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Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value

[A] man does not consist of memory alone. He has feeling, will, sensibilities, moral being . . . And it is here . . . that you may find ways to touch him.
—A. R. Luria

Mrs. Rogoff was always an independent woman. Raised in an immigrant family, she was used to working hard for what she wanted. Most of her life she ran a successful business selling liquor. She also developed local fame as an outstanding cook and hostess. After her third husband’s death she lived alone, enjoying what she considered, by old-country standards, a luxurious lifestyle: keeping up a nice big house and indulging in restful leisure. She was an introvert, always carefully guarding the way she presented herself to others. Life inter-

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ested her insofar as she could live according to her own sense of comfort, making her own mistakes and relying on her own strength and wisdom.

In her early eighties Mrs. Rogoff developed severe motor impairments, which could only be corrected by a risky neurosurgery. She decided to undergo the procedure, insisting that she would rather die than be immobile. She prepared a living will, requesting not to have her life prolonged if she became a burden to her family or if she could no longer enjoy her current quality of life.

The surgery was successful, but shortly thereafter Mrs. Rogoff developed early signs of dementia: memory and word-finding difficulties. As she became more and more disoriented, her daughter hired a housekeeper, Fran, who moved in with Mrs. Rogoff. Fran takes care of Mrs. Rogoff the way one would take care of a child. Mrs. Rogoff enjoys the long hours she spends with Fran, and with her grandchildren whenever they visit, telling them somewhat disjointed stories about her earlier ventures. She watches TV a lot and her stories often incorporate the more exciting episodes from TV as if they pertained to her own life. In her more lucid moments, Mrs. Rogoff tells her grandchildren that she is scared to die, that “she doesn’t want to go anywhere.” She usually cries when Fran is away and when her grandchildren wrap up their visits.

Fran has to make day-to-day decisions for Mrs. Rogoff: Should Mrs. Rogoff get dressed if her family is coming to visit and she insists on wearing pajamas? Should she take a bath every day even if she is afraid of water? Should she be taken to fix her dentures, if every excursion out of the house makes her scared and unhappy? In general, should the current decisions reflect the care Mrs. Rogoff used to take in how she presented herself to others? Mrs. Rogoff’s daughter faces the more weighty decisions: Should she use up Mrs. Rogoff’s savings to pay Fran’s salary, allowing Mrs. Rogoff to keep enjoying her companion, or should she place Mrs. Rogoff in a nursing home, increasing the likelihood that, when the time comes, there will be some money left to execute Mrs. Rogoff’s will? What treatments should she authorize if Mrs. Rogoff develops a dangerous but treatable infection?

People who care for Alzheimer’s patients—family members, nursing home providers, physicians, medical researchers—face such dilemmas
routinely, and these dilemmas are likely to become more and more familiar as baby-boomers approach the age of high risk for Alzheimer's. The particulars of each dilemma may seem unique, but they typically have the same underlying structure. Consider two further cases, also drawn from real life:

Mr. Burke has been diagnosed with moderate Alzheimer's dementia. He is still able to take care of his basic needs, and he gets around on his own. One day he shows up at home, thrilled, driving a brand-new red pickup truck that he has just bought at a local dealership. He has always wanted to own a truck like this, but he and his wife agreed long ago that they were not ready for the sacrifices in their lifestyle required by such a purchase. Their finances have not changed since. Mr. Burke's doctor, trying to help the family sort out the situation, asks Mr. Burke about his decision. "A man needs his truck," Mr. Burke explains. He is no doubt fulfilling his long-standing desire for this important status symbol. He also says that he can afford it. The family faces a difficult decision: Should they return the truck to the dealership or should they allow Mr. Burke to keep the truck and live with the consequences?

Mr. O'Connor was a deeply religious man for whom thoughts of taking his own life or of withholding lifesaving measures for whatever reason were completely unacceptable. In his seventies he developed Alzheimer's disease. He lost his ability to do many of the things he used to enjoy, such as playing the piano; soon he could no longer take care of himself. With the loss of capacity for complex reasoning, most of his religious beliefs gradually faded away. Then came a terrible emotional blow: the death of his wife. He has now begun saying that he does not want to go on, that he does not want to live. His daughters no longer know what would be best for him: Should they make decisions for him based on his earlier life-philosophy or should they respect and take seriously his current wishes?²

² These three cases were reported by family members and a doctor. Throughout the article, I use fictitious names in cases not drawn from published literature. Also, to protect privacy of the patients, I do not list the names of my sources, but I would like to thank them for their generous help.
All three stories recount a conflict between the attitudes and values the patients professed when they were still healthy and their later preferences as people afflicted with dementia. The quandary, in a nutshell, is this: Should we, in our efforts to best respect a patient with dementia, give priority to the preferences and attitudes this person held before becoming demented, or should we follow the person's present preferences?

I. Overview

There are two dominant theoretical perspectives on how such dilemmas ought to be resolved, expressed most prominently by Rebecca Dresser and Ronald Dworkin. According to Dresser, decisions affecting a demented person at a given time must speak to the person's point of view as current at that time. Heeding values and wishes that the patient no longer espouses and that cannot be said to represent her present needs and interests can do no good for the patient. In the most radical expression of this position, Dresser argues that a patient's earlier preferences should not be taken into account, because the demented patient is not necessarily the same person as the one who expressed these preferences. But even setting this metaphysical argument about personal identity aside, the moral pull of Dresser's position is undeniable: the caregiver (say Fran, Mrs. Rogoff's caregiver) is faced with a person—or if not a fully constituted person, at least a conscious being capable of pleasure and pain—who, here and now, makes a claim on the caregiver to fulfill her needs and desires; why ignore these needs and desires in the name of values that are now extinct?

Dworkin directly challenges this line of reasoning, adducing compelling reasons to adhere to the demented patients' earlier wishes and values. In Dworkin's view, we fail to take seriously both the autonomy and the well-being of a demented patient unless we adhere strictly to the patient's earlier wishes, wishes that originated when she was still capable of acting autonomously and still able to judge what was required for her overall well-being. In brief, we ought to respect the patient's earlier wishes because we ought to respect and defer to the abilities and

thought processes that gave rise to those wishes—we ought to respect the person's personhood as it was when it was still intact.5

In this article, I develop an alternative to both Dresser's and Dworkin's analyses. Like Dresser, I want to take seriously the current interests of demented patients, but for very different reasons: I believe that many of these patients may still be capable of autonomy to a significant degree and that they may still have authority concerning their well-being. Yet I emphasize very different aspects of both autonomy and well-being from those of Dworkin, who predicates autonomy on decision-making capacity, and for whom well-being depends centrally on promoting one's own design for one's life as a whole. I associate potential for autonomy primarily with the capacity to value, and well-being with living in accordance with one's values.6 Thus, the central question for a caretaker attempting to best respect an Alzheimer's patient becomes not, “Can this patient reason thoroughly and come to a rational decision?” or “Does he grasp what’s best for his life as a whole?” but “Does this patient still value?” I will argue that the capacity to value is not completely lost in dementia, and to the extent that it is not, respect for the immediate interests of a demented person is contrary neither to his well-being nor to the respect for his autonomy.

Dworkin's arguments are a fruitful point of departure because their kernel is very plausible: After someone loses her status as an agent—as a creature capable of guiding her actions—her earlier autonomously chosen values should continue to govern what happens to her, despite her current inability to appreciate these values. This accurately locates the central issue of our dilemmas: At what point in the course of dementia are the attributes essential to agency lost? My answer reexamines Dworkin's assumptions about what is essential to agency, or, more specifically, his minimal requirements for the capacity for autonomy and for the authority concerning one's well-being. Since Dworkin's understanding of the essence of agency and autonomy—privileging the decision-making capacity and the ability to plan one's life—is quite preva-

5. Dworkin's analysis of these cases may differ depending on the degree to which the patient's earlier wishes involve an explicit decision about what should be done in the circumstances at hand.

6. I develop more fully the account of moral psychology underlying this approach in “Rescuing Oblomov: A Search for Convincing Justifications of Value” (Ph.D. diss., Harvard University, 1997).
lent in medicine, in law, and in everyday life, my inquiry challenges not only Dworkin’s philosophical position, but also our ordinary attitudes toward Alzheimer’s and other dementias.

Dworkin puts forth two main arguments to justify adhering to the wishes the patient expressed before becoming demented. As he sees it, this course of action both promotes the patient’s well-being and is required in order to respect the patient’s autonomy. In each argument, while I consider most of the ideas well-founded, I challenge the crucial premise. In the argument focused on the patient’s well-being, I dispute the claim that demented patients are no longer capable of generating what Dworkin calls “critical interests.” In the argument concerning autonomy, I question the premise that demented patients no longer possess the “capacity for autonomy.” In each case, I will trace how the problematic premise arises within Dworkin’s argument and then develop an alternative account of the relevant capacity.

II. RECONCEIVING WELL-BEING

When we take enhancement of the demented patient’s well-being as the caregiver’s goal, we need to distinguish two types of prudential interests the patient may have. Dworkin labels these two types of interest “experiential” and “critical.” Experiential interests concern the quality of the person’s experience, her state of mind. We have an interest in experiencing pleasure, satisfaction, enjoyment, contentment, lack of pain, etc.; what states of mind count here and how they can be brought about is determined fully by how these experiences feel to the person in question. But most of us also have critical interests—interests in doing or having in our lives the things we consider good and in avoiding the things we consider bad, no matter what sorts of experiences result from fulfilling these interests. A person’s critical interests may, for example, include being a successful soldier or securing contentment and harmony for his family, however much stress or anguish the pursuit of these goals may engender.

Experiential interests are inherently time-specific—to satisfy them at

7. Given this focus, I will not discuss other possible criticisms of Dworkin’s arguments.
8. The exact relevance of a person’s opinions about the good to her critical interests depends on the merits of these opinions. I will discuss this complication only to the extent that it is relevant to my arguments.
a given time, the person must still espouse them at that time. For example, it only makes sense to want to satisfy your experiential interest in having a good time with your guests if at the time they arrive you will still be interested in enjoying their company. Not so with critical interests; it may make sense to have your critical interest satisfied even if you are unaware of its being satisfied, even if you are dead at the time, or unconscious, or too demented to grasp what your critical interest has been all along. Fulfillment of a critical interest bears only on the object of that interest.\(^9\) It involves bringing about whatever state of affairs the person in question judged good; the fate of the person herself is not relevant to this, provided that the object of the interest is external to the person. Thus, fulfilling a father's critical interest in the well-being of his family does not require his awareness of how well they are doing. This critical interest could be advanced, for example, by obeying a deathbed promise to take care of his wife and children after he passes away.

Dworkin readily grants that Alzheimer's patients, even at late stages of their illness, can experience pleasures as well as frustrations, and thus have the basis for contemporaneous experiential interests. He would interpret the dilemmas under discussion in this article as cases of conflict between these experiential interests and critical interests the person professed when he was still healthy (e.g., a conflict between Mr. Burke's experiential interest in enjoying his new truck and his critical interest in assuring a comfortable standard of living for his wife). And here Dworkin assumes that, at least in the types of cases he wants to address, the demented patient is not capable of generating contemporaneous critical interests. From this point, there follows a very plausible analysis. The fact that the demented patient no longer affirms critical interests in no way implies that he does not have critical interests. Since such interests are not inherently time-specific, the prudential importance of satisfying them may survive the person's unawareness of their satisfaction, whether due to unconsciousness, dementia, or even death. Thus, a demented person who cannot generate contemporaneous critical interests may still have some of the same critical interests he professed when he was healthy. And this means that the conflict occurring in our dilemmas is best described as a conflict between the patient's ongoing experiential interests and his ongoing critical interests.

\(^9\) I leave out the case where the person changes her mind about her critical interest—the old critical interest does seem to become truly obsolete then.
This description helps clarify how the conflict ought to be resolved. In the case of an ordinary competent person, when his critical interests (his judgments and values) come into conflict with his experiential interests (what would lead to the optimal state of mind for him), we do not hesitate to give precedence to his well-considered values and judgments, and we concede that this is, overall, best for him. For example, we would accept that it is in the best interest of a devoted father to sacrifice his experiential interest in his current comfort for the sake of the future of his children; or that it is in the best interest of a patriotic soldier to forgo his experiential interest in a carefree life and sign up for demanding military training. And the case of our demented person turns out to be no different: in his conflict between ongoing experiential and critical interests, it is also best to privilege the latter. We serve Mr. Burke best if we promote his critical interest in assuring a comfortable lifestyle for his wife, at the expense of his experiential interest in enjoying his new truck. And we serve Mrs. Rogoff best by satisfying her critical interest in not being a burden to her family, at the expense of her experiential interest in enjoying TV and storytelling.

This analysis stands or falls with the assumption that demented patients no longer originate critical interests. For if they do—if the conflict in our dilemmas is between the patient’s contemporarily professed critical interests and the critical interests she professed before becoming demented—Dworkin’s framework would readily allow that contemporarily professed critical interests ought to take precedence. In this case, the demented person would be viewed as any other person whose values and commitments change over time and whose currently professed values are taken to have bearing on what is best for her.

Note that the idea that a demented person can originate critical interests need not imply that the person generates brand new critical interests. What matters is whether the person still has an ongoing commitment to her critical interests. After all, the most likely scenario of a conflict between a demented person’s current critical interests and her critical interests from the predementia period is not one in which a person’s demented mind generates completely new critical interests, but rather one in which dementia causes a person to lose some of her earlier more complex interests, so that in the new, simpler configuration the remaining interests gain import.
Here is how Dworkin defends the claim that the demented cannot generate critical interests:

[B]y the time the dementia has become advanced, Alzheimer’s victims have lost the capacity to think about how to make their lives more successful on the whole. They are ignorant of self—not as an amnesiac is, not simply because they cannot identify their pasts—but more fundamentally, because they have no sense of a whole life, a past joined to a future, that could be the object of any evaluation or concern as a whole. They cannot have projects or plans of the kind that leading a critical life requires. They therefore have no contemporary opinion about their own critical interests.10

In contending that demented persons cannot have opinions about their critical interests, Dworkin presupposes that one needs to have a sense of one’s life as a whole in order to originate critical interests, a sense that a person may begin to lose relatively early in the progression of dementia. Dworkin thinks of critical interests as stemming from “convictions about what helps to make a life good on the whole.”11 But do critical interests have to reflect the person’s comprehensive design for the progression of her life? An alternative view, tacitly embedded in Dworkin, is more plausible.

Critical interests may well be understood to issue from something less grand—simply from convictions about what is good to have, which do not require the ability to grasp or review one’s whole life. Dworkin himself describes “opinions about my critical interests” as “opinions about what is good for me,”12 indicating that these are opinions about values, and that the ability to generate critical interests goes hand in hand with the ability to value. And it does seem possible for a person to value something at a given time, without referring this value to his conception of his life as a whole. This possibility is evident in patients with severe loss of memory and linguistic ability who are still aware of their decline and deeply regret it. I recently observed a patient who, in response to a simple question about what he did that day, had great difficulties keeping track of the sequence of his thoughts and of the sequence of

11. Ibid., pp. 201-2.
words in the sentence he was composing, and after several starts and long pauses, said slowly, his voice trembling, “Here you can see Alzheimers at work.” There was no doubt that this man, who had little grip on “his life as a whole,” nevertheless valued the abilities he could no longer command and was expressing profound regret.

Intuitively, it is easy to recognize when someone expresses a value—and not merely a simpler attitude such as a craving, a desire, or a wish. But to exhibit more clearly that valuing need not involve a grasp of one’s life as a whole, let us characterize more systematically what valuing is and distinguish it from these simpler attitudes, which even Dworkin readily attributes to Alzheimer’s patients.

The main difference between mere desiring and valuing is this: One way to deal with one’s non-value-laden desires is to try to eliminate them—to try to bring it about that one does not feel them; but this would not be a satisfactory response to a valuing. A person could contemplate being free of a mere desire with a sense of relief, but one would always view the possibility of not valuing something one currently values as an impoverishment, loss, or mistake. We can all recognize clear cases when a strong desire is definitely not a value: Think of a priest eager to rid himself of his sexual desires, or a temporarily depressed person seeking relief from his persistent wish to hurt himself. And even if one’s attitude toward a desire is more neutral—perhaps one views it only as a nuisance—so long as one would not mind lacking it, it is still a mere desire; cravings for specific food items are paradigmatic cases here. By contrast, when you value something, say, you value a particular friendship or a local community, you cannot be indifferent to whether you happen to value these things or not—a state in which you lacked your feelings for your friend or your need for a sense of belonging would be one to regret. And we can see this in our patient mourning the losses

13. Sometimes the term “desire” is used to cover all possible kinds of pro-attitudes. On this usage, any value would also count as a species of desire. I do not favor this usage, but it would still allow for the distinction I am drawing here, the distinction between values and “mere desires,” that is, desires that neither are also values nor are accompanied by parallel values.

14. In the case of some (often less central) values, one may anticipate a gradual transformation and loss of a value without thinking it would be a mistake. This is not a counterexample to my characterization of valuing, because my claim concerns our attitudes to our present espousal of a value: It is part of valuing something that you would view the possibility of not caring about it here and now as an impoverishment, loss, or mistake. Imagining a future without the alleged value is a good test for this in many cases, but it does not
caused by Alzheimer's—he would view with horror the projected future in which he will no longer care about these losses.

So values have special attributes that do not apply to mere desires: We think it would be a mistake to lose our current values—we hold our values to be correct, or at least correct for us.\textsuperscript{15} And this means that we can typically give a rationale for why we consider something valuable or good, usually by situating this value in a larger normative framework. Also, since values are the sorts of attitudes that we allow could be correct or incorrect, they are open to criticism and revision. At minimum, there are consistency requirements on what one can consider good—if you value something and also value its opposite you will be under rational pressure to resolve the conflict. For example, if you truly value a committed relationship you cannot just as easily value the freedom of a lack of commitment; you may well see the merits of both, but you cannot be fully committed to your spouse unless you cease to care as deeply about your freedom. By contrast, as a matter of sheer desire, one may surely remain ambivalent without any rational impetus to settle the conflict—one may simply keep craving just as strongly the kind of intimacy possible only in an ongoing partnership as well as the excitement of always being able to walk out and entice a new partner.

Another mark of valuing as opposed to mere desiring is that a person's values are usually entangled with her sense of self-worth: A person values herself in terms of how well she lives up to her values. Some people pay little attention to their own value, so what I am now describing is not a necessary condition of having values. However, it is a sufficient condition: Anyone who has a conception of herself, a set of ideals that

\textsuperscript{15} Values overlap significantly with second-order volitions which, in Harry Frankfurt's familiar account, distinguish a person from a mere wanton ("Freedom of the Will and the Concept of a Person," in \textit{The Importance of What We Care About} [Cambridge: Cambridge University Press, 1988], p. 16). A value would almost always involve a second-order volition—insofar as a person considers a way of acting correct, she would want her desire to act in this way to effectively move her to action. But not all second-order volitions involve values—one could want a certain desire to effectively motivate one's actions without the conviction that it would be correct to act in this way. Frankfurt himself suggests this distinction between second-order volitions and values (ibid., p. 16, note 6). The capacity to value is a somewhat more demanding capacity than the capacity for second-order volition, and thus, presumably, it is easier to lose in Alzheimer's.
she wants to live up to and in virtue of which she assesses her own value, is no doubt a valuer.

Dworkin's very contrast between critical interests (which derive from the person's values) and experiential interests (which concern the person's state of mind) points to another, more contingent, difference between valuing and mere desiring or wishing. Dworkin's contrast only makes sense because values frequently do not have as part of their object or rationale the quality of their holder's experience or state of mind—in this sense, they express the person's concern with something fully independent of himself. By contrast, in merely desiring something, part of the person's aim is usually the pleasure or the agreeable state of mind that will result from achieving or contemplating the object of desire. Admittedly, this is also true of some values; people do, after all, come to value some of their pleasures—a food connoisseur, for instance, will likely value the pleasures of fine dining. Still, there is a significant difference here, because whenever something matters to a person regardless of how it would affect her own experience, this is very likely not a mere desire, but a value.

I have isolated three features essential to, or strongly indicative of, valuing: the person thinks she is correct in wanting what she wants; achieving what she wants is tied up with her sense of self-worth; and the importance of achieving what she wants is, for her, independent of her own experience. Nothing here suggests that valuing would require a grasp of the narrative of one's whole life.

Furthermore, for the purposes of the argument I outlined earlier, Dworkin does not need to interpret the capacity to generate critical interests as anything more than the so-specified capacity to value. As we have seen, the backbone of Dworkin's justification for disregarding current wishes of patients who can no longer originate critical interests is the perception that, ordinarily, critical interests take precedence over experiential interests in determining what is best for a person. But, presumably, critical interests are of such overriding importance because they stem from the person's values—because they reflect the person's opinion of what is correct for her. And this standing of critical interests is independent of whether they encompass the person's design for her life as a whole. For instance, a devoted father's critical interest in the well-being of his children overrides his interest in having optimal experiences, no matter whether he came to value his children by reflecting
on the narrative of his whole life. Thus, to endorse Dworkin’s compelling argument that deference to current wishes of a demented patient ought to depend on whether the patient can still originate critical interests, we have no need to understand critical interests in terms of the person’s grasp of what is good for her life as a whole; we can just trace critical interests to the person’s convictions about what would be good and correct for her—to the person’s values as understood in the above specifications.

Of the three claims I have made—that critical interests are values; that, conceptually, such values may be understood as quite independent of the agent’s grasp of her life as a whole; and that this is the interpretation relevant to Dworkin’s argument—the second is most contentious. But it is confirmed by many real-life Alzheimer’s cases in which valuing becomes uncoupled from the person’s grasp of the narrative of her whole life. Alzheimer’s patients typically lose early on the thread of their lives’ narratives, but they often still exhibit attitudes incorporating the three features I isolated above as essential to, or strongly indicative of, valuing.

Consider, for example, a patient interviewed in Steven Sabat’s study, Mrs. D., diagnosed with probable Alzheimer’s for five years. As for her level of impairment,

she was moderately to severely afflicted (stage 4, Global Deterioration Scale, score of 7 on the Mini-Mental State Test). She could not name the day of the week, the date, the month, the season, year, the city and county she was in. . . . She underestimated her age. . . . and had difficulty finding her way to the bathroom at the day-care center she attended two days each week.16

Mrs. D.’s memory deficiency was rather acute. Since she could not keep track of the passing time or of her own age, and had severe difficulties forming new memories, Dworkin could safely assume that she had lost grasp of the narrative of her whole life, that she lacked a sense of “a past joined to a future.” However, Mrs. D. still conducted herself as a valuer. She often volunteered as a research subject for tests and experiments at the NIH. Although she did not choose to do so through systematic reflection on the whole trajectory of her life, she clearly felt that this was,

for her, the right choice: “That was the nicety of it, cause I could have said, ‘no,’ but believe me, if I can help me and my [fellow] man, I would do it.” 17 Her conviction that it would have been a mistake to say “no” comes across rather starkly here. And she had no need to review her life as a whole to affirm this conviction. What mattered for her was that this felt right to her, then and there. One has the sense that Mrs. D. was simply enacting a basic part of her personality, one that had remained relatively intact despite her other impairments.

Mrs. D. also became a useful assistant at the adult day-care center she attended, making others laugh and reassuring newcomers with her amiable manner. And she had similar reflections about the appropriateness of her attitude: “That’s what you have to do almost if you want to get along. . . . I would work, you know, with somebody just to keep them happy.” 18 In both activities Mrs. D. was concerned with “her fellow man” rather than with her own experience, which again indicates that her attitudes qualify as values.

For a less altruistic example, consider another of Sabat’s interviewees, Dr. B., an Alzheimer’s patient who scored even lower than Mrs. D. on cognitive tests. Like Mrs. D., he “could not recall the day of the week, the month, or the year.” 19 His ability to evaluate his life as a whole could not have been better than that of Mrs. D. Yet he, too, proved capable of valuing. He got very interested in Sabat’s research project. Although his grasp of its design was rather rudimentary, he thought of the project as his “salvation,” as a way to engage, despite his impairments, in something other than “filler,” in something giving him a mark of distinction. 20 He told Sabat more or less explicitly that he considered the project right and appropriate: “And you know I feel a way is that, I feel that this is a real good, big project, and I’m sure you do too. This project is a sort of scientific thing.” 21 This assessment of the project went hand in hand with a boost to Dr. B.’s sense of pride and self-worth that ensued from his participation. The impact on his self-esteem was most evident whenever he compared the project to various “filler” group activities at the day-care center: “If I’m working with you, I can—look, I can work in here for 30 times and all that, but in this group, I’m nothing.” 22 That his

17. Ibid.
18. Ibid.
19. Ibid., 41.
20. Ibid.
21. Ibid., 41–42. Emphasis added.
22. Ibid., 41. Emphasis added.
role in the project could so alter his self-image demonstrates most poignantly that he valued the project.

This example brings out very vividly a subtle conceptual distinction: Having a normative conception of oneself, a practical identity, need not involve pondering the narrative of one's whole life.\(^{23}\) As I discussed earlier, one sure indication that a person professes a value or a critical interest rather than a mere desire or preference is that the person seems to uphold a conception of himself, a set of ideals in terms of which he perceives his own value. But, as Dr. B.'s case illustrates, this need not be the person's conception of his life as a whole, need not be, that is, his understanding of what gives meaning to the narrative of his life. Rather, it could just be an ideal that happens to be relevant to the person at this specific time, his way of assessing the worth of the person he is now, without referring backward or forward to other parts of his life. Thus, while it matters very much to Dr. B.’s self-image that he take part in an activity elevating him above the mundane, this standard of self-image does not rely on a judgment that such an activity would aptly supplement the narrative of his life. Similarly, Mr. Burke’s declaration, “A man needs his truck,” expresses an ideal, a standard to judge himself against, even though Mr. Burke did not necessarily develop this ideal by reflecting on the trajectory of his entire life.\(^{24}\)

My other two initial cases also demonstrate that the ability to value may outlast the patient's grasp of her life as a whole. Mrs. Rogoff's confusion between a TV-generated world and events of her own life easily rules out her having an adequate grasp of her life's narrative. She does, however, remain a valuer, most clearly when her former reputation as a great cook is at stake. She invariably gets upset and agitated seeing Fran usurp the mastery of the kitchen. One day, after Fran made a particularly delicious chicken leg roast, Mrs. Rogoff insisted that she would cook dinner herself, and asked her granddaughter, in secret, to buy “a hen with five legs,” clearly in the spirit of one-upmanship with Fran.


\(^{24}\) Nothing I say here should be taken to imply that we ought simply to allow Mr. Burke to realize this ideal. At this stage, I only intend to show that Mr. Burke is still a valuer. I take up the question of how such valuers ought to be treated, depending on the details of the case, in Section IV.
such times, Fran arranges small make-work kitchen tasks that appease Mrs. Rogoff. Here, as before, the clearest indication of retained values comes from visible effects on the person’s self-esteem: Mrs. Rogoff’s self-image suffers whenever she realizes that Fran has taken over as a culinary expert, and these effects can be mitigated, at least temporarily, by semblance of participation in culinary affairs.

As for Mr. O’Connor, his grandson described him as a person who “lived in the present” and had “no narrative moorings.” He had trouble recognizing most family members and sometimes mistook people on TV for his daughters. Again, we can safely say that his grasp of his life as a whole was tenuous. However, he did have an intense connection with his wife, and her absence made him profoundly sad. The fact that he wanted to die after she was gone strongly indicates that his feelings for her did not focus primarily on his own experience, and thus that he truly valued her.

The stories of Mrs. B. and Mr. O’Connor ought not suggest that an Alzheimer’s patient can be deemed a valuer only if he is still concerned with something lofty, with something beyond himself and his own experience. Such a concern, remember, is merely a strong indicator of valuing, and certainly not a necessary condition. We have seen that Dworkin’s distinction between critical and experiential interests is not a dichotomy, and that it is possible to value having certain experiences. Moreover, the content of critical interests of many demented individuals may well be primarily experiential, because, given their diminishing capabilities, they are naturally inclined to savor and appreciate their simpler pleasures. Thus, after developing Alzheimer’s, even former highbrow intellectuals come to value, or value more highly, the pleasures of listening to music, gardening, yoga, simple art-making, telling fanciful stories to their grandchildren, or the like. Still, these are values as opposed to mere desires if the person can give some rationale for choosing such activities. For instance, an Alzheimer’s patient may view engaging in simple pleasures as a way of holding on, as a way to still lead a recognizably human existence despite his disease; such a person values his particular pleasures because he values being still capable of pleasure.25 Given these possibilities, we cannot assume that a demented

25. See Ann Davidson, Alzheimer’s, a Love Story: One Year in My Husband’s Journey (Secaucus, N.J.: Carol Publishing Group, 1997), for a case of this sort.
person has ceased to value just because he is now focused on his own pleasure and experience.

My observations that valuing may be quite independent of grasping the narrative of one's life, and that this separation often occurs in Alzheimer's patients, are also supported by current findings in neurophysiology and in the neuropathology of Alzheimer's disease.26 The neuronal loss characteristic of Alzheimer's is not distributed evenly in the cerebral cortex. The disease affects most severely an area of the brain indispensable for maintaining the sense of one's life as a whole, but not particularly important for the ability to value.

In the early stages of Alzheimer's the neuronal damage affects primarily the hippocampus. As the damage spreads, the hippocampus continues to be affected much more severely than other regions of the brain.27 The hippocampus is of crucial importance in acquisition and processing of long-term explicit memory for facts and events. Not involved in short-term memory or in the eventual storage of long-term memories, the hippocampus nonetheless plays an essential role in transforming a fresh short-term memory into a lasting long-term memory.28 Accordingly, while damage to the hippocampus affects neither a person's processing of her immediate experience nor her memories of events that occurred long before the damage, it causes her to lose track of ongoing events soon after they happen, so that she typically has no recollection of the previous day.29 Such damage impairs a person's ability to come back to a recent thought or memory after a shift of attention to something new.30 These very impairments are, of course, the typical first clinical indications of Alzheimer's disease. They are also central to Dworkin's assessment that Alzheimer's destroys one's sense of one's life as a whole. Damage to the hippocampus alone leaves the person unable to update her autobiographical narrative. Given sufficiently severe damage, the person not merely cannot recall trivial details about what has

26. I would like to thank Marion Danis for prompting me to investigate the neuroanatomical evidence for my claims.
recently happened, but she is altogether unable to turn her recent experience into long-term memories. As she continually forgets her immediate past, she loses the sense of “a past joined to a future,” which Dworkin deems necessary for the ability to formulate critical interests. However, there is no reason to think that impairment of the hippocampus would obliterate one’s ability to espouse critical interests when this is understood, following my recommendation, as the ability to value. For one, while removal of the hippocampal formations leads to the memory defects described above, it does not otherwise compromise the patient’s mental functions. Moreover, there is neurophysiological evidence that other regions of the brain are primarily responsible for interactions of reasoning and decision-making processes—especially those concerning personal and social matters—with feelings and emotions. It is damage to these regions that is most likely to directly compromise a person’s ability to value.

Thus consider Elliot, a patient with brain damage localized in the ventromedial prefrontal cortices. He performed normally or even superiorly on a full battery of psychological tests (including intelligence, knowledge base, memory, language, attention, and basic reasoning), and yet was a very poor decision-maker in everyday life. He showed no abnormalities in means-ends reasoning and problem solving; he was perfectly able to come up with a full array of options for action in a particular situation as well as to work out the consequences of each option. As it turned out, his impairment concerned the ability to choose among the options he could reason through so well. After a full analysis of all the options he would comment, “I still wouldn’t know what to do!” His emotional responses and feelings were severely blunted and this “prevented him from assigning different values to different options, and made his decision-making landscape hopelessly flat.” He lacked the very starting points of the ability to value: he was no longer sufficiently invested in anything; he ceased to care.

33. Ibid., pp. 34–51.
34. Ibid., pp. 46–49.
35. Ibid., p. 49.
36. Ibid., p. 51.
The ability that Elliot lacked is the indispensable core of the capacity to value. When you value something—be it a particular friendship or a local community—your commitment to these things is first and foremost a form of emotional engagement. You would not call it "valuing" or "being committed" unless there is some confluence between thinking about and acting upon what you say you value and your emotional life. True enough, since the conviction that it is right for you to care about these things and that you would be mistaken if you did not care is open to criticism, sophisticated and varied cognitive abilities are required to develop a robust set of values, values most immune from such criticisms. But having such convictions in the first place amounts to attaching emotional significance to the object of value; it involves having the corresponding emotional attitudes and reactions, so that some things simply "feel" important to you. Elliot was unable to value due to the numbing of his affective response.

The neuronal destruction of Alzheimer's disease does eventually reach the regions of the brain most responsible for "giving emotional quality to occurrences which renders them important to the person concerned." However, the destruction and the isolation of the hippocampus are always several steps ahead of the pathologies in the areas most likely to affect the capacity to value. Therefore, on the basis of neuropathological findings, one would expect Alzheimer's patients to lose their sense of life as a whole even as the essence of their ability to value remains relatively robust.

On the neuropathological picture of full-blown Alzheimer's, the loss of the sense of one's life as a whole is typically acute, while the destruction of the areas implicated in valuing remains more selective. We would thus expect a patient in the moderate stage to have lost some but not all of his former values. With his ability to form new long-term memories

37. It may also be that Elliot's desires were severely diminished. But this only shows that both desiring and valuing involve emotions. This point does not interfere with the arguments in this section.
38. For an elaboration of the relationship between emotional engagement, critical evaluation, and the person's conviction that an object of value is correct, see my "Rescuing Oblomov," pp. 179–99.
compromised, he is unlikely to develop any new values. But his selective loss of former values may well result in changes of values pertinent to our dilemmas: As I previously observed, once some of the earlier values drop out, the exact content and the importance of the remaining values are typically reconfigured. Mr. O’Connor’s transformation may be viewed as a case in point. As his cognitive abilities faded, the complex values based on his religious beliefs were no longer available to him. But the value he attached to his relationship with his wife remained relatively intact. Absent the religious restrictions, his profound attachment to his wife and the lack of anything else of comparable importance in his life turned a previously unthinkable course of action into the best option: Given his new, more limited set of values, it makes perfect sense that Mr. O’Connor wanted to die after his wife was gone.41

In this section I have chiefly argued that the ability to value is independent of the ability to understand the narrative of one’s whole life, and that demented people may well retain the former ability long after they lose the latter. We also saw that, at least when well-being of the demented is the focus, Dworkin’s recommendation to disregard the patient’s current wishes derives from the loss of the former capacity, the capacity to value. Thus, for a Dworkinian, the threshold capacity level necessary to lend prudential authority to a person’s current wishes

41. Since Alzheimer’s patients are unlikely to develop any new values, the values that they still espouse are typically traceable to their previous values. This is certainly true in our examples: Mrs. Rogoff’s interest in being a good cook, Mr. Burke’s interest in cars, Mrs. D.’s interest in helping her fellow man, and Dr. B.’s interest in contributing to science are all continuous with these patients’ interests from the predementia period. It is tempting to view the current attitudes of these patients as values simply by virtue of the fact that they are traceable to the patients’ former critical interests. But on my view, continuity of this sort is not sufficient to make an attitude of an Alzheimer’s patient a value. The current attitude itself must exhibit the features essential to valuing that I outlined earlier in this section. I have argued that the patients in my examples meet this more demanding requirement.

This point notwithstanding, continuity of a demented patient’s conviction about the good with one held previously could serve to confirm that the conviction in question is indeed a value. In addition, continuity of this sort indicates the authenticity of the value—it shows that the current value is not some random product of the disease process, but that it is anchored in the mental history of the living person. Authenticity of values certainly contributes to their moral standing: If a patient developed entirely new values that were not the result of any new experience or reasoning, but instead were only caused by a brain pathology, these values would not have nearly as much moral weight as the surviving values of Alzheimer’s patients which I have discussed here. (I ignore this complication in the main text, because the values of Alzheimer’s patients are typically authentic in this sense.)
should not be set at the ability to grasp one's life as a whole, but rather at the ability to value. So long as the demented person still espouses values, we have seen no reason to override these in the name of values she professed earlier—Dworkin's recommendations do not apply.

III. RETHINKING AUTONOMY

Let us now turn to respect for the patient's autonomy as the primary goal of those caring for demented patients. How should we now approach our dilemmas? According to Dworkin, we need to consider whether the demented patient, in her current condition, still possesses the capacity for autonomy. The rationale here is that respecting people's autonomy is morally important only because human beings' very ability to act autonomously is morally important. If a person is not even capable of making autonomous decisions, allowing her to carry out her current wishes would do nothing to promote her autonomy; respect for autonomy in no way requires adherence to the current wishes of someone incapable of autonomy. As Dworkin sees it, the only way to respect autonomy of such patients is to respect their earlier ability to act autonomously; if their autonomous choices from that earlier time are still satisfiable now, these should be the focus of respect for autonomy. And, of course, choices associated with critical interests are often still satisfiable, since, as we saw earlier, critical interests can be meaningfully fulfilled at a time when the person no longer espouses these interests. Thus, for Dworkin, the only way to respect the autonomy of patients who lost their capacity for autonomy is to adhere to critical interests they professed before this loss. He readily concludes that the sorts of demented patients he is interested in lack the capacity for autonomy, and hence, that in order to respect their autonomy one must adhere to their earlier wishes, wishes that expressed this capacity.

The claim that demented patients no longer possess the capacity for autonomy is clearly pivotal to this part of Dworkin's analysis. But how plausible is the underlying interpretation of the capacity for autonomy? Dworkin describes the capacity for autonomy as “the capacity to express one's own character—values, commitments, convictions, and critical as well as experiential interests—in the life one leads.”

42. Dworkin, Life's Dominion, p. 224.
derstood, this is the capacity to be fully in charge of one's life—to enact one's own values and convictions in the life one leads. Demented people may easily lose this capacity, because as they lose the understanding of the world around them and become increasingly disoriented, they no longer know how to translate their values and convictions into appropriate activity in the world. But suppose a demented person who still espoused values and convictions got some help enacting those values in his environment. Imagine, for instance, a demented man who values his independence above all else, but who is confused about what he is still able to do on his own. Were he left to make his own decisions, his choices would not ultimately enhance his independence, and perhaps would even lead to his harm. But imagine further that his family makes living arrangements for him that allow him a maximum degree of independence feasible in his predicament. There is an important sense in which this man is still capable of exercising his capacity for autonomy, of living according to his convictions and values, albeit with some help in translating ends into means. Thus a possibility opens up that the capacity for autonomy ought not to be thought of as the capacity to carry out one's convictions into action without external help, a capacity that requires reasoning through complex sets of circumstances to reach the most appropriate autonomous decisions; rather, that the capacity for autonomy is first and foremost the capacity to espouse values and convictions, whose translation into action may not always be fully within the agent’s mastery.

In his own elaboration of why the demented lack the capacity for autonomy, Dworkin does not explicitly focus on their inability to lead their lives on their own, but rather on the lack of consistency and stability in their choices. It may thus seem that, for Dworkin, the main mark of the capacity for autonomy is the coherence of a person’s expressed preferences—a patient who makes conflicting and contradictory demands from one moment to the next is not an autonomous agent.

However, Dworkin’s emphasis on coherence of preferences turns out to be misplaced for the situations he discusses. The dilemmas under investigation do not normally arise for patients who constantly change

43. Ibid., p. 225.
44. This understanding of the capacity for autonomy does concur with the formulation I cited in the previous paragraph, since a person lacking a stable set of preferences is hardly able to consciously express her preferences in the life she leads.
their preferences, because it is usually impossible to satisfy the wishes (especially, experiential wishes) of a person who keeps changing her mind. Satisfying most desires takes time—specifically, it takes time to satisfy the kinds of desires opposing earlier instructions that Alzheimer's patients typically express, for example, the desire to be taken out of day care, or to be saved from a life-threatening illness. There is little pressure to satisfy such desires if one can reasonably predict that, by the time the desires could be satisfied, the patient's preferences will likely change to indifference or opposition. (How would you satisfy a patient who, upon arrival in a research hospital, demands to go home, but once taken home wants to return to the hospital?) If desires of this sort come into conflict with the patient's prior instructions (suppose that our capricious patient had written a prior directive requesting enrollment in research), there is no strong dilemma for the caregiver: The current preferences of the patient are likely not satisfiable in a meaningful way, and thus can be discounted with no moral qualms. By contrast, the caregivers' dilemmas are starkest in cases in which the current wishes of the patient that contradict her earlier choices are consistent and unwavering: for example, contrary to her earlier instructions, the patient clearly and consistently wants to remain independent or she clearly does not want to die. And Alzheimer's patients do often express such unwavering preferences that contradict their earlier designs—to stay home rather than go to day care, not to be bathed every day, or to go on living at all cost. Thus, if Dworkin's recommendation to ignore the wishes of those who have lost the capacity for autonomy is meant to equate a lost capacity for autonomy with inconsistency of preference, the recommendation does not solve the dilemmas arising in the care of Alzheimer's patients, but is simply irrelevant to most of them.

Besides, to sustain his interpretation of the capacity for autonomy in terms of coherence of preferences, Dworkin must distinguish the inconsistencies of purpose that ordinary people exhibit in everyday life from deeper inconsistencies allegedly attributable to Alzheimer's. Dworkin does so by claiming that, unlike the ordinary people who lack stable purposes, Alzheimer's patients have "no discernible even short-term aims."45 This lack, however, is even harder to impute to Alzheimer's patients than the more generic inconsistency of purpose. Presumably,

45. Dworkin, Life's Dominion, p. 225.
Dworkin thinks that Alzheimer’s patients cannot have even short-term aims, because as soon as they embark on a course of action they forget just what it was that they have been doing and are forced to start anew. But he should distinguish between an inability to form and then remember a plan for fulfilling one’s purposes, and a lack of a stable set of purposes and preferences. For we can imagine an Alzheimer’s patient who always wants the same set of things—say, he wants to feel useful and appreciated—and yet is unable to set up and carry through a plan for achieving any of them, partly because he cannot figure out the means to his ends, and partly because he cannot keep track of the steps he is taking. These latter deficiencies seem to be at stake in Dworkin’s claim that the demented lack the capacity for autonomy, despite his explicit focus on their lack of consistent purposes.

Although Dworkin’s analysis ostensibly relies on the idea that Alzheimer’s patients typically lose consistency of preference, none of the patients he refers to as examples display such inconsistency. This further confirms that his assessment that the patients he describes clearly lack the capacity for autonomy is based not on a lack of stability in their preferences, but on their inability to enact their preferences in their lives without assistance. They cannot be autonomous because, left to their own devices, they cannot lead their lives by their own lights. And this is largely because they have lost the ability to reason from their preferences to the appropriate decisions and actions—they have lost the adeptness for means-ends reasoning and planning.

However, there is no good reason to restrict the right to autonomy only to people who possess these abilities. After all, as the case of Elliot and other patients with prefrontal brain damage powerfully brings home, the very idea of governing one’s life autonomously is a complete nonstarter unless the person knows how she wants her life to be governed—unless she has her own substantive principles or directives for running her life. These principles constitute the foundation of autonomy; means-ends reasoning and planning are mere tools for implementing the principles. Moreover, while having one’s own directives is indispensable for exercising autonomy, we can well imagine that the tools of means-ends reasoning and planning could be supplied for the autonomous person from the outside. Accordingly, the essence of the capacity for autonomy consists in the ability to lay down the principles.
that will govern one's actions, and not in the ability to devise and carry out the means and plans for following these principles.46

Dworkin's analysis, then, focuses on peripheral rather than essential aspects of the capacity for autonomy. However, to offer a convincing alternative, we must specify more precisely what the essence of the capacity for autonomy amounts to, and in particular, what counts as one's own principle or guideline for running one's life. Presumably this cannot be just any run-of-the-mill wish or desire, because a person may distance herself from a mere desire and not recognize it as truly her own.47 So, at the very least, a principle suitable as a basis for self-governance must be viewed by the person as correct for her.

To explore this proposal, let us consider if autonomy would be possible even for a creature unable to judge the correctness or appropriateness of her desires.48 Suppose that this creature can control whether or not she will act on a desire,49 and yet she experiences her desires simply as events in her body. There are two possibilities here. In one, the creature is ultimately indifferent to whether she will act on her desires—she finds herself inclined toward certain things, but upon reflection she never sees anything worthwhile in what she is inclined to do. In the other variant, although the creature finds herself inclined toward certain choices, she is altogether incapable of reflecting on the merits of these inclinations. In both cases, the desires, precisely because they lack the approval of the one who feels them, are too passive to be regarded as authentic directives for self-governance. So, indeed, to qualify as

46. None of what I say here should be taken to imply that, in a normal case, a person's own exercise of means-ends reasoning and planning could be ignored by those aiming to respect her autonomy. My point is that a person largely incapable of such reasoning may still be able to exercise autonomy, and not that such reasoning can be taken lightly in an ordinary person who exercises her autonomy through the use of such reasoning.

47. Some readers may think that this requirement is too stringent, and that the hypothetical individuals I go on to describe are still capable of autonomy. If so, it is only easier for me to claim that many Alzheimer's patients retain the capacity for autonomy.

48. I speak of a "creature" rather than a "person" here to allow for the view that the ability that my hypothetical creature lacks is essential to personhood.

49. Why this stipulation? If we imagined a creature who was also unable to control her response to a desire, it would have been easier to see her as lacking the capacity for autonomy. However, I want to show that our intuition that my imagined creature lacks the capacity for autonomy depends on something else: even a creature in control of her desires seems to lack the capacity for autonomy if she can never approve or disapprove her desires.
such an authentic directive, a principle must be viewed by the person as correct for her.

Following my earlier observations, this means that a principle qualifying as such an authentic directive must have the status of a value. As I explained in Section II, a person’s values specify her own sense of what is correct and appropriate for her; they are her guidelines for behavior. Values are also directly connected with a person’s sense of self, since the person measures her own worthiness according to how well she lives up to her values. This connection further confirms that values are genuinely the person’s own principles of behavior, that they are the apt foundation for self-governance.

We can now restate in a more familiar form our earlier finding that the mere laying down of principles for one’s conduct makes one capable of autonomy. Since such principles are values, the very ability to value, even if more instrumental abilities are absent, supplies the starting points for the exercise of autonomy, and thereby renders the person capable of autonomy.

Of course, possessing the capacity to value does not guarantee that the person can exercise autonomy to a full degree. Full-blown autonomy involves not only acting on one’s own principles and convictions, but also the ability to scrutinize these principles and to revise them in light of critical evaluation, so that they are well-articulated and robust.50 The capacity to value merely makes possible the most minimal and basic level of autonomy; other capacities are necessary to further develop and perfect autonomy. All the same, the capacity to value by itself does, in a very important sense, render a person capable of autonomy.

Alzheimer’s patients usually retain their ability to value long after other capacities necessary for making their own decisions and fully directing their lives are gone. All the patients I discussed in Section II are, as we saw, valuers, and now we can appreciate that they lack not only the grasp of the narratives of their lives, but also the ability to independently implement their values, and that, despite these impairments, they are capable of autonomy.

50. While the ability to understand the temporal progression of one’s life as a whole may not be a necessary condition of this reflective scrutiny, its nontemporal analogue—the ability to attain a critical perspective on all the various aspects of one’s current self—does indeed seem essential. Yet, again, this is a requirement of full-blown autonomy, and not of the minimal capacity worthy to be dubbed “autonomy.”
Mrs. D.'s conviction that she ought to help her fellow man any way she could, be it by volunteering for medical research or by making her fellow day-care visitors laugh, certainly comes across in the interview as a truly self-given, authentic principle of conduct. She talked of this conviction just as any other person would ordinarily talk of her commitments to her principles. Yet, since Mrs. D. struggled even to find her way to the bathroom in a relatively familiar place, she clearly would have had trouble implementing her altruistic principles on her own; she would not have been able to figure out, for instance, how to enroll in a research study to help her "fellow man." With the help of others, however, she was able to continue to lead a life informed by her valued, self-selected principles, and thereby to continue to exercise a measure of self-government.

The cases of Dr. B., Mrs. Rogoff, and Mr. O'Connor are similar. The intensity with which they communicated the values described in the previous section convinces us that these are very authentic ideals. At the same time, Dr. B., with his tenuous grasp of intellectual constructs, could not have taken part in a "real good big project" without the researcher's help; likewise, Mrs. Rogoff could not have held on to her self-image as a prominent player in culinary affairs without significant help from Fran; and Mr. O'Connor, who mistook people on TV for his daughters and believed that the Rockefellers would take care of his finances, would have certainly needed assistance with concrete decisions reflecting his feelings about his wife's death. Given the help, however, they all can live up to their own ideals again, and to that extent exercise autonomy.

The paramount symptom of Alzheimer's, as we saw in Section II, is the inability to form new long-term memories. This does not affect very much a person's ability to value, but it does directly and severely hamper his efforts to implement his values—even more than it affects his grasp of his life as a whole. Even a modest impairment of long-term memory limits the person's access to information about the world around him and distorts his assessment of his own competence, compromising his ability to select the course of action befitting his values. Yet, such a modest impairment does not usually destroy the person's awareness of the passage of time, his sense of "a past joined to a future," and hence his basic understanding of the narrative of his life. Thus, having already recognized that there are valuers with severely attenuated
sense of their lives as a whole, we should expect to find many more valuers who can no longer implement their values.

In her account of her husband’s battle with Alzheimer’s, Ann Davidson provides beautiful testimony that simultaneously illustrates Julian Davidson’s relatively intact capacity to value and his slipping ability to implement his values.

Julian insisted that he had to compose a “Thank You” speech to be delivered at a banquet honoring his scientific contributions. On his own he was only able to produce phrases such as:

\[
\ldots \text{it will be a pleasure and joy to come back with and me tu omar see and and attend to the evening of June and its and day. } \ldots \text{Although I have not in worked in the day most loved and I will be a persual } \ldots \text{strangely I was finished re this important and pleasure.}^{51}
\]

But when Ann patiently interviewed him about what he wanted to say, he “spoke haltingly, but passionately, about leaving his career. In garbled phrases he described what he felt about science and why he was quitting. He needed his colleagues to know why he had left. He wanted them to know, too, that people with Alzheimer’s are still ‘regular folks.’”^{52}

Julian communicated his conviction that it was right for him to care deeply about science, and, likewise, that it was appropriate to give his colleagues an explanation. He was definitely conveying values here, his authentic ideals. At the same time, he needed Ann’s help to translate these values into appropriate actions—he could not have figured out on his own that Ann needed to rewrite his speech and that it would be best if someone else delivered the speech on his behalf.

Consider next a patient I observed personally, Mr. Gray, a cofounder of a major national corporation who was staying in a hospital as a research subject for an Alzheimer’s protocol. His grasp of his surroundings was consistently confused—he was unaware of his memory impairments, did not seem to know that he was in a hospital, did not seem to understand that he was a patient. He also had trouble with many simple tasks of daily living, such as opening a milk carton, or putting a coin in a vending machine. Yet, despite being so disoriented, he was also very friendly and outgoing, and tried to make everyone feel comfortable. To

52. Ibid.
questions about how his stay at the hospital was going, he would say things like: “Yes, but how could I make things better for you? How can we work together to make this as successful as possible?” He would not let on where he thought he was, but it was quite clear that he was trying to hold on to the ideal of himself as a successful and caring executive.

Given his impairments, it is tempting to read Mr. Gray’s behavior as simply an old, hard-to-die habit, short of an enactment of values. But Mr. Gray was not simply resorting to a rote set of behaviors, not simply enacting an “executive” script. He conveyed a consistent image of himself as the one in charge of helping others in many different unique ways, in different, and often novel, situations. For example, the nurses reported that he was uncomfortable with his role as a patient, that he did not like to be ministered to. He always attempted to deflect the care he was getting and to turn it into an arrangement in which he would be the one helping others. The nurses found him most cooperative when they emphasized to him that he was in charge of the decision and that they needed his help. To get him ready for a blood test, it worked best to ask, “Would you help us draw your blood?” And when a nurse wanted to hold him to prevent him from falling, he responded most willingly when she asked, “May I take your arm?”

Mr. Gray communicated in a variety of ways that being competent and in charge deeply mattered to him. Yet he needed the constant cooperation of those around him to allow him to retain the image of himself that he so desperately cared about.53

As these vignettes illustrate, there are abundant variations of cases of Alzheimer’s patients who remain valuers despite severe impairments of their decision-making capacity. On my analysis, these patients are still capable of fundamentals of autonomy. Accordingly, a caregiver committed to respect for autonomy must respect these patients’ contemporaneous autonomy. This is a perfectly coherent goal, albeit respecting the autonomy of such patients usually requires much more active participation of the caregivers than what is required for ordinary competent patients. To properly respect the autonomy of many an Alzheimer’s patient one must do quite a bit to enhance her autonomy. One must help the person no longer able to do so on her own to lead her life according to her remaining values, to the extent that this is still feasible. This in-

53. I would like to thank Dave Wendler for a helpful discussion of this case.
volves figuring out how her values would be best upheld in a reality she no longer fully understands, as well as helping her implement these solutions in practice. We saw this approach employed by Mr. Gray's nurses, Julian Davidson's wife, Mrs. Rogoff's caregiver Fran, and the researcher working with Dr. B. Sometimes enhancing a person's autonomy in this way may even involve going against his explicit choices. Ann Davidson did not simply allow Julian to try to deliver his jumbled speech and Mr. Gray's nurses did not just let him fall down when he resisted their assistance. The caregiver must learn to pay attention to the person's values rather than to her concrete, yet perhaps ill-informed, selection of options. All the same, whatever the details of the case, so long as the patient is still able to value, respect for autonomy does not license the caregiver to altogether disregard the patient's immediate interests.

In sum, contrary to Dworkin's assumptions, in the context of dementia, the capacity for autonomy is best understood not as the ability to lead one's life by one's lights when one is left to one's own devices, not as a full capacity to make a decision from the beginning to end, but as the capacity to value—to originate the appropriate bases for one's decisions that can then be, if the need arises, partly taken over by others. An Alzheimer's patient may be too disoriented to form a life plan or to choose specific treatment preferences, but so long as he still holds values, he is, in the most basic sense, capable of self-governance, and this fact about him commands utmost respect. Dworkin's recommendations to disregard contemporaneous interests have no purchase.

One may object that, both here and in the previous section, I have overstated my criticism of Dworkin. Dworkin explicitly states that his focus is only on the late stages of Alzheimer's. To be sure, at these late stages we may be quite certain that the patient not only cannot translate her values into action, and not only does not have a sense of her life as a whole, but also no longer possesses the capacity to value. These patients likely fail Dworkin's criteria as well as mine, and my analysis of their well-being and autonomy parallels Dworkin's.

However, the very late stages of Alzheimer's are not the main locus of the special kind of dilemmas illustrated by my initial examples. The status of end-stage patients is often analogous to that of other terminally ill, unresponsive, physically incapacitated and suffering patients, for whom the question whether to end or prolong a life may seem appropriate. More often than not, these patients are not capable of ex-
pressing their current preferences, so conflicts between their current and former preferences do not arise. And Dworkin himself, despite the official disclaimer, applies his framework to patients who are, or at least could be, in earlier stages of dementia.54 These patients may well still be valuers and my criticisms of Dworkin's analysis are very relevant in their circumstances.

IV. Weighing Values

If a demented patient remains a valuer, her contemporaneous interests and her contemporaneous autonomy have full moral standing. Nonetheless, in cases of conflict between a demented patient's current and prior wishes, hard questions remain. Granting that the patient's contemporaneous best interest matters, to what extent is it a function of the patient's often imperfect current values? Granting that the patient's contemporaneous autonomy matters, does it involve enacting her current values or her actual preferences? What if the patient's contemporaneous best interest conflicts with her contemporaneous autonomy? Or if the patient's contemporaneous interests and/or autonomy conflict with her prior, more informed, autonomous requests? I will not attempt to fully resolve these questions. The key insight for our purposes is that once a demented patient is recognized as a valuer, the problems are not, in principle, different from those encountered when working with ordinary competent people—these problems belong to an already familiar territory of practical reasoning.

Intent on promoting the patient's contemporaneous interest and autonomy, the caregiver may still not know whether to follow the patient's current or earlier preferences. Many demented patients are valuers, but they may not be very sophisticated valuers, and for this reason their earlier choices often seem as relevant to their contemporaneous circumstances as their current value-based preferences. For example, fulfillment of Mr. Burke's current value-based desire for the red truck may seem crucial to his contemporaneous well-being. However, if Mr. Burke's purchase of the truck were to seriously jeopardize his ability to function financially, and Mr. Burke is incapable of recognizing these

54. Dworkin’s main case-study, Margo, whose grasp of her surroundings and her past is no doubt seriously impaired, is still able to interact with a visitor and also attends an art class for Alzheimer’s patients; she is hardly representative of end-stage Alzheimer’s.
consequences, it might be that his earlier resolution to forego the truck best matches his contemporaneous interests. How much does owning the truck contribute to Mr. Burke's well-being, if Mr. Burke overvalues this powerful status symbol by underestimating its impact on his overall financial situation, and thus on his ability to realize his other values? Stated more generally, the problem is how much an earnestly held but poorly conceived value matters for the person's well-being. This problem is all too familiar from cases in which competent people espouse imperfect values.

In other circumstances, the real import of a conflict between a demented patient's earlier and current preferences is an ambiguity in how to interpret her contemporaneous autonomy. Mrs. Rogoff prefers not to bathe and not to get dressed; while these particular choices do not stem from values, by insisting on them, Mrs. Rogoff exercises her agency. Fran may think that to respect Mrs. Rogoff’s current autonomy she should honor these choices. Yet suppose Mrs. Rogoff’s grandchildren limit their visits because they think that their grandma smells bad and looks disheveled. Now Mrs. Rogoff’s former grooming preferences also appear to support her current autonomy. Mrs. Rogoff seems to value highly her chatty interactions with her grandchildren, but her ability to translate these values into choices is impaired and she needs Fran's assistance. Fran may thus think that the best way to promote Mrs. Rogoff’s current autonomy is to overrule her protests and bathe and dress her. Ultimately, Fran has to decide between allowing Mrs. Rogoff to exercise her own agency and imposing on Mrs. Rogoff options that promote her overall autonomy. Again, the same problem would arise with a competent person whose autonomous choices undermine her overall autonomy.

Suppose Fran decides that, in this case, allowing Mrs. Rogoff to exercise her own agency would optimally respect her current autonomy. Nevertheless, given how much Mrs. Rogoff values her grandchildren’s visits, dressing and bathing seems to be in Mrs. Rogoff’s best interest. So Fran still faces a dilemma. Should she promote Mrs. Rogoff’s contemporaneous best interest or her contemporaneous autonomy? Of course, again, the dilemma is not unique to the case of dementia.

Next let us consider the conflict between contemporaneous interests and/or autonomy and earlier requests. These dilemmas typically involve advance directives prepared by demented patients earlier in life.
The fact that a person is no longer competent to make decisions for herself, or that she has lost the thread of her life as a whole, does not imply that her advance directive is automatically authoritative in guiding what should happen to her. So long as the person is still a valuer, current decisions on her behalf ought to take seriously her current values. But does this mean that a caregiver should always implement the person’s current values rather than the values articulated in the advance directive?

One could object that this solution misses the whole point of instituting advance directives for dementia. If a person prepares an advance directive in anticipation of becoming demented, her intention is to control now what will happen to her in the future; her concern is precisely to guard against people following her contemporaneous wishes in her future demented state. The author of the advance directive would be dismayed to learn that in her demented state, a dreaded state of alienation from many things she now holds dear, she would have the power to overrule the well-considered wishes she has conveyed in her directive. Note, however, that the position of a person executing an advance directive for dementia is not at all analogous to that of a person executing an advance directive in anticipation of a loss of consciousness. In the latter case, the advance directive has full authority, because, at the time it is meant to take effect, there is no active agent whose interests need to be taken into account. In contrast, by preparing an advance directive for dementia, the author attempts to control his future at a time when he may still be a valuer, that is, at a time when he may still possess essential attributes of agency, which command deference. For this reason, the person executing an advance directive for dementia is more akin to someone who anticipates that his values will change for the worse in the future and attempts to hold his future self to his current values by making others promise that they will, at a future time, enforce his current values against his will.

Imagine here an intellectual who anticipates that, later in life, he will lose the sharpness of his critical faculties in examining and revising his values—that he will not be used to thinking for himself anymore after many years in a stultifying job. Imagine that he believes that his wife, who is more independent and strong-minded than he is, will not undergo a similar transformation. He makes his wife promise that, when the time comes, she will force him to follow her decisions, even against
his will. Is such a “Ulysses” contract morally acceptable? Is the promisor obliged to keep the contract?

The answer requires a detailed discussion, and an extensive body of philosophical literature has developed around conflicting answers. Dworkin himself seems to think that one ought not to be held to such a promise.55 Thus, if he accepted my analogy, Dworkin should also be against employing advance directives for demented patients who are still valuers. Of course, Dworkin’s answer is not beyond dispute. My point is that an advance directive for a demented person who is still a valuer is equivalent to a Ulysses contract, and whether one thinks such directives ought to be employed depends on one’s take on the validity of such contracts.

No doubt, I have not covered all possibilities, and other subtypes of our dilemma will also challenge the guardians of Alzheimer’s patients. In approaching all such dilemmas, caretakers must be mindful of Julian Davidson’s insight that many people with Alzheimer’s are still “regular folks.” In some morally very important respects, many Alzheimer’s patients remain, at least for a time, surprisingly similar to ourselves.

55. See Dworkin, Life’s Dominion, pp. 226–27. Dworkin takes the position that we are not required to disregard the contemporary wishes of a Jehovah’s Witness who, having signed an advance directive categorically refusing blood transfusions, now, in a moment of weakness of will, pleads for a life-saving transfusion.