

Interpreting and Improving Advanced Directives for Dementia Patients: balancing Dresser and Dworkin

JAYUN BAE

In Ronald Dworkin's *Life's Dominion* (1993), he recounts the interactions of a medical student named Andrew Firlik with Margo, a woman with advanced dementia. Firlik describes Margo as severely incapacitated, but also as "one of the happiest people I have known" (Dworkin 221). Dworkin then asks us to imagine that Margo had created an advance directive where she instructed her power of attorney to withhold treatment beyond that of a palliative nature if she developed dementia.¹ Margo's reasoning for creating the advance directive is that a life with dementia lacks the capacity for two things she deems essential to a worthwhile life: self-awareness and

¹Advance directives, also commonly referred to as "living wills," allow people to specify their own medical treatment prior to developing a condition that impedes their ability to formulate or communicate their will.

Jayun Bae is a senior at the University of Toronto where she is pursuing a BSc in Bioethics, Neuroscience, and Philosophy. She is an undergraduate fellow at the Centre for Ethics at the University of Toronto and has engaged in research across a wide range of fields, including data privacy, sociolinguistics, personal health information, and early education. Her philosophical interests include bioethics, applied ethics, medical autonomy, patient decision-making, and disparities in public health. She plans to pursue graduate studies in applied ethics and become a clinical bioethicist.

planning.² After her dementia sets in, she contracts pneumonia, which will be fatal if left untreated. Though her previous wishes are clear, the patient now expresses that she enjoys her life and wants the treatment so she can continue living. In response to this case, I will argue that the most important good to protect is the patient's autonomy, which is best achieved by following the advance directive. Drawing on *Life's Dominion*, I will analyze why following the advance directive would maximize the patient's autonomy, and respond to the objections raised by Rebecca Dresser. Ultimately, I respond that many of Dresser's concerns can be alleviated by improving the recording and interpreting process for advance directives, rather than discounting advance directives altogether.

First, to examine the grounding of Dworkin's position, we must reflect on the concept of autonomy. It is a founding principle of bioethics that all humans should be afforded the ability, when possible or appropriate, to make choices regarding their own lives (Radden and Sadler 11). Dworkin believes that autonomy ought to be respected whenever possible, as it is precisely what allows an individual to shape their own life and furnish a coherent sense of self. He writes, "Autonomy encourages and protects people's general capacity to lead their lives out of a distinctive sense of their own character, a sense of what is important to and for them" (Dworkin 224). In current application, as long as we have no reason to think that an individual's ability to make their own decisions is significantly impaired, nor any reason to think that those decisions would infringe on the rights of others, we grant individuals a variety of personal choices (e.g. one's pursuit of career, family, romance, gender expression, and other endeavors). Dworkin calls these "critical interests," or the things that give our individual lives meaning and significance.³

²This additional piece of information was provided by an essay prompt rather than by Dworkin or Firkin. It does not substantially change the nature of Margo's case, except to detail the precise reason why she submitted an advance directive. Since patients are likely to hold substantial reasons for submitting a directive, I have included it in this paper to serve as an example of how this reasoning can be incorporated into a caregiver's assessment of the directive itself.

³It should be noted that Dworkin delineates the concept of critical interests in contrast to experiential interests, which are interests that are valuable in terms of the satisfaction or pleasure gained from experiencing them. For example: for someone who takes a casual interest in golf, playing a game of golf would be an experiential interest rather than a critical interest, since "people who do not enjoy an activity I do... are not making a mistake; their lives are not worse for not sharing my tastes" (Dworkin 201). However, when critical interests like autonomy or health are not satisfied, people are genuinely worse off. Dworkin classifies critical interests as more important, generally speaking, than experiential interests, and uses this prioritization to argue for respecting Margo's advance directive. A significant portion of Dresser's objection also responds to the distinction between critical and experiential interests. However, I have chosen to put aside this distinction as it is not especially relevant to the conclusion I wish to motivate.

In medical contexts, doctors protect autonomy by requiring informed consent from their patients and are not permitted to provide treatment without consent. This standard is set in order to prevent doctors from acting paternalistically by assuming authority over decisions which would normally be made by the patient. By extension, Dworkin establishes the legal right afforded to patients to refuse a life-saving treatment and subsequently die. For example, patients diagnosed with cancer may choose to go home instead of receiving chemotherapy as long as they sign an “against medical advice” form. An important corollary that Dworkin adds is that the right to autonomy should not be hindered by any external judgment regarding the prudential value of the agent’s decision. The observation that an individual’s decision does not furnish the best possible outcomes, or is a worse decision than an alternative readily available, is not sufficient to justify overriding their right to autonomy.⁴ Dworkin believes that we must protect autonomy not because we need to ensure that patients act in their own best interests, but rather because the integrity and individual personhood of the agent is a critical interest that is good in itself. In any case, the question of what others consider to be the most prudential or advantageous decision for a competent individual does not give us the justification to intervene and circumvent the making of that poor decision. The implication of this right to autonomy combined with the inability of others to restrict an agent’s autonomy on the basis of prudential good is that Margo is fully within her right to make poor decisions, as some might characterize them, about her own life. Thus, doctors are not justified in simply making decisions that they consider to be in Margo’s best interests because Margo is exercising her right to make decisions against some of her own interests in order to protect her *critical* interests, namely, living a worthwhile life. However, the issue with the case at hand is that Margo’s will and interests have fragmented temporally, such that the current and former versions of Margo have competing interests and potentially competing rights to autonomy. Whose will should we respect, when one Margo desires life and the other death?

⁴We should not, for example, prevent individuals from marrying someone for their money rather than marrying for love, even if we can reasonably predict that the individual will be extremely unhappy in the loveless marriage. Happiness in marriage, no matter how unequivocally good it may seem, is not so crucial to the dignity of human life that we ought to force it upon an individual who has decided not to pursue that end. We do not prevent sober adults from tattooing all sorts of unfortunate things on their bodies, even when we think that they will eventually come to regret that decision. With some exceptions, which will be discussed later, we allow people to make all sorts of poor decisions because it is their right to do so.

For Dworkin, the currently demented Margo no longer reflects a coherent sense of self, which is the worthwhile thing that one granting autonomy serves to protect. Therefore, it would not respect Margo's autonomy to respect the wishes of the demented specter of her self. Respecting the current Margo's wishes would interfere with the competent Margo's right to control the narrative of her life and how it ends. Dworkin argues that right to autonomy includes the right to *precedent* autonomy, whereby actors are permitted to make binding decisions for their future selves, using the values they hold in the present state. Margo's right to an advance directive is a right to precedent autonomy, derived from her right to direct her own future by living and dying by her own values. Under this right, the competent Margo can bind herself through an advance directive just as she can sign a will, mortgage, divorce agreement, or do-not-resuscitate form, as long as she is competent when it is signed. Just as those contracts are not rendered null because she succumbs to dementia, the advance directive should also continue to represent her autonomous choices even though she loses the capacity to express them. The fact that these contracts now have to apply to someone who is not presently competent and will not regain competency should not affect the legitimacy of the contract.⁵ It follows that this right to precedent autonomy, manifested in the advance directive, should be respected by any ethical caregiver who is committed to respecting the autonomy of competent patients. In this case, we must ensure that any hesitation to execute Margo's advance directive does not derive from the insertion of our own value judgments into the case—specifically, we must remember that enjoyment of life is not the sole metric by which a life is deemed worth living by its owner.

When the patient becomes incompetent and thus unable to dictate her own life, a diverse range of actors including lawyers, family members, caregivers, and other health professionals are tasked with determining the right course of action, especially when the stated wishes of the incompetent agent directly conflict with stipulations of the advance directive.⁶ I agree

⁵ Consider that we respect wills even though the deceased person in question is unquestionably gone, or do-not-resuscitate orders when the patient is irreversibly brain-dead. Take the case of a wealthy dog-lover whose last will states that her money should be given to dog-related charities, as she did when she was alive. She is able to dictate these arrangements in a legally binding way because the right to control what happens to her money and her body that she enjoys while alive extends beyond her death. Similarly, Margo can make a living will despite the fact that it will come into effect when the person we know as Margo is gone.

⁶ This essay is primarily concerned with what the caregiver should do or is morally justified in doing, rather than answering legal questions or advising family members when they are given the power of attorney.

with Dworkin and argue that the advance directive must be followed even when (and perhaps especially when) the incompetent agent desires that the directive be struck down. I argue that when the patient loses competency, it now becomes the role of the treatment team to interpret the advance directive and execute it, rather than making judgments external to the ones necessitated by the advance directive and subsequently acting on those judgments. The reasoning for this will become clear once it is established that advance directives are necessarily logical conditionals: *if X condition is fulfilled, then Y treatment must follow*. Here is one possible alternative interpretation of Margo's internal argument for refusing treatment:

Premise 1: My life is worth living only if I possess self-awareness and the ability to make plans for my future.

Premise 2: Dementia deprives a person of self-awareness and the ability to plan.

Premise 3: Because I will not possess those essential goods, my future life with dementia will not be worth living.

Conclusion: Therefore, I do not want to receive life-saving treatment if I were to develop dementia.

To improve this interpretation, I believe that it would strengthen Margo's autonomy by considering her argument as a logical conditional, rather than accepting the premises as fact, as is indicated by premise-conclusion form. I argue that the best interpretation of her argument is in the following conditional: *if my life with dementia lacks self-awareness and planning, then it will not be a worthwhile one*. Furthermore, *if my life is not a worthwhile one, then I do not want life-saving measures*. This modified interpretation is important because the reason Margo wishes to withhold treatment is not simply because of the dementia (which could be understood abstractly as the diagnosis or the atrophy of her brain), but because those things facilitate the loss of self-awareness and planning, which she holds as central to a worthwhile life.

It also allows for the precise unfolding of Margo's life with dementia to have an impact on the decision that is made for her. Margo's present objection that she desires the treatment should be paid close attention, not because the will of the incompetent patient is important in itself, but because it could shed light on the will of the competent patient. If she turns out to be incorrect about her second premise, then the antecedent is not satisfied and caregivers should not withhold treatment. The truths obtained by observing Margo's actual life with dementia may have caused the competent Margo to conclude as follows:

Premise 1: My life is worth living only if I possess self-awareness and the ability to make plans for my future.

Premise 2: *Dementia did not end up taking away those essential goods.*

Conclusion: My life with dementia is still a worthwhile one.

Importantly, note that this method still respects the values and principles of the former self. If Margo knew that she would retain the elements of a life worth living despite her dementia, we have very good reason to believe that she would revise her conclusion that she wants to die. I recommend that the ethical caregiver respond by launching an inquiry into the antecedents of Margo's conditional argument: would the competent Margo truly consider dementia to have taken away the elements of a life worth living? Since there is no competent Margo available to perform this assessment herself, these are questions that can be best answered by the combined efforts of those familiar with her present state, who are likely to be attending caregivers and psychiatrists.⁷ Contrast this with the previous interpretation, where there is no assessment of whether dementia actually took away the essential goods underlying the patient's reasoning. Ultimately, I wish to use this improved method of assessing advance directives to defend Dworkin's position from concerns raised by Dresser.

In "Dworkin on Dementia: Elegant Theory, Questionable Policy," Dresser raises several objections to Dworkin, concluding that Margo's advance directive should be ignored in favour of the demented Margo's desire for life-saving treatment. The primary objection that will be addressed in this essay is that people who submit advance directives often hold insufficient or mistaken information about what their future life with dementia will look like. It would therefore be a justified form of paternalism to ignore directives based on faulty information in order to "preserve the life of someone as contented and active as Margo" (Dresser 37). First, Dresser notes that the lives of incompetent patients with dementia are not as miserable and meaningless as commonly assumed by healthy agents,

⁷For example, the caregiver will be familiar with the day-to-day behaviours and thoughts of the patient and can provide detailed reports to the psychiatrist. The caregiver may note that Margo has not been able to remember her own name or recognize herself in a mirror for some time, thus providing evidence that she has lost self-awareness. The psychiatrist can then determine whether the essential good is considered lost using those notes in conjunction with inquiries such as interviews with the patient, discussion with the patient's family and other treatment providers, and consultation of patient medical notes.

revealing a crucial epistemic mistake that could be made by individuals submitting advance directives. She criticizes Dworkin's model for adhering to common portrayals of dementia as "tragic, horrible, degrading, humiliating, to be avoided at all costs." (37) In an earlier piece, she expands on this by questioning the basis for assuming the views expressed in the advance directive can truly represent what the competent patient would desire if they were still present (Dresser and Robertson 236). Surely it is possible that the competent patient would have changed their directive if they knew what the incompetent patient knows about their life now.⁸ Philosophers such as Terrence Ackerman frequently emphasize the transformative effects of illness, which include a reconfiguration of one's values due to a disease introducing the agent to new perspectives (15).⁹ Although Dresser does not explicitly apply the lens of transformative experience to Margo's case, she alludes to it in her defense of the validity of Margo's new interests. Perhaps Margo has realized since she submitted her advance directive that it is not self-awareness and planning that are essential to a good life, but rather one's sense of satisfaction and fulfilment, motivating her to contradict her former directive.¹⁰ Agents are generally permitted to revise their desires and incorporate new values, experiences, and knowledge into their decision-making. Dresser wishes to accord this right to the demented Margo and strongly advocates for her ability to overrule the advance directive. The values of the competent agent cannot be taken (with certainty) to represent what the same patient would desire should they become incompetent, so they should not be given such ultimate and final credence over the incompetent patient's interests. This motivates Dresser's argument that the transformative effects of illness have serious implications for the informed aspect of informed decision-making, such that we should act paternally in

⁸We can imagine that an elderly woman devoted to her family might have chosen to withstand the pain of terminal illness rather than choosing physician-assisted suicide if she had known that she could witness the birth of her first grandchild. Recall the cancer patient from before who decided to take their savings and travel around the world if they became just healthy enough to leave the hospital, rather than passing on their savings to family.

⁹These transformative effects may look like a busy working father realizing after a heart attack that he should spend more time with his children at home, for example, or a terminal cancer patient deciding to cash in their savings and travel around the world. In each case, we can observe the trading of previous values for new ones, facilitated by the disease experience and done so without a loss of competency.

¹⁰This is a view supported by Agnieszka Jaworska (1999), among others who advocate for the continued ability of dementia patients to hold beliefs and values despite having a serious neurological condition. This is especially likely if the patient has not progressed much in terms of her disease, and retains much of the same autonomous decision-making capacities as she did when she advanced the directive.

Margo's case. Informed consent for refusal of treatment can only be given if the patient has sufficient information on their condition in order to compare their life with and without treatment. If we accept this standard for informed consent, then patients who submit advance directives for dementia may automatically fail to meet it because they cannot predict the quality of their future life with dementia. Dresser argues that it does not promote an agent's autonomy to accept decisions made on insufficient or mistaken information, as is the case with healthy agents who submit advance directives without a complete understanding of what their lives will be like once they develop dementia.¹¹ According to Dresser, we must remember that when competent people express their wishes before the onset of disease, they are thinking about what they value as competent decision-makers, limited by the inability to foresee with absolute certainty what they will desire as incompetent decision-makers.

I am sympathetic to this view, but do not believe that it would be morally permissible for the adjudicators of the advance directive to allow the incompetent person's stated wishes to override the competent agent's precedent autonomy. I am not convinced that respecting the incompetent patient's interests is valuable in cases where it fundamentally opposes the competent patient's interests. Here is the crucial distinction I propose: the treatment team should only judge whether the antecedents of the conditional directive were met, rather than judging the directive itself. The competent Margo did not identify loss of enjoyment or pleasure as the reason why she would not find life worth living if she had dementia, so it does not matter that she did not or could not predict that she would be happy, nor does it matter that she did indeed find happiness in her current life. Thus, it is not Dresser's place to object by noting that the present patient enjoys her life and therefore wishes to continue her life by receiving the treatment. Neither Dresser nor the ethical caregiver should attempt to replace the values expressed in the patient's advance directive with their own. No such paternalism is justified under this lens because, as previously established, we allow competent people to make all sorts of incoherent,

¹¹ When patients lack a proper basis for decision-making, Dresser says we may intervene in an act of justified paternalism. When a doctor proposes a life-saving blood transfusion to a dying Jehovah's Witness, they must be clear about what will happen with the transfusion and without. If the patient is not sufficiently informed that the treatment can save their life or that their condition will result in death, their decision to refuse treatment may be invalidated. Consider that one cannot sign up for a clinical trial without being told that there is a risk of death, or submit a do-not-resuscitate (DNR) order without confirming that they understand what that order would entail. Even Dworkin agrees that autonomous decisions are only valid when one is not being deceived or withheld information from (222).

unwise, and silly future-oriented decisions. Competent agents are perfectly justified in making decisions that discount their own happiness or some alternative value others may consider important.¹² In some cases, we do observe that intervention occurs and is justified: take, for example, the near-universal legal ability to place suicidal patients on a mandatory psychiatric hold to make sure they do not kill themselves, or the marriage restrictions on people under the age of 12. The common element that characterizes these cases is the lack of competency observed in the agent. Suicidal people and children are considered incapable of making these sorts of decisions, which is the justification for restricting their autonomy. However, I argue that advance directives for dementia patients do not fit into this category of justified paternalism, since the agent is competent at the time when they create the directive.¹³ What matters is that the competent agent has decided that a life with dementia will not be valuable to them, not that others may consider it valuable. We must remember that the competent Margo did not differentiate between the medical treatment that she wanted if she was happily living with dementia, versus the treatment she wanted if she was miserably living with dementia. Combining the right to autonomy and the right to precedent autonomy means that Margo is fully justified in selecting and living by whichever values she deems important to her, which includes binding her future self to her present values. We need not criticize her for holding some values and not others, and we should only examine these interests closely when it becomes relevant to the conditional: in order to evaluate whether the consequent should be applied, we must ask whether it is true or false that dementia took away this essential good.

On the issue of changing one's mind, it is perhaps possible that the new information would have caused a radical reformulation of one's beliefs

¹²One may, for example, choose to break up with a partner in order to accept a lucrative job offer in another country, a decision that will make them absolutely miserable. However, we do not intervene in order to replace the agent's values (in this case, money) with what we might consider to be a more important value (love or happiness). The selection of an unusual value may be reason to assess competency, but once competency is established, it is unquestionable. For example, an agent's claim that they hold their stamp collection to be the exclusive source of meaning in their life may raise questions about their state of mind, but once their competency is established, we cannot prevent them from spending their entire salary on stamps, creating a stamp museum, or tattooing stamps over their face.

¹³Another concern may be the possibility of regret, such that the agent might decide differently if given more time to consider. This is solved in most places that allow physician-assisted suicide by requiring the patient to consent over a number of different time points. There is no reason why we cannot implement the exact same type of check for advance directives and dementia. We can require that an agent confirm the directive over the course of a month, year, or however long we determine necessary to assuage concerns about regret.

and values if the competent Margo had a chance to reassess, but an additional problem arises for Dresser's case: that chance does not exist, and at no point between receiving the information and acting on it does a rational agent get to make that reassessment. If it is not in dispute that irrational or incompetent actors should not be taken as autonomous representations of their competent selves (e.g. severely depressed patients trying to kill themselves), then we need not respect the decisions produced by agents in that state. Margo may not have known that she would find happiness at the care facility, but this does not mean that the desire she expressed earlier, to end her life if rational capacities seemed absent, is rendered null. Even if it is impossible to perfectly predict one's future desires, I believe we should be unconcerned with satisfying the wishes of an incompetent patient if those wishes conflict with wishes the patient previously—and competently—deemed more important. Dresser, however, argues that the present demented self's wishes matter more than the former self, who is no longer existent and will not return, since it is the present self who will be harmed or benefitted by the decisions made on their behalf. She criticizes Dworkin for assuming that the demented Margo is the same person as the competent Margo, when in reality there are considerable grounds to think that the condition has produced a completely different person with new interests. The validity of precedent autonomy rests on the continuity of the person who submitted the advance directive, who may have been replaced by a wholly unfamiliar person who merits her own autonomy, and thus precedent autonomy may fail to apply. The new Margo, as Dresser argues, is the one who will experience clear harm from her wishes being disregarded in favour of the advance directive, which should bear weight when deciding whose interests to satisfy. However, I see little reason to value the incompetent patient's wishes simply because they harm or benefit the present person more than the past person, and do not accept that we cannot rule over our future selves if they were to develop radically new interests.¹⁴ Dresser laments that the interests of incompetent people are not taken seriously, but again fundamentally ignores that this is at the request of the formerly competent patient. The reason why we should disrespect an incompetent patient's wishes is not *simply because* they are incompetent, but because the competent person *themselves* wished to disrespect their

¹⁴ At what point should someone's transformation deem them a completely new person? Are adults the same people they were as children? If a staunch Democrat grows up to be a conservative senior citizen, are they the same person? If I develop a serious mental illness such as depression or schizophrenia, am I no longer the same person as I once was? I am utterly confused by Dresser's assertion that developing different interests over time means that a new person was created.

incompetent interests and remove their own ability to change their minds when incompetent. When Margo submitted her advance directive, she had to have considered the fact that dementia may cause her to become unable to identify or communicate her interests and concluded that she herself wished to negate this possibility by binding herself and her caregivers to a legal contract. This was done precisely in order to prevent both her unfamiliar future self and some external decision-maker from deviating from her wishes. In other words, Margo explicitly knew that dementia could impede her reasoning and ability to express her true desires and chose not to allow her future interests to be taken as a more accurate or otherwise better representation of her true desires than the ones she would express while fully competent.

A possible objection to my arguments may be that Margo has not actually considered the possibility that she may be happy despite her dementia, and therefore we cannot assume that the agent herself wished to disrespect her future happiness. While I cannot delve into the mind of this fictional actor, I believe the simple solution to this in real-life application is to force actors to consider these cases when they are submitting the advance directive. Through requiring “even-if clauses” to be a part of the directing process, we can avoid the objection that agents have not given consideration to future values they may develop. An example of an even-if clause is outlined by Dworkin, though not for this purpose: a Jehovah’s Witness expresses that he is not to be given blood transfusions, *even if* he changes his mind and begs for it at the relevant time (227). When Margo expressed that she wished to forgo life-saving treatment if she succumbed to dementia because she does not value a life without self-awareness and the capacity to plan, she should have been asked, “Do you desire this *even if* you are still capable of self-awareness and planning?” If Dresser is concerned about the epistemic mistake made regarding the happiness of dementia patients, we can include a question that asks, “Do you still want to die *even if* you seem to be happy with your life?” If the agent says yes, then this is a clear exercise of one’s precedent autonomy. This preventative measure should address the complex situation that results from a patient’s past directive conflicting with the desires of the patient today. The patient, while competent, will have considered the possibility that she may be surprised or wrong about her future life with dementia.

This requires Margo to be thoroughly questioned when directing her wishes in advance, like so: what do you consider to be good tests of self-awareness and planning? What should be done if you continue to demonstrate the capacity to plan and be self-aware occasionally but not most of the time? Are you aware that dementia patients frequently express contentment with their lives? I anticipate the objection that this is incredibly strenuous,

and perhaps overzealous. I respond that any modification where agents have to give more thought to their values, predictions, and preferences before submitting an advance directive is conducive to the best exercise of an agent's autonomy. Though we cannot apply this second half of the proposal to patients who have already declined without the opportunity to clarify their advance directive, we can use it in the future to prevent situations where caregivers and psychiatrists are left to make educated guesses and difficult decisions about what a patient would truly want. Most importantly, I conclude that in order to truly respect a person's autonomy, we cannot act paternally by disregarding their advance directive.

Works Cited

- Ackerman, Terrence F. "Why Doctors Should Intervene." *Hastings Center Report*, vol. 12, no. 4, 1982, pp. 14-17.
- Dresser, Rebecca, and Robertson, John A. "Quality of Life and Non-Treatment Decisions for Incompetent Patients: a critique of the orthodox approach." *Law, Medicine and Health Care*, vol. 17, no. 3, 1989, pp. 234-244.
- Dresser, Rebecca. "Dworkin on Dementia: Elegant Theory, Questionable Policy." *Hastings Center Report*, vol. 25, no. 6, 1995, pp. 32-38.
- Dworkin, Ronald. *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom*. New York, Alfred A. Knopf, 1993.
- Jaworska, Agnieszka. "Respecting the margins of agency: Alzheimer's patients and the capacity to value." *Philosophy & Public Affairs*, vol. 28, no. 2, 1999, pp. 105-138.
- Radden, Jennifer, and Sadler, John Z. *The Virtuous Psychiatrist: Character ethics in psychiatric practice*. New York, Oxford UP, 2010.