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PLANNING FOR ALZHEIMER'S DISEASE WITH MENTAL HEALTH ADVANCE DIRECTIVES

Lisa Brodoff

Mental Health Advance Directives (MHAD) have long been used for life planning in the context of debilitating mental conditions such as dementia and schizophrenia. As early detection and diagnosis of Alzheimer's disease has become increasingly more possible, Professor Brodoff argues in this Article that MHADs can be an extremely effective tool for planning for a future with Alzheimer's disease. Professor Brodoff suggests that all attorneys who assist clients with estate planning create a MHAD, particularly those clients who have been diagnosed with Alzheimer's disease and those with the disease in their families. The MHAD is designed to aid caregivers and medical professionals with determining the best methods for administering care for this individual, listing particular life values, preferred methods of care and treatment, and other life decisions, such as how to finance long-term care, when to stop driving, and how to handle future intimate relationships. Professor Brodoff argues that this will result in better care tailored to a particular individual's needs and increased patient involvement in his or her own decision making, which reduces the burden of shifting the decision making to a family member or other caregiver.

Lisa Brodoff is a clinical law professor and Faculty Fellow, Fred T. Korematsu Center for Law and Equality, at Seattle University School of Law, where she teaches courses and clinics in Elder Law, Administrative Law, and Estate and Disability Planning. I would like to thank my research assistant Carla Calogero for her intelligent comments and extraordinary contributions to this article; Stephanie Wilson, my talented research law librarian; Professor Anne Enquist for her comments on my early draft and encouragement to continue on; Professor Connie Krontz for her excellent editing suggestions; and Dean Kellye Testy and Vice Dean Annette Clark for supporting both my scholarship and teaching. Finally, I want to thank my partner, Lynn Grotsky, for, once again, being there.

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I. Introduction

An Alzheimer's disease diagnosis is a devastating event. For the person receiving it, it presages the slow but inexorable loss of autonomy due to deterioration of memory, personal identity, cognitive and decision-making abilities, and the loss of control over body functions. For family members, caring for a loved one with Alzheimer's disease means watching the gradual loss of the person they have known and loved and eventually assuming all of the care needs and decisions for their loved one. Alzheimer's disease is the most common form of dementia, and it accounts for 60–80% of all dementias affecting older people.[1] It affects a significant portion of the elderly population, by some estimates up to 20–40% of people who reach the age of eighty-five.[2] And the numbers being diagnosed with Alzheimer's disease are growing, with diagnosis occurring at earlier ages and earlier stages of the disease.[3] Thus, many of us will have a loved one with Alzheimer's disease or will ourselves experience the debilitating and humiliating loss of volitional control caused by the disease.

Caregivers for a family member with Alzheimer's may be placed in the position of having to make difficult decisions for their loved ones involving when to institutionalize them, how to finance their care, when to stop them from driving, even when or if to have them involuntarily committed to a psychiatric hospital if they should become violent or sexually aggressive.[4] In attempting to care for themselves, caregivers and partners can face difficult choices involving whether or not they should seek other intimate relationships, get a divorce if it results in significant financial savings, or place their partner in a nursing home.[5] Too often caregivers must make these critical and emotional decisions without knowledge of what the person with Alz-

1. ALZHEIMER'S ASS'N, 2008 ALZHEIMER'S DISEASE FACTS AND FIGURES 5 (2008), http://indydiscoverynetwork.com/report_alzfactsfigures2008.pdf [hereinafter 2008 AD FACTS].

2. Thomas D. Bird & Bruce L. Miller, *Alzheimer's Disease and Other Dementias*, *in* HARRISON'S PRINCIPLES OF INTERNAL MEDICINE 2393 (Dennis L. Kasper et al. eds., 16th ed. 2005).

3. *See* Jeffrey R. Petrella, R. Edward Coleman & P. Murali Doraiswamy, *Neuroimaging and Early Diagnosis of Alzheimer's Disease: A Look to the Future*, 226 RADIOLOGY 315, 315–16 (2003).

4. *See* discussion *infra* Parts III.C–E, H.

5. *See* discussion *infra* Parts III.C, E, F.2.

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heimer's disease would advise or choose if he or she could say and without the express consent of the person with Alzheimer's disease.[6]

There are currently few planning tools available for those diagnosed with this illness to use in retaining decisional control and independence and in anticipating future needs. Other than living wills, which typically involve planning for end-of-life decisions and the refusal of treatment that prolongs the dying process,[7] people with Alzheimer's disease have had almost no ability to plan for or decide in advance on their care.[8] This Article proposes that there is one planning tool that has great potential to meet the decisional needs of both Alzheimer's disease patients and their caregivers and family members—the Mental Health Advance Directive (MHAD).

Typically, MHADs have been used by clients with mental disabilities like bipolar disorder, schizophrenia, and severe depression.[9] Clients with these illnesses tend to have periods of relative stability followed by decompensation.[10] During less active periods of the illness, the client can draft a MHAD to make predictions about what kind of care he or she would likely need at a future time and to decide on options.[11] These decisions are generally based on a client's prior experiences during decompensation, giving him or her the knowledge of what treatment and planning has worked well in the past, and de-

6. *See* Bruce J. Winick, *Foreword: Planning for the Future Through Advance Directive Instruments*, 4 PSYCHOL. PUB. POL'Y & L. 579, 581 (1998) [hereinafter Winick, *Planning for the Future*].

7. *See generally* Patrick Triplett et al., *Content of Advance Directives for Individuals with Advanced Dementia*, 20 J. AGING & HEALTH 583 (2008) (discussing how patients who have documented their end-of-life treatment preferences tend to request supportive care rather than more aggressive treatments).

8. *See* Winick, *Planning for the Future*, *supra* note 6, at 581.

9. Most commonly, people with mental disabilities such as bipolar disorder, schizophrenia, and severe depression create MHADs in anticipation of future, temporary incapacity resulting from their mental illness. MHADs typically preauthorize for certain treatments, specify medication and facility preferences, designate a surrogate decision maker, and may include provisions for irrevocability. *See* Debra S. Srebnik et al., *Interest in Psychiatric Advance Directives Among High Users of Crisis Services and Hospitalization*, 54 PSYCHIATRIC SERVS. 981, 981 (2003) [hereinafter Srebnik, *Interest in Psychiatric Advance Directives*]; Debra S. Srebnik et al., *The Content and Clinical Utility of Psychiatric Advance Directives*, 56 PSYCHIATRIC SERVS. 592, 594–96 (2005) [hereinafter Srebnik, *Utility of Psychiatric Advance Directives*]; Marvin S. Swartz et al., *Patient Preferences for Psychiatric Advance Directives*, 5 INT'L J. FORENSIC MENTAL HEALTH 67, 67–68 (2006).

10. *See* HUMAN RIGHTS WATCH, ILL-EQUIPPED: U.S. PRISONS AND OFFENDERS WITH MENTAL ILLNESS 30–31 (2003), http://www.hrw.org/reports/2003/usa1003/usa1003.pdf.

11. *See* Srebnik, *Interest in Psychiatric Advance Directives*, *supra* note 9, at 981.

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scribing and rejecting treatment that has previously failed or exacerbated the illness.[12]

People with dementia tend to get increasingly worse rather than cycling up and down.[13] Unlike those with cyclical mental illnesses, people with Alzheimer's disease face a progressively debilitating illness with which they have little familiarity.[14] How does this difference affect planning and future decision making about their care? When can and should planning be done by these clients? What care needs and treatments are predictable early on with Alzheimer's disease? Can MHADs offer a useful planning option? What are some of the pitfalls of MHAD use? Are there ways to improve the document to take into account the special needs of people with dementia? What legal and ethical issues come up in doing this planning for Alzheimer's disease? These are some of the questions this Article addresses.

There are a number of predictable future decisions that Alzheimer's disease patients and their families can anticipate and make either while the person with the disease is at an early stage or even when no diagnosis has yet been made. By advising clients on these decision points and helping them draft these anticipatable decisions into MHADs, attorneys working with other care providers can go a long way towards empowering both people with Alzheimer's disease and their families and caregivers to retain control over their future, even at the most out of control point of this illness.

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12. *See* Michaela Amering, Peter Stastny & Kim J. Hopper, *Psychiatric Advance Directives: Qualitative Study of Informed Deliberations by Mental Health Service Users*, 186 BRIT. J. PSYCHIATRY 247, 251 (2005); Srebnik, *Utility of Psychiatric Advance Directives*, *supra* note 9, at 596; Jeffrey Swanson et al., *Psychiatric Advance Directives Among Public Health Consumers in Five U.S. Cities: Prevalence, Demand and Correlates*, 34 J. AM. ACAD. PSYCHIATRY & L. 43, 54 (2006) (explaining that greater insight into their illness and treatment preferences among people with psychiatric disorders correlated with greater completion rates of MHADs).

13. *See* Alzheimer's Ass'n, Stages of Alzheimer's, http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp (last visited Nov. 9, 2009) [hereinafter Stages of Alzheimer's]; ElderCare Online, The Stages of Alzheimer's Disease, http://www.ec-online.net/Knowledge/Articles/alzstages.html (last visited Nov. 9, 2009); Helpguide.org, Alzheimer's Disease: Signs, Symptoms, and Stages, http://www.helpguide.org/elder/alzheimers_disease_symptoms_stages.htm (last visited Nov. 9, 2009); Mayo Clinic, Alzheimer's Stages: How the Disease Progresses, http://mayoclinic.com/health/alzheimers-stages/AZ00041 (last visited Nov. 9, 2009) [hereinafter Mayo AD Stages]; Barry Reisberg, Stages of Alzheimer's (1984), http://www.ec-online.net/Knowledge/Articles/alzstages.html (last visited Nov. 16, 2009).

14. *See* Helpguide.org, *supra* note 13.

This Article focuses on planning for Alzheimer's disease, as opposed to other types of dementia,[15] for a number of reasons. First, Alzheimer's disease, unlike other dementias,[16] has a fairly predictable and lengthy course of progression from diagnosis to death.[17] It is unique in that there are predictable stages of mental decline more or less typified by certain behaviors or deficits, giving individuals a real opportunity to anticipate and plan.[18] In the first stages of the disease, patients' symptoms are relatively mild with short-term memory lapses affecting job performance, confusion over where they are, loss of spontaneity and initiative, changes in mood and personality, trouble completing routine chores, and difficulty handling money.[19] While these early stage symptoms are difficult, clients may still possess the ability to make informed decisions about their care.[20] Furthermore, the typically long lifespan of people suffering from this disease, generally between seven and ten years, means that with an early diagnosis, there is still time to anticipate and plan for future needs.[21]

15. Other types of dementia and diseases in which dementia occurs are vascular dementia, Lewy Body dementia, Huntington's disease, and Parkinson's disease. Many of the uses and benefits of MHADs for persons with Alzheimer's disease may be applicable for these other conditions as well. *See* Ronald Schouten, *Commentary: Psychiatric Advance Directives as Tools for Enhancing Treatment of the Mentally Ill*, 34 J. AM. ACAD. PSYCHIATRY & L. 58, 59 (2006).

16. "Dementia" is defined as a group of disorders that cause irreversible cognitive decline as a result of various biological mechanisms that damage brain cells. Two criteria must be met to have a disorder classified as dementia. First, it must cause a decline in both memory and at least one of the following four essential cognitive functions: (1) ability to generate coherent speech or understand spoken or written language (aphasia); (2) ability to perform motor activities (apraxia); (3) ability to process and interpret visual information (visual recognition or agnosia); or (4) capacity to plan, make sound judgments, and carry out complex tasks (executive functioning). Second, the decline must be severe enough to interfere with day-to-day life. AM. PSYCHIATRIC ASS'N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 134–35 (4th ed. 1994).

17. *See* sources cited *supra* note 13.

18. *See* sources cited *supra* note 13.

19. *See* sources cited *supra* note 13.

20. Early-stage, or mild, Alzheimer's is typified by lapses in memory, concentration, and organization, but major gaps in memory and cognitive function do not usually present until midstage, or moderate, Alzheimer's. *See* Karen B. Hirschman et al., *How Does an Alzheimer's Disease Patient's Role in Medical Decision Making Change over Time?*, 17 J. GERIATRIC PSYCHIATRY & NEUROLOGY 55, 59 (2004) (explaining that patients with mild Alzheimer's disease are still involved in their health care decision making, but patient involvement in decision making decreases as the dementia increases to moderate or worse stages).

21. On average, people with Alzheimer's live for four to six years after diagnosis, though many may live for a decade or longer after the initial onset of the disease (diagnosis is typically not possible until the disease has progressed

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Second, the symptoms and needs of people with Alzheimer's disease are particularly troubling and unusual for both the family and the patient, which makes planning even more critical.[22] These include the possibility of previously unseen sexual and physical aggression, loss of willpower, suspiciousness, delusions, hallucinations, and compulsive behavior.[23] There is a high prevalence of psychiatric symptoms that come with Alzheimer's disease, with 80% experiencing agitation, 40% depression, 40% aggression, and 30% psychosis.[24] This high likelihood of mental health issues arising during the course of the disease makes the need for and desirability of mental health advance planning greater than with other illnesses.[25]

Third, people with Alzheimer's disease, on average, will need significantly more personal and decisional care than people with *all* other illnesses.[26] Eventually, everyone with Alzheimer's disease will need extensive help with all activities of daily living including dressing, bathing, toileting, bladder and bowel incontinence care, and mobility.[27] And, as the disease inevitably progresses, most people with Alzheimer's disease will need assistance with managing finances and legal issues, supervision if wandering, arranging placements in assisted living or nursing homes, and managing behavioral symptoms.[28] This care is done, in large part, by unpaid caregivers, such as family members, friends, and neighbors.[29] A loved one with Alzheimer's disease may be uncooperative and resistant to care, and can be confused

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through the earliest stages). Eric B. Larson et al., *Survival After Initial Diagnosis of Alzheimer Disease*, 140 ANN. INTERNAL MED. 501, 508 (2004); *see* Mayo AD Stages, *supra* note 13.

22. *See* THE PERSON WITH ALZHEIMER'S DISEASE: PATHWAYS TO UNDERSTANDING THE EXPERIENCE 49–74 (Phyllis Braudy Harris ed., 2002).

23. *See* sources cited *supra* note 13.

24. Amie T. Blaszczyk & Monica Mathys, *Treatment of Cognitive Decline and Psychiatric Disturbances Associated with Alzheimer's Dementia*, 20 J. PHARMACY PRAC. 13 (2007) (explaining that 80–90% of people with Alzheimer's disease experience symptoms including depression, anxiety, etc.); Alzheimer's Ass'n, Behavioral and Psychiatric Symptoms of Alzheimer's Disease 1 (2008), http://www.alz.org/national/documents/topicsheet_behavepsych.pdf.

25. Rebecca S. Allen et al., *End-of-Life Issues in the Context of Alzheimer's Disease*, 4 ALZHEIMER'S CARE Q. 312, 312 (2003).

26. 2008 AD FACTS, *supra* note 1, at 14. Twenty-three percent of caregivers of people with Alzheimer's disease and other dementias provided more than forty hours per week of care, compared with just sixteen percent for all other older people. *Id.*

27. *See* sources cited *supra* note 13.

28. 2008 AD FACTS, *supra* note 1, at 16.

29. *Id.* at 14.

and disoriented, making this type of caregiving extraordinarily difficult, stressful, and even unhealthy.[30] Virtually everyone with Alzheimer's disease will need placement in a long-term care facility because patients will ultimately need more care than can be provided by family members.[31] These unique hallmarks of Alzheimer's disease—nursing home placement, extensive personal care needs, possible assaultive and compulsive behaviors, and loss of decisional capacity—make a focus on planning for this disease particularly compelling. If, by their loved one doing advance planning, some relief can be provided to caregivers, then the impact of this planning will be exponentially greater than with other illnesses.[32]

Finally, the enormous and growing number of people affected by Alzheimer's disease beg for a response and planning solutions from the legal community.[33] Just as the horror and difficulty of pro-

30. *Id.* at 16–18. More than 40% of unpaid caregivers of loved ones with Alzheimer's rate the emotional stress of caregiving as high or very high; about one-third experience depression, and these caregivers are more likely than noncaregivers to have high stress hormone levels, reduced immune function, new hypertension, new coronary disease, and higher rates of hospitalization. *Id.*

> Caregivers—one-third of whom are Medicare beneficiaries themselves—have serious health problems that result directly from their caregiving role. They report 46 percent more physician visits, use 70 percent more prescription drugs, and are more likely to be hospitalized than others their age. Spouses who are suffering from the strain of caregiving are 63 percent more likely to die within a four-year period than other spouses of the same age.

Alzheimer's Ass'n, Medicare and Medicaid Costs for People with Alzheimer's Disease III (2001), http://www.alz.org/national/documents/alzreport.pdf [hereinafter ALZHEIMER'S ASS'N, MEDICARE AND MEDICAID COSTS].

31. 2008 AD FACTS, *supra* note 1, at 25.

32. Michael R. Greenberg, Marc D. Weiner & Gwendolyn B. Greenberg, *Controlling Personal Health Decisions for the Oldest Old*, 98 AM. J. PUB. HEALTH 1160, 1161 (2008). "We cannot understand the anguish felt by family members who argue with other members about treatment and financial matters, sometimes to the point of lawsuits and family disintegrations. Conversely, many of us have witnessed a sense of relief for the oldest old who have prepared these [advance planning] documents." *Id.*

33. *Id.*

> We believe that public health practitioners, social workers, attorneys, religious advisers, and others can play a major role in persuading the oldest old to secure these [planning] documents and take more control of their health and resources, and we urge them to do so. In particular, we encourage the exploration of partnerships between the elder and disability law sections of federal, state, and local bar associations with their counterparts in the public health arena.

Id.

> The *Schiavo* case provides an opportunity to explore the therapeutic jurisprudence/preventive law model of lawyering. This model con-

viding care and decision making for a family member in a permanent and irreversible coma prompted a legal response in the form of living wills and durable powers of attorney,[34] care for people with Alzheimer's disease involves even more people, time, resources, and decisions, and requires more creative and effective tools for dealing with the choices that lay ahead.[35] The number of people either diagnosed with Alzheimer's disease or providing care to a family member with Alzheimer's disease is large and growing.[36] In 2008, there were 5.2 million people in the United States with this disease.[37] Because the incidence of Alzheimer's disease in the population increases as people age, predictions are that, as the baby boomers age, the number of people with Alzheimer's disease will also rise dramatically.[38] For example, the number of new cases of Alzheimer's disease is expected to increase from 411,000 in 2000 to 615,000 by 2030 and almost 1 million by 2050.[39] Considering that there are currently 9.8 million family caregivers, a number that can be expected to grow along with the increase in Alzheimer's disease diagnoses,[40] the impact of this disease now and in the future is ubiquitous.

Part II of this Article looks at the typical uses of MHADs and where they have been both beneficial and problematic for people with mental illness. This Article also examines the use of the most common

templates lawyers acting with an ethic of care. These lawyers value their clients' emotional needs and interests in addition to their legal interests and seek to prevent legal difficulties through creative lawyering and litigation alternatives.

Bruce J. Winick, *A Legal Autopsy of the Lawyering in* Schiavo: *A Therapeutic Jurisprudence/Preventive Law Rewind Exercise*, 61 U. MIAMI L. REV. 595, 595 (2007).

34. *See, e.g.*, George J. Alexander, *Durable Powers of Attorney as a Substitute for Conservatorship: Lessons for Advance Directives*, 4 PSYCHOL. PUB. POL'Y & L. 653, 661 (1998); Edward J. Larson & Thomas A. Eaton, *The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act*, 32 WAKE FOREST L. REV. 249, 285 (1997); Ben A. Rich, *Personhood, Patienthood, and Clinical Practice: Reassessing Advance Directives*, 4 PSYCHOL. PUB. POL'Y & L. 610, 611, 623–28 (1998); Winick, *Planning for the Future*, *supra* note 6, at 579–83.

35. MARC A. COHEN ET AL., U.S. DEP'T OF HEALTH & HUMAN SERVS., SERVICE USE AND TRANSITIONS: DECISIONS, CHOICES AND CARE MANAGEMENT AMONG AN ADMISSIONS COHORT OF PRIVATELY INSURED DISABLED ELDERS 1 (2006), http://aspe.hhs.gov/daltcp/reports/2006/admcohort.pdf.

36. 2008 AD FACTS, *supra* note 1, at 12, 14.

37. *Id.* at 9.

38. Ten million baby boomers in the United States will develop Alzheimer's disease. *Id.* at 12, 33–34.

39. *Id.* at 12.

40. *Id.* at 14.

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advance planning tool, the living will, to see its benefits and deficits and to help shed light on the pros and cons of advance planning in a context outside of the end-of-life framework. Next, Part III outlines the predictable and most difficult decision points that people with Alzheimer's disease are likely to face during the course and progression of this disease. Possibilities for deciding in advance in-home caregiver choices, how to deal with issues like future nursing home placement, avoidance of involuntary commitment in the event of combative behavior, financing the high cost of long-term care with Medicaid planning and Medicaid divorce, consent to involvement in other intimate relationships, prior consent to participation in Alzheimer's drug trials, and when driving privileges should be taken away will be considered.[41] Legal, ethical, and emotional issues that are likely to arise will be explored. Finally, Part IV discusses the appropriate timing of writing the MHAD and examines the potential benefits and downsides to Alzheimer's disease clients and their families and caregivers of doing this advance planning.

II. Typical Uses of Advance Directives for Mental Health and End-of-Life Planning

In order to understand how MHADs can best be used to plan for Alzheimer's disease, it is constructive to look first at how MHADs traditionally have been used to plan for people with mental illnesses that are more cyclical in nature. This is because people with mental illness, like people with Alzheimer's dementia, may be unable to make reasoned decisions regarding their care, need for hospitalization, and various treatment options at their greatest time of need.[42] Mental Health Advance Directives have served as one method of tak-

41. Each of these planning issues will be explored for the possibility of advance decision making. My purpose with this Article is to provide an overview of possible MHAD planning and to raise these issues generally, so that commentators and experts in the field can consider the pros and cons of doing this planning with clients. Every one of the issues I raise alone could be the subject of a separate law review article. My hope is that this Article will initiate the discussion, rather than provide an in-depth analysis of each planning issue. There are also other planning issues that could be considered that I have not discussed in this article, e.g., planning for end-of-life care, wandering, and medication choices.

42. *See* Bruce J. Winick, *Advance Directive Instruments for Those with Mental Illness*, 51 U. MIAMI L. REV. 57, 58 (1996) [hereinafter Winick, *Advance Directive Instruments*].

ing control of decision making while a person is capable, and for the most part they have worked well for people with mental illness.[43] This Part examines these typical uses of MHADs and shows their benefits, as well as their downsides, in planning for future care. This Part also explores end-of-life planning with living wills to determine the effectiveness of advance planning in the congruous situation where people believe they would know what they would want in a future situation without having had any actual direct experience themselves. After looking at these more typical uses of advance directives, we can better see what the predictable decision points are for people with Alzheimer's disease and the benefits and pitfalls of using MHADs to accommodate planning for those decisions.

A MHAD[44] is a legal planning document typically made by people with mental illnesses like schizophrenia spectrum disorder, bipolar disorder, and major depression to state their treatment preferences and to appoint a substitute decision maker.[45] The idea is that,

43. *See id.*

44. A MHAD can be variously defined as "a written document in which the principal makes a declaration of instructions or preferences or appoints an agent to make decisions on behalf of the principal regarding the principal's mental health treatment, or both," WASH. REV. CODE § 71.32.020(11) (2008); a legal resource that allows a person to document his or her wishes about receiving mental health services in the event that he or she is unable to provide consent at a future time, Marcia Sue Bosek DeWolf et al., *Do Psychiatric Advance Directives Protect Autonomy?*, 10 JONAS HEALTH L. ETHICS REG. 17, 18 (2008); and "a legal tool[] that allow[s] competent individuals to declare preferences for future mental health treatment when they may not be capable of doing so as a result of a psychiatric crisis," Mimi M. Kim et al., *Understanding the Personal and Clinical Utility of Psychiatric Advance Directives: A Qualitative Perspective*, 70 PSYCHIATRY: INTERPERSONAL & BIOLOGICAL PROCESSES 19, 19 (2007).

45. Twenty-seven states have statutes authorizing the use of Mental Health Advance Directives in some form: ALASKA STAT. §§ 13.52.010–.395 (1996); ARIZ. REV. STAT. §§ 36-3281 to -3287 (LexisNexis 1999); D.C. CODE § 7-1231.06 (2001); HAW. REV. STAT. §§ 327G-1 to -14 (2004); IDAHO CODE ANN. §§ 66-601 to -613 (1998); 755 ILL. COMP. STAT. 43/1–43/85 (1995); IND. CODE § 16-36-1-7 (2004); KY. REV. STAT. ANN. §§ 202A.420–.432 (LexisNexis 2003); LA. REV. STAT. ANN. §§ 28:221–:237 (2001 & Supp. 2009); ME. REV. STAT. ANN. tit. 34-B, § 11001 (1993); MD. CODE ANN., HEALTH-GEN. §§ 5-601 to -618 (LexisNexis 1993); MICH. COMP. LAWS §§ 700.5501–.5520 (1998); MINN. STAT. § 253B.03 (1991); MONT. CODE ANN. § 53-21-153 (2001); N.J. STAT. ANN. §§ 26:2H-102 to -125 (West 2005); N.M. STAT. ANN. §§ 24-7B-1 to -16 (West 2006); N.C. GEN. STAT. §§ 122C-71 to -77 (1997); OHIO REV. CODE ANN. §§ 2135.01–.14 (LexisNexis 2003); OKLA. STAT. ANN. tit. 43A, §§ 11-101 to -113 (West 1995); OR. REV. STAT. §§ 127.700–.737 (1993); 20 PA. STAT. ANN. §§ 5801–5845 (West 2005); S.D. CODIFIED LAWS §§ 27A-16-1 to -18 (1997); TENN. CODE ANN. §§ 33-6-1001 to -1015 (West 2000); TEX. CIV. PRAC. & REM. CODE ANN. §§ 137.001–.011 (Vernon 1997); UTAH CODE ANN. §§ 62A-15-1001 to -1004 (West 1996); WASH. REV. CODE §§ 71.32.010–.901 (2003); WYO. STAT. ANN. §§ 35-22-

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while in a period of capacity and stability, people could state their wishes and instructions in advance to be implemented during a period of compromised capacity.[46] In this way, psychiatric patients who have episodic illnesses that impair insight can meaningfully participate in their own treatment decisions at a time when they would otherwise be incapable of making those decisions.[47]

Typical advance decisions that can be made in a MHAD include listing preferred medications that have worked well in the past;[48] refusing the use of certain medicines that did not work or caused unacceptable side effects;[49] stating what alternatives to psychiatric hospitalization were most workable and desirable during a crisis;[50] describing ways of de-escalating crises when they occur;[51] making decisions in the MHAD irrevocable by the client during a time of incapacity (a "Ulysses Clause");[52] and consenting in advance to voluntary psychia-

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301 to -308 (1999); *see also* 42 U.S.C.A. § 1395cc(f) (West 2003) (the Patient Self-Determination Act, which requires health care providers receiving federal funding to inform patients about the availability of advance directives).

46. John Q. La Fond & Debra Srebnik, *The Impact of Mental Health Advance Directives on Patient Perceptions of Coercion in Civil Commitment and Treatment Decisions*, 25 INT'L J.L. & PSYCHIATRY 537, 538 (2002).

47. *Id.*

48. *See* Jeffrey W. Swanson et al., *Facilitated Psychiatric Advance Directives: A Randomized Trial of an Intervention to Foster Advance Treatment Planning Among Persons with Severe Mental Illness*, 163 AM. J. PSYCHIATRY 1943, 1944 (2006). In one study, 93% of people executing a MHAD included advance consent to one or more psychotropic medications, 77% included refusal preferences to one or more psychotropic medications, and none refused psychotropic medications altogether. *Id.* at 1947 tbl.3. Consumers may include preferences, consents, and refusals for a range of medications including antidepressants, antipsychotics, anticonvulsants, medications for nonpsychiatric medical conditions, mood stabilizers, medications to manage side effects, and anxioltyics. Srebnik, *Utility of Psychiatric Advance Directives*, *supra* note 9, at 594 tbl.1.

49. *See* Srebnik, *Utility of Psychiatric Advance Directives*, *supra* note 9, at 595.

50. Sixty-eight percent of consumers who completed MHADs in one study expressed a preference for alternatives to hospitalization. Among the alternatives included were modifications to medications, contacting a trusted caregiver, staying overnight in a respite bed, and visiting with a mental health provider. However, most participants also included information about preferred hospitals and hospitals to avoid in the event that hospitalization was emergent. *Id.*

51. *Id.* Examples of preferred methods of de-escalating crises include offering privacy or "time outs," avoiding restraints, specific communication approaches, and decreasing environmental stimulation. *Id.*; *see also* Eric B. Elbogen, *What Information Goes into Psychiatric Advance Directives?*, Webcast, http://www.nrc-pad.org/education/EricPresentation/042406duke.html (last visited Nov. 10, 2009).

52. Ryan Spellecy, *Reviving Ulysses Contracts*, 13 KENNEDY INST. ETHICS J. 373, 374–75 (2003). The Ulysses Clause prospectively binds clients to the treatment decisions they made in advance, anticipating that their illness will impair their ability to make reasonable decisions at the time they need them. *Id.* If the client refuses

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tric hospitalization, even if the person is likely to say no to admission at the time.[53] Further, patients can make advance plans for maintaining and caring for their homes, pets, bill payments, cars, and minor children while hospitalized or in a period of mental incapacity rendering them unable to focus on these critical needs.[54] Finally, people with mental illness can appoint a surrogate decision maker to effectuate the decisions and instructions for care in their MHAD, as well as to make other care decisions not fully anticipated in the advance directive.[55]

The benefits of MHADs in the psychiatric context are numerous. Patient involvement in treatment decision making, if done before the fact while able to make reasoned and individualized choices, has been shown to increase motivation for treatment, improve crisis intervention options thus more quickly de-escalating crises, and lead to reduced hospitalizations by providing for reasonable alternatives.[56] Patients who have created MHADs feel less coerced into treatment and more like collaborators in their care.[57] The result is that the treatment tends to be much more effective.[58] Finally, patients and their families may experience reduced worry and stress when they are more assured that their treatment choices will be respected and followed in the future.[59] This planning provides the greatest deference possible to clients' decisions regarding the treatment of their illnesses.[60] Mental Health Advance Directive execution results in clients "retain[ing] the maximum degree of control possible over their lives and over their

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the treatment choice made in advance in the MHAD, the MHAD binds them to the earlier decision. *Id.*

53. *See* N.J. STAT. ANN. § 26:2H-107(b)(2)(a) (West 2007); 20 PA. CONS. STAT. 5823(b)(1) (2005); WASH. REV. CODE § 71.32.050(3)(b) (2003); *see also* Srebnik et al., *Utility of Psychiatric Advance Directives*, *supra* note 9, at 502.

54. *See, e.g.*, WASH. REV. CODE § 71.32.050(3).

55. *See, e.g.*, 755 ILL. COMP. STAT. 43/15 (2004); N.J. STAT. ANN. § 26:2H-107(b)(2)(a); 20 PA. CONS. STAT 5823; WASH. REV. CODE § 71.32.050(3)(g); La Fond & Srebnik, *supra* note 46, at 41; *Making the Most of Psychiatric Advance Directives: Potential Benefits, Controversies, and Why a Team Approach Is Best*, HARV. MENTAL HEALTH LETTER, Dec. 2007, at 1.

56. Srebnik, *Utility of Psychiatric Advance Directives*, *supra* note 9, at 596.

57. *See* Winick, *Advance Directive Instruments*, *supra* note 42, at 83.

58. *Id.* at 81; *see also* Srebnik, *Utility of Psychiatric Advance Directives*, *supra* note 9, at 595–96, 598.

59. Winick, *Advance Directive Instruments*, *supra* note 42, at 81–82.

60. A. KIMBERLY DAYTON ET AL., ADVISING THE ELDERLY CLIENT §§ 33:12, 33:18 (2007); *see also* Greenberg, Weiner & Greenberg, *supra* note 32, at 1161 ("Without question, possessing up-to-date legal documents advances the dignity and autonomy of the incapacitated and dying and enhances public health . . . .").

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medical care, even in the face of the most severe and disabling episodes of illness."[61]

However, there are downsides to the use of MHADs in the psychiatric setting. First, there are many medical providers who do not trust patients with mental illness to make informed choices about their care.[62] They fear that MHADs are used as a way of avoiding treatment and limiting options that would be helpful, rather than optimizing care consistent with patient preferences.[63] MHADs "are nested in larger structures of mental health law and policy that protect the interests of parties other than the patient, and which, in situations of conflict involving the treatment of incapacitated patients, tend to favor the clinician's professional judgment over the patient's manifest wishes to avoid standard treatment."[64] For this reason, many MHAD statutes contain a significant contradiction—while the intent of these directives is to promote patient autonomy, the statutes allow physicians to override treatment requests they deem inappropriate.[65] Because clinicians are granted broad discretion to override advance directives, many observers believe that they "have no teeth" and are not effective tools for enacting patient preferences.[66]

Second, there are barriers to both patient completion and provider implementation of MHADs.[67] The vast majority of patients with mental illness do not actually execute this planning document.[68] This is true despite the large demand for MHADs by consumers—66–77% of patients surveyed who do not have a MHAD express an interest in

61. Elizabeth M. Gallagher, *Advance Directives for Psychiatric Care: A Theoretical and Practical Overview for Legal Professionals*, 4 PSYCHOL. PUB. POL'Y & L. 746, 747 (1998).

62. *See* Henry S. Perkins, *Controlling Death: The False Promise of Advance Directives*, 147 ANNALS INTERN. MED. 51, 53 (2007).

63. Ronald Schouten, Comment, *Psychiatric Advance Directives as Tools for Enhancing Treatment of the Mentally Ill*, 34 J. AM. ACAD. PSYCHIATRY & L. 58, 59 (2006).

64. Jeffrey W. Swanson et al., *Superseding Psychiatric Advance Directives: Ethical and Legal Considerations*, 34 J. AM. ACAD. PSYCHIATRY & L. 385, 385 (2006).

65. *See, e.g.*, 20 PA. CONS. STAT. § 5804(a)(2) (2005); WASH. REV. CODE § 71.32.150 (2008).

66. Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34 HASTINGS CTR. REP. 30, 36–37 (2004); Perkins, *supra* note 62, at 53.

67. *See generally* Debra Srebnik & Lisa Brodoff, *Implementing Psychiatric Advance Directives: Service Provider Issues and Answers*, 30 J. BEHAV. HEALTH SERVS. & RES. 253 (2003).

68. Only between four and thirteen percent of mental health consumers surveyed had completed MHADs. Jeffrey Swanson et al., *supra* note 12, at 54.

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completing one.[69] The reasons for this gap between the high demand for this planning and the low completion rate are numerous: people with mental illness are often marginalized and lack the social resources necessary to arrange for the completion of the document; as mental illness progresses, cognitive impairments increase, making planning difficult; both consumers and mental health providers are frequently uninformed about this planning tool and how it can be used; and states have not invested in education of stakeholders about MHADs or in supplying assistance to complete them.[70]

Perhaps the most well known advance planning tool is the living will. A living will is a written document wherein a person states his or her preferences for treatment, or more likely the refusal of treatment,[71] in the event he or she is in a permanent unconscious condition or terminally ill where death is reasonably imminent.[72] Typically, living wills direct physicians to withdraw artificial life support like tube feeding, a respirator, and intravenous hydration that only prolongs the dying process and state a preference to allow death to take its natural course.[73] However, additional instructions and value statements about care goals can be included in the document.[74]

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69. *Id.*

70. *Id.* at 55.

71. Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261, 278 (1990), *aff'g* Cruzan v. Harmon, 760 S.W.2d 408 (Mo. 1988) (establishing the constitutional right to refuse treatment in this situation).

72. *See, e.g.*, ARIZ. REV. STAT ANN. § 36-3261 (2009); CAL. PROB. CODE § 4701 (West 2008); WASH. REV. CODE § 70.122.030 (1992).

73. Examples of statutory living will language include the following:

> If at any time I should be diagnosed in writing to be in a terminal condition by the attending physician, or in a permanent unconscious condition by two physicians, and where the application of life-sustaining treatment would serve only to artificially prolong the process of my dying, I direct that such treatment be withheld or withdrawn, and that I be permitted to die naturally.

WASH. REV. CODE § 70.122.030. "If I have a terminal condition, I do not want my life to be prolonged, and I do not want life-sustaining treatment, beyond comfort care, that would serve only to artificially delay the moment of my death." ARIZ. REV. STAT. ANN. § 36-3262.

> I do not want my life to be prolonged if (1) I have an incurable and irreversible condition that will result in my death within a relatively short time, (2) I become unconscious and, to a reasonable degree of medical certainty, I will not regain consciousness, or (3) the likely risks and burdens of treatment would outweigh the expected benefits.

CAL. PROB. CODE § 4701.

74. Individuals can include instructions for personal preferences such as the desire to die at home or in a hospice setting, preferences for religious or spiritual rituals, or decisions to reject chemotherapy, etc. ROBERT PEARLMAN ET AL., YOUR

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This planning presumes that the patient will be incapacitated at the time a decision to withdraw life support is being made, and so the living will speaks for the patient. As with a MHAD, the concept is that people can accurately predict well in advance of being in a permanent coma or terminal illness whether or not they would want to continue treatment in that situation.[75] By making that critical decision ahead of time, patients retain decision-making autonomy, while at the same time relieving family members of the difficult and painful decision about whether to withdraw life support.[76] The process of planning has the further benefits of preparing patients for death, giving patients a sense of some control, and allowing them to attend to the needs of their loved ones.[77] While the concept of a living will to direct care at the end of life is a good one, in practice there have been many obstacles to its effectiveness.[78] Just as with MHAD execution, only a small minority of people, some 29% of adults, have signed living wills, and this is despite a vast national educational and legislative effort to encourage the public to use this planning tool.[79] Further, many studies show that living will instructions may not accurately reflect the actual desires of the patients who sign them.[80]

> [D]rafting a living will requires imagining situations that, to most people, are simply beyond imagination . . . . One of the limitations of the living will is that it presumes that people, when they are young and healthy, are going to be able to accurately assess how

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LIFE YOUR CHOICES 21–23, http://stevebuyer.house.gov/UploadedFiles/Your_Life_Your_Choices.pdf; AGING WITH DIGNITY, FIVE WISHES 8 (2007), http://www.fivewishes.org/forms/5wishes.pdf.

75. *See* ROBERT PEARLMAN ET AL., *supra* note 74, at 10.

76. *See, e.g.*, Carol Levin, *She Died the Same Way She Lived: Planning Well in Advance*, N.Y. TIMES, Dec. 6, 2005, at F5 (rejecting critics' pronouncements of the failure of advance directives as evidenced by the triumph of autonomy for author's mother, a victim of colon cancer, who, through her advance directives, felt she was able to meet death on her own terms, and discussing the relief that her mother's planning and acceptance brought to the author and her sister); *see also* Pam Belluck, *As a Life Ebbs, the Ultimate Family Quarrel*, N.Y. TIMES, Sept. 27, 2004, at A1 (describing the bitter and avoidable family dispute between an adult brother and sister over whether or not to terminate treatment for their critically ill mother who had no living will).

77. Douglas K. Martin, Linda L. Emanuel & Peter A. Singer, *Planning for the End of Life*, 356 LANCET 1672, 1672 (2000).

78. *See* Emily Clough, *A Critique of Advance Directives and Advance Directives Legislation*, 11 APPEAL REV. CURRENT L. & L. REFORM 16, 17 (2006).

79. News Release, Pew Research Ctr., Strong Public Support for Right to Die: More Americans Discussing—and Planning—End-of-Life Treatment (Jan. 5, 2006), http://people-press.org/reports/pdf/266.pdf.

80. *See* Clough, *supra* note 78, at 29–30.

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> they would feel in the face of serious and debilitating illness . . . [but] the bulk of evidence points in the other direction.[81]

Some commentators critique living will planning as being too general in nature and therefore of limited clinical utility because it fails to resolve later and more specific treatment questions.[82] On the other hand, others fault living wills that have more specific checklists and instructions regarding the type of care one can have or reject because in a real medical crisis decisions regarding the details of medical care cannot be reasonably predicted.[83] As a result, the "promise of advance directives to improve end-of-life care remains unfulfilled . . . [they are] infrequently used and seldom effective."[84] However, several scholars do recommend a disease-specific advance directive with specific instructions for care for people who currently have a disease that follows a predictable course and for which specific treatment options can be more easily anticipated.[85] These diseases include conditions like AIDS, cancer, end-stage renal disease, and amyotrophic lateral sclerosis as having great potential for well-informed advance decision making because of the general predictability of the disease processes.[86] Certainly, Alzheimer's disease falls within this category of predictable stages as well and therefore may be similarly well-suited for advance planning.[87]

To overcome these perceived downsides to advance planning with living wills, many commentators urge that the focus of planning be on the process, rather than the legal product.[88] They argue that the emphasis should shift from creating a legal document to discussions of end-of-life care between patients and their medical providers and

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81. Ray D. Madoff, *Autonomy and End-of-Life Decision Making: Reflections of a Lawyer and a Daughter*, 53 BUFF. L. REV. 963, 965 (2005).

82. Rebecca Dresser, Schiavo *and Contemporary Myths About Dying*, 61 U. MIAMI L. REV. 821 (2006); Bernard Lo & Robert Steinbrook, *Resuscitating Advance Directives*, 164 ARCHIVES INTERNAL MED. 1501 (2004).

83. Perkins, *supra* note 62, at 53.

84. Lo & Steinbrook, *supra* note 82, at 1501.

85. Joseph Klager et al., *Huntington's Disease: A Caring Approach to the End of Life*, 9 CARE MGMT J. 75 (2008); Lo & Steinbrook, *supra* note 82, at 1501; Martin, Emmanuel & Singer, *supra* note 77.

86. Lo & Steinbrook, *supra* note 82, at 1503.

87. *See infra* Part IV.A.

88. Charles P. Sabatino, *A Shifting Legal Landscape: From a Transactional Approach to a Communications Approach*, *in* THE CHANGING FACE OF HEALTH DECISIONS ADVANCE PLANNING, at 2, 10–20 (2008); Lo & Steinbrook, *supra* note 82, at 1501.

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among family members and surrogate decision makers.[89] A broad discussion of the patient's values, preferences, and experience of illness is a much better approach to advance care planning than a checklist living will, they argue, as it focuses on personal relationships and helps guide loved ones to making the best decisions in a variety of situations.[90] "Quality advance care planning . . . depends on an iterative process of discussion and feedback within the network of relationships that are meaningful to the patient."[91]

Many of these benefits of advance planning available to people with mental illness and at end-of-life could also inhere in people with Alzheimer's disease—patient autonomy, preparation for disabling conditions to come, discussions between family and medical providers, better care, and reduced stress over making difficult decisions.[92] At the same time, many of the downsides of MHADs, in particular, are likely avoidable by people with Alzheimer's disease. The stigma of mental illness and concomitant lack of trust in the decisions made in advance by these patients is less likely to occur with people with Alzheimer's disease than with other mental health diagnoses.[93] As will be shown, these patients should be advised to make decisions regarding their care before the most debilitating impacts of the disease occur, making the decisions more likely to be respected and followed by the medical community and family members.[94] Patients with Alzheimer's disease, unlike some people with schizophrenia, bipolar disorder, or severe depression, will be much less likely to have had a history of refusing to take medications or seek treatment, delusional behavior, criminal conduct, fractured family relationships, homelessness, or flagrant spending.[95] Because of this, family and provider rela-

89. Lo & Steinbrook, *supra* note 82, at 1504; Thomas J. Prendergast, *Advance Care Planning: Pitfalls, Progress, Promise*, 29 CRITICAL CARE MED. N34, N37 (2001).

90. *See* Lo & Steinbrook, *supra* note 82, at 1504–05; *see also* Prendergast, *supra* note 89, at N37–N38.

91. Lauren G. Collins, Susan M. Parks & Laraine Winter, *The State of Advance Care Planning: One Decade After SUPPORT*, 23 AM. J. HOSPICE & PALLIATIVE MED. 378, 380 (2006).

92. *See* Triplett et al., *supra* note 7, at 584.

93. *See* Winick, *Advance Directives Instruments*, *supra* note 42, at 64–65.

94. *See infra* Part IV.A.

95. *See, e.g.*, Breanne M. Sheetz, *The Choice to Limit Choice: Using Psychiatric Advance Directives to Manage the Effects of Mental Illness and Support Self-Responsibility*, 40 U. MICH. J.L. REFORM 401, 401–03 (2007); *see also* B.L. Miller et al., *Aggressive, Socially Disruptive, and Anti-Social Behavior Associated with Fronto-temporal Dementia*, 170 BRIT. J. PSYCHIATRY 150, 150 (1997) (comparing patients with

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tionships will likely still be intact at the time of the making of MHAD decisions, thus resulting in a more trusted, well-thought-out document and a higher likelihood that the decisions made will be respected and followed. Therefore, patients and family members can be more confident that treatment choices and personal care decisions made will be followed in the future.

The low incidence of completion of MHADs and living wills may also be a problem for people with Alzheimer's disease. However, by educating social workers, medical providers, and advocacy groups like the Alzheimer's Association[96] about the benefits of this advance planning, there is a great opportunity to overcome the barriers to completion experienced in these other contexts. And, as patients are diagnosed and treated at an earlier and earlier phase of the disease, there is significantly more time and ability to do advance planning in the Alzheimer's disease context. Unlike the completion of living wills, where most people who are considering writing them are being asked to plan for the unlikely hypothetical situation of being in a permanent coma[97] or having a terminal illness, here the person doing the MHAD planning may have already been diagnosed and may be looking to plan for the certainty of care needs in the years ahead. The motivation for completion of a MHAD when faced with the reality of Alzheimer's disease, together with the additional time to do the planning, should result in a higher completion rate with this group of patients. Finally, as some commentators have noted,[98] advance directives may be most useful when tailored to specific conditions for which certain advance care decisions can be reliably predicted. Alz-

Alzheimer's disease to those with fronto-temporal dementia and finding that disinhibition tends to occur later in the course of Alzheimer's disease and that aggressive or antisocial behaviors seem to appear considerably less frequently).

96. *See* Alzheimer's Association, Home, www.alz.org (last visited Nov. 10, 2009). The mission of the Alzheimer's Association is "[t]o eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health." *Id.*

97. By one estimate, between 10,000 and 25,000 people are in a persistent vegetative state in the United States. Christian Borthwick, *The Permanent Vegetative State: Ethical Crux, Medical Fiction?*, ISSUES IN L. & MED., Fall 1996, at 167, 170; Joy Hirsch, *Raising Consciousness*, 115 J. CLINICAL INVESTIGATION 1102, 1102 (2005) (citing that there may be as many as 15,000 patients in the United States who are in a persistent vegetative state and more than 100,000 others who are in a minimally conscious state).

98. *See* Srebnik, *Interest in Psychiatric Advance Directives supra* note 9, at 984–85.

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heimer's disease, as will be shown below, falls squarely in the realm of reliably predictable stages and reasonably anticipated decisions that can and should be considered for planning by people with this illness.

III. Predictable Decision Points for Clients with Alzheimer's Disease

The first section began by describing the more typical uses of advance directives—planning for the ups and downs of particular mental illnesses and planning for end-of-life decisions when a person is terminally ill or in a permanent coma. Having looked at the pros and cons of planning in these contexts, this Part moves on to explore what the potential applications of the MHAD planning tool for people with Alzheimer's disease are. What are the predictable decision points that Alzheimer's disease patients are likely to face and about which they may be able to make an informed advance judgment in a MHAD?

This Part describes reasonably foreseeable future decisions in the areas that are particularly difficult or troubling for Alzheimer's disease patients and their family members: choosing in-home care options and out-of-home placements when the almost inevitable need arises; dealing with the possibilities of combative or sexually aggressive behaviors; paying the high and burdensome cost of long-term nursing home care with Medicaid planning, including agreeing to a Medicaid divorce if necessary to ease family financial burdens; consideration of possible future intimate relationships for oneself or one's spouse or partner; agreeing to participate in new Alzheimer's disease medication and treatment research studies, even if doing so could result in an earlier death or difficult side effects; and decisions about when driving privileges should be taken away. As each of these critical decisions can be influenced by the personal values of the client, all MHADs for Alzheimer's disease should include an introductory section describing the personal history of the client and his or her general ideals with regard to future care. This introductory statement can be used by providers, family, and surrogate decision makers to guide them in determining the best course of treatment when the specific choices the client stated are not available or an unanticipated situation occurs. This Article presents its own Mental Health Advance Directive for Alzheimer's disease in Attachment A to demonstrate how

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each of these advance decisions might play out in the reality of writing such a plan.[99]

This Part will show how the MHAD document can be used as an educational tool and template for family discussion with appropriate professionals on each of these decision points. Each of these potential decisions, fraught with legal, ethical, and emotional considerations, is described and evaluated for MHAD planning. This Part will also discuss the professionals that are available to help a client with Alzheimer's disease make an educated decision based on his or her personal preferences, necessary funding, and the actual choices available in the community.

A. Personal History and Care Values Statement

One of the most reliable hallmarks of excellent dementia care is that caregivers know and understand the values, history, and personality of their patient.[100] The more providers understand the person

99. *See* Attachment A, Sample Alzheimer's Disease Mental Health Advance Directive of Lisa E. Brodoff [hereinafter Brodoff Sample]. While I do not have Alzheimer's disease, I have worked with hundreds of clients and their families who have dealt with this illness. I have also consulted with geriatric care planners, medical and mental health providers, family members, and patients in drafting my plan. My hope is that by attempting to put myself in the shoes of clients with Alzheimer's disease, I can approximate the planning I or others could actually achieve with an advance directive.

100. *See* Sandy C. Burgener et al., *Expressions of Individuality in Cognitively Impaired Elders Need for Individual Assessment and Care*, 19 J. GERONTOLOGICAL NURSING 13 (1993) (stating that recognizing the individual and uniquely expressed needs of patients with Alzheimer's enhances the quality of the individual's living experience); Lois K. Evans, *Knowing the Patient: The Route to Individualized Care*, 22 J. GERONTOLOGICAL NURSING 15 (1996) (describing how the nurse's experience in caring for patients, chronological time, and a sense of closeness between the patient and the nurse are related to "knowing the patient" which results in positive patient outcomes); Mary Beth Happ et al., *Individualized Care for Frail Elders: Theory and Practice*, 22 J. GERONTOLOGICAL NURSING 6 (1996). Individualized care for frail elders is defined as an interdisciplinary approach which acknowledges elders as unique persons and is practiced through consistent caring relationships. The four critical attributes of individualized care for frail elders are (1) knowing the person; (2) relationship; (3) choice; and (4) participation in and direction of care. Cognitively impaired elders can direct their care through the staff's knowledge of individual past patterns and careful observation of behavior for what is pleasing and comfortable to each resident. Studies show that personal knowledge of the patient leads to the highest quality of care. *Id.*; Anne Hegland, *Residents Set Their Own Pace*, CONTEMPORARY LONG TERM CARE, June 1993, at 72, 74, 115 (explaining that establishing meaningful activities that are individualized to the residents, based on conversations with residents and their families about the resident's values, habits, likes and dislikes, and updating this information regularly results in more success-

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and his or her needs, the better they are able to react to and deal with situations as they arise. A recent study of caregiving for people with Alzheimer's disease in nursing homes revealed that patients who are patronized and spoken to like children are more frustrated and resistant to care than those who are spoken to as adults.[101] This suggests that the person with Alzheimer's disease, even in the later stages of the illness, retains a sense of adulthood and wants to be treated with respect and understanding.[102]

Particularly in the late stages of Alzheimer's disease, patients are not able to express effectively who they are, their history, their interests, or their desires or feelings.[103] This can lead to frustration and anger on the part of the Alzheimer's disease patient and misunderstandings by care providers of the cause of the patient's distress.[104] Standards of care for Alzheimer's disease have changed over the last twenty years. In the past, it was believed that when the Alzheimer's disease patient misstated a fact (e.g., "I want to see my mother" when the patient's mother was deceased), it was important to correct the misconception and convince the patient of the truth (e.g., "Your mother died twenty years ago!").[105] Now, experts say that the old approach

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ful and enjoyable interactions between residents and staff); Janet K. Specht et al., *Partnering for Care: The Evidence and the Expert*, 35 J. GERONTOLOGICAL NURSING 16 (2009) (asserting that plans of care for persons with Alzheimer's that are individualized to the person's self-identified needs provide the best way to meet their changing needs from diagnosis through the course of the disease).

101. Kristine N. Williams et al., *Elderspeak Communication: Impact on Dementia Care*, 24 AM. J. ALZHEIMER'S DISEASE & OTHER DEMENTIAS 11, 18 (2009) (describing how "elderspeak," or infantilizing communication, can trigger resistiveness in individuals with dementia).

102. *See id.* at 12.

103. Michelle S. Bourgeois, *The Challenge of Communicating with Persons with Dementia*, 3 ALZHEIMER'S CARE Q. 132, 132 (2002); Andrew Kertesz & Martha Kertesz, *Memory Deficit and Language Dissolution in Alzheimer's Disease*, 3 J. NEUROLINGUISTICS 103, 105 (1988); Andrew Kertesz et al., *The Dissolution of Language in Alzheimer's Disease*, 13 CAN. J. NEUROLOGICAL SCI. 415 (1986); Kelly Lyons et al., *Oral Language and Alzheimer's Disease: A Reduction in Syntactic Complexity*, 1 AGING & COGNITION 271, 278–79 (1994).

104. *See* Jary M. Lesser & Susan V. Hughes, *Psychosis, Agitation and Disinhibition in Alzheimer's Disease: Definitions and Treatment Options*, 61 GERIATRICS 14, 16 (2006) (describing how a confused or exhausted caregiver's insistence, for example, that the hallucinations a person with Alzheimer's is experiencing are false can escalate the situation and incite agitation or aggression); *see also* Louis D. Burgio et al., *Agitation in Nursing Home Residents: The Role of Gender and Social Context*, 12 INT'L PSYCHOGERIATRICS 495, 495 (2000).

105. *See also* Hegland, *supra* note 100, at 74; Abbey M. Luterick, *Don't Redirect. Validate*, ASSISTED LIVING TODAY, May 2002, at 29, 29–30. Until recently, caregivers of persons with dementia would attempt to "redirect" the individual by changing

led to increased frustration and uncooperative behaviors in patients.[106] The better practice now is to "enter into a patient's reality instead of forcing that person into our reality. Don't remind them of their disability. Don't tell them they're wrong. And, by all means, don't be condescending or critical."[107] It follows from these studies that the more providers know about their patients, the better able they are to enter their world, treat them with respect, and figure out their needs. On the other hand, when a person with Alzheimer's disease is being cared for by a new or uninformed provider, for example, upon a change in shift at the nursing home, there is a greater chance that the client's symptoms or behaviors will be misunderstood, thus delaying or denying the best treatment option.[108]

Given what we now know about current best practices for care, this Article suggests that all MHADs have an introductory section that sets out who the client is, his or her work history, important past and

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the activity or using "therapeutic lying." Newer approaches focus on the need of the agitated individual, rather than the agitation or behavior and empathize with or validate those needs or behaviors (the "validation" approach). *Id. See generally* Anna N. Rahman & John F. Schnelle, *The Nursing Home Culture-Change Movement: Recent Past, Present, and Future Directions for Research*, 48 GERONTOLOGIST 142 (2008) (describing a current movement to shift toward more resident-directed care).

106. *See* Ethel Mitty & Sandi Flores, *The Language of Dementia: Theories and Interventions*, 28 GERIATRIC NURSING 283, 285–87 (2007). These new models of patient-centered dementia care include: the Need-Driven Dementia-Compromised Behavior Model, which holds that "disruptive" behaviors can be understood as expressing unmet needs (e.g., psychosocial or physiologic) that can be addressed in an individualized care plan (e.g., addressing need for attachment, pain relief, or a calmer environment); the Progressively Lowered Stress Threshold Model, which holds that environmental conditions must be modified for those with progressive cognitive decline, for example, by reducing stressors, assisting with decision making, and unconditional respect and acceptance; the Self-Identity Roles for Designing Interventions, which focuses on the reinforcement and construction of identity. *Id. See* Janice Penrod et al., *Reframing Person-Centered Nursing Care for Persons with Dementia*, 21 RES. & THEORY FOR NURSING PRAC.: AN INT'L J. 57 (2007).

107. Judith Graham, *A New Approach to Caring for Alzheimer's Patients*, CHI. TRIB., July 28, 2008, at 1.

108. *See, e.g.*, Gary Rotstwin, *No Place Like Home: Nursing Homes Find "Culture Change" Necessary to Make Patients Happier, Healthier*, POST-GAZETTE (Pittsburgh, Pa.), Sept. 24, 2002, at A1 (recounting how a nursing home assigned staff permanently to particular residents instead of rotating assignments, and the residents were much happier as a result because staff got to know them and their needs). *But see* Louis D. Burgio et al., *Quality of Care in the Nursing Home: Effects of Staff Assignment and Work Shift*, 44 GERONTOLOGIST 368, 376 (2004) (describing how in the first study attempting to measure the impact of permanent staffing on resident behavior and care quality, results were inconclusive).

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present relationships, interests, and values.[109] This allows clients the opportunity to express who they are and what is important to them for a future time when they know that they will be unable to do just that. This section of the MHAD will give future care providers more information about the person they are serving, allowing for better and quicker responses to needs. By knowing and understanding the person before them, caregivers can more easily develop a relationship with their patient by connecting on a more personal level.[110] Better relationships result in higher quality of care—the more individuals like the people with whom they work, the more attentive those individuals are to the patient's needs.[111]

Second, when general values about care are stated in the MHAD, surrogate decision makers will have a better sense of how to decide what care the person with Alzheimer's disease would have wanted in all kinds of situations not previously anticipated.[112] For example, the client could put in a values statement that "I prefer care in the smallest and most homelike setting possible," or that "I hope to preserve as much of my assets and income for my spouse." These simple statements could help family members decide between placement in a specialized Alzheimer's unit in a nursing home or a small adult family home, as well as determine when and if to apply for Medicaid or even to divorce in order to cover long-term care costs.

These benefits—timely, appropriate, and quality care as well as decision making congruent with the wishes and values of the person with Alzheimer's disease—make the writing of a personal history statement a real and important advantage of using a MHAD document for planning.

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109. *See* Brodoff Sample, *supra* note 99, at Part II.

110. "These [personal stories written by three people diagnosed with early onset Alzheimer's disease] reinforce the critical need for professionals to learn the life histories of the clients they serve. They remind professionals, too, to stress to families the need to hear these life stories while the person can still tell them." LIVING WITH GRIEF: ALZHEIMER'S DISEASE 86 (Kenneth J. Doka ed., 2004).

111. *See id.*

112. Michael N. Kane, *Legal Guardianship and Other Alternatives in the Care of Elders with Alzheimer's Disease*, 16 AM. J. ALZHEIMER'S DISEASE & OTHER DEMENTIAS 89, 92 (2001). This article notes the importance of a values history in preplanning for future care. There are four kinds of instructional directives that inform others of one's value history: inferred communication, oral communication, personal written instructions, and living wills. *Id.*

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B. In-Home Care

An initial decision that people with Alzheimer's disease will need to make concerns the type of care they would want to receive while still in their own home. At the beginning stages of the illness, most Alzheimer's disease clients are able to remain in their homes either on their own, if they had previously lived alone, or with a spouse, partner, family member, roommate, or friend.[113] As the disease progresses, clients will need some assistance with personal care (e.g., bathing, dressing, toileting, cueing all tasks), reminders to take medications and go to appointments, and safety monitoring.[114] Clients may also need assistance with housekeeping, cooking, grocery shopping, and driving to appointments.[115]

This personal care can be delivered in a number of ways. It can be provided by family members (for pay and as volunteers),[116] individuals hired for this service,[117] and agencies that are paid to cover this care.[118] Some people may prefer that personal care be done only by family members, while others would never want their family to do those tasks. Some who would have consented to outside care when well may refuse care from anyone but a spouse while sick. Cultural mores may dictate client preferences in this regard.[119] For example, in

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113. H. Forstl & A. Kurz, *Clinical Features of Alzheimer's Disease*, 249 EUR. ARCHIVES PSYCHIATRY & CLINICAL NEUROSCIENCE 288, 289 (1999).

> At the mild stage of [Alzheimer's disease], patients may still be able to live independently for most of the time. But due to significant cognitive difficulties in several domains, they will need support with a variety of organizational matters. If a patient wishes to remain at home, arrangements for a support system should be made at this stage before more intensive or permanent supervision is necessary.

Id.

114. NAT'L INST. ON AGING, U.S. DEP'T OF HEALTH & HUMAN SERVS., PUBL'N NO. 01-4013, CAREGIVER GUIDE: TIPS FOR CAREGIVERS OF PEOPLE WITH ALZHEIMER'S DISEASE 4, 5, 13, 15 (2008), http://www.nia.nih.gov/NR/rdonlyres/C2F11D41-E5FE-435D-9C9D-A3489319D4AD/11286/CaregiverGuideFINAL_08DEC.pdf.

115. *Id.* at 13–15.

116. ALZHEIMER'S ASS'N, 2009 ALZHEIMER'S DISEASE FACTS AND FIGURES 33 (2009) [hereinafter 2009 ALZHEIMER'S DISEASE FACTS AND FIGURES]. Approximately ten million Americans provide free care to people with Alzheimer's and other dementias. *Id.* Most are family members, while the remaining are friends and neighbors. *Id.* at 34.

117. *See id.* at 47–48. Paid personal care providers are covered by Medicaid and Medicare Home Health. *Id.*

118. *Id.*

119. *See generally* LIVING WITH GRIEF: ALZHEIMER'S DISEASE, *supra* note 110, at 61–64 (describing how each culture may define differently who is responsible for

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Chinese culture, caregiving by paid formal outside providers is considered a poor reflection on the family's ability to fulfill traditional responsibilities and is, therefore, frowned upon; in African-American culture, church-based semiformal networks may be looked to for assistance.[120] In a MHAD, the client can express these cultural and personal care preferences in advance while still doing well and discuss the range of possibilities and feasibility of choices with family members.

C. Out-of-Home Placements

One of the most predictable decisions that a person with Alzheimer's disease will have to face concerns a future placement outside of the family home.[121] Given the increasingly burdensome and difficult care required of people with Alzheimer's disease as they progress through the stages of the disease, it is nearly certain that all but the wealthiest, who can afford to pay privately for enough care to stay in the home, will ultimately need an out-of-home placement, most likely in a nursing home.[122] When, where, and how that out-of-home placement will occur are decisions that can be anticipated and dealt with by Alzheimer's disease clients in consultation with their family, their medical providers, and other geriatric care professionals.[123] This is

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caregiving, how those responsibilities are fulfilled, and when and if accepting formal outside help is appropriate).

120. *Id.* at 62.

121. Forstl & Kurz, *supra* note 113, at 289.

> Patients in this moderate state of illness cannot survive in the community without close supervision. They are incapable of managing financial or legal matters. Household gas or electrical appliances are a constant source of danger to the patients, but also to their carers. Hospital or nursing home admission may be delayed or even avoided, if a closely knit support system is in place. During this phase, there is a maximum strain on partners and other carers due to the patient's non-cognitive behavioral problems and somatic symptoms. Restlessness, aggression, disorientation, and incontinence are the most frequent factors that precipitate the breakdown of family support.

Id.

122. In 2008, 47% of all nursing home residents and 45–67% of assisted living residents had Alzheimer's disease or other dementia. 2009 ALZHEIMER'S DISEASE FACTS AND FIGURES, *supra* note 116, at 54. In 2007, 66.9% of people sixty-five or older who died of dementia did so in nursing homes. *Id.* at 31.

123. *See generally* Marshall B. Kapp, *A Place Like That*, 4 PSYCHOL. PUB. POL'Y & L. 805 (1998) (exploring the use of advance directives to plan for future nursing home admission).

particularly helpful for family members, in that Alzheimer's disease patients may verbally or physically reject such care at a later stage of the disease, or lack the capacity to consent to admission.[124] Knowing the patient's actual desires and care goals when the patient was well enough to decide can result in lessened stress on the family and more control of care by the patient. Advance consent in a MHAD after a reasoned and informed discussion can lead to a quicker and less stressful placement during this most painful time of moving from the home setting.[125]

There are now a variety of out-of-home placements that can be discussed and decided upon in advance. Care in assisted living facilities[126] and adult family homes[127] that specialize in dementia care[128] can be excellent options as a first step for placement. Clients with Alzheimer's disease can choose among the available options in their own community based upon preferences for care in a family home setting or a more private apartment with services attached to it. Geriatric care managers can be consulted to discuss the local options and the relative experience and competencies in working with clients with dementia.[129]

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124. *Id.* at 809–10.

125. "At best, the time of potential nursing home admission ordinarily is one of tremendous emotional and intellectual stress and turmoil." *Id.* at 815.

126. 2009 ALZHEIMER'S DISEASE FACTS AND FIGURES, *supra* note 116, at 73 ("Assisted living residences generally provide 24-hour staffing, recreational activities, meals, housekeeping, laundry and transportation to their residents, who typically need help with some but not all activities of daily living."); AGENCY FOR HEALTHCARE RESEARCH & QUALITY, U.S. DEP'T OF HEALTH & HUMAN SERVS., *Environmental Scan of Instruments to Inform Consumer Choice in Assisted Living Facilities* 16–17 (2006), http://www.canhr.org/reports2006/ltcscan.pdf.

127. An adult family home is defined as "a residential home in which a person or persons provide personal care, special care, room, and board to more than one but not more than six adults who are not related by blood or marriage to the person or persons providing the services." WASH. REV. CODE § 70.128.010(1) (2007); *see also* KAN. REV. CODE § 39-1501(a) (2008); OHIO REV. CODE ANN. § 3722.01(9) (2007).

128. *See* Philip D. Sloane et al., *Evaluating Alzheimer's Special Care Units: Reviewing the Evidence and Identifying Potential Sources of Study Bias*, 35 GERONTOLOGIST 103, 103 (1995). Alzheimer Special Care Units (SCUs) or Memory Care Units are typically group or cluster settings within various types of residential care settings that are designed to meet the specific needs of individuals with Alzheimer's disease and other dementias. *Id.*

129. A Professional Geriatric Care Manager (PGCM) is a health and human services specialist who helps families care for older relatives, while encouraging as much independence as possible. The PGCM may be trained in any of a number of fields related to long-term care, including, but not limited to, nursing, gerontology, social work, or psychology, with a specialized focus on issues related to aging and

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In addition, decisions can be made in advance about if and when the person with Alzheimer's disease would agree to move away from his or her local hometown and closer to family who live far away. With the mobility of today's society, it is frequently the case that future family caregivers live hundreds, if not thousands, of miles away; at some point moving parents with Alzheimer's disease closer to, or even with, adult children is a real option that could be considered in advance.[130]

Each of these less-than-nursing-home institutional options will likely become unsustainable at some point in the course of the disease because the care needed in the final stages of Alzheimer's disease is beyond that provided in most assisted living and adult family home facilities.[131] The point where a resident becomes incontinent or needs substantial supervision is often the first step toward an eviction from most assisted living or adult family homes.[132] Clients who wander or become combative are also at risk of losing their adult family home or assisted living placements.[133] Until staff in these lower levels of care receive the specialized training and expertise in working with Alzheimer's disease residents, families will continue to be faced with loved ones being evicted from, or denied placement in, these residential settings. Without prior planning, families can find themselves in an emergency situation, faced with their relatives with Alzheimer's

elder care. The PGCM acts as a guide and advocate—identifying problems and offering solutions, from assessment of an aging parent's needs to addressing the life change of a family affected by Alzheimer's disease, Parkinson's, or other symptoms of dementia. Nat'l Ass'n of Prof'l Geriatric Care Managers, What Is a Professional Geriatric Care Manager?, http://www.caremanager.org/displaycommon.cfm?an=1&subarticlenbr=76 (last visited Nov. 10, 2009).

130. *See* Alzheimer's Ass'n, Long-Distance Caregiving, http://www.alz.org/living_with_alzheimers_long_distance_caregiving.asp (last visited Nov. 10, 2009).

131. *See generally* Eric M. Carlson, *Disability Discrimination in Long-Term Care: Using the Fair Housing Act to Prevent Illegal Screening in Admissions to Nursing Homes and Assisted Living Facilities*, 21 NOTRE DAME J.L. ETHICS & PUB. POL'Y 363, 369 (2007) ("An inability to provide certain types of care is much more likely in assisted living. Assisted living facilities generally are not required to provide nursing care on-site, and most facilities choose not to do so. Under state assisted living law, facilities have a great deal of discretion in deciding the extent of the health care provided, and in evicting residents when a resident needs care that the facility does not wish to provide.").

132. *Id.* at 370.

133. *Id.*

disease being evicted from their homes with no place to go and no alternative plan of action.[134]

Because nursing home placement is currently the likely end option, advance plans and agreements regarding that ultimate decision can go a long way towards relieving the family's stress over making that difficult decision on their own.[135] Alzheimer's disease clients can express their desires regarding remaining at home until certain symptoms or needs occur either that they would not want done by family members (e.g., incontinence care) or that simply could not be done (e.g., transfers of a spouse who is now immobilized or resisting transfer by a smaller or less healthy partner). They can choose which facility they would most prefer if and when the need for nursing home placement should arise. Research can be done on which nursing homes provide the best and most advanced dementia care in the local community, and a preference can be stated for that placement if available.[136]

These in- and out-of-home placement decisions can best be made in consultation with a professional case manager who is familiar with the various placement options in the patient's community. Geriatric care managers[137] know what different levels of care are available in the community, and they understand the potential level of need at each stage of the disease. They can help in advising about placements that would best work for the client in the near and more distant future, given the particular values and preferences of the client. Further, geriatric care managers can be tasked by the patient in a MHAD with doing assessments along the course of his or her disease to help decide when an outside placement is necessary as well as what facility would meet the patient's particular needs. This advance permission would take the pressure and guilt off of the family for making a nursing home placement or for bringing in nonfamily care providers.

134. *See, e.g.*, Warren Wolfe, *Troubled Minds Find a Home*, STAR TRIB. (Minneapolis, Minn.) May 14, 2008. Combative or aggressive AD residents of nursing homes can suffer the same fate of eviction and emergency transfer to a hospital or commitment to a psychiatric facility. *See infra* Part D.

135. Kapp, *supra* note 123, at 816.

136. *See, e.g.*, Wolfe, *supra* note 134 (describing Summit House, an assisted living facility that specializes in care of combative residents).

137. *See supra* note 129 and accompanying text.

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D. Response to Combative or Aggressive Behaviors

Possibly the most difficult effect of Alzheimer's disease on some people with the illness is the appearance of new and unexpected behaviors. Between thirty and fifty percent of Alzheimer's disease clients become combative, assaultive, or sexually aggressive during the course of their illness.[138] This awful change in behavior can come as a surprise to family and caregivers, who have never before seen their loved one behave in this way. It also can be dangerous for both the caregiver and the client.[139]

Most combativeness and aggressive behavior by patients with Alzheimer's disease can be dealt with and minimized by good care rather than by restraints or other restrictive interventions.[140] Caregivers who are appropriately trained and who know the person's history and needs can reduce the frustration experienced by the patient and, thus, reduce or eliminate the difficult behaviors. People could state in their MHADs a preference for trained caregivers who know them and their history, are trained to recognize when and why frustration is building, and who know how to handle this situation.[141]

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138. Dag Aarsland et al., *Relationship of Aggressive Behaviour to Other Neuropsychiatric Symptoms in Patients with Alzheimer's Disease*, 153 AM. J. PSYCHIATRY 243, 244–45 (1996). Approximately 88,000 nursing home residents exhibited aggressive behavior just prior to assessment. Linda Williams, *When Residents Attack Residents*, NURSING HOMES LONG-TERM CARE MGMT., Aug. 2004, at 64, 64.

139. *See, e.g.*, Creasy v. Rusk, 730 N.E.2d 659 (Ind. 2000) (involving a nursing home resident with Alzheimer's disease who kicked a caregiver; the court rejected the caregiver's suit against the resident for damages from resulting injuries); Williams, *supra* note 138, at 64–65 (discussing liability of nursing home for injuries inflicted by patient with Alzheimer's disease).

140. *See, e.g.*, Philip D. Sloane et al., *Effect of Person-Centered Showering and the Towel Bath on Bathing-Associated Aggression, Agitation, and Discomfort in Nursing Home Residents with Dementia: A Randomized, Controlled Trial*, 52 J. AM. GERIATRICS SOCIETY 1795, 1800 (2004) (describing how person-centered showering constitutes a safe and effective method of reducing agitation, aggression, and discomfort during bathing); Christine Arenson, Concetta Forchetti & Eric G. Tangalos, *Update on Managing Problem Behaviors in Alzheimer's Disease*, PATIENT CARE, Dec. 2004, at 40, 40 (explaining how a combination of environmental and drug therapy is an effective strategy for patients exhibiting aggression).

141. In a 2008 interview I did with David Robinson, a social worker and expert in helping families plan for Alzheimer's disease care, I asked him where he would prefer to receive care if he had Alzheimer's disease. He stated that he would prefer care in a small adult family home with appropriately trained personnel where there is less turnover (a family run home), fewer shifts, and where the caregivers know and care about the residents. He contrasts that scenario with the "Alzheimer's unit," which is often large, has three shifts and revolving door employees who do not know the residents. They, therefore, miss problems, which leads to resident frustrations and combativeness. He believes that Alzheimer's units and

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The complexity of this situation is multiplied when the person with Alzheimer's disease is a large man being cared for by a smaller spouse, relative, or paid caregiver, or when the person with Alzheimer's disease is physically fit, ambulatory, and young. If this person should become combative or sexually aggressive, the result could be an emergency situation involving law enforcement and emergency medical care.[142] Sometimes, people with Alzheimer's disease who are resistant or combative end up being committed to psychiatric hospitals on an emergency basis, which is viewed as the only available way to take control over the client and minimize the danger posed to the patient and caregivers.[143] The call for civil commitment can be made from the patient's home by a scared spouse or from the nursing home seeking to have violent or difficult residents removed.[144] This emer-

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nursing homes are frequently badly understaffed, leading to stressed out caregivers who cannot take the time to deal with problems. As a result, David would go to a small family home for care over these Alzheimer's units. David stated that the most important predictor of good care for a person with Alzheimer's disease is the relationship with the caregiver. Interview with David Robinson, Owner/Geriatric Care Manager, Eldercare Res. of Olympia, in Olympia, Wash. (July 21, 2008).

142. Kerry Hannon, *The Trouble with Alzheimer's Care: One Family's Story*, U.S. NEWS & WORLD REPORT, Mar. 11, 2009, http://health.usnews.com/articles/health/best-nursing-homes/2009/03/11/the-trouble-with-alzheimers-care-one-familys-story.html.

> Generally, nursing homes are required by the federal Nursing Home Reform Law to give 30 days' written notice before they evict someone, giving the reason for the eviction along with the facts of the case. . . . Some nursing homes try to evade the 30-day notice requirement and possible appeal process by transferring the resident to a hospital or psychiatric unit, then refusing to take him back, says Eric Carlson, an attorney with the National Senior Citizens Law Center in Los Angeles. "Hard-to-manage nursing home residents with Alzheimer's and other dementia are often committed involuntarily from nursing home facilities to psychiatric units," Carlson says.

Id.; *see also* Austin Fenner et al., *Alzheimer's Slay Horror*, DAILY NEWS (New York), Sept. 8, 2004, at 6; Wolfe, *supra* note 136 (describing eviction from assisted living and nursing homes of a combative resident with Alzheimer's disease via civil commitment four times during one year).

143. *See* Arlene S. Kanter, *Abandoned But Not Forgotten: The Illegal Confinement of Elderly People in State Psychiatric Institutions*, 19 N.Y.U. REV. L. & SOC. CHANGE 273, 280 (1991) ("Alzheimer's Disease is not only the most common disease affecting the mental state of older people, it is the most common justification for the initial civil commitment of older people who had never previously suffered from a mental disorder."); Gary Moak & William H. Fisher, *Geriatric Patients and Services in State Hospitals: Data from a National Survey*, 42 HOSP. & COMM. PSYCHIATRY 273 (1991).

144. Kanter, *supra* note 143, at 281; *see also* Jennifer L. Wright, *Protecting Who from What, and Why, and How?: A Proposal for an Integrative Approach to Adult Protective Proceedings*, 12 ELDER. L.J. 53, 69 (2004) ("[T]he elder may already be receiving

gency measure is extremely upsetting and distressing for the patient and the family.[145] For the first time in their lives, they are placed in one of the most out-of-control situations one can be in—medical professionals, law enforcement, and courts taking all rights away and confining a spouse or loved one to treatment in a psychiatric hospital.

The ability to plan in advance to avoid the use of sudden and involuntary commitment to receive care is one of the great advantages of a MHAD for people with up and down mental illnesses, and it has real potential for use for people with Alzheimer's disease.[146] As knowledge about Alzheimer's disease has increased, there continue to be improved models of care that work well for people exhibiting combative or aggressive behaviors.[147] However, a small percentage of Alzheimer's disease clients do become "predatorily aggressive," that is, they will, without provocation or reasoning, and despite good care protocols, hit or attack other patients or providers.[148] Alzheimer's disease clients can be advised of this unlikely possibility and decide in advance if they would like to plan for this if it does happen. For example, a person diagnosed early with Alzheimer's disease could be educated about the possibility of future combative or aggressive behavior and the types of care and treatment that tend to work best in that situation.

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care and may have become 'difficult,' meaning anything from less amenable to following the rules of the care facility to actively assaultive. Civil commitment may be used as a way to evict a difficult-to-care-for resident from a care facility.").

145. *See* Hannon, *supra* note 142. Nursing home residents with Alzheimer's and other dementia are often committed involuntarily from nursing home facilities to psychiatric units. A family described the commitment process as "frantic and powerless." *Id.*

146. Debra S. Srebnik & Joan Russo, *Consistency of Psychiatric Crisis Care with Advance Directive Instructions*, 68 PSYCHIATRIC SERVS. 1157, 1160–62 (2007) (describing how, overall, crisis care was largely consistent with directive instructions). *See generally* Jeffrey W. Swanson et al., *Psychiatric Advance Directives: An Alternative to Coercive Treatment?*, 63 PSYCHIATRY 160 (2000) (exploring the benefits of advance directives for psychiatric patients).

147. *See* sources cited *supra* note 140.

148. *See, e.g.*, Fenner et al., *supra* note 142, at 6 (describing the murder of a spouse by her husband with Alzheimer's disease); Denise Grady, *Alzheimer's Steals More Than Memory*, N.Y. TIMES, Nov. 2, 2004, at F1 (describing changes in a spouse caused by Alzheimer's disease: "The man she had always known to be kind and gentle could in an instant turn 'cunning, nasty, aggressive, menacing,' she said. 'The behavioral changes I've seen are absolutely frightening,' she said. 'I understand now why so many families institutionalize someone, because I was afraid of him.'"); Wolfe, *supra* note 134 (describing eviction from assisted living and nursing homes of a combative resident with Alzheimer's disease).

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Some psychiatric hospitals specialize in the treatment and stabilization of Alzheimer's patients who are in an acute phase and who are combative or sexually aggressive by using medications and behavior techniques to calm and reduce resistance to care.[149] The MHAD could describe the circumstances under which a person would consent to *voluntary* hospitalization and state a preference for the type of specialized hospital and treatment he or she would prefer, thus avoiding the pain and danger of an involuntary commitment in an emergency situation.[150]

Further, clients could agree to bind themselves to hospitalization and treatment decisions even if they are objecting at the time by using a Ulysses Clause.[151] The Ulysses Clause prospectively binds clients to treatment decisions made in the MHAD, like consent to voluntary hospitalization and the use of calming medications and techniques, anticipating that the illness will impair the ability to make reasonable decisions at the time they need them.[152] If clients verbally refuse to be hospitalized at the time of need,[153] the MHAD binds them to that earlier decision, and it should be implemented.[154] With this advance consent in a MHAD to voluntary hospitalization and stabilization and calming treatment, there is an increased likelihood that a combative person will receive specialized quality treatment. Treatment in the psychiatric or Alzheimer's unit of the hospital should be quicker and more targeted to the particular needs of the patient as written in the MHAD, rather than the more generalized treatment afforded to invo-

149. *See, e.g.*, McLean Hospital, Geriatric: Geriatric Neuropsychiatry Unit, http://www.mclean.harvard.edu/patient/geriatrics/gnu.php (last visited Nov. 10, 2009); Minnesota Help, Glossary, http://minnesotahelp.info/Public/taxonomy_glossary.aspx?code=RM-330.660-25 (last visited Nov. 10, 2009) (describing Alzheimer's disease treatment programs that specialize in treating acute phases of Alzheimer's disease characterized by combative or aggressive behaviors).

150. *See* Srebnik & Russo, *supra* note 146, at 1157.

151. *See* Spellecy, *supra* note 52, at 375.

152. *See, e.g.*, Sheetz, *supra* note 95, at 401–03.

153. If a person who has signed a MHAD with a Ulysses Clause refuses hospitalization, and physical force would be needed to make the person go to the hospital, then the Involuntary Commitment procedure would have to be used to hospitalize him or her. *See, e.g.*, WASH. REV. CODE ANN. §§ 71.32.130–.140 (2003).

154. Nick Anderson, *Dr. Jekyll's Waiver of Mr. Hyde's Right to Refuse Medical Treatment: Washington's New Law Authorizing Mental Health Care Advance Directives Needs Additional Protections*, 78 WASH. L. REV. 795, 800 (2003); Spellecy, *supra* note 52, at 374–75; *see, e.g.*, WASH. REV. CODE ANN. §§ 71.32.010–.901 (2003) (giving clients the right to choose voluntary hospitalization in advance and to bind themselves to that decision if refusing treatment at the time, with safeguards built in).

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luntarily committed patients whose values and preferences are virtually unknown to medical staff.[155] Once stabilized in this way, the person with Alzheimer's has a greater chance of returning home (whether to the family home or to a nursing home setting) than a resident admitted on an emergency basis after a combative incident.[156] These particular benefits of MHAD planning—choosing in advance specialized treatment and consenting to voluntary hospitalization—make its use for Alzheimer's clients especially effective and a real option for consideration.

E. Planning for Financing Long-Term Care

The financial burdens imposed upon people with Alzheimer's disease and their families can be overwhelming.[157] The costs of providing a paid caregiver for supervision, housekeeping, cooking, shopping, and assistance with activities of daily living while still living at home are high.[158] Moreover, those costs are exponentially greater when nursing home care is required. Basic nursing home care costs in the range of $6,000 to $10,000 per month, depending on the location of the home and needs of the patient.[159] As a result, even relatively well-off patients may find it impossible to meet their care needs in the later stages of Alzheimer's disease without depleting their assets and savings, putting the remaining healthy family members and dependents at risk of impoverishment.[160] Clients who hope to leave their home

155. *See* Spellecy, *supra* note 52, at 375.

156. *See, e.g.*, Hannon, *supra* note 142 (a nursing home resident with Alzheimer's is unlikely to be readmitted post-commitment to psychiatric units).

157. ALZHEIMER'S ASS'N, MEDICARE AND MEDICAID COSTS, *supra* note 30, at I. "The United States enters the 21st century facing an imminent epidemic: by the middle of the century, up to 14 million of today's baby boomers will have Alzheimer's disease. For most of them, the process that will destroy their memories, their lives, and their savings has already begun." *Id.* at IV.

158. *See* CTRS. FOR MEDICARE & MEDICAID SERVS, U.S. DEP'T OF HEALTH & HUMAN SERVS., OWN YOUR FUTURE: PLANNING GUIDE FOR LONG-TERM CARE, PUBL'N NO. CMS-11026 1 (2002). "People who receive long-term care services at home spend an average of $1,600 a month." *Id.* The average cost in 2008 in the United States is $29 per hour for a home health aide and $18 per hour for homemaker services. U.S. Dep't of Health & Human Servs., Costs of Care, http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Costs_Of_Care/Costs_Of_Care.aspx#What (last visited Nov. 10, 2009) [hereinafter Costs of Care].

159. Costs of Care, *supra* note 158.

160. Alzheimer's Ass'n, New Report Says Alzheimer's Disease and Dementia Triple Healthcare Costs for Americans Age 65 and Older (Mar. 24, 2009), http://www.alz.org/news_and_events_2009_facts_figures.asp.

and savings to children, family, and friends after they die may find this dream quashed. This financial burden adds significant stress and worry to an already difficult diagnosis. Given that a substantial percentage of Alzheimer's disease patients will ultimately need this expensive care in either their home or nursing facility, it is critical that advance planning on how to finance care be considered, discussed, and ultimately executed.[161] A MHAD could provide an ideal forum for discussing and setting out a client's goals and values with respect to care options, paying for that care, and providing for family.

There are three major ways in which the high cost of long-term care is financed in this country: private pay with current savings and income,[162] long-term care insurance coverage,[163] or Medicaid.[164] Fre-

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> Total healthcare costs are more than three times higher for people with Alzheimer's and other dementias than for other people age 65 and older. . . . People with Alzheimer's are high consumers of hospital, nursing home and other health and long-term care services, which translates into high costs for Medicare, Medicaid and millions of families. As families struggle to survive in a deepening recession and as states grapple with budget shortfalls, Alzheimer's disease threatens to overwhelm them both. . . . With family members providing care at home for about 70 percent of people with Alzheimer's disease, the ripple effects of the disease can be felt throughout the entire family. . . . [I]n 2008, nearly 10 million Alzheimer caregivers in the U.S. provided 8.5 billion hours of unpaid care valued at $94 billion. In addition to the unpaid care families contribute, the report also reveals that Alzheimer's creates high out-of-pocket health and long-term care expenses for families.

Id.

161. *See* ALZHEIMER'S ASS'N, MEDICARE AND MEDICAID COSTS, *supra* note 30, at IV.

162. Out-of-pocket payments for long-term custodial nursing home care account for 28% of total expenditures paid. Kaiser Comm'n on Medicaid Facts, Medicaid and Long-Term Care (2005), http://www.kff.org/medicaid/upload/Medicaid-and-Long-Term-Care-2005-Fact-Sheet.pdf.

163. In 2002, long-term care insurance paid for 10% of nursing home and home care expenditures, compared to less than 1% in 1999. LAWRENCE A. FROLIK & ALISON MCCHRYSTAL BARNES, ELDER LAW: CASES AND MATERIALS 285 (4th ed. 2007).

164. The 2004 National Nursing Home Survey showed that of all of the approximately 1.5 million nursing home residents at the time of interview, 255,000 paid privately, 118,000 had Medicare coverage, and 875,000 had Medicaid coverage. Nat'l Ctr. for Health Statistics, National Nursing Home Survey 2004 tbl.8 (2008), http://www.cdc.gov/nchs/data/nnhsd/Estimates/nnhs/Estimates_PaymentSource_Tables.pdf#Table08. Therefore Medicaid is the primary form of coverage for nursing home care, at almost 60%. Medicaid is the largest payor of long-term care in the United States. In 2003, Medicaid expenditures accounted for 40% of all long-term care expenditures and 46% of nursing home expenditures. Kaiser Comm'n, *supra* note 162, at 1. "Approximately half of all nursing home residents have Alzheimer's disease. In addition, people with Alzheimer's disease

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quently, some combination of all three of these financing methods is used during the course of the disease.[165] Once any long-term care insurance is depleted, then savings and Medicaid cover the cost of care.[166]

Only a small percentage of people with Alzheimer's disease carry long-term care insurance.[167] Even if they have this coverage, there are often waiting periods and coverage time limits that fall short of the lengthy stays required by people with Alzheimer's disease.[168] Many clients mistakenly believe that Medicare will be available to cover their long-term custodial nursing home costs should they need that

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tend to have lengthy stays in nursing homes, and are likely to spend down their assets and become Medicaid eligible." ALZHEIMER'S ASS'N, MEDICARE AND MEDICAID COSTS, *supra* note 30, at IV.

165. *See* Kenneth M. Langa et al., *Out-of-Pocket Health Care Expenditures Among Older Americans with Dementia*, 18 ALZHEIMER DISEASE & ASSOCIATED DISORDERS 90, 91 (2004).

166. Older people with dementia are more likely to require long-term care services, and because private and public insurance coverage for long-term care services is more limited than coverage for physician and hospital services, the expected out-of-pocket expenditures for long-term care services for people with dementia are high, with many individuals spending through their private assets and insurance coverage to become eligible for Medicaid. *Id.* at 91.

167. Less than 10% of all Americans have long-term care insurance. Janemarie Mulvey, *The Importance of LTC Insurance for the Retirement Security of the Baby Boomers*, 21 BENEFITS Q. 48, 48 (2005). Presently, long-term care insurance payments account for as little as 1% of all long-term care expenditures. *See* Richard L. Kaplan, *Financing Long-Term Care in the United States: Who Should Pay for Mom and Dad?, reprinted in* AGING: CARING FOR OUR ELDERS 65, 73 (David N. Weisstub et al. eds., 2001).

168. Typically, long-term care consumers select a daily benefit amount (e.g., $150 per day) and a maximum lifetime benefit (e.g., $150,000). Once the maximum lifetime benefit amount is paid out, the coverage ceases. *See* AM. HEALTH INS. PLANS, GUIDE TO LONG-TERM CARE INSURANCE 5 (2004), http://www.ahip.org/content/default.aspx?bc=41|329|450; U.S. DEP'T OF HEALTH & HUMAN SERVS., NATIONAL CLEARINGHOUSE OF LONG-TERM CARE INFORMATION, LONG-TERM CARE INSURANCE?, http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Private_Programs/LTC_Insurance/index.aspx.

Thus, a policy with a maximum benefit amount of $150,000, with a daily benefit of $150 would last for approximately 1000 days or about three years. However, because persons with Alzheimer's may require long-term care services and assistance sooner and may require more specialized care and care for several years, both the daily benefit amount and the maximum lifetime benefit amount of the typical, more affordable policies may be inadequate for individuals with Alzheimer's. In 2004, the average Medicare costs of skilled nursing facility care for beneficiaries with Alzheimer's or other dementias was nine times that of nursing home care for beneficiaries without Alzheimer's or other dementias ($3,030 versus $333 per person); home health care costs for beneficiaries with Alzheimer's is more than four times that for beneficiaries without Alzheimer's or other dementias ($1,256 versus $282 per person). 2009 ALZHEIMER'S DISEASE FACTS AND FIGURES, *supra* note 116, at 51.

care in the future.[169] However, the Medicare nursing home coverage benefit is very limited, and coverage for custodial care is completely excluded.[170] Although Medicare does cover skilled nursing facility care, it only fully covers that cost for twenty days, and even then after a three-day prior hospitalization.[171] Neither Medicare nor Medigap insurance[172] pay for any nursing home care past one hundred days.[173] The average length of stay in a nursing home for people with Alzheimer's disease is 944 days, or almost three years.[174] These patients almost always need custodial care rather than skilled care.[175] It is these Medicare coverage gaps and the lack of long-term care insurance coverage that frequently make Medicaid the only choice for clients who need nursing home or in-home care for long periods of time. As a re-

169. A survey sponsored by the AARP and conducted by Gfk NOP Roper Public Affairs & Media found that 59% of people believe that Medicare would cover a long-term stay in a nursing home. Kaisernetwork.org, Long-Term Care of Home Health Care and Medicare, http://www.ropercenter.uconn.edu/cgi-bin/hsrun.exe/roperweb/HPOLL/HPOLL.htx;start=hpollsearchAM?sid=H4 (last visited Nov. 10, 2009).

170. The client must need "skilled" care or rehabilitative care on a daily basis in the nursing home. U.S. Dep't of Health & Human Servs., Paying for Nursing Home Care, http://www.medicare.gov/nursing/Payment.asp (last visited Nov. 10, 2009). Generally, skilled care means care provided to the patient by a licensed nurse seven days per week or physical therapy five days per week. 42 C.F.R. §§ 409.41(b)(1), 409.34(a)(1)–(2) (2005).

171. Medicare will pay up to 100 days of nursing home care. 42 U.S.C. 1395d(a)(2). The first twenty days of care are paid in full, with no client co-payment or deductible. After that, if the client is still receiving "skilled" care, he or she must pay a large co-payment of $133.50 per day for year 2009 for days 21 through 100, while Medicare covers the remaining cost. U.S. Dep't of Health & Human Servs., Medicare Premiums and Coinsurance Rates for 2009, http://questions.medicare.gov/cgi-bin/medicare.cfg/php/enduser/std_adp.php?p_faqid=2100 (last visited Nov. 10, 2009).

172. Medigap insurance is one of twelve different standardized private insurance policies that supplement Medicare Parts A and B coverage by paying for some of the health care costs not covered by Medicare. U.S. Dep't of Health & Human Servs., Medigap (Supplemental Insurance) Policies, http://www.medicare.gov/medigap/default.asp (last visited Nov. 10, 2009).

173. CTRS. FOR MEDICARE & MEDICAID SERVS., CHOOSING A MEDIGAP POLICY: A GUIDE TO HEALTH INSURANCE FOR PEOPLE WITH MEDICARE 11–12 (2009), http://www.medicare.gov/Publications/Pubs/pdf/02110.pdf.

174. CTRS. FOR DISEASE CONTROL & PREVENTIONS, NURSING HOME CURRENT RESIDENTS tbl.38 (2008), http://www.cdc.gov/nchs/data/nnhsd/Estimates/nnhs/Estimates_Diagnoses_Tables.pdf#Table38.

175. *See* Alzheimer's Ass'n, Choosing a Care Facility, http://www.alz.org/nyc/in_my_community_17490.asp (last visited Nov. 10, 2009).

sult, Medicaid covers about two-thirds of nursing home residents in the United States.[176]

In order to meet the care needs of people who require long-term custodial care but cannot afford the $6,000 to $10,000 monthly cost without depleting all of their income and savings, Congress allowed for a number of tools to permit people needing such care to preserve income and assets while qualifying for Medicaid coverage of this service.[177] In particular, under the Medicare Catastrophic Coverage Act and Medicaid Spousal Anti-impoverishment Amendments to the Social Security Act, Congress sought to protect spouses and dependent children from poverty when one spouse needs long-term care.[178] Congress did this by allowing Medicaid applicants to own a number of "exempt" assets,[179] preserving some income for maintaining the home for the noninstitutionalized family members,[180] allowing some nonpenalized gifting of assets into trusts[181] and annuities[182] to benefit the

176. Jean Accius, Myths About the Medicaid Program and the People It Helps, Nov. 2009, http://www.aarp.org/research/ppi/health-care/medicaid/articles/fs146_myths.html. "Medicaid spending on nursing facility services for those with Alzheimer's Disease is approximately 46 percent of total nursing facility spending. Medicaid nursing facility spending for those with Alzheimer's is projected to increase to $33.0 billion, an increase of 81.3 percent, in 2010." ALZHEIMER'S ASS'N, MEDICARE AND MEDICAID COSTS, *supra* note 30, at 5.

177. *See, e.g.*, 42 U.S.C. § 1396r-5 (2006). The spousal anti-impoverishment provisions of the Medicare Catastrophic Coverage Act of 1988 provide protections so that the noninstitutionalized spouse's resources and income need not be depleted by the nursing home care expenses of the ill spouse. Medicare Catastrophic Coverage Act of 1988, Pub. L. No. 100-360, 102 Stat. 683.

178. § 1396r-5; *see also* L. RUSH HUNT ET AL., UNDERSTANDING ELDER LAW: ISSUES IN ESTATE PLANNING, MEDICAID, AND LONG-TERM CARE BENEFITS 186–87 (2002).

179. *See, e.g.*, 42 U.S.C. § 1382b (allowing for the exemption of certain resources including a home, car, qualifying irrevocable trusts, limited burial expenses, and life insurance policies); *see also* 42 U.S.C. § 1396p (qualifying irrevocable trusts); 20 C.F.R. § 416.1210 (2009) (general exemption provisions); 20 C.F.R. § 416.1212 (home); 20 C.F.R. § 416.1218 (car); 20 C.F.R. § 416.1230 (life insurance up to face value of $1,500); 20 C.F.R. § 416.1231 (burial plot and expenses).

180. 42 U.S.C. § 1396r-5(d)(1). Under the Medicare Catastrophic Coverage Act of 1988, states are required to set a minimum income level, which can be retained by the community spouse. This income, referred to as the monthly maintenance needs allowance, can be set by the state at an amount between $1,821.25 and $2,739 for 2009. CTRS. FOR MEDICARE & MEDICAID SERVS., 2009 SSI AND SPOUSAL IMPOVERISHMENT STANDARDS, http://www.cms.hhs.gov/MedicaidEligibility/downloads/1998-2009SSIFBR052209.pdf (last visited Nov. 10, 2009).

181. A Qualified Income Trust (QIT), or "Miller Trust," may be established if the Medicaid applicant's or recipient's income exceeds the monthly income limit ($2,022 in 2009). A QIT allows individuals with disqualifying income to accumulate that income in a trust. To be a Qualified Income Trust, the trust must be irre-

noninstitutionalized spouse, and providing for ways to avoid a Medicaid lien against remaining property at the death of the institutionalized spouse.[183] Elder law attorneys have become experts at helping clients maximize their asset and income preservation by engaging in "Medicaid planning."[184] Often, with the help of an experienced and knowledgeable attorney, couples where one member has Alzheimer's disease, and some single people with the disease as well, can plan in advance to preserve some amount of income and assets for themselves, their spouse or partner, their minor or disabled children, and their heirs.[185]

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vocable and contain income (no resources) only; trust funds must be kept in an account separate from other funds, and assets of the trust up to the amount paid by Medicaid for the person's care must be payable to the state upon the individual's death. 42 U.S.C. § 1396p(d)(4)(b) (2008).

182. A spousal sole benefit annuity may be purchased in the amount that is the difference between the total nonexempt resources and the community spouse resource allowance. An annuity will not be counted as an available resource or as a disqualifying transfer if it is irrevocable, immediate, paid out in equal monthly installments, will be paid out within the actuarial lifetime of the annuitant, and names the state as a remainder beneficiary to the extent of benefits paid. Deficit Reduction Act, Pub. L. 109-171, §§ 6012(a)–(b) (2005); 42 U.S.C. § 1396p(d)(1)(6) (2007); *see, e.g.*, 130 MASS. CODE REGS. 520.007(C)(4) (2008); WASH. ADMIN. CODE § 388-561-0200(4) (2009).

183. A Medicaid lien allows the state to recover all expenses paid for Medicaid benefits, and the lien attaches to the estate of the Medicaid recipient at his or her death. A Medicaid lien only applies to property owned by the Medicaid recipient at death—not the estate of the surviving spouse. A Medicaid lien cannot be recovered during the lifetime of the recipient or surviving spouse or while there is a surviving child under twenty-one years old or who is blind or disabled. 42 U.S.C. § 1396p(a) (1994).

184. *See, e.g.*, Alison Barnes, *An Assessment of Medicaid Planning*, 3 HOUS. J. HEALTH L. & POL'Y 265, 267 (2003) ("The process of 'Medicaid planning,' or arranging assets and income for an individual or couple in order to achieve earlier Medicaid eligibility for nursing home benefits and protect assets for other uses than nursing home payments, is an important legal service that is identified with the broader field of elder law."); John A. Miller, *Voluntary Impoverishment to Obtain Government Benefits*, 13 CORNELL J. L. & PUB. POL'Y 81, 91–92 (2003); Ellen O'Brien, *What Is Wrong with the Long-Term Care Reforms in the Deficit Reduction Act of 2005?*, 9 MARQ. ELDER'S ADVISOR 103, 110–11 (2007) (explaining that despite the availability of Medicaid planning, many who could benefit from such tools and strategies fail to employ them); John M. Broderick, Note, *To Transfer or Not to Transfer: Congress Failed to Stiffen Penalties for Medicaid Estate Planning, but Should the Practice Continue?*, 6 ELDER L.J. 257, 286 (1998) (providing a critique of Medicaid planning).

185. *See generally* Barnes, *supra* note 184 (discussing the evolution and techniques of Medicaid planning); Timothy L. Takacs & David L. McGuffey, *Medicaid Planning: Can It Be Justified?: Legal and Ethical Implications of Medicaid Planning*, 29 WM. MITCHELL L. REV. 111, 131–32 (2002) ("[E]ffective Medicaid planning can result in the creation of a pool of protected assets that a family member uses to pay for goods and services that Medicaid does not pay for, such as dental care or sit-

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Some Alzheimer's patients faced with the high cost of long-term care may opt to use this Medicaid-planning method to preserve assets for a spouse or significant other, or to pass on their property after death;[186] others may choose to use all savings and income on purchasing the highest quality of private care, and only to apply for Medicaid if and when their money is spent, believing that Medicaid planning is unethical[187] or not wanting to divest themselves of life savings.[188] Given the array of potential choices about how to finance long-term care, clients could state their preferences and values in advance in a MHAD. For example, a client could state a preference to "maximize the use of all of my savings, assets, and income to buy the best private in-home care first, and only use Medicaid when and if my assets are depleted, even if this means selling my home to pay for my care." For a client who wants to preserve assets, the MHAD could state, "My hope is that my care costs will not consume the lifetime of saving we have done to be able to pass on a legacy to our children. I further want my spouse to maintain the standard of living we have now as much as possible. Please pursue any possible planning options, including Medicaid planning, available to preserve our income and assets for this purpose."

Even with the various Medicaid planning options available, the potential for heart-breaking situations remains. For some married couples, the best plan to preserve assets and income for family members is a "Medicaid divorce."[189] When a couple divorces, the income

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ters, thereby improving the Medicaid recipient's health and enhancing his quality of life.").

186. *See* Takacs & McGuffey, *supra* note 185, at 140–46; Eldon L. Wegner & Sarah C. W. Yuan, *Legal Welfare Fraud Among Middle-Class Families: Manipulating the Medicaid Program for Long-Term Care*, 47 AM. BEHAV. SCIENTIST 1406, 1410–11 (2004) (contending that upper-middle class persons who employ the services of financial planners and estate lawyers are those most likely to utilize and benefit from Medicaid planning).

187. Diana Conway, *Cheating Uncle Sam for Mom and Dad*, NEWSWEEK, Jan. 27, 2003, at 14; Knight Kiplinger, *"Medicaid Planning" Is the Wrong Call*, WASH. POST, Mar. 22, 2009, at G03.

188. *See* Takacs & McGuffey, *supra* note 185, at 122. Medicaid planning requires transferring assets to others during one's life.

189. *See* Miller, *supra* note 184, at 96 (explaining that the strategy of a Medicaid divorce is to have the decree disproportionately divide the property in the community spouse's favor; as the property passes by decree, rather than by gift, neither the Medicaid look-back period nor a Medicaid lien should apply); Michael Farley, Note, *When I Do Becomes I Don't: Eliminating the Divorce Loophole to Medicaid Eligibility*, 9 ELDER L.J. 27, 28 (2001); *see also* L.M. v. State of N.J., Div. of Med. As-

and assets in the name of the noninstitutionalized spouse can no longer be counted in determining Medicaid eligibility.[190] By putting all or most of the property, savings, and income into the name of the healthy spouse in the divorce decree, the couple can preserve their lifetime of savings and monthly income for the healthy spouse and family while providing for Medicaid coverage for long-term care for the spouse with Alzheimer's disease.[191]

A decision to get a Medicaid divorce is rife with moral, religious, and ethical issues.[192] When one spouse has to make that decision unilaterally, without the input or consent of the partner, then layers of guilt, and even depression, are added to the mix. Consider this story of a married couple, Gene and Debra Muren, reported in the *Seattle Times* in 2004. Debra was diagnosed with early onset Alzheimer's disease in 1999 at the age of forty-seven, thirty years into her relationship with Gene. Just two years later, Debra's needs became so great that her doctors recommended nursing home care. Gene consulted several different attorneys, receiving the same advice:

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sistance & Health Servs., 659 A.2d 450, 500 (N.J. 1995) ("[G]overnment is equally concerned about federal and state Medicaid policies that are so restrictive that they encourage married couples, like L.M. and his wife, to seek judicial authorization to sever the bonds of a fifty-three-year-old marriage that they would otherwise preserve at all costs . . . . We assume that . . . modifications of the Medicaid eligibility requirements will make it unnecessary for families in the future to resort to the extreme steps taken by L.M. and his spouse to become Medicaid-eligible.").

190. "If a court has entered an order against an institutionalized spouse for the support of the community spouse, section 1396p of this title [Medicaid lien] shall not apply to amounts of resources transferred pursuant to such order for the support of the spouse or a family member (as defined in subsection (d)(1))." 42 U.S.C. 1396r-5(f)(3) (2008). 42 U.S.C. 1396r-5(h)(2) (2008) says that "[t]he term 'community spouse' means the spouse of an institutionalized spouse," not the former spouse.

191. *See* 42 U.S.C. § 1396r-(5)(f)(3); *id.* § 1396r-5(h)(2); Michael Wytychak III, *Payment of Nursing Home Bills Through the Medicaid Program*, 36 IDAHO L. REV. 243, 260 (2000) (describing how a Medicaid divorce may be particularly appropriate for couples in which the community spouse has a significant amount of separate property that she wants to preserve).

192. The ethical issue of a Medicaid divorce involves the prevention of the healthy spouse of an Alzheimer's patient from being "driven to poverty." Randy Cohen, *Get a Divorce*, N.Y. TIMES, July 28, 2002, § 6, at 14 ("People marry late in life for various reasons, but the pursuit of financial ruin is not one of them. So it is through divorce, paradoxical as it sounds, that you can best honor your marriage vow to cleave to your husband for better or worse. Preserving your small savings will be enormously beneficial to you both . . . . [Y]ou can help him most by offering tenderness and reassurance, not by joining him in penury . . . . It is a grim irony that while the president touts marriage as the road to financial security, your staying married would mean a descent into poverty.").

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> "[The] only way that I could protect my retirement assets and adequately cover Debbie's needs was to get a [Medicaid] divorce." It still took months of agonizing and counseling—from his minister and supervisor—for Gene to settle on a divorce. He felt he would be abandoning his best friend and his marriage vows. But he also felt if their roles were reversed, or *if Debra could speak for herself, she'd vote for divorce.* "It wasn't out of lack of love or lack of desire to care for her, but financial need," he says.[193]

What if Debra and Gene had entered into the process of creating a MHAD for Alzheimer's disease as this Article proposes, right after she was first diagnosed and still had the capacity to express her goals? They could have entered into a full discussion of financial planning for her long-term care costs, as well as the possibility of Medicaid planning and even a Medicaid divorce. Debra could have spoken for herself and given her consent or approval in advance to Medicaid planning, including approval of a Medicaid divorce if necessary to maintain income and savings for her young family and medical benefits to cover her long-term care. At a minimum, MHAD planning would have provided a platform for the couple's discussion of these difficult and personal issues. If done with sensitivity and care, using trained professionals including an elder law attorney, a geriatric care planner, or mental health provider, Gene would not have been on his own making these decisions, and Debra would have retained a sense of control over her and her family's future. What a relief this might have been for her husband and family—he might have been spared the depression and guilt of making these agonizing decisions alone.[194]

F. Planning for Intimate Relationships with Partners and Others

People with Alzheimer's disease experience the gradual loss of the self; their spouses and partners lose the person they know and love. Ultimately, both partners in the relationship lose the personal and sexual intimacy that can be such a crucial part of their lives together.[195] This Part looks at the potential use of MHADs to discuss

193. Marsha King, *Losing Debra: Cruel Dilemmas Clutter the Trail of a Failing Mind*, SEATTLE TIMES, Apr. 27, 2004 (emphasis added).

194. *See* Greenberg, Weiner & Greenberg, *supra* note 32, at 1161.

195. Helen D. Davies et al., *Sexuality and Intimacy in Alzheimer's Patients and Their Partners*, 16 SEXUALITY & DISABILITY 193, 194 (1998) ("People afflicted with [dementia] experience progressive declines in cognitive, behavioral, and social functioning that affect all areas of their lives, not the least of which is sexual functioning.").

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and plan for three limited possibilities involving the intimate relationships of people with this illness: first, the continuation of sexual intimacy within the committed couple where one partner has Alzheimer's disease; second, an agreement about if and when the well partner can seek outside intimate relationships; and third, if and when the person with Alzheimer's disease, whether or not currently partnered, would consent to other future intimate relationships for themselves.

The topic of sexuality in this context is extremely complex and has moral, religious, legal, and ethical considerations for partners, family, and service providers.[196] Moreover, there are societal taboos about discussing sex in general and about discussing the sexuality of old people in particular.[197] Much of the literature dealing with the sexual intimacy needs of people with Alzheimer's looks at the issues at the point where a difficult and fracturing situation has arisen, and the patient, providers, and family members can no longer engage in a full discussion due to the patient's advanced stage of the disease.[198] It focuses on how to deal with these problems rather than on anticipating them at a point before the caregivers and patient are in the throes of the illness.[199] This Part gives a brief overview of the potential advance decision points in the hopes of opening a discussion between people with Alzheimer's disease and their partners, adult children, and caregivers on the issues raised. Having at a minimum discussed general hopes and values with regard to intimacy within the current primary relationship, as well as feelings about entering into other intimate relationships, should, at a minimum, help to sort out the numerous tricky situations that could arise at a later time when consulta-

196. *See generally* BARBARA SHERMAN, SEX, INTIMACY AND AGED CARE 123–67 (1999); Daniel Kuhn, *Intimacy, Sexuality, and Residents with Dementia*, 3 ALZHEIMER'S CARE Q. 165 (2002); Jennifer Hagerty Lingler, *Ethical Issues in Distinguishing Sexual Activity from Sexual Maltreatment Among Women with Dementia*, 15 J. ELDER ABUSE & NEGLECT 85 (2003); Nili Tabak & Ronit Shemesh-Kigli, *Sexuality and Alzheimer's Disease: Can the Two Go Together?*, 41 NURSING FORUM 158 (2006).

197. *See* Davies et al., *supra* note 195, at 196.

198. *See e.g.*, SHERMAN, *supra* note 196, at 123–67; Carole Archibald, *Sexuality and Dementia: The Role Dementia Plays When Sexual Expression Becomes a Component of Residential Care Work*, 4 ALZHEIMER'S CARE Q. 137, 140–41 (2003); Andrew Casta-Kaufteil, *The Old & the Restless: Mediating Rights to Intimacy for Nursing Home Residents with Cognitive Impairments*, 8 J. MED. & L. 69, 72–77 (2004); Davies et al., *supra* note 195, at 201; Kuhn, *supra* note 196, at 165–66; Tabak & Shemesh-Kigli, *supra* note 196, at 160–62.

199. *See* sources cited *supra* note 198.

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tion with the patient is no longer feasible. Working with therapists trained in sexuality and dementia would be particularly critical in coming to agreements about these charged topics in advance.[200]

1. CONSENTING TO CONTINUING OR FOREGOING SEXUAL RELATIONSHIPS WITH CURRENT PARTNERS

Alzheimer's disease can have a significant negative impact on the affectional relationships of partners; eighty percent of well spouses report a decrease in both sexual and emotional intimacy as the disease progresses, with most characterizing their relationship as nonsexual in the late stages of the disease.[201] Yet both caregiver partners and the patients themselves frequently want to continue their intimate relationship for as long as possible. For caregivers and partners, sexual intimacy can be an important way to maintain connection, give support, and to cope with their partner's disease.[202] For Alzheimer's patients, "remaining sexually active provides one of the few remaining ways in which they feel they can maintain their role identity and provide something of value to their partners."[203] Maintaining sexual relationships has further benefits for both partners. Clinical depression is not uncommon for both partners in the couple in the early stages of Alzheimer's disease.[204] Maintaining sexual intimacy can ease the depression in the couple by providing positive emotional and physical support.[205] Further, research has shown that partners with Alzheimer's are likely to stay at home longer when the caregiver feels there is some "reciprocity gained from the [sexual] relationship."[206]

Despite the significant benefits to committed couples who keep their sexual relationship intact, there are formidable barriers to doing so.[207] Beyond the physical barriers to sexuality created by the cogni-

200. *See e.g.*, Davies et al., *supra* note 195, at 201; Jeanne Shaw, *When You're Asked to Speak About Sex, Intimacy, and Alzheimer's*, 26 J. SEX EDUC. & THERAPY, 140, 142–43 (2001).

201. Lore K. Wright, *Affection and Sexuality in the Presence of Alzheimer's Disease: A Longitudinal Study*, 16 SEXUALITY & DISABILITY 167, 168 (1998).

202. Davies et al., *supra* note 195, at 195.

203. *Id.*

204. *See* Shaw, *supra* note 200, at 140.

205. Davies et al., *supra* note 195, at 195.

206. *Id.*

207. These barriers include agitation, memory lapses, inability to sequence, and erectile dysfunction. Helen D. Davies, Antonette Zeiss & Jared R. Tinklenberg, *'Til Death Do Us Part: Intimacy and Sexuality in the Marriages of Alzheimer's Pa-*

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tive changes due to Alzheimer's disease,[208] well spouses can be upset by the sexual advances of their partner when he or she can no longer remember their name or recognize them.[209] They agonize over how to deal with partners who become sexually aggressive or who forget that the couple has already been intimate and demand sexual relations numerous times during the night.[210] Caregivers also worry that their spouse or partner may have reached a point where they cannot consent to sexual relations, thus creating the concern that they are "raping" their ill partners when they do have sex.[211]

Couples report that their medical providers do not talk to their patients with dementia about their sexuality. "Many health professionals do agree that [Alzheimer's disease] patients have a right to sexual expression. However, cultural values, personal beliefs, and inadequate training provide obstacles for clinicians to address confidently their patient's sexual needs."[212]

Because medical professionals generally fail to raise this important issue with their patients, having sexual intimacy matters listed as a point of discussion in a MHAD for Alzheimer's would at least put the issue on the table for consideration by couples. While not resolving the issues of memory loss and consent, raising them in advance in a MHAD could help lessen some of the conflicts, guilt, and obstacles to sexuality that arise for these couples. For example, the couple could talk about the nature of their intimate relationship, express a desire to maintain it as long as possible, and consent to continuing to be sexual, even if the partner with dementia no longer appears to know or recognize his or her spouse. Agreements could be made about how to deal with a partner who becomes sexually aggressive.[213] The MHAD could include or exclude the desire to maintain a sexual

tients, 30 J. PSYCHOSOCIAL NURSING 5, 5–10 (1992) [hereinafter *'Til Death Do Us Part*].

208. Alzheimer's disease causes declines in cognitive, behavioral, and social functioning that result in changes in sexual functioning from cognitive sequencing problems to erectile dysfunction in men. In a study of thirty-eight spouses and caregivers, all reported changes and decline in the sexual functioning of their partner. Davies et al., *supra* note 195, at 194.

209. *'Til Death Do Us Part*, *supra* note 207, at 5–10.

210. SHERMAN, *supra* note 196, at 83–85.

211. Davies et al., *supra* note 195, at 194; *see also* Shaw, *supra* note 200, at 142.

212. Davies et al., *supra* note 195, at 196.

213. For example, the MHAD could specify that the well partner could choose to place the person with Alzheimer's in a residential care facility at that point, or it could state that the spouses could sleep separately at night.

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relationship in the event that the ill spouse enters a nursing home and request the privacy needed for that relationship to continue.[214]

2. CONSENTING TO WELL PARTNERS SEEKING OUTSIDE RELATIONSHIPS

Because of the emotional stresses, loss of sexual intimacy, and depression experienced by the caregiver or partner of the person with Alzheimer's disease, as well as the long duration of the illness, it is not uncommon for the well partner to seek out other adult intimate relationships.[215] The *Seattle Times* article about Debra, who had early onset Alzheimer's, and her husband Gene describes Gene's emotional struggles once he had to institutionalize his spouse: "'I was totally lost . . . . I didn't have a purpose anymore . . . . [T]he Debbie I loved really left us a while ago.'"[216] It was only after Gene started getting out, socializing with friends, and dating that he began to recover from his loneliness. "He realized he didn't want to be 'a lifelong victim of Alzheimer's.'"[217] But the guilt suffered by partners in Gene's situation can be enormous and debilitating; they believe they have violated marriage vows or their ill partners' wishes when they enter into other relationships.[218]

It may or may not be the case that ill partners would consent to their loved ones having another intimate relationship when they are no longer able to be there for their partner emotionally or sexually. Advance consents or agreements might lessen the guilt and loss that partners like Gene experience when they seek out new relationships. The MHAD could discuss the ethical, moral, and religious beliefs of the couple. It could, for example, state that the well partner has the blessing of the ill partner to seek out other relationships at a point where there is no longer consistent recognition of him or her by the ill spouse. Or the MHAD could state that the person's religious and moral code holds that the couple be together and faithful through sickness as well as health, so that no permission is given for relationships outside of the marriage. In either case, having discussed this

214. Workers in nursing homes are frequently uncomfortable with residents expressing sexual needs, even between spouses. *See* SHERMAN, *supra* note 196, at 97–101.

215. *See* Shaw, *supra* note 200, at 142.

216. King, *supra* note 193, at A1.

217. *Id.*

218. *See id.*

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charged topic in advance may allow both Alzheimer's patients and their partners a sense of respect for each other's dilemmas and lead to agreements and consents about future behavior.

3. PERSONS WITH ALZHEIMER'S DISEASE CONSENTING TO NEW FUTURE INTIMATE RELATIONSHIPS

Numerous issues are raised when the person with Alzheimer's disease who is in a long-term care facility wants to have a sexual or romantic relationship with another person in the facility. This issue comes up in a number of ways: one resident with dementia who has a well spouse develops a relationship with another resident;[219] a resident mistakenly believes another resident is his or her deceased and beloved spouse and wants to have a sexual relationship with him or her;[220] or a single resident develops a romantic attachment to another resident. Long-term care staff are required to consider whether or not the relationship should be allowed at all,[221] whether to let family know about it and seek their approval, and whether the resident has the capacity to consent to a sexual relationship at all.[222]

People with Alzheimer's disease, even in the stage where the dementia is most severe, still can and do have sexual desires.[223] There is heated debate among caregivers and professionals in the nursing home setting about whether and how to manage or encourage the sexuality of residents with Alzheimer's disease.[224] The debate has centered around "problematic" sexual expression, where all sexual de-

219. Joan Biskupic, *A New Page in O'Connor's Love Story*, U.S.A. TODAY, Dec. 11, 2007, at 1A; *The Alzheimer's Project* (HBO television broadcast 2009) (depicting how the husband of Sandra Day O'Connor developed a relationship with another resident of a nursing home that lifted him from depression).

220. *See, e.g.*, STEPHEN POST, THE MORAL CHALLENGE OF ALZHEIMER DISEASE 87–88 (2d ed. 2000).

221. *Id.* at 87–88. Staff are uncomfortable with resident sexuality, based on stereotyping of older people as asexual and by ascribing people with dementia with child-like attributes, thus minimalizing their adult sexual desires and needs. *See* Lisa P.L. Low et al., *Promoting Awareness of Sexuality of Older People in Residential Care*, 8 ELECTRONIC J. HUMAN SEXUALITY, Aug. 24, 2005, http://www.ejhs.org/volume8/sexuality_of_older_people.htm.

222. Kuhn, *supra* note 196, at 168.

223. Generally, interest in and ability to be sexual decreases in the later stages of Alzheimer's disease. However, sometimes sexual needs increase and continue through to the end. SHERMAN, *supra* note 196, at 31.

224. *See, e.g.*, Archibald, *supra* note 198, at 139; Kuhn, *supra* note 196, at 167–68; Tabak & Shemesh-Kigli, *supra* note 196, at 163–64.

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sires of the resident are viewed as negative and unwanted by many facility staff.

> The person with the label of dementia is treated differently and often no longer trusted and seen as responsible. [P]eople so labeled as having dementia may, as a consequence, be subjected both internally and often externally to a debilitating onslaught that erodes their sense of personhood. They can be disempowered, infantilized, and intimidated.[225]

The ethical and legal issues are complex, and their explication, let alone resolution, is beyond the scope of this article.[226] However, most would agree that having advance knowledge of that person's values and wishes around the issue, prior to the onset of late-stage dementia, would help in determining how to approach handling a resident's sexual desires. Clients can state in a MHAD whether or not they would ever agree to a relationship with another resident, and if so, under what circumstances. For example, one person's religious or moral code might dictate that he or she would never consent to any other relationship while married, even if he or she appeared to be happier when the other person was with them. Another might say that a relationship with another patient would be fine as long as the client did not appear to be coerced in any way.

Well spouses often understand and tolerate their ill spouse having another relationship because they see their spouse happy again.[227] The well spouse has already done much of the grieving of the relationship and has begun to separate, so a new relationship is not as difficult as one would suspect. A case in point is that of Justice Sandra Day O'Connor and her husband John, who has advanced Alzheimer's disease.[228] She responded with equanimity to his starting up a romantic relationship with another resident of his assisted living facility.[229] Justice O'Connor's son Scott described his father's response to his new romance with the resident as like '"a teenager in love.' . . . 'For mom to visit when he's happy . . . visiting with his girlfriend, sitting on the porch swing holding hands' was a relief after a painful period."[230]

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225. Archibald, *supra* note 198, at 139.
226. In fact, there are currently only a few articles that give practical guidance to staff in assessing competency to consent to sexual relationships of people with dementia. *See id.* at 140 (citations omitted).
227. SHERMAN, *supra* note 196, at 106–07.
228. Kate Zernike, *Love in the Time of Dementia*, N.Y. TIMES, Nov. 18, 2007, at 41.
229. *Id.*
230. *See* Biskupic, *supra* note 219.

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Often the people who do take issue with a developing romantic relationship are the adult children of a parent with Alzheimer's disease. Upon discovering that their parent with dementia is having a sexual relationship with another resident with dementia, they may get upset with the parent and nursing staff for letting it happen and require that the couple be separated.[231] An advance consent or statement by the parent in a MHAD that he or she would be agreeable or not to such a relationship could spare the family, facility staff, and resident the grief and upheaval that can result when trying to guess what the patient would want in that circumstance.

G. Advanced Consent to Participation in Research Studies

Although as of yet there is no cure for Alzheimer's disease, there are currently clinical trials being conducted on over twenty new drugs that have the potential to ameliorate the symptoms or prevent the full onset of the illness.[232] Many people with Alzheimer's want to participate in research studies, not only to improve their own outcomes but also in the hopes of contributing to the research for a cure for future generations.[233] In order to participate in a drug trial, people with Alzheimer's disease must be able to give informed consent themselves after learning of the possible side effects and benefits of the treatment,[234] or they must have a proxy decision maker give consent on

231. *See, e.g.*, Melinda Henneberger, *An Affair to Remember*, SLATE, June 10, 2008, www.slate.com/id/2192178 (describing Bob and Dorothy's relationship at an assisted living facility, and how Bob's adult son "assumed that his father didn't fully understand what was going on. . . . [He] became determined to keep the two apart and asked the facility's staff to ensure that they were never left alone together. After that, Dorothy stopped eating. She lost 21 pounds, was treated for depression, and was hospitalized for dehydration. When Bob was finally moved out of the facility in January, she sat in the window for weeks waiting for him."); *see also* POST, *supra* note 220, at 87–88.

232. Fisher Ctr. for Alzheimer's Research Found., Alzheimer's Treatment, http://www.alzinfo.org/alzheimers-treatment-drug.asp (last visited Nov. 10, 2009).

233. POST, *supra* note 220, at 18 ("[T]here are many expressions of profound altruism in which individuals with the disease indicate an explicit desire to contribute to an eventual cure for AD for the benefit of future generations."); *see, e.g.*, Victoria Colliver, *USA: Alzheimer's Trials Make a Dent*, S.F. CHRON., May 8, 2009, at F1 ("There's also the feel-good aspect. You're contributing, making it easier for your neighbors and children who may face this disease. The tsunami is coming.").

234. Greg A. Sachs, *Advance Consent for Dementia Research*, 8 ALZHEIMER DISEASE & ASSOCIATED DISORDERS, Suppl. 4., 19 (1994).

their behalf.[235] While it is often possible for patients to give informed consent to participate while they are in the earliest stages of the disease, in the later stages, consent is not feasible even for those whose families believe they would have wanted to be part of the study.

A MHAD that includes a section describing if and when consent is given to participate in clinical drug trials, along with a description of the person's values and preferences around participation, may be one way to help remedy this problem.[236] Using the MHAD, clients could give advance consent to participate in drug studies that they may be unable to give at the time of need.[237] The National Bioethics Advisory Commission and others have proposed "research advance

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> Research on human subjects with Alzheimer disease and other conditions that impair cognition represents a fundamental challenge to the usual model of informed consent for research. Informed consent, the willingness of an individual to be used as an object in an experiment, has been seen as a cornerstone for the protection of human subjects in research.

Id. See generally Barry Rosenfeld, *The Psychology of Competence and Informed Consent: Understanding Decision-Making with Regard to Clinical Research*, 30 FORDHAM URB. L.J. 173 (2002) (exploring the importance of informed consent and patient autonomy).

235. "The current consent process for most research on dementia subjects who are incompetent involves obtaining informed consent from a proxy for the subject . . . along with the subject's assent or willingness to go along." Sachs, *supra* note 234, at 23.

236. [M]ost proxies know very little about their demented relative's preferences regarding research participation . . . . The information that could go into advance consent for dementia research . . . could either give instructions or designate a proxy. Individuals who have very clear ideas about the kinds of risks they would be willing to accept for certain potential benefits could spell these out.

Id.

237. *But see* Scott Y.H. Kim & Karl Kieburtz, Editorial, *Appointing a Proxy for Research Consent After One Develops Dementia: The Need for Further Study*, 66 NEUROLOGY 1298, 1299 (2006).

> A policy consensus on proxy consent for research has been elusive partly because theoretically appealing solutions have proved inadequate. One such solution—advance directives for research, completed prior to onset of dementia—is unlikely to play a major role because only a minority of persons complete an advance directive even for treatment decisions, and fewer still will contemplate ahead of time the unpleasant possibility of developing dementia and participating in research.

Id. I am suggesting here that the availability of a MHAD for Alzheimer's could increase the likelihood that people would consider the issues raised even at a time before developing the disease. *See infra* Part IV.A.

directives" as a possible solution to the difficulty of conducting research with persons with Alzheimer's and other forms of dementia.[238]

> A directive modeled on those types of research currently being conducted would allow the patient to choose whether to enroll in specific types of projects and provide reasons for those choices. Such a document, prepared jointly with the proxy, might help the proxy to make decisions using a substituted judgment standard by providing a sense of the range of risks the patient would be willing to assume.[239]

The MHAD for Alzheimer's disease could include what would essentially be a Research Advance Directive section among the many decisions covered. It could discuss what side effects of tested drugs would be intolerable (e.g., nausea, headache) or what procedures the person would reject or accept (e.g., I hate/I have no problem with injections or blood draws). A person could state generally a willingness to be a study participant or specify an agreement to participate only for certain types of research. The MHAD could state whether or not the person is motivated to participate by altruism, that is, to help others when the trial provides no hope of cure or symptom amelioration for them, or by the possibility of an improvement of his or her own symptoms. While there is still much debate about the efficacy of Research Advance Directives generally,[240] the inclusion of such a decision point about clinical research participation in the MHAD raises the issue for discussion at a much earlier point and starts the process of thinking about if and when a person might agree to inclusion.

H. Driving

Eventually, everyone with Alzheimer's dementia will need to stop driving because in the later stages of the illness impairments in judgment, reaction time, sequencing, and focus will make driving dangerous.[241] However, most people with mild dementia are still able

238. C.B. Stocking et al., *Speaking of Research Advance Directives*, 66 NEUROLOGY 1361, 1361 (2006).

239. *Id.*

240. *See, e.g.*, R.L.P. Berghams, *Advance Directives for Clinical Research in Dementia: Some Ethical and Policy Considerations*, 5 ITAL. J. NEUROL. SCI. SUPPL. 29, 29 (1997); Kim & Kieburtz, *supra* note 237, at 1298; Stocking, *supra* note 238, at 1361.

241. Deni Z. Erten-Lyons, *When Should Patients with Alzheimer's Disease Stop Driving?*, 70 NEUROLOGY e45, e45 (2008).

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to drive safely, sometimes for years after diagnosis.[242] A decision about when driving is no longer safe is a difficult one for patients and family—it signifies a significant loss of independence and autonomy, and it results in guilt for the family members imposing the revocation of privileges.[243] The person with Alzheimer's can feel demeaned by the loss of decisional control and new dependence on others to get from place to place.[244] Therefore, he or she may be resistant to agree to restrictions imposed.

One option for reducing the guilt of the family and for allowing the person with dementia to retain decisional control is to set out the parameters for when driving privileges should be terminated in a MHAD. The MHAD could set out the warning signs for decreased driving acuity,[245] and it could even name a trusted person to convey the decision that the time has come to stop driving.[246] It could set out an agreement to take a driving test or require a medical evaluation from a trusted provider when family suspects that the person is becoming too impaired to continue to drive. Finally, the MHAD can put in place what to do if the person with Alzheimer's disease refuses to stop driving despite the advance agreements. For example, the person could agree to have the keys removed or have the car taken away or disabled. These simple advance agreements about the difficult and touchy subject of driving privileges could preserve the dignity of the Alzheimer's patient while protecting the family and community from potential harm.

242. POST, *supra* note 220, at 47; *see also* Richard M. Dubinsky, Anthony C. Stein & Kelly Lyons, *Practice Parameter: Risk of Driving and Alzheimer's Disease (An Evidence-based Review): Reports of the Quality Standards Subcommittee of the American Academy of Neurology*, 54 NEUROLOGY 2205, 2205–11 (2000) ("Driving was found to be mildly impaired in those drivers with probable AD at a severity of Clinical Dementia Rating 0.5. This impairment was no greater than that tolerated in other segments of the driving population, e.g., drivers age 16 to 21 . . . .").

243. POST, *supra* note 220, at 47.

244. *Id.*

245. *See* The Hartford, Driving Warning Signs, www.thehartford.com/alzheimers/warning_signs_form_V2.pdf (last visited Nov. 10, 2009).

246. *See, e.g.*, The Hartford, Agreement with My Family About Driving, www.thehartford.com/alzheimers/agreement_form.html (last visited Nov. 10, 2009).

IV. When and Whether to Do MHAD Planning for Alzheimer's Disease

Now that the predictable decision points faced by a person with Alzheimer's disease have been reviewed, this Part explores possible recommendations for when a client should engage in MHAD planning for this dementia. It will look at the potential for drafting a MHAD as part of normal estate planning done by all clients as well as by those who have just been diagnosed and are in an early stage of the illness. Finally, the benefits and downsides of doing MHAD planning for Alzheimer's disease will be analyzed.

A. Timing

The type of advance planning that this Article suggests requires personal insight and thoughtfulness about relationships, placements, finances, and values. Many of the decisions called for here necessitate a level of emotional and intellectual maturity and insight that would be difficult to grapple with for a person in perfect physical and mental health, let alone someone who has the symptoms of Alzheimer's disease. This raises the question: when should a person engage in MHAD planning for Alzheimer's?

Those in the best position to make informed decisions about Alzheimer's care are likely people who have experienced the disease through the eyes of a caregiver or provider. Individuals who have watched the impact of Alzheimer's disease on a parent, sibling, significant other, client, or patient inevitably ask themselves what they would want to have happen if they were faced with this diagnosis. Caregivers are the ones who have had to wrestle with making these decisions for their loved ones, wondering or guessing what they would have wanted if they could say. Given their experience with the disease and its impact on the lives of the patient, client, and family, it makes sense for people who have a history of Alzheimer's disease in their family or those medical, legal, and social work professionals who have experience treating or providing services to people with dementia to do this planning as part of their regular estate plan. Attorneys who are trained in this area should screen clients to see if their family or work history might give them particular insight into the decision points discussed in this Article and to advise them on the possibility of engaging in MHAD-for-Alzheimer's planning.

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Secondarily, those who have been diagnosed with Alzheimer's disease while in its earliest stages should immediately consider doing this planning. New testing is being developed to diagnose Alzheimer's disease at earlier stages.[247] There is hope that some day there will be a simple test that will diagnose the disease even before symptoms appear.[248] With an early diagnosis, the ability and need to plan for a future with this illness becomes even greater. People with Alzheimer's disease can still be capable of competent decision making on many or all of the issues discussed here.[249] Capacity to give informed consent to health care is generally defined as the ability to take in information and options, reflect on the risks and benefits, and make a

247. Currently, there is no single test for Alzheimer's disease. Instead, a series of dementia screening tests, mental status tests, a medical history, physical, diagnostic, and neurological exams, and brain imaging tests are done to both rule out other causes of symptoms and to positively diagnose the disease. A trained physician can diagnose Alzheimer's disease at an early stage with 90% accuracy. Alzheimer's Ass'n, Steps to Diagnosis, http://www.alz.org/alzheimers_disease_steps_to_diagnosis.asp (last visited Nov. 10, 2009).

248. *See, e.g.*, Kaj Blennow & Ingmar Skoog, *Genetic Testing for Alzheimer's Disease: How Close Is Reality?*, 12 CURRENT OPINION IN PSYCHIATRY 487, 490 (1999); Jean Francois Dartigues & Luc Letenneur, *Genetic Epidemiology of Alzheimer's Disease*, 13 NEUROLOGY 385, 385–89 (2000); M.B. Liddell et al., *Genetic Risk of Alzheimer's Disease: Advising Relatives*, 178 BRIT. J. PSYCHIATRY 7, 7–11 (2001); Ingmar Skoog, *Detection of Preclinical Alzheimer's Disease*, 343 NEW ENG. J. MED. 502, 502 (2000).

249. *See* Thomas A. Cavalleri, *How Physicians Approach Advance Care Planning in Patients with Mild to Moderate Alzheimer's Disease*, 102 J. AM. OSTEOPATHIC ASS'N 541, 543 (2002); J.S. Huthwaite et al., *Declining Medical Decision-Making Capacity in Mild AD: A Two-Year Longitudinal Study*, 24 BEHAV. SCI. & L. 453, 453–63 (2006). *See generally* Thomas Grisso & Paul S. Applebaum, *The MacArthur Treatment Competence Study. III: Abilities of Patients to Consent to Psychiatric and Medical Treatments*, 19 LAW & HUM. BEHAV. 149 (1995) (finding that up to 52% of mentally ill patients hospitalized with schizophrenia and depression have substantially impaired decision-making abilities).

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decision based on that reflection.[250] People in the earliest stages of the disease[251] can still be capable of engaging in this level of consideration.

Alzheimer's disease typically progresses in seven stages: (1) No Cognitive Impairment (unimpaired); (2) Very Mild Decline (not diagnosable, minor memory lapses, not evident to others); (3) Mild Cognitive Decline (some individuals may be diagnosable, memory and concentration problems may be measurable in clinical testing); (4) Moderate Cognitive Decline (mild or early-stage, diagnosable); (5) Moderately Severe Cognitive Decline (moderate or midstage); (6) Severe Cognitive Decline (moderately severe or midstage, extensive help with daily activities like dressing and toileting required, most awareness of recent experiences and surroundings severely impaired, significant psychological symptoms emerge (e.g., suspiciousness, delusions), wandering behavior); and (7) Very Severe Cognitive Decline (severe or late-stage, progression to complete loss of ability to respond, speak and control movement).[252] Up to and including Stage 3 of this disease, people still may have the ability to make many decisions regarding their care and preferences.[253] However, at Stage 3 and beyond, caregivers are beginning to share, and then take over, deci-

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250. Washington State's MHAD statute defines the capacity to execute as the ability to give informed consent.

> "Informed consent" means consent that is given after the person: (a) [i]s provided with a description of the nature, character, and anticipated results of proposed treatments and alternatives, and the recognized serious possible risks, complications, and anticipated benefits in the treatments and alternatives, including nontreatment, in language that the person can reasonably be expected to understand; or (b) elects not to be given the information included in (a) of this subsection.

WASH. REV. CODE § 71.32.020(8) (2003); *see also* CAL. PROB. CODE § 4609 (2002); UTAH CODE ANN. § 1953-62A-15-1002(1) (2002); WYO. STAT. ANN. § 35-22-302 (1999).

251. Staging systems are frames of reference that can assist in understanding the progression of symptoms and in making future plans. However, the stages are artificial benchmarks in a continuous process that differs for each affected individual. After diagnosis, people live for between three to twenty years (the typical range is seven to ten, and the average is eight years). Reisberg, *supra* note 13; *see also* Mayo AD Stages, *supra* note 13.

252. Reisberg, *supra* note 13.

253. Hirschman et al., *supra* note 20, at 59. By studying seventy-seven patient-caregiver dyads, the authors examined the transition period when persons with Alzheimer's disease lose the ability to make decisions for themselves and caregivers assume decision making for patients' health care decisions. Over half of mild-stage Alzheimer's disease patients involved in the medical decision making at the start of the study remained involved at their first visit. *Id.*

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sion making from the patient.[254] From that point forward, it is likely that a person with Alzheimer's will be too far along in the progression of the illness to make informed decisions.

Finally, all people should consider doing a MHAD for Alzheimer's disease as part of their regular estate planning, just as they would consider drafting a living will or medical power of attorney, even though they are not ill or anticipating incapacity. For some of these decisions, no specialized information is needed to make an informed prediction. For example, a personal history and care values statement could be written without particular experience with Alzheimer's disease. The same may well be true for planning for in-home care options, planning for financing long-term care, deciding on when to revoke a driver's license, and planning for intimate relationships with partners and others. Making informed decisions on these difficult issues can be done by examining personal values and the nature of relationships with partners, family, and friends, and basic information about the likely progression and costs of Alzheimer's disease. On the other hand, an advanced decision by someone with little or no experience with this illness may not be possible where current options available to the individual require specialized knowledge. For example, decisions about out-of-home placements, dealing with combative or aggressive behaviors, and advance consent to participation in research studies likely require specialized knowledge. Still, a MHAD that covers basic values and broad preferences would go a long way in assisting family and surrogate decision makers in making all kinds of determinations using substituted judgment[255] should the client later develop dementia. Lawyers, therefore, should consider suggesting this type of planning for all of their clients who come in for estate planning advice.

254. *Id.* (showing that when dementia severity surpassed a threshold indicated by an MMSE score of less than twenty, patient involvement in decision making declined).

255. The substituted judgment standard requires the surrogate decision maker to carry out the previously expressed preferences of the incapacitated person. *See* TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 99–100 (4th ed. 1994); Dan W. Brock, *Surrogate Decision-Making*, *in* ENCYCLOPEDIA OF BIOETHICS 2483, 2483–86 (3d ed. 2004). *See generally* ALLEN E. BUCHANAN & DAN W. BROCK, DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING (1989) (exploring medical treatment decision making for incompetent patients).

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B. Potential Benefits and Pitfalls of MHAD Planning for Alzheimer's Disease

Previous parts of this Article have laid out some of the potential benefits of anticipating future decisions in a MHAD for persons with Alzheimer's disease, their families, and caregivers.[256] These benefits are numerous: A MHAD offers clients with Alzheimer's disease the ability to exercise control over their treatment at a time when they are unable to speak for themselves.[257] Advance decision making can result in better quality of care,[258] as well as improved mental health and peace of mind for clients, who know that hard decisions have been made and that their family has been spared the guilt and difficulty of doing this alone.

Perhaps the best part about MHAD planning is that it creates the opportunity for an important conversation and education about the future among the client, his or her doctors, caregivers, and family members. Even if the client decides not to execute a MHAD, this conversation alone can give family members an idea of the client's feelings about the critical issues likely to be faced in the coming years. In addition, the possible decision points discussed can serve to educate the client and family about the real possibilities in the future, issues that may not have been addressed by traditional medical providers because they are too sensitive and there may not be enough time with the patient to engage in a lengthy discussion.[259] For example, clients may not have even thought about future participation in drug trials, the potential for choices about in-home care and ultimate nursing

256. *See supra* Parts II–III.

257. *See supra* notes 56–61 and accompanying text.

258. *See supra* notes 56–61 and accompanying text.

259. *See generally* Wendy L. Adams et al., *Physicians' Perspectives on Caring for Cognitively Impaired Elders*, 45 GERONTOLOGIST 231 (2005) (describing how physicians experience feelings of inadequacy, frustration, and a sense of loss and grief as to the personhood of impaired patients, and these social and emotional issues are difficult to manage in the context of the current model of primary practice); Ladson Hinton et al., *Practice Constraints, Behavioral Problems, and Dementia Care: Primary Care Physicians' Perspectives*, 11 J. GEN. INTERNAL MED. 1487 (2007) (indicating that primary care physicians report insufficient time, difficulty in accessing and communicating with specialists, low reimbursement, poor connections with community social service agencies, and lack of interdisciplinary teams as difficulties in providing health care for their patients with dementia, and physician narratives suggest that these difficulties may lead to delayed management of dementia and increased reliance on pharmacological rather than psychosocial approaches to dementia care).

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home placement, financing long-term care with Medicaid, or the likely loss of driving ability. Attorneys raising these planning issues with their clients can team up with a competent geriatric psychiatrist, geriatric care manager, social worker, or mental health therapist to help guide clients and their families through the minefield many of these discussions may generate.[260]

Despite these numerous potential benefits, there are also hazards in doing this advance planning. Similar to issues that have arisen in the context of making end-of-life decisions in living wills, it may be difficult for a person to predict accurately what type of care he or she would want at a future time, especially when the person has no experience with Alzheimer's disease and its impacts.[261] And, as with MHADs generally, it is questionable whether or not the MHAD for Alzheimer's disease will be read, let alone followed, by providers and family members.[262]

Another potential disadvantage of MHADs for Alzheimer's disease is the impact of what some might consider "bad" or totally unrealistic choices made in the MHAD by clients. For example, one can imagine that a person could state in the MHAD, "I never want to go to a nursing home under any circumstances, and I would rather die than

260. *See generally* Lawrence A. Frolik, *The Developing Field of Elder Law Redux: Ten Years After*, 10 ELDER L.J. 1, 13 (2002); Timothy L. Takacs, *The Life Care Plan: Integrating a Healthcare-Focused Approach to Meeting the Needs of Your Clients and Families into Your Elder Law Practice*, 16 WTR NAELA Q. 2 (2003).

261. *See supra* notes 82–87 and accompanying text. However, the general public now has more extensive experience with family and friends with this illness, and media attention to public figures (e.g., Ronald Reagan and Sandra Day O'Connor's husband) with Alzheimer's disease. Home Box Office's recent documentary series on Alzheimer's disease demonstrated many of the potential decision points discussed in this Article. *The Alzheimer's Project*, *supra* note 219. It may well be possible to predict what we would want in a number of areas even without prior actual experience.

262. *See supra* notes 62–70 and accompanying text. In some ways, MHADs for Alzheimer's disease may be better suited to implementation than for mental illnesses that are cyclical in nature. The MHAD for Alzheimer's will not often be used in a crisis situation (upon commitment, etc.) but rather to make the longer range and harder decisions, allowing for real consideration of the wishes of the person with Alzheimer's disease. Generally, the regular providers for patients with Alzheimer's disease, rather than emergency providers, who know these patients over the long term, will be involved in the implementation of the MHAD. Therefore, these providers are more likely to honor the decisions of the people they know. Many of these providers will have known a person with Alzheimer's disease when he or she had capacity and could make these decisions with consideration, again diminishing some of the problems that other mental illness patients have in getting their planning decisions honored and implemented.

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be institutionalized," or, "I don't want anyone but my wife caring for me," or, "I would never want my spouse to divorce me or have another relationship while I am alive." These decisions can cause even more guilt for the family forced to make choices they now know were anticipated and rejected by their loved one with Alzheimer's disease but where no other realistic alternative care plan is available.

An additional potential challenge of this proposed MHAD planning is that some, maybe most, families will not understand what they will be facing with an Alzheimer's disease diagnosis. Family members and Alzheimer's patients themselves may be completely unprepared to talk about these difficult decisions, and they may even be unwilling to hear about what the future may hold. One of the many challenges for medical, legal, and social work providers will be to use the MHAD document as a doorway to educate families about the possibilities and future in a sensitive and less fearful way.

Lawyers are accustomed to helping their clients plan ahead for *worst* case scenarios—for what could happen at death to their property, body, children, and dependents, and for what could happen, and who would make medical and financial decisions for them, if they should have severe injuries or illnesses that result in loss of capacity. Attorneys sometimes do this planning without considering that, when they talk about worst case scenarios, clients can be given a potentially skewed and scary picture of the future. One danger of having a MHAD for Alzheimer's disease is that there are many decision points raised for discussion here that are unlikely to happen to most people with Alzheimer's disease—talking about future combativeness,[263] a civil commitment possibility,[264] sexual relations with other partners,[265] and obtaining a Medicaid divorce[266] can paint an extremely scary, needlessly foreboding, and in most cases erroneous picture of life in the future with Alzheimer's disease. With good care, a more accurate and likely picture may be the pleasantly confused man or woman with humor intact living in relative peace with the disease, rather than

263. Aarsland et al., *supra* note 138, at 243 (stating that 30–50% of Alzheimer's patients exhibit increased irritability or aggressiveness); Williams, *supra* note 138, at 64 (indicating that approximately 88,000 nursing home residents exhibited aggressive behavior just prior to assessment).

264. *See supra* Part III.D.

265. *See supra* Part III.F.2.

266. *See supra* Part III.E.

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the large and aggressively predatory person who needs to be restrained and sedated prior to placement in a locked ward.[267] Caution needs to be taken in approaching this discussion with Alzheimer's disease clients and their families to make sure that they are educated about the likelihoods (e.g., out-of-home placement, financing care), as well as the scenarios that are much less likely and even avoidable with good care (e.g., combativeness, civil commitment).

But the fact that this suggested planning can be difficult and even scary to discuss is not reason enough to avoid it. This type of sensitive planning is already being done in the equally difficult situation of clients with a terminal illness. With the advent of hospice care,[268] professionals broach the topic of the closeness of death and raise upsetting issues like making funeral and burial arrangements, writing a will, discussing who will have care of children and pets upon incapacity and death, paying for care, grief, anger, family conflict, and future relationships for partners.[269] The hospice experience shows us that, while people are frequently afraid to talk with the dying person about these topics, if done with skill and sensitivity, it can be a huge relief for both the patient and family to deal with these important issues up front.[270] The benefits of preparing for the future to

267. *See* POST, *supra* note 220, at 88–89 (showing the twelve indicators of well-being in people with severe dementia, including affectional warmth, humor, creativity, showing pleasure with smiles and laughs, relaxation, and expression of a range of emotions).

268. Hospice is a form of care for people with terminal illnesses who prefer to receive palliative rather than curative care. Services are provided by a team of professionals and center on care for the whole person—physical, emotional, and spiritual needs. Hospice services are provided generally in the patient's home, and support is provided for the whole family. Medicare will pay for hospice care if all the following requirements are met: (1) prognosis that life expectancy is 6 months or less; (2) terminal illness is certified by physician; (3) patient elects hospice benefit; (4) care is specified in the hospice plan of care; and (5) hospice program is Medicare-certified. 42 C.F.R. §§ 418.3, 418.21, 418.22, 418.24. *See generally* STEPHEN R. CONNOR, HOSPICE: PRACTICE, PITFALLS, AND PROMISE, (1998) (providing an overview of hospice and an analysis of its development).

269. CONNOR, *supra* note 268, at 20–21; Susannah L. Rose & Wayne Shelton, *The Role of Social Work in the ICU: Reducing Family Distress and Facilitating End-of-Life Decision-Making*, 2 J. SOC. WORK IN END-OF-LIFE & PALLIATIVE CARE 3, 8–12 (2006).

270. In a study done to determine whether difficult end-of-life discussions with their doctors improved patients' outcomes, these discussions did not result in higher rates of depression and did have very positive outcomes for both the patient and family caregivers. End-of-life discussions resulted in lower rates of invasive care and ICU admission, earlier hospice enrollment, and improved quality of life. Caregivers had less regret and an easier ability to face their loved one's death.

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terminally ill clients and their loved ones can be the most empowering and stress-reducing counseling that can be done for the family.[271] Similarly, planning for Alzheimer's disease with a MHAD could secure the same benefits of personal autonomy and of retaining some control over life decisions for the millions of people faced with this illness.

V. Conclusion

MHAD planning, when done with compassion and care, may provide a real sense of relief and control for people with Alzheimer's disease and their loved ones. Working in concert with mental health, medical, and other appropriate professionals, attorneys have the unique opportunity to help their clients anticipate future needs and decision points during the course of this illness, discuss viable options, and write up a plan of care that gives a voice to clients at the most out-of-control time of their lives. With the ever-growing number of people whose lives and livelihoods are seriously affected by Alzheimer's disease, the challenge of planning should be taken up by the legal profession. This Article is designed to move the discussion to a place beyond planning for end-of-life to engaging the difficult, yet crucial, decisions that lay ahead for both clients and attorneys.

"[E]nd-of-life discussions may have cascading benefits for patients and their caregivers." Alexi A. Wright et al., *Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment*, 300 JAMA 1665–73, 1668–71 (2008); *see also* Carol Potera, *End-of-Life Conversations Benefit Patients and Caregivers: They May Also Improve the Quality of Patients' Lives in Their Final Days*, 109 AM. J. NURSING 21, 21 (2009).

271. *See* Wright, *supra* note 270, at 1671.

Attachment A

Return Address:
Lisa Brodoff
Oak St.
Seattle, WA 98888

ALZHEIMER'S DISEASE
MENTAL HEALTH ADVANCE DIRECTIVE OF
LISA BRODOFF
WITH APPOINTMENT OF
LYNN G.
AS AGENT FOR ALL HEALTH CARE DECISIONS

PART I.
STATEMENT OF INTENT TO CREATE A
MENTAL HEALTH ADVANCE DIRECTIVE FOR ALZHEIMER'S CARE

I, **LISA BRODOFF**, being a person with capacity, willfully and voluntarily execute this mental health advance directive, so that my choices regarding my mental health care and Alzheimer's Dementia care will be carried out in circumstances when I am unable to express my instructions and preferences regarding my future care. If a guardian is appointed by a court to make mental health decisions for me, I intend this document to take precedence over all other means of ascertaining my intent.

The fact that I may have left blanks in this directive does not affect its validity in any way. I intend that all completed sections be followed. If I have not expressed a choice, my agent should make the decision that he or she determines is in my best interest. I intend this directive to take precedence over any other directives I have previously executed, to the extent that they are inconsistent with this document, or unless I expressly state otherwise in either document.

I understand that I may revoke this directive in whole or in part if I am a person with capacity. I understand that I cannot revoke this directive if a court, two health care providers, or one mental health professional and one health care provider find that I am an incapacitated person. In executing this directive, I have chosen not to be able to revoke this directive while incapacitated.

I understand that, except as otherwise provided in law, revocation must be in writing. I understand that nothing in this directive, or in my refusal of treatment to which I consent in this directive, authorizes any health care provider, professional person, health care facility, or agent appointed in this directive to use or threaten to use abuse, neglect, financial exploitation, or abandonment to carry out my directive.

I understand that there are some circumstances where my provider may not have to follow my directive, specifically if compliance would be in violation of the law or accepted standards of care.

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PART II.
PERSONAL HISTORY AND CARE VALUES STATEMENT

(Insert here a statement describing why the client is doing this MHAD, important people and events in his/her life, work history, and general values around care)

I am both devastated by my recent diagnosis of early onset Alzheimer's Disease and yet optimistic about my future and the outlook for improved care and treatment. I want to give my family, friends, and future caregivers a sense of who I am, my history, and my values to better understand my abilities and to know how best to treat me during the course of my illness. I hope that all of my future caregivers are given this statement to read.

I am an optimistic and happy person by nature. I love family and friends, and especially enjoy being at my lakeside home in Seattle, Washington. My spouse Lynn is the love of my life (28 years together so far), the person I trust the most in the world to care for me and support me (and to laugh at my lame jokes!). I have two fabulous, fun, smart, and funny adult children, daughter Evan and son Micha, whom I adore. My extended family include my sisters, their spouses, my wonderful mother, nieces and nephews, and their children. I consider my closest friends part of my family as well: Betty and Don, John and Don, The Righteous Mothers—Clare, Marla, Wendy, and my Lynn; the Gourmet Club; the book club. I am also a great lover of pet dogs. We have had in our family two dogs—Eli and Sophie.

I am an attorney and law professor by trade, and I love my work. I specialized in Elder Law, Administrative, Estate Planning, Disability, and Poverty Law. I worked for 13 years at the legal aid office in Olympia, two years for the state of Washington as chief administrative law judge at DSHS and the Office of Administrative Hearings, and then as a clinical law professor at Seattle University School of Law. I love my clients, colleagues, and especially the wonderful students that I have had the honor of working with over the last 12 years.

Anyone that knows me knows that I love to have fun—in my teaching, working with clients, with my students, with my family, and with my music. Humor is a critical part of my life. So is delicious food, fabulous music, art, TV, and the movies. I am in a Gourmet Club and a Book Club (the YaYa's). I love politics, and am a progressive liberal Democrat. I love to watch CNN, MSNBC, Washington Week, all the Sunday political shows, John Stewart.

One of the most important and influential parts of my life has been being a part of the feminist rock band, The Righteous Mothers. I have had the luck, joy, and honor of creating, playing, writing music with this amazing band of women. We have made six recordings and played all over the USA and Canada together. I learned to play bass and perform, create family, arrange, sing harmony, write music, so many things with this band. We grew up together. We also front a funk cover band called Func Pro Tunc. I love singing back-up harmonies!

My care values are pretty simple. I totally trust Lynn with making the right decisions for my well being and for hers as well. I would like to remain in our home together as long as possible, but understand that the burdens on her may become too great. When I do need care out of the home, my preference is first a smaller setting like an Adult Family Home or Assisted Living with specialty care in dementia. I know and

accept that I may need nursing home care at some point in the future. I also accept that Lynn may need other adult relationships when I become unable to recognize her or be an active and supportive partner to her. I encourage her to do that, and want her to lead a full and happy life. I also want Lynn to make our financial and my care decisions that preserve as much of our assets and income for her and our children as possible. I do not want this illness or the final years of my life to eat up our savings. Use of our long term care insurance and, if necessary, Medicaid coverage, and any planning that establishes my eligibility or lien avoidance is strongly encouraged.

I want to be treated with respect by my caregivers, and treated like the adult that I am, despite my illness. Please do not use patronizing or childlike language with me, even when you think the dementia makes me not understand.

When I can no longer recognize my family and communicate with them, life no longer has meaning for me. My ability to talk, read, sing, focus on the computer or TV, listen to music, enjoy humor are the things that make life worth living. If I can no longer do these things, then please stop any nonpalliative care and let me go.

PART III.
WHEN EFFECTIVE & DURATION

(A client can choose to have the MHAD effective immediately or upon incapacity)

I intend that this directive become effective ***immediately*** upon signing and that it remain valid and in effect for an indefinite period of time.

PART III.
WHEN I MAY REVOKE THIS DIRECTIVE

(A client can choose to have the MHAD remain in effect when incapacitated even if he/she is objecting to the chosen treatment at the time—this is the Ulysses Clause)

It is my intent that I may only revoke this directive in writing ***only when I have capacity***. I understand that if I become incapacitated while this directive is in effect I may receive treatment that I specify in this directive, even if I object at the time.

PART IV.
PREFERENCES AND INSTRUCTIONS
ABOUT MY CARE AND TREATMENT

In order to assist in carrying out my directive I would like my providers and my agent to know the following information.

(Place here a statement about the client's current diagnosis/stage of illness, any medications he/she is taking, current care and treatment regime, the names of trusted providers/therapist/geriatric care managers etc.)

A. Preferences regarding care in my home

(Place here any instructions or preferences about the delivery of care to the client while he/she is still in the home setting. This section could include who the client prefers to provide hands on

care—family members, spouse/partner, paid formal caregivers, agencies, volunteers, church members—and can talk about cultural preference for care)

I trust my partner Lynn to make decisions about if and when to hire paid caregivers to assist with my care. I am happy to receive care from her or other family members, but I am also open to the hiring of trained caregivers. We are working with Eldercare Resources to plan my care. That agency's recommendations and assessments as to my care needs and appropriate caregivers should be given top consideration. I hope to remain at our home for as long as possible. I would like Lynn to balance my preference to remain at home as long as I can with the financial and physical burdens on her of my being at home.

B. Preferences and instructions regarding out-of-home placements

(Place here preferences regarding when and where out-of-home placements will occur. Possible placements include Adult Family Homes, Assisted Living Residences, nursing homes, moving in with or near family far away. Place here names of any people/agencies preferred for assessment and recommendations.)

I recognize that I may need to receive care outside of my home, and even in my least desirable setting (nursing home placement) when my care at home becomes too burdensome or difficult to manage. This may be necessary if I become combative, aggressive, incontinent, resistant to care, or too difficult to transfer. If my agent Lynn decides that I need to live in a setting outside of our home, then the following are my preferred placements, in order of preference:

Placement in a small Adult Family Home near our home that specializes in dementia care, preferably XYZ Family Home.

Placement in an Assisted Living residence that specializes in dementia care, preferably ABC Assisted Living.

If determined that my needs can best be met in a nursing home setting, then my current top choice for placement is FGH Nursing Home, because it has the lowest staff turnover and the best trained dementia care staff.

If none of the above placements are possible locally, then I would prefer to move to a care facility near my son's home in California.

Decisions regarding out-of-home placement should be made in consultation with and after an assessment by a geriatric care manager, preferably Eldercare Resources.

C. Preferences and instructions about dealing with combative, assaultive, or aggressive behaviors, with authority to consent to inpatient treatment

(Place here client preferences for care in the event of emergencies caused by combative or aggressive behaviors that cannot be dealt with safely with other strategies. The client can consent in advance to voluntary hospitalization to avoid the problems attendant to involuntary treatment, and use a Ulysses Clause to bind him/her to that decision. Client can state preferences about where voluntary hospitalization/treatment/stabilization should occur.)

I recognize that sometimes people with Alzheimer's disease become aggressive, assaultive, or combative, despite good care. If this happens, and emergency or other treatment is necessary, I consent, and authorize my agent, Lynn, to consent to voluntary

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admission to inpatient treatment for up to 14 days, if deemed appropriate by my agent and treating physician. I prefer to receive treatment in a facility specializing in Alzheimer's care, to work on the reduction of my behavioral symptoms and stabilization of my condition. My preference is to be admitted to the specialized geriatric unit at Lakeview Hospital, or a similar facility if available.

_____

Signature of Lisa Brodoff

D. Preferences regarding the financing of my care

(Place here the client's preferences, goals, and values regarding paying for care and providing for family. Options can include Medicaid Planning, including the acceptability of a Medicaid divorce; use of long term care insurance; sale of assets and use of savings to pay privately for care; considerations regarding preserving assets for family/heirs.)

I know that the cost of my care could become high over the course of my illness. My hope is that my care costs will not consume the lifetime of savings Lynn and I have reserved to provide for ourselves in retirement and for our children at our deaths. I want my partner to maintain the standard of living we now have as much as possible. Therefore, my preferences for financing my care are as follows:

1. I have a long term care insurance policy with MetLife, policy # 00001. Maximize the use of that policy.
2. I want to preserve as much as possible my income, assets, and savings for my partner, children, and heirs. Please use all available planning options to meet this goal, including, but not limited to:
    a. Medicaid Planning
    b. Gifting
    c. Divorce or legal separation
    d. Changing of Estate Planning documents
    e. Tax planning

***(Example of other optional language**: Please use my income, assets, and savings to buy privately the highest quality care for me. I want to remain in my home with purchased services for as long as possible. If my savings run out, I want my home to be sold to finance any further noninstitutional care. Only rely on public assistance if no other option for paying for my care exists.)*

E. Preferences regarding future intimate relationships

(Place in this section choices and preferences regarding the continuation of sexual intimacy within the client's committed relationship; any preferences the client has about their partner seeking outside intimate relationships; and if and when the client would consent to other future intimate relationships for themselves.)

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a. Continuation of my intimate relationship with my spouse/partner

My intimate relationship with my partner Lynn is important to both of us. We have discussed this with our therapist, and have decided that we want to maintain our sexual relationship for as long as possible. I know that I may forget my partner as the dementia progresses. Even if this happens, I want to continue to be intimate for as long as Lynn wants and feels comfortable doing so. If I need nursing home care, I request the privacy needed for us to continue our relationship. I completely trust Lynn to make any judgments about the continuation of our intimate relationship, including when to stop it if she is no longer comfortable.

b. Preference regarding my spouse/partner seeking/having outside intimate relationships

I understand that my illness may last a long time, and that I likely will no longer recognize or be there emotionally or sexually for my partner Lynn. I also care deeply that Lynn not continue to be a victim of this disease and that she live her life to the fullest. This could include her becoming involved in other relationships. I would not consider this a violation of our vows to each other. Rather, I hope that Lynn does seek out companionship and intimacy when I can no longer provide that in the relationship.

***(Example of alternate language:** Our moral, religious, and ethical values dictate that we be together and faithful to one another through sickness and in health. We have both discussed this, and believe that a relationship outside our marriage is immoral and should not be pursued.)*

c. Preference regarding future intimate relationships for myself

I know that sometimes nursing home residents develop relationships with each other that can result in a less depressing and happier time for both. I am not completely opposed to my having such a relationship if, in Lynn's judgment, I seem happier in it and not coerced in any way.

***(Example of alternate language:** My moral, religious, and ethical beliefs preclude my engagement in any other relationship besides my marriage. I do not consent to any other intimate relationships, even if I appear to be happier at the time.)*

F. Consent to participation in experimental Alzheimer's drug trials

I consent to participation in any clinical drug trials for drugs that have the potential to ameliorate the symptoms of Alzheimer's disease or prevent the full onset of the disease. I not only hope to improve my own health, but also to contribute to research to find a cure for AD. I give my agent Lynn full power to consent on my behalf to my participation in any such study, considering my preferences regarding side effects. I do not want to take medications that have the side effects of nausea or headaches. These are particularly uncomfortable conditions for me. I have no problem getting blood drawn. If my memory loss can be slowed down by the tested drug, I am willing to participate in the trial even if it could lead to my earlier death. I would rather die sooner but with my memory more intact.

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G. Consents regarding suspension of my driving privileges

(Place here the client's preferences regarding how to determine when driving should be suspended and how to implement that decision.)

My ability to drive is a very important part of my maintenance of independence. I enjoy driving, and want to continue to do so as long as I am safe. On the other hand, I know that the time will come when I no longer have the ability to drive safely. I trust my doctor, Dr. B at GHC, or if she is not available, any other family doctor at GHC, to test my visual and mental acuity to see if I am no longer safe to drive. I also trust Lynn's judgment on this issue. If, after testing, it is determined that I am no longer safe to drive, I consent to my driving privileges being suspended. If I continue to drive or attempt to drive after this, I agree to my keys being hidden or taken away from me, and/or access to my car being eliminated.

PART V.
DURABLE POWER OF ATTORNEY (APPOINTMENT OF MY AGENT) FOR HEALTH AND CARE DECISIONS

I authorize the person(s) named below, as my agent, to make health and treatment decisions on my behalf. The authority granted to my agent includes the right to consent, refuse consent, or withdraw consent to any mental health care, treatment, service, or procedure, consistent with any instructions and/or limitations I have set forth in this directive. I intend that those decisions should be made in accordance with my expressed wishes as set forth in this document. If I have not expressed a choice in this document and my agent does not otherwise know my wishes, I authorize my agent to make the decision that my agent determines is in my best interest. This agency shall not be affected by my incapacity. Unless I state otherwise in this durable power of attorney, I may revoke it unless prohibited by other state law.

A. Designation of an Agent and Alternate

I appoint my partner, **Lynn**, as my agent to make health treatment decisions for me as authorized in this document and request that this person be notified immediately when this directive becomes effective:

Oak St.	day phone: (206) 444-4444
Seattle, WA 98888	home phone: (206) 555-5555
	email: _____

In the event that **LYNN** is unable or unwilling to serve as my agent, or I revoke her authority to serve as my agent, I hereby appoint my sister, **LOUISE LEWIS**, as my alternate agent and request that this person be notified immediately when this directive becomes effective or when my original agent is no longer my agent:

3333 Green Willow Tree Court	phone: (206) 222-2222
Seattle WA	email: _____

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B. Limitations on My Ability to Revoke this Durable Power of Attorney

I choose to limit my ability to revoke this durable power so that ***I may not revoke while incapacitated,*** even if I am saying that I want to do so.

C. Preference as to Court-Appointed Guardian

In the event a court appoints a guardian who will make decisions regarding my mental health treatment, I nominate **LYNN** as my guardian. The appointment of a guardian of my estate or my person or any other decision maker shall not give the guardian or decision maker the power to revoke, suspend, or terminate this directive or the powers of my agent, except as authorized by law.

_____

Signature of Lisa Brodoff

PART VI.
OTHER DOCUMENTS

In planning for my health care, estate and potential incapacity, I have executed a Durable General Power of Attorney and Health Care Directive that include the power to make decisions regarding health care services.

PART VII.
SIGNATURE

By signing here, I indicate that I understand the purpose and effect of this document and that I am giving my informed consent to the treatments and/or admission to which I have consented or authorized my agent to consent in this directive. I intend that my consent in this directive be construed as being consistent with the elements of informed consent under RCW chapter 7.70.

_____ _____

Signature of LISA E. BRODOFF Date

This directive was signed and declared by the "Principal," **LISA E. BRODOFF,** to be her directive, in our presence who, at her request, has signed our names below as witnesses. We declare that, at the time of the creation of this instrument, the Principal is personally known to us, and, according to our best knowledge and belief, has capacity at this time and does not appear to be acting under duress, undue influence, or fraud. We further declare that none of us is:

(A) A person designated to make medical decisions on the principal's behalf;

(B) A health care provider or professional person directly involved with the provision of care to the principal at the time the directive is executed;

(C) An owner, operator, employee, or relative of an owner or operator of a health care facility or long-term care facility in which the principal is a patient or resident;

(D) A person who is related by blood, marriage, or adoption to the person, or with whom the principal has a dating relationship as defined in RCW 26.50.010;

(E) An incapacitated person;

(F) A person who would benefit financially if the principal undergoes mental health treatment; or

(G) A minor.

Witness 1:

Signature:_____ Date: _____

Printed Name: _____ Address:_____

Telephone: _____ _____

Witness 2:

Signature: _____ Date:_____

Printed Name: _____ Address:_____

Telephone: _____ _____

PART IX.
RECORD OF DIRECTIVE

I have given a copy of this directive to the following persons:

Sophia B. Serene 7777 Chrysanthemum Petals Road Seattle, WA 98888	(206) 555-5555 (206) 444-4444
Dr. Christian Christiansen Dr. Willem Willemsen	work: (206) 888-8888 work: (206) 999-9999 or (206) 000-0000
Harborview Medical Center 326 Ninth Ave Seattle, WA	

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DO NOT FILL OUT THIS PAGE UNLESS YOU INTEND TO REVOKE
THIS DIRECTIVE IN PART OR IN WHOLE

REVOCATION OF MY MENTAL HEALTH DIRECTIVE FOR ALZHEIMER'S DISEASE

(*Initial any that apply*):

_____ I am revoking the following part(s) of this directive (specify): _____
_____.

_____ I am revoking all of this directive.

By signing here, I indicate that I understand the purpose and effect of my revocation and that no person is bound by any revoked provision(s). I intend this revocation to be interpreted as if I had never completed the revoked provision(s).

_____ _____
Signature of LISA BRODOFF Date

DO NOT SIGN THIS PART UNLESS YOU INTEND TO REVOKE THIS DIRECTIVE IN PART OR IN WHOLE

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