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# Ethics of the Advance Euthanasia Directive: Death Within Dementia

Honors Thesis - Philosophy

**Isabella Braga**

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## Foreword: Argument Overview

This thesis argues that the advance directive for euthanasia (ADE) is morally permissible, and that it is morally obligatory to respect and fulfill the ADE in the clinical setting.

This thesis was inspired by a practical dilemma: in many jurisdictions, only patients of sound mind (designated *compos mentis*) have access to physician-assisted euthanasia. It is not like physician-assisted suicide, wherein the patient may be prescribed a killing pill and take it at a later date. In current practice, because physician-assisted euthanasia is administered by a medical professional, the patient must be euthanized while she is of sound mind, typically not long after consent to the procedure.

When a patient receives a dementia diagnosis, then, she is in an unusual position with two unfavorable options. Assuming that she wants to be euthanized, she can choose to die while *compos mentis*, thus securing control over her future, at the potential price of years of living with a sound mind. Alternatively, she can wait it out, trying to see how closely she can toe the line of being non-*compos mentis* before it is too late, at the risk of rapid and unexpected decline. If she were to fail this gamble, she would experience all the harms she fears: among them, indignity, loss of control over her body, and emotional burden on her loved ones.

With an ADE, the patient neither fears her future nor risks harm to herself and loved ones. She is able to live out the full extent of her *compos mentis* years, and have control over the fate of her living remains, the body containing the demented version of herself.

Chapter I opens with an overarching view of the hopelessness, indignity, and fears dementia patients experience. Its purpose is to show that there is demand for the ADE, and that a properly-applied ADE will be well-received. In the course of this, I use the case of Gillian

Bennet's suicide to illustrate public desire for right-to-die procedures. I also state the practical benefits of the ADE and explain the procedure of an ADE. I supplement this with potential concerns for the execution of an ADE, and first introduce the idea of a clinical ADE taskforce.

Chapter II is about "Margo, the Happy Sufferer." This chapter introduces a key philosophical conflict of the ADE: what do we do when the non-compos mentis patient refuses the conditions of the ADE? Chapter II forms a thought experiment based on the real-life case of a woman named Margo—a woman who requested life-ending procedures in case of full descent into dementia, but who exhibited signs of emotional fulfillment once fully demented. My thought experiment asks who makes the final judgment call—"Margo 1" in her past compos mentis form, or "Margo 2" in her current non-compos mentis state? To determine this, I raise three key questions. (1.) Is Margo the same person once she is fully demented? (2.) If they are different, can Margo 1 call for Margo 2's death? (3.) If they are the same person, can past Margo call for current Margo's death anyway? At this point in the paper, I have not gone into the complexities of my position, as I will soon argue that Margo is a different person after her full dementia diagnosis, that Margo 1 has effectively died, and that Margo 1 still maintains rights over the fate of the body she knew while alive.

The purpose of Chapter III is to answer the three questions raised in Chapter II. These questions enable us to disentangle the complex tensions of Margo's dilemma. We are setting the groundwork so that we may argue that Margo 1 and 2 are different people, that Margo 2 is not a person, and that Margo 1 still maintains the ability to determine the fate of the body Margo 2 inhabits. However, because each question in Chapter III has multiple responses, the argument spiderwebs. The positions explained in Chapter III are as follows:

Question 1: Is Margo the same being before and after a full dementia diagnosis?

- Answer 1: Margo 1 and Margo 2 are different, and Margo 2 is a person.
- Answer 2: Margo is the same person before and after a full dementia diagnosis.
- Answer 3: Margo 1 and Margo 2 are different, and Margo 2 is not a person.

Question 2: Assuming they are different people, should Margo 1 be able to kill Margo 2?

(In sum, is this not murder?)

- Answer 1: Yes, it is murder. (Margo 2 is a person.) (*Aligns with Question 1, Answer 1.*)
- Answer 2: No, it is not murder. Margo 2 is not a person, and Margo 1 has a substantial enough claim to justify Margo 2's death. (*Aligns with Question 1, Answer 3.*)
- Other potential responses: Margo 2 is not a person but should not be killed. (One might appeal to animal rights argumentation for the rights of less rational beings.)

Question 3: Assuming that Margo is the same person before and after a full dementia diagnosis, should "past Margo" call for Margo's death, even if "present Margo" objects? (*All arguments under Question 3 are in line with Question 1, Answer 2.*)

- Answer 1: Yes, because Margo's critical interests persist. (Full Dworkinian argument.) Her past self is like a parent determining what is right for the child, her present self.
- Answer 2: No, Margo has present interests that have validity.
- Other potential responses: Yes, on the basis of contracts (legal argument); it depends on her family's call (the "social circle" argument); no, this is suicide (religious argument).

Our argument only holds that Margo 1 and 2 are different, that Margo 2 is not a person, and that Margo 1 has substantial claim to determine the fate of the body she has always known. We argue this in Chapter IV.

Chapter IV is where the bulk of the argumentation occurs. After the groundwork of the dilemma is set, its claims proceed roughly as follows: 1) the demented patient (referred to in the paper as “Margo 1,” to indicate the patient’s initial state) dies after the full onset of dementia, 2) the being that remains in that body (“Margo 2”) is a non-person, 3) Margo 1 has certain claims over her living remains, 4) Margo 1 will be harmed if those claims are jeopardized, and 5) medical practitioners are obligated to abide by the ADE (as argued in Chapter V).

Chapter IV argues for the ADE from the ground up. It establishes what happens to Margo in dementia, what claims she possesses and why, and why these claims must be respected with an ADE. The first step is establishing that Margo 1 dies. The second step is defining Margo 2 as a non-person. The third step is determining Margo 1’s claims over her living remains. The fourth step is examining the harms done unto Margo 1 if those claims are defied. The fifth step is justifying the practical obligations of the medical practitioners.

We reject the idea of death as a total loss of brain activity. However, we are not dualists, and believe that the loss of self (which, we will argue, constitutes death) is based in biological function and the physical capacity of the brain. Margo dies because her brain can no longer rationalize, acknowledge her interests, or identify with Margo’s narrative. However, this does not require full neural failure.

Neural function, as it is currently observable, we argue, cannot delineate identity, personhood, or full consciousness. This is why we involve Furberg, who mentions a biological

idea of personhood—that because Margo is physically there with working neurons, she is a person. We rebut this, saying that without any rationality, continuity of memory, or sense of life narrative and the interests that defined it, the being inside Margo’s body is like being a lesser-order animal, with little moral weight.

To define Margo’s identity, we draw from DeGrazia, Schechtman, Christman, and Parfit. DeGrazia argues that psychological unity is dependent on one’s stakes in continuing to exist, as well as one’s capacity for consciousness and action. Schechtman proposes the concept of narrative identity, which she identifies as “patterns of identification, values, and a sense of self.” Christman claims that unified personhood requires self-acknowledgment of a consistent character at the center of one’s life. Parfit argues that identities can splinter based on one’s beliefs, desires, and motivations.

Our definition of an identity is thus “a conscious, rational, and autonomous sense of an individual life narrative, with an acknowledgement of one’s stakes, values, and quality of life, in a manner constituting a unified and consistent character” (35).

To argue that Margo 2 is a non-person, we draw from Ott and Kuhse (whose argument relies on Singer). Ott argues that the personhood of the individual is reliant on the “mental person,” not on the physical constitution of the body. This means that if the person loses rationality, they lose personhood. Kuhse argues that Margo 2 is not a person because she lacks “strong psychological continuity,” and that Margo 2 is not the author of the advance directive. Nevertheless, Kuhse says, Margo 1 has legitimate claim to her “living remains” (the body Margo 2 inhabits) because she has “surviving interests,” which are stronger than the fleeting desires of a non-person. Kuhse involves Singer’s animal rights argumentation, to claim that much like an animal, Margo 2 has some moral weight; but, she says, much like an animal, the demented patient



has no vested interest in continued existence. Kuhse's resounding claim is that while Margo 2 has some interests, they are less weighty than Margo 1's, and so Margo 2 can be killed as long as it is humane and without unnecessary suffering.

Kuhse's assertion of Margo's claims leads to the next step of our argumentation. If Margo 1 has "surviving interests" with more moral weight than Margo 2's fleeting interests, then we must show that these claims exist after her death. Persad argues that by virtue of having lived in her body, Margo 1 maintains a historical right to bodily autonomy. Furthermore, Persad argues that this historical right is posthumous, such that it exists though Margo 1 is dead. He states that because she lived her life in this vessel, she has the most significant claim to its wellbeing. We synthesize Persad's argument with Kuhse's surviving interests theory and Dworkinian critical interest theory<sup>1</sup> to argue that the historical claim to one's body is a fundamental critical interest. By virtue of Margo 1 writing an advance directive at all, she expresses a clear critical interest for her historical bodily rights. We also utilize Woien's "now-for-then" desire theory. She claims that Margo 1 expresses "now-for-then desires" in an ADE, meaning that her desires were well-informed, autonomous, and constructed to be implemented "now" for her best interests "then." Woien contrasts this with Margo 2's temporary "now-for-now" desires, which, she says, must be disregarded in favor of Margo 1's autonomous and informed desires.

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<sup>1</sup> We use Ott to extricate Dworkin's critical interest theory from the rest of his argumentation. Ott argues that Dworkin's claim that the demented patient is one person (that Margo 1 and Margo 2 are not different people) is not substantiated. My assertion is that if we acknowledge this hole in his theory, every step of his argumentation could just as well be used to support our theory of a splintered identity with posthumous critical interests. The key difference is just that he believes they are one person, and we believe they are two. But if we are able to breach that barrier of claims—as we attempt to do—with posthumous rights, then our theories are compatible.

It is also worth addressing that Dworkin is not a consequentialist. Though this paper is consequentialist in nature, it is strongly founded in conceptions of moral claims and duties. The difference is that we believe these claims and duties are valid insofar as they bottom out in benefits or harms (as discussed in Chapters IV and V). So while we do not agree with every argument of every philosopher mentioned in this paper, we utilize arguments that fit into this framework of rule utilitarianism.

Persad's argument that Margo 1 has posthumous claims may seem odd, but he is not without company. Feinberg and Pitcher also argue that claims and harms can breach death. To explore how harm is done unto Margo, we use Feinberg, Nagel, Pitcher, and Luper. First, we describe Feinberg's analysis of types of moral harm, to determine that if Margo 1's ADE is disregarded, her interests will have been thwarted and her bodily rights will have been infringed upon. Nagel argues, then, that death can deprive us of desires. We mention that if death can deprive us of desires, then we surely can be deprived *in* death. Pitcher discusses the temporal confusions of posthumous harm, leaving Luper to more clearly and thoroughly describe how posthumous harm works applicable to our case. In sum, if an event endangers our interests tomorrow, it harms us today, because our interests currently exist. We therefore argue that if Margo 1's critical interest over bodily autonomy is endangered after her narrative death (if the doctor disrespects the ADE), then she is harmed posthumously.

To argue for the obligation of medical practitioners to maximize benefits for Margo, we draw on Beauchamp and Childress's four principles of bioethics (beneficence, non-maleficence, autonomy, and justice). We argue that respecting the ADE enhances benefits for Margo 1, secures her autonomy over her body, and prevents the injustice of the thwarting of her critical interests. In Chapter V, we expound on the practical side of the ADE, including concerns for doctor participation and wellbeing, mechanisms needed for the proper implementation of the ADE (including clinical frameworks and political culture), and issues of access. We conclude that while the ADE prevents posthumous harm to Margo, protects her critical interests, and gives her the agency to direct the fate of her living remains, we maintain reservations about its practical application.

## Chapter I. An Introduction to Advance Directives for Euthanasia

Without a planet-wide healthcare revolution, by the year 2050, over 131.5 million people worldwide will have dementia.<sup>2</sup> Despite recent revelations within the medical research community regarding prospective treatments for dementia, specifically Alzheimer's Disease, there is currently no cure. Accordingly, the high degree of suffering conferred by the disease compels us to discuss means of mitigating patients' pain.

To conceptualize the harms of the disease, we must understand its physical and psychological impacts, which transcend loss of memory, function, and cognition. Patients "may...die earlier from dementia-related health problems such as pneumonia and intake problems or comorbid disease...[with] means or medians of [survival] between about 3 and 10 years."<sup>3</sup> As for the psychological harms, in *Legal Medicine*, Cipriani and Di Fiorino explain that patients fear not only loss of control, but also dependence on others, inability to report suffering, and institutionalization. They state, "Many people fear dementia and some would prefer an earlier death over having to progress to the final stages of Alzheimer's disease."<sup>4</sup>

One theoretical solution for patients' fears is the ADE—the advance directive for euthanasia.

An advance directive allows an individual to assert control of her own future; prevents family members from navigating difficult ethical, emotional, and financial healthcare dilemmas;

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<sup>2</sup> Cipriani, Gabriele, and Mario Di Fiorino. "Euthanasia and Other End of Life in Patients Suffering from Dementia." *Legal Medicine* 40 (2019): 54-59. Web.

<sup>3</sup> Cipriani, Gabriele, and Mario Di Fiorino. "Euthanasia and Other End of Life in Patients Suffering from Dementia." *Legal Medicine* 40 (2019): 54-59. Web.

<sup>4</sup> Cipriani, Gabriele, and Mario Di Fiorino. "Euthanasia and Other End of Life in Patients Suffering from Dementia." *Legal Medicine* 40 (2019): 54-59. Web.

and guides healthcare professionals to act in a manner consonant with the previously compos mentis individual's interests. Types of advance directives include a living will, which expresses the competent individual's desires for their future treatment when incompetent, and a proxy directive, which appoints a competent agent to delineate medical decisions in the case of one's incompetence.<sup>5</sup> However, the advance directive can also be a straightforward contractual expression of the individual's desires in a specific scenario, including a case of post-dementia diagnosis incompetence.

Via an advance directive for euthanasia (ADE), a compos mentis individual would be able to state her desire to be killed in the case of her becoming non-compos mentis. In other words, the individual could be able to call for the physical death of her post-dementia diagnosis state, for reasons that might include but might not be limited to dignity, personal identity, and notions of familial burden.

With this theoretical advance directive, a compos mentis patient diagnosed with dementia and/or Alzheimer's would delineate a brightline for the time of their physician-assisted euthanasia. This brightline would be the threshold of the mental faculties with which they would like to live. For example, one might ask that they be euthanized when they can no longer remember the names of their children. Or the line may be more complex, involving a series of questions, a logic puzzle, or a passcode. Most vitally, the patient would have full autonomy over this brightline.

Unfortunately, the theoretical ADE is not legal in the United States. In common practice, the advance directive for euthanasia is barred, and to access physician-assisted suicide, patients

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<sup>5</sup> Kuhse, Helga. "Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity." *Kennedy Institute of Ethics Journal* 9.4 (1999): 347-364. Web.

must be fully *compos mentis* and diagnosed with a fatal illness (with death anticipated in the next six months or earlier). A dementia diagnosis falls into a gray area: it is associated with fatal conditions, but typically takes longer than six months to reach a critical point; and it is impossible for the patient to take the medication at the exact tipping point of being non-*compos mentis*, because the line is not black-and-white. By the time she reaches the point at which she wanted to terminate her life—the point at which she is non-*compos mentis*—she will not have the mental awareness *nor* the legal ability to articulate this desire. It is self-defeating: to prevent herself from living as a non-*compos mentis* being, the *compos mentis* person must kill herself before it is too late. Yet she will often not be in a fatal position until she is deeply demented, and so she cannot access physician-assisted suicide. The case law simply does not accommodate her trials as a demented individual. Instead of allowing her to live her *compos mentis* life to its fullest, the law's strictures can only drive her to suicide.

To understand what is at stake for the dementia patient, consider the case of Gillian Bennett, author of *Dead at Noon*, a website chronicling Bennett's descent into dementia.<sup>6</sup> Bennett programmed the website to release at the time of her suicide, to which she was driven in the absence of options for euthanasia given her increasingly non-*compos mentis* state. Bennett died in 2014, before euthanasia for even the *compos mentis* and terminally ill was commonplace, but in the present context, there remains a prevailing message—a plea, really. Stories like Bennett's ask us to consider euthanasia for those dementia patients who need it most: those who are already non-*compos mentis*. If it is not given, the demented may opt for suicides, unbecoming in their indignity, unlike the metered, well-considered and counseled processes necessary for viable normalization of physician-assisted euthanasia. It is almost as if we add insult to injury. Furthermore, if they do

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<sup>6</sup> Bennett, Gillian. "Dead at Noon." <http://www.deadatnoon.com/>

not opt for suicides, the issue is not rectified, as the patient is still left to crumble in a manner contrary to their own interests and wishes.

Permitting advance directives for physician-assisted euthanasia dodges the ills of this scenario. Note its parallels to the do-not-resuscitate (DNR) order. Patients who issue a DNR may have the same concerns as patients who would pursue ADE: quality of life, loss of dignity, and inordinate suffering. Yet the patient with dementia will be forced into one of two uncomfortable scenarios. One, she may live out her days, gradually becoming a shell of herself, terrified, paranoid, and likely reduced to the functional capacity of an infant before suffering a slow and painful death. Or, two, she may lose years of her life, choosing to die before she is non-compos mentis. The latter is an option increasingly embraced by Americans in eight American jurisdictions (seven states and Washington, D.C.), which have legalized euthanasia for the terminally ill and suffering.<sup>7</sup> The catch-22 is that the same strictures from physician-assisted suicide apply: the dementia patient must consent to euthanasia in real time.

While societally we are quick to honor the wishes of the dying in DNR cases, we are hesitant to fulfill the wishes of the living in dementia cases. Again, there is a pervasive irony. Both suffer the same concerns for quality of life, dignity, and the rest. Yet because death is inflicted in the case of a dementia patient with an advance directive and merely allowed for a patient with a DNR order, there is a sense of culpability on behalf of the medical professional which damns the dementia patient. It seems to be a distinction based in killing versus letting die. While I could tout my utilitarian ideals and argue that it is silly to make such a distinction, it won't change the fact

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<sup>7</sup> Roehr, Bob. "Assisted Dying in US and Canada: Controversy Subsides after Legalisation." *BMJ: British Medical Journal (Online)* 360 (2018): K503. Web.

that some medical professionals may be reluctant to embrace ADE. Indeed, if this were not the case, the present conversation would not be so prominent in medical ethics today.

It is not difficult to see why there would be fears associated with the ADE. Unlike physician-assisted suicide, euthanasia is physician-administered, not just physician-prescribed. Also, the non-compos mentis individual may very well protest the ADE, as they are by definition no longer of sound mind. What, then, is in the patient's best interest? We will address these concerns in the final chapter of this thesis, which discusses practical considerations and reservations for the ADE. These concerns also include the creation and enforcement of the brightline for euthanasia's administration; the prevention of abuse of the ADE (by family members, medical practitioners, mentally ill patients, and the law); and disadvantaged populations' access to the mechanisms necessary for the ADE's ethical implementation.

The crux of the ADE is that, with it, we avoid unnecessary suffering and indignity, save years of the patient's life, and preserve her autonomy to end her life in a manner consonant with her ideals. We advocate that the compos mentis individual has the right to opt to be euthanized in the advanced stages of dementia, such that she can enjoy the full capacity of her remaining years. We will recommend safeguards to this method, including a taskforce of professionals enlisted to ensure that the patient's best interests are maximized.

## Chapter II. Margo, the Happy Sufferer

There is a primary obstacle to the implementation of ADE, an obstacle that will constitute the meat of the thesis. As a narrative, it has immense illustrative power, and will allow us to highlight crucial ethical entanglements at the core of the ADE.

In short: what do we do when the demented patient's desires conflict with her pre-dementia self? At surface level, it seems simple. However, the problem complicates itself quickly. We'll begin with the bird's eye view.

One prominent objection to the ADE notes the individual's inability to foretell his demented version's options in life, feelings toward death, conceptions of personal identity, or medical circumstances. Kuhse states that objectors "hold that advance directives should, in some circumstances, be overridden. If it is in an incompetent patient's interests to live, [objectors to post-diagnosis euthanasia believe] he or she should not be made to die simply because the formerly competent person executed an advance directive."<sup>8</sup> Yet proponents of post-diagnosis ADE would emphasize the will of the *compos mentis* individual, regardless of the will of the current non-*compos mentis* patient.

There are multiple ways of viewing this *compos mentis* predecessor and non-*compos mentis* successor—Are they the same person? Are they different people? Is the second individual a person at all?—but the thrust of the clash is that some value the interests of the non-*compos mentis* dementia patient, while others would say, simply put, that a good book cannot end on a bad

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<sup>8</sup> Kuhse, Helga. "Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity." *Kennedy Institute of Ethics Journal* 9.4 (1999): 347-364. Web.



chapter. Moreover, a good book cannot end on a deteriorating chapter lacking narrative, higher consciousness, and even its most basic daily functions.

The latter analogy, however, is a contentious one. While some might be more than ready to accept the innate harms of dementia *prima facie*, others may claim that dementia is not intrinsically detrimental to quality of life. In other words, because of dementia, *not* in spite of it, one might experience increased contentedness. Take, for example, Andrew Firlik's example of the happy sufferer Margo.<sup>9</sup>

In 1991, in the *Journal of American Medicine*, medical student Andrew Firlik now-famously chronicled his experience with a patient during a gerontology course. Margo's life was a charmed one. Although she did not read mystery books in a linear manner, she enjoyed them. Although she did not know Firlik's name, she was happy to see him. And although she painted the same picture and listened to the same song every day, she loved the arts. Her mental degeneration led her to a state of bliss, inspiring both awe in Firlik and an inquiry as to her identity. He asks, "Who is Margo?"<sup>10</sup>

Andrew Firlik describes Margo as such: "[D]espite her illness, or maybe somehow because of it, Margo is undeniably one of the happiest people I have ever known."<sup>11</sup> Yet while *compos mentis*, Margo articulated her desire of the rejection of treatment should her dementia-ridden self contract treatable illnesses. However, once stricken with pneumonia, she (*non-compos mentis* Margo) desires treatment. What is a physician to say when a woman sits before him, requesting treatment, while a piece of paper orders him to deny her?

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<sup>9</sup> Firlik, Andrew D. 1991. Margo's Logo. *Journal of the American Medical Association* 9: 201.

<sup>10</sup> Firlik, Andrew D. 1991. Margo's Logo. *Journal of the American Medical Association* 9: 201.

<sup>11</sup> Firlik, Andrew D. 1991. Margo's Logo. *Journal of the American Medical Association* 9: 201.

And now the problem is emotionally complicated by Firlik's reluctance to condemn a happy person to death based on the desires of an entity who, in the loss of Margo's mental faculties, is no longer physically present.

Helga Kuhse offers the following thought experiment:

*"Let us suppose that years ago, Margo was a philosophy professor who relished complex mental activities. Let us also suppose that Margo, while fully competent, executed an advance directive. Adequately informed, she knows that dementia affects different people differently, leaving some happy and some distressed. She makes it quite clear that even if she were to be experiencing no visible distress and were seemingly 'pleasantly demented,' she would wish to be allowed to die if and when the opportunity were to present itself. Margo, now demented, contracts pneumonia. This is likely to be fatal, unless Margo were prescribed a course of antibiotics. Should Margo be treated or not?"<sup>12</sup>*

Of course, the central tension in the thought experiment is the concern for the current, "pleasantly demented" individual in light of the compos mentis individual's advance directive, though we are not to presuppose that these individuals are necessarily different people. From Kuhse's experiment, we are left to question what the non-compos mentis Margo wants, and whether this should matter.

A notable distinction between Margo's situation and the situation of someone who would request an ADE is that Margo requested the withholding of nutrition. This is in practice not the same as the ADE, as one may intuit that a doctor may be more comfortable withholding nutrition but not administering a lethal drug cocktail. As previously mentioned, this difference rests in the distinction between killing versus letting die. However, for the purpose of this thesis, we will use Margo's case as a template for someone in exactly the same situation, but who utilized a theoretical ADE instead of the withholding of nutrition. The reason for this is that Margo's case bears exactly

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<sup>12</sup> Kuhse, Helga. "Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity." *Kennedy Institute of Ethics Journal* 9.4 (1999): 347-364. Web.

the same tensions in the areas of interest to us—identity, death of the self, and the claims a compos mentis person has over the life of their non-compos mentis form. These are present in Margo’s case exactly as they are in the case of someone requesting an ADE. In both, compos mentis Margo wrote that non-compos mentis Margo will die, and non-compos mentis Margo does not agree. The killing versus letting die distinction is not relevant here, because we are not going to focus on the practicalities of the situation until the thesis’ final chapter. Accordingly, we will use Margo’s case as a form of extended thought experiment, and envision a parallel case involving ADE instead of withheld nutrition. For shorthand, we will still use the name Margo.

When wrestling with the philosophical implications of Margo’s case, the bioethicist is confronted with three essential questions, each with its own ensuing complications.

One: is Margo the same being pre- and post-diagnosis? We use the word being because one should not yet assume the personhood of the post-diagnosis individual, if distinct from the pre-dementia individual. Wrapped within this question is the exploration of what constitutes personhood, and whether advanced dementia can lead to the death of personhood. Overarchingly, Margo’s potential loss of self is a vital inquiry because to apply the ADE to the post-diagnosis individual, the pre- and post-diagnosis Margos must fall within *one* of the ensuing categories. 1) The pre- and post-diagnosis Margos must be the same person regardless of mental deterioration, with deference given to Margo’s compos mentis decision, as she possesses jurisdiction over herself. 2) They must be distinct persons, but with deference given to the pre-dementia individual for reasons that may include historical bodily rights, weighed interests, or notions of posthumous harm. 3) They must be distinct, with the second “Margo” (heretofore Margo 2) lacking personhood insofar as she is devoid of some to-be-delineated qualification such as rationality or consciousness,

assuming her interests are less important than Margo 1's and/or that Margo 1 bears jurisdiction over the body.

Of course, one could discount this trichotomy altogether and claim that the doctor must act in Margo's best interest at the advice of her family; but then, this only pushes the question back, as we are forced to ask which best interests are Margo's—her expressed *compos mentis* desires, or the basic desires of Margo 2, which may or may not be Margo? For the doctor and family to act ethically, they must have a sense of whose wishes they are respecting and whose wishes they are sacrificing. At root, this first question is about allocating and weighing interests. Determining whether Margo 1 and Margo 2 are the same allows us to question Margo 1's jurisdiction over the fate of Margo 2, which is complex even if they are the same person. As previously stated, one could object to the advance directive on the mere basis of failed foresight; I am in my twenties, for example, and have no conception of my desires in my eighties. Regardless, this first question leads us to examine the status of Margo 1 at the time of the advance directive's fulfillment—for if she is not present, one might argue, her personhood has died. The latter in turn contributes to the complexities of the advance directive.

Two: if Margo 1 and Margo 2 are distinct, should Margo 1 be permitted to call for Margo 2's death? Intuitively, the answer to this is reliant on three factors, which are the personhood of Margo 2, the interests of Margo 1 versus Margo 2, and Margo 1's rights over the body Margo 2 inhabits. Once more, the notion of death of personhood versus change is vital to this distinction, and this will be duly examined. We are reminded of Judith Jarvis Thomson's "A Defense of Abortion." Thomson describes a scenario in which the reader has been kidnapped and plugged up

to a world-famous violinist as a form of life support.<sup>13</sup> The reader may refuse and walk away, leaving the violinist to die, or the reader may stay at his own detriment, but only temporarily. Surely it is morally praiseworthy to stay, but not morally obligatory. Though Thomson compares this to the case of an unwanted pregnancy, the upshot is the same. As she puts it, “This body is my body!”<sup>14</sup> If Margo 1 and Margo 2 are separate people, why must Margo 1 tolerate this houseguest inside of the body she has always known—the body that bore her children, married her spouse, and signed her legal documentation? Even if one argues that Margo 2 has claim to the body due to her present existence within it, does Margo 1 still have any sort of claim to the body that had always been hers, and does this claim outweigh Margo 2’s?

Three: if not two distinct beings, should Margo be allowed to call for her own death, and should doctors be obligated to obey her *compos mentis* wishes despite her present pleas to stay alive? This question is seemingly simpler, but is in actuality not without its complications. The contentions in this scenario are the legitimacy of an advance directive over time, the right of the medical practitioner or family member to intervene on the patient’s behalf, and the patient’s right to potentially withdraw consent due to previous lack of foresight.

In the following chapter, we will explore responses to each of these questions, paring up the foremost philosophical theories in relation to our argument in favor of the advance directive for euthanasia.

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<sup>13</sup> Thomson, Judith J. *A Defense of Abortion*. New York, N.Y: Association for the Study of Abortion, 1971. Print.

<sup>14</sup> Thomson, Judith J. *A Defense of Abortion*. New York, N.Y: Association for the Study of Abortion, 1971. Print.

### Chapter III. Three Essential Inquiries: Defining the Personhood and Rights of Margo

#### Inquiry I. Continuity of Identity and the Self

Our foremost inquiry concerns the identity of Margo. Essentially, is she the same being before and after dementia? If not, is the post-diagnosis individual a person?

Before we go about the philosophical answer to these questions, it is appropriate to address the purely medical aspect of the inquiry. For example, one's gut reaction is likely to say, *Hold on. Dementia is not a hard line. No matter how one goes about it, dementia is gradual.* By that vein of logic, it seems silly to say 'before' and 'after' dementia. But for our purposes, the point is moot, as we will address only certified late-stage dementia, focusing on Alzheimer's. If we were to deal with early stages of dementia and merely give the patient license to say which stage of dementia is too much, then that sliding scale might very well give into a slippery slope, and advance directives could have nearly fully functional adults signing for early deaths—a type of euthanasia which conjures a different sort of debate entirely.

This said, the initiation of an advance directive in this case is very much dependent on the evaluation of the depth of one's descent into dementia. Is there a specific bar the patient must pass to be too far gone? Is it a series of questions to be completed by the dementia patient, previously written by the patient's *compos mentis* form? Is dementia purely at the hands of the doctor to diagnose? We will, as stated, detail more practical considerations in the final chapter.

In any case, acknowledging that Margo's dementia is so progressed that she has little conception of herself, her former life, or her daily functions, we are able to chalk out two entities, Margo 1 and Margo 2, be they the same person or not. For example, I was Isabella at age five, and

I am Isabella at age twenty-two, and universe-willing, I will be Isabella at age forty; and though we are the same, I have changed greatly, and may delineate Isabellas 1, 2, and 3 respectively. Because I am *compos mentis* at twenty-two, if I were to get married now, then at age forty, even if I had chronic amnesia, I would still be married: my legal identity would have remained intact, though I refer to forty-year-old Isabella as Isabella 3, and twenty-two-year-old Isabella as Isabella 2. Therefore, when we inquire as to whether Margo 1 and Margo 2 are the same, we do not ask whether they have the same legal attachments such as marriages, property, or debt, but rather whether they have a sense of continuity in self. Whether Margo 2 has the same identity as Margo 1 will have vast implications for the power of the advance directive. So we will carve out this one corner of the issue, and try to address it succinctly.

*Theory 1. Margo 1 and 2 Are Different Beings*

DeGrazia links psychological unity to rational egoism, one's "stake in continuing to exist."<sup>15</sup> His theory of unity agrees with Marya Schechtman, who argues that "a distinct sense of 'identity' is more closely tied to our patterns of identification, values, and sense of self: narrative identity."<sup>16</sup> The latter includes one's sense of self, the story of one's life, and is important because of its prominence in one's quality of life and in its connection to one's concern over one's future. His "biological theory" then suggests a cohesive narrative identity as a brightline by which to evaluate the sameness or splintering of Margo over time. Additionally, DeGrazia adds, "[M]ost of us value not mere survival—or numerical identity—but survival with the capacities for consciousness and action."<sup>17</sup> This capacity allows us to plan for our futures. In other words, if

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<sup>15</sup> DeGrazia, David. "Identity, Killing, and the Boundaries of Our Existence." *Philosophy & Public Affairs* 31.4 (2003): 413-42. Web.

<sup>16</sup> Schechtman, *The Constitution of Selves*. Ithaca, N.Y.: Cornell University Press, 1996.

<sup>17</sup> DeGrazia, David. "Identity, Killing, and the Boundaries of Our Existence." *Philosophy & Public Affairs* 31.4 (2003): 413-42. Web.

Margo 1's valuation of consciousness, action, and control over her future compelled her to write an advance directive, then Margo 1 intended to preserve her own narrative. She meant to have control over how her book ended. And if Margo 2 lacks Margo 1's sense of self, story of her life, and concern for her preservation of the overall narrative (so to speak), then her narrative identity has changed, and she ceases to be the same person. As Christman corroborates, "What is required for unified personhood is that the subject of that life be a reflecting subject whose self-interpretations make enough sense of those events that a consistent character can be seen at their center."<sup>18</sup> Margo 1, the austere philosopher, and Margo 2, drawer of concentric pastel circles, are not a consistent character.

In *Reasons and Persons*, Parfit argues that an individual shifts through different selves as her beliefs, desires, and motivations evolve, potentially constituting a splintering of identity.<sup>19</sup> Perhaps this notion of two distinct Margos, one might argue, is far-fetched. One could say that, yes, Margo 2 lacks Margo 1's personality and motivations, but perhaps this is only because Margo 1 could not know that dementia spelled out a happy ending. Perhaps Margo 2 is a wiser Margo. Nevertheless, applying DeGrazia's theory to Parfit's notion of a splintered identity, one might just rebut that Margo 2's complete obliviousness to her personal history, preexisting traits, and lifelong relationships constitutes a significant change in the core pillars of identity, thus producing a new "self." In Margo's case, the latter would be a product not of learned happiness but of obliviousness, emergent from mental deterioration.

### *Theory 2. Margo 1 and 2 Are the Same Person*

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<sup>18</sup> Christman, John. "Narrative Unity as a Condition of Personhood." *Metaphilosophy* 35.5 (2004): 695-713. Web.

<sup>19</sup> Parfit, Derek. *Reasons and Persons*. Oxford [Oxfordshire: Clarendon Press, 1987.



In *Life's Dominion*, Dworkin argues that the life of a person is defined by critical interests.<sup>20</sup> These are the binding goals and desires which give one's story coherence and meaning. For example, one's desire to be a good father may well constitute a critical interest, purposeful or unwitting. He states that "even people whose lives feel unplanned are nevertheless often guided by a sense of the general style of life they think appropriate, of what choices strike them as not only good at the moment but in character for them."<sup>21</sup> Dworkin acknowledges the importance of the method of one's death to one's life, constituting a critical rather than one of the less poignant "experiential interests," which are the less meaningful desires ubiquitous to all life, such as the consumption of good food—important, but not critical.<sup>22</sup> Critical interests are the building blocks of a person's truest desires, their core identity, and though Margo has lost the ability to understand anything but basic experiential interests, Dworkin argues, this does not mean her critical interests should not be respected.

Dworkin therefore does not argue for a splintering of the individual's identity, but rather for a loss of the ability to understand the narrative arc of one's life. Much like a parent counseling a child, the competent Margo 1 stated her desires for her *own* self, the incompetent Margo 2, and to override Margo 1 would be to ignore her critical interests, interfere with her autonomy over herself, and engage in medical paternalism. If we are to follow the logic of *Life's Dominion*, then obeying the advance directive is not only morally praiseworthy but morally obligatory, as Margo

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<sup>20</sup> Dworkin, Ronald. *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. New York: Vintage Books, 1994. Print.

<sup>21</sup> Dworkin, Ronald. *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. New York: Vintage Books, 1994. Print.

<sup>22</sup> Dworkin, Ronald. *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. New York: Vintage Books, 1994. Print.

1 and Margo 2 are much the same person, and in penning the ADE, Margo is only making decisions that uphold her lifelong critical interests.

*Theory 3. Margo 1 is a Person, and Margo 2 is a Different Being and a Non-Person*

Rather than argue that Margo is a *different* person, as DeGrazia implicates, or that she is the *same* person, as Dworkin implicates with critical interests, Kuhse argues that a patient in the position of Margo 2 would *no longer be* a person. About a competent patient, she states, “As long as strong psychological connections continue to exist, there is little reason to doubt that the executor of the advance directive and the patient are the same person.”<sup>23</sup> But in the case of the Alzheimer’s patient? “Even if some psychological continuity continues to exist between the person at  $t_1$  and the incompetent patient at  $t_2$ ,” Kuhse explains, “it does not follow that the incompetent patient at  $t_2$  is a *person*.”<sup>24</sup> Her logic is based on the Lockean tradition of a person’s identity as a conscious being composed of rationality, self-consciousness, and agency over time. If Margo 2 is not in a position to be rational, conscious of herself, actionable, or cognizant of time, then she lacks the identity she once had. Kuhse argues for the division between *compos mentis* Margo and *non-compos mentis* Margo, writing, “[I]f a severely demented patient is not a person, it follows that she...cannot be the same person as the author of the advance directive.”<sup>25</sup> However, Kuhse notes the issue with this line of argumentation: if Margo 2 is not the writer of the advance directive and is enjoying her life, why would we permit a separate being’s (Margo 1’s) advance directive to sign away her death? Kuhse cites the argumentation of Buchanan, who claims that “living interests”—

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<sup>23</sup> Kuhse, Helga. "Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity." Kennedy Institute of Ethics Journal 9.4 (1999): 347-364. Web.

<sup>24</sup> Kuhse, Helga. "Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity." Kennedy Institute of Ethics Journal 9.4 (1999): 347-364. Web.

<sup>25</sup> Kuhse, Helga. "Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity." Kennedy Institute of Ethics Journal 9.4 (1999): 347-364. Web.

such as one's loved ones, assets, and "living remains"—constitute surviving interests, which are morally weightier than the fleeting emotions of a non-person like Margo 2.<sup>26</sup> Kuhse then notes Singer's speciesism argumentation, and compares demented human nonpersons to non-human animals to draw the link that while it is wrong to inflict undue suffering upon beings like Margo 2, it is not wrong to kill them painlessly, especially if for the benefit of a human person. She further explains, "Although persons and all sentient animals can experience pain, only persons can anticipate, and have desires about, their own future."<sup>27</sup> While demented patients may experience visceral pleasures, says Kuhse, this does not mean they have a vested interest in continued existence. By this line of reasoning, when the non-person's basic enjoyments are weighed against the surviving interests of the advance directive's author, it is clear that *the morally weightier desires of compos mentis Margo 1 defeat the momentary pleasures of non-compos mentis, non-person Margo 2.*

Note—though DeGrazia argues primarily for the separation of Margo 1 and Margo 2 as persons, his definition of a "person" actually supports Margo 2's nonperson status. He states, "[B]oth psychological theorists (e.g., Parfit, Baker, McMahan) and their critics (e.g., Olson) use the term *person* to refer, roughly, to beings with the capacity for complex forms of consciousness such as self-awareness over time and the ability to plan...[or] 'a being with the potential to develop complex forms of consciousness.'"<sup>28</sup> In other words, to be a person, one must exhibit a state of awareness including knowledge of oneself beyond the present state and the ability to grasp

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<sup>26</sup> Kuhse, Helga. "Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity." *Kennedy Institute of Ethics Journal* 9.4 (1999): 347-364. Web.

<sup>27</sup> Kuhse, Helga. "Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity." *Kennedy Institute of Ethics Journal* 9.4 (1999): 347-364. Web.

<sup>28</sup> DeGrazia, David. "Identity, Killing, and the Boundaries of Our Existence." *Philosophy & Public Affairs* 31.4 (2003): 413-42. Web.

concepts of the future while anticipating intended actions. If this is not the case, then one must have the potential to do so. Margo 2 cannot rise to this standard of personhood.

What this means is that DeGrazia's narrative unity theory and Kuhse's living interest theory are not mutually exclusive. Though DeGrazia's focus is not designating Margo 2 a non-person, it can be used in tandem with Kuhse's argumentation. Accordingly, in Chapter IV, we will synthesize them in our defense of the advance directive.

Note, too, that Dworkin's critical interests theory does not mutually exclude conceptions of narrative disunity nor living interests. Though he reasons to different conclusions, the theory itself may be applied to our analysis of Margo; thus, in Chapter IV, we will apply Dworkin's critical interests to a synthesized theory of self and personhood.

In response to the inquiry as to the unity of Margo's identity, we have provided three potential lines of thought. Even more, within those lines of thought, we have already begun to unravel potential answers to the second and third inquiries. We will address the remaining two questions in order, referring to previous analyses as appropriate.

#### Inquiry II. Should Margo 1 Kill Margo 2?

The second major issue in the case of Margo is as follows: if Margo 1 and Margo 2 are distinct entities, does Margo 1's advance directive apply to Margo 2?

One side of the argument is straightforward. No, one might argue, applying the advance directive would constitute murder. Along this vein of reasoning, if Margo 1 and Margo 2 are distinct, then Margo 1 cannot ethically kill Margo 2, regardless of whether she is a person, non-person, or a person with limited moral standing. One might defend Margo 2's right to life as a

person; one might argue for the rights of people with mental incapacities; or, if one believes Margo is not a person, but a lesser-order being, one might defend her right to life along the lines of animal rights argumentation.

The other side of the argument is more complex. To argue that it is not murder for Margo 1 to order the death of Margo 2 requires a convincing argument that Margo 1 has a claim to the body she had always known. It becomes even more complex when we consider the possible contemporaneous claims of Margo 2.

Kuhse argues that it is not wrong to painlessly execute the advance directive, because the interests of the preexisting person outweigh the desires of the severely demented nonperson. To rephrase, the morally weighty interests of the *compos mentis* person to control the future of her living remains thwart any daily pleasures of nonpersons which “no longer have an interest in their own continued existence.”<sup>29</sup> Thus, while Margo 2 may enjoy literature, music, and art, Kuhse argues that she is a nonperson due to her inability to conceptualize and have a vested interest in her own future. Therefore Margo 1’s advance directive would apply to Margo 2, because Margo 1’s lifelong interests, self-fulfillment, and control over the body she has always known are more significant than Margo 2’s contemporaneous enjoyments.

Ott supplements this with an analysis of “constitutional”<sup>30</sup> concerns, arguing that a body only has its personhood because of the “mental person” within it, and that the mental, rational, autonomous person will naturally have concerns over that body, whose characteristics would be moot without the person inside. This establishes the connection between the mental person and

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<sup>29</sup> Kuhse, Helga. "Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity." *Kennedy Institute of Ethics Journal* 9.4 (1999): 347-364. Web.

<sup>30</sup> Ott uses this term to refer to that which *constitutes* the person, not the American social contract.

their physical body, even after that mental person has gone, and asserts that should that occur, the body is bereft of personhood. Ott states that constitutional concerns are “even stronger than concern for another family member.... This...makes the person a better possible advocate for the sentient nonperson than a parent or proxy.”<sup>31</sup> She designates the fulfillment of an advance directive as “autonomy-preserving,” because the previously autonomous person can act for the bodily organism when the second sentient nonperson (Margo 2) is in the “twilight of autonomy.”<sup>32</sup>

In Chapter IV, we will argue that Margo 1’s interests are substantial justification for her advance directive for euthanasia, and that even if Margo 2 possesses claims, their significance pales in comparison to the claims related to Margo 1’s critical and living interests.

### Inquiry III. If There is Only Margo 1, Can She Kill Herself?

While the latter arguments answer the posed second inquiry to Margo’s situation, we have not yet addressed the third hypothetical: if demented Margo is the same person as compos mentis Margo, is it morally justified to allow the compos mentis Margo 1 to pen an advance directive for her older self? Additionally, should doctors be obligated to obey her advance directive despite her present pleas to stay alive?

Now, one may ask why we would bother to explore this option. Clearly, we believe that Margo 1 has died, or at least experienced a disruption her narrative unity. Regardless, it is important to explore the arguments surrounding Margo’s unified personhood, because to fully argue our thesis, we must give credence to the question from all angles.

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<sup>31</sup> Ott, Andrea. "Personal Identity and the Moral Authority of Advance Directives." *The Pluralist* 4 (2009): 38-54. Web.

<sup>32</sup> Ott, Andrea. "Personal Identity and the Moral Authority of Advance Directives." *The Pluralist* 4 (2009): 38-54. Web.

To that end, recall Dworkin's analysis of critical interests. This notion of critical interests rests in the unity of the individual over time, such that a breach of her advance directive constitutes violation not only of her deepest desires, but of her autonomy.<sup>33</sup> Dworkin views Margo 1 not as dead, but as mentally incapacitated, unable to recall, conceptualize, and express the critical interests she once held so dear. Because she is incapacitated, her critical interests mandate respect for the advance directive.

Ott remarks, "Dworkin's basis for his position is grounded on a firm respect for the life as one whole autonomous unit, and therefore the former wishes must take precedence."<sup>34</sup> However, as prefaced, we will utilize the definition of a critical interest in an analysis grounded in splintered identities. (The key is to show that critical interests can survive after death. If we show that critical interests endure, we will not need to support a unified personal identity to argue for the advance directive on the basis of critical interests.)

Dresser proposes a rebuttal to Dworkin's view. Yes, Dresser posits, it is very well to claim that respecting the advance directive in turn respects the precedent autonomy of Margo; but, she adds, "Dworkin assumes that Margo...is the same person who issued the earlier requests to die, despite the drastic psychological alternation that has occurred."<sup>35</sup> Dworkin's argumentation depends on an assumption that Margo's personal identity remains intact, even though "substantial memory loss and other psychological changes may produce a new person, whose connection to

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<sup>33</sup> Dworkin, Ronald. *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. New York: Vintage Books, 1994. Print.

<sup>34</sup> Ott, Andrea. "Personal Identity and the Moral Authority of Advance Directives." *The Pluralist* 4 (2009): 38-54. Web.

<sup>35</sup> Dresser, Rebecca. "Dworkin on Dementia: Elegant Theory, Questionable Policy." *The Hastings Center Report* 25.6 (1995): 32-8. Web.

the earlier one...could be no stronger than that between you and me.”<sup>36</sup> Dresser’s logic suggests that if one disagrees with Dworkin’s “assumption,” then Margo 1’s authority over Margo 2 is shattered. (This is one of the reasons why we adopt and synthesize the Dworkinian view into a more enduring conception of interests.)

Dworkin’s theory is one of the most commonly propagated views on advance directives, but is by no means ubiquitously accepted. Take, for example, the argument of Jaworska, who does *not* defer to preexisting interests of the *compos mentis* Margo 1 who wrote the advance directive, and instead argues that we should pay deference to the present individual’s (Margo 2’s) ability to value. Therefore, because Margo 2 is able to value her life, even in the simplest sense, her current wish to remain alive should be respected. Autonomous decision-making stems from values, Jaworska argues, and therefore a being who can value is still worthy of contemporaneous moral consideration.<sup>37</sup>

It is easy to see the appeal of this theory. While it is easy to claim that one sees Margo 2 as a nonperson, one can imagine that a medical practitioner would struggle to look a human being in the eyes and euthanize them. This is not at all an attempt to claim that Jaworska’s theory of valuation is based in pathos. On the contrary, it is to say that no matter its philosophical nuances, Jaworska’s theory may be more readily accepted by a doctor, nurse, or caretaker, because it at a glance seems more in line with their training, which dictates immediate beneficence to the patient before them. Other thinkers may disagree with Jaworska and claim that to euthanize the patient is to disrespect her prior wishes, thereby inflicting harm; but, practically speaking, doctors and nurses

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<sup>36</sup> Dresser, Rebecca. "Dworkin on Dementia: Elegant Theory, Questionable Policy." *The Hastings Center Report* 25.6 (1995): 32-8. Web.

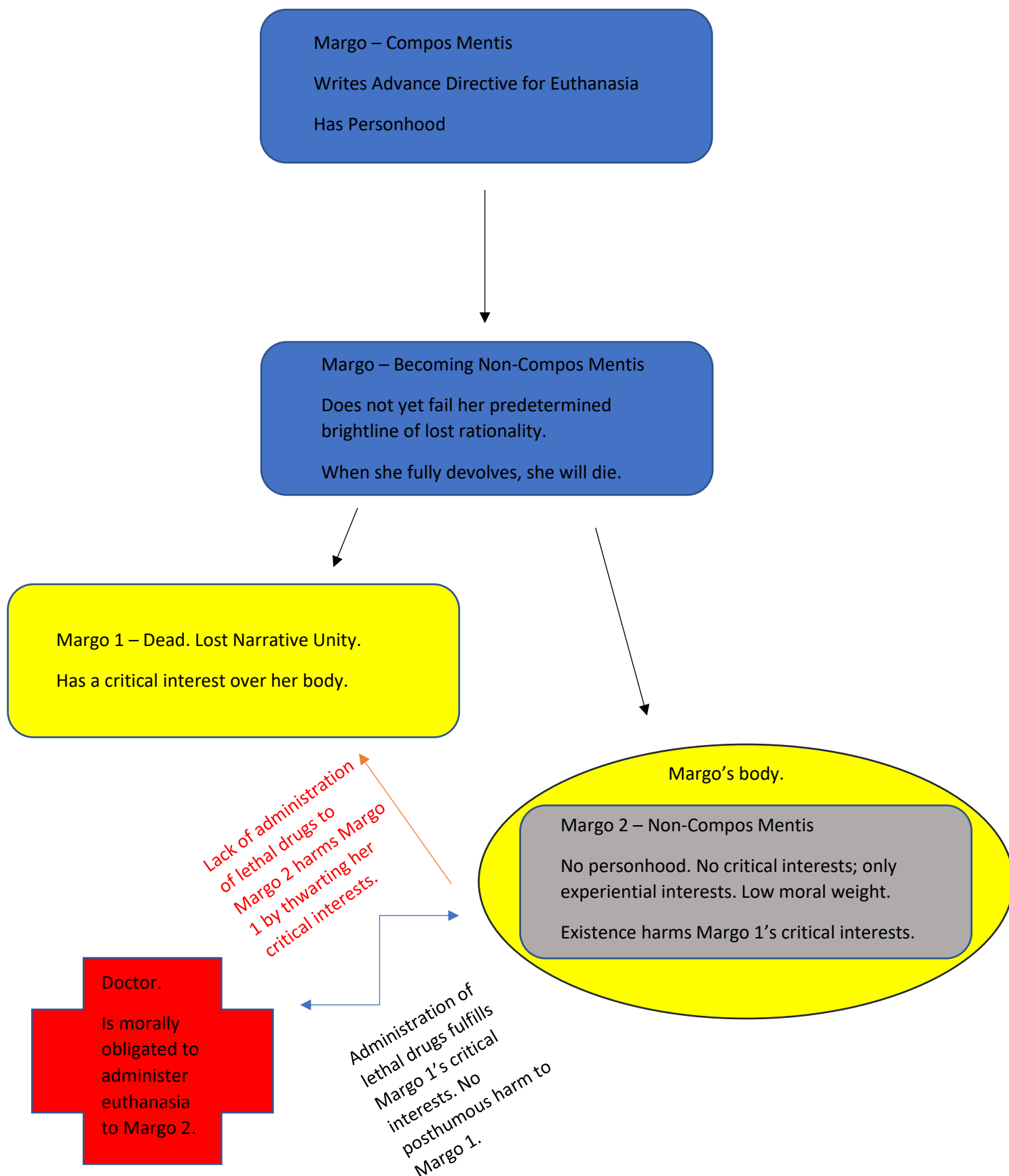
<sup>37</sup> Jaworska, Agnieszka. "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value." *Philosophy and Public Affairs* 28 (1999): 105-32.



might be uncomfortable with the advance directive, regardless of the philosophical implications of disobeying it. The practicalities of this will be discussed in Chapter V.

In this chapter, we have provided an overview of possible responses to the complexities of Margo's identity and claims. In the following chapter, we will synthesize some of the given perspectives and provide a defense for the ADE based in Margo's narrative disunity, historical bodily rights, and critical interests. This will culminate in the argument that if Margo's historical bodily rights are violated, the desecration of these critical interests constitutes posthumous harm.

## Illustration of Case Dynamics (“The Happy Sufferer”)



## Chapter IV. Synthesizing Narrative Disunity, Non-Person Theory, and Critical Interests

### *Section A: Death in Dementia*

To argue for Margo 1's right to an advance directive for euthanasia, we must delineate her claims to her body after the onset of dementia. To delineate her claims, we must determine her rights to the body. To determine her rights to the body, we must determine whether Margo 1 is functionally dead.

In his essay *Dementia and social death*, Paul Spicker explains, "Dementia is a condition in which the self is gradually eroded, both in a psychological and a social sense. In psychological terms, the loss of intellectual faculties, the loss of will and the loss of emotional control undermine the person's perception of the self, the self as 'I'. In social terms, people with dementia also witness the erosion of the self through the eyes of...the people who care for them."<sup>38</sup> The "social death" Spicker describes is significant insofar as it constitutes the shattering of narrative unity which is so vital to considerations of advance directives. Hence, we see the glaring issue of the advance directive for physician-assisted euthanasia: how can the *compos mentis* person, Margo 1, make decisions for the *non-compos mentis* person, Margo 2, who constitutes that "self" after the destruction of narrative unity, social self, and identity?

A philosopher in line with Dworkin may dismiss the idea and state that Margo 1 is actually still Margo 2, and that as such, Margo 1's interests persist. As stated, Dworkin supports the carrying-out of *compos mentis* Margo's requests to the detriment of the desires of *non-compos mentis* Margo, but only on the basis that Margo *became* demented, as in, retained her identity such that her autonomous desires carried and her interests persisted. Dworkin did not claim that Margo

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<sup>38</sup> Spicker, A. (2000). *Dementia and social death*. *Self Agency and Society*, 2(2), 88-104.

died and a non-person alien took over—which is, interestingly, what Dena Davis will claim in Section B of this chapter.

Before we argue for Margo 2’s non-personhood, we must address the matter of the “death” itself. Did Margo die? From there, we will question if the body’s inhabitant is merely Margo 1 in new form (as in, whether she retains vestiges of the former person), or whether the destruction of the former identity constitutes a new person. Indeed, what are the grounds for Margo 2 existing at all, and what claims would this alleged person have, legally and morally?

Thomas Nagel defines death “to mean permanent death, unsupplemented by any form of conscious survival.”<sup>39</sup> This is the intuitive answer, but does not respond to our question of Margo’s existence. We must still ask whether what occurred constitutes death. Margo 1, to clarify, *is* permanently gone, without conscious survival insofar as her identity has eroded. Nagel’s definition only pushes the question back to become a matter of identity—because if Margo 1 and 2 are distinct people, then, yes, Margo 1 is dead, as she maintains no conscious survival. If we are to agree with Schechtman’s theory of narrative identity over time<sup>40</sup>, Christman’s consistent character theory<sup>41</sup>, or even DeGrazia’s cohesive narrative theory<sup>42</sup>, we will agree that Margo 1 is not Margo 2. Margo 2 may be conscious, but she is not who she was before.

To identify our own view of Margo’s identity, we will draw from DeGrazia, Schechtman, Christman, and Parfit, to synthesize a cohesive definition of identity and the death of the self. In

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<sup>39</sup> Nagel, Thomas (1970). Death. *Noûs* 4 (1):73-80.

<sup>40</sup> Schechtman, *The Constitution of Selves*. Ithaca, N.Y.: Cornell University Press, 1996.

<sup>41</sup> Christman, John. "Narrative Unity as a Condition of Personhood." *Metaphilosophy* 35.5 (2004): 695-713. Web.

<sup>42</sup> DeGrazia, David. "Identity, Killing, and the Boundaries of Our Existence." *Philosophy & Public Affairs* 31.4 (2003): 413-42. Web.

our view, we align categorically with the theory that not only has Margo 1 died, but she and Margo 2 are different entities.

DeGrazia argues that one's stake in continuing to exist, grounded in the capacity for consciousness and action, constitutes the self.<sup>43</sup> We agree that Margo 1's conception of self is grounded not only in her conscious action and desire to preserve the narrative direction of her life, but also her valuation of this act of preservation. Seeing as Margo 1—in our hypothetical—necessarily wrote an ADE, control over the arc of her life is a key aspect of her narrative. Margo 2, the happy sufferer, is by definition too far gone to register these concerns, or much else other than baseline pleasures such as pudding and scribbling pictures. We combine this view of self with Schechtman's narrative identity argument, the view that values, self-identification, a sense of one's life story, and concerns for quality of life and one's future constitute a narrative identity.<sup>44</sup> We also draw from Christman's view of unified personhood and the standard of the consistent character<sup>45</sup>, as well as Parfit's notion of splintered identities.<sup>46</sup>

Thus, we posit that an identity is defined not by current state of being, but by a conscious sense of an individual life narrative, along with acknowledgment of one's stakes, values, and quality of life, in a manner constituting a unified and consistent character. Once this definition no longer holds, we have a splintered identity. Effectively, Margo 1's identity dies. With this, we once

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<sup>43</sup> DeGrazia, David. "Identity, Killing, and the Boundaries of Our Existence." *Philosophy & Public Affairs* 31.4 (2003): 413-42. Web.

<sup>44</sup> Schechtman, *The Constitution of Selves*. Ithaca, N.Y.: Cornell University Press, 1996.

<sup>45</sup> Christman, John. "Narrative Unity as a Condition of Personhood." *Metaphilosophy* 35.5 (2004): 695-713. Web.

<sup>46</sup> Parfit, Derek. *Reasons and Persons*. Oxford [Oxfordshire: Clarendon Press, 1987.

again quote Kuhse: “[I]f a severely demented patient is not a person, it follows that she...cannot be the same person as the author of the advance directive.”<sup>47</sup>

This is not without dissent. As a rebuttal to philosophers like Schechtman and Kuhse, Elisabeth Furberg delineates three ethical schools of thought regarding identity in cases of advance directives. They are the biological, psychological, and narrative.<sup>48</sup> Biological selves are *animal*, as in, physical continuities; psychological selves entail consistency in one’s psyche; and of the narrative view, she states the following:

“In the advance directives debate, most ethicists who appeal to a narrative view of identity conclude that this view offers support for the authority of advance directives – even when there is lack of psychological continuity between the author and the later patient. Their argument to this affect usually builds on two distinct claims. One is, as we have seen, that (strict) identity (persistence) does not matter to the moral authority of advance directives. The second claim is that even if there is lack of psychological continuity between the author of the directive and the later patient, we can defend the directive’s authority by appeals to ‘surviving interests.’”<sup>49</sup>

She offers three rebuttals. Firstly, she questions that identity is necessary to the moral authority of advance directives. Secondly, she posits that one could say psychological continuity is necessary for identity, while identity itself is too normative to be the foundation of the power of an advance directive. Finally, she says, “it could be argued that even if the author of the advance directive is not identical to the later dementia patient, she is at least kin to her closest relative, in which case her earlier preferences ought to be granted at least some authority.”<sup>50</sup> In other words, we should

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<sup>47</sup> Kuhse, Helga. "Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity." Kennedy Institute of Ethics Journal 9.4 (1999): 347-364. Web.

<sup>48</sup> Furberg, Elisabeth, 2012, “Advance Directives and Personal Identity: What is the Problem?” *Journal of Medicine and Philosophy*, 37(1): 60-73; first published online 2011, doi:10.1093/jmp/jhr055

<sup>49</sup> Furberg, Elisabeth, 2012, “Advance Directives and Personal Identity: What is the Problem?” *Journal of Medicine and Philosophy*, 37(1): 60-73; first published online 2011, doi:10.1093/jmp/jhr055

<sup>50</sup> Furberg, Elisabeth, 2012, “Advance Directives and Personal Identity: What is the Problem?” *Journal of Medicine and Philosophy*, 37(1): 60-73; first published online 2011, doi:10.1093/jmp/jhr055

respect Margo 1's directive not because of her interests, but because she is like Margo 2's closest relative.

Because we utilize the narrative view of identity in this argumentation, I will respond to each of Furberg's objections in turn.

Firstly, identity is necessary to the moral authority of advance directives because the sense of identity is vital to the notion of an advance directive altogether. It is very well and good if one would like to judge the consistency of an individual by biology or psychology—though it really isn't, as I will address in my rebuttal to Furberg's second objection—but without a sense of identity, the impetus for an advance directive is moot.

As we will argue soon, identity is tied crucially to one's critical interests. These interests are at the root of the decision for an advance directive. It goes without saying that identity, the sense of who we are, is grounded in our individual consciousness as well as our specific sets of values and interests. Without them, we would be superfluous beings, conscious but without agency. Of consciousness, identity, and narratives, Julian Jaynes states, "In consciousness, we are always seeing our vicarial selves as the main figures in the stories of our lives. ...[S]ituations are chosen which are congruent to this ongoing story, until the picture I have of myself in my life story determines how I am to act and choose in novel situations as they arise."<sup>51</sup> We are all metaphors to ourselves and others, by his account.

By my own account, we may extend this to Furberg's psychological view of identity. While it is, again, well and good if one chooses to have a scientific notion of self, insofar as you, the

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<sup>51</sup> Jaynes, Julian. *The Origin of Consciousness in the Breakdown of the Bicameral Mind*. Boston: Houghton Mifflin, 1976. Print.

individual with an identity, perceive the matter empirically, your unique consciousness is the arbiter of those autonomous decisions to be made utilizing the hardware you describe, and which is only substantial insofar as you perceive it. I say this because even with the psychological in mind, one's identity persists as a sum of these disparate parts, and is the thrust of the autonomous decision-making, regardless of what scientific mechanisms compose the whole "I" and "you."

Secondly, I would argue that the psychological argument is flimsier than the narrative-based concept of identity which Furberg refers to as normative. Psychology, if it is not identity-based, is neurological. If it is neurological, it is biological. And biology is quite variable. At the most basic level, our cells, tissues, organelles, organs, organ systems, and full bodies are reconstructed on a daily basis; even our DNA changes, what with mutations, differing regional proteins, and epigenetics. Biological consistency is an oxymoron.

Indeed, while the narrative identity argument presents concerns of changes over time, it is at least more plausible than psychological continuity in the absence of identity. If Furberg is saying that a lack of psychological continuity constitutes a shift between Person 1 and Person 2—again, in the absence of any form of identity—then think of prisoners on death row. It is not as if they are released every seven years, when their neural cells have been completely replaced. They are the same person because of a consistent identification that transcends these empirical changes. I am not attempting to strawman Furberg—I understand that neurology and psychology are distinct. What I *am* doing is pointing out that without some conceptions of values, interests, and/or identity, this notion of psychology as a standard *alone* just bottoms out in neurological changes. Strawman, no. Reductio ad absurdum? In essence.



Going along with this, if we tried to make an argument for ADE from brain structure, we only push the question back, and fall into the same hole—one's DNA mutates every day, and neurons are constantly dying.

While I can envision an effective argument on behalf of the consistency of psychology, it is certainly not the argument Furberg makes, because *that* effective psychological argument necessitates some form of identity, values, and critical interests.

Finally, to rebut Furberg's last objection, we need only to say this: kin do not automatically have authority over one's wellbeing. Furberg offers little support for her point, but taking her objection seriously, we cannot favor the advance directive of Margo 1 on the basis of her resemblance to a relative. If Furberg were to argue from Margo 1's interests or claims to Margo 2's wellbeing and body, this would be a different argument; however, arguing solely on the basis of Margo 1 being *like* Margo 2's family member fails to prove that Margo 1 has the power to kill Margo 2. Surely, we can all think of relatives who make poor decisions on behalf of loved ones. Even if we are in favor of the advance directive, we cannot accept Furberg's reasoning.

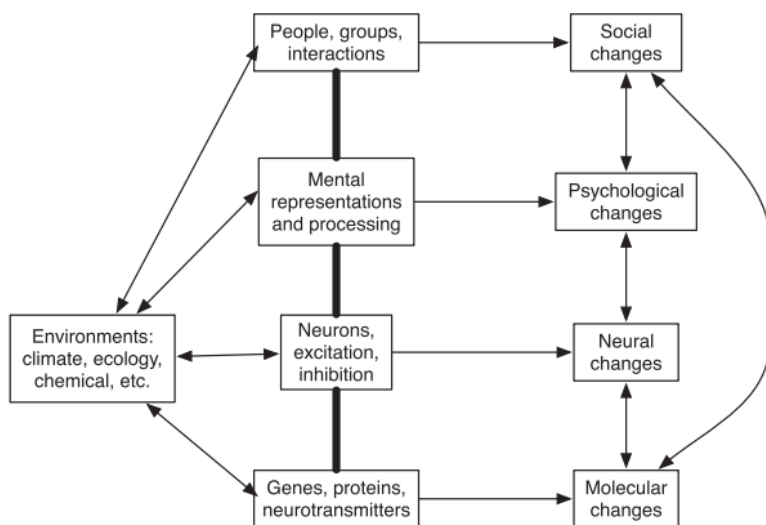
This is not to say Furberg's reasoning is unusual. Notions of familial inclusion in end-of-life decision-making are often associated with "social death." Borgstrom describes the death of one's social relationships as a valid theory of death of identity. One's relationships, her analysis posits, constitute the summation of one's being; and so not only does this confer moral significance to socialization, but it indicates that loved ones should be consulted before the ending of one's physical life.<sup>52</sup>

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<sup>52</sup> Borgstrom, Erica. "Social Death in End-of-life Care Policy." *Contemporary Social Science* 10.3 (2015): 272-83. Web.

I am not sure if I agree with this. It is more in line with our argumentation to place the autonomy of the individual above all else. However, this sort of reasoning does raise new considerations—if a person believes they are best represented by their family, there is no reason why their autonomous decision should not be to include their family in the ADE process, or, furthermore, to allow their family to delineate the conditions under which they should be euthanized. Even so, it is overly complex. We may as well grant these family members power of attorney, designate them living wills, or otherwise vest decision-making powers in their hands. To that end, social death theory seems discordant with the principle of autonomy undergirding our defense of ADE.

These rebuttals in mind, we must acknowledge that biology and psychology can play *into* and work *with* notions of narrative identity and therefore of self, and all the rights that follow. They are interconnected, as Paul Thagard posits.<sup>53</sup> He presents the following diagram as a representation of the “self”:



**Figure 1** Diagram of the self as a multilevel system. Lines with arrows indicate causality. Thick lines indicate composition.

<sup>53</sup> Thagard, Paul (2014). The self as a system of multilevel interacting mechanisms. *Philosophical Psychology* 27 (2):145-163.

It is notable that the social, psychological, neural, and molecular are limited to influencing one another, with a unique link between the social and molecular. All of these levels contribute to the overall unified narrative of one's singular identity.

The upshot of this conversation about identity and self is that an individual has narrative identity and unity which is indeed disrupted with the onset of dementia. However, her body, insofar as she is a physical being, persists, with interests that persevere beyond the disruption of her narrative unity. In other words, the non-demented person must use the advance directive to plan for the preservation of her dignity and interests after she is demented, Dworkin asserts.<sup>54</sup>

This idea of a leftover body, living remains, leads us to the next core question of identity: personhood. If the pre-diagnosis individual is distinct from the post-diagnosis individual, does this post-diagnosis individual have personhood status? What is left in the body Margo 1 had always known, and does it now have the power to govern her body, her resources, her relationships?

On the topic, Dena Davis frets:

“[The] person I will become if I become demented will be someone radically different from my present self, so different that there is no justification for taking my present wishes as dispositive for making decisions for this demented self. ...Legally, this new being will have a very odd relationship to my former self. She will be me in that she will retain my name and other identifiers and will be able to use up my assets; my spouse will not be free to remarry; but she legally will not be me when it comes to honoring advance directives. ...Socially, our relationship is equally odd. Former friends and relatives will think of that person as me, and may persist in visiting her or contributing financial support, despite the fact that she does not know them. But they will not think of her as me when it comes time to make decisions, because they will not honor my advance directive.”<sup>55</sup>

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<sup>54</sup> Dworkin, Ronald. *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. New York: Vintage Books, 1994. Print.

<sup>55</sup> Davis, Dena. "Help! My Body Is Being Invaded by an Alien." *The American Journal of Bioethics* 7.4 (2007): 60-61. Web.

If the situation seems grim, that's because it is. She adds:

“For the autonomy-oriented person... a diagnosis of impending dementia is a warning that one is about to be invaded by an enemy alien that will always win. It is thus entirely sensible to burn down the fort and refuse it a home.”<sup>56</sup>

Unabashedly, we posit that Margo 2 does not have personhood. We align with Kuhse's argumentation that the incompetent patient in Margo 2's position is not a person<sup>57</sup>, due to lost rationality, agency, and self-consciousness. These are our standards of personhood, and Margo 2, unlike Margo 1, does not embody them. She may be a being with lesser-order claims, but, as we will argue in Section B, these cannot hold a candle to Margo 1's claims.

Our view of personhood synthesizes Kuhse's standard of rationality, agency, and self-consciousness with Ott's analysis of Margo 1's body as devoid of personhood after the death of her narrative identity and “mental person.”<sup>58</sup> Ott raises substantial concerns over Margo 1's claim over her physical body after it loses personhood, and on this matter we subsume Kuhse's argument that painless execution of the advance directive is not morally problematic, because, as discussed in the previous chapter, the late compos mentis person's surviving interests thwart the fleeting desires of a nonperson.<sup>59</sup>

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<sup>56</sup> Davis, Dena. "Help! My Body Is Being Invaded by an Alien." *The American Journal of Bioethics* 7.4 (2007): 60-61. Web.

<sup>57</sup> Kuhse, Helga. "Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity." *Kennedy Institute of Ethics Journal* 9.4 (1999): 347-364. Web.

<sup>58</sup> Ott, Andrea. "Personal Identity and the Moral Authority of Advance Directives." *The Pluralist* 4 (2009): 38-54. Web.

<sup>59</sup> Kuhse, Helga. "Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity." *Kennedy Institute of Ethics Journal* 9.4 (1999): 347-364. Web.

In the following section, we will defend Margo 1's claim to her body, incorporate Dworkinian critical interests into the framework of Margo's claims, and show that the thwarting of these interests constitute harm beyond her narrative grave.

*Section B: The Bodily Autonomy of Margo 1, Posthumous Harm, and Critical Interests*

In "Authority without identity: defending advance directives via posthumous rights over one's body," Govind Persad argues that Margo 1 retains the ability to govern her body even though Margo 2 inhabits it.<sup>60</sup> We align with this philosophy.

Persad points to the emphasis on posthumous rights over one's property, which are, he says, strongest in the case of one's body, as it is the vessel through which we live our lives. In other words, though Margo 1 is dead, her having lived her life in this body is enough to constitute a significant claim to its wellbeing.

He admits, "[A]lthough it may be wrenching to deny an individual who is currently embodied in a body the use of that body when she needs it to remain alive, [her death] can be morally justified when another person has a prior right to the body."<sup>61</sup> Prior rights, he says, are established through a history of use. He gives the example of a woman who authors an advance directive requesting that life support not be administered in the event of her brain death, even if she is pregnant; and when this woman is injured and pronounced brain dead, she is pregnant and not far along enough for the fetus to be viable without her. The theoretical asks whether it is wrong to administer life support for the sake of the gestating fetus. Persad maintains that it is wrong to

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<sup>60</sup> Persad G. Authority without identity: defending advance directives via posthumous rights over one's body. *Journal of Medical Ethics* (2018):1–8. doi:10.1136/medethics-2018-104971

<sup>61</sup> Persad G. Authority without identity: defending advance directives via posthumous rights over one's body. *Journal of Medical Ethics* (2018):1–8. doi:10.1136/medethics-2018-104971

defy the conditions of her advance directive, especially because she provided conditions for this scenario; insofar as her body is her most intimate property, tied to interests existing beyond her lifetime, she has established historical rights over how it is treated even in her death.<sup>62</sup>

We may apply this to Margo, in claiming that Margo 1 maintains historical rights over the treatment of her body, regardless of whether it harms Margo 2, who is in a sense an unwelcome guest—I would say even more so than the fetus in Persad’s example, given Margo 1 did not willingly opt for Margo 2 to exist, and in fact went to great lengths to limit her access to their mutual body.

Sandra Woien argues that in the case of conflicting bodily rights in the case of a pre- and post-diagnosis patient, there exists now-for-then preferences (made by the writers of the advance directives) and now-for-now preferences (which live within the individuals currently inhabiting the post-diagnosis body).<sup>63</sup> She criticizes those who argue now-for-now preferences are superior in the strength felt by Margo 2, and echoes Dworkin in saying, “[It] is doubtful that [dementia patient’s] current preferences are consistent with their critical interests such as their life plans and their deep values that they were still mindful of when filling out [the advance directive].”<sup>64</sup>

As these critical interests are cogent to the individual’s true wants and first-order desires, the patient’s cognizance when completing the advance directive is morally significant. It is the individual’s true desire. Woien concludes, “As in the case of Ulysses, who told his crew to disregard his pleas to be released on hearing the enticing cries of the sirens, both precedent autonomy and welfare beckon us to disregard their present desires, and since their now-for-then

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<sup>62</sup> Persad G. Authority without identity: defending advance directives via posthumous rights over one’s body. *Journal of Medical Ethics* (2018):1–8. doi:10.1136/medethics-2018-104971

<sup>63</sup> Woien, S. Conflicting Preferences and Advance Directives. *American Journal of Bioethics* 2007\_7(4):64-65.

<sup>64</sup> Woien, S. Conflicting Preferences and Advance Directives. *American Journal of Bioethics* 2007\_7(4):64-65.

desire, as explicitly stated in their AED<sup>65</sup>, is more informed than their present desire to live, we have a strong reason to honor it.”<sup>66</sup>

Core to this discussion is the notion of historical bodily autonomy as a legitimate critical interest. If Margo 1 is writing an advance directive, historical bodily rights are necessarily tied to her critical interests, because her right to govern her body is a part of her life’s central narrative. Surely, she cared about those rights enough to assert them—and to respect her critical interests, respecting her ADE must follow.

As previously stated, though we disagree with Dworkin’s view of narrative unity throughout dementia, we agree that critical interests are the binding goals and desires granting coherence to one’s story, as stated in *Life’s Dominion*.<sup>67</sup> We reiterate the Dworkinian view that the method of one’s bodily death is a necessary critical interest of one’s life, as opposed to shallow experiential interests (the only thing Margo 2 can experience). We choose to synthesize this key aspect of the Dworkinian perspective on the ADE, because other than the splintering of identity, we concur with his philosophical framework. We would even point to the verbiage Dworkin uses—he claims Margo has merely lost the ability to understand anything beyond her experiential interests<sup>68</sup>—to posit that the loss of critical interests *he himself* describes equals the death of identity, as we have defined it. Thus, using his description of what happens to Margo cognitively, we argue that she has in effect died. Our main contention with Dworkin, then, is the definition of mental death and the death of identity. Everything else is cogent. Thus, we choose to subsume his

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<sup>65</sup> “Advance Euthanasia Directive,” another way of referring to an ADE.

<sup>66</sup> Woien, S. Conflicting Preferences and Advance Directives. *American Journal of Bioethics* 2007\_7(4):64-65.

<sup>67</sup> Dworkin, Ronald. *Life’s Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. New York: Vintage Books, 1994. Print.

<sup>68</sup> Dworkin, Ronald. *Life’s Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. New York: Vintage Books, 1994. Print.

notion of the critical interest, to argue that Margo 1's interests are critical, while Margo 2's are not.

Because Margo 1's interests have significant moral weight in the context of her life, and because Margo 1 is a being of higher rational order and personhood, Margo 1's interests must win out against Margo 2's. If a medical professional would choose to disrespect Margo 1's critical interest of historical bodily rights, then he violates one of the four principles of bioethics: autonomy.

(He also posthumously harms her. We will begin by discussing autonomy, for the purpose of explicating its infringement in this scenario, and then end with a discussion of posthumous harm.) On autonomy:

Beauchamp and Childress' four principles of bioethics—autonomy, justice, beneficence, and non-maleficence<sup>69</sup>—are core in this case, as it concerns medical practice. The four principles of medical ethics are used by medical professionals, bioethicists, and legislators as a general, typically nonbinding brightline by which to evaluate field cases. They are grounded in the elevation of the patient and the affected stakeholders, such that beneficence is maximized, harm is avoided, negative externalities are minimized, fairness and justice are upheld, and, perhaps most essentially in this case, the autonomy of the patient is prioritized. Insofar as the philosophical aspects of this case are arguable, bioethicists might disagree on the doctors' fulfillments of the four principles. For Margo 1, we would posit that it is not only morally permissible and praiseworthy

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<sup>69</sup> Childress. *Principles of Biomedical Ethics*. New York: Oxford University Press, 2009.



to respect her advance directive, but morally obligatory. It is most expedient to represent this with the potential for doctors' violations of her bodily autonomy.

Of the four principles applicable to this case, autonomy is the most noticeably applicable. More specifically, if the doctors were to ignore Margo's advance directive, her autonomy would be jeopardized. The autonomy at stake is not *just* bodily autonomy. It is the very autonomy to govern her life's story—to fulfill her critical interests. Additionally, Margo 1's body is historically hers, but also legally, socially, and financially hers, in the sense that the accumulation of her life's choices is tied to her corporeal form. That body is, in a sense, her living remains, and Margo 2 is a being unlike her, who has moved in to enjoy the most basic sensory pleasures that Margo 1's body can still process. If Margo 1 anticipated this visitor while *compos mentis* and explicitly stated that she would like Margo 2 evicted (via an ADE), then because it is Margo 1's body in that moment, it is within her rights to anticipate how it will be treated in the future. If in the future, a doctor does not respect this, then he violates Margo 1's autonomy, posthumously harming her.

In *A Theory of Justice*, John Rawls states that “acting autonomously is acting from principles that we would consent to as free and equal rational beings.... Also, these principles are objective. They are principles that we would want everyone (including ourselves) to follow....”<sup>70</sup> Significantly, the patient's autonomous decree in favor of her interests—which are in dementia patients commonly related to quality of life, freedom from suffering, and dignity—is an objective assessment in favor of what is for her most beneficial and/or most beneficial to those whose interests are equivalent or primary to her own.

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<sup>70</sup> Rawls, John. *A Theory of Justice*. Cambridge, Mass: Belknap Press of Harvard University Press, 1971. Print.

Ronald Dworkin combats the evidentiary substantiation for a right to autonomy<sup>71</sup> which Rawls seems to suggest—evidentiary, as in, the view that objective factors affecting the individual’s self-interests are best weighed by the individual, who should know her interests best. By presenting counterexamples of self-destructive behaviors, Dworkin shows that the evidentiary view is not always tried and true. On the contrary, he proposes a view based in integrity. He states that an individual’s behaviors exemplify her character, such that she may act autonomously in promotion of interests to fulfill her character. In other words, an individual may rush into a burning building not for her own best interest, but because she wants to save a child, a decision consistent with her character. This I mention because autonomy is at the fore of the advance directive for euthanasia; the person signing the document has autonomy, whereas the non-compos mentis person being euthanized does not.

It is not a matter of acting in one’s best interest but rather a matter of supporting the integrity of the autonomous being. Dworkin argues: “[I]f we accept the integrity view, we will be drawn to the view that Margo’s past wishes must be respected. A competent person making a living will providing for his treatment if he becomes demented is making exactly the kind of judgment that autonomy, on the integrity view, most respects: a judgment about the overall shape of the kind of life he wants to have led.”<sup>72</sup>

The expression of this autonomy is necessarily tied to the critical interest of historical bodily autonomy, as described by Persad.

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<sup>71</sup> Dworkin, Ronald. *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. New York: Vintage Books, 1994. Print.

<sup>72</sup> Dworkin, Ronald. *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. New York: Vintage Books, 1994. Print.

In this case, when we enhance autonomy, the other three principles of bioethics (beneficence, non-maleficence, and justice) follow. Yet if someone does not respect Margo 1's advance directive, he does not act in a *beneficent* manner, because he harms the *compos mentis* patient for a non-*compos mentis*, non-person patient's momentary beneficence. Due to Margo 2's lack of ability to understand the future, it is a beneficence without lasting moral weight—a temporary beneficence immediately and severely outweighed by the *maleficence* toward Margo 1, whose dignity, agency, and choice are dashed in a most unjust manner. The *injustice* is compounded by the effects on Margo's loved ones who know her wishes are not respected, and who know she would not have wanted her body to be treated in an uncharacteristic, undignified manner. Additionally, this will deter potential writers of advance directives, who anticipate their wishes will also be disrespected. In turn, they will die in manners similar to Margo, with living remains, whose painful and disgraceful declines are contrary to the ends the patients would have desired if they had been afforded narrative agency. We are then led to understand that the harms of disrespecting an advance directive are exponential.

And in that scenario, despite Margo 1's death, the immediate harms would be very real.

Now, one might be eager to disregard posthumous harm with Epicurean notions of death. However, practically, legally, and ethically, it is difficult to be ambivalent toward one's demise. For example, estate planning, wills, and, indeed, advance directives are institutions of society which exemplify a very human desire to control our interests beyond our own demises.

Even so, these institutions are legal in nature. Many *would* wonder if there are moral claims to be had after death in the same manner that one would tarry over the division of one's assets. As applicable to the case of Margo, these moral claims would be over one's body after the death of

the identity. Insofar as Margo's narrative unity has been divided as Margo 1 has "died," does Margo 1 still have moral authority, and therefore can she be harmed by the refusal to heed her historical rights? I will of course argue yes on both accounts.

Once the notion of the death of Margo 1's identity has been accepted, the argument for the advanced euthanasia directive on the basis of posthumous harm is fairly straightforward. Simply put, if Margo 1 has historical rights to her body as established by Persad, and if these are not heeded after the death of her identity, then this constitutes harm to her worldly interests. Furthermore, it constitutes an infringement upon her autonomy—she, after all, still possesses the integrity and objective first-order interests which compel our heeding her preferences. As Woien stated, these do not merely dissipate after one's death. So to ignore these rights is to do harm unto Margo 1, as strongly as one would have harmed her while alive. The latter is evident by the mere fact that there was no way to infringe upon her historical bodily rights in such a manner until after her death. Therefore the magnitude of the infringement upon these rights exist in their fullest capacity.

In volume one of *The Moral Limits of the Criminal Law, Harm to Others*, Joel Feinberg delineates three types of harm: harm in the derivative sense, the thwarting of one's interest, and, lastly, the infringement upon one's rights.<sup>73</sup> Feinberg dismisses the first on the basis of shallowness, to emphasize the latter two, and this is just as well, as we will follow suit. Under Feinberg's definition of harm, Margo 1's interests have been thwarted *and* her rights have been infringed upon. Namely, her interest to end her life in a manner cogent with the rest of its narrative

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<sup>73</sup> Feinberg, Joel. *The Moral Limits of the Criminal Law Volume 1: Harm to Others*. New York: Oxford University Press, 1987. Print.

integrity (a bad last chapter makes a bad book, as the analogy goes), and her historical rights over the welfare of her body, based on precedent and the lifelong ownership of herself as property.

Feinberg's account of posthumous harm acknowledges the Epicurean logic, but also acknowledges that death is a great thwarting of interests and therefore qualifies as inflicting harm.<sup>74</sup> Any healthy person in reasonable conditions, he argues, will dread death, and this is an expression of an innate notion of having been deprived of the benefits of continued life. Nagel agrees, stating, "Clearly if death is an evil at all, it cannot be because of its positive features, but only because of what it deprives us of."<sup>75</sup> 'What it deprives us of' is the fulfillment of our interest, at most basic the interest to keep living and more potently the interests which uphold our respective narrative integrities. I, for example, want to write a book; other people want to have children; and yet others simply want to keep living happily with their families. Death is harmful to us in that capacity. And if death can be harmful to an entity which no longer exists—as it must be, because its existence immediately entails the termination of one's own existence—then by temporal extension, it is not farfetched to say that the further thwarting of that dead entity's interests can be harmful. In other words, if death itself is harmful, and one cannot be harmed by death until one is already dead, then the chronological floodgates have opened—one may be harmed after the event of death as well.

Of course, there is the issue of backwards causation. George Pitcher, a proponent of the notion of posthumous harm, admits that a common objection is temporal confusion, as in, a lack of conceptualization of how one can be harmed by events after death while one is still alive. He

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<sup>74</sup> Feinberg, Joel. *The Moral Limits of the Criminal Law Volume 1: Harm to Others*. New York: Oxford University Press, 1987. Print.

<sup>75</sup> Nagel, Thomas (1970). *Death*. *Noûs* 4 (1):73-80.

argues that such an objection is flawed because it falsely assumes that a harm must result in some change in one's metaphysical being. To illustrate this, he tells the story of a man whose son is killed in an airplane crash, unbeknownst to the man, who tragically dies before he can be notified of his son's demise. If his son's welfare is one of his strongest interests, then his interests have been thwarted even before he knows; and if his son's death occurs after his own, his interests have been thwarted regardless.<sup>76</sup>

Steven Luper elaborates on Pitcher's account. He states, "On Pitcher's view, posthumous events can only be indirect harms. ...[Direct] harms are certain facts about us that come to hold by virtue of the posthumous events that occur much later. ...Partly because of these [indirect posthumous] events, 'certain desires of ours will be thwarted, certain goods unattained' is true of us, and its being true of us is the direct harm for which the corresponding posthumous events are responsible."<sup>77</sup> In other words, while posthumous harm exists, it is not the direct punch-in-the-face sort of thwarting of interests that someone might think if they were to read Feinberg's notion of harms. Luper goes on to claim that posthumous events can harm an individual without changing our intrinsic properties; an event that will tangibly harm us tomorrow by proxy harms us now, insofar as our present interest is thwarted (our present interest being to live unharmed tomorrow). Because our present interest is as a matter of fact going to be harmed, our wellbeing today is damaged, as our interest exists in the present.

To reframe this in the context of our argumentation, if Margo 1 authors an advance directive today requesting physician-assisted euthanasia once she is non-compos mentis, and if as a matter of truth the physician will (in the future) deny her the euthanasia, then her present interests

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<sup>76</sup> Pitcher, G. (1984). "The misfortunes of the dead," *American Philosophical Quarterly*, vol. 21:2, pp. 183-188.

<sup>77</sup> Luper, S. Posthumous Harm. *American Philosophical Quarterly* 41 (1):63 - 72 (2004).

are thwarted. Her interests could be to maintain dignity, to live fully and not as a shell of herself, to not burden her family members, or any other number of factors personal to her, and significant insofar as they are expressions of her autonomy. The crux of the matter is that they will only be upheld if she is given physician-assisted euthanasia as written in the advance directive. If the euthanasia is denied her in the future, *after the death of Margo 1*, her present interests *as living Margo 1* are thwarted.

Because she, Margo 1, bears historical and precedent-based bodily rights, the potential prioritization of Margo 2, who bears no legal standing and significantly reduced moral standing, will constitute harm to Margo 1 even after her death. And insofar as she *will* be harmed after her death, Margo 1 is harmed now.

The purpose of this argumentation has been to establish a moralistic foundation for the utilization of advance directives for physician-assisted euthanasia. All of this said, we are then faced with the practical dilemma of having doctors follow through with the euthanasia procedure. Posthumous harm or not, it is difficult to look into the eyes of a smiling Margo and tell her that she is going to die against her will. Margo 2 is a reduced being, yes, but in practice, killing her is a tough sell to a medical professional.

## Chapter V. Practicalities, Considerations, and Reservations

Or so one would think. In actuality, a primary concern of the ADE is not the reluctance of medical professionals to comply with procedure, but rather their *willingness*. In countries that have implemented euthanasia, public health officials criticize its dangerous normalization and routinization, as seen in the case of Dr. Fenigsen.

Fenigsen, who originates from and practices in the Netherlands, laments the zealous use of euthanasia in light of negligence and normalization of euthanasia.<sup>78</sup> He describes the case of a fourteen-year-old child who was about to be euthanized before his intervention. The child was unconscious, but doctors did not spend much time trying to revive her before resorting to euthanasia. If Fenigsen had not intervened, the child would have died. She was revived hours later.

Other concerns include the fear that if euthanasia is normalized with the ADE, there will be discrimination against the disabled, in the form of pressure to pursue euthanasia<sup>79</sup>; that while doctors generally *do* support euthanasia, it will be difficult to extricate death from maleficence in their minds, causing psychological harm to medical professionals<sup>80</sup>; and that there will be inequalities in access to the mechanisms necessary for ethical practice of ADE.

Interestingly, public support is not a concern. Although religion is a major impeding factor in people's willingness to accept euthanasia, the public overwhelmingly supports euthanasia. In

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<sup>78</sup> Fenigsen, Richard, and Fenigsen, Ryszard. "Chapter XXIII: Doctors Who Practice Euthanasia." *Issues in Law & Medicine* 28.2 (2012): 273. Web.

<sup>79</sup> Davis, Jacky, and Ilora Finlay. "Would Judicial Consent for Assisted Dying Protect Vulnerable People?" *BMJ: British Medical Journal (Online)* 351 (2015): H4437. Web.

<sup>80</sup> Roehr, Bob. "Assisted Dying in US and Canada: Controversy Subsides after Legalisation." *BMJ: British Medical Journal (Online)* 360 (2018): K503. Web.



fact, euthanasia is more publicly favored than physician-assisted suicide, yet euthanasia remains illegal.<sup>81</sup>

Before we address the listed concerns, there is a conversation to be had here concerning killing versus letting die. We could of course reference the classic hypotheticals of drowning one's cousin versus not saving one's already-drowning cousin. However, such a discussion haphazardly assumes that to fulfill a patient's autonomous request for physician-assisted euthanasia is to take a primarily active role in the death. I would posit that ADE is actually more morally akin to letting die, given that the physician has taken an oath of beneficence and non-maleficence, and is bound in their duty to do right by the patient in the manner she delineates, as an autonomous being.

(As an aside, I will also preemptively rebut the potential objection that some "autonomous" patients desire procedures which are inherently damaging, and that therefore an ADE falls within the self-harming realm of, for example, a patient with dysmorphia who may feel "overcomplete" and desire to lose healthy limbs. These dysmorphias result out of abnormalities in the parietal lobe, and for the purposes of this discussion on practicalities, I will simply say that such cases are not analogous to ours, as they do not constitute the same moral, biological, or legal stakes. Dementia involves a loss of identity and the mitigation of future harms, whereas the case of someone with parietal body dysmorphia would typically be more concerned with the treatment of mental illness.)

The aforementioned concerns of discrimination, normalization, and psychological harms in ADE can be addressed with the assembly of a well-focused team of caseworkers, bioethicists, physicians, psychologists, counselors, lawyers, and family members (if the patient desires her

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<sup>81</sup> Emanuel, Ezekiel J, Bregje D Onwuteaka-Philipsen, John W Urwin, and Joachim Cohen. "Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe." *JAMA* 316.1 (2016): 79-90. Web.

family to be present, in respect of her autonomy). This task force must advise and aid the patient, while *compos mentis* and while *non-compos mentis*. Only with their input, mediation, and enthusiastic support can the advance directive complete its protection of the patient's most critical interests.

Preventing abuses, though, begins with one of the most problematic aspects of the advance directive, which is writing it. The patient, with the advice of her medical institution's ADE team, must be able to designate the brightline past which her mind will no longer be sound.

The designation of one's mind as sound versus unsound is an extremely sensitive subject, and a huge practical hurdle. Traditionally, rationality is determined by age and medically-designated status of mental wellness; however, when dealing with mental regression (such as dementia) rather than maturation (such as coming of voting age), the line of rationality is not so clear. In fact, it is less a brightline and more a gray zone. The ethicist is faced with a conundrum, as if we were to designate the conditions for one's rationality, we would struggle to find criteria applicable to every patient. Yet if we allow each patient to designate what constitutes a loss of rationality, we are in danger of the patient making the standards too difficult or too lenient. If the test of rationality is too difficult, then the patient lives with the harms she intended to avoid by penning the advance directive. If the test of rationality is too lenient, then the patient will be fully cognizant of her situation and prematurely sent to death despite her own protests—a truly chilling scenario.

It is therefore important to take a mediated approach. Because the government cannot designate a single test of one's faculties for every patient—some people, for example, struggle to remember birthdays even while fully rational; and some demented people can remember birthdays

but cannot remember their own names—it must be the patient’s duty to write the conditions for qualifying as non-compos mentis. The patient must, however, be advised in her decision by ethicists, social workers, lawyers, psychologists, counselors, and doctors. I would also argue that the patient’s test of rationality cannot be a mere one, two, or three question test, as there is great potential for error with so few determining factors. Someone who fails a test about the date of their birth may still be able to live a fulfilled life, at least for a small while longer. The purpose of the advance directive for euthanasia is to prolong fulfilled living as much as possible. Thus, it is in the spirit of the advance directive for euthanasia to have the patient designate a long series of questions—ideally twenty to thirty—with great personal magnitude, before the medical professional can deem her compos mentis or non-compos mentis. These questions should revolve around the persistence or loss of one’s critical interests. Insofar as one’s critical interests define one’s self, their disappearance connotes a loss of identity, as occurs with the severe onset of dementia.

This is an imperfect answer. Hence, it is a major reservation of the implementation of the ADE. We will not pretend to have all the answers. Rather, we intend to open the dialogue for further questions.

What of the concerns regarding doctors, nurses, and other medical staff? How do we prevent potential abuses as well as psychological harms as a result of having to defy their ethical inclinations?

Let us also note that the political and religious culture of the Netherlands is distinct from the United States, and we would likely face resistance from medical practitioners far before normalization became a real concern. Changing the hearts and minds of doctors to accept and

respect the ADE as typical practice may seem a difficult first step. Nevertheless, I assert that it is a moral obligation for the doctor to respect the advance directive. While it may be difficult to look a seemingly happy person in the eye and euthanize them, it is the doctor's duty to remember that this is not the real person to whom the body belongs. The real person gave explicit and detailed consent to die. To refuse the author her dignified death is malpractice, a violation of every one of the four bioethical principles. The author signed the advance directive trusting that a medical professional would fulfill it. It is not within the doctor's jurisdiction to act paternalistically. It is only within the doctor's jurisdiction to uphold the best interests of the patient.

However, a doctor may still refuse. I would draw a parallel to the case of abortions—on ideological, personal, or religious grounds, a doctor may refuse to carry out a procedure resulting in the termination of a pregnancy. While I do believe this is malpractice, I live in the real world, and understand that not every doctor is going to be willing to check her moral baggage at the door. Thus, I would argue that it is permissible for the doctor to refrain from the abortive procedure; and I would argue the same for euthanasia. *But* this renders it *morally obligatory*, without exception, for the hospital or clinic to have another medical professional euthanize the advance directive's author. I conjecture that with the dissemination of new ethical standards for euthanasia, doctors will fall into line with less resistance than expected. Over millennia of medical practice, doctors change their practices according to what is acceptable in medical lessons and literature. One need only to look to the normalization of euthanasia in the Netherlands to see that with increasing social and academic normality, euthanasia will lose its abrasiveness in medical culture.

Because of this, we must educate doctors about the nuances of the euthanasia advance directive. If the doctor is determined to ignore the advance directive, then hospital caseworkers

and ethicists must interfere with this malpractice. If the doctor is too casual with her administration of euthanasia, then hospital caseworkers and ethicists must interfere with this malpractice as well.

The last enormous issue we have not yet addressed is a matter of access and distributive justice. In order to ethically implement the ADE, a patient would need a sizeable task force in a sizeable medical institution with sizeable resources. This is not viable for everyone. To have an ethical ADE, it seems, one needs to be affluent in an affluent region. This is an emblem of the flaws of the American healthcare system, but we cannot have “fix the healthcare system” as a tenet of this paper. We must acknowledge this practical barrier.

Furthermore, there may be an access issue when it comes to communicating with this team. Some people are illiterate; some people may struggle with working with this team to define their brightline of rational faculties; and some people may not fully comprehend the complexities of it all, not because they are demented, but because it is a difficult thing for most of the population to understand.

Once more, these are reservations. We cannot pretend to be omniscient or omnipotent. But we can identify these issues and seek the changes necessary to rectify them. We conclude this report with the knowledge that a conclusion has not yet been reached—or, at least, in a manner that is satisfactory and convincing beyond a doubt.

While this exploration of Margo’s dilemma by no means solves its practical entanglements, it provides groundwork for more definitive suggestions as to how the medical community should approach advance directives for euthanasia. Moreover, we definitely argue that the ADE is imperative for the wellbeing of the American people, who will with its implementation enjoy so many more *compos mentis* years of life; the prevention of undue suffering; and the fulfilment of

their critical interests to bodily autonomy. With the ADE, one would only hope that there would never again be a case like Gillian Bennet's, and that people like Margo would finally rest in peace.

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