

Advance Directives and Alzheimer's Disease

Deena S. Davis

Alzheimer's Disease (AD) has finally achieved the dubious distinction of surpassing cancer as the disease Americans fear the most.¹ Alzheimer's is seen as the disease that destroys one's identity, and robs people of their ability to make decisions. As one journalist put it, "Most illnesses attack the body; Alzheimer's destroys the mind — and in the process, annihilates the very self."² In one study, many respondents said that dementia was a state "worse than death."³

We know that at age 85, half of Americans will suffer from some form of dementia, primarily AD.⁴ Faced with concerns about losing control at the end of one's life, people naturally think of various kinds of advance directives. It is the thesis of this essay that advance directives do not address most people's concerns about Alzheimer's Disease. I also argue that other end-of-life strategies, such as laws that allow assistance in dying, and Voluntary Stopping of Eating and Drinking (VSED), are equally unhelpful.

Advance directives would seem to be almost uniquely relevant for any discussion about Alzheimer's and medical ethics. A recent study asked 874 people over 65 if they would want to take a (hypothetical) free and definitive test predictive of getting Alzheimer's. Then they were asked to imagine that they knew they would develop the disease, and were asked to rate their interest in "advance care planning activities." 75% of the study subjects said they would take the hypothetical test. And, asked to imagine that they knew they would develop Alzheimer's, 81% said they would complete an advance directive (although only 15% had done so already).⁵ Advance directives give at least the illusion that one can still control important elements of one's life even when one is no longer competent. However, where Alzheimer's is concerned that *is* largely an illusion. This paper will explain why.

What Are Advance Directives?

Advance directives are exercises in prospective autonomy. Looking ahead to the possibility that one may

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be physically or mentally incompetent to direct one's medical care, one states *in advance*, how one wishes to be treated, in the event of a serious medical condition. For example, one might direct that, should one be diagnosed as existing in a permanent vegetative state, one not be given artificial nutrition or hydration. Advance directives come in more than one form.

A Living Will (LW) is a document — it could be a piece of paper, a video, or a voice recording — that expresses what you want to happen medically if you are no longer able to decide for yourself.⁶ LWs are usually thought to protect people from receiving more medical care than they want, but they can also be used to express one's preference for aggressive care.

A Durable Power of Attorney for Health Care (DPA)⁷ allows you to designate a person who will make health care decisions for you, if you become incapacitated. The advantage of being able to appoint

person's wishes are outside the norm, the LW can be a useful back-up, giving the proxy something concrete she can use to assure others (and herself) that she is doing the right thing.

The Course of Alzheimer's Disease

The average length of time between clinical diagnosis of late onset Alzheimer's and death is four to eight years, although some people can live as long as twenty years after diagnosis.¹⁰ *This is the most salient fact about advance directives and Alzheimer's Disease.* Advance directives are aimed at having some say over what happens to you at the end of your life, when you are no longer able to make your own decisions. But with AD, the end of your physical life can happen six, or eight, or even twenty years after the end of your life as a competent person. This is a radically different situation than that for which advance directives were designed.¹¹

Probably the greatest reason people fear Alzheimer's is the loss of dignity and independence, even the loss of "self," as one loses interest in hobbies, becomes unable to read or to follow the plot of a movie, fails to recognize family members and friends. For many people, an eight-year road that begins with giving up the car keys and the checkbook, and progresses to wearing a diaper and being fed by spoon while wearing a bib, seems like "a fate worse than death." Many of us care a great deal about how we are remembered. Ronald Dworkin writes, "We worry about the effect of [our] life's last stage on the character of [our] life as a whole, as we might worry about the effect of a play's last scene or a poem's last stanza on the entire creative work."

a legally recognized decision maker, is that the person is there, in real time, making medical decisions with all the facts. On the other hand, there is evidence that designated proxies do not do a good job of discerning patients' wishes, and that they sometimes refuse to comply with patients' wishes, especially when these involve withdrawal of treatment.⁸ Journalist Paula Span has documented a number of recent cases where the patient and family did everything right, including a Living Will and a Durable Power of Attorney, and the hospital or nursing home disregarded the patient's wishes by attempting to resuscitate, or administering antibiotics.⁹

DPAs and LWs can be seen as complementary. LWs can add life and nuance and background to the DPA, by reminding the proxy of the person's beliefs and values where there is space to expand and explain. Also, if the family is likely to be divided about care, or if the

If your chief concern about Alzheimer's is what happens to you in the last months of the disease, when you have reached the final stage of severe dementia, then directives can be helpful. They can express your wish not to receive antibiotics for pneumonia, not to have a feeding tube, etc. In some hospital settings, one in three patients with severe dementia were given feeding tubes, even though there is no evidence that they prolong life or improve quality of life. Family members reported that their permission was not asked, or that they felt pressured by physicians to allow the surgery.¹² This is the type of medical situation in which a strongly worded advance directive could be very helpful to a proxy decision maker, enabling her to resist physician pressure.

However, it is not the short-term indignities of severe Alzheimer's that most people fear. Rather, people speak of diversion of financial resources that they

had hoped to use for a grandchild's education, or to endow a scholarship. They fear the burden Alzheimer's places on family members. At present, 15 million Americans provide unpaid care for family members with AD or other dementias. In 2016, that represented 18.2 billion hours of care.¹³ Caring for elderly parents

which can last for many years. This stage is marked by increasing confusion, often accompanied by frustration and anger. The person may act in uncharacteristic ways, such as refusing to bathe or to brush their teeth. Living independently is no longer possible.¹⁹ Thus, by the time one enters the moderate stage, the

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goals delineated above — conservation of resources, not burdening one's family, preserving the narrative arc of one's life — have all been defeated; the things people fear have come to pass long before they become severely demented. An advance directive dealing with the conditions of severe dementia is useless in addressing those fears. To quote Norman Cantor:

With the increasing prevalence of Alzheimer's disease and similar degenerative dementias, the focus of advance directives has changed for some people. The primary specter is neither an unavoidable looming demise nor the insensate limbo of permanent unconsciousness. Rather, the emerging concern is protracted maintenance during progressively increasing cognitive dysfunction and helplessness. For

is a task that falls largely to women,¹⁴ and it can derail their careers and fracture their marriages.¹⁵ Caregivers of people with Alzheimer's were twice as likely to report a decline in their own health as were caregivers for older people without Alzheimer's.¹⁶

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Advance Directives and Alzheimer's Disease
AD progresses in stages, from mild through moderate to severe. The longest stage is the moderate one,

For some, being mired in a demented state is an intolerably degrading prospect well before the advanced stage when the person no longer recognizes loved ones and is totally uncomprehending.²⁰ (In fact, failure to recognize loved ones can occur well before the advanced stage.)

Therefore, if advance directives are to address most people's concerns about Alzheimer's Disease, they must somehow be efficacious in ending one's life before or soon after one moves into the "moderate" stage. The question is, how useful are advance directives in shortening one's life before one becomes even moderately demented, before one needs to move into a nursing home, or into the home of one's daughter, or if one is very lucky, have a full-time caregiver at home? The answer is, not very useful, for three reasons. First, a directive can only direct your decision makers to refuse an intervention, not to affirmatively hasten your death. Thus, a directive is only useful if there is something to refuse, whereas many people with AD live long and (physically) healthy lives. Second, some ethicists question whether directives governing the care of patients with dementia should even be respected, given that the current patient no longer shares interests in independence and autonomy with her former self. Third, there is moral distress on the

part of caregivers who are directed to allow someone to die who seems to be happy and content.

To understand the first reason, imagine the following scenarios:

Jane, a fiercely independent and rather anti-social person all her life, has written a LW and DPA and named her daughter as her proxy. She explains that she would rather die if she cannot live independently. If she becomes unable to make her own decisions, she directs her daughter that, if she becomes ill she should not be given IV fluids or antibiotics, that she not be given vaccines against flu or pneumonia, etc. This is one of the scenarios described in Gaster's excellent article on advance directives for dementia, in which he envisions a choice of four possible responses to each of the three states of Alzheimer's. In this case, Jane would have chosen that, if in the mild stage, she would choose "comfort care only," with no life-prolonging interventions should she become ill.²¹

Now imagine that Jane is diagnosed with AD. Jane lives for the next eight years, remaining physically healthy, as she goes deeper and deeper into dementia. She ends up in assisted living because there are no other practical options. She might well prefer to die, but has lost the ability to act on that belief, or even to articulate it, and there is nothing her daughter can (legally) do to help her. If you are relying on an advance directive to shorten your life if you develop dementia, remember that the directive only works if there is some life-prolonging intervention to refuse; there may not be.

To understand the second reason, imagine that while Jane is still managing to live at home with only part-time help, she does get pneumonia. Her daughter realizes that this pneumonia is an opportunity: her mother will need to go into assisted living within a year, as her mental condition is deteriorating, so the pneumonia, if fatal, could be a blessing. But Jane is currently doing well, despite her memory issues; she seems to enjoy life, and is often unaware that she has dementia. As in Ronald Dworkin's famous example, she may spend hours every day reading a book — that is, reading the same page over and over and over again.²² If her daughter tries to ask her, "Mom, would you rather die now or live in a nursing home," she cannot comprehend the question, and says, "Of course I don't want to die!" Does anyone really think that the daughter will follow the advance directive? If you are in Jane's position (the original Jane, who wrote the directive), would you be willing to trust your daughter to follow your directive? I doubt it.

I want to touch very lightly on a complex philosophical problem that is always somewhere in the background as we discuss these issues. We can call

it the identity problem, or the problem of "prospective autonomy." A directive gives someone now, as a competent person who currently has autonomy, a way to extend that autonomy into a future in which they are no longer competent. But — is the Jane Jones who is deep into dementia, living in a nursing home, unable to remember her name, really the same person as the earlier Jane Jones who wrote that directive? Rebecca Dresser and some others would say not — the demented person does not share the values of dignity and autonomy that motivated Jane Jones when she was competent. The demented person cares about petting the dogs that come to visit, and eating chocolate pudding, and having cheerful caregivers. So why should we respect the directive of the Jane Jones who no longer exists — especially if respecting the directive means cutting short the existence of the current Jane Jones, who seems to be enjoying her life?²³

I am not persuaded by this argument, but many bioethicists are.²⁴ It is influential enough that it adds to my distrust that my directive will be followed once I am no longer in control of what happens to me.

Finally, coming to the third reason, advance directives do not account for the moral distress of the people caring for Jane. Let's imagine that Jane does end up in a nursing home. The people caring for her there never met the "real" Jane, the anti-social, fierce, irascible woman who valued her privacy above all else. They know the vague, pleasant woman who enjoys singing "You Are My Sunshine" with the other residents. When that Jane gets pneumonia, can they really be expected to allow her to die when she could so easily be "saved" — saved to be demented for many more years?

Physician Assistance in Dying and Voluntary Stopping of Eating and Drinking

Currently, seven states allow physicians to prescribe lethal drugs to terminally ill people under certain conditions.²⁵ A surprising number of people seem to think that these "death with dignity" laws can be the answer to our fears about Alzheimer's.²⁶ But these laws are completely irrelevant to AD. Every law that now exists in the United States, and that is likely to exist in the foreseeable future, requires two things: that the person be mentally competent, and that the person has fewer than six months to live. If you are within six months of dying from AD, you are probably not mentally competent.

Another topic worth considering is VSED: Voluntary Stopping of Eating and Drinking. The basic idea around VSED is that it is always legal to refuse to eat and drink, and therefore VSED could be an option for people living in jurisdictions that do not allow physician aid in dying.²⁷ As an alternative to physi-

cian assisted suicide for the terminal cancer patient, VSED might be an option, but it is virtually useless in the context of dementia, and for the same reasons I have emphasized above. VSED is only relevant to the case of severe dementia.²⁸ VSED is really only appropriate for someone nearing the end of his life, where appetite is lost and food becomes distasteful — but at that point, in Alzheimer's, one has been demented for many years. And, again, if one's concerns are dignity, burdening one's family, conserving one's resources, those concerns are long lost.

Conclusion

Advance directives are rarely relevant or useful for controlling or shortening one's life between the beginning of dementia and the final few months of life. People who are determined to avoid dementia at all costs, have few alternatives but to move to Belgium, where euthanasia (rather than assisted suicide) for dementia based on an advance directive is legal.²⁹ Or they could use a variety of strategies to try to pinpoint the onset of dementia, and end their lives while they still possess the will and ability to do so.³⁰

Note

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