

January 2014

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Recommended Citation

PAUL T. MENZEL, *Advance Directives, Dementia, and Eligibility for Physician-Assisted Death*, 58 N.Y.L. SCH. L. REV. (2013-2014).

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Advance Directives, Dementia, and Eligibility for Physician-Assisted Death

58 N.Y.L. SCH. L. REV. 321 (2013–2014)

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I. INTRODUCTION¹

In most of the jurisdictions where some form of physician-assisted death (PAD)² is legal,³ the requesting individual must be competent to make medical decisions at the time of assistance. The requirement of contemporary competence is intended to ensure that PAD is limited to people who genuinely want to die and have decisionmaking cognitive ability at the time of a final choice with such enormous import. Along with terminal illness, defined as the prognosis of death within six months, contemporary competence is regarded as an important safeguard against mistake and abuse, which are arguably the strongest objections to legalizing PAD.

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1. Much of this article's factual data and moral analysis, and many segments of its specific articulation, are contained in the primary and longer paper from which it is derived. *See generally* Paul T. Menzel & Bonnie Steinbock, *Advance Directives, Dementia, and Physician-Assisted Death*, 41 J.L. MED. & ETHICS 484 (2013). The *Journal of Law, Medicine, and Ethics* paper pursues the moral argument at greater length through eight paradigm cases of persons with dementia. The current article's analysis in Parts III–VI is considerably shorter, and it focuses more on all three of the basic eligibility conditions for legal physician-assisted death, not only current competency. Part VII of this article is entirely new. The background research that enabled me to construct this article was supported by a month as Visiting Researcher at the Brocher Foundation, Hermance, Switzerland, in April 2012. I am greatly indebted to my co-author of the primary article that resulted from that research, Bonnie Steinbock. While at Brocher, we benefited greatly from consultation with Dr. Samia Hurst of the Institute of Biomedical Ethics, University of Geneva Medical School. I also received helpful feedback at the *Freedom of Choice at the End of Life: Patients' Rights in a Shifting Legal and Political Landscape* symposium at New York Law School on November 16, 2012, especially in conversation with Professor Peter J. Strauss, the symposium chair.
 2. The term “physician-assisted death” covers both physician-assisted suicide and euthanasia. In physician-assisted suicide, the patient takes lethal drugs made available through a physician's prescription; in euthanasia, the physician delivers the lethal drugs, usually by injection. The term “physician-assisted suicide” has fallen out of favor among many proponents, who wish to distinguish it from suicide in general and therefore prefer “aid in dying.”
 3. Namely, in Vermont, Oregon, Washington, and Montana in the United States, and in Belgium and Switzerland. Aid in dying is legal by statute in Vermont, Oregon, and Washington. *See* Patient Choice and Control at End of Life Act, ch. 113, VT. STAT. ANN. tit. 18, § 5291 (West 2013); Oregon Death with Dignity Act, OR. REV. STAT. ANN. §§ 127.800–897 (West 2013); Washington Death with Dignity Act, WASH. REV. CODE §§ 70.245.010–904 (West 2013). It is legal by a decision of the state supreme court in Montana. *See* *Baxter v. State*, 224 P.3d 1211 (Mont. 2009). In June 2012, it became conditionally legal by court decision in British Columbia, though that decision was subsequently overturned by the British Columbia Court of Appeal in October 2013. *Carter v. Canada* (Att'y Gen.), 2012 BCSC 886 (Can. B.C.), available at <http://www.courts.gov.bc.ca/jdb-txt/SC/12/08/2012BCSC0886cor1.htm>, *rev'd*, 2013 BCCA 435 (Can. B.C. Ct. App.), available at <http://www.courts.gov.bc.ca/jdb-txt/CA/13/04/2013BCCA0435.htm>. In Belgium, the patient must be legally competent and conscious at the moment of making the request for euthanasia. *See* The Belgian Act on Euthanasia of May 28, 2002, 9 ETHICAL PERSPECTIVES 182 (2002), available at <http://www.ethical-perspectives.be/viewpic.php?LAN=E&TABLE=EP&ID=59> (unofficial translation by Dale Kidd & Herman Nys), although legislation was introduced in 2013 that would expand euthanasia to minors and those suffering from dementia. *See* Connor Adams Sheets, *Belgian Parliament Posed to Approve Child Euthanasia Law*, INT'L BUS. TIMES (June 11, 2013, 3:03 PM), <http://www.ibtimes.com/belgian-parliament-posed-approve-child-euthanasia-law-1301825>. In Switzerland, both physician-assisted suicide and assisted suicide more generally are legal by statute, and though voluntary self-administration is required, it is not restricted to terminal illness. *See* Samia A. Hurst & Alex Mauron, *Assisted Suicide and Euthanasia in Switzerland: Allowing a Role for Non-Physicians*, 326 BMJ 271, 271–73 (2003), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1125125/>.

In the Netherlands and Belgium, where euthanasia is legal, terminal illness is not required. In the Netherlands, neither is contemporary competence; the focus is instead on voluntariness, a requirement that can in some cases be satisfied by the patient's previous decisions and directives. In both countries, unbearable suffering is also required.⁴

These various qualifying conditions for PAD—contemporary competence, terminal illness, and unbearable suffering—preclude its use for patients with chronic severe dementia. Although patients in the early stages of dementia may still be competent, they lose the ability to make medical decisions for themselves as dementia progresses. Nor are most patients in even severe dementia considered terminally ill; chronic progressive dementia is typically not seen as terminal illness until its very final stages, and, even then, prognoses of six months or less to live due to end-stage dementia are treacherous. Nor is unbearable suffering a common characteristic of people with severe dementia, yet many are as opposed—or even more strongly opposed—to having their lives end in years of severe dementia as they are to enduring a few months of suffering at the end of life. If they have a right to choose death to avoid the latter, why do they not have a right to avoid the former?

Dementia thus poses a strong challenge to the current legal limits on PAD. Access to PAD for persons with dementia, not just for those who are currently competent, terminally ill, or unbearably suffering, will become an increasingly pressing issue as the world's population ages. By 2040, the number of those over age eighty-five will nearly quadruple from what it was in 2000.⁵ Almost half of people over eighty-five have some form of dementia.⁶ About 5.2 million Americans have Alzheimer's disease, the most common form.⁷ These numbers will rise progressively over the next several decades.

This article will make the case that through clear, informed, and persistent advance directives, people should be allowed to direct their future death in the event of severe dementia. Neither current competency, terminal illness, nor unbearable suffering should be retained as strict qualifying conditions for legalized PAD. Other limitations can preserve its voluntariness, prevent its abuse, and respect the value of patients' lives.

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4. For Dutch law, see Termination of Life on Request and Assisted Suicide (Review Procedures) Act (2002), available at <http://www.eutanasia.ws/documentos/Leyes/Internacional/Holanda Ley 2002.pdf>. The procedures codified in the 2002 law reflect Dutch medical practice since 1973, when doctors began openly providing euthanasia on request. Two doctors must certify that the patient's desire to die stems from "hopeless and unbearable suffering." Under the Belgian Act on Euthanasia of May 28, 2002, *supra* note 3, two physicians must certify that the person endures constant and unbearable physical or psychological pain from incurable illness or accident; a third medical opinion to the same effect must be obtained if the person is not terminally ill.
 5. *The U.S. Population Is Aging*, URBAN INST., http://www.urban.org/retirement_policy/agingpopulation.cfm (last visited Dec. 29, 2013).
 6. *Dementia: Hope Through Research*, NAT'L INST. OF NEUROLOGICAL DISORDERS & STROKE, http://www.ninds.nih.gov/disorders/dementias/detail_dementia.htm (last updated Oct. 21, 2013).
 7. *Alzheimer's Facts and Figures*, ALZHEIMER'S ASS'N, http://www.alz.org/alzheimers_disease_facts_and_figures.asp (last visited Dec. 29, 2013).

Those limitations include the three conditions on advance directives already indicated—they must be clear, informed, and persistent. To be *clear*, a directive for implementation in later dementia must not refer to just “dementia” without further specification; it must convey what stage of severity of dementia the person wants to trigger application of the directive, including specific conditions that one may regard as relevant (for example, an inability to recognize close friends and loved ones). The directive must be *informed* about the primary condition, dementia, to which it speaks; it should recognize, for example, that persons with dementia have great emotional variance—they can be distressed, or angry, or relatively content and happy. Directives are also more authoritative when they are *persistent*—when they have been reiterated in the early stages of dementia (for example, when a person becomes more familiar with the condition but can still understand her directive).

Throughout the last two decades in the Netherlands, and just recently in Belgium, the prospect of using PAD for patients with dementia has sparked a great deal of discussion.⁸ In 2011, an important Dutch case raised precisely the question of whether the voluntariness requirement demands contemporaneous competence.⁹ The Dutch concluded that it did not.¹⁰ For PAD as well as the refusal of life-supporting treatment, they concluded that voluntariness can be satisfied by clear and reiterated advance directives.¹¹

In a jurisdiction—such as the Netherlands—where euthanasia is permitted, patient directives for later use of PAD naturally warrant the term “advance euthanasia directives” (AEDs). Where euthanasia is illegal, however, it will be difficult to refer to such directives as advance *euthanasia* directives. Nonetheless, even where aid in dying, but not euthanasia, is permitted, competent individuals could still be allowed to write advance directives for aid in dying in the event of a mentally debilitating condition such as severe dementia. In those jurisdictions, such directives would technically be “advance directives for aid in dying” (ADAID). Instead of using this awkward neologism, I will use the shorter term “AED” for this situation as well and make the case for AEDs in that broader context.

While AEDs for dementia can be morally justified and acted on in their primary intended circumstances, I will also argue that the issue of when they should actually be followed is exceedingly complex and multifaceted. One complexity has to do with the range of cognitive abilities and quality of life in dementia. Another has to do with the fact that the demented person may change her mind about preferring death to living with dementia, in which case we should not hold the person to her AED. In still other cases, even where there has been no change of mind and the directive is clear and

8. See Cees M.P.M. Hertogh et al., *Would We Rather Lose Our Life than Lose Our Self? Lessons from the Dutch Debate on Euthanasia for Patients with Dementia*, 7 AM. J. BIOETHICS 48, 48–56 (2007). For recent developments in Belgium, see Sheets, *supra* note 3.

9. See Michael Cook, *Informed Consent in Netherlands: Euthanasia*, BioEDGE (Nov. 12, 2011), http://www.bioedge.org/index.php/bioethics/bioethics_article/9826.

10. See *id.*

11. See *infra* Part II for a discussion of both this case and Dutch law on PAD.

informed, due consideration of both the demented person's best interests and relevant societal considerations can point toward not implementing it. Thus, whether the use of AEDs should be permitted to avoid prolonged life in dementia does not have a simple yes-or-no answer. It depends on important differentiating details.

Part II briefly reviews the main arguments in favor of PAD, noting that they apply not only to terminal illness, but also to avoiding prolonged life in dementia. It also describes the developing situation in the Netherlands, including the 2011 case mentioned above. Part III lays out some basic information about dementia and relates that to the requisite clarity and voluntariness of actionable AEDs and the issue of later changes of mind. Part IV takes up the most fundamental challenge for advance directives that is posed by the difference between the competent pre-dementia self (the "then-self") and the current self in dementia (the "now-self"); the prominent views of Rebecca Dresser, John Robertson, Ronald Dworkin, and Agnieszka Jaworska are considered.

I delineate my own view in Parts V, VI, and VII. Part V explains how the value of life varies greatly in dementia and why that makes a patient's advance into severe dementia critical to the authority of an AED. Part VI pulls the most important moral considerations into the notion of a "sliding scale," where the case for implementing an AED gains as the person's capacity to generate new values and to enjoy life decreases. In Part VII, I argue that—despite the fact that severe dementia can rarely be deemed a "terminal illness" in the sense of death being likely within six months—it is a terminal illness in other highly relevant respects. In Part VIII, I review the previous moral analysis and articulate a conceptual path for moving from legalized aid in dying to actionable AEDs for severe dementia.

II. BASIC MORAL ARGUMENTS FOR PHYSICIAN-ASSISTED DEATH AND DUTCH LAW

The two basic moral arguments in favor of PAD focus on suffering and on autonomy. The former maintains that it is cruel to force a terminally ill patient to continue to suffer terrible pain at the end of life when such pain cannot be eradicated or adequately controlled and has no purpose (such as restoring the patient to health). Clearly the argument based on suffering is not limited to competent individuals; a person in dementia may suffer as much as someone with greater cognitive capacity.

The argument based on autonomy focuses on the right of people to make crucial decisions about how their lives will go for themselves, without interference from the state.¹² Many have argued that the same value of autonomy that underlies the right to refuse life-sustaining treatment is also implicated in a right to choose death.¹³ They regard as irrational a situation where the law allows people to die certain and expedited

12. The right to refuse medical treatment, including life-sustaining medical treatment, is well established in the United States by common law and landmark court decisions, including *Quinlan*, *Cruzan*, and *Bouvia*. See *In re Quinlan*, 355 A.2d 647, 659–60, 663–64 (N.J. 1976) (reasoning that an individual's right to discontinue life-sustaining medical treatment overcomes state interests); *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 263 (1990); *Bouvia v. Superior Court*, 179 Cal. App. 3d 1127, 1134 (1986) (holding that a patient has a fundamental right to refuse medical treatment).

13. See, e.g., Dan W. Brock, *Voluntary Active Euthanasia*, 22 HASTINGS CTR. REP. 10, 10–22 (1992).

deaths by refusing to eat and drink,¹⁴ or by refusing life-supportive treatment, but does not allow them to have their doctors provide them with a quick and painless death.¹⁵ It would seem to be similarly irrational to allow people to use advance directives to expedite death by refusing life-supportive treatment, but not by PAD.

The arguments based on suffering and autonomy are not inherently limited to terminal illness. Suffering can be as great, if not greater, when it extends through the much longer time of chronic, non-terminal illness, and people can have strong, fully voluntary, and informed convictions that death would best come sooner rather than later even if they are not terminally ill.

In this article, I will assume that these basic arguments for aid in dying are ultimately convincing and put to one side the general debate about its fundamental moral and legal legitimacy.¹⁶ The focus, instead, will be on the question of whether—by dropping the requirements of contemporaneous competence, prognosis of death within six months, and unbearable suffering—PAD can be justifiably expanded to allow for its application to situations of severe dementia.

In the Netherlands, PAD has recently been expanded in respect to terminal illness and contemporaneous competence. For two decades, the Dutch have had a vigorous debate about the eligibility for euthanasia of patients with severe dementia.¹⁷ Traditionally, Dutch doctors have interpreted the requirement that euthanasia be a voluntary and carefully considered decision of patients to rule out persons with dementia. In March 2011, however, a Dutch woman in severe dementia received euthanasia.¹⁸ The woman was not named, but I will refer to her as “Lotte.” She was sixty-four years old and a long-time supporter of the Dutch euthanasia law. When fully competent, she had written an advance directive in which she expressed her desire to die rather than go into a nursing home. Lotte repeated this desire over time to her family physician, and she was supported in her request by husband and children. As dementia grew more severe, she could remember only bits of her directive. Nevertheless, in every conversation with her doctor, she said that she would rather die than go into a nursing home. She also appeared to be suffering; she was frequently angry, confused, and cried often. Ultimately, her doctors judged that both

14. For an extensive defense of this path to death, see generally STANLEY A. TERMAN ET AL., *THE BEST WAY TO SAY GOODBYE: A LEGAL PEACEFUL CHOICE AT THE END OF LIFE* (2007). For an extensive treatment of the legal status of voluntarily stopping eating and drinking (VSED), see generally Thaddeus Mason Pope & Lindsey E. Anderson, *Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life*, 17 WIDENER L. REV. 363 (2011).

15. See, e.g., RONALD DWORKIN, *LIFE'S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA AND INDIVIDUAL FREEDOM* 184 (1993); Brock, *supra* note 13, at 19.

16. For an opposing view, see Herbert Hendin & Kathleen Foley, *Physician-Assisted Suicide in Oregon: A Medical Perspective*, 24 ISSUES L. & MED. 121, 121 (2008).

17. See Hertogh et al., *supra* note 8, at 48; KONINKLIJKE NEDERLANDSCHE MAATSCHAPPIJ TOT BEVORDERING DER GENEESKUNST (KNMG ROYAL DUTCH MED. ASS'N), *THE ROLE OF THE PHYSICIAN IN THE VOLUNTARY TERMINATION OF LIFE* (2011) [hereinafter DUTCH POSITION PAPER], available at <http://knmg.artsennet.nl/Publicaties/KNMGpublicatie/Position-paper-The-role-of-the-physician-in-the-voluntary-termination-of-life-2011.htm>.

18. See Cook, *supra* note 9.

of the essential legal requirements—voluntariness and unbearable suffering—were met. All five relevant review committees concluded the same.¹⁹

The significance of the decision for Lotte was magnified by the fact that shortly thereafter, in June 2011, the Royal Dutch Medical Association (KNMG) issued a major position paper including new guidelines for interpreting the Dutch euthanasia law.²⁰ An obvious concern about the expansion of euthanasia to patients in dementia or with chronic psychiatric illness is abuse. The KNMG called such cases especially difficult: “Any assessment of the considerations prompting such a request and of whether the suffering is indeed unbearable and lasting is generally much more complicated in this category of patients [P]hysicians [need to] act with extreme caution and restraint”²¹

Voluntariness is also critically important in the Dutch euthanasia law. Under the new guidelines of the KNMG, the voluntariness requirement can be satisfied by evidence that euthanasia is what the patient wanted, even if the patient is now no longer competent.²² Carefully considered advance directives are one of the best kinds of evidence, especially if they are reiterated over time,²³ including in early dementia when one presumably has a clearer idea of what life in dementia means, and they speak clearly to the patient’s current dementia situation.

Lotte’s case and the Dutch guidelines that emerged shortly thereafter have set the stage for a mature discussion of legally actionable AEDs. The directives that Dutch law considers viable, and on which the discussion of this article will focus, are not just any AEDs. They are directives that clearly speak to dementia, and that have been carefully considered and persistently reiterated by their authors. This article will focus on whether and when directives *of this specific sort* should be implemented.

III. VOLUNTARINESS: UNDERSTANDING DEMENTIA

To be truly voluntary in the morally relevant sense, a directive needs to be well informed. If it harbors misinformation about dementia, it carries less moral force, and perhaps much less. To expand the legalization of PAD to advance directives for dementia, therefore, the directives need to emerge from a reasonably accurate understanding of dementia—its varying stages and qualitative types, the risk of prejudicially stereotyping it, and the potential for adaptation and changes of mind.

Dementia refers to a wide range of cognitive impairments and memory loss severe enough to interfere with the normal functions of daily life. The range from mild to severe or advanced dementia is conveyed in the array of deficits used in clinical

19. *See id.*

20. *See id.*

21. DUTCH POSITION PAPER, *supra* note 17, at 7.

22. *See id.* at 12.

23. This moral condition was foreshadowed by Leslie P. Francis in 1993. *See generally* Leslie P. Francis, *Advance Directives for Voluntary Euthanasia: A Volatile Combination?*, 18 J. MED. & PHIL. 3, 297–322 (1993).

assessment tests, such as the Functional Assessment Staging Test.²⁴ According to this test, the deficits in “mild” dementia affect daily functions such as bill paying, cooking, house cleaning, and traveling. A person in “moderate” dementia requires help in slightly more basic daily activities, such as selecting one’s clothes. In “moderately severe” dementia, the person has difficulty putting on clothes, bathing, and toileting (with urinary or fecal incontinence). In “severe” dementia, one is unable to speak daily more than five to six words in all, or more than two words clearly, and one lacks either the ability to walk, to sit up, to hold up one’s head, or to smile. Inability to recognize even the closest friends and relatives often accompanies severe dementia.

Some scales define a more advanced “very severe” stage, in which “all verbal abilities are lost These patients . . . require assistance in toileting and in eating. They . . . lose psychomotor skills [as though the brain is] no longer . . . able to tell the body what to do.”²⁵ It will become clear in my later analysis (Parts V–VII, especially) that the features of severe and very severe dementia are highly relevant to the authority that an AED holds for its implementation. I will refer to the achievement of this morally relevant stage as “severe” or “advanced” dementia, without attending to any more refined differences between “severe” and “very severe” dementia.

The extent to which the impairments of dementia interfere with subjective quality of life varies. When the cognitive level of mental life has changed, the effect on affective temperament can range from positive to highly negative. Some with dementia are continually frightened or at moments extremely scared, or anxious and irritable, perhaps even violent. Others are evidently happy, sometimes eagerly participating in the activities of which they are still capable. Only rarely, however, do such fortuitous characteristics obtain in severe or advanced dementia.

Judgments about the degree of personality change with dementia are complicated by the fact that, most of the time, capacities lost may briefly re-emerge in moments of temporary lucidity. At such times, it may be possible to determine whether the individual still holds the beliefs or values previously expressed in an advance directive or in actions throughout their lives. The patient may show flashes of “her old self,” even into fairly severe dementia.

The variety and unpredictability within dementia—even within a given diagnostic type such as Alzheimer’s—must be taken into account for a directive to be reasonably well informed. No one can know in advance whether she will be among the “happy demented” or the terribly frightened and anxious. Nonetheless, advance directives can make helpful reference to clinically defined stages such as “severe” or “advanced,” and to specific manifestations such as the inability to recognize close

24. See, e.g., MED. CARE CORP., FUNCTIONAL ASSESSMENT STAGING TEST, available at http://www.mciscreen.com/pdf/fast_overview.pdf (last visited Dec. 29, 2013).

25. This corresponds to Stage Seven of the longstanding Global Deterioration Scale used since 1982. See Barry Reisberg et al., *The Global Deterioration Scale for Assessment of Primary Degenerative Disease*, 139 AM. J. PSYCHIATRY 1136, 1138 (1982). Other authors label this stage “advanced,” adding the clarification of the inability to recognize familiar faces or to walk, as well as the incontinence of urine and stool. See Susan L. Mitchell et al., *Advanced Dementia: State of the Art and Priorities for the Next Decade*, 156 ANNALS INTERNAL MED. 45, 47 (2012). Sometimes the “advanced” or “very severe” stage is referred to as “end-stage” dementia.

friends and relatives that the author of the directive regards as especially relevant to her concerns. The directives that create the strongest case for their implementation will be those that indicate an understanding that dementia comes in a variety of stages and affective characters.

Difficulties in writing an informed AED for application in dementia stem not only from unpredictable variation in dementia's stages and effects. A further related problem is that people often think prospectively that they would find a particular disabling condition unbearable or worse than death, only to find that, when they actually experience the condition, it is not nearly as bad as they thought it would be.

Sometimes such misjudgment is due to a failure of imagination about future life. People focus only on the abilities and pleasurable experiences they will lose, without recognizing potentially positive aspects to living in an "eternal present" with severe memory loss.²⁶ Another relevant factor is later adaptation.²⁷ While people experience a drop in subjective well-being upon becoming disabled, they often regain the level of happiness they had previously. An AED written in ignorance of this potential for adaptation has less moral force.

One of the ways in which the reality of adaptation can be revealed is later changes of mind about the value of life in dementia. All parties—authors of the directives, later caregivers, and loved ones—should be sensitive to this possibility. Increasing forgetfulness and failure to recognize most friends, for example, may sometimes not be experienced as nearly as destructive of quality of life as people thought it would be. In early and moderate stages of dementia, therefore, people may actually change their minds about what they said in their directive. In two ways, at least, this fact should be accommodated. First, explicitly in a directive, an author can express awareness of such possible changes of mind, and second, third parties later should watch for changes of mind, an issue I will return to in Part V.

Attitudes toward disability, including dementia, can also stem from societal prejudice. Some of what people recoil from in the prospect of severe dementia—the incontinence, drooling, loss of mobility, and extreme dependence, for example—may spring from unenlightened attitudes.²⁸ Persuasive advance directives for dementia will not evidence such attitudes, and perhaps they should even expressly acknowledge their danger.

26. See, e.g., ROBERT LELEUX, *THE LIVING END: A MEMOIR OF FORGETTING AND FORGIVING* 101 (2012). As his grandmother—who was estranged from her daughter—lost memory and sense of time, grudges and old hurt feelings disappeared. She forgot what had made her angry. *Id.*

27. This is strongly confirmed in the psychological literature. See SHANE FREDERICK & GEORGE LOEWENSTEIN, *HEDONIC ADAPTATION IN WELL-BEING: THE FOUNDATIONS OF HEDONIC PSYCHOLOGY* 302–29 (Daniel Kahneman et al. eds., Russell Sage Found. 1999); Paul T. Menzel et al., *The Role of Adaptation to Disability and Disease in Health State Valuation: A Preliminary Analysis*, 55 *SOC. SCI. & MED.* 2149, 2149–58 (2002); David Arnold et al., *Comparison of Direct and Indirect Methods of Estimating Health State Utilities for Resource Allocation: Review and Empirical Analysis*, 339 *BMJ* 385 (2009), available at <http://www.bmj.com/content/339/bmj.b2688.pdf%2Bhtml>.

28. See Adrienne Asch, *Recognizing Death While Affirming Life: Can End of Life Reform Uphold a Disabled Person's Interest in Continued Life?*, 35:6 *HASTINGS CTR. REP.* S31 (2005).

Some people, too, may view living in dementia as a fate worse than death because of lamentable, sub-standard conditions that can characterize nursing homes. It goes without saying that such conditions are unacceptable and that steps to improve the lives of people with dementia need to be taken. Certainly, however, not all nursing home care is deficient.

All of these factors—failure to understand dementia, prejudice, lack of imagination, failure to appreciate adaptation, fear of poor nursing home care—can diminish a directive’s moral weight. The desire to die to avoid years in severe dementia, however, does not have to reflect such biasing factors. As will be argued later in Part V, that desire can be based on strong and legitimate convictions about the meaning and narrative of one’s life. Dementia has profound effects on selfhood, making it arguably different from other disabling conditions.

This point is illustrated, ironically, by the way that a strong critic of prejudice against disabled persons, Adrienne Asch, explains how many people with profound disabilities can be helped to live full, meaningful lives. With assistance, they can

hold jobs, engage in volunteer activities, visit friends . . . and generally participate in ordinary family, civic, and social life. Wheelchairs do not confine; they liberate . . . Using the services and skills of a personal assistant who helps them . . . is no more shameful or embarrassing than it is for a nondisabled person . . . to value the expertise of a mechanic . . .²⁹

Note how little of this applies to people in severe dementia. They do not hold jobs, engage in volunteer activities, or socialize with family and friends. Moreover, the interest in determining how one’s life should go, including how it would best end, is an interest shared equally by the “temporarily abled” and disabled alike.

A strong directive for PAD in dementia should manifest an awareness of dementia’s varying stages, its variable effects, prejudicial attitudes toward it, and the potential to adapt to it.

IV. THE FUNDAMENTAL CHALLENGE: THE “NOW-SELF” AND THE “THEN-SELF”

The most serious and difficult challenge to the authority of advance directives is that the very condition that gives rise to them—the inability to participate in medical decisionmaking—can dramatically change one’s interests. Rebecca Dresser and John Robertson make this criticism of the so-called “orthodox approach” of American courts.³⁰ The logic of that approach begins with the right of competent patients to refuse medical treatment even when it is necessary to preserve their lives. And then, since people do not lose their rights simply because they happen to become

29. *Id.* at S32–S33.

30. Rebecca Dresser & John S. Robertson, *Quality of Life and Non-Treatment Decisions for Incompetent Patients*, 17 J.L. MED. & ETHICS 234, 234–40 (1989). For an insightful and comprehensive treatment of this challenge, which also relates to Dresser’s numerous other writings, see L.W. SUMNER, *ASSISTED DEATH: A STUDY IN ETHICS AND LAW* 103–17 (2011). Sumner also gives a detailed treatment of Dworkin’s position, including the Margo case that features centrally in Dworkin’s discussion. *See id.* at 108–17.

incompetent, respect for patients who are incompetent requires according them the same right to refuse treatment. Refusal should be based on the patient's own wishes, either as conveyed in an advance directive or as determined by the patient's appropriate proxy. Such "substituted judgment" respects a person's autonomy and rights in her current incompetence.

For Dresser and Robertson, this approach is based on a fiction. The now-incompetent person is not an autonomous chooser; that person—the autonomously choosing person—is no longer present. The incompetent individual now before us may have quite different interests than the previously competent person who wrote the directive. She may, for example, no longer have the same interest in preserving control or in not being dependent on caregivers.³¹

This critique rests in part on epistemic considerations: "It is difficult, if not impossible, for competent individuals to predict their interests in future treatment situations when they are incompetent"³² Philosophical theories of identity that emphasize psychological continuity provide added support. Derek Parfit, for example, has suggested that a person's life can consist in a series of successive selves, with a new self emerging as the individual undergoes significant changes in beliefs, desires, memories, and intentions.³³ If the successive selves are not identical, the authority of the prior self over the later self becomes questionable. David DeGrazia perspicuously labels this the "someone else" problem.³⁴

The phenomenon of a very different self is well illustrated by the case of Margo, brought to prominence in the literature by Dworkin.³⁵ Andrew Firlík, a medical student, repeatedly visits Margo, a patient with Alzheimer's disease. With each arrival, Margo behaves as if she knows him, though without ever using his name. She says she reads mysteries, but Firlík notices that "her place in the book jumps randomly from day to day [S]he feels good just sitting and humming to herself . . . nodding off liberally, occasionally turning to a fresh page."³⁶ She takes abundant pleasure in simple acts, such as eating peanut-butter-and-jelly sandwiches.³⁷ Firlík writes that "despite her illness, or maybe somehow because of it, Margo is undeniably one of the happiest people I have ever known."³⁸ Undoubtedly, Margo's past life and concerns were different than the concerns and life she has now. Does such difference, considerable as it is, now make her a different person?

31. See Dresser & Robertson, *supra* note 30, at 236.

32. *Id.*

33. See DEREK PARFIT, REASONS AND PERSONS 199–379 (1985).

34. See DAVID DEGRAZIA, HUMAN IDENTITY AND BIOETHICS 159–202 (2005); David DeGrazia, *Advance Directives, Dementia, and 'the Someone Else Problem'*, 13 *BIOETHICS* 373 (1999).

35. See DWORKIN, *supra* note 15, at 220–32.

36. Andrew D. Firlík, *Margo's Logo*, 265 *JAMA* 201, 201 (1991).

37. See *id.*

38. *Id.*

It does not. The driving desire behind the very notion of an advance directive is that people want control over *their* later lives; the unspoken assumption is that the incompetent individual is numerically the same person as the prior competent one. Departing from this common assumption would create all kinds of difficulties, especially in the law.³⁹ Bodily identity has huge pragmatic advantages as a criterion of same-individual identity compared to any psychological continuity standard, with its much greater difficulties for line-drawing and inter-subjective discernment.⁴⁰ Interpersonally, people just do, in fact, use bodily identity, such as when they uphold contracts, blame people or praise them, or discern criminal and civil liability. People also, of course, speak of “becoming a different person,” but their usual reference in such cases is to *personality* changes, not to a going-out-of-existence of one person and a coming-in of another. In any remotely realistic framework for discussing the authority of advance directives, therefore, we should presume that a patient like Margo is numerically the same person as she was before her change in dementia.

That said, however, even with Margo regarded as still Margo, a “then-self”/“now-self” problem still remains: Although Margo’s identity has not changed, have her *interests* changed so much that her earlier directive should not be followed?

A. Dworkin’s View: The Dominance of Critical Interests

In confronting this question, Dworkin maintains that the radical change in some of a person’s interests in dementia does not undercut the moral authority of advance directives, including AEDs.⁴¹ His argument comes in two key steps. First, the choice that the competent “then-self” expressed in a directive does not just manifest autonomy; it also defines the person’s continuing “critical interests.”⁴² Second, such interests dominate mere “experiential interests” in determining what is in the overall best interests of the person with dementia.⁴³

Because infants and young children lack the mental capacity to weigh different (and often conflicting) factors and to make their own decisions, it does not make sense to ascribe to them a right of autonomy. It is also absurd to invoke respect for autonomy in the case of never-competent adults who have been severely impaired from birth. In both cases, decisions should be made for them on the basis of their best interests.

The situation is different for incompetent adults who were previously competent. The beliefs, desires, and values they have while autonomous choosers form what Dworkin calls “critical interests.” These are second-order interests, involving a

39. See Dresser & Robertson, *supra* note 30, at 236, 239–40.

40. See Howard Klepper & Mary Rorty, *Personal Identity, Advance Directives, and Genetic Testing for Alzheimer Disease*, 3 *GENETIC TESTING* 99 (1999); Nancy Rhoden, *The Limits of Legal Objectivity*, 68 *N.C. L. REV.* 845, 845–65 (1990).

41. See DWORKIN, *supra* note 15, at 209–13.

42. *Id.* The use of the “now-self”/“then-self” terminology originates with this author, not with Dworkin.

43. *Id.* at 234.

certain level of thought and reflection about one's interests.⁴⁴ They include, for example, convictions about "what helps to make a life good on the whole."⁴⁵

Such convictions have, as their object of valuation, states of affairs that can obtain when people are no longer competent or even alive. While experiential interests continue to exist only as long as someone is experiencing them, critical interests are not so confined. They exist, to be satisfied or not, even after one no longer experiences them. Thus, while the dead and those in a persistent vegetative state no longer have experiential interests, they continue to have critical interests. If someone cares about what happens to his property, his family, or his reputation after he dies, he has a critical interest in these things. To dispose of property contrary to his will, to violate the provisions of his advance directive, or to unfairly tarnish his reputation after his death are all ways of still harming him.⁴⁶ That we make such judgments is evidence that people have non-experiential, critical interests.

While dead and permanently unconscious individuals can have only critical interests, people with dementia have both types of interests—experiential and critical—and these may conflict.⁴⁷ Suppose that Margo wrote a strong directive stipulating PAD in any level of dementia as bad as or worse than what she now has, but that she now experiences her days as a largely happy, and at times even an energetic, person. According to Dworkin, respect for autonomy requires us to respect the directive because it represents "a judgment about the overall shape of the kind of life he [or she] wants to have led."⁴⁸ To ignore it, and sacrifice a person's critical interests to satisfy experiential interests, would violate autonomy.⁴⁹

Dworkin's further claim is that doing so would not only be a violation of autonomy, but would also misconstrue what is in Margo's best interests.⁵⁰ This is because, for Dworkin, what is ultimately best for Margo is not determined by her experiential interests but by her critical interests.

44. The distinction between second-order and first-order applies to both desires and interests. One simply has first-order desires—reflection about another desire is not involved. Second-order desires are desires about one's first-order desires. Just as first-order interests form in relation to one's first-order desires (the interests that one has in one's first-order desires being satisfied), similarly, second-order interests form in relation to one's second-order desires (the interests that one has in one's second-order desires being satisfied). An alternative way of explaining second-order interests is that they form when one has desires about one's first-order interests. Both second-order desires and second-order interests involve a degree—and a kind—of reflection not required of first-order desires and interests.

45. DWORKIN, *supra* note 15, at 201–02.

46. An extensive treatment of this matter is found in RAYMOND ANGELO BELLIOU, *POSTHUMOUS HARM: WHY THE DEAD ARE STILL VULNERABLE* (2012).

47. *See* DWORKIN, *supra* note 15, at 192.

48. *Id.* at 226.

49. "Making someone die in a way that others approve, but he believes a horrifying contradiction of his life, is a devastating, odious form of tyranny." *Id.* at 217.

50. *See id.*

If I decide, when I am competent, that it would be best for me not to remain alive in a seriously and permanently demented state, then a fiduciary could contradict me only by exercising an unacceptable form of moral paternalism Once we rule out that form of paternalism—once we accept that we must judge Margo’s critical interests as she did when competent to do so—then the conflict between autonomy and beneficence seems to disappear.⁵¹

Critical interests reflect a person’s integrity and reflective, second-order desires. They outweigh—they trump—experiential interests in construing what is in a person’s best interests because they are reinforced at the second-order level. They are interests *about what ultimately matters to people* and, thus, are their most important interests. For Dworkin, then, Margo’s best interests—as well as her autonomy—support following her advance directive.

B. Jaworska’s Critique: New Critical Interests

Jaworska, perhaps Dworkin’s most well-known critic on advance directives for dementia, grants him his claim about the dominant weight of critical interests.⁵² Where Jaworska differs from Dworkin is in seeing persons with dementia as still capable of generating new critical interests, including ones about the value of life.⁵³

Jaworska appeals to the distinction between values and desires. Desiring is the more basic, first-order notion. By contrast, valuing involves reflection. We do not always value what we desire—we try to break habits, for example. To value something is not merely to want it, but to think that it is good—that is a kind of second-order appraisal. For Dworkin, to form critical interests one must be capable of having convictions about what makes life—one’s own life—good as a whole. This cannot be said for Jaworska, for whom critical interests can issue from simpler second-order desires. “[C]onvictions about what is good to have . . . do not require the ability to grasp or review one’s whole life.”⁵⁴

Jaworska provides the example of Mrs. D., who was diagnosed with probable Alzheimer’s disease, and is now moderately to severely impaired. Mrs. D. volunteers for medical research and explains her decision: “I could have said, ‘no,’ but believe me,

51. *Id.*

52. See Agnieszka Jaworska, *Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value*, 28 PHIL. & PUB. AFF. 105, 112 (1999).

In the case of an ordinary competent person, when his critical interests (his judgments and values) come into conflict with his experiential interests (what would lead to the optimal state of mind for him), we do not hesitate to give precedence to his well-considered values and judgments, and we concede that this is, overall, best for him. . . . The case of our demented person turns out to be no different: in his conflict between ongoing experiential and critical interests, it is also best to privilege the latter.

Id.

53. See *id.* at 112–14.

54. *Id.* at 113.

if I can help me and my [fellow] man, I would do it.”⁵⁵ This suggests that Mrs. D. had considered her decision and thought it would be wrong to refuse, which is a clear second-order activity. Mrs. D. does not have mere desires and experiential interests; she has values. She can form new critical interests.⁵⁶

Jaworska believes that what often happens to persons in dementia is that they *change* some of their values. They “are naturally inclined to . . . appreciate . . . simpler pleasures. Thus, after developing Alzheimer’s, even former highbrow intellectuals come to value, or value more highly, the pleasures of listening to music, gardening, yoga, simple art-making, telling fanciful stories to their grandchildren . . .”⁵⁷

For Jaworska, such changes are crucial to assessing the validity of an advance directive. It is one thing for someone to write an advance directive directing their treatment in case of permanent unconsciousness; the directive has full authority because later there is no currently active agent. It is quite different with an advance directive for dementia, when there will still be a valuer. “The person executing an advance directive for dementia is more akin to someone who anticipates that his values will change for the worse in the future and attempts to hold his future self to his current values by making others promise that they will, at a future time, enforce his current values against his will.”⁵⁸ What, Jaworska asks, would justify privileging the earlier values? Few of us, for example would want to be held to the values we espoused in our teens or twenties. Then why should the demented person be held to values she no longer holds?

C. *Taking Stock of the Dworkin-Jaworska Argument*

Jaworska may seem to have the more compelling view. She is right in claiming that a person’s values and self-concept, not merely experiential interests, can change in dementia—at least in dementia’s early stages when people sometimes come to appreciate different activities. This is the force of Jaworska’s highly intellectual grandmother,⁵⁹ whom I choose to call “Helen.” Her new appreciation for yoga, gardening, simple art-making, and telling stories to her grandchildren not only indicates new values, but likely also a change of mind about what makes living worthwhile, even if she no longer has sufficient memory to consider her life as a whole.

To a large extent, however, Jaworska and Dworkin talk past each other. Their points often depend on different accounts of critical interests, and they work with different paradigms of dementia. For Jaworska, anyone capable of second-order desires is a valuer, someone who is capable of generating new critical interests and changes of mind. For Dworkin, critical interests are more than just any values or second-order desires; they involve notions such as character, life-long convictions,

55. *Id.* at 118.

56. *See id.*

57. *Id.* at 120.

58. *Id.* at 137.

59. *See id.* at 120.

and views of “what makes life good as a whole.” Jaworska has thus not shown that Dworkin is mistaken about the ability of patients in dementia to have new critical interests *in his sense*. Rather, she has offered a different conception of critical interests, one that arguably does not address the kinds of reasons Dworkin offers for saying that critical interests trump experiential ones in the overall construal of best interests—their roots in character, conviction, and the value that people see in their lives as a whole.

Though someone like Helen has new values and a new appreciation of certain activities, it is not clear that she has changed her mind about the value of her life in dementia, which is the primary evaluation she was expressing in her AED. In any case, even if an engaged Helen is an example of a demented person who has changed her mind, at some point further into progressive dementia people cannot change their minds in the relevant sense. As Ron Berghmans poignantly puts it, if you write a directive to refuse life support and request death assistance with the onset of severe dementia, then “at the time you would most likely ‘change your mind’” your experiences have become so radically different that “you don’t have enough mind left to change.”⁶⁰ At that point, a person’s only critical interests are the ones that were generated previously.

Jaworska’s claim that Margo falls into the category of someone capable of generating new critical interests⁶¹ is plausible only because Margo is not severely demented. Her critique fails to apply to someone in severe dementia, incapable of valuing of any kind and certainly incapable of generating new critical interests. A person in dementia at that stage does not reflect on her desires or deem them good or bad; she simply has them, like an infant or a very young child.

She may, though, give an indication of being happy, or at least feeling content. She may, for example, eat with pleasure, smile occasionally, and utter sounds of apparent pleasure when stroked and talked to or when cuddling stuffed animals. Even with severe dementia, a person can be one of the happy demented. I will refer to such a person as “Ruth.”

Suppose that Ruth wrote a well-informed AED to be applied in severe dementia, and that she reiterated it over time, as recently as in her early dementia. Dresser and Robertson, focusing on her present experiential interests, would say that we should not follow the directive. Dworkin would say we should, on the grounds of both respecting her autonomy and satisfying her best interests because her best interests are ultimately dominated by her critical interests. Jaworska does not consider this sort of case, but since she agrees with Dworkin that critical interests trump in determining best interests, it would seem she would also say that Ruth’s directive should be followed. However contented or happy Ruth is, even in Jaworska’s analysis, people in this stage no longer have the capacity for self-governance or autonomy. They cannot generate new critical interests. They cannot change their mind about their advance directive.

60. Ron Berghmans, *Advance Directives and Dementia*, 913 ANNALS N.Y. ACAD. SCI. 105, 107 (2000).

61. See Jaworska, *supra* note 52, at 135 n.54.

This analysis, using Dworkin and Jaworska, makes many convincing claims about a person in severe dementia, but, in the end, it does not provide an adequate analysis about whether to follow the AED expressed by someone like Ruth or Margo. The heart of the problem is that, in construing a demented person's best interests, it is a stretch to claim that critical interests should always dominate experiential ones.

V. THE VARYING VALUE OF LIFE

People in late-stage dementia still have worth, must be treated with dignity, and are entitled to respect. The notion of dignity applicable to dementia has to do with more than present capacities. In that respect, Dworkin's central claim is correct: we respect people with dementia in part because of what they were—autonomous, self-constituting, self-conscious selves, with narrative identities that they manifested in multiple ways, perhaps explicitly proclaimed, and still retain. But in late-stage dementia, we also respect people because of the present consciousness that remains, and because of their continuing roles in networks of relations. Patients with severe dementia are still husbands or wives, mothers or fathers, grandmothers or grandfathers. They are still part of the human family.

So the question remains: How do we best demonstrate respect for them—by following the AED they may have or by disregarding it? Numerous complicating elements require multiple answers to this question. One complicating element is that the value of life to the demented person herself varies widely. Two factors, psychological continuity and narrative identity, fundamentally affect that value.

What, in severe dementia, is the *experiential* value of life? Experiential interests remain, but there is very little—if any—anticipation or memory. Without them, psychological continuity within the person's subjective life is weak. This greatly affects the stake that someone with dementia has in continuing to exist.⁶² The person lives in a kind of eternal present, without the ability to envisage her future existence or have desires about it. In that state the value of survival *to the person at the time* is greatly diminished.

Consider Ruth. She derives enjoyment from various kinds of experiences and, in a certain minimal and simple sense, she wants to have these experiences. In that respect, she wants to go on living—since being alive is a condition of her having the experiences that, at the time she has them, she apparently wants. One cannot conclude from this, however, that she values her *survival* or has a stake in her *continued existence*, for her cognitive deficits prevent her from even anticipating them. Without that ability to anticipate, any *future* existence is not what matters to her. And when she survives and actually arrives at the future moment that she cannot anticipate, she will not see it as her *survival* if she has no memory of her earlier existence.

In these respects, she is comparable to an infant. In contrast to an infant, however, Ruth's psychological continuity with her future will continue to weaken. As it does,

62. See JEFF McMAHAN, *THE ETHICS OF KILLING* 503 (2002). McMahan develops a Time-Relative Interest Account (TRIA) of the harm of death. It is not determined solely by how much good life (in terms of quantity and quality) one loses, but also by the extent to which one is psychologically connected with one's future.

her stake in her own existence diminishes further. This progression is also true for someone like Margo, although Margo's experiential interests—her enjoyment of a range of activities, her energy for living—are considerably stronger than Ruth's. The conflict between Margo's experiential interests in continuing to live and her critical interest in not living in dementia, as expressed in her AED, is thus sharper than this conflict is for Ruth.

And Ruth's dementia is far from the most severe that dementia can be. A person can be utterly passive and unresponsive, not even merely contented as is Ruth, in which case the person's stake in survival is even lower. Let us call such a person "Walter." To be sure, if Walter is not suffering, life may still hold some experiential value for him, but that value is slim. There is thus barely any conflict between his experiential value in living and his critical interest in dying, per his AED. To say in such a case that even for Walter his critical interest in dying still does not outweigh his extremely low experiential interest in living would imply that we were attributing an exceptionally low value to his critical interests. We would be treating him as a virtually never-competent person who had no critical interests—treatment that would badly disrespect him as the person he is.

In addition to the role that psychological continuity plays in the strength of someone's interest in survival, narrative identity also affects the value of life in dementia. Our stake in continuing to exist is largely as the individuals we conceive ourselves to be—that is, with narrative identity. The further a future departs from our conception of ourselves and the story of our lives—our character, commitments, and values—the weaker the stake we have in it. What makes survival into severe dementia to many so valueless—and to some, even horrifying—is that they will have lost this identity in any conscious sense and thus will no longer be themselves.

The matter, however, is worse yet. The narrative identity people have staked out, in part with an AED if they have one, does not disappear when they become severely demented. This identity, and the critical interests it defines, continues to be attached to the person who now lives in severe dementia. Continuing their lives, against the request of their AED, snubs that identity. Because of this, the continued life here is not just valueless; it has *negative* value. Death is preferable.

In situations like that of Lotte (the Dutch woman whose dementia involved unrelievable suffering), there is no positive experiential value in continuing life to stand in conflict with the critical interests expressed in her AED. There, the case for respecting the AED is strong and clear. The case for respecting it is also clear, however, for a person like Walter, who is in such severe dementia that he does not show even the minimal contentment and happiness of someone like Ruth. In his sort of situation, there is still some experiential interest in life, but because it is so minimal, it is readily outweighed by continuing critical interests. The hard cases occur when there is a significant conflict between experiential and critical interests, as with Margo and, arguably, Ruth. In those hard cases, we cannot avoid the difficult task of looking closely at both critical and experiential interests to discern their respective weights in determining the value of life and best interests.

VI. A SLIDING SCALE

This wide range of cases can be handled by employing a “sliding scale.” One of its dimensions concerns narrative identity and a person’s AED. Another dimension concerns the experiential value of life.

How people end life is an important part of the meaning of their lives. Respect for persons includes giving them control over that end. Advance directives enable them to do this, and, in general, should be followed. Otherwise we treat them very disrespectfully, as if they were never competent.

Not all advance directives, however, have the same moral force. Carefully considered advance directives based on a realistic assessment of the facts and that reflect a person’s enduring values have greater moral force than AEDs that do not. People who wish to avoid severe dementia through an advance directive need to be informed about dementia’s various stages and what life may be like in them. They should be aware that it is likely impossible to know whether the later person with dementia will be one of the happy demented, or one of the frightened, anxious, or distressingly confused. Furthermore, moral weight is added to a directive if it is reiterated in the relatively early stages of dementia when a person can still understand it. All of this places a burden on people who want to make advance directives for PAD, but not an unreasonable burden given the gravity of what they are asking others to do at a later time.

Carefully considered AEDs should also not be the result of mere prejudice or an unthinking assumption that life in dementia is unmitigated horror, nor should they express other kinds of blatantly unreasonable preferences. To Ludwig Minelli, founder of the Swiss organization Dignitas, which caters to foreigners coming to Switzerland for aid in dying, it does not matter why the person wants to die; the only value is self-determination.⁶³ But it does matter. As Rhoden put it, “When they start saying, ‘If I can’t do higher mathematics, kill me,’ we will have to worry in earnest about the limits of precedent autonomy.”⁶⁴

Even when an AED is written with adequate knowledge of, and without prejudice against, dementia, however, the substantive question of employing it to avoid living in dementia may not lend itself to a simple yes-or-no answer. One complicating factor is the possibility that the writer of the AED, who preferred death to living in dementia, might change her mind. Helen is arguably such a person.⁶⁵ Jaworska sees Margo as a person who also has changed her mind.

Indeed, Margo generally enjoys her current life, but it does not follow that she has necessarily changed her mind about the value of her life in dementia. From her engagement in various activities and enjoyment of them, one might infer that her life

63. See Amelia Gentleman, *Inside the Dignitas House*, *GUARDIAN* (London) (Nov. 17, 2009), <http://www.guardian.co.uk/society/2009/nov/18/assisted-suicide-dignitas-house>.

64. Rhoden, *supra* note 40, at 860.

65. Unlike Mrs. D., who is based on an actual person, Helen is a fictitious example. How realistic is Helen? It should be pointed out that at one presentation of parts of this article, an experienced physician in the audience said that he had never met a demented person like Helen.

now has value to her—a value she did not anticipate when she wrote her AED. On this interpretation, Margo has changed her mind, and it is plainly wrong to hold her to her prior values. One could also argue, however, that while Margo retains capacity for enjoyment, she no longer has the cognitive capacity to consider or reflect on what makes her life as a whole worth living, and therefore she is not capable of revising or rejecting her previous values in the sort of robust form necessary to generate an AED. In the last analysis, between these two conflicting perceptions, it may simply be unclear whether Margo has changed her mind about the value of her life.

Suppose, amidst this ambiguity about change of mind, that one decided that Margo's clear AED should be regarded as indicative of her reflective preferences and relevant critical interests. To respect her autonomy, we should then implement her AED. But autonomy is not the only consideration. Margo also has experiential interests in continued life. The happier and more engaged she is, the stronger are her experiential interests in living, and the harder it is to justify ending her life—even if her AED is informed and clear, and she has not changed her mind in the relevant sense.

Hesitancy springs from more than just her experiential happiness. Would acceding to her directive be socially tolerable? Aid in dying implicates many more people than just the recipient. It involves the individual physician who participates, and the medical community as a whole insofar as it provides guidelines and safeguards. Also involved, as part of the web of relationships of the person with dementia, are friends, family members, and other caregivers. The decision to allow people to receive aid in dying is a social one and, to put the point starkly, do we really want to be the sort of society where some people who are living happy lives, lives they now apparently enjoy and want to continue, are put to death?

Even Dworkin acknowledges that there might be valid reasons for refusing to follow the directive of a happily demented person.⁶⁶ He only insists that if such refusal is justifiable, “we cannot claim to be acting for *her* [Margo's] sake,”⁶⁷ for he thinks that when we consider the critical interests of the happily demented, carrying out their directives is still in their overall best interests.

Carrying out Margo's AED would indeed respect her autonomy, but it is doubtful, at least, that it would be in her best interests. For Dworkin, the matter is simple: critical interests invariably trump experiential ones.⁶⁸ But what is the argument for thinking that *invariably* they trump?⁶⁹ Even if we acknowledge that autonomy favors implementing the directive, it strains credibility to insist that the happily demented person who still has some zest for life would be *better off* dead.

The clearest case of the opposite sort, when the argument for following a person's AED is strongest, is when the individual experiences severe and irremediable suffering,

66. Dworkin makes this point in his response to Seana Shiffrin. DWORKIN AND HIS CRITICS: WITH REPLIES BY DWORKIN 370 (Justine Burley ed., 2004).

67. DWORKIN, *supra* note 15, at 232.

68. *See id.* at 231.

69. Similar reservations about the dominance of critical interests are expressed by L.W. Sumner. SUMNER, *supra* note 30, at 115–16.

as Lotte apparently did. It is clearly in Lotte's interest that her directive be carried out. That does not mean, however, that the Dutch position is right in making unbearable suffering a *necessary* condition for voluntary euthanasia. I reject the Dutch view that voluntary euthanasia is permissible *only* in the presence of unbearable suffering.

A definitive case for this claim is Walter. He is more passive than Ruth, neither happy nor miserable, and no longer capable of changing his mind about his AED. When autonomous and reflective on his life as a whole, he found death preferable to the prospect of living in complete dependence, without any compensating pleasures, unable to recognize—much less converse with—family and loved ones, and using up all the final resources he badly wanted to leave for particular persons and causes. Suppose that Walter reiterated that choice in the last part of his life, including the stage when he was mildly demented. Then, both out of respect for his autonomy and in recognition that his stake in continuing to live is vanishingly small, his directive should be followed. We should not have to show that he is experiencing “unbearable suffering” to carry out his AED. The justification for following it is the combination of two facts: that he has clearly, knowledgeably, and persistently said that he did not want to end his life in years of severe dementia, and that his current experiential interest in living is so weak.

It is possible to summarize these various considerations into a sliding scale that incorporates both autonomy and the current capacity for enjoyment.⁷⁰ An advance directive for PAD, written by an informed and competent person, gains in authority as the capacities of a person to generate new critical interests and to enjoy life decrease. It has less authority, by contrast, when the person retains the ability to value and generate new critical interests and still gives indication of enjoying her life. Helen, and perhaps Margo, exemplify the latter, Walter and Ruth the former.

To be sure, for Ruth the application of the sliding scale is difficult, but it still leans toward implementing her directive. Yes, Ruth is somewhat happy, but not as happy as Margo; still less does she have any of the zest for life exemplified by someone like Helen. Whether Ruth's AED should be followed depends on the strength of the relevant critical and experiential interests. If Ruth had very strong views about not living in dementia—like Lotte did, for example—her AED should be followed. Her critical interest in not living in severe dementia is clear and strong, she no longer has the capacity to change it, and her experiential interest in life is relatively weak.

The determining factor is not, as it would be under Dworkin and Jaworska's analysis, that Ruth's critical interests define her best interests; it is that her experiential interest in continued life is weak and her critical interests are clear and strong. The larger moral picture now comes into view. If we maintained that the experiential value of Ruth's survival, as weak as it is, still outweighed the autonomy and deep convictions

70. The notion of a sliding scale is borrowed from Allen Buchanan and Dan W. Brock. See Allen Buchanan & Dan W. Brock, *Deciding for Others: Competency*, 64 *MILBANK Q.* 17, 67–80 (1986). Some of the same factors included in the sliding scale here are used by Leslie P. Francis. See Leslie P. Francis, *Decisionmaking at the End of Life: Patients with Alzheimer's or Other Dementia*, 35 *GA. L. REV.* 539, 588–92 (2001).

that comprise a significant part of her narrative identity, we would be saying, in effect, that such autonomy and conviction counted for very little indeed. We would be treating the now incompetent but previously competent person as if she had never been competent, a great affront to autonomous persons and their narrative identity.

VII. PROGRESSIVE DEMENTIA AS A KIND OF TERMINAL ILLNESS

Thus, neither unbearable suffering nor contemporary competence holds up as a necessary moral requirement for justified assisted death. The extremely important requirement of voluntariness that is the rationale for contemporary competence can be met by a sufficiently clear, informed, and persistent AED that a person did not change when she still had the capacity to do so. So, too, the rationale behind a requirement of unbearable suffering can be met in other ways. Its underlying rationale is that with such unmitigated suffering, the balance of value left in life has turned negative, and therefore, life is worse than death. But that rationale can also be met when severe dementia greatly diminishes the stake that a person continues to have in her own survival. There, too, in the face of the strong critical interests reflected in a person's clear, knowledgeable, and persistent AED, the value that is now left in life has, on balance, turned negative.

Terminal illness, the rationale for the third of the legal eligibility conditions used to prevent abuse, can also gain traction in dementia. Dementia itself is seldom labeled a terminal illness, but in severe dementia of the typical progressive sort, degeneration occurs "gradually and inexorably, usually leading to death in a severely debilitated, immobile state between four and twelve years after onset."⁷¹ The relevant element is not merely the inevitability of the years-long march toward death, but the kind of debilitation involved along the way. In most chronic, progressive disease situations other than dementia, there is good reason for not seeing as "terminally ill" someone who is probably still years away from death. First, line-drawing issues present themselves—would we then categorize advanced old age itself, for example, as "terminal illness," for the march toward death is inevitable there, too? Second, too much life will often still be left to live to put all that remains under the color of impending death; death may indeed be coming, down the road, but the road has many segments yet to travel before getting there. A third consideration is that any prognosis of death within a certain number of months becomes less certain the larger that the requisite number of months becomes.

Progressive dementia that is already severe is different on all three of these scores. It is utterly different than non-demented old age itself: much less *valuable* life is left in the years of severe dementia than in the years of non-demented old age. And the prognosis of eventual death from the advance of the dementia itself is at least as secure as a prognosis of death within six months in most fatal illnesses.

Overlying all of these considerations is the central fact of the degree of mental debilitation in severe dementia. That has already brought to an end—or very near to

71. DWORKIN, *supra* note 15, at 219 (quoting Dennis J. Selkoe, *Amyloid Protein and Alzheimer's Disease*, 265 *SCI. AM.* 68, 68 (1991)).

the end—the life that the person regards as valuable and that the person is gratified to have had. In severe dementia, the self has literally withered. *From a personal perspective*, therefore, severe dementia already constitutes *real dying*. The point is bolstered by reflecting on the comparison between an illness in which our prognosis is that we are within six months of death, and the years-long chronic illness of severe dementia. To me, anyone who writes a clear and persistent AED for dementia is likely to see severe dementia as equally, if not more so, their “last stage” years when life is nearly over as they are likely to see any last six months when diagnosed with a more typical terminal illness. In the terms *that matter to people*, the rationale for limiting PAD to terminal illness applies just as much to multiple years of severe progressive dementia as it does to life predicted to end within six months.

VIII. THE ROAD FROM CURRENT LEGALIZATION TO ADVANCE EUTHANASIA DIRECTIVES

Morally, the previous argument can be summarized in four points. First, there is a strong prima facie case for following advance directives in dementia, both for the withdrawal of life-sustaining treatment and for aid in dying. Advance directives enable people to have some measure of control over the way they die, and the way they die is an important reflection of how they have lived. This cannot be said better than Nancy Rhoden has:

Something is wrong . . . when we treat formerly competent patients as if they were never competent. Someone who makes a prior directive sees herself as the unified subject of a human life. She sees her concern for her body, her goals, or her family as transcending her incapacity [O]ne . . . component of treating persons with respect [is] that we view them as they view themselves. If we are to do this, we must not ignore their prior choices and values.⁷²

At the same time, countervailing factors must be considered. These can be summarized in the remaining points.

Second, the clearer and more informed and persistent an advance directive, the more moral authority it has. Writers of AEDs need to be aware of the varying stages and affective dimensions of dementia, and they should assess and reiterate them well into beginning dementia.

Third, the case for following an AED is strongest in the presence of severe and irremediable suffering. This is exemplified by the case of Lotte, the woman in advanced dementia who received euthanasia in the Netherlands in March 2011.

Fourth, for other cases, a sliding scale that considers both autonomy and the capacity for enjoyment provides the justification for determining when an AED should be followed. As the demented person’s capacity to generate new critical interests and to enjoy life decreases, a clear, informed, and persistent AED gains in authority for implementation.

Applying this sliding scale generates conclusions to all the cases; Mrs. D. and Helen, on the moderate or mild end of dementia’s spectrum, are two of the easiest.

72. Rhoden, *supra* note 40, at 860.

The compelling conclusion about implementing their AEDs is “not yet.” Significant dementia has diminished their capacity to change their minds and their critical interests, but Helen, especially, has adapted to her dementia with new interests and real zest for life. Both enjoy and value the lives they are living. Their strong experiential interests in living outweigh any critical interest they have, from their AEDs, in not living in dementia. *As of this point in time*, dementia has turned out not to be as dreadful as they feared.

Another relatively easy case is at the opposite end of the spectrum: Walter, who is very severely demented and without the minimal contentment and happiness of Ruth. If his AED is informed, clear, and persistent, it should be implemented. He now has no capacity to generate new critical interests, and he takes little—if any—enjoyment in life.

Ruth’s directive, too, should be implemented, though her case is more complex because she is largely content and somewhat happy. As such, she has some experiential interest in continued survival, but because she has no capacity to generate any new critical interests, and because the value of her life to herself is greatly diminished by her inability either to remember or to anticipate, any clear and persistent AED she has should be implemented.

The hardest case is Margo. She can likely still value particular experiences, and many she now has she certainly enjoys. It is not clear, however, whether she can observe or reflect on life enough to value it, and she appears not to have the capacity to reflect on her life as a whole. If she has a strong and reiterated AED stated to include the moderately severe level of her current dementia, she exemplifies a sharp clash between autonomy and critical interests, on the one hand, and current experiential interests on the other. Margo has enough capacity for memory and anticipation to generate real enjoyment of life. In light of that enjoyment, on balance, society should firmly say for her, “Not yet.”

The road from legalized aid in dying and euthanasia to legally actionable AEDs for severe dementia thus has a sound moral basis. By their very own rationales, none of the three eligibility conditions currently in place for legally permissible PAD is strictly required. Contemporary competence is not the only context in which the crucial moral demand for voluntariness can be satisfied; a clear, well-informed, persistent advance directive also satisfies it. The requirement of terminal illness in the sense that people are with reasonable certainty near the end of their lives is met just as clearly by end-stage progressive dementia as it is by other illnesses with prognosis of death within six months. The rationale that there is no positive balance of value left in life is satisfied not only by unbearable suffering, but when the experiential value of survival is so minimal that it is outweighed by the strong critical interests reflected in a clear and persistent AED.

In conclusion, two observations can be added about the larger legal context for AEDs. First, the emergence of AEDs as morally acceptable can have more than one logical legal home. One is the Netherlands, where euthanasia is legal (evidenced by the real case of Lotte). There, voluntariness, not just unbearable suffering, is a required condition for permissible euthanasia, and a strong and reiterated AED can

be interpreted as making euthanasia voluntary. An equally logical home for AEDs, however, is the legalized aid in dying of Vermont, Oregon, Washington, British Columbia, and Switzerland. There, too, the emphasis on voluntariness can be plausibly extended to include AEDs. Those jurisdictions' laws, of course, would have to be rewritten (or their court decisions extended), but the current requirements of terminal prognosis within six months and current competency⁷³ are at odds with aid in dying's fundamental emphasis on voluntariness. The underlying legal and moral framework of these jurisdictions, too, can incorporate carefully implemented AEDs.

Second, most of this analysis of implementing advance directives for dementia applies as much to the refusal of life-supporting treatment as it does to PAD. The same dilemmas arise about interpreting change of mind and weighing critical and experiential interests. All of the types of persons with dementia analyzed regarding implementation of an AED can also have a more traditional directive for refusal of life support. Presumably, those whose aim in having an AED is to not live long in severe dementia would want to include in their directive not just PAD—but also the withholding and withdrawal of feeding tubes, for example, and the refusal of most hospitalization from nursing homes. Such “regular” directives for refusing life-supportive treatment in dementia are legally actionable and pair logically with AEDs, yet AEDs are not now legally permitted. The precedent of these already actionable advance directives has great practical importance. A high percentage of patients with advanced dementia in nursing homes develop infectious episodes and eating problems, and many are hospitalized for acute crises multiple times a year.⁷⁴ In so far as advance directives to refuse life support are already being implemented for patients like Ruth and Walter, and to the extent that we are confident about the appropriate contexts in which their implementation is justified, they provide important precedent for the eventual acceptance of AEDs.

73. In Switzerland, only current competency is required. *See supra* text accompanying note 3.

74. In a study of 323 nursing home residents with advanced dementia, 45% lived longer than eighteen months, 86% developed an eating problem, and the average number of transfers to a hospital in the last ninety days of life was 1.6 transfers. *See* Mitchell et al., *supra* note 25, at 45–46; Susan L. Mitchell et al., *The Clinical Course of Advanced Dementia*, 361 *NEW ENG. J. MED.* 1529, 1529–38 (2009).