).

⁴³ See, e.g., *Burns v. Marshall*, 767 So.2d 347, 352 (Ala. 2000); *McKasson v. Hamric*, 20 S.W.3d 446, 450 (Ark. Ct. App. 2000); *Pope v. Fields*, 536 S.E.2d 740, 743 (Ga. 2000); *In re Estate of Herbert*, 979 P.2d 39 (Haw. 1999); *Verdi v. Toland*, 733 N.E.2d 25, 28 (Ind. Ct. App. 2000); *In re Estate of Morris*, No. A-99-028, 2000 Neb. App. LEXIS 142, at *13 (Neb. Ct. App. May 16, 2000); *Johnson v. Avery*, No. 02A01-9803-CV-00079, 1999 Tenn. App. LEXIS 394, at *9 (Tenn. Ct. App. June 22, 1999); *In re Estate of Schlueter*, 994 P.2d 937, 940-41 (Wyo. 2000).

would have the capacity to appoint a special power of attorney for health care. Here, the understanding required would be the identity of the "natural" person to speak for him (perhaps a spouse or a child), the fact that important decisions about care are being made, and the result that the identified surrogate will make them for him. With such understanding, which seems possible when patients with dementia can still recognize loved ones and participate in relationships, the power to appoint a surrogate decisionmaker would remain. Wary of possibilities of undue influence, however, North Dakota requires that when nursing home residents execute powers of attorney for health care, the execution must be witnessed by a religious representative, an attorney, or a patient advocate.⁴⁴

When testamentary capacity is challenged, the burden of proof is on the challenger to show that the testator lacked capacity or was influenced unduly. The proof may be required to meet the preponderance of the evidence standard, or it may be required to meet the higher clear and convincing evidence standard.⁴⁵ There are apparently no reported adjudications of challenges to the capacity to create an advance directive. Courts that insist on clear and convincing evidence of a patient's wishes before permitting termination of life-sustaining treatment might, however, insist on clear and convincing evidence of the capacity to make an advance directive as well.⁴⁶

II. DECISIONMAKING ABOUT CARE: PRECEDENT AUTONOMY

What Ronald Dworkin calls "precedent autonomy" allows a now-capable person to control decisionmaking at a later point in time when he no longer has the capacity to do so.⁴⁷ There are several, importantly different arguments for the recognition of precedent autonomy. Most obviously, precedent autonomy recognizes the

⁴⁴ N.D. CENT. CODE § 23-06.5-10(2) (1999).

⁴⁵ See *Cupples v. Pruitt*, 754 So.2d 328, 333 (La. Ct. App. 2000) (applying clear and convincing evidence standard to determination of lack of testamentary capacity in challenge to will bequeathing property to blood relative).

⁴⁶ LIEBERSON, *supra* note 12, at 727.

⁴⁷ Ronald Dworkin, *Autonomy and the Demented Self*, 64 MILBANK Q. 4, 10 (Supp. 2 1986).

freedom of a person with present capacities to make plans for his own future. Second, it allows now-capable people to further their interests in determining how they will die, shaping the ends of their lives and how they will be remembered. Perhaps more controversially, precedent autonomy may also be defended as the best way to give effect to whatever value autonomy continues to have for the later-incapacitated person about whose care decisions must be made. These arguments are different, and subject to different objections to the authority of precedent autonomy, as discussed in section III below.

Three standard legal methods further the exercise of precedent autonomy. A patient may prepare a living will. A patient may authorize a surrogate to make health-care decisions on his behalf, through creation of a special, durable power of attorney for health care (SPA). Or, a patient may have expressed his wishes in less formal ways, telling family members or friends what he would want to have done, in circumstances more or less well articulated. Such wishes might then be employed in a surrogate's exercise of "substituted judgment," with the surrogate deciding for the patient as it is thought the patient would have decided for himself. This section describes how these three forms of precedent autonomy operate; the following section discusses criticisms of their authority: whether they are really to be regarded as the exercise of autonomy, and whether they should control when they direct care that is at odds with the patient's best interests at a later time.

A vast amount of law has contributed to the realization of precedent autonomy. Since 1976, the year in which *In re Quinlan*⁴⁸ was decided and the California Natural Death Act⁴⁹ was adopted, all states have adopted some form of advance directive statute. States were encouraged in this effort by Justice Sandra Day O'Connor's concurring opinion in *Cruzan v. Director*,⁵⁰ and by the ensuing federal Patient Self-Determination Act. Many states have also adopted statutes authorizing surrogates to exercise judgment on

⁴⁸ *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

⁴⁹ CAL. HEALTH & SAFETY CODE § 85-7195 (West Supp. 1988) (repealed).

⁵⁰ 497 U.S. 261 (1990) (finding that if state insists on clear and convincing evidence of patient's wishes before permitting withdrawal of life-sustaining treatment, it is constitutionally required to provide patients with means of reaching this standard).

behalf of the patient, when the patient has not executed a formal advance directive. These precedent autonomy statutes come in a myriad of varieties. Some follow the Uniform Rights of the Terminally Ill Act. A few others follow the more recent, more sweeping and integrated Uniform Health-Care Decisions Act. In addition to the statutes, a modest, but persisting number of court decisions address end of life care. What follows is a summary of major approaches and trends in the statutes and case law of particular relevance to patients with dementia.

A. "LIVING WILLS"

A "living will" is a directive by a person concerning the care he would or would not want to have in future circumstances. It is the best known and most popular form of advance directive. But it is not the best. Under most state statutes, living wills are of limited import and there is evidence that physicians do not follow them even when they are applicable.⁵¹ Even so, living wills can provide helpful guidance and moral support for surrogates seeking to make health-care decisions in accord with the patient's prior wishes.⁵²

A threshold standard for a living will or other advance directive to become operative is that the declarant no longer has the capacity to make current decisions with respect to his health care.⁵³ The understanding of capacity and its application to patients with dementia was discussed in section I above. Advance directive statutes, however, frequently contain helpful reminders about what capacity means that are relevant to patients with dementia. The Uniform Health-Care Decisions Act Section 1(3) defines "capacity" as "an individual's ability to understand the significant benefits, risks, and alternatives to proposed health care and can make and communicate a health-care decision."⁵⁴ Connecticut defines

⁵¹ LIEBERSON, *supra* note 12, § 9.7; David Orentlicher, *The Illusion of Patient Choice in End-of-Life Decisions*, 267 JAMA 2101 (1992); Joan M. Teno et al., *Do Advance Directives Provide Instructions that Direct Care?*, 45 J. AM. GERIATRICS SOC'Y 508 (1997).

⁵² MEISEL, *supra* note 12, § 10.3.

⁵³ *E.g.*, UNIFORM RIGHTS OF THE TERMINALLY ILL ACT § 2(b)(c), 9B U.L.A. 176 (Supp. 2000).

⁵⁴ 9, Part IB, U.L.A. 148 (2000).

incapacity as "being unable to understand and appreciate the nature and consequences of health-care decisions, including the benefits and disadvantages of such treatment, and to reach and communicate an informed decision regarding the treatment[.]"⁵⁵ Kentucky's statute likewise includes both understanding and communication.⁵⁶ Maryland includes both understanding and communication, and specifies that communication may be by means other than speech.⁵⁷ Oregon adds that communication may be through an intermediary familiar with the principal's manner of communicating.⁵⁸ New Jersey specifies that capacity be assessed relative to particular decisions.⁵⁹

A further limit under most statutes is that living wills do not become effective until the patient meets a specified requirement as to his or her medical condition. Under the most stringent statutes, the patient must be "terminally ill." Definitions of terminal illness typically include only the end stage of the dying process. The Uniform Rights of the Terminally Ill Act Section 1(9) for example, defines a terminal condition as "an incurable and irreversible condition that, without the administration of life-sustaining treatment, will, in the opinion of the attending physician, result in death within a relatively short time."⁶⁰ Utah's living will statute has perhaps the most impressively limited definition of terminal condition: a condition that "regardless of the application of life-sustaining procedures, would within reasonable medical judgment produce death, and where the application of life-sustaining procedures serve only to postpone the moment of death of the person."⁶¹ North Dakota's statute, like Utah's, is severely time-limited: an "incurable or irreversible condition which, without the administration of life-prolonging treatment, will result in my imminent death."⁶² Connecticut's statute refers to end-stage disease: "the final stage of an incurable or irreversible medical condition which,

⁵⁵ CONN. GEN. STAT. § 19a-570(6) (1999).

⁵⁶ 1997 KY. REV. STAT. & R. SERV. 311.621(5) (Banks-Baldwin).

⁵⁷ MD. CODE ANN., HEALTH-GEN. I § 5-601(l) (1999).

⁵⁸ OR. REV. STAT. § 127.505(13) (1998).

⁵⁹ N.J. STAT. ANN. § 26:2H-55 (West 1996).

⁶⁰ 9B U.L.A. 174 (Supp. 2000).

⁶¹ UTAH CODE ANN. § 75-2-1103(10) (2000).

⁶² N.D. CENT. CODE § 23-06.4-03(3) (2000).

without the administration of a life support system, will result in death within a relatively short time, in the opinion of the attending physician[.]”⁶³ None of these definitions encompass patients during the long downhill course of dementia. Alzheimer’s patients might, however, meet less time-restrictive statutes such as New Jersey’s, which sets no outer limit but presumes that a life span of six months or less is terminal.⁶⁴

Some living will statutes add persistent vegetative state or persistent coma to terminal illness as a condition that triggers efficacy of a living will.⁶⁵ Even Alzheimer’s patients with severely diminished capacities are unlikely to meet this standard, however.

Still other states expand living wills to include conditions from which the patient will not recover. Florida, for example, extends advance directive statutes to an end stage condition “caused by injury, disease, or illness which has resulted in severe and permanent deterioration, indicated by incapacity and complete physical dependency, and for which, to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective.”⁶⁶ Oregon allows a patient to give directions for a “progressive illness that will be fatal and is in an advanced stage” when improvement is “very unlikely.”⁶⁷ These descriptions would seem to include the later stages of dementia.

Finally, the Uniform Health-Care Decisions Act Section 4 eliminates the requirement of a triggering medical condition altogether.⁶⁸ In states following the Uniform Act, living wills apply to any patient lacking capacity, regardless of the stage of disease.

Advance directive statutes adopted before *Cruzan*⁶⁹ frequently prohibited patients from refusing medically-provided nutrition and hydration by means of advance directives, or singled out nutrition and hydration for special treatment. These requirements have been largely eliminated. There are exceptions, however. Missouri’s

⁶³ CONN. GEN. STAT. ANN. § 19a-570(3) (West 1997).

⁶⁴ N.J. STAT. ANN. § 26:2H-55 (West 1996).

⁶⁵ E.g., O.C.G.A. § 31-32-3 (2000); UTAH CODE ANN. § 75-2-1104 (2000).

⁶⁶ FLA. STAT. ANN. ch. 765.101(4) (Harrison 1999).

⁶⁷ OR. REV. STAT. § 127.531 (1998).

⁶⁸ 9, Part IB, U.L.A. 157 (2000).

⁶⁹ *Cruzan v. Director*, 497 U.S. 261 (1990).

advance directive statute still prohibits the use of advance directives to forego nutrition or hydration.⁷⁰ Oregon singles out nutrition and hydration for a separate decision by the patient and otherwise prohibits its withdrawal unless it is not medically feasible or would cause severe pain.⁷¹ Oklahoma requires specific authorization by the declarant for nutrition and hydration to be included in the life-sustaining treatment that is refused by a directive.⁷² Medically-assisted nutrition and hydration may be an issue in the care of Alzheimer's patients nearing the end of life, although recent studies have questioned its therapeutic efficacy.⁷³

B. SPECIAL POWERS OF ATTORNEY FOR HEALTH CARE

A second type of advance directive is the special, durable power of attorney for health care. There are two importantly different senses in which the SPA may be thought of as exercising precedent autonomy. The creation of an SPA is a direct exercise of precedent autonomy in that the patient chooses his decisionmaker. To the extent that the SPA also attempts to choose as the patient would have chosen for himself in the current situation, the SPA may be viewed as exercising precedent autonomy indirectly. Part III below argues that criticisms of precedent autonomy are more telling against the second than against the first sense in which the SPA involves precedent autonomy.⁷⁴

The SPA has several advantages over the living will. Most obvious is flexibility: the SPA can respond to medical circumstances that were not anticipated by the patient in drafting a living will.⁷⁵ Another advantage is that the SPA gives the patient an identified advocate. The SPA may be able to speak forcefully on behalf of the patient to health-care providers who might otherwise be unwilling to follow or to interpret an advance directive.

⁷⁰ MO. ANN. STAT. § 459.010(3) (West 1992).

⁷¹ OR. REV. STAT. §§ 127.531, 127.580 (1998).

⁷² OKLA. STAT. ANN. tit. 63, § 3103.3(6) (West 1999).

⁷³ Thomas E. Finucane & Colleen Christmas, *More Caution About Tube Feeding*, 48 J. AM. GERIATRICS SOC'Y 1167 (2000); Thomas E. Finucane et al., *Tube Feeding in Patients with Advanced Dementia: A Review of the Evidence*, 282 JAMA 1365 (1999).

⁷⁴ *Infra* notes 129-70 and accompanying text.

⁷⁵ MEISEL, *supra* note 12, § 10.4.

In many states, an additional advantage of the SPA over the living will is that it does not limit applicability by triggering medical conditions, except incapacity itself.⁷⁶ The Uniform Rights of the Terminally Ill Act Section 2(c), however, does limit SPAs to terminally ill patients, apparently because the SPA was added as a later amendment to its living will provisions.⁷⁷ A few states likewise impose condition limits on the actions of the SPA. Oklahoma, for example, will only allow termination of life-sustaining treatment by an SPA when the patient is terminally ill or in a persistent coma.⁷⁸ In such states, the SPA does not have applicability advantages over a living will for patients with dementia.

Despite these advantages, there are difficulties in the use of SPAs that may be particularly relevant to the circumstances of patients with dementia. No willing or appropriate proxy might be available. An appointed proxy might himself become incompetent or debilitated; this is especially likely to be a problem when elderly couples give health-care proxies to each other.

Of perhaps most concern, the appointed SPA might make decisions that subordinate the patient to the needs and concerns of others. Such concerns might be financial—the dissipation of an estate, or emotional—exhaustion by the burdens of care. The Uniform Health-Care Decisions Act Section 4 sets out the duties of the SPA to make patient-centered decisions, in accord with the patient's wishes to the extent known, or the patient's best interests to the extent wishes are unknown.⁷⁹ Many state statutes impose similar guidance on SPAs.⁸⁰ Finally, an appointed proxy might overreach or act in bad faith. A few state statutes specify that a proxy's actions may be challenged on this basis;⁸¹ other states might permit such challenges despite the absence of specific statutory authorization for them. A number of states require special safeguards when SPAs are appointed by patients in nursing homes, and

⁷⁶ *E.g.*, ARIZ. REV. STAT. ANN. § 36-3224 (West 2000); N.D. CENT. CODE § 233-06.5-17 (2000).

⁷⁷ 9B U.L.A. 176 (Supp. 2000).

⁷⁸ OKLA. STAT. ANN. tit. 63, § 3101.4 (West 1999).

⁷⁹ 9, Part IB, U.L.A. 159 (2000).

⁸⁰ MEISEL, *supra* note 12, § 12.2, n.120.

⁸¹ *E.g.*, OR. REV. STAT. § 127.550(1)(b) (1998).

prohibit health-care providers or employees of health-care facilities from service in the capacity of SPA.

C. CONFLICTS BETWEEN LIVING WILLS AND THE DIRECTIVES OF POWERS OF ATTORNEY: THE PROBLEM OF PRIORITY

Many state advance directive statutes authorize both living wills and SPAs without any comment about how the two fit together. Hopefully, the choices of the SPA will not conflict with the directions in a living will. But it is certainly possible for the two to be in apparent conflict, if the SPA believes that a treatment refusal in a living will conflicts with the patient's values or interests. When the conflict arises between a general refusal of treatment in a living will and the SPA's response to specific, unanticipated circumstances, it may be only apparent. When the SPA believes that a specific advance directive should not be followed in the patient's current circumstances, however, the conflict is very real.

The few state advance directive statutes that anticipate such conflicts resolve them in several different ways. In Florida, the holder of the SPA is directed to be guided by a living will, if there is one.⁸² This approach is justified if the living will is thought to be a better indication of the patient's precedent autonomy, but it loses the SPA's advantage of flexibility. Several states provide that the most recent directive prevails.⁸³ This approach makes sense on the assumption that the later expression better reflects current choices. Utah resolves disputes in favor of the directions of the SPA.⁸⁴ This approach allows the SPA, who is the principal's chosen agent, to respond to changed circumstances, but it has the risk that the SPA might ignore the patient's antecedent choices.

The Uniform Health-Care Decisions Act Section 4 lets the patient coordinate directions to an SPA with a living will.⁸⁵ It assigns the SPA authority to make all health-care decisions, unless the patient specifies otherwise. This approach to conflicts may be most

⁸² FLA. STAT. ANN. ch. 765.304 (Harrison 2000).

⁸³ ARIZ. REV. STAT. ANN. § 36-3209 (West 2000); N.D. CENT. CODE § 23-06.5-13 (1991); OKLA. STAT. ANN. tit. 63, § 3101.5 (West 1997).

⁸⁴ UTAH CODE ANN. § 75-2-1106(2) (1993).

⁸⁵ 9, Part IB, U.L.A. 156 (2000).

reflective of patients' choices, but has the disadvantage of inflexibility when patients place limits on the SPA and unforeseen circumstances arise.

D. DECISIONMAKING ABOUT CARE: CURRENT PREFERENCES AND THE REVOCATION OF ADVANCE DIRECTIVES

All advance directive statutes provide that the current wishes of a patient with decisional capacity govern care decisions, and that advance directives may be revoked. Many also provide that current wishes control and that directives may be revoked even when patients lack decisional capacity. Patients with dementia pose difficult issues about revocations. Although lacking decisional capacity, they may express wishes that are in apparent conflict with advance directives or that are difficult to interpret. Agitation, combativeness, and suspicion of others may accompany dementia. Persons with advancing dementia may forget family members or friends and identify with others, apparently rejecting the ministrations of an SPA or a family surrogate and evidencing the desire to rely on someone else as a decisionmaker instead.

Many state advance directive statutes allow the contemporaneous desires of an incapacitated person to override a living will.⁸⁶ Apparent expressions of wishes may be difficult to interpret, however, depending on the patient's level of incapacity. A patient with dementia who had previously expressed the desire to have all possible life-sustaining treatment and who rejects food and attempts to dislodge a feeding tube is sometimes interpreted as desiring that nutritional support be ceased. Conversely, a patient who had declined all life-sustaining treatment but who apparently enjoys his present circumstances is sometimes interpreted as wanting treatment to continue or at least being indifferent to its continuation.⁸⁷ Whether these interpretations are accurate reflections of

⁸⁶ MEISEL, *supra* note 12, § 10.14, n.135.

⁸⁷ See Rebecca Dresser, *Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law*, 28 ARIZ. L. REV. 373, 377-78 (1986) (discussing *In re Spring*, 405 N.E.2d 115 (1980)).

preferences or external constructions is disputed; the character and significance of these disputes is discussed in Part III below.

By far the majority of advance directive statutes treat the creation and revocation of advance directives asymmetrically, requiring capacity for the former but not for the latter. Despite specifying that a declarant be "of sound mind" to create an advance directive, the Uniform Rights of the Terminally Ill Act Section 4 provides for revocation "at any time and in any manner, without regard to the declarant's mental or physical condition."⁸⁸ The Uniform Health-Care Decisions Act Section 3 likewise allows anyone to revoke regardless of capacity.⁸⁹ This Act, however, places barriers in the way of revoking a power of attorney that it does not impose on revoking a care directive. A power of attorney can only be revoked by a signed writing or by personally informing the supervising health-care provider. Other directives can be revoked "at any time and in any manner that communicates an intent to revoke."⁹⁰

There are exceptions to asymmetry of revocation. Maine and New Mexico, in adopting the UHCDA, limit revocation to individuals "with capacity."⁹¹ North Dakota also limits revocation to competent patients.⁹² Oregon has an unusual variant of asymmetry: a directive refusing nutrition and hydration can be revoked by a principal regardless of capacity, but other directives require capacity to revoke.⁹³

The principal argument for asymmetry of revocation is the desire to honor the patient's current wishes, regardless of expression of precedent choice. There are notable problems, however, in applying asymmetry of revocation of patients with dementia. Apparent expressions of wishes may be difficult to interpret and to disaggregate from symptoms such as agitation, depression, or paranoia. Loss of memory and the inability to remember family and

⁸⁸ 9B U.L.A. 181 (Supp. 2000).

⁸⁹ 9, Part IB, U.L.A. 155 (2000).

⁹⁰ *Id.*

⁹¹ ME. REV. STAT. ANN. tit. 18-A, § 5-803 (West 1998); N.M. STAT. ANN. § 24-7A-3(A) (Michie 2000).

⁹² N.D. CENT. CODE § 23-06.4-05 (1991 & Supp. 1999).

⁹³ OR. REV. STAT. § 127.545(1) (Supp. 1998).

friends may lead to apparent revocations of SPAs, even when the SPA was originally chosen by the patient, has long-standing knowledge of the patient's values, and continues to care for the patient. Finally, the irony of allowing asymmetry of revocation is that a patient might be able to revoke an advance directive, but be left without the power to create a new one. The result would be either to leave the patient in a decisionmaking vacuum, or to defer to precedent autonomy without a formal advance directive or to the best interests standard. In states with a surrogate consent statute, the SPA might in any event be one of the listed statutory surrogates. One recommendation to draw from this confusion is reconsideration of whether incapacitated patients should be able to revoke SPAs to the same extent they are able to revoke living wills. An alternative would be to require capacity for the revocation of an SPA, unless there are additional grounds for challenging whether the SPA is acting in good faith. PART III below argues that the criticisms of precedent autonomy apply with more plausibility to living wills than to the selection of SPAs.⁹⁴

E. PRECEDENT AUTONOMY WITHOUT FORMAL ADVANCE DIRECTIVES: THE USE OF SUBSTITUTED JUDGMENT

Despite widespread publicity, living wills and SPAs are not used by the majority of Americans. Even when a living will exists, it may be inapplicable or too general to direct care in the specific circumstances of the patient's case. To fill in the breach, about half of the states have adopted surrogate consent statutes. New Jersey, for example, provides that when an instruction directive is not specific to the patient's condition, surrogates should be consulted for a reasonable understanding of the patient's wishes.⁹⁵ These statutes authorize a prioritized list of decisionmakers to act on the patient's behalf: the SPA, a court appointed guardian, followed by family members in order of degree of relationship. Some statutes also include close friends at the end of the list. For example, Florida adds to the list "close personal friend," defined as:

⁹⁴ *Infra* notes 129-70 and accompanying text.

⁹⁵ N.J. STAT. ANN. § 26:2H-64(b) (West 1996).

any person 18 years of age or older who has exhibited special care and concern for the patient, and who presents an affidavit to the health care facility or to the attending or treating physician stating that he or she is a friend of the patient; is willing and able to become involved in the patient's health care; and has maintained such regular contact with the patient so as to be familiar with the patient's activities, health, and religious or moral beliefs.⁹⁶

In the absence of family members, the Uniform Health-Care Decisions Act and states following it allow any adult "who has exhibited special care and concern for the patient, who is familiar with the patient's personal values, and who is reasonably available" to act as a surrogate.⁹⁷

Some of these statutes impose limits on when listed surrogates may act and on what they may do. The Uniform Rights of the Terminally Ill Act Section 7 limits the surrogate's authority to terminal illness, but contains this limit in virtue of drafting the surrogacy provision into an already-limited format.⁹⁸ Maine limits the power of the statutory list of surrogates to the following procedures: "a surrogate may not deny surgery, procedures or other interventions that are lifesaving and medically necessary [where a] medically necessary procedure is one providing the most patient-appropriate intervention or procedure that can be safely and effectively given."⁹⁹ Other surrogacy statutes give more general directions to the surrogate to act in accord with the patient's wishes or interests.

Even without statutory authorization of listed surrogates, or formal appointment of a guardian, surrogate decisionmakers may have the legal power to make decisions on behalf of incapacitated patients. Advance directive statutes complement underlying

⁹⁶ FLA. STAT. ANN. ch. 765.101(3) (Harrison 2000).

⁹⁷ UNIFORM HEALTH-CARE DECISIONS ACT § 5(c), 9 U.L.A. 167 (1993); *see, e.g.*, ME. REV. STAT. ANN. tit. 18-A, § 5-805(C) (West 1998) (following UCHDA).

⁹⁸ 9B U.L.A. 184 (Supp. 2000).

⁹⁹ ME. REV. STAT. ANN. tit. 18-A, § 5-805(a) (West Supp. 2000).

common law and constitutional rights.¹⁰⁰ They give patients and physicians new assurances: patients have a formal means for expressing their wishes, and physicians have a shield against legal liability.¹⁰¹ Oklahoma's statute, for example, puts forth as a goal keeping these "highly sensitive, personal issues" away from courts.¹⁰² Many other state statutes are explicit that the rights given in them are cumulative upon common law and constitutional rights.¹⁰³

Unlike the SPA, the surrogates discussed in this section cannot be regarded as exercising precedent autonomy in the sense that they have been chosen by the patient. Instead, their exercise of precedent autonomy is at best indirect, as they attempt to decide as the patient would have chosen for him or herself. Some critics of the substituted judgment standard regard this indirection as critical: if the surrogate has not been chosen by the patient and if the patient has not stated his or her choices for the situation at hand, how can substituted judgment be regarded as autonomy at all?¹⁰⁴ Both the litigated cases and the statutes struggle with the substantive standard to be applied to decisions based on substituted judgment. To the extent possible, surrogates are to try to choose as the patient would have chosen under the circumstances given his values and interests. The term "substituted judgment" has been used to describe this process; but it is misleading if it is taken to suggest that the surrogate should "substitute" his judgment for the patient's. Instead, what is "substituted" is the surrogate as processor, applying the patient's values to the problem at hand.¹⁰⁵ When evidence of the patient's values is lacking, statutes and case law require the surrogate to base decisions on the patient's best interests.¹⁰⁶ A widely emulated New Jersey case sets out a three-tiered structure: the substituted judgment standard, a "limited objective test" in which the surrogate follows limited evidence of the

¹⁰⁰ David Orentlicher, *The Limits of Legislation*, 53 MD. L. REV. 1255 (1994).

¹⁰¹ MEISEL, *supra* note 12, § 10.12, n.100 (citing statutory provisions to this effect).

¹⁰² OKLA. STAT. ANN. tit. 63, § 3101.2(A)(3) (West 1997).

¹⁰³ *E.g.*, O.C.G.A. § 31-32-11(a) (1996).

¹⁰⁴ *E.g.*, Personal Communication with Teresa Collett, Joint Conference on Legal/Ethical Issues in the Progression of Dementia, Athens, Ga., 2000.

¹⁰⁵ *See infra* Part III (criticizing this process as precedent autonomy).

¹⁰⁶ *Infra* Part IV.

patient's wishes to discontinue care when the burdens of care clearly outweigh its benefits to the patient, and an "objective" best interests standard.¹⁰⁷

The litigated cases also have struggled with the evidentiary standard to apply to these surrogate decisionmakers. While the prevailing view is that lesser evidentiary standards are required,¹⁰⁸ a few jurisdictions have insisted on the more stringent clear and convincing evidence standard.¹⁰⁹ Connecticut provides for the more stringent standard in its surrogacy statute: "[w]ith respect to any communication of a patient's wishes other than by means of a document executed in accordance with section 19a-575a the court shall consider whether there is clear and convincing evidence of such communication."¹¹⁰ In *Cruzan*,¹¹¹ the Supreme Court held that insistence on the more stringent standard does not impinge on an arguable constitutional liberty right of the patient to refuse unwanted medical care.¹¹²

A few quite recent, reported decisions take up the evidentiary standard required for discontinuation of life-sustaining treatment when a patient is neither terminally ill nor in a persistent vegetative state. These cases speak to the situations of many dementia patients. In *Martin v. Martin*,¹¹³ the Michigan Supreme Court held that clear and convincing evidence of prior wishes is required to remove a life-sustaining feeding tube from a patient with severe cognitive impairments.¹¹⁴ Michael Martin suffered a closed head injury in an automobile accident, which left him unable to care for himself or interact with his environment in more than minimal ways.¹¹⁵ Five years later, his wife, formally appointed as legal guardian, sought authorization to remove medically-assisted nutrition, relying on testimony about his expressed wishes before

¹⁰⁷ *In re Conroy*, 486 A.2d 1209 (N.J. 1985).

¹⁰⁸ See, e.g., *In re Lawrance*, 579 N.E.2d 32 (Ind. 1991).

¹⁰⁹ *In re Westchester County Med. Ctr.*, 531 N.E.2d 607 (N.Y. 1988).

¹¹⁰ CONN. GEN. STAT. § 19a-580(c) (1997).

¹¹¹ *Cruzan v. Director*, 497 U.S. 261 (1990).

¹¹² *Id.* at 261.

¹¹³ 538 N.W.2d 399 (Mich. 1995).

¹¹⁴ *Id.* at 410.

¹¹⁵ Medical testimony was divided on whether he was capable of any meaningful interaction at all, even of the most minimal sort. *Id.* at 402-03.

the accident. His mother and sister opposed the discontinuation. The Michigan court applied the clear and convincing evidence standard and concluded that it was not met by the evidence in Martin's case.¹¹⁶ In the court's words, "[o]nly when the patient's prior statements clearly illustrate a serious, well thought out, consistent decision to refuse treatment under these exact circumstances, or circumstances highly similar to the current situation, should treatment be refused or withdrawn."¹¹⁷ Martin's statements that he would not want to live like a vegetable, made when he was young and healthy, were in the court's judgment too remote from his present circumstances to provide clear and convincing evidence of his preferences under the current circumstances.¹¹⁸ The court reached this conclusion despite testimony that some of Martin's comments had been made with respect to young people or accident victims, and had rejected severe dependency as well as life in a persistent vegetative state.¹¹⁹

In a second such case, the Wisconsin Supreme Court refused to allow a guardian to withdraw nutritional support from a patient with Alzheimer's dementia.¹²⁰ Edna F. was described by the court as responsive to stimuli and bedridden.¹²¹ Her sister, who was her court-appointed guardian, sought withdrawal of the feeding tube; the sister's only evidence of Edna's wishes was a statement made nearly thirty years earlier to the effect that she would rather die of cancer than lose her mind. The nursing home's ethics committee had approved the withdrawal provided no family member objected; a niece, however, refused to sign an approval required by the facility. Distinguishing an earlier case which had permitted withdrawal of a feeding tube from a patient in a persistent vegetative state, the Wisconsin court applied a presumption that continuing life was in Edna F.'s best interests so long as she was not in a

¹¹⁶ *Id.* at 411.

¹¹⁷ *Id.*

¹¹⁸ *Id.*

¹¹⁹ *Id.* at 413.

¹²⁰ *In re Guardianship of Edna M.F.*, 563 N.W.2d 485 (Wis. 1997).

¹²¹ *Id.* at 487. A concurring opinion added that she was utterly dependent, showed no purposeful responses to stimuli, and was immobile with limb contractures. *Id.* at 499-500 (Abrahamson, C.J., concurring).

persistent vegetative state.¹²² Through the court-appointed guardian *ad litem* agreed with Edna F.'s sister that withdrawal of the feeding tube was appropriate, the court refused to authorize discontinuation of the feeding tube without clear and convincing evidence of her wishes, an evidentiary standard not met by statements remote in time and in circumstance.¹²³

A similar case is currently under review by the California Supreme Court.¹²⁴ Injured in an automobile accident, Robert Wendland was comatose for 16 months and thereafter minimally able to interact with his environment. Two years after the accident, his wife Rose, as his conservator, sought removal of nutrition and hydration; her request was opposed by his mother and sister. The probate court refused to grant Rose Wendland's request, concluding that although there was clear and convincing evidence that she was acting in good faith, clear and convincing evidence of his wishes was lacking. The appellate court reversed on the ground that under the California Probate Code Section 2355 the conservator is required to act in good faith but not to provide clear and convincing evidence of the patient's wishes.¹²⁵ Further, the court distinguished *Martin* and *Edna F.* on statutory grounds.¹²⁶ Briefing for the *Wendland* review has just been completed.

Application of the clear and convincing evidence standard to the use of substituted judgment to discontinue life-sustaining treatment in a non-PVS patient is indicative of heightened judicial concern about such decisions. Section III turns to the justifiability of these concerns.¹²⁷ Section IV takes up the best interests standard and is critical of the presumption, applied by the Wisconsin court, that continued life-sustaining treatment is always in the best interest of a patient who is not terminally ill or in a persistent vegetative state.¹²⁸

¹²² *Id.* at 491-92 (distinguishing *In re Guardianship of L.W.*, 482 N.W.2d 60 (Wis. 1992)).

¹²³ *Id.* at 492.

¹²⁴ *Wendland v. Wendland*, 93 Cal. Rptr. 2d 550 (Cal. Ct. App. 2000), *review granted and opinion superseded by, In re Conservatorship of Wendland*, 2 P.3d 1065 (Cal. 2000).

¹²⁵ *Id.* at 553-54.

¹²⁶ *Id.* at 567-68.

¹²⁷ See *infra* notes 129-70 and accompanying text.

¹²⁸ See *infra* notes 171-219 and accompanying text.

III. THE AUTHORITY OF PRECEDENT AUTONOMY

Despite the many advance directive statutes and court decisions supporting them, doubts continue to be expressed about the justifiability of relying on precedent autonomy. Although courts insist on the clearest of evidence, and statutes require even chosen surrogate decisionmakers to take into account both an incapacitated patient's wishes and his best interests, there is evidence that physicians ignore advance directives in light of what they think might be best for the patient, and there is evidence that patients sometimes want physicians to act in this manner. Staunch defenders of advance directives deplore these departures from precedent autonomy. But critics argue that they reflect appropriate concerns about the authority of precedent autonomy when its exercise conflicts with the apparent expressed wishes or the best interests of an incapacitated person. These criticisms of precedent autonomy have particular force for patients with dementia when their illness assumes a long and fluctuating downhill course. Such patients may anticipate extended periods of limited capacity or full incapacitation.

A. VAGUENESS AND INACCURACY

Whether formal or informal, advance directives may not be very specific. Living wills may simply specify refusal of "life-sustaining care" or "extraordinary treatment." Comments to family and friends, such as "I don't want to live like that" or "I don't want to be dependent on machines" may not speak to the patient's condition, treatments, or prognosis. A living will is at least drafted with the intent of governing end-of-life decisionmaking; remarks to family and friends may be made without any intent that they be taken as guidance. There is thus reason to doubt that even living wills and surely remarks in casual conversation are actually precedent choices for particular choices about patient care.¹²⁹ Lynn et al. suggest that

¹²⁹ See Rebecca S. Dresser, *Autonomy Revisited: The Limits of Anticipatory Choices, in DEMENTIA AND AGING: ETHICS, VALUES, AND POLICY CHOICES* 71 (Robert H. Binstock et al. eds., 1992)

vagueness can be grounded theoretically: People who are in good health may have no well-developed preferences about what they would want were they to become ill, for such preferences are formed in interaction with ongoing experiences of illness and in dialogue with others.¹³⁰

One empirical study questions whether statements in a general living will are consistent with patients' preferences for specific life-sustaining procedures under a variety of health scenarios.¹³¹ Another study casts doubt on whether choices can be generalized from one health-care situation to another. Reilly, Teasdale & McCullough interviewed a sample of 218 community-dwelling elders with regard to their preferences for a range of life-sustaining treatments under four different health-care scenarios.¹³² Their four scenarios were sudden life threatening illness with some possibility of return to current health status, terminal illness, persistent coma, and acute illness for a patient with "moderately advanced Alzheimer's" (described as no longer allowing independence, but allowing interaction with family and friends). Respondents were most likely to choose interventions in the first scenario (12% never, 52% trial and 36% always) and least likely to do so for persistent coma (62% never, 28% trial, and 11% always).¹³³ Responses for acute illness for a patient with moderately advanced Alzheimer's were more divided (43% never, 36% trial and 21% always), with a majority of interviewees preferring less invasive interventions for this scenario, such as hospital admission (74%) and antibiotics (73%).¹³⁴ In response, Volicer & Hurley note that this study is limited to extrapolation from one scenario to another, and caution that it should not be characterized as invalidating more general directives in living

¹³⁰ Joanne Lynn et al., *Dementia and Advance-Care Planning: Perspectives from Three Countries on Ethics and Epidemiology*, 10 J. CLINICAL ETHICS 271, 273 (1999).

¹³¹ Lawrence J. Schneiderman et al., *Relationship of General Advance Directive Instructions to Specific Life-Sustaining Treatment Preferences in Patients with Serious Illness*, 152 ARCHIVES INTERNAL MED. 2114 (1992).

¹³² Rebecca B. Reilly et al., *Projecting Patients' Preferences from Living Wills: An Invalid Strategy for Management of Dementia with Life-Threatening Illness*, 42 J. AM. GERIATRICS SOC'Y 997 (1994).

¹³³ *Id.* at 1000.

¹³⁴ *Id.*

wills.¹³⁵ Contrary to the study just described, a smaller study recently concluded that cognitively normal older adults would be less likely to opt for invasive interventions (CPR, ventilator support, or tube feeding) for patients with moderate dementia, and that 95% would reject more invasive interventions for patients with severe dementia.¹³⁶ This later study also identified a positive association between the desire for life-sustaining treatment and less education, greater independence, and a higher perceived quality of life.

Fazel, Hope & Jacoby, in a sample of patients from Oxford, England, found a positive association between preferences for treatment intervention and cognitive impairment.¹³⁷ They suggest three explanations. First, cognitively impaired patients may have more limited understanding of the consequences of their decisions. Second, they may be more willing to defer to medical authority. Most critical of precedent autonomy is their third explanation: "people who already have cognitive impairment may put a higher value on their life than the value that people without cognitive impairment put on their future hypothetical life with dementia."¹³⁸

If there is reason to doubt the meaning of patients' prior statements, there may be even more reason to doubt the accuracy of surrogates' predictions of what patients would choose. Leaving aside the possibility that surrogates might engage in intentional or careless misrepresentation, there is evidence that they are at best imperfect predictors of what their loved ones would choose. Sulmasy et al. report 66% accuracy in surrogates' predictions about what patients with a predicted less than 50% chance of two-year survival would choose for end-of-life care in several scenarios.¹³⁹ Other findings were as follows: accuracy was less for the scenario

¹³⁵ Ladislav Volicer & Ann Hurley, *Protecting Self-Determination of Dementia Patients*, 43 J. AM. GERIATRICS SOC'Y 938, 938-39 (1995).

¹³⁶ Dwenda K. Gjerdingen et al., *Older Persons' Opinions About Life-Sustaining Procedures in the Face of Dementia*, 8 ARCHIVES FAM. MED. 421 (1999).

¹³⁷ Seena Fazel et al., *Effect of Cognitive Impairment and Premorbid Intelligence on Treatment Preferences for Life-Sustaining Medical Therapy*, 157 AM. J. PSYCHIATRY 1009, 1011 (2000).

¹³⁸ *Id.*

¹³⁹ Daniel P. Sulmasy et al., *The Accuracy of Substituted Judgments in Patients with Terminal Diagnoses*, 128 ANNALS INTERNAL MED. 621 (1998); see also Daniel P. Sulmasy et al., *More Talk, Less Paper: Predicting the Accuracy of Substituted Judgments*, 96 AM. J. MED. 432 (1994).

of severe dementia than for the scenario of permanent coma; accuracy was greatest for invasive procedures such as ventilator care (84%); accuracy was also greater for more highly educated surrogates and patients, and for surrogates who had conducted explicit discussions with patients; surprisingly, religiosity was negatively associated with accuracy; furthermore, there was no significant difference in accuracy between the predictions of patients' chosen surrogates and the predictions of surrogates provided for in standard statutory lists.¹⁴⁰

Another quite small study of the decisions that would be made prospectively by spouses of patients with Alzheimer's disease found them far more likely to withhold care in cases of coma than in cases of critical illness.¹⁴¹ As in the Sulmasy study, spouses in this study were far more willing to withhold invasive therapies such as CPR and ventilator support than antibiotics. These judgments were based on perceptions of patients' interests and quality of life independent of cognitive status. There was a slight association between spouses perceiving themselves as more burdened and being less willing to forego life-sustaining care.¹⁴²

Several studies of health-care providers suggest they are not good predictors of patients' preferences either. In an initial study of this question, Uhlmann, Pearlman & Cain found that physicians and nurses were no better than chance in predicting patients preferences for resuscitation.¹⁴³ In a later study, Uhlmann and Pearlman provided this possible explanation: Physicians rank the quality of life of their chronically ill patients as lower than their patients do; and physicians are more likely than patients to associate perceived quality of life with attitudes towards life-sustaining treatment.¹⁴⁴

Although the studies are limited, these data suggest reason for concern about extrapolating decisions regarding current care from

¹⁴⁰ Sulmasy et al., *The Accuracy of Substituted Judgments in Patients with Terminal Diagnoses*, *supra* note 139, at 625-26.

¹⁴¹ Mathy Mezey et al., *Life-Sustaining Treatment Decisions by Spouses of Patients with Alzheimer's Disease*, 44 J. AM. GERIATRICS SOC'Y 144 (1996).

¹⁴² *Id.* at 148-49.

¹⁴³ Richard F. Uhlmann et al., *Understanding of Elderly Patients' Resuscitation Preferences by Physicians and Nurses*, 150 W.J. MED. 705 (1989).

¹⁴⁴ R.F. Uhlmann & R.A. Pearlman, *Perceived Quality of Life and Preferences for Life-Sustaining Treatment in Older Adults*, 151 ARCHIVES INTERNAL MED. 495, 497 (1991).

patients' prior choices about other circumstances or surrogates' beliefs about what these choices would be. If precedent autonomy means relying on prior reasoned directives to govern present choices, it is not furthered by inaccurate extrapolations. Risks of inaccuracy, however, appear to be lower for more invasive forms of care and to be reduced significantly by discussion and communication. Concerns about accuracy do not, therefore, entail rejection of the authority of precedent autonomy altogether. Instead, they suggest increased efforts to encourage communication about preferences and care in scrutinizing the evidence, with particular attention to the extent to which reports about preferences are grounded in discussions of particular circumstances.

B. PREFERENCE INSTABILITY

The likelihood that patients will change their minds about care decisions is another basis for challenging the authority of advance directives. Several studies have explored the stability of antecedent preferences. Everhart and Pearlman found significant stability of treatment preferences over a month-long period among a sample of thirty patients in a Seattle VA ICU.¹⁴⁵ In a study conducted by the same research group over a longer time frame, however, Patrick et al. found considerable changes in preferences for life-sustaining treatment.¹⁴⁶ Patients were interviewed at baseline, 6, 18, and 30 months. Changes in preferences for life-sustaining treatment varied with patients' assessments of their health status. These changes may reflect an increased willingness to tolerate conditions when their effects have been experienced and have become familiar to the patient.

When patients have decisionmaking capacity, such changes in preferences do not undermine respect for autonomy. Genuine changes of mind about health-care decisions should be respected, just as are changes of mind about other important life choices.

¹⁴⁵ Maria A. Everhart & Robert A. Pearlman, *Stability of Patient Preferences Regarding Life-Sustaining Treatments*, 97 CHEST 159 (1990).

¹⁴⁶ Donald L. Patrick et al., *Validation of Preferences for Life-Sustaining Treatment: Implications for Advance Care Planning*, 127 ANNALS INTERNAL MED. 509 (1997).

When they rest in more complete knowledge, moreover, they are all the more to be respected. Suppose, however, that the apparent change of mind occurs on the part of a patient whose decisionmaking capacities are diminished, or who lacks capacities altogether. How should precedent directions be weighed against later apparent expressions of wishes by such patients?

One solution is to encourage patients to answer this question for themselves. One study reports that a considerable percentage of patients would prefer to give their health-care providers "leeway" in deciding whether to follow their advance directives for care—Sehgal et al. asked dialysis patients whether they would want dialysis continued if they developed advanced Alzheimer's disease (52% overall yes; 67% African-Americans yes), and whether they would want health-care providers to follow their advance directives about dialysis under the same circumstances.¹⁴⁷ Only 39% of patients wanted their advance directives followed strictly; 19% wanted physicians to take "a little leeway," 11% wanted "a lot of leeway," and 31% wanted "complete leeway."¹⁴⁸ Patients with written advance directives (60%), younger patients (44%), and patients without a history of cancer (41%) were more likely to want directives to be followed strictly.¹⁴⁹ Factors involved in the desire for leeway included pain or suffering, quality of life, possibility of a new treatment, indignity, financial impact, and religious beliefs. The authors of this study conclude that the SPA may more accurately reflect many patients' choices than specific living wills, because the SPA can respond to changed circumstances, and further recommend that patients be asked to describe for their surrogates the extent to which they would want advance directives followed strictly.¹⁵⁰

Nonetheless, even if patients instruct their surrogates in advance about the extent to which they want prior directives to be followed, conflicts may still arise between these instructions and the apparent expressed wishes or best interests of an incapacitated person. Such conflicts pit precedent autonomy against concerns that might be

¹⁴⁷ Ashwini Sehgal et al., *How Strictly Do Dialysis Patients Want Their Advance Directives Followed?*, 267 J. AM. MED. 59, 61 (1992).

¹⁴⁸ *Id.*

¹⁴⁹ *Id.*

¹⁵⁰ *Id.* at 62-63.

voiced on behalf of the now-incapacitated. Ronald Dworkin takes a hard line in favor of precedent autonomy: that unless the later expressions reflect reasoned decisions, respect for autonomy requires following the advance directive.¹⁵¹ Rebecca Dresser, on the other hand, defends protecting the interests of the now-incapacitated person for the most part over the earlier choices.¹⁵²

Dworkin's picture is that if a now-incapacitated person cannot reason according to a plan, the precedent directives reflect autonomy but the later expressed wishes do not. The later wishes do not reflect a deeper sense of self, of character, or of values. On Dworkin's view, therefore, autonomy supports honoring the earlier directives; but there is no case from autonomy for protecting the later wishes. The conflict lies instead between precedent autonomy and the interests of the now-incapacitated person, with expressions of present wishes—to the extent that the person remains able to express any wishes at all—considered in understanding the experiential interests of the incapacitated person.

At least one recent commentator, Agnieszka Jaworska, questions this picture. Jaworska argues that Dworkin discounts the extent to which patients with dementia are capable of autonomy because he relies on a misguided view of autonomy.¹⁵³ In Jaworska's view, the capacity to value is what is critical to autonomy. Patients with dementia may maintain the capacity to value even when they have lost short term memory or the ability to engage in means-end reasoning. If they maintain consistency of ends, Jaworska contends, they can be assisted in the exercise of autonomy by others working with them and supporting them in the realization of their ends.¹⁵⁴ Moreover, she asserts, Dworkin is just wrong in asserting that the expressions of wishes by persons with dementia are characteristically fleeting, conflicting, or absent a link to identity. Jaworska reports stories of patients with moderate to severe dementia who nonetheless evidence values through their behavior, such as the desire to help others, the desire to remain independent, the desire

¹⁵¹ RONALD DWORKIN, *LIFE'S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA, AND INDIVIDUAL FREEDOM* (1993); Dworkin, *supra* note 47, at 14.

¹⁵² See *infra* note 158 for a list of Dresser's works.

¹⁵³ Jaworska, *supra* note 13, at 125-29.

¹⁵⁴ *Id.*

not to go to day care, or the desire not to die.¹⁵⁵ She concedes that patients with advanced dementia are not capable of deliberating about the adoption of new values or the resolution of conflicts among ends. With loss of the ability to form new memories, they become unable to form new values. Nor are they capable of critical reasoning about means. What they may maintain is a sense of what is of value to them, however faint and flickering. Jaworska also recognizes that the values maintained may be altered or diminished and that with the loss of capacity to reason will come a loss of abstract values, such as religious identity.¹⁵⁶

Jaworska seems clearly right that a sense of what is valuable may remain even when the capacity for choice has been lost. Whether respect for these valuations is properly viewed as respect for autonomy is another matter, however. If autonomy means deliberating about one's course in life and choosing for oneself, it should not be. Although patients with advancing dementia remain capable of having ends, they need assistance with the processes of choice that are crucial to autonomy. Jaworska does importantly remind us that the cognitive life of many persons with even severe dementia is far richer than Dworkin supposes. Precedent autonomy thus may conflict with a complex set of concerns and interests of the person with dementia, although it does not conflict with their autonomy. Along these same lines, Fellows suggests that we should try to understand the experiences of patients with dementia, of what their lives are like for them from the inside.¹⁵⁷ If we do so, we will see that the significant moral conflict lies between precedent autonomy and the experiential interests of the now-incapacitated person.

¹⁵⁵ For a number of such reports, see JOHN BAYLEY, *ELEGY FOR IRIS* (1999); ANN DAVIDSON, *ALZHEIMER'S, A LOVE STORY: ONE YEAR IN MY HUSBAND'S JOURNEY* (1997); Steven R. Sabat, *Voice of Alzheimer's Disease Sufferers: A Call for Treatment Based on Personhood*, 9 J. CLINICAL ETHICS 35 (1998).

¹⁵⁶ Jaworska, *supra* note 13.

¹⁵⁷ Fellows, *supra* note 27, at 925.

C. TRANSFORMATION OF THE SELF

At this point, critics of precedent autonomy may reach to a deeper metaphysical level. In addition to the concerns about precedent autonomy already discussed, Rebecca Dresser questions whether the precedent self has any authority over the now-incapacitated person.¹⁵⁸ Her contention is that if the psychological connections between the now-incapacitated person and the person he used to be have become sufficiently attenuated, we should reconsider whether they are even the same person. If the patient with Alzheimer's is genuinely "no longer himself," the directives of precedent autonomy are as irrelevant to him as are the choices of an entirely different human being.

This "different person" argument draws on a view of personal identity developed by Derek Parfit, that identity consists in psychological connectedness.¹⁵⁹ As the memories and other cognitive capacities of Alzheimer's patients diminish, so do their psychological connectedness become increasingly attenuated. As psychological links fade, the former self disappears, to be replaced by a different self with a different mental life. Parfit's view of personal identity is intriguing and deeply controversial, but there are several reasons for rejecting it as a definitive argument against the authority of precedent autonomy for patients with dementia. First, it is a view about personal identity that is controversial for reasons far beyond the scope of this article. Second, patients with dementia may not experience dislocations sufficiently complete to be regarded as the emergence of a new self.¹⁶⁰ If the descriptions of observers such as Sabat are correct, these patients first experience the

¹⁵⁸ Rebecca S. Dresser, *Autonomy Revisited: The Limits of Anticipatory Choices*, in *DEMENTIA AND AGING: ETHICS, VALUES, AND POLICY CHOICES* 71 (Robert H. Binstock et al. eds., 1992); Rebecca Dresser, *Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law*, 28 *ARIZ. L. REV.* 373, 376, 379 (1986); Rebecca Dresser, *Missing Persons: Legal Perceptions of Incompetent Patients*, 46 *RUTGERS L. REV.* 609, 612 (1994) [hereinafter Dresser, *Missing Persons*]; Rebecca Dresser & Peter J. Whitehouse, *The Incompetent Patient on the Slippery Slope*, 24 *HASTINGS CENTER REP.*, July-Aug. 1994, at 6.

¹⁵⁹ See generally DEREK PARFIT, *REASONS AND PERSONS* (Clarendon Press 1984).

¹⁶⁰ Norman L. Cantor, *Prospective Autonomy: On the Limits of Shaping One's Postcompetence Medical Fate*, 8 *J. CONTEMP. HEALTH L. & POL'Y* 13, 31-33 (1992).

disconnectedness associated with a loss of short-term memory.¹⁶¹ Psychological connectedness to the memories of youth may be especially strong.¹⁶² As dementia progresses, they may lose sight of ends that require complex cognitive skills: the ability to do science, or religious faith. But even in these respects they may not be entirely disconnected from their earlier psychological histories. Sabat, for example, describes a man with moderate to severe dementia who had lost the ability to do science but who retained the sense of accomplishment associated with helping Sabat's own study of Alzheimer's disease.¹⁶³ Jaworska's account of the capacity of Alzheimer's patients to value relies on just this connectedness with former aims.

A third reason to reject the "different person" argument is that it does not answer the full moral force of the argument for precedent autonomy. The argument for precedent autonomy is not only that persons have a right to have their choices respected across time. It is also that they have interests in the overall shape of their lives, including the form that will be taken at the end.¹⁶⁴ They have interests in how they will be remembered by others, memories that will surely be affected by the character of their dying process. These interests are not expunged by the interests of the now-incapacitated, whether regarded as the same or a different person.

Fourth, the "different person" argument may prove too much. If the "different person" argument undermines the authority of precedent autonomy for health care, it may also undermine the authority of precedent autonomy more generally. Drickamer & Lachs point out that if precedent autonomy is undermined for the patient with dementia, it is also undermined for the patient with a

¹⁶¹ Sabat, *supra* note 155, at 38.

¹⁶² STEPHEN G. POST, *THE MORAL CHALLENGE OF ALZHEIMER DISEASE* (1995). Post relates this as a story about the importance of honoring the patient's former relationship. But there is another way to tell this story. Suppose that the patient's attraction to the resident is based on liking in him, albeit in an inchoate way, the characteristics she had loved in her husband. Then there might be a sense in which the new relationship honors the old, even if it involves a confusion of identity as well. See also Stephen G. Post, *Alzheimer Disease and the 'Then' Self*, 5 KENNEDY INST. ETHICS J. 307, 307-08 (1995).

¹⁶³ Sabat, *supra* note 155, at 41-43.

¹⁶⁴ DWORKIN, *supra* note 151, at 227. For good examples of the shape of a life, see ROBERT C.S. DOWNS, *THE FIFTH SEASON* (2000), BAYLEY, *supra* note 155, G. ROBERT ARTLEY, *GINNY: A LOVE REMEMBERED* (1993).

swifter cognitive decline, such as a patient who has become incapacitated from metastatic brain cancer.¹⁶⁵ Post relates the tale of a nursing home resident who mistakes another resident for her deceased spouse and wants to cohabit with him; her daughter refused consent because it would make a “mockery” of her parents’ loving relationship, now past.¹⁶⁶ Cantor observes that it is difficult to distinguish rejecting precedent autonomy for health-care decisions but not for other decisions, such as property arrangements or wills.¹⁶⁷ Many social mechanisms have been developed specifically to allow people to be confident that their present desires to provide for the future will be respected over time. A response to this argument is that health-care decisions are special; they may mean life and death itself. But even property arrangements may be similarly critical, if resources otherwise assigned are required for life-saving care.

Moreover, the “different person” argument may have particularly troublesome implications for the SPA for health care. Even if the argument is limited to health-care decisions, it applies with equal force to living wills and to SPAs. It then suggests that if the now-incapacitated person has formed different attachments, new surrogate decisionmakers would be appropriate even when an SPA was appointed through the exercise of precedent autonomy. The particularly counter-intuitive result is that the authority of the patient’s chosen surrogate to make health-care decisions would be undermined, but the surrogate would retain authority to make all other decisions. This distinction seems odd at best; the chosen SPA should have the authority to make health-care decisions as well as other decisions, unless there is some reason for doubting his good faith. There are reasons for doubting the authority of the SPA, but they arise when the SPA fails to act in good faith to protect the patient, not because the patient has become an ostensibly different person.

¹⁶⁵ Margaret A. Drickamer & Mark S. Lachs, *Should Patients with Alzheimer’s Disease be Told Their Diagnosis?*, 326 *NEW ENG. J. MED.* 947 (1992).

¹⁶⁶ Post, *supra* note 162, at 309.

¹⁶⁷ Cantor, *supra* note 160, at 28.

Finally, the “different person” argument is not necessary to the central moral point of those who challenge precedent autonomy. Jaworska observes that conflicts between precedent autonomy and the interests of incapacitated persons are apparent without resort to metaphysics:

the moral pull of Dresser’s position is undeniable: the caregiver . . . is faced with a person—or if not a fully constituted person, at least a conscious being capable of pleasure and pain—who, here and now, makes a claim on the caregiver to fulfill her needs and desires; why ignore these needs and desires in the name of values that are now extinct?¹⁶⁸

Dresser contends that autonomy is not the sole value involved in decisions; it may be overridden by the present benefits and burdens of a treatment decision. Even Ronald Dworkin puts the dilemma starkly: “Does a competent person’s right to autonomy include, for example, the power to dictate that life-prolonging treatment be denied him later, or that funds not be spent on maintaining him in great comfort, even if he, when demented, pleads for it?”¹⁶⁹ The real conflicts here lie between prior choice and present interests; resolving them requires analyzing the interests of persons with dementia and understanding their potential moral force. Dresser powerfully points out the deception frequently involved in wanting to believe in the accuracy of a reconstruction of what the patient “would have wanted”; she may also be right in speculating that this deception should be attributed to the fact that it is people with competence who have developed decisionmaking models for people who lack competence.¹⁷⁰

Thus arguments against precedent autonomy are either incomplete or flawed. Nonetheless, they rest on an important underlying moral concern: that respect for precedent autonomy may conflict

¹⁶⁸ Jaworska, *supra* note 13, at 108.

¹⁶⁹ DWORKIN, *supra* note 151, at 211.

¹⁷⁰ Dresser & Whitehouse, *supra* note 158, at 7.

with the current interests of a demented patient, and it requires argument to determine which should prevail.

IV. DECISIONMAKING ABOUT CARE: THE PATIENT'S BEST INTERESTS

Critics of precedent autonomy contend that the interests of incapacitated persons should take priority over values that are no longer experienced by patients with dementia. The need to protect the interests of an existing, incompetent being is a powerful moral concern. The "best interests" standard is generally recommended as the means to that protection. The "best interest" standard is also recommended for decisionmaking when patients' advance wishes are not fully known. Evaluating these arguments requires a clear understanding of what is meant by "interests." But there are several different accounts in the literature of what is meant by "interests" for purposes of the "best interests" standard. This section begins by explaining several different concepts of "interests," arguing that interests should be understood in the "experiential" sense when care decisions must be made for patients with dementia.

A. BEST INTERESTS: UNDERSTANDING THE CONCEPT OF "INTEREST"

The concept of "interests" is understood in significantly different ways in the law, in commentary about it, and in the bioethics literature. To take one legal example, the Uniform Health-Care Decisions Act Section 2(e) provides that health-care agents should make decisions based on the patient's best interests, if there are no individual instructions for care by the patient himself.¹⁷¹ The Act further provides that "In determining the principal's best interest, the agent shall consider the principal's personal values to the extent known to the agent."¹⁷² This recommendation links values formerly held by a person to a determination of present interests. To take a second example, the Maryland statute governing end of life

¹⁷¹ 9, Part IB, U.L.A. 152 (2000).

¹⁷² *Id.*

decisionmaking specifies a remarkably expansive definition of "best interest":

'Best interest' means that the benefits to the individual resulting from a treatment outweigh the burdens to the individual resulting from that treatment, taking into account: (1) The effect of the treatment on the physical, emotional, and cognitive functions of the individual; (2) The degree of physical pain or discomfort caused to the individual by the treatment, or the withholding or withdrawal of the treatment; (3) The degree to which the individual's medical condition, the treatment, or the withholding or withdrawal of treatment result in a severe and continuing impairment of the dignity of the individual by subjecting the individual to a condition of extreme humiliation and dependency; (4) The effect of the treatment on the life expectancy of the individual; (5) The prognosis of the individual for recovery, with and without the treatment; (6) The risks, side effects, and benefits of the treatment or the withholding or withdrawal of the treatment; and (7) The religious beliefs and basic values of the individual receiving treatment, to the extent these may assist the decisionmaker in determining best interest.¹⁷³

This provision incorporates the patient's experiences, dignity, and values, among other factors, into the determination of interests.

Commentators employ at least four different ways "interests" may be understood in statutes like these and in the legal cases applying the best interests standard: experiential interests, patient preferences, patient values, and "objective" or "critical" interests. This section distinguishes the four, and argues that the idea of "experiential interests" best captures the moral concerns raised by critics of precedent autonomy.

¹⁷³ MD. CODE ANN., HEALTH-GEN. I § 5-601(e) (2000).

“Experiential interests” rest on the patient’s own experiences. They include perceptions of pleasure and pain, comfort and discomfort, along with other sensations felt by the patient. Because pleasure and pain figure importantly in the experiences of patients, these may be called “hedonic” theories, but it is important to remember that patients’ experiences include far more than pleasure and pain.¹⁷⁴ In arguing that the interests of an incapacitated person should be favored over precedent autonomy, Dresser employs this concept of experiential interests: “Whether there is pain, distress, pleasure, physical movement, or interaction with people and objects in the surrounding world.”¹⁷⁵ It is in the experiential sense that patients in a persistent coma are said to have no interests because they have no cognitive experiences. To be sure, there may be difficulties in ascertaining the experiential interests of patients who cannot communicate. Dresser, however, provides a helpful account of why we should not assume that there are theoretical barriers to understanding the experiences of people with dementia as well as an account of how these experiences can be accessed.¹⁷⁶

A second understanding of interests identifies them with expressed preferences. On this view, patients have interests in what they say they want. When patients cannot communicate preferences directly, however, this understanding of interests may be difficult to employ. One strategy is to extrapolate preferences from behavior. Patients who attempt to remove feeding tubes, for example, may be understood as wanting the tube removed, and thus as having interests in its removal. Dresser criticizes this account as insufficiently attentive to the meaning of patients’ behavior.¹⁷⁷ She contends that we are too likely to read our own understandings into such behaviors and to see them as meaningful expressions of preference when they are not. To the extent that they are meaningful, she contends, these behaviors should be taken as indicative of

¹⁷⁴ Bruce Jennings, *A Life Greater Than the Sum of Its Sensations: Ethics, Dementia, and the Quality of Life*, 5 *J. MENTAL HEALTH & AGING* 95, 100 (1999).

¹⁷⁵ Dresser, *Missing Persons*, *supra* note 158, at 638.

¹⁷⁶ See generally *id.* (arguing courts should focus on patient’s actual experiences rather than patient’s hypothetical, rational choice).

¹⁷⁷ *Id.*

the nature of the patient's experiences.¹⁷⁸ Thus the patient's pulling at a feeding tube might reflect experienced discomfort, rather than the desire that the tube be removed. For patients who cannot express preferences, therefore, the expressed preference account is arguably not independent of the experiential account.

A third understanding of interests rests on the patient's values. Jennings calls this a "rational desire" theory; the idea is that patients may be thought to rationally desire (if not actually desire) what they value.¹⁷⁹ The patient's values are incorporated into the definition of interests in both the Uniform Act and the Maryland statute.¹⁸⁰ The possibility that a patient with dementia might have interests in this sense is controversial, however. Dworkin rejects the possibility that patients with severe dementia can value; just as he rejects the possibility that a patient can exercise autonomy without having a sense of self, so he rejects the possibility that such a patient can value.¹⁸¹ Jaworska, in contrast, describes how patients with dementia can still engage in valuing.¹⁸² She argues that such patients can have ends and can have beliefs about what is worthwhile, even when they have lost the thread of the narrative of their own lives.¹⁸³ Jaworska distinguishes such valuing from "experiential" interests because they may not be fully occurrent for the patient.¹⁸⁴ Depending on the extent of the patient's cognitive disorganization, valuing may not be reflected in the patient's present experiences even though the patient continues to rely on them in an inchoate way. What becomes problematic, then, is why such valuing should matter in decisionmaking for an incapacitated person. On the one hand, to the extent they are reflected in the patient's experiences, valuing are captured by the experiential sense of interests. On the other hand, the case for including them would seem to be respect for the person as a holder of values. But why should such respect be grounded in what is admittedly a pale

¹⁷⁸ *Id.*

¹⁷⁹ Jennings, *supra* note 174.

¹⁸⁰ See *supra* note 173 and accompanying text (discussing Uniform Act and Maryland Statutes).

¹⁸¹ DWORKIN, *supra* note 151.

¹⁸² Jaworska, *supra* note 13, at 109.

¹⁸³ *Id.*

¹⁸⁴ *Id.*

reflection of the person's prior values? The best answer lies in terms of prior autonomy: that to the extent that they remain values at all, they are continuations of the person's prior goals. Viewed in this way, the understanding of interests as values dissolves either into concern for the nature of the patient's present experiences or respect for precedent autonomy.

Finally, commentators identify the "critical" or "objective" interests of patients. These are interests all people have, such as the ability to interact with other human beings. This is called by Parfit and others the "objective" interest standard;¹⁸⁵ Jennings refers to it as a theory of human flourishing.¹⁸⁶ As a standard that refers to what is valuable for all, "critical interests" are independent of the patient's own values or experiences. Thus "critical interests" should not be identified with the patient's values. Indeed, a patient's values such as identification with a religious tradition that rejects certain forms of health care might be inconsistent with the critical interest in being free of pain. The "critical interests" standard is normative: it represents an account of what is good for the patient, rather than what the patients actually experiences or value themselves. Dworkin, for example, holds that experiential interests are interests in pleasant feelings such as being comforted and reassured, whereas "critical interests" involve what is needed to make one's life better on the whole.¹⁸⁷ In describing critical interests, Dresser includes: "The usual candidates for interests include biological life, sensations, emotions and other conscious experiences, physical functioning, individual preferences and desires, and such higher-level matters as concern for others and the pursuit of complex goals and long-term projects."¹⁸⁸ She rejects reliance on critical interests in decisionmaking for patients with dementia, arguing that many such patients will lack critical interests in Dworkin's sense and that it is the quality of their experiences which matter the most to them.¹⁸⁹ It is not clear, however, that Dresser and Dworkin are right to conclude that

¹⁸⁵ PARFIT, *supra* note 159.

¹⁸⁶ JENNINGS, *supra* note 174, at 101.

¹⁸⁷ DWORKIN, *supra* note 151, at 229-30.

¹⁸⁸ DRESSER, *Missing Persons*, *supra* note 158, at 658.

¹⁸⁹ *Id.* at 639.

incapacitated persons lack critical interests. Such interests could be defended on the basis of a general theory about what is good for persons, even when incapacitated. What they are right about is that the case for critical interests must be a normative one, separated from both precedent autonomy and the patient's current experiences. To the extent that decisionmaking for incapacitated persons should be limited to their own values and experiences, reliance on "critical interests" represents making value judgments for them rather than on their behalf.

There are thus four separable concepts of interest that figure into the discussions of decisionmaking for patients with dementia. "Experiential" interests refer to the nature of the patient's actual experiences. Apparent preferences, to the extent they can be ascertained, are evidence of experiences. What might be called "valuings" refer to the patient's presently existing values to the extent that the patient is capable of valuing, and arguably are but a pallid reflection of precedent autonomy. Finally, "critical" interests refer to normative judgments of what would be good for the patient. The moral concern of the critics of precedent autonomy is that it ignores the felt experiences of the now-incapacitated person. On the basis of that moral concern, the interests of patients with dementia should be viewed as experiential interests.¹⁹⁰

B. CARE DECISIONS AND THE EXPERIENTIAL INTERESTS OF PATIENTS WITH DEMENTIA

An assessment of the experiential interests of patients with dementia must face the initial problem that knowledge about such patients is sketchy and quite possibly biased. Knowledge is lacking both about what might be medically beneficial for such patients in terms of extending life or reducing morbidity, about what their experiences are like, and about what various therapies might feel like for them.

Until quite recently, there has been little systematic study of the benefits of different care modalities for patients with dementia.

¹⁹⁰ See *id.*; Sanford H. Kadish, *Letting Patients Die: Legal and Moral Reflections*, 80 CAL. L. REV. 857, 871-78 (1992); Lynn et al., *supra* note 130, at 274.

This lacuna has begun to be addressed by several quite recent studies in the medical literature. Morrison and Siu identify quite high six-month mortality rates for patients with dementia and hip fractures (55%) or pneumonia (53%) compared to cognitively intact patients with the same conditions.¹⁹¹ They also find no difference in the rate of care interventions between the two groups.¹⁹² An ongoing problem, however, is assessing whether the level of intervention affects both survival and quality of life. Morrison and Siu also find that patients with dementia are less likely to receive pain medication than cognitively intact patients;¹⁹³ moreover, only 24% of patients with dementia and hip fracture received standing orders for analgesics, despite the likelihood that they would have difficulty in communicating about pain.¹⁹⁴ Finucane, Christmas & Travis question whether tube feeding is beneficial either in extending life or in preventing aspiration pneumonia.¹⁹⁵ Brauner, Muir & Sachs consider how dementia affects the risk/benefit ratio of medications for patients with dementia, observing that common medications may be less safe in a patient population who may have difficulty taking medications as directed and who are unable to report side effects.¹⁹⁶ Their examples are warfarin for atrial fibrillation (with the complication of bleeding from bruising suffered in falls, more likely in dementia patients) and alendronate for osteoporosis (erosive esophagitis, more likely to pass unreported in dementia patients).¹⁹⁷ They also question the advisability of dietary restrictions to lower cholesterol in a population with problematic nutritional status and the possible disturbing nature of routine screening for colorectal cancer by colonoscopy in a population that cannot understand the procedure.¹⁹⁸

¹⁹¹ Morrison & Siu, *supra* note 6, at 50.

¹⁹² *Id.*

¹⁹³ *Id.*

¹⁹⁴ *Id.*

¹⁹⁵ Thomas E. Finucane et al., *Tube Feeding in Patients with Advanced Dementia: A Review of the Evidence*, 282 JAMA 1365, 1369 (1999).

¹⁹⁶ Daniel J. Brauner et al., *Treating Nondementia Illnesses in Patients with Dementia*, 283 JAMA 3230, 3230-35 (2000).

¹⁹⁷ *Id.* at 3231-33.

¹⁹⁸ *Id.* at 3233.

Several other studies address the problem of bias in assessing the experiences of patients with dementia. MacKenzie, Robiner & Knopman report a nearly four-fold increase in diagnoses of depression for patients with Alzheimer's disease when diagnoses included information from family members rather than just interviews with the patient.¹⁹⁹ Another problem is how much the quality of patients' experiences is affected by how these patients are treated. Kutner et al. studied family members' perceptions of improvement for patients with dementia admitted to care facilities.²⁰⁰ Family members did not perceive improvement in physical or cognitive status.²⁰¹ However, the study reports that family members did perceive significantly increased quality of life for patients admitted to a special care unit for patients with dementia (55% improved emotional functioning and 46% improved social functioning on a special care unit in comparison to 27% improved emotional function and 7% improved social functioning on a non-special-care floor).²⁰² This study also reports increased improvement in special care units that are more highly staffed.²⁰³

Several recent studies have addressed the issue of assessing quality of life for patients with dementia. These studies suggest the need to broaden accounts of the experiential interests of patients with dementia from a narrow focus on pleasure and pain. Brod et al. report success in using an instrument for measuring quality of life in patients with mild to moderate dementia.²⁰⁴ They note that domains such as aesthetic experience and the capacity to interact with the environment may be especially important to assessing quality of life for patients with dementia. Teri and Logsdon describe the involvement of patients with dementia in evaluating their

¹⁹⁹ Thomas B. Mackenzie et al., *Differences Between Patient and Family Assessments of Depression in Alzheimer's Disease*, 146 AM. J. OF PSYCHIATRY 1174, 1178 (1989). The study revealed a 13.9% rate of depression based on interviews with the patients, but a 50% rate when the patient interviewed was supplemented by information from the family. *Id.*

²⁰⁰ Nancy G. Kutner et al., *Family Members' Perceptions of Quality of Life Change in Dementia SCU Residents*, 18 J. APPLIED GERONTOLOGY 423 (1999).

²⁰¹ *Id.* at 432.

²⁰² *Id.* at 432-33.

²⁰³ *Id.* at 434-35.

²⁰⁴ Meryl Brod et al., *Conceptualization and Measurement of Quality of Life in Dementia: The Dementia Quality of Life Instrument (DQoL)*, 39 GERONTOLOGIST 25 (1999).

enjoyment of activities.²⁰⁵ But Fellows cautions against reading physicians' values into the assessments.²⁰⁶ Jennings also points out how assessments may be biased.²⁰⁷ A recent British study indicates that cognitively impaired elders can give meaningful answers to quality of life questions, even if they appear to be significantly impaired on the MMSE (scores of 10-17).²⁰⁸ Gonzalez-Salvador et al. measured quality of life among dementia patients in a Maryland long-term care facility.²⁰⁹ They concluded that higher quality of life scores were associated with residency in assisted living rather than in skilled nursing facilities, and lower scores with increased physical dependency, depression, and treatment with anxiolytic agents.

The lack of information about treatment effects and patient experiences may be reflected in decisionmaking about patients with dementia. A recent study by Mitchell et al. found that a sample of patients in American facilities who were receiving tube feeding were far more likely to have a diagnosis of dementia than a sample of patients in a Canadian facility.²¹⁰ The study was designed to find out how tube feeding decisions are made, given the questionable benefit of the intervention in patients with dementia. Surrogates felt that they understood benefits (83%) but not the risks (45.6%) of tube feeding. Tube feeding was instituted to prolong life (84%) and to prevent aspiration (67%). Fewer than 20% of the patients had a living will, and fewer than half of the surrogates were confident that tube feeding was what the patient would have wanted. In a bow towards prior autonomy, the authors suggest surrogates need better medical information and better information about patients' wishes in making decisions about tube feeding.²¹¹

²⁰⁵ Linda Teri & Rebecca G. Logson, *Identifying Pleasant Activities for Alzheimer's Disease Patients: The Pleasant Events Schedule-AD*, 31 *GERONTOLOGIST* 124 (1991).

²⁰⁶ Fellows, *supra* note 27.

²⁰⁷ Jennings, *supra* note 174.

²⁰⁸ Caroline Godlove Mozley et al., *Not Knowing Where I am Doesn't Mean I Don't Know What I Like: Cognitive Impairment and Quality of Life Responses in Elderly People*, 14 *INT'L J. GERIATRIC PSYCHIATRY* 776 (1999).

²⁰⁹ Teresa Gonzalez-Salvador et al., *Quality of Life in Dementia Patients in Long-Term Care*, 15 *INT'L J. GERIATRIC PSYCHIATRY* 181 (2000).

²¹⁰ Susan L. Mitchell et al., *A Cross-National Survey of Tube-Feeding Decisions in Cognitively Impaired Older Persons*, 48 *J. AM. GERIATRICS SOC'Y* 391 (2000).

²¹¹ *Id.* at 396-97.

Decisions about end of life care for patients with dementia may involve management of conditions that are directly linked to the dementia, such as nutritional compromise and the possibility of medical intervention by means of a feeding tube. They may involve treatment for conditions that are unrelated to the dementia, such as cancer or diabetes. Finally, they may involve management of distress and pain that accompany whatever care modalities are—or are not—employed. On an experiential account of interests, decisions of each of these kinds should center on the character of the patient's experiences. Dresser summarizes this as a revised best interests standard: "give priority to protection of incompetent patients' experiential interests, yet also acknowledge that significant cognitive impairment can minimize the value of prolonged life for some patients."²¹² If life-extending medical care will prolong, to a significant extent, a life of relatively pleasurable experiences, it should be chosen for the patient. On the other hand, as Dresser argues, on the experiential standard life-extending care may be foregone when the patient has very limited capacities for experiences; extending life itself is not in the patient's experiential interests in such cases.²¹³

Consider first the application of such principles based on experiential interests to conditions related to the dementia itself. Care that would not be effective should not be provided; further research is clearly required on the effectiveness of care modalities frequently employed in end stage dementia, such as antibiotics for aspiration pneumonia or tube feeding. Care may also be foregone when it would prolong life in a patient of limited capacity for experiences at all, such as Edna F.²¹⁴ It would also be appropriate to withhold care that is burdensome in comparison to the extent to which it would extend the patient's likely capacity for pleasurable experiences; ventilator support for a pneumonia from which the patient might recover is a possible example. On the other hand, care should be provided when it would help the patient to retain the capacity for ongoing satisfying experiences.

²¹² Dresser, *Missing Persons*, *supra* note 158, at 692.

²¹³ *Id.* at 694-709.

²¹⁴ *In re Guardianship of Edna M.F.*, 563 N.W.2d 485 (Wis. 1997).

Now consider care for conditions that are independent of the dementia. Care decisions generally should be evaluated in light of their safety and efficacy in patients with dementia, rather than in light of the experience of the general patient population. Recommendations for otherwise ordinary diagnostic care might be altered in light of the extent to which they are intrusive and disturbing, in comparison to the likelihood that the results would influence management decisions that would prolong satisfying life. Care may also be foregone if the treatment needed has serious, persisting adverse experiential consequences such as the need for ongoing restraint to administer it. Dresser and Whitehouse suggest that patients with multi-infarct dementia who are bedridden may experience even hygienic care as "torture"; treatment of associated illnesses might be forgone in these patients.²¹⁵ Another group in which care might be foregone is dementia patients who are severely agitated or paranoid, who experience terror at care modalities including restraints.

Finally, palliative care is central to the experiences of many patients, but may be forgotten in the situation of patients with dementia. The limitation of the hospice benefit to patients with life expectancies of six months or less may contribute to this absence, since patients with dementia may not be identified as "terminally ill" during the downhill course of disease.²¹⁶ Pain from conditions such as arthritis may be under-treated in patients with dementia because of their inability to communicate distress. Other forms of comfort care, such as the warmth of a personal touch or the individual interaction in an effort to provide nutrition orally may be very difficult in an under-staffed long-term care facility. Focus on experiential interests warrants a particularly strong endorsement of the importance of comfort care and symptom management in patients with dementia.

As the review above indicates, too little is known about the medical potential of treatment in patients with dementia or about the experiences of patients. Several cautions are especially important, in light of these difficulties. It is important not to

²¹⁵ Dresser & Whitehouse, *supra* note 158.

²¹⁶ See *Recommendations of the Joint Conference*, 35 GA. L. REV. 423, 435-37 (2001).

assume in the absence of data that care will be beneficial—or that it will not be. It is important not to confuse a judgment that care is futile in the medical sense with the judgment that it is not worthwhile on some other standard: the quality of the patient's experiences, the judgments of others about such experiences, or the costs of the care. And it is important not to confuse the experiences of the patient with the judgments of others about whether care violates "dignity" or is something they would value.

C. CARE PARADIGMS AND THE INTERESTS OF OTHERS

Commentators with leanings towards communitarian or feminist moral theories point out that patients' interests are not alone in decisionmaking about care. Dresser²¹⁷ and Lynn et al.²¹⁸ suggest that the family should play a role in shaping the understanding of the interests of an incapacitated person, just as parents may play legitimate roles in shaping the interests of their children. And the family has interests, too. Statutes identifying surrogates, as well as support for SPAs sometimes reflect these interests. High defends the role of families in making care decisions on the basis that they have important interests, too.²¹⁹ These observations take the focus of decisionmaking away from the patient viewed as an individual, or away from the patient altogether. Although this article's primary focus has been the patient as an individual, two brief observations are perhaps in order. First, on the experiential account of interests the role of others is secondary; they matter only insofar as their actions and interactions with the patient affect the patient's experiences. Second, to base decisionmaking on the concerns of families shifts the moral focus away from the patient, a shift that may be justified but that raises issues far beyond the treatment of patients with dementia.

²¹⁷ Dresser, *Missing Persons*, *supra* note 158.

²¹⁸ Lynn et al., *supra* note 130.

²¹⁹ Dallas M. High, *Families' Roles in Advance Directives*, 24 HASTINGS CENTER REP., Nov.-Dec. 1994, at S16.

V. RESOLVING CONFLICTS BETWEEN PRECEDENT AUTONOMY AND EXPERIENTIAL INTERESTS

The central conflict in decisionmaking for patients with dementia thus lies between precedent autonomy—following what is known about the patient's prior choices—and the patient's current experiences. Patients may have left directives that, if followed, will limit their ability to continue with ongoing, pleasant experiences. Or, they may have left directives for continuing care that will now cause them pain that they do not understand. Precedent autonomy may be exercised directly through prescribed decisions or through the appointment of a surrogate, or indirectly through extrapolation from what is known about expressed wishes. Defenders of precedent autonomy would resolve conflicts in its favor, observing that many choices against interests are honored for competent patients.²²⁰ Dresser and other critics are correct in observing, however, that even the most explicit prior pronouncements by a patient may not be an accurate measure of what the patient really meant to choose for current circumstances. The further the departure from explicit guidelines, moreover, the less reliable the guidance. Dresser would, therefore, resolve the conflicts in favor of protecting the interests of the now-incapacitated person.

At the same time, the case for reliance on experiential interests may also be overstated. Continuing treatment that will cause pain, failing to provide appropriate palliative care, and providing or withholding care in a manner that is disturbing to the patient is clearly injurious to the now-incapacitated person. Following an advance directive against providing life-extending therapy when a patient still has some pleasurable experiences is not injurious in the same sense. It may not prolong the pleasurable experiences, but it does not cause pain, either. This observation suggests a different resolution of the conflict between precedent autonomy and experiential interests.

To the extent that the directives of precedent autonomy are clear, they should control. They should not control, however, when the result would be to cause significant harm—pain, terror, or other

²²⁰ Cantor, *supra* note 160, at 39.

immediately dysphoric experiences—to the patient with dementia. As the guidance in prior directives becomes less clear, it should be weighed against the experiential interests of incapacitated persons. Experiential interests in turn are less weighty to the extent that cognitive capacities fade. Thus a relatively clear advance directive would prevail over fading experiences of the incapacitated person; and relatively intense pleasant experiences of the incapacitated person would prevail over fragmentary guidance. These recommendations are messy; their force may not be obvious in particular cases. But they seem to capture what is morally important about precedent autonomy—guidance for how one's life winds down—as well as what is morally important about experiential interests: avoiding pain and continuing experiences of relative quality to the extent that clear prior autonomy is not compromised.