

Ending One's Life IN ADVANCE

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People newly diagnosed with progressive dementia may not want to live through its later stages, but the options for those who wish to choose an earlier death are inadequate and can be dependent on others' cooperation. What if, while still competent, these people could opt for implantation of a device that would achieve their goals—timed to release a painless, fatal drug at a future point they have selected?

Over 5.8 million Americans are afflicted by Alzheimer disease, with hundreds of thousands more afflicted by other types of dementia, including vascular dementia and frontotemporal dementia.¹ The lifetime risk of developing dementia, from age forty-five, is about 10 percent for men and 20 percent for women. It is estimated that by 2050, due to population growth and an aging population, 13.8 million Americans and 131.5 million persons worldwide will be living with dementia.²

Some of us, at least when in command of our faculties, think we would not want to live with dementia. The spectrum of Alzheimer's severity is divided into seven stages, reflecting increasing degrees of memory loss and functional impairment.³ The later stages—five through seven—generally begin

years after the onset of obvious symptoms. They can involve severe memory loss, complete loss of speech, inability to provide for one's own basic needs, paranoia, hallucinations, and aggression against family members.⁴ We do not want to lose control of ourselves, become permanently dependent, burden family with our care, or risk ruinous medical expenses. Nor do we wish our loved ones to suffer the emotional anguish of watching us be gradually eclipsed as an interactive person, to see our mind dying while the body lives on.

Viewing the prospect of advanced dementia for ourselves, we may not want to live through the later stages of it. Instead, we may well want

- to have control over how we die;
- to avoid pain and suffering;
- not to burden family members with overwhelming care needs;

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- not to impose overwhelming medical or other financial costs;
- not to lose what we may experience as still-good life in the early and middle stages of progressive dementia;
- not to impose painfully difficult decisions on our family members or loved ones—for example, between caring for us or facing unsupportable financial burdens;
- not to have to ask our doctors to do what might violate their oaths or personal commitments or be emotionally unbearable for them; or
- not to have to turn to preemptive suicide to avoid all of the above.

Many of these desires may not be achievable, at least not all at once. Even where we are empowered to control how we die to some degree, in part by means of advance directives or medical aid-in-dying (MAID), we may still end up imposing material and moral burdens on family, physicians, and others. Is there a way to satisfy all these desires at once, making our ongoing life with Alzheimer's better, without making other things worse?

We think there could be.

Making Things Better?

Some years ago, one of us (Peggy Battin) proposed a thought experiment: Suppose there is a simple medical device, based on the triple technology of the timed-release capsule, the subdermal contraceptive implant, and a painless, quick-acting euthanasia drug developed in the Netherlands, where euthanasia is legal: it's a delayed-onset, rapid-acting, painless euthanasic implant. Anybody newly diagnosed with Alzheimer's or other irreversible progressive dementia, while still lucid and competent, can request one. Positioned painlessly and invisibly in the body, the implant

is designed to release its lethal drug instantaneously after a designated delay—say, two or three years, or five years, or ten, whatever the patient requesting the implant stipulates. The implant can be easily removed, and there are full legal guarantees, rigorously observed in practice, that a patient can have it removed at any time, for any reason, with no test or cost or delay. Or it can be self-removed. If it is removed, there are no aftereffects. But if the implant is not removed, it will release the euthanasic drug after the designated delay—without further warning, without pain or discomfort, and without requiring activation of any sort. It will just go off, and, as with an instantly fatal but pain-free heart attack, that will be the end.⁵

Call this a conjecture, a hypothetical exploration, a “real-life thought experiment with normative force,”⁶ a protoproposal, or what you will. In what follows, we want to take this seemingly radical idea seriously and explore whether the use of such a device—let us now call it an “advance directive implant,” or “ADI”—would be morally permissible. To prime readers' intuitions, we first consider some technological issues related to ADI development, examine reasons to permit patients to choose ADIs for themselves, and evaluate objections to doing so. We then ask whether it would be permissible for physicians, family members, researchers, and medical device firms to participate in ADI use should a person facing the prospect of dementia want it.

Technological Matters

The ADI would require extensive engineering and may not be feasible with current technologies. Still, we suspect it could become feasible in the near future. We imagine the ADI as something like a computerized subdermal implant containing a lethal dose of a medication or combination of medications. Release of these medications would occur rapidly after a predetermined interval

or after some specific event had occurred. The ADI would likely require a long-lasting battery, computerized control, and a pump or microfluidic mechanism. Despite its purpose, it would need to be safe: it should not carry an excessive risk of infection or allergic reaction; should be incapable of accidental activation by electromagnetic interference, physical shocks, or extremes of temperature; and should be strongly encrypted to make it difficult to hack.

It is crucial that the ADI be easily and immediately removable. After all, even those certain of their wish to obtain it would still like the option of changing their minds, at least prior to the onset of dementia, whether for personal reasons or because an effective treatment for their condition has been developed.

The medications used in the ADI should exhibit several characteristics. They should be highly potent, so that even the small amount contained in the ADI is guaranteed to be lethal. They should ensure a rapid but comfortable death—causing near-immediate unconsciousness without producing difficult symptoms like pain. Drugs already used for MAID could be appropriate: these include a sedative like secobarbital or pentobarbital, sometimes very potent opioids like fentanyl or carfentanil,⁷ or even arrhythmogenic compounds like digoxin.⁸ Potentially, dosing would have to be individualized to ensure efficacy across persons with a broad range of metabolisms, weights, and body compositions.

When should one have the device implanted if desired, and when should it activate? This should depend on things like the patient's views about what stage of cognitive deterioration is unacceptable, her current mental status, the expected course of her illness, and her views about her social circumstances. Alzheimer disease almost always progresses, though at varying rates, with functional decline tending to accelerate in its later stages. Reported median survival times from diagnosis vary from as few

as 3.3 years⁹ to around 5 years¹⁰ or as many as 10 years.¹¹ Presumably, the ideal use of the ADI would involve implanting it, at the patient's request, when she is clearly competent, either in the earliest stages of dementia or during a presymptomatic phase where diagnosis is predicted only by biomarkers, to activate at a later time chosen by the patient.

The device could be programmed to operate in many ways, but the simplest would be to have it activate after a predetermined interval—perhaps two years, or five years, or as many as ten years—where this could be chosen based on one's prognosis. To be sure, dementia prognosis is currently not very reliable,¹² but we expect it to improve over time. It is also important to ask how good prognosis really needs to be; use of the ADI will unavoidably involve some risk either that one's life will be cut somewhat shorter than necessary or go on somewhat longer than one wishes. Patients may choose to accept these risks even in the absence of reliable prognosis.

Activation of the device could occur probabilistically within a defined period, or at a specific, known time. Probabilistic activation would have the advantage of seeming more “natural,” but scheduled activation would enable the patient and her family to plan more effectively. One could say one's goodbyes, have a ceremony, and go to bed with the idea that, the device having activated, one would not wake up. Ideally, patients could choose between these options.

Should an ADI be “smart” or “dumb”? A “dumb” device would be essentially inert except for its internal programming that regulates the time to release. A “smart” device, in contrast, could process biological information from the user as well as communicate with the outside world. It could, we imagine, track some physiological markers, or even be regulated by outside control, by the patient, doctors, family members, or other parties authorized to delay, speed up, or cancel its activation.

These two forms of ADI would bring different ethical challenges. The “dumb” device would have the advantage of remaining set as the person originally chose, which would permit removal but no other interference; it would guarantee the patient that their choice would be respected. The “smart” version would be more flexible and responsive to changes in the patient's condition, but vulnerable to control by others, which may be just what the patient would not have wanted. We imagine both types should be available to the early-dementia patient, who could then choose one, the other, or neither.

A compromise version could involve a reactivation schedule managed by the patient. It might, for

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instance, require periodic input of a code known only to the patient, perhaps every six months, to delay the device's activation; without the code, the device would start a countdown and eventually activate itself. Transmitting the code would reaffirm the patient's wish to have the device *and* delay its activation, but requiring the code might ensure that the device activated after significant cognitive impairment had arisen, when the patient could no longer remember the code or even that she had the device.

Although there would surely be difficulty in surmounting these technical issues (and other technical issues we do not foresee), the bigger hurdles to ADI use would be the ethical issues it would raise. In what follows, we consider whether, despite some *prima facie* objections, the practice could be morally permissible.

Repugnance versus Safeguards

To begin, let us acknowledge the sorts of initial responses offered by people who read early drafts of this paper. While some regarded it as a potentially welcome innovation, others were distressed. We quote: “Yuck,” “Gross,” “That causes me fear, disgust.” One early reader described the ADI as creating “a living thing with a dead kill-switch inside it” and said that was “the grossest thing I've ever heard.” Another reported ambivalence: “During the thought experiment I found myself somewhat tempted by that option, were my future self to develop Alzheimer disease, while at the same time I was quite apprehensive about the implications.”

We certainly recognize the reality and importance of initial emotional reactions, of the wisdom of repugnance, in the phrase so memorably coined by Leon Kass.¹³

But repugnance cuts both ways. Should “yuck factor” responses outweigh sober reflection on the way the end stages of dementia may go? After all, the last third of the Alzheimer's trajectory can be a period of quiet withdrawal, or it can be marked by paranoia, hostility, confused wandering, aggression, and bedboundness. These different courses may be viewed variously with resignation or with dread. The end stages of Alzheimer's can be benign, or they can be awful, but what counts as benign or awful is open to interpretation.

Sometimes it takes a poet—in this case, Philip Larkin in “Heads in the Women's Ward”—to remind us of what we might see:

*On pillow after pillow lies
The wild white hair and staring eyes;
Jaws stand open; necks are stretched
With every tendon sharply sketched;
A bearded mouth talks silently
To someone no one else can see.*

*Sixty years ago they smiled
At lover, husband, first-born child.*

*Smiles are for youth. For old age come
Death's terror and delirium.*¹⁴

If initial distaste for the idea of the ADI is not decisive, there are nonetheless many uses that would be unacceptable. We would need rigorous safeguards around its use. The permissibility of ADIs would, first, depend on reasonable standards of care and preimplantation assessment criteria. One would not want healthy adults with minimal risk of dementia to receive them; one would not want them to be implanted under external pressure, forcibly, or surreptitiously; one would not want them to be implanted in persons whose decision-making capacities are impaired by severe depression. One possible set of criteria would be those used for physician aid-in-dying in Oregon: that the requestor be an adult; able to make and communicate health care decisions; seen by at least two physicians who concur in the diagnosis, prognosis, and assessment of decision-making capacity; not suffering impaired judgment due to a psychiatric or psychological disorder, not coerced, and informed of alternatives.¹⁵ We would add to these that the potential ADI recipient should be well-informed about its limitations, the risk that it could malfunction, and the possibility of removal. As with Oregon's law, ADI access should probably require both an initial verbal request and, later, a written request; indeed, since there should certainly be an extended waiting period, we might even require two written requests separated by weeks, months, or even years. The diagnosis of dementia should be confirmed via current guidelines and with the best available tests. If there

is doubt about the requestor's competence or mental health, she should be referred to a psychologist or psychiatrist.

Advantages over Current Practice

Improving the dying process and avoiding preemptive suicide. Given adequate regulations, we imagine that the voluntary use of ADIs would have several advantages over current practice for those who receive them. Most obviously, for those anxious about their future with dementia, an ADI would provide some assurance that they will die in what they regard as a timely fashion, allowing them to avoid an outcome that they dread.

There are many currently available means for ending one's life electively in advance of suffering, as with cancer or other serious medical conditions. These include do-not-resuscitate orders, refusing life-saving treatments like antibiotics during acute illness, and voluntarily stopping eating and drinking (VSED). And there are do-it-yourself methods that do not involve the medical profession, like the helium hood, the stockpiling of drugs and, of course, guns.

The use of ADIs is likely to have advantages over all these measures. Compared to VSED or death arising from refusal of life-sustaining treatment, death caused by an ADI is likely to be easier for the person with dementia. Forgoing treatment for pneumonia or kidney failure can be made more comfortable with pain medication, sedation, and supportive care, but these are not always fast enough and not always adequate. Likewise, although proponents of VSED often assert that it is not as uncomfortable as one might think, especially for physically frail patients, there can be little doubt that it is still quite challenging.¹⁶ As for do-it-yourself methods, there is the risk of incomplete effect, where an attempt to end one's life fails, resulting in brain damage or other permanent injuries.¹⁷

ADIs would also mean that a person with incipient dementia should feel less pressure to engage in preemptive suicide,¹⁸ thereby reducing the risk that they will cut short a life they might regard as worth living. Preemptive suicide generally involves acting while one can still anticipate future years of good life, since it requires knowledge of one's likely future deficits as well as the ability to obtain and use lethal means. This is not to suggest that preemptive suicide is morally wrong but, rather, that, to be able to perform it, one must do so well before one might wish. Suicide is likely to be much more difficult, if not impossible, for someone in the late stages of severe dementia. Similar problems arise with VSED. This is sometimes called the "too soon, too late" problem—you have to do it early, or it will be too late to do it at all.

ADIs might also improve the circumstances under which those who would otherwise choose preemptive suicide die. When patients with incipient dementia die of suicide, the death is often violent, just as it is for persons without dementia.¹⁹ Suicide can be alienating; frequently, neither family members, nor one's physician, close associates, or spiritual advisor can be informed, since knowing would enable them to intercede and might implicate them in the death, exposing them to social and legal repercussions. Those who die by suicide typically do so alone, and their deaths are often stigmatized. Given a collective understanding that the families of those who receive ADIs have neither authority over nor culpability for the deaths that result, the devices would greatly reduce the likelihood of such unfortunate outcomes.

Reducing distress for others. Perhaps the greatest advantage of ADIs is that they would reduce the distress that living and dying with dementia imposes on others. This is true in two senses. First, there is the obvious sense that ADIs would tend to shorten the period in which the person living with dementia represents a burden for others. Although

there are difficult questions about how we should think about being a burden, such as whether the desires of others to provide care for the person during dementia should override that person's wish to refuse such care, it is plausible that the person facing dementia can reasonably desire to limit the burdens she will impose upon others.

ADIs would also reduce the distress that dementia imposes on others because the device, relatively free of any external input or activity, mostly immune to the judgments, misgivings, and second-guessings of family members, physicians, and friends, would absolve people of many of the burdens of judgment once the patient developed advanced dementia. It would keep a patient from having to off-load decisions about what they want onto others. Those decisions can create severe moral distress for the caregivers authorized to make them. One source of distress is in deciding when to implement a directive. Ask anyone who has been called upon to serve as proxy for a family member with dementia: it is very hard to make life-and-death decisions for someone else, whether one opts for continuing life (and possibly suffering) or for some form of allowing to die (and perhaps missing some still-good life).²⁰ Even with conventional advance directives that reject life-saving interventions after a certain stage of cognitive decline has been reached, there can still be questions about when the specified decline has occurred or whether the interventions considered are life saving. In the more controversial case of advance directives that stipulate withholding nutrition and hydration (called "stopping eating and drinking by advance directive")²¹ or, where legal, as in the Netherlands, directives that request euthanasia after dementia becomes severe, the difficulties created for others are even more serious. How advanced must one's loved one's dementia be before it makes sense to withhold food and fluids?

Another problem is that doing the things required by an advance directive can be difficult once one has decided to act. Even the advance directives that are easiest to implement—those that involve refraining from giving a person with a potentially fatal physical illness like pneumonia antibiotics or other life-saving treatments—can still provoke moral distress. It is hard, in medicine, to do nothing; much of the pressure that physicians (and family members) face is to do more. These problems are surely amplified when the advance directive requires that a person's caregivers stop giving her food and water, or, as in the Netherlands, provide di-

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rect euthanasia: there, a cooperating physician must administer the lethal substance and also make a judgment about whether the criterion of "irremediable suffering" is met.²² Even if those practices are justified and are legally permissible, they can surely cause serious distress for participants. The ADI may still place some burden on the physician who implants it to assess whether the patient has capacity and whether the request is genuine, but this involvement would take place while the patient was still competent and able to make a voluntary, informed request. This would be a considerable advantage over the Dutch version of postcompetence implementation of MAID, a practice that is legal but rarely used.

Reversibility. All these benefits of ADIs presuppose that they are reversible, like contraceptive implants, with no aftereffects or institutional impediments. This means that if it turned out that there was another explanation for a person's dementia—say, the vitamin B12 deficit of pernicious anemia, a treatable autoimmune condition like Hashimoto encephalopathy, or an operable condition

like normal pressure hydrocephalus—then she could have the device removed. Likewise, if there was some dramatic change in her social circumstances that greatly improved the care available to her or if the public resources devoted to long-term care were expanded dramatically, obviating any need to worry about the monetary impact of her dementia, then she could have it removed. If she had executed an advance directive (which might be needed to explain her wishes in the case of acute illness before the ADI's activation), it could stipulate under what conditions, if any, the ADI should be deactivated or removed. And were an effective

treatment for Alzheimer's and other dementias to be discovered, all these devices, in every user, could be removed right away.

Social Implications

What is permissible for patients sets boundaries on what is permissible for all other parties involved in their treatment. Thus, the development of ADIs, clinical assessment for their use, and implantation would be wrong if it were wrong for patients to choose this for themselves. But that it is permissible for patients does not necessarily imply that it is permissible for physicians or other parties to participate.

May physicians participate? It is conceivable that physicians could not permissibly provide ADIs. In particular, it might be thought that physicians have, because of the Hippocratic Oath and similar professional codes, an obligation not to harm their patients and that implanting an ADI in a living human being would conflict with this.

Two independent considerations suggest that physicians could per-

missibly participate in this practice, however. First, it would provide a service to the patient that, if appropriate criteria have been met, would potentially be beneficial as soon as it was provided. Most persons who would request an ADI would presumably do so because they have substantial anxiety about a future with dementia—where this means that any number of fearful scenarios might play out. To the extent that there is relatively little that physicians can do otherwise to prevent these scenarios, providing an ADI could be justified.

Second, providing an ADI would be similar in important respects to other, permissible acts that help bring about a patient's death. Whether the physician provides MAID, comfort measures during VSED, palliative sedation, or high, possibly lethal doses of opioids for pain relief, she engages in some unconventional action, or refrains from some other action that is conventionally and statistically expected, and thereby makes the patient's death more likely in order to provide comfort. Except for the time lag, the ADI would do essentially the same thing.

Some will appeal to the doctrine of double effect to drive a wedge into this argument. With palliative sedation, the use of lethal doses of medication for pain relief, or comfort care in cases of VSED, they might claim, the physician's intention is merely the reduction of suffering—not to cause death; death is merely a foreseen but unintended side effect. But physicians who wish to provide ADIs to qualified patients could avail themselves of this rationalization, too: although they would recognize that death is likely to result from the ADI, they could plausibly claim that their intention is merely to provide an intervention that, because of the security and control it provides, will powerfully mitigate their patients' current suffering in the face of an uncertain future.

May families participate? When a person who anticipates that she will develop dementia decides to obtain

an ADI, family members may be called upon to participate. They may help her get to appointments or provide financial or emotional support, for example. There are no strong, prima facie reasons that these acts by family members would be morally impermissible if it was permissible for patients to request ADIs in the first place.

To be sure, with families or other caregivers, there is a fine line to be walked: emotional support may blend seamlessly into encouragement, and encouragement into persuasion, then persuasion into pressure, and those acts may be regarded as morally beyond the pale. Just the same, the role family members play should be determined, initially, by the patient. The patient may wish to make her decision alone, without consulting or notifying anyone else beyond the physician involved. Or she may welcome input from family or others, perhaps including spiritual advisors, but retain decision-making authority. Or the patient, in the bosom of a family she trusts, may want to come to a joint decision with them, such that they all concur about whether it is the right thing to do.

May designers, engineers, researchers, and medical-device firms participate? Even if it is permissible for patients to request ADIs, for physicians to implant them, and for families to facilitate this, could it still be impermissible for medical device companies to design, test, and produce such devices? Conventionally, there is a low bar for permissibility in making artifacts for sale: private companies are already licensed to produce things (like guns or potentially addictive drugs) that can be dangerous if used incorrectly and that could lend themselves to wrongful use.

There might be ethical and practical challenges in designing clinical trials to assess the efficacy of ADIs. The primary outcome of interest for any such device would be the death of the bearer years after implantation. Institutional review boards and regulatory agencies like the U.S. Food

and Drug Administration would balk at approving research with that aim. But would double-blind testing in humans even be warranted? Given that the drugs to be used in ADIs are already, we are imagining, independently known to be effective from their use in MAID, it would seem unnecessary to demand trials in humans. In any case, double-blind studies could hardly be defended as ethical, given that the people in the placebo arm, all of whom would have initially wanted an ADI (on whom else could it conceivably be tested?), would experience its nonfunctioning only during advanced dementia, with no way to restart or re-request it. Anyway, it is the delivery device, not the drugs, that requires testing, and that could be done with traceable placebos in healthy volunteers.

Objections

Killing oneself. The most immediate objections to the ADI insist that it involves killing—killing oneself, or if not oneself, then another, future person one will become. Various ways of countering this objection have been employed in debates about MAID. For one thing, killing oneself, or setting things up so that one will die at a predictable point, is permissible in other settings. The soldier who sacrifices himself to save his comrades, the martyr who dies to avoid recanting their faith, and the emergency rescuer who accepts mortal risk to herself to save others are all doing something permissible, even praiseworthy.

Then too, obtaining an ADI is relevantly similar to other ways of shortening one's life in the face of dementia that are permissible. Writing an advance directive that involves withholding life-saving treatment if one later develops dementia is not as morally distinct from having an ADI as one might think. Like an ADI, advance directives have the effect of reducing life expectancy for a person after dementia develops—although the reduction occasioned by obtaining an ADI may be greater or lesser,

depending on how the delay is set and on when, if ever, a life-threatening illness like pneumonia occurs. Similarly, one might regard the withdrawal of life-sustaining medical interventions as a form of killing, albeit one that, if requested by the patient, is permissible.²³

It might be argued that the important difference with an ADI is that it involves intending to kill oneself in the future, rather than simply allowing oneself to die. But advance directives can also involve the intention to end one's life. In choosing to write the advance directive because one's goal is to minimize, within certain constraints, the risk that one will live with severe dementia, one might think that the advance directive is the only practical or legal means of doing so. So rather than merely setting up things so that you will be "allowed to die" when some illness occurs, you are actually right now doing everything in your legal power to end the life of your future self: your clear and central intention is to die before something you consider worse happens to you.

The "then-self" versus "now-self" problem. Much discussed in the academic literature is the issue of the "then-self" versus the "now-self." How do we balance the interests of the "then-self"—the person who did not have severe dementia when electing an ADI or advance directive—with the interests of their future "now-self," the person with severe dementia whom the person with an ADI has become? Although the past person without dementia did not want to live with dementia in the future, she may be perfectly happy to do so once she has developed dementia. Whose wishes have priority?

Answers to this question vary. Ronald Dworkin claims that one's "critical" interests—the interests that are established by the nondemented self while she is engaged in rational deliberation about how she wants her life to go—always override one's future "experiential" interests, interests in having positive experiences and

avoiding negative ones.²⁴ The future person with dementia can develop and sustain experiential interests—we might imagine having pleasant experiences such as being gently touched, eating favorite foods, or hearing familiar music—but her critical interests in not being diminished by cognitive impairment and dependency remain what they were before dementia afflicted her. For Dworkin, her critical interests should govern what happens to her. If she wrote an advance directive or obtained an ADI before developing dementia, those actions reflect her critical interests and should be respected.

Paul Menzel and Collette Chandler-Cramer, considering the possibility of stopping eating and drinking by advance directive, suggest that the experiential interests of the person with dementia can sometimes

override critical interests represented by an advance directive, although these experiential interests are likely to weaken with the progression of dementia, so the advance directive will eventually win out.²⁵ Given their view, obtaining an ADI would still be permissible, but it might be necessary to delay the activation of the device relative to what Dworkin's stance would permit.

A number of scholars have challenged Dworkin's prioritization of predementia critical interests over postdementia experiential interests, or have for other reasons cast doubt on whether we should honor dementia advance directives.²⁶ Many compelling defenses for following advance directives during someone's dementia have also been developed.²⁷ Perhaps the most severe critique of

Dworkin's view—and the one that would be most problematic for the use of ADIs—has been articulated by Rebecca Dresser, who argues that the current person without dementia and the future person with dementia are not, in fact, the same person, since the cognitive and emotional changes accompanying dementia render one a new and different person; according to her view, the wishes and the critical interests of the person who wrote the advance directive (or who chose an ADI) have no grip on the (new) person with dementia.²⁸ In Dresser's view, by having an ADI placed, I would now be acting with the intention of killing a different person in the future without that person's consent.

That would be clearly wrong. I am never permitted, except perhaps in legally extenuating circumstances

We concede that slippery-slope arguments may have more purchase in this context than in ordinary requests for medical aid in dying. That argues for greater safeguards, not for prohibiting advance directive implants altogether.

like self-defense or war, to kill another person without their consent. Nor does it make a difference if the killing is temporally remote from my act. But the view Dresser articulates about personhood in dementia is both implausible and excessively demanding. Although the future person with dementia is partially cognitively disjointed from the past person without dementia, there may still be some cognitive continuity; that future person may share some of the past person's memories, for instance. Cognitive continuity is also only part of what makes for the maintenance of personal identity. In virtually every other moral and legal respect, that future person with dementia is the same person as she is now, before dementia. Her current property will still be her property; her spouse will

still be her spouse; her children will still be her children; the obligations of care her family owe her will, in general, continue to be owed to her; if she had committed a crime, she will still be responsible for it, even if her dementia excuses her from criminal penalties. If others wrong her now, she may be owed redress even after developing dementia. Moreover, it makes a great deal of sense for her to care now about what happens to her later—and, indeed, to care more about what happens to her future self than she does about what happens to other future persons with dementia who are not her. After all, that future person's life after dementia still determines how a part of her life goes; and the end of that person's life is the end of her life. Finally, she has special obligations to plan for how that future person's life is going to go. Setting aside any ideas about shortening that life, she is obligated to try to ensure, as far as she can, that she has adequate resources to continue living, that her basic needs will be met, and she should, if possible, try to do things like save for retirement or purchase long-term care insurance. To adopt Dresser's view would commit us to denying each of these ways in which that future person with dementia is still her.

Is it really as bad as all that? Another objection to measures like ADIs emphasizes that life with dementia can be generally good—that the things that seem to make it bad are not really as bad as all that.²⁹ This approach is connected to classic arguments about the experiential interests of persons with dementia. Clearly, with adequate care and support, with a chance to adapt to one's circumstances in the way many with new disabilities do,³⁰ life even with severe dementia can still be good. Advances in technology and caregiving approaches, such as robot pets for companionship and surveillance, or the development of Alzheimer villages, might also make dementia less bad. But the objection, taking inspiration from feminist writings about the eth-

ics of care and from disability rights criticisms of MAID,³¹ emphasizes that wanting to avoid dependency or states that seem to be undignified or humiliating (such as needing assistance in toileting) is mistaken: these states are not intrinsically undignified or humiliating. Not wanting to impose burdens on others is also mistaken, since they may accept these responsibilities willingly. There is nothing wrong with being dependent because needing help from others does not mean that one's life has less value and because part of being human is needing and accepting care.³² If having dementia is bad at all, this objection suggests, it is only because of unjust biases against persons with dementia, structural inequalities, and injustices in systems of care and resource allocation.

We are sympathetic to many of these claims but do not regard them as definitive arguments against ADIs. At best, by emphasizing the ways life with dementia could still, sometimes, be satisfying for the person with dementia and for people close to her, they articulate considerations that might make persons who are inclined to obtain an ADI reconsider. They suggest that it could be reasonable to regard one's future life with dementia as still good; but they do not compellingly demonstrate that it is unreasonable for an individual to regard that future life as potentially bad. Some people with dementia will choose to make the best of it, but others may still reject what they perceive as a tortured end, marred by deep confusion, fear, hallucinations, and dysfunction—the kind of picture portrayed by the poet Larkin.

Slippery slopes. It is worth considering the perennial set of concerns about social pressures and slippery slopes: that permitting the practice would expose persons who would not willingly choose an ADI to pressures to do so. In the 1970s, at the beginning of open discussion of proposals to legalize physician aid-in-dying, allegations were legion that it would yield a slippery slope, at the foot of

which would be the wholesale abuse of vulnerable persons: the poor, the uneducated, the elderly, people with disabilities, and others. No data from the Netherlands or Oregon or other jurisdictions where MAID has become legal support these allegations, however; on the contrary, it is generally persons with higher socioeconomic status, education, and wealth that make use of it.³³

Would the risk of abuse be greater with ADIs? After all, ADIs would be, we assume, simple to place, difficult to detect once placed, and cheap. Meanwhile, incentives for clandestine placement by unscrupulous doctors, cost-conscious insurance companies, and unsympathetic families might be considerable: avoiding, say, five years of burdensome and expensive care might be too strong a temptation to resist, especially since the person in whom the device was implanted would never know it was there.

A more realistic slippery slope is that insurance companies and federal payor systems would simply nudge their clients into accepting ADIs, either through such heavy-handed means as providing full coverage for the device but reducing coverage for other dementia care or through lighter-touch methods like sending clients information about ADIs but not providing information about alternatives. This must be considered a real risk. Accordingly, the legalization of ADIs should be attended by legislation specifically designed to prevent malfeasance, whether subtle or direct, much as the physician aid-in-dying statute in Oregon includes safeguards against and penalties for coercion.

A related issue is whether ADIs would reduce impetus for clinical research or improving systems of care for persons with dementia and their family members. This is an empirical question. We suspect that even most of those who would want an ADI would still support intensive research into effective prevention and treatment of Alzheimer's. Still, it is possible that, if ADIs were widely used, less attention would be paid to

improving the care of persons with dementia generally. Wide adoption of ADIs could, however, have a paradoxical impact, increasing attention to dying with and of dementia, leading to improvements in dementia care indirectly. What would happen is unclear, but it is clear that a society that permits ADIs should carefully monitor for such effects.

Some people might raise concerns about the effects on other vulnerable groups: how would ADIs impact persons with intellectual disabilities, physical disabilities, or mental illnesses? Again, it is hard to be sure. But these concerns would be considerably attenuated by the fact that, as conceived, ADIs would exclusively be provided for persons with early dementia or a presymptomatic diagnosis based on reliable biomarkers and would have to be voluntarily chosen in the context of stringent safeguards to ensure the quality of the patient's decision-making.

Could sufficient safeguards for the use of an ADI—that it should be implanted only voluntarily, that undue influence is not brought to bear, and that its removal on request would be guaranteed, with no delays, no explanation needed, no charge—be absolutely assured? Perhaps not. It is difficult to guarantee that an otherwise permissible and useful practice will not be turned to bad uses. So we would concede that slippery-slope arguments may have more purchase in this context than in ordinary requests for MAID. We think that that argues for greater safeguards, not for prohibiting ADIs altogether.

Getting the Better of Alzheimer's

A distinguished physician writing on dementia, Tia Powell, concludes her perceptive book *Dementia Reimagined: Building a Life of Joy and Dignity from Beginning to End* with a highly personal account of what you should do to keep the bad options in dying of Alzheimer's from "ensnaring you once you are too ill and impaired

. . . to avoid the death you don't want when you die of dementia." "Recognize what's at stake," she says, and understand that "when you reach the final stage, seven, you will not go back to a higher level of functioning; a person in end-stage dementia cannot walk, may not be able to sit up, or even hold up her head. She may be entirely bed-bound, incapable of saying words or understanding them. Incontinence is the norm. Difficulties with swallowing and eating affect almost 90 percent of patients with severe dementia. The capacity to feel pain is as strong as ever, yet it is difficult to identify and treat it in people who can't tell you what the matter is."³⁴ Powell tells us directly what her strategy is: avoid bad care, avoid life-

What we now ask of family members, of clinicians who provide long-term care for patients with sustained, irretrievable, long-term deteriorative cognitive loss, and of patients who are told they have no better option than to keep going on with lives they may not have wanted is unconscionable.

prolonging care, have an advance directive that makes it clear what you don't want, do not let your children put you in a nursing home unless you've left close to a million dollars for them to carry out that wish—*after* you've lived off your retirement funds for twenty-five years. Get palliative care—but no hospital, no ventilator.

But to refuse these measures does not guarantee the end of life that some might want. The gains provided by the ADI, over this approach, would be real. We began by listing a set of things one might want in the face of Alzheimer's or some other equally long-term, irreversible dementia, including having control over how you die, not burdening family members with care needs or financial costs, not losing still-good life by having to undertake avoidance measures like preemptive suicide too

soon, and not asking one's doctor or family members to make difficult decisions or take personally wrenching actions to try to honor your wishes.

The ADI would satisfy all these seemingly inconsistent wishes. Giving people real control over the ends of their lives in the face of a deteriorative disease they do not want to endure, without imposing obligations of decision-making or direct killing on other parties, seems like a good thing. How to balance these considerable gains in the options we have for facing Alzheimer's against the risks of abuse is a matter for further reflection. But one thing is clear: what we now ask of family members, of clinicians who provide long-term care for patients with sustained, irretrievable, long-

term deteriorative cognitive loss, and of patients who are told they have no better option than to keep going on with lives they may not have wanted, that they deeply feared, is unconscionable.

As we said at the outset, whether this consideration of the ADI is understood as a conjecture, as a hypothetical exploration, as a real-life thought experiment, or as a proto-proposal, we think it important to take this seemingly radical idea seriously. We may not currently have the technology to realize it, and perhaps not the social conditions that would allow it to be used without abuse. It may even be hard to conceive of this idea: "Horrible," said one friend, "even if I agree with the conclusion." But we think it is an important idea nevertheless: it makes us see what is so problematic about how we re-

spond to dementia in our current world, forcing some to suffer a future they dread and burdening others with acting for them. No one, really, wants to live with dementia: for most of us, it is bad to lose the memories and cognitive capacities that contribute to who we are and that enable us to do many of the things we care about. Life with mild and moderate dementia, especially when supported with adequate technological and personal care, may still be enjoyed; but in many cases, though certainly not all, living with advanced dementia is difficult for both the person afflicted and those who care about her. Not everyone thinks that these difficulties are sufficient to make that life no longer worth living, but some do. For some, a life that ends in profound dementia is perhaps the worst fate one can realistically foresee. Even if our laws were liberalized dramatically to allow MAID by advance directive during dementia, applying those laws would remain controversial and would continue to impose great burdens on those left behind—on family members, friends, nurses, and, perhaps most acutely, on physicians called upon to act. The development of means to enable persons in the early stages of dementia to choose, while competent, the timing of their own deaths without the subsequent intervention of anyone else would go a long way to ameliorating this situation: they can get the better parts of dementia if they wish but avoid the worse parts they reasonably fear.

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