

Dementia, Advance Directives, and Discontinuity of Personality

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Abstract: We argue that an advance directive (AD) is not invalidated by personality changes in dementia, as is claimed by Rebecca Dresser. The claim is that a new person results under such personality changes, and that the former person cannot write an AD for the new person. After stating the argument against ADs in cases of dementia, we provide a detailed examination of empirical studies of personality changes in dementia. This evidence, though not strong due mainly to low sample sizes and different notions of personal identity, does not support Dresser's position. Given the weakness in the empirical evidence, we turn to a philosophical defense of ADs based on a social contract view supporting the current interests of those writing ADs. Additionally, we argue that personality change is not equivalent to change in personal identity, as would be required by the argument against ADs in cases of dementia.

Keywords: advance directives; dementia; personality change; personal identity

Introduction

We explore and reject the claim that advance directives (ADs) should not apply when a person undergoes a significant personality change in cases of dementia. The claim is that such diseases cause personality changes to the extent that a different personality, and thereby a different personal identity, is created, invalidating the moral acceptability of an advance directive.

After stating the problem, we present Ronald Dworkin's support of the use of ADs in cases of dementia and Rebecca Dresser's rejection of Dworkin's position via claims that dementia may create a new personal identity. We address the issue of personality change in dementia, examining empirical studies about personality loss and change in dementia and also findings about the effects of dementia on various parts of the brain. Although the evidence about personality change is inconclusive, it mainly conflicts with Dresser's claim but fails to support Dworkin's position.

Because the empirical evidence is not strong, we next assume that dementia causes significant personality change. Despite this assumption, we offer arguments in favor of respecting ADs through the various stages of dementia. To do so, we consider possible harm done to a current person by future events. We claim that a social contract view about present harm is the best support for the application of ADs in dementia. Finally, we argue against the idea that personality change and the change in personhood are equivalent.

Advance Directives and the Problem of Change in Personality

In her recent defense of preventive suicide involving people diagnosed with dementia, Dena Davis refers to the argument that changes in personality invalidate ADs.

We thank an anonymous reviewer for thoughtful and helpful comments about an earlier draft.

Davis admits that it is arguably true that dementia changes personality, but she finds the argument against ADs to be unpersuasive. Nevertheless, she adds that the rejection of ADs is not easily refuted,¹ the task we set for ourselves.

Allen Buchanan views the change in the personality in cases of dementia as a threat to ADs. He puts the argument into the form of a syllogism.

- i) One person's advance directive has no moral authority to determine what is to happen to another person.
- ii) In some cases of severe and permanent neurological damage—for example, that due to advanced Alzheimer's dementia—psychological continuity is so disrupted that the person who issued the advance directive no longer exists.

Therefore,

- iii) In such cases the advance directive has no moral authority to determine what is to happen to the individual who remains after neurological damage has destroyed the person who issued the advance directive.

To ensure validity, Buchanan changes (ii) to (ii'), noting that the changed premise is open to challenge.

- ii') The individual who remains after neurological damage has destroyed the person who issued the advance directive is a (different) person.²

We shall eventually present empirical evidence to blunt the impact of (ii'). Furthermore, we shall offer a philosophical argument against the truth of that premise. We shall conclude that the argument is not sound.

Ronald Dworkin and Rebecca Dresser on Advance Directives in Dementia

In *Life's Dominion* Dworkin argues in defense of ADs that include treatment rejected due to dementia.³ These arguments, although sophisticated, have been criticized by Dresser based on issues regarding what she calls "personal identity" and the difficulty of projecting all of the subtleties and nuances of future states of affairs.⁴ For our purposes, we only consider Dresser's arguments against ADs centering on changes in personality.

Terminology is troublesome in the debate over ADs. We believe that Dresser's argument is about change in personality and not about personal identity. We use the terms "personal identity" and "person" as synonymous and use "personality" in a generic sense of enduring patterns of behavior under varying conditions.

Dworkin's position on respecting ADs in dementia is supported by his distinction between experiential interests and critical interests. Experiential interests involve satisfaction from activities such as eating a good meal and experiencing art and athletic events.⁵ Critical interests are more fundamental. These interests involve the attempt to establish meaningful coherence in one's life through projects such as close friendships, loving family relationships, and excellence in one's work/career.

Based on the greater significance of critical interests over experiential interests, Dworkin distinguishes an evidentiary view of autonomy from an integrity view of

autonomy. An evidentiary view, related to experiential interests, maintains that individuals are the best judges of their interests. Even so, the integrity view is more basic. As its name suggests, it supports the attempt to create the kind of life that a person wants, even if that sort of life is not in a person's best interests.

Dworkin believes that the integrity view of autonomy justifies ADs covering dementia. The evidentiary view would not provide sufficient justification for limiting treatment of a demented patient based on an AD because competent persons cannot project what their best interests would be if demented. However, the integrity view would hold, because it moves beyond a best-interest standard.

For Dworkin's view to work, critical interests must persist through dementia, including its advanced stages. Showing this is not an easy task. If critical interests persist, given their priority over experiential interests, then Dworkin's argument seems strong. However, moderate to advanced dementia might destroy critical interests. Dworkin does claim that the distinction between experiential interests and critical interests explains our convictions about forms of abuse, such as brainwashing, that destroy what we formerly valued: abuse destroys critical interests.⁶ Dementia may also destroy critical interests.

Dresser similarly attacks Dworkin's view based on her contention that dementia may involve a change in personal identity, which would thereby destroy critical interests. Her argument is that it is unacceptable to make an AD for another person. So if the person suffering from moderate to advanced dementia is a different person from the person who wrote the AD, the AD would be morally invalid.⁷ For the claim to work, the change must be dramatic, amounting to a new person, as in Buchanan's syllogism. For the attack against ADs to be significant, the occurrence of such a change among those with dementia should be relatively frequent, certainly not idiosyncratic. We take this to be Dresser's position. Because it is a strong claim, we expect strong evidence in its favor.

Dresser defines personal identity as a coherent set of memories as well as psychological coherence—for example, one's consistent desires and goals.⁸ Dresser contends that a person with dementia often does not have the same coherent set of memories and desires and goals as he or she previously had. As a result, the demented person (let us refer to her as Jane II) may be a different *person* from the one that made the original AD (refer to her as Jane I). The AD of Jane I should not apply to Jane II.

Dresser is staking out an empirical position on change of identity based on personality changes in dementia. Her position is strong only if the weight of empirical evidence supports it.

Empirical Studies of Change in Personal Identity

In this section we explore empirical evidence about personality change using the terminology of the studies we examine. We believe these studies actually involve personality and not personal identity, selfhood, or personhood, though these terms are used. Later in this article we present our view of features involved in being a person, a term we equate with personhood and personal identity.

Lisa S. Caddell and Linda Clare examine the question of personality change in dementia by way of a review of a variety of studies exploring the issue.⁹ The results of the review not only call into question Dresser's claims that Jane II has

a different personal identity but also point to the difficulties involved in the notions of personhood that form the basis of claims about changes in personal identity.

Caddell and Clare recognize that their conclusions are tentative, partly due to low sample sizes, different methods (qualitative and quantitative), and different concepts of self. Still, they say, "Almost all of the studies suggest that there is at least some evidence for the persistence of self in both the mild and moderate to severe states of the illness."¹⁰ Unknown is the extent to which dementia affects the whole self or isolated parts of the self. Also unknown is how the self changes over time and whether a persisting self is the old self or a modified self.

Various different concepts of self are used in the studies covered. In the social constructionist model, language is used to create a social reality that influences thought and experience. Personal identity is thought to be revealed by the use of personal pronouns. Five studies listed by Caddell and Clare use this approach: "The majority of these studies suggested that people in the moderate to severe stages of dementia . . . commonly used the first person indexical ('I') and also a range of other personal pronouns."¹¹ Social constructionists also look for selfhood in talk about the past. Such talk is evident in three studies. These studies suggest that there is a link between the person writing the AD and the incompetent subject of the AD, conflicting with the view of Dresser that, in the case of dementia, a new person is the target of the AD.

Interactivist models of self are based in the notion that the self flows from interactions with others. Some studies using this approach concluded that nonverbal behavior indicates a persistence of self-identity. But such conclusions may be weak because discovery of a retained sense of self may be the result of assumptions and pretenses by relatives and staff members.¹²

The final model is the notion of the self as narrative, a view similar to that of Dresser. This appealing concept is explored by means of the ability to communicate a model of one's self. Three studies, all based on small samples, report that "most people in the moderate to severe stages of dementia were able, at least to some degree, to construct a narrative which consisted of autobiographical memories, and that this process enabled them to preserve aspects of their self and identity." Nevertheless, as the disease progressed, sharing a narrative became more difficult.¹³

The authors present a convenient table summarizing the results of the studies covered. The table indicates that most studies show persistence of a self. Of the 20 studies summarized, 7 failed to show a persisting self. However, 6 of the 7 used self-recognition in photographs or mirrors as the touchstone. It may be that dementia makes difficult self-identification in mirrors and photos even when a sense of self persists. Where persistence was evident, some studies indicated a weaker sense of identity than exhibited by controls. One study found that "many identities were forgotten or reduced in significance, but some are preserved—particularly the familial role. This suggests that some sense of self continues to exist even in the advance stages of dementia."¹⁴ Another study found that "identities are being preserved despite memory loss." Yet another study concluded that the self "can be preserved and manifested in the face of degenerative illnesses."¹⁵ No studies support the existence of a basically different self.

A suggestive report by S. Klein, L. Cosmides, and K. Costabile is a case analysis involving a single subject.¹⁶ This study is especially interesting given Dresser's

claim about a new personal identity. The study is about 76-year-old K.R., a former high school guidance counselor who is living in assisted living after being diagnosed with Alzheimer's dementia. She cannot name simple objects such as pencils and is often disoriented. She cannot recall events that happened minutes before. Sometimes she believes her husband is still alive and has no idea of how long she has lived in the assisted living facility. Although K.R.'s personality has changed, she has little knowledge of the change. This suggests that she has an inability to update her mental records related to personality changes. Accordingly, the authors tested this hypothesis: "If her self-knowledge is intact but not being updated, then K.R.'s ratings should reflect her premorbid personality rather than her current one."¹⁷ We note that the account of K.R. uses "personality" as we use it. We believe this is superior to using the more complex terms "personal identity" and "self." K.R.'s daughter was asked to rate her mother's current personality traits compared to those traits prior to the onset of dementia. There was a strong correlation between her daughter's ratings using the past and her mother's current ratings of personality traits. The high correlation between the mother's and the daughter's responses indicates that "K.R.'s fund of personality knowledge was created pre-morbidly, and remains intact."¹⁸

The conclusion that K.R. retains her prior personality traits, without significant updating, suggests that at least some of her critical interests did not change. This would support Dworkin over Dresser. However, the report may be considered idiosyncratic, because it examines a single person's experiences. Even so, the authors claim there is a growing body of knowledge about similar cases. After providing seven citations, they claim: "Across these cases, trait self-knowledge has been preserved in the face of impairments to episodic retrieval, personal temporality, general world knowledge, and the meta-representational skills that allow self-reflection. In contrast, there are no documented cases in which a person has lost trait self-knowledge while retaining other components of the self."¹⁹

The statement about loss of trait self-knowledge is in contrast to Dresser's concerns about a new person. In our interpretation of the statement, various forms of dementia are best viewed as disease states, much like other late-stage diseases, that eventually destroy personality, whereas earlier stages leave intact some personality traits even while destroying other personality traits. If this is true, then there is no new person as in Buchanan's syllogism. In this way, ADs covering dementia should be treated the same as ADs for other diseases.

A concluding sentence of the study of K.R. is telling: "Clinicians and family may need to be sensitive to the possibility that such individuals may see themselves as they were, not as they are."²⁰ An AD indicates from a prior perspective how a patient should be treated. If the report accurately portrays dementia, then that prior state in which the AD is written is not contradicted by the sense of self of the current state. The current state is a combination of the effects of a disease, which is covered by the AD, and the remaining traits of the prior self.

The authors of the study of K.R. offer support from neuroscience about her intact personality traits. Various studies indicate that the apparently unified self is composed of at least five isolable components. These are listed as follows: (1) episodic memories; (2) self-representation of personality traits; (3) facts about one's own personal history; (4) the experience of personal continuity over time, including personal agency; and (5) self-reflection on thoughts and experiences.²¹

The multifaceted nature of personality is corroborated by several fMRI studies. In a review article, M. Kennisa, A. Rademakera, and E. Geuzea explore the use of fMRI studies to locate correlations between various parts of the brain and behavioral traits indicating personality.²² These studies associate the following areas with behavioral traits: the dorsal and ventral prefrontal cortex; brain areas anterior to the central sulcus; the anterior cingulate cortex, which is included in the prefrontal cortex; the cingulate cortex; the posterior cingulate cortex; the insular cortex; and the temporal, parietal, and occipital lobe. Given different aspects of personality, it is likely that not all parts of the brain related to different aspects of personality will be affected by dementia in its moderate to advanced stages.

S. Sabat and M. Collins note that the areas of the brain most affected by Alzheimer's disease are the occipital, parietal, and temporal lobes' lateral surfaces as well as the limbic system. "There are, however, areas of the brain that show far less degeneration . . . and these relatively intact areas include the primary project areas of the occipital, parietal and temporal lobes; the classic motor strip of the precentral gyrus of the frontal lobe; and most relevant for the present discussion, the prefrontal association areas." These relatively intact areas are involved in "complex, contextually based, goal oriented, and temporally organized behavior."²³

Sabat and Collins provide an account of 63-year-old Mrs. F, a former teacher and a musician, who suffered from Alzheimer's disease. She was proud of her accomplishments as a teacher and musician. They conclude: "It is clear that Mrs. F. would rather be seen as someone possessing the positive attributes of her past, in the role of a teacher, than as someone who is seen primarily as an [Alzheimer's disease] sufferer and a participant in an adult day care center."²⁴ They suggest that the areas of the brain less affected by the disease account for the preservation of her sense of self.

To defeat an AD, more must be involved than changes—even dramatic changes—in personality. Buchanan correctly states in premises (i) and (ii') that the argument against ADs is based on the invalidity of one person writing an AD for another person. The changes must be deep enough to entail a different person, just like I am a different person than my twin sister. Being a different person in that strong sense should be defended with clear empirical evidence, and with a clear account of what it means to be a different person. Without solid empirical evidence, the position rejecting ADs fails, at least until evidence establishes the difference. The evidence we have is not fully compelling, but overall it conflicts with the view Dresser supports.

Does the empirical evidence support Dworkin's viewpoint? At the core of his argument, Dworkin claims that people with dementia retain critical interests that are much like their previous interests. The problem with this view is that people with dementia may not have critical interests, even if their personhood does not fundamentally change. The evidence we explored is mainly silent on this point. Recall that critical interests for Dworkin involve a desire to maintain coherence in one's life. A person with dementia may place an enduring value, for example, on friendship. This might be based on current experiential interests that might overwhelm critical interests in moderate to advanced stages of dementia.

All in all, Dworkin's defense of ADs in cases of dementia is not philosophically adequate. He does not fully explain critical interests and does not explain how

those are maintained in the face of overwhelming disease. The evidence from empirical studies on personality in dementia supports neither Dworkin's idea that critical interests are maintained nor Dresser's claim of a deep change in personhood.

We seek a stronger defense of ADs in dementia, one that will resist possible new evidence of a change in personality and one that is not dependent on the maintenance of critical interests. The view we support is that ADs should be respected even when there is a major change in personality. We attempt to support ADs by examining the relationship between present interests and future circumstances, starting with Joel Feinberg's notion of harm.

In his four-volume study of harm, Feinberg defines "harm" in relation to interests. Harm is a "thwarting, setting back, or defeating of an interest."²⁵ An act of harming is a single case of doing harm, but a harmful condition is a state leading to other harms. Having a disease may mean that a person cannot pursue other interests and so would create a harmful state. However, whether a harm causes a harmful state depends on the person's situation. For example, a blister on one's finger may be a small harm but to a violinist could be a harmful state.

As the blister example suggests, harms come in degrees. Harms that thwart our ability to accomplish the things we have interests in are typically the most serious. These are harms to our *welfare interests*. "These are interests in conditions that are generalized means to a greater variety of possible goals and whose joint realization, in the absence of special circumstances, is necessary for the achievement of more ultimate aims."²⁶

ADs created when one is competent can be used to protect one's interests should one become incompetent. These interests may be known or unknown by the incompetent person. With profound dementia it is likely that welfare interests would be unknown, while other interests, for example, in simple enjoyment, might be known. Under our interpretation of Feinberg's view, simple enjoyments do not have the same status as welfare interests; dementia places a patient in a harmful state in that it causes a person to be unable to maintain welfare interests. Under this interpretation, ADs for dementia are much like ADs for other conditions. An AD to withhold treatment can be viewed as avoiding a harmful state and so may be in the best interest of the patient even while the patient enjoys a variety of pleasures.

Using the view that ADs for dementia may avoid a harmful state is, we think, a better defense than Dworkin's use of critical interests. Although better defined than critical interests, Feinberg's notion of a harmful state as a defense of ADs suffers from some of the same problems. If Dresser proves to be correct that dementia leads to the existence of a new personality, then old welfare interests may be replaced by new welfare interests. For example, the old interest might be in musical accomplishments, whereas the new welfare interest might be in maintaining a supportive environment. Such changes may undermine the moral legitimacy of ADs in the way that Dresser argues. The task we set ourselves is to defend ADs in a way that is immune to the personality change caused by dementia.

ADs and a Stake in the Future Events

We provide a hypothetical but realistic case, one loosely based on actual circumstances. This case will be referred to as we proceed.

Mrs. R was diagnosed with Alzheimer's at the age of 85. She most valued her 3 children, her 10 grandchildren, and her 5 great-grandchildren. Although she sometimes aggressively protected her family, her disposition was otherwise loving and caring. By 89, her dementia had already caused serious memory loss and had created significant anxiety. She could not tell time and did not know whether it was day or night. Always concerned with being prompt, this inability created stress for her and her loved ones. She was often agitated in a way that her family had not previously noticed. This stress over not knowing the time lasted until her dementia worsened. Eventually, she did not recognize her children; she showed signs of apprehension when they kissed her or tried to hold her hand. At 91 she no longer talked and was wheelchair bound. Her daughter, who made medical decisions for her, approved an antibiotic when Mrs. R. suffered from a serious infection. Mrs. R. did not have an AD, and her daughter would likely refuse invasive treatment, even if it was a life-saving treatment. However, her daughter could not bring herself to reject an antibiotic. Mrs. R. lived two additional years. The staff at her nursing home eventually gave her a baby doll. Mrs. R. spent her days caressing the doll, until she lost nearly all reaction to her external conditions. After being moved to the nursing home, the cost of her care increased dramatically; at death she left her children about one-quarter of what they otherwise would have received. She died relatively peacefully at the age of 94.

Mrs. R. seems to have maintained a similar personality, as is evident in, for example, her emphasis on being on time. Yet at the point when she is no longer concerned about time and does not recognize her children, she might be thought of as having a greatly diminished personality, perhaps none at all. Whether or not she has a different personal identity, for the time being we make that assumption.

The assumption we now make is that a person writing the AD, Jane I, is dead in the sense that at some point in the progression of the disease a new personality has overtaken the old personality. We call this *personality death*. Later on we address the issue of whether a new personality is equivalent to a new person. If Jane I underwent personality death, then a key issue is whether Jane I can be harmed now by anticipating that her AD will not direct events in Jane II's life. If so, is it appropriate to give priority to Jane I's interests?

Some philosophers, including Joel Feinberg,²⁷ George Pitcher,²⁸ and Ernest Partridge,²⁹ have argued that a person can be harmed by future events, even after death. The basic idea is that current interests, things that people have a stake in, can be set back by future events. In the case of an AD covering dementia, this may involve a kind of competition between the future interests of the patient suffering from dementia and the interests before incapacity.

The person writing the AD, Jane I, is the person who takes on the personality of Jane II. Let us say that, presently, Jane I has an interest in stopping actions that prolong the demented state, such as antibiotics to address pneumonia. Jane II faces the prospect of a new narrative in dementia, one that may include agitation, loss of memory of loved ones, the inability to speak, and so on. This is also part of Jane I's narrative, her future, even if she takes on the new personality of Jane II.

Is it permissible for Jane I to dictate treatment options for Jane II under our assumption of a new personality? The new personality is the death of the old personality. We turn to Ernest Partridge's philosophical defense of current interests

as binding after death. Partridge insists that we have moral obligations relating to the dead: "Moral requirements toward the dead, such as refraining from libel and respecting wills, I will term 'duties of respect toward the dead,' or 'posthumous respect,' or 'giving the dead their due.'"³⁰

What is the basis for moral obligations toward the dead? The answer begins with the claim that "I have an interest in affecting events beyond my death because I can imagine, anticipate, and evaluate such events now, I can now perceive their impact upon things and persons I care for now."³¹ A person such as Mrs. R., before diagnosis of dementia, had an interest in affecting events after the diagnosis. Partridge understandably considers such interests to be morally important. Mrs. R. can, in Partridge's words, "imagine, anticipate, and evaluate such events now."³²

Partridge offers the Nobel Prize as an example in order to emphasize the importance to the living of events beyond death. Nobel financed the prize because he wanted to advance his interest in science, literature, and peace. Once dead, violations of Nobel's stipulations about the prize would not harm him. "Still, such an act would be a violation of a contract made with the deceased during his lifetime. And the violation of such contracts, when widespread, can make a profound difference to the living, and to those who follow."³³ The conclusion is clear: "Because the living have expectations and concern for having their own wills respected, they also have an interest in respecting the wills of the deceased."³⁴

ADs are analogous to wills. Generally, ADs can express the interests of a now-competent person in relation to the person he or she becomes when incompetent. That future person may be unconscious, in great pain, in a circumstance of hopelessness, or facing loss of dignity. Those who write an AD are expressing their current interests about the treatment they want for the incompetent person they might become. ADs are institutionalized into law in order to respect these previous interests, regardless of the interests of the future person. Socially speaking, such institutions attempt to do what wills do. These current interests in cases of dementia may involve future costs, prolonged treatment, loss of dignity, and so on. All of these happened to Mrs. R. Whether each is experienced by the incompetent future person is not the issue. The issue is about respecting the interests of the now-competent person. To paraphrase Partridge, violating ADs can make a profound difference to the living.

Partridge's view provides support of a societal agreement to respect ADs even when the person in the future has a different personality and is no longer a competent version of his or her present self. He offers a social contract perspective on wills³⁵ and so, by our extension, on ADs.

In the novel *Still Alice*, Alice looks at her future in light of the predictable ravages of Alzheimer's:

She needed a better plan, one that didn't include her playing beanbags ... with Evelyn in the Alzheimer's Special Care Unit. One that didn't cost John a fortune to keep alive and safe a woman who no longer recognized him and who, in the most important ways, he didn't recognize either. She didn't want to be here at that point, when the burdens, both emotional and financial grossly outweighed any benefit of sticking around.³⁶

Alice expresses her interests as a competent person with Alzheimer's. We respect Alice's viewpoint by supporting an AD she might write that limits treatment.

It is not enough to claim that Alice II is happy playing beanbags, as she might or might not be. People with Alzheimer's often suffer anxiety, as did Mrs. R.; they also may suffer from hallucinations, depression, and delusions.³⁷ Still, the real issue is about socially designed ways to respect Alice's highly significant interests before incapacity.

We assumed that Mrs. R., now Mrs. R. II, has a different personality. We did not assume any particular notion of personality. However, having a personality is not all there is to being a person. Mrs. R. II has the same DNA, many of the same traits, probably similar feelings, and the same brain structure insofar as it is not ravaged by her dementia. She looks the same, has the same social security number and bank accounts, has the same children and grandchildren, and so on. These are all aspects of what it means to be a person. These traits are a good part of the reason that the legacy of Mrs. R. II is the legacy of Mrs. R. If Mrs. R. wrote an AD, she would have had an interest in what happens to Mrs. R. II that is at least as great as the interest a person writing a will has about how that will is administered. Social enforcement of an AD involving treatment during dementia is supported by the importance of the current interests of the writer.

Nancy Rhoden differently expresses a similar position about the person with dementia: "Viewing the patient only in the present divides her from her history, her values and her relationships—from all those things that made her a moral agent."³⁸

We return to Buchanan's syllogism.³⁹ Premise (i) claims that one person cannot write an AD for another person. We do not contest this under an ordinary sense of "person" but note that term "person" is left vague. We argued previously that a change in personality, even a radical change, does not amount to a new person. Thus, we reject the truth of premise (ii'), even though it makes a weak claim that *sometimes* a change in personality amounts to a different person. We argued that a person is more than a set of behavioral traits—that is, more than a personality. Dementia is not capable of destroying many of the features of personhood. We conclude that the syllogism is not sound, because premise (ii') is false.

Concluding Remarks

Our conclusion is that dementia should be treated as other diseases covered by ADs. Dementia's devastating effect on cognitive abilities is a good reason to support ADs. These ADs should be socially supported in order to protect the interests of a person facing the devastating effects of the disease.

Those of us who care for loved ones with advanced dementia, people like Mrs. R., understand the devastating nature of the disease. Intuitively one knows that one's mother, holding a plastic baby, unresponsive, and unable to speak or walk, would not want life-saving treatment, despite her seeming pleasure at stroking the baby. Had Mrs. R. written an AD stating her interests, her decisionmaker daughter would not have approved the antibiotic she received, a tough decision without an AD.

A patient diagnosed with dementia might not have an AD, or an existing AD might not contain directions about acceptable treatments in various stages of dementia. After an initial diagnosis, it is advisable for the healthcare team to recommend that, for example, a living will be written or reexamined with future stages of dementia in mind. The changes to an AD may indicate withholding

treatment, even less intrusive treatment such as antibiotics, or it might include instructions that support continuing lifesaving interventions. Neurotechnologies and new drugs might be developed that would lead a patient, given his or her values, to reconsideration of past AD directives. Since developments that may delay or even reverse the neurological disease progression, Assya Pascalev and James Giordano propose an AD especially designed for neurological disorders, which they label a *neurological AD*. It is also advisable for ADs to be revisited in different stages of the disease until a patient becomes incapable.⁴⁰ By revisiting an AD a patient has an opportunity to reevaluate treatment options in light of changing circumstances.

Notes

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35. See note 29, Partridge 1981.
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