

Advance Directives and Research Advance Directives: Preserving Legacy and Autonomy in Alzheimer's Disease

Dean Evan Hart*

ABSTRACT

This paper explores a way to ensure a person's autonomy and legacy are preserved during the experience of dementia due to Alzheimer's disease. Due to the profound effect the disease has on memory, the "person of the lifetime" (the person's past experiences and their future aspirations prior to disease progression) becomes seemingly disconnected from the "person of the moment," or the person experiencing memory loss. Thus, directives are important to recognize and maintain continuity of person. Yet, a person's "legacy," based on the person's values and philosophy, can serve as a bridge between those two identities. Ultimately, people with significant memory loss from Alzheimer's disease are unable to secure their own legacy due to the diminishing ability to make autonomous decisions as the disease progresses. A legal system that codifies the ability to create a requirement to honor ADs and research advance directives (RADs) can best secure the autonomy of the person of the lifetime, and thus the person's legacy, of the person Alzheimer's disease.

Keywords: Autonomy, Alzheimer's Disease, Cognitive Function, Decisional Capacity, Advanced Directives

INTRODUCTION

At present, there is no effective treatment or cure for Alzheimer's disease's cognitive decline and ensuing dementia. While the definitive diagnosis is confirmed only after death via brain autopsy, Alzheimer's is diagnosed by symptoms and scans.¹ Over the course of an eight-to-twelve-year post-diagnosis period, people progressively lose memory and cognitive functions in an irreversible pattern.² Because Alzheimer's disease remains incurable despite significant scientific research into its causes, its biological qualities,³ and its symptoms, many people with Alzheimer's disease may wish to document care choices in advance while they have capacity to do so. Those experiencing early-stage Alzheimer's disease or mild cognitive impairment wanting to determine the best path for their private and public future life's agenda must have the legal tools needed to make sound plans for their future.

* Dean Evan Hart, MA Hofstra University, MS in Bioethics Columbia University, OD, F.A.A.O.

I. Preserving Legacy: The Benefits of Advance Directives for People with Alzheimer's Disease

A legacy is the part of a patient that will persist into the future, even after death. Autonomy can be increased by permitting Alzheimer's patients to document their legacy and wishes prior to significant cognitive impairment. Whether a legacy is in others' memories of personality traits or is something concrete like a business, named building, charity, or a cookie recipe, many people with Alzheimer's disease wish their person of a lifetime to be remembered. Many do not want to be remembered only as they are in the end of life, or as the cognitively impaired person of the moment. I argue that the best legacy for oneself is defined by one's own autonomy and his or her most personal, private philosophy and values. When third-party caregivers or healthcare workers seek to impose their views of the best interests on the person of the moment, they may be disrespecting that person's legacy interests. Having an AD that the caregivers must respect can help all stakeholders make decisions with moral legitimacy.

The preservation of the person of the lifetime can be maximized by focusing on both past and present life experiences. Significant memory loss from Alzheimer's disease interrupts the usual relationship between the person of the lifetime and the person of the moment, who may understand the present but may experience near-complete short- and long-term memory loss.⁴ Reconciling these two "personhoods" in one person in a formal process best serves the legacy for Alzheimer's patients by assessing various perspectives and providing a decision-making framework for caregivers and stakeholders. I assert that the autonomy of the person of the lifetime deserves equal or more weight than a decision-making third party when the person of the moment lacks capacity to make a healthcare decision. This argument is compatible with Samuel Dale's argument that "precedent autonomy morally authorizes ADs when dementia renders patients medically incompetent because it respects their dignity as persons, not merely pleasure-seeking creatures."⁵ Dale relies on Dworkin's view that critical interests should carry more weight than "experiential interests."⁶ The pursuit of critical interests gives meaning to human life and is encoded in ADs to represent the whole person.⁷

Nevertheless, the person of the moment has value and can enjoy the pursuit of happiness. Treatment for Alzheimer's disease focuses on comfort and happiness as a driver for the patient's best interests, thus attending to the needs of the person of the moment while balanced with the interests in an AD if it conflicts, to not damage the legacy. The person of the moment needs care to avoid pain and arguably to achieve some happiness, while simultaneously relying, insofar as still possible, on the person of the lifetime to obtain peace and contentment.⁸

Respecting Alzheimer's ADs is consistent with the strong individualism inherent in the US. The rule of law attempts to maximize autonomy and theoretically to ensure individual rights.⁹ In the US and other liberal democracies, recognizing the power and inalienable rights of the individual involves securing the right to make one's own decisions. Yet, as with other individual rights, there are situations where ADs are not absolute and where laws limit their full effect. Some statutory and regulatory restrictions make it legally difficult to honor ADs, especially with respect to nutrition and hydration directives.¹⁰ Arguably that is a poorly considered approach; notably, at least one scholar, Corinna Porter, argues that "statutes that disregard or invalidate ADs are discriminatory against the life lived."¹¹

II. The Benefits of Research Advance Directives for People with Alzheimer's Disease

The scientific research necessary to better treat people who have Alzheimer's disease requires engaging patients in research. A major bioethical question immediately arises: how can we obtain informed consent from a person unable to weigh different options and risks/rewards properly? Research advance directives

(RADs) could allow advanced consent for participation in research and could place limits on the consent.¹² People who have Alzheimer's disease should be able to express their desires in ADs during the early stages or before diagnosis. Directives must be able to allow people to express a desire to join clinical trials. The National Bioethics Advisory Committee in the US recommended RADs,¹³ which allow people to join studies when the treatment or medicine would benefit them, and possibly when it would benefit the larger public and has some potential to benefit the person.¹⁴ Porteri asserts that RADs should include consent based on the type and degree of risk, as it is impossible to predict the types of treatment or the anticipated side effects in future studies.¹⁵ Ultimately, the person's autonomy of a lifetime should take precedence because further research offers patients hope for both their legacy and the legacies of others.

Still, there may be cases in which the societal interest in protecting the person takes precedence. Societal interests may include preserving dignity and avoiding suffering. It may be necessary to safeguard people by limiting participation to low-risk studies and requiring additional consent from a proxy or caregiver.

RADs are appealing because they guide decisions, as do ADs; their unique appeal that is specific to RAD as part of AD is that the certainty of a permanently preserved legacy of valuing medical research in writing could take precedence over the uncertainty facing the person of the moment. At present, these are still tenuous grounds, requiring philosophical and other solutions.

A moral question arises regarding the ability to change one's mind after the threshold established for ADs and RADs takes effect. How can it be known if patients would have changed their minds given current circumstances and the often-lengthy progress of Alzheimer's disease? If a person wanted to withdraw an AD or RAD and expressed an unwillingness to engage in research, there is a moral argument that the person of the moment must not be deprived of a right to withdraw. By limiting the AD and RAD to treatment and research decisions after significant memory loss occurs, those with mild cognitive impairment certainly would decide about research for themselves, possibly with the input of family, friends, or doctors. Early diagnosis permits time for the patient to alter ADs before they develop significant memory loss. When patients understand the progression of the disease, their autonomous decisions regarding their care should be honored. Porteri asserts the ADs are the necessary proof of the person's desires and thus should govern when capacity is lost.¹⁶ Bodily integrity, philosophical belief, and autonomy must be respected once the capacity to make decisions is lost.

III. Recommendations

Capacity is task-specific; therefore, determining when the healthcare AD should be implemented must be based on capacity testing.¹⁷ This process turns ADs into a framework for interpreting the person of the lifetime's wishes as applied to the person of the moment. For example, dying in battle is quite a different memorial outcome compared to experiencing a vegetative state while fed artificial hydration and nutrition through a feeding tube. Establishing the desired legacy of the person with Alzheimer's disease in an AD allows the patient more autonomy to choose how they wish to be remembered.¹⁸

One problem with our current system for ADs is that it deviates substantially from state to state. The Patient Self Determination Act does not prescribe how state laws should address significant memory loss.¹⁹ Therefore continuity of person is not assumed in all state laws. A federal law that supports the acknowledgment of ADs would be preferable. The right to determine how you live and die is a fundamental choice and should not depend on the state in which one lives.

Fortunately, perspectives between stakeholders and other parties align in many cases, and their expressed wishes respect the person of a lifetime. To maintain the patient's dignity during disease progression for a greater proportion of Alzheimer's patients, states should honor ADs and RADs. Currently, ADs offer an unpredictable degree of protection, especially as patients move from state to state. Unpredictable factors include judicial discretion, shifts of thinking within the body politic, and the power of stakeholders with interests at odds with those of the person of the lifetime. Judicial discretion should be limited to invalidating only those ADs that were based on fraud, undue influence, or incapacity at their inception.

Administrative personnel and other stakeholders should not have authority to redefine a person's legacy once the person reaches the stage at which they no longer have capacity. ADs and RADs could include dispute resolution mechanisms as well as directives with respect to those persons the person of the moment does not want involved in their care. In declaring the continuity of person yet acknowledging the differences due to significant memory loss, Giovanni Boniolo concludes, "We have to respect them and their choices and decisions as long as they are capable of choosing and deciding. Then, when this capacity has vanished, we must continue respecting not only them, but also the choices and decisions they made."²⁰ Boniolo is absolutely correct; one is capable of creating AD until they are not. A sharper scientific approach would base the point at which one no longer has capability to make decisions on biological or clinical markers. The law should ensure that ADs and RADs made prior to that point govern care and research decisions.

CONCLUSION

Permitting an unfaithful surrogate or an administrator with a different philosophy to reinterpret patient desires based on current circumstances would create a "slippery slope," compromising the known wishes of a person with Alzheimer's disease as preserved in writing. ADs and RADs are the best opportunities for people with early Alzheimer's disease, or those who recognize the risk of dementia, to preserve their legacy and to use their autonomy to govern care of the significantly memory-impaired person of the moment. Preserving the legacy of patients in binding documents avoids the quagmire of courts, doctors, surrogates, and caregivers. Ultimately, ADs and RADs can maintain continuity of the person of a lifetime's dignity even when that person experiences cognitive impairment, evolving into the person of the moment.

1 Weller J, Budson A. Current Understanding of Alzheimer's Disease Diagnosis and Treatment. *F1000Res*. 2018;7:F1000 Faculty Rev-1161. Published 2018 Jul 31. doi:10.12688/f1000research.14506.1

2 Gauthier S, Leuzy A, Racine E, Rosa-Neto P. Diagnosis and management of Alzheimer's disease: Past, present and future ethical issues. *Progress in Neurobiology*. 2013;110:102-113; Naylor M, Karlawish J, Arnold S et al. Advancing Alzheimer's disease diagnosis, treatment, and care: Recommendations from the Ware Invitational Summit. *Alzheimer's & Dementia*. 2012;8(5):445-452.

3 The combination of Tau proteins becoming defective, creating neurofibrillary tangles, and β amyloid plaques building up in the neural connections of the brain prevents neural functioning, resulting in brain cell incapacity and death; Zetterberg H, Schott J. Biomarkers for Alzheimer's disease beyond amyloid and tau. *Nat Med*. 2019;25(2):201-203.; Qin K, Zhao L, Gregory C, Solanki A, Mastrianni J. "Dual Disease" TgAD/GSS mice exhibit enhanced Alzheimer's disease pathology and reveal PrPC-dependent secretion of A β . *Sci Rep*. 2019;9(1). doi:10.1038/s41598-019-44317-w; Qin K, Zhao L, Gregory C, Solanki A, Mastrianni J. "Dual Disease" TgAD/GSS mice exhibit enhanced Alzheimer's disease pathology and reveal PrPC-dependent secretion of A β . *Sci Rep*. 2019;9(1).

4 Kitwood T. *Dementia Reconsidered, Revisited: The Person Still Comes First*. 2nd ed. New York: Open University Press; 2019.

⁵ Dale S. Personhood, Critical Interests, and the Moral Imperative of Advances Directives in Alzheimer's Cases. *Voices in Bioethics*. 2021;7:1-6.

⁶ Dale S. Personhood, Critical Interests, and the Moral Imperative of Advances Directives in Alzheimer's Cases. *Voices in Bioethics*. 2021;7:1-6, citing Dworkin R. (1994) *Life's Dominion; An Argument About Abortion, Euthanasia, And Individual Freedom*. 1st ed. New York: Vintage Books.

⁷ Dale S., 2021.

⁸ Person M, Hanssen I. Joy, Happiness, and Humor in Dementia Care: A Qualitative Study. *Creative Nursing*. 2015;21(1):47-52.; Yeaman P, Ford J, Kim K. Providing Quality Palliative Care in End-Stage Alzheimer Disease. *American Journal of Hospice and Palliative Medicine*[®]. 2012;30(5):499-502.

⁹ Kim S. The Ethics of Informed Consent in Alzheimer Disease Research. *Nature Reviews Neurology*. 2011;7(7):410-414.; Porteri C. Advance Directives as A Tool to Respect Patients' Values and Preferences: Discussion on The Case Of Alzheimer's Disease. *BioMed Central Medical Ethics*. 2018;19(1).; Naue U. 'Self-care without a self': Alzheimer's Disease and The Concept of Personal Responsibility for Health. *Medicine, Health Care and Philosophy*. 2008;11(3):315-324.

¹⁰ Sieger CE, Arnold JF, Ahronheim JC. Refusing artificial nutrition and hydration: does statutory law send the wrong message?. *J Am Geriatr Soc*. 2002;50(3):544-550. doi:10.1046/j.1532-5415.2002.50124.x

¹¹ Porteri C. Advance Directives as A Tool to Respect Patients' Values And Preferences: Discussion On The Case Of Alzheimer's Disease. *BioMed Central Medical Ethics*. 2018;19(1).

¹² Buller T. Advance Consent, Critical Interests and Dementia Research. *Journal of Medical Ethics*. 2014;41(8):701-707.; Jongasma K, van de Vathorst S. Dementia Research and Advance Consent: It Is Not About Critical Interests. *Journal of Medical Ethics*. 2014;41(8):708-709.; Jongasma K, Perry J, Schicktanz S, Radenbach K. Motivations for people with cognitive impairment to complete an advance research directive – a qualitative interview study. *BioMed Central Psychiatry*. 2020;20(1).

¹³ National Bioethics Advisory Commission (NBAC) *Research Involving Persons with Mental Disorders That May Affect Decision making Capacity*. Rockville: National Bioethics Advisory Commission; 1998. <https://pubmed.ncbi.nlm.nih.gov/12747354/>

¹⁴ Porteri C. Advance Directives as A Tool to Respect Patients' Values and Preferences: Discussion on The Case Of Alzheimer's Disease. *BioMed Central Medical Ethics*. 2018;19(1). <https://pubmed.ncbi.nlm.nih.gov/29458429/>; Jongasma K, van de Vathorst S. Dementia Research and Advance Consent: It Is Not About Critical Interests. *Journal of Medical Ethics*. 2014;41(8):708-709. <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.997.8037&rep=rep1&type=pdf>

¹⁵ Porteri C. Advance directives as a tool to respect patients' values and preferences: discussion on the case of Alzheimer's disease. *BioMed Central Medical Ethics*. 2018;19(1). <https://pubmed.ncbi.nlm.nih.gov/29458429/>

¹⁶ Porteri C. Advance directives as a tool to respect patients' values and preferences: discussion on the case of Alzheimer's disease. *BioMed Central Medical Ethics*. 2018;19(1).

¹⁷ McDonald A, D'Arcy R, Song X. Functional MRI On Executive Functioning in Aging and Dementia: A Scoping Review Of Cognitive Tasks. *Aging Medicine*. 2018;1(2):209-219; Sclan S, Reisberg B. Functional Assessment Staging (FAST) in Alzheimer's Disease: Reliability, Validity, and Ordinality. *Int Psychogeriatr*. 1992;4(3):55-69; Appelbaum P, Grisso T. Assessing Patients' Capacities to Consent to Treatment. *New England Journal of Medicine*. 1988;319(25):1635-1638; Fisher C, Appelbaum P. Diagnosing Consciousness: Neuroimaging, Law, and the Vegetative State. *Journal of Law, Medicine & Ethics*. 2010;38(2):374-385.

¹⁸ Menzel P. Ethical Perspectives on Advance Directives for Dementia - The Hastings Center. *The Hastings Center*; 2018. <https://www.thehastingscenter.org/ethical-perspectives-advance-directives-dementia>. Accessed December 8, 2018.

19 HR 5835 Omnibus Budget Reconciliation Act of 1990, Title IV, Section 4206. US Congress.

²⁰ Boniolo, G. Demented Patients and The Quandaries of Identity: Setting the Problem, Advancing A Proposal. *HPLS* **43**, 21 (2021).
<https://doi.org/10.1007/s40656-021-00365-y>