THE MODERATE APPROACH TO ADVANCE REQUESTS FOR MEDICAL ASSISTANCE IN DYING IN ADVANCED DEMENTIA

by

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ABSTRACT

The purpose of this thesis is to provide an approach to advance requests for MAiD in the setting of advanced dementia. Development of such an approach will require facing important ethical questions and metaphysical challenges. A small number of international jurisdictions permit advance requests for MAiD but there is no universal standard approach. Canada permits advance requests for MAiD in the very limited capacity of the Final Waiver of Consent and Advance Consent. However, advance directives for other life-or-death decisions such as withholding therapies or withdrawing interventions are permitted much more broadly – even when the intention is to hasten the patient's death. Many authors argue that advance requests for MAiD and advance directives for other life-or-death decisions ought to be seen as ethically equivalent. There are several approaches to advance directives for life-or-death decisions in the setting of advanced dementia. The most prominent approaches attempt to prioritize the apparent tension between autonomy and beneficence while prioritizing self-determination. I will argue that the most prominent approaches fail due to underlying issues with their metaphysical foundations. I propose a Moderate Approach to advance requests for MAiD that I argue will provide sufficient ethical consideration to the apparent tension while maintaining sound metaphysical footing. Under this Moderate Approach, we ought to maximize the psychological connectedness and anticipate potential tensions between the person creating the advance request and the person who will be the subject of the advance request. If this tension occurs, we ought to resolve this tension by determining if the opposition is due to a change within the person themselves, or due to an unwanted influence from the disease process.

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Chapter 1: Introduction

It is only a matter of time until Canada must settle the question of whether to honour advance requests for Medical Assistance in Dying (MAiD), and if so, how. When parliament passed Bill C-14 and MAiD became legal in Canada, advance requests were identified as one of three outstanding issues.[1] However, the issue of advance requests is incredibly complex. Any resolution on this problem will require facing both ethical and metaphysical challenges. These concerns are especially poignant in patients with advanced dementia. To draw this problem into focus, consider the classic 'Margo' case; first described by Andrew Firlik who knew Margo when he was a medical student.[2]

> *Margo is a 55 year old woman with advanced Alzheimer's Dementia. She cannot remember Firlik's name at their daily visits. Her door has many locks to prevent her from slipping out in the middle of the night and getting lost or hurt. She will play a song on her stereo and immediately forget she listened to it and play it again. However, every time she plays it, she is delighted as if it's a favourite song she hasn't heard in years. She reports that she loves to read her mystery novels. However, day-to-day she jumps her place within her current novel by hundreds of pages in either direction and has a dozen dog-eared pages at any given time – clearly not remembering what she has read from one sitting to another. She cherishes the simple pleasures of life such as her peanut-butter & jelly sandwiches. Despite being in the advanced stages of a dreaded disease, Firlik reports that "Margo is undeniably one of the happiest people I have known."*[3]

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[1] The other two issues being mature minors and mental illness as a sole underlying condition.
[2] Firlik, "Margo's Logo."
[3] Firlik, "Margo's Logo," 201.

For the purposes of this thesis, I will focus on a modified-Margo case with all the same circumstances as described above by Firlik and the following addition:

> *When Margo was first diagnosed with Alzheimer's dementia, she drafted an advance request for the provision of MAiD once she reached the advanced stages of her disease. At the time, she was early in the disease process and deemed to have capacity to make decisions regarding MAiD. She has now reached the advanced stage of dementia. Her family, friends, and health-care team are aware that the advance request was meant to be acted on at this time. They consider Margo in her current state of pleasant confusion and are unsure as to how they ought to proceed.*

The purpose of this thesis is to provide an approach to advance requests for MAiD in the setting of advanced dementia.[4] Development of such an approach will require facing important ethical questions such as the tension between autonomy and beneficence: How do we consider pre-dementia Margo's autonomous decision regarding MAiD against the prospect of cutting short the pleasure that advanced dementia Margo derives from music and peanut butter & jelly sandwiches.[5] As well, such an approach will require facing important metaphysical questions regarding the persistence of personal identity: Are pre-dementia Margo and advanced dementia Margo the same

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[4] A full exploration of the moral standing of MAiD in general is outside the scope of the thesis. The purpose of this thesis is to provide an approach for advance requests for MAiD under the assumption that MAiD is permissible.

[5] Throughout this thesis, I will use the term 'pre-dementia Margo' as shorthand to refer to Margo when she still had capacity in the standard medical model of comparative decision-making capacity. This could be prior to the diagnosis of dementia, in early stages of dementia or, possibly, even moderate dementia. For specificity, I could say 'pre-advanced dementia Margo,' however, such language would be cumbersome and therefore I will use 'pre-dementia Margo' as shorthand.

person? If not, what right(s), if any, would pre-dementia Margo have to request MAiD for advanced dementia Margo?

Alzheimer's Dementia

It is worth noting that Margo's pleasant state is not characteristic of Alzheimer's Dementia.[6] Alzheimer's dementia is a progressive neurodegenerative disease which usually presents with difficulties in short-term memory. At the early stages, the memory issues tend to be superficial such as forgetting who the Prime Minister of Canada is or what year it is. As the disease progresses, memory problems worsen such that the person will slowly forget people they've recently met, friends, or second-degree family members like cousins or grandchildren. At the advanced stages, the person will forget their closest loved ones and even their own name. During this decline, the disease will also impair other cognitive functions such that the person will have problems with language, will get lost easily, will forget how to follow simple instructions, and will have difficulties with basic activities of daily living such as dressing, toileting, and eating. At the terminal stages, patients generally succumb to advanced debilitation complications such as dehydration, malnutrition, and infection.[7] Neuropsychiatric symptoms such as mood, behaviour and personality changes are seen in almost all Alzheimer's patients at some point in their disease process.[8] While Margo has been fortunate to enter a state of pleasant confusion, many people with Alzheimer's dementia may become increasingly agitated, angry, scared, or withdrawn. While euphoria, similar to Margo's state, can occur, this happens in less than 10% of patients and tends to decrease with time.

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[6] I will be using the term Alzheimer's dementia throughout this thesis. It is also often referred to as Alzheimer's disease.

[7] Wolk & Dickerson, "Clinical features and diagnosis of Alzheimer disease."

[8] Lyketsos et al, "Neuropsychiatric symptoms in Alzheimer's disease," 532.

Meanwhile, neuropsychiatric symptoms such as delusions, agitation, depression, anxiety, apathy, irritability, aberrant motor behaviour, and sleep disorder occur in more than half of patients and many of these symptoms worsen with time.[9] Given that Alzheimer's is by far the most common dementia, this disease often plays a central role in discussions about advance directives. While Margo's case is an exceptional case among patients with Alzheimer's, it is an important case to consider when discussing advance directives as it brings some of the most difficult ethical issues to the forefront when considering advance requests for MAiD.

While the Margo case specifically refers to Alzheimer's dementia, the purpose of my thesis is meant to capture dementia more broadly. Dementia itself is not a specific disease but rather a collective term for disorder or decline of cognitive functions such as memory, learning, executive function, or social cognition. Dementia is not normal aging. There are many different diseases that can cause dementia such as Alzheimer's, Lewy body, frontotemporal, vascular, or Huntington's.[10] In all cases, dementia causes a progressive, predictable decline in cognitive function which causes major changes in the person's memories, dispositions, and cognitive capacity.

Capacity, Autonomy & Self-Determination

Questions of capacity play a central role throughout this thesis. In what follows, when I use the word 'capacity' on its own, I mean to the standard medical model which focuses on comparative decision-making capacity (DMC). Comparative DMC requires the patient to have capacity to understand and appreciate the various natures, risks, and

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[9] Ryu et al, “"Persistence of and changes in neuropsychiatric symptoms in Alzheimer disease over 6 months: the LASER–AD study," 981-982.

[10] Larson, Eric, B. “Evaluation of cognitive impairment and dementia.”

benefits of potential outcomes for each proposed treatment option, including no treatment. The patient is also expected to have the cognitive capacity to compare the various options and reasonably balance out the risks and benefits. It is worth noting that capacity is not an all-or-none phenomenon. Capacity is time and decision specific and not a global determination of the person's overall decision-making abilities. A patient may have capacity for a simple decision but lack capacity for a more complex decision. While comparative DMC is the most common model for how capacity assessments are carried out in medicine today, there is no universally accepted approach.[11,12,13]

We assess capacity to determine if the patient has sufficient cognitive ability to decide for themselves. The reason we care about allowing them to decide for themselves is out of respect for autonomy.[14] Under the standard medical model, if a patient has comparative DMC, then we believe that the person is making an autonomous decision that ought to be respected.[15]

However, debates regarding what qualifies as an autonomous decision worthy of respect are incredibly complicated. Immanuel Kant is seen as a foundational thinker on respect for autonomy. However, Kant's definition of what counts as an autonomous decision is far narrower than how the term is used in modern bioethics. From a strict

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[11] Navin, Brummett & Wasserman. "Three Kinds of Decision-Making Capacity for Refusing Medical Interventions," 1-3.

[12] Council of Canadian Academies. "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 31.

[13] Sumner, "Assisted death," 90-91.

[14] Hawkins & Charland, "Decision-Making Capacity", *The Stanford Encyclopedia of Philosophy.*

[15] In Chapters 3 and 4, I will explore different approaches to capacity assessment in greater detail. A patient could be deemed to have capacity under one approach to capacity assessment and not in another. Under the standard model of comparative DMC, Margo would likely not have capacity. However, under other models of DMC, she may have capacity. If Margo maintains capacity for a decision regarding MAiD, then it would seem she should be able to overturn her previous advance request. However, if she does not have capacity, it seems the advance request ought to be upheld (or some other factor would have to be considered). In Chapter 3, I will explore work by Dresser, Jaworska, and Carter that points to such other factors.

Kantian perspective, any decision not driven by reason is not autonomous.[16] Therefore, our decisions may not be autonomous if they are influenced by simple things like a craving for a cigarette, an interest in science fiction, or the love of our children. This diverges from the way the term is used in modern bioethics: The right to autonomy as the right to choose for oneself. I can choose to smoke a cigarette even though it is bad for my health because I have the right to choose for myself.[17] However, this does not diverge as far from Kant as it may seem. Kant's position was based on the notion that we are rational agents and all the other influences beyond reason were not truly *our* decisions. The important common theme is that both Kant and modern bioethics are aiming to respect the agent's decision. The divergence occurs due to a disagreement about who is the relevant agent: For Kant the relevant agent is our pure rational self once we have stripped away the desires, natural dispositions, and other non-rational inclinations[18] but modern bioethics sees those desires, dispositions, and inclinations as part of the relevant moral agent.[19]

A full exploration of autonomy is beyond the scope of this thesis. My goal here is to highlight that what counts as an autonomous decision will depend on who we determine as the moral agent. This is relevant to temporal considerations (e.g., between pre-dementia and advanced dementia Margo) and, also to which influences we consider to be legitimate parts of the relevant moral agent (e.g., are the cognitive changes due to Alzheimer's disease part of the moral agent or influences that are external to the moral

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[16] O'Neill, "The Inaugural Address: Autonomy: The Emperor's New Clothes," 16.
[17] O'Neill, "The Inaugural Address: Autonomy: The Emperor's New Clothes," 3.
[18] Hill, "Kantian autonomy and contemporary ideas of autonomy," 18-19.
[19] O'Neill, "The Inaugural Address: Autonomy: The Emperor's New Clothes," 3-4.

agent). Determining which *self* is the relevant moral agent is central in developing an approach to advance requests for MAiD.

Notes on Terminology

In this thesis, I will use the term Medical Assistance in Dying (MAiD) to refer collectively to both clinician-assisted suicide[20] and voluntary euthanasia.[21] A clinician-assisted suicide involves a health-care professional (e.g., physician or nurse practitioner) prescribing a lethal medication that the patient will self administer for the purpose of ending their life. By contrast, in voluntary euthanasia, the patient requests the clinician to administer a lethal medication for the purposes of ending the patient's life.[22]

Throughout the thesis, I will use the term 'life-or-death decisions' to refer to decisions regarding MAiD, withholding potentially life-saving therapies, and withdrawing potentially life-sustaining interventions. For the purposes of brevity, I may alternate from 'withholding potentially life-saving therapies' to simply 'withholding therapies' and from 'withdrawing potentially life-sustaining interventions' to 'withdrawing interventions' – or simply 'withholding/withdrawing' to encompass both. The latter part of Chapter 2 will include a more in-depth comparison of these terms.

Finally, within this thesis, I will use the term "advance request" in reference to MAiD and "advance directive" to refer to withholding therapies or withdrawing interventions. "Advance request" refers to legal framework under Criminal Code and

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[20] This is more commonly referred to as physician-assisted suicide. However, in Canada nurse practitioners can also prescribe medications for the purpose of assisted suicide. I use 'clinician' to capture any relevant health-professional that is involved in this process.

[21] Throughout this thesis, I will treat assisted-suicide and voluntary euthanasia as ethically equivalent. A full defence of this position is beyond the scope of this thesis. See Chapter 4 of L.W. Sumner's book, "Assisted Death," for a full discussion.

[22] Sumner, "Assisted Death," 73

“advance directives” refers to legal framework under provincial/territorial legislation. This distinction is also commonly used in the literature.

Chapter Summary

In this introductory chapter, I have introduced the purpose of this thesis: To propose an approach to advance requests for MAiD in the setting of dementia. As noted earlier, such an approach will need to consider both the ethical and metaphysical challenges that are intertwined with advance requests for MAiD. I provided a brief overview of capacity, autonomy, and self-determination as they pertain to this thesis. Finally, I clarified some terms that will be commonly seen throughout this thesis.

In the next chapter, I will review the legal standing of MAiD in jurisdictions where advance requests for MAiD are permitted. I will then focus on the Canadian approach to advance requests for MAiD and contrast the legal standing of advance requests for MAiD and advance directives for other life-or-death medical decisions. As I will show, there is a discrepancy between the legal authority of advance requests for MAiD and advance directives for withholding therapies or withdrawal of interventions. At the close of Chapter 2, I will argue that there is no ethical distinction between a patient’s decision regarding MAiD, withholding therapy, or withdrawing interventions so long as all other relevant factors are the same.

In Chapter 3, I will describe various approaches to advance directives for life-or-death decisions. Specifically, I explore the work of Ronald Dworkin and assess some of the most important responses to Dworkin’s Critical Interests Approach. As I will show, these authors face a challenge regarding the apparent tension between autonomy and beneficence when considering advance directives for life-or-death decisions in the setting of advanced dementia. To overcome this apparent tension, these approaches tend to point towards some overarching guiding concept that helps overcome this apparent tension. I will highlight that the primary tension between Dworkin and the responding authors lies between their approach to persistence of personal identity.

In Chapter 4, I will delve into the philosophy of persistence of personal identity. I will argue that Dworkin's Critical Interests Approach fails due to a lack of reliable metaphysical footing. I will turn to Derek Parfit's work on persistence of personal identity to draw out some important considerations for developing an approach to advance requests for MAiD. The various responses to Dworkin tend to follow in the same vein as Parfit's work and therefore have more stable metaphysical footing as compared to Dworkin. However, I will argue that these approaches also fail for different reasons. In pointing out why those approaches fail, I will set the stage for my approach to advance requests for MAiD in the setting of dementia.

In the Chapter 5, I will then describe my proposed Moderate Approach in detail. Under this Moderate Approach, we ought to maximize the psychological connectedness and anticipate potential tensions between the person creating the advance request and the person who will be the subject of the advance request. If this tension occurs, we ought to resolve this tension by determining if the opposition is due to a true change from within the person themselves, or due to an unwanted influence from the disease process. I will argue that my Moderate Approach is a metaphysically sound, ethical approach to advance requests for MAiD. Finally, in Chapter 6, I will provide a summary of this thesis, recommendations for legislation and practice standards, discuss some limitations of this thesis, and provide suggestions for future work in this area.

Chapter 2

In this chapter, I will provide a brief overview of the legal and regulatory status of MAiD in jurisdictions where advance requests for MAiD are permitted. In doing so, I will show that there is little agreement as to which circumstances to consider for an advance request for MAiD to be respected, even in jurisdictions that agree that advance requests ought to be permitted. After reviewing the international status of advance requests for MAiD, I will then provide a summary of the status of advance requests for MAiD in Canada and contrast this with the status of advance directives for other life-or-death decisions such as withholding potentially life-saving therapies or withdrawing life-sustaining interventions. This comparison will show that there is a discrepancy between how such advance directives are dealt with, both in Canada and in many other jurisdictions around the world. I will argue that advance directives for withholding therapies, withdrawing interventions, and MAiD should be regarded as ethically equivalent.

International Standing of MAiD & Advance Requests for MAiD

In this section, I will review the status of MAiD in non-Canadian jurisdictions where advance requests for MAiD are currently permitted.[23] This will not be a complete review of the status of MAiD in all jurisdictions. Specifically, I will look at Belgium, Luxembourg, the Netherlands, and Colombia.[24]

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[23] As of October, 2022.

[24] Switzerland's Criminal Code does not specifically prohibit advance requests. However, the Swiss Academy of Medical Sciences' requirement for the patient to have capacity effectively prohibits advance requests – Samuel Blouin, email correspondence with author, September 2022. Therefore, Switzerland has been omitted from this review.

Belgium

In 2002, Belgium enacted legislation that permits MAiD. Under Belgian law, physicians are permitted to administer euthanasia if: the patient is competent when the request is made; the request is voluntary, well-considered and repeated, and is not due to coercion; and the patient is in a "medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident."[25]

Advance requests for MAiD are permitted in cases where a patient can no longer express their will. The advance request must be in writing when the person was competent and the physician must ensure: the patient suffers from a serious and incurable disorder, caused by illness or accident; the patient is unconscious; and their condition is irreversible.[26] The person may designate one or more person(s) to inform the attending physician about the advance directive. The advance directive is only valid for 5 years but is renewable.[27]

Luxembourg

In 2009, Luxembourg enacted MAiD legislation similar to Belgium. The criteria are the same, however, Luxembourg has not expanded MAiD to include mature minors as is the case in Belgium. Like Belgium, Luxembourg permits advance requests for MAiD. The criteria for advance requests for MAiD are also largely the same.[28] One slight

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[25] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 110.

[26] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 110.

[27] Ministère de la Santé et des Services sociaux, "L'aide médicale à mourir pour les personnes en situation d'inaptitude: le juste équilibre entre le droit à l'autodétermination, la compassion et la prudence," 75-76.

[28] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 112.

variation concerns the expiration of advance requests for MAiD. In Belgium, the advance directive will expire after 5 years if it is not renewed. In Luxembourg, the person will be sent a request for confirmation of the advance directive every 5 years. However, the person is not obliged to confirm and the advance request for MAiD will hold without time limit. The person can revoke the advance directive at any time, even orally, with their physician.[29]

Netherlands

In 2001, the Netherlands passed legislation permitting MAiD, which came into effect in 2002. It is worth noting that MAiD was an accepted medical practice in the Netherlands well before the legislation was put in place. Even prior to the legislation, there were well-established standards of care regarding MAiD. However, the medical community requested legislation to formalize these accepted practices.

In the Netherlands, MAiD is permitted if: the patient's request is voluntary and well considered; the patient's suffering is unbearable, with no prospect of improvement; the patient is informed about their situation and prognosis; the physician has come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation;[30] the physician has consulted at least one other, independent physician, who must see the patient and give a written opinion on whether these 'due care' criteria have been fulfilled; and the physician has exercised due medical care and attention in terminating the patient's life or assisting in their suicide.[31]

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[29] Ministère de la Santé et des Services sociaux, "L'aide médicale à mourir pour les personnes en situation d'inaptitude: le juste équilibre entre le droit à l'autodétermination, la compassion et la prudence," 77-78.

[30] It is worth noting that the physician comes to this conclusion with the patient. This adds an element of outside the patient's subjective experience that is not present in the Canadian context.

[31] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 107-108.

Advance requests are permitted in the Netherlands. Any patient over the age of sixteen may prepare a written advance request for MAiD.[32] In the Netherlands, the physician must confirm that a patient is suffering before enacting the advance request for MAiD. According to the *Code of Practice* that governs the practice of MAiD in the Netherlands, an unconscious patient is unable to suffer, therefore an unconscious patient cannot receive MAiD. This is the opposite situation from Belgium and Luxembourg where patient must be unconscious.[33] There is no time limit to the advance directive, but it is suggested that it be updated regularly.[34] As of 2005, approximately, 7% of adults over the age of 20 have an advance request for MAiD in place, however, enacting advance requests for MAiD in people with dementia is quite low.[35]

There is a 2016 case of an enacted advance request for MAiD that warrants some description. This case led to criminal charges against the physician, who was eventually deemed not guilty. The patient was a 74-year-old woman with advanced Alzheimer's dementia. The patient had written an advance request for MAiD years prior while she still had capacity. When the family and attending physicians felt that the criteria laid out in the advance request had been met, they arranged for her MAiD procedure. The patient was given sedatives prior to the procedure. An initial sedative was placed in the patient's coffee without informing her. A second sedative was given subcutaneously because the initial sedative was insufficient. Thiopental was used as the lethal medication. While the thiopental was being administered, the patient suddenly tried to get up. The patient's

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[32] Patients aged 12 to 16 may also prepare and advance request for MAiD under additional requirements.

[33] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 108-109.

[34] Ministère de la Santé et des Services sociaux, "L'aide médicale à mourir pour les personnes en situation d'inaptitude: le juste équilibre entre le droit à l'autodétermination, la compassion et la prudence," 79.

[35] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 109.

family helped to hold her in place while the physician completed the injection. Later, the Dutch review committee found the physician failed to follow the Dutch statutory criteria. The review committee took issue with three factors in the case: (i) the wording in the advance request could be read in different ways and the committee felt that in one interpretation, the patient would not have wanted MAiD and the physician should have erred on the side of ‘caution’ and not performed MAiD in the ambiguous situation, (ii) administering the initial oral sedative surreptitiously was an intentional effort to undermine the patient’s ability to resist, and (iii) the patient’s reaction to the thiopental injection was a significant sign that she did not want the injection administered.[36] In 2019, the case was brought before the criminal court and the physician was eventually acquitted of all charges. Interestingly, the court was more focused on the ambiguity of the advance request. Whereas the review board felt that the ambiguity should be interpreted by ‘erring on the side of caution’ and not proceeding with MAiD, the court decided the family and physicians acted appropriately by interpreting the advance request’s ambiguity by referring to patient’s history of verbal communications around her wishes. The surreptitious sedative in the coffee was deemed appropriate given the patient’s lack of capacity. By the court’s reckoning, any attempt to explain the planned MAiD procedure to an incompetent patient would only have created undue stress.[37]

Colombia

In 1997, MAiD was decriminalized by the Colombia Constitutional Court. Due to this ruling, patients suffering from a terminal illness that causes suffering could receive

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[36] Miller, Dresser & Kim, “ Advance euthanasia directives,” 84-86.

[37] Asscher & van de Vathorst. "First prosecution of a Dutch doctor since the Euthanasia Act of 2002,” 73-74.

MAiD if they provide free and informed consent and the procedure was done by a physician. In 2015, the Colombia Ministry of Health and Social Protection provided a resolution that effectively legalized MAiD. This resolution mandated that a patient must be of legal age, and it added other stipulations regarding the availability of curative treatments that could efficiently alter the trajectory towards death.[38]

The 2015 resolution also permits advance requests for MAiD. A patient's surrogate may present a written advance request for MAiD to their physician. The surrogate may also withdraw the advance request. Colombia does not place any restrictions on advance requests for MAiD based on the consciousness of the patient.[39]

Synopsis

Belgium, Luxembourg, the Netherlands, and Colombia allow advance requests for MAiD. These jurisdictions require that the advance request for MAiD be made in writing by the person themselves (i.e., the directive cannot be made by a proxy). The case must be reviewed by an independent consulting physician and discussed with the patient's family and/or designated representative.[40] In general, there is no time limit on the advance request for MAiD.[41] In these four jurisdictions, MAiD provisions are reported to an oversight committee.[42]

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[38] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 112.

[39] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 113.

[40] In the Netherlands, the requirement to discuss with family and/or designated representative is a suggestion rather than a mandatory requirement.

[41] Belgium is the only country where the advance directive will expire if it is not renewed every five years. Luxembourg sends a request for renewal every 5 years, but the advance directive will not expire even if the patient does not respond to the request for renewal.

[42] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 114.

When enacting MAiD through an advance request, Belgium and Luxembourg require that the patient must be unconscious, whereas the Netherlands requires that the patient must have some degree of consciousness. Colombia makes no specifications as to the degree of consciousness, however, there is no information that I could find regarding advance requests for MAiD being enacted on conscious patients in Colombia. As such, Belgium, Luxembourg, and Colombia would only allow an advance request for MAiD at the very terminal stages of dementia where a patient is unconscious. Therefore, the Netherlands is the only jurisdiction where advance requests for MAiD are provided for conscious patients with advanced dementia.

Canadian Context

Medical Assistance in Dying

In the 1990s, Sue Rodriguez, a woman with amyotrophic lateral sclerosis (ALS) challenged the Criminal Code prohibition on assisted suicide. Her challenge was ultimately denied at the Supreme Court of Canada in 1993.[43] From 2006 to 2012 regarding MAiD, the province of Quebec conducted a series of studies and reports. [44,45] This resulted in the province passing legislation permitting MAiD in 2014. This legislation came into effect in 2015. In 2015, in the unanimous *Carter* Decision, the Supreme Court of Canada ruled that the challenged sections of the Criminal Code were unconstitutional insofar as they violated the section 7 rights[46] of competent adults suffering with a grievous and irremediable condition and that this violation was not

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[43] Supreme Court of Canada, (1993) *Rodriguez v. British Columbia.*

[44] Government of Quebec (2012) Select Committee on Dying with Dignity: Report.

[45] Collège des médecins du Québec. (2009) Physicians, Appropriate Care and the Debate on Euthanasia.

[46] “Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.”

justified under section 1[47] of the Canadian Charter of Rights and Freedoms.[48] The Supreme Court provided a year for the federal government to enact legislation in response to the ruling.

In 2016, the federal government passed Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying),* which created the legal framework for MAiD in Canada. Under the 2016 legislation, any person eligible for health-care services in Canada, who is at least 18-years-old is eligible for MAiD if: They have decision-making capacity and *a grievous and irremediable medical condition*; they have made a voluntary request without coercion; they give informed consent, and they are aware of the options that are available to relieve their suffering, including palliative care.[49] Under Bill C-14, a patient had a *grievous and irremediable medical condition* if: They had a serious illness, disease or disability; they were in an advanced state of decline that cannot be reversed; they experienced unbearable physical or mental suffering that cannot be relieved by means acceptable to the patient, and their natural death was reasonably foreseeable. Bill C-14 required a patient have capacity and provide consent immediately prior to the procedure for MAiD and therefore did not permit advance requests for MAiD. However, through Bill C-14, the federal government called for an independent review of three outstanding issues which included advance requests for MAiD.[50]

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[47] "The *Canadian Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society."

[48] Supreme Court of Canada, (2015) *Carter v. Canada.*

[49] Bill C-14, "An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)."

[50] It is worth noting that Quebec 2015 provincial legislation remained in effect even after Bill C-14 was passed. This created two parallel but slightly different legislative frameworks for MAiD within Quebec.

In 2016, Julia Lamb launched a court challenge against the requirement that death be 'reasonably foreseeable'. The case was eventually adjourned when a federal government's medical expert deemed her eligible for MAiD under the medical community's evolving understanding of the criteria. In 2017, Jean Truchon and Nicole Gladu challenged the MAiD legislation in Canada and Quebec. At the time, Truchon was a 49-year-old man with cerebral palsy and Gladu was a 71-year woman with post-polio syndrome. Given that the current legislation required that a person's natural death was reasonably foreseeable, and, in Quebec, the person would need to be at the end of life, neither Truchon nor Gladu could access MAiD.[51] In 2019, Justice Christine Baudouin ruled in favor of Truchon and Gladu. Neither the federal nor the provincial government sought to appeal her decision. This led the federal government to pass Bill C-7 in 2021 which, among other things, created a second track to permit MAiD for patients whose death was not reasonably foreseeable.[52]

Advance Requests for MAiD

While Truchon and Gladu were challenging MAiD legislation regarding the 'reasonably foreseeable natural death' criteria, Audrey Parker was raising awareness regarding the prohibition on advance requests for MAiD. Parker died at age 57 in Halifax, after a lengthy battle with cancer. While Parker was able to access MAiD, she had to access MAiD earlier than she wished. Parker had been planning for her MAiD procedure in late 2018 after one final Christmas with friends and family. However, Parker was at risk of losing capacity due to her illness and Bill C-14 required capacity

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[51] Council of Canadian Academies, "The State of Knowledge on Advance Requests for Medical Assistance in Dying," 22.

[52] Bill C-7, "An Act to amend the Criminal Code (medical assistance in dying)."

and consent immediately prior to MAiD. Therefore, Parker was forced to move the procedure to November 2018. She publicly called for a change to the legislation that was forcing her to die earlier than she wished. Parker's case sparked national attention and received public support.[53]

While parliament was drafting Bill C-7 to ensure that MAiD laws in Canada were reflective of the Truchon and Gladu decision, they also added in additional legislation commonly referred to Audrey's Amendment. Under Bill C-7, a patient can arrange for a 'waiver of final consent' which will remove the requirement for the patient to have capacity and provide consent immediately prior to their MAiD procedure if the patient's natural death is reasonably foreseeable. To arrange a waiver of final consent, a patient must first meet all the other criteria and safeguards for MAiD. If there is a concern that the patient may lose capacity prior to their planned date for their MAiD procedure, the patient may then enter into a written agreement with their MAiD provider so that they can still receive MAiD on or before their planned date. The patient must be informed that they may lose capacity and the written agreement must indicate a specific date for MAiD and indicate the patient's consent to have MAiD provided even if they lack capacity. If the patient loses capacity prior to the scheduled date for MAiD, MAiD may still be provided so long as "the person does not demonstrate, by words, sounds or gestures, refusal to have the substance administered or resistance to its administration."[54] It is worth noting that the legislation specifically states, "For greater certainty, involuntary

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[53] Library of Parliament. "Legislative Summary of Bill C-7," 10.

[54] Bill C-7, *An Act to amend the Criminal Code (medical assistance in dying).* (3.2)(c)

words, sounds or gestures made in response to contact do not constitute a demonstration of refusal or resistance..."[55]

Bill C-7 also clarified that a MAiD provider can provide MAiD after a case of failed self-administration of MAiD. This would be in the scenario where a person has self-administered an oral lethal medication (clinician-assisted suicide), but the medication has not resulted in their death, and they are now unresponsive. In this scenario, the MAiD provider could administer an intravenous medication to ensure the patient dies as desired. Bill C-14 was not clear as to the legality of this practice.

Advance Directives for Life-or-Death Decisions

In 1979, Georgette Malette, was involved in a major motor vehicle collision. She suffered considerable blood loss due to the accident. Dr. David Shulman was her treating physician in the emergency department and determined that Malette may die if she did not receive a blood transfusion. In Malette's purse, a nurse discovered a card indicating her refusal to receive blood transfusions because of her religious beliefs as a Jehovah's Witness. Ms. Malette's daughter also arrived at the hospital and confirmed her mother's beliefs and the validity of the advance directive against blood transfusions. The unconscious patient was unable to provide consent or refusal for this treatment. Despite the advance directive, Shulman administered the blood transfusion. Malette survived and filed legal action against Shulman. In 1990, the Ontario Supreme Court sided with Malette. The court ruled that Malette's right to control over her own body had been violated. [56] This case established that a patient may create an advance directive to refuse

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[55] Bill C-7, *An Act to amend the Criminal Code (medical assistance in dying).* (3.3)

[56] Ministère de la Santé et des Services sociaux, "L'aide médicale à mourir pour les personnes en situation d'inaptitude: le juste équilibre entre le droit à l'autodétermination, la compassion et la prudence," 67.

potentially life-saving therapies and sets the stage for advance directives for life-or-death decisions in Canada.[57]

In Quebec City, in the late 1980s, Nancy B was diagnosed with Guillain-Barre Syndrome (GBS). GBS renders a person completely unable to move or breath for themselves. The condition usually resolves, and patients can often return to their usual lives after a period in intensive care on ventilator support. However, in 1991, Nancy B was informed by her physicians that her condition was irreversible, and she would be forever rendered immobile and dependent on ventilator support to live. She did not want to continue living in this condition and sought to have her ventilator stopped so she could die. In 1993, the Quebec Supreme Court ruled in favor of Nancy B, and she was permitted to die. While Nancy B's physicians did provide sedation prior to disconnecting her ventilator, the cause of death was the withdrawal of a life-sustaining intervention. This ruling does not specifically permit advance directives for withdrawal of life-sustaining interventions. However, it is worth noting because it does allow withdrawal of life-sustaining interventions for the purposes of ending a person's life because they consider their current life not worth living.[58]

Synopsis

MAiD is permitted in Canada in the form of both clinician-assisted suicide and voluntary euthanasia. The adoption of Bill C-7 also allows for advance requests for MAiD in the form of the 'waiver of final consent' and 'advance consent'. As such, Canada joins Belgium, Luxembourg, the Netherlands, and Colombia as one of the jurisdictions that permits advance requests for MAiD in some form – although, Canada's

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[57] Dickens "Medically Assisted Death," 1054-1055.

[58] Dickens "Medically Assisted Death," 1054-1055

options for advance requests are far more limited than these other jurisdictions. There is a discrepancy between how Canada permits advance requests for MAiD and advance directives for other life-or-death decisions. Such a discrepancy warrants analysis. In the next section I will provide an ethical analysis of the purported differences between withholding therapies, withdrawing interventions and providing MAiD.

Advance Directives for Life-or-Death Decisions

In the previous section, I outlined how the legislative frameworks for advance requests for MAiD are far more restrictive than the frameworks for advance directives for other life-or-death decisions such as withholding potentially life-saving therapies or withdrawing life-sustaining interventions. In this section, I will argue that all such life-or-death decisions are ethically equivalent. If my arguments are correct, then a difference in our approach to advance requests for MAiD and advance directives for other life-or-death decisions would seem unwarranted. This should motivate a deeper analysis of our approach to these advance requests/directives.

Historically, some authors have attempted to differentiate between ‘active’ (MAiD) and ‘passive’ (withholding/withdrawing) means of hastening a patient’s death.[59] I will review two important rebuttals of this differentiation below. First, I will review the classical work by James Rachels. Second, I will review the more contemporary work by L. W. Sumner.[60]

Nearly 50 years ago, James Rachels provided a famous challenge to this distinction.[61] Rachels provides various compelling arguments that point to the logical

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[59] Sumner, “Assisted Death,” 92.

[60] It is also worth noting that Justice Smith’s express reliance on Wayne’s affidavit dismissed this distinction in the Supreme Court of Canada’s *Carter* decision.

[61] Rachels, “Active and Passive Euthanasia.”

inconsistency of permitting ‘passive’ means to hasten death while denying ‘active’ means:

1. Withholding treatment can prolong suffering as compared to providing a lethal injection.[62]
2. Drawing a moral distinction between ‘passive’ and ‘active’ euthanasia[63] results in life-or-death decisions being dependent on trivial and irrelevant grounds. To elucidate this point, Rachels paints the famous thought experiments of Smith, Jones, and the drowning child. In the first variation, Smith stands to gain a large inheritance if his six-year-old cousin dies. While the six-year-old cousin is in the bath, Smith sneaks in and drowns the child and makes it look like an accident. The Smith example is contrasted with the second example of Jones. Jones likewise stands to gain a large inheritance if his six-year-old cousin dies. One evening when the six-year-old cousin is in the bath, Jones sneaks in with the intention to drown the child. Conveniently, the child slips and hits his head as Jones enters the bathroom. Jones stands by and watches the child drown even though it would be quite easy for Jones to save the child. The child dies ‘accidentally,’ and Jones happily receives his large inheritance. Smith actively ‘killed’ the child, whereas Jones passively ‘let the child die.’ All other features of the case are identical, including motive and outcome, which allows us to test our intuitions on this distinction specifically. On reflection on the Smith and Jones

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[62] Rachels, “Active and Passive Euthanasia,” 78-79.

[63] Rachels referred to passive means as passive euthanasia and active means as active euthanasia.

thought experiment, this ‘active’ versus ‘passive’ distinction seems to be irrelevant from an ethical perspective.[64,65]

3. Killing and letting die hold equal moral weight. The reason killing and letting die are morally wrong is because *death* is regarded as a moral evil. However, if we have determined that a patient’s ongoing suffering is morally worse than their death, then both killing and letting die lose their status as morally wrong actions.[66,67]

Following in a similar vein, L.W. Sumner lays out his arguments against the passive/active distinction in his 2011 book, “Assisted Death: A Study in Ethics and Law.” Sumner argues against the various ways the distinction could be drawn:

1. Act/omission distinction: MAiD is often construed as doing *something* whereas the ‘passive’ means of hastening death involves doing nothing. While not providing an antibiotic can be seen as doing nothing, turning off a ventilator or removing a feeding tube involves recognizably active action. Therefore, this distinction does not hold.[68]

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[64] Rachels, “Active and Passive Euthanasia,” 79.

[65] Likewise, we can draw similar parallels in MAiD and withholding life-saving therapies. Opponents of active euthanasia may deny MAiD for a patient with advanced dementia but would allow withholding antibiotics if they developed pneumonia. The pneumonia holds similar moral grounds as the slip-and-fall for the six-year-old in the Jones example. Whether we are providing MAiD or denying antibiotics, we are doing so because we wish to hasten death due to the advanced dementia. It seems trivial that the development of pneumonia should determine whether the patient’s death may be hastened given that the advanced dementia is the true motivating issue.

[66] Rachels, “Active and Passive Euthanasia,” 80.

[67] If we determine that it is ethically permissible to let a patient die because the patient would choose death over their ongoing suffering, then it would be logically inconsistent to say that killing would not be allowed. In this circumstance, we have nothing else to point to as a morally relevant factor. What reason can killing be bad aside from the fact that it results in death. If we determine that the result of death is morally preferable over ongoing life, then it follows that killing should be permitted. On the flipside, if we determine that a patient’s ongoing life is morally preferable to dying, then allowing them to die by withholding a simple life-saving therapy would be as morally wrong as killing.

[68] Sumner, “Assisted Death,” 93.

2. Intending/Foreseeing: Death is the intended consequence of MAiD whereas death is merely foreseen when withholding therapies or withdrawing interventions. Sumner points out, though, that when a patient is choosing to withhold a therapy or withdraw an intervention for the purpose of hastening their death, then death is intended not merely foreseen. Therefore, this distinction cannot hold when death is the intended consequence.[69]
3. Doing/allowing distinction: MAiD is *killing*, whereas the 'passive' means of hastening death are *letting die*. Sumner points out that under both means, the intention is the same therefore the distinction cannot be due to intention. Further, causation cannot be the differentiating factor as *letting die* often involves events that have a position in the causal chain leading to the person's death.[70] If *doing* an action that leads to a person's death is wrong, then providing sedation or removing a feeding tube must be deemed wrong.[71,72]

There is much more that could be said on this matter, however a full exploration of these arguments is beyond the scope of this thesis. My goal in this section is to lay out the basic arguments that dismiss the active/passive distinction. For the remainder of this thesis, I will proceed with the assumption that there is no ethical distinction between a patient's

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[69] Sumner, "Assisted Death," 97.

[70] Consider turning off a ventilator: The physician's action of turning off the ventilator leads to a direct series of cause and effect that eventually result in the patient dying. It could be argued that the medical condition causing the patient to be on the ventilator is a preceding cause and therefore not the act of turning off the ventilator. However, this strategy of argument could be applied to MAiD as well: The medical condition is what causes the suffering that leads the patient to request MAiD which then results in the physician administering a lethal injection.

[71] Sumner, "Assisted Death," 93-95

[72] On pages 98-99 of "Assisted Death," Sumner points out that the active/passive distinction can hold relevance insofar as the obligation on other people relative to the patient. We have a duty to provide treatment and assistance to others which is a positive duty. We also have a duty not to violate another person's body or administer unwanted therapies which is a negative duty. Positive duties have a weaker obligation than negative duties. This distinction was discussed in Chapter 1 of this thesis regarding the terminology of advance requests vs advance directives.

decision regarding MAiD, withholding potentially life-saving therapies, and withdrawing life-sustaining interventions assuming the relevant factors are kept constant (i.e. the intention to hasten the patient's death, the decision plays a step in a causal chain that leads to death).[73]

Chapter Summary

In the first section of this chapter, I reviewed the regulations surrounding MAiD in jurisdictions where advance requests for MAiD are permitted. In the second section of this chapter, I reviewed the status of MAiD, advance requests for MAiD, and advance directives for other life-or-death decisions in Canada. As noted in that section, advance requests for MAiD have quite different standing from advance directives for other life-or-death decisions.

In the third, and final, section, I surveyed arguments that advance directives for withholding potentially life-saving therapies, withdrawing life-sustaining interventions, and MAiD should be seen as ethically equivalent. If these arguments are accepted, then this calls for re-examination of the discrepancy that is seen in the legal standing of advance requests for MAiD and advance directives for other life-or-death decisions. In the next chapter, I will turn to a decades long philosophical debate regarding advance directives for life-or-death decisions for patients with advanced dementia. A full exploration of this debate will provide important insights for our approach to advance requests for MAiD in the setting of dementia.

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[73] Historically, some philosophers had tried to differentiate withdrawing life-sustaining interventions from withholding life-saving therapies on the grounds that there is an important distinction between stopping and not-starting an intervention or therapy. These arguments attempt to use the act/omission distinction described by Sumner but draw the line between withholding life-saving therapies and withdrawing life-sustaining care rather than between MAiD and withholding/withdrawing. Attempts at this distinction fall to similar arguments as laid out by Sumner and Rachels above. For a full exploration of this distinction see Brock, "Death and Dying," 1415-1416.

Chapter 3

In the previous chapter, I reviewed the legal standing of MAiD and advance requests for MAiD in jurisdictions where advance requests for MAiD are permitted. Within the Canadian context, I also contrasted the legal standing of advance requests for MAiD and advance directives for other life-or-death medical decisions. At the close of the chapter, I argued that there was no ethical distinction between a patient's decision regarding MAiD, withholding therapy, or withdrawing intervention so long as all other relevant factors are the same (e.g., the intention is to hasten death, the decision will hold a place the causal chain that results in death). If there is no ethical distinction between these life-and-death decisions, then it is odd that the legal standing of advance directives and requests with respect to these acts is so different.

In this chapter, I will review the literature on advance directives for life-or-death decisions for patients with advanced dementia. The goal of this thesis is to propose an approach to advance requests for MAiD in the setting of dementia. Assuming the arguments in Chapter 2 hold and we accept the ethical equivalence of decisions regarding MAiD and other life-or-death decisions, then the literature regarding advance directives for life-or-death decisions in the setting of dementia will be relevant to advance requests for MAiD.

There is a long history of rich debate on advance directives for life-or-death decisions. Much of this debate continues to be shaped by an influential chapter from Ronald Dworkin's 1994 book, *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom*. This chapter will begin by explaining the 'Critical Interests Approach' first espoused by Dworkin. I will then look through the classic responses to Dworkin's arguments. As I work through the work by these authors, I will apply their approaches to the modified-Margo case from Chapter 1. This will help draw out the distinctions between these approaches. Finally, I will synthesize this debate to draw out the common themes and highlight the unresolved tensions.

Critical Interests Approach: Dworkin

In Chapter 8 of his book, *Life's Dominion*, Dworkin sets out his arguments regarding advance directives.[74] Dworkin centres his discussion around the "Margo case" which I introduced in Chapter 1 of this thesis. To recap, Margo is a woman with Alzheimer's Dementia. She reads the same book every day but skips hundreds of pages from sitting to sitting. She thoroughly enjoys her repeated songs and peanut butter & jelly sandwiches. Despite being in the advanced stages of a dreaded disease, Firlik reports that "Margo is undeniably one of the happiest people I have known."[75]

Dworkin asks us to imagine that Margo has created an advance directive to withhold potentially life-saving therapies once she has reached the stage of advanced dementia for the purpose of hastening her death.[76] The question as to whether to respect the advance directive in this case is at the crux of this thesis. Do we respect the previous wishes of pre-dementia Margo or the best interests of current advanced dementia Margo? There seems to be an apparent tension between respecting the autonomy (i.e., respecting the advance directive of pre-dementia Margo) and beneficence (i.e., ignoring the advance directive so that advanced dementia Margo can continue to enjoy the pleasures of her blissful confusion).

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[74] Dworkin, "Life's Dominion," 218-241
[75] Firlik, "Margo's Logo," 201.
[76] Dworkin, "Life's Dominion."

Dworkin's arguments begin with a focus on respect for autonomy. He begins by exploring why autonomy warrants our respect. Dworkin proposes two possible answers:

1. The *Evidentiary View* holds that we should value autonomy because each person knows what is in their best interest better than any other person.[77]
2. The *Integrity View* holds that we should value autonomy because it allows a person to express their critical values, commitments, and convictions that give their life meaning.[78]

Before discussing how Dworkin applies these two views to the autonomy of a person with dementia, it is worth taking a moment to differentiate between *experiential* and *critical* interests because these concepts play a central role in differentiating between these two views. Dworkin proposes that there are two types of interests, "*experiential interests* in the quality of our future experiences"[79] and "*critical interests* in the character and value of our lives as a whole."[80] Considerations of our experiential interests are more related to our in-the-moment enjoyment of our experience. While this is related to considerations of beneficence, it does relate to a particular person's determination of what *their* experiential interests are. In this way, experiential interests also tie in considerations of self-determination insofar as a person determines for themselves what are *their* experiential interests. Critical interests are much broader than experiential interests and require the person to consider their entire life narrative. Dworkin contends

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[77] While Dworkin does explore how the Evidentiary View could apply in cases of advance directives in advanced dementia, it is worth noting that he doubts whether we can take the Evidentiary View seriously at all. He contends that it cannot be correct because we frequently see people acting in ways that are clearly not in their best interests, yet we still allow them to make those decisions. For example, a person who continues to smoke cigarettes even though they they understand the harms and state a clear desire to quit.

[78] Dworkin, "Life's Dominion," 223-224.

[79] Dworkin, "Life's Dominion," 235.

[80] Dworkin, "Life's Dominion," 235.

that critical interests are those which give our lives' meaning and it is only by taking perspective of our life *as a whole* that we can comprehend and properly consider our critical interests. Dworkin acknowledges that both experiential and critical interests are important and would allow both categories to be considered together when we are trying to determine a person's 'best interests.' However, critical interests are given a higher standing for Dworkin, especially under the *Integrity View* of autonomy.

According to Dworkin, whether we espouse an *Evidentiary View* or an *Integrity View*, a person with advanced dementia does not have a right to autonomy. They do not have the cognitive capacity to know what is in their best interests as is central to the *Evidentiary View*. Therefore, the *Evidentiary View* does not provide justification for a right to autonomy for a person with advanced dementia. The person with advanced dementia does not have the cognitive capacity to extrapolate from their current situation to consider their critical interests, therefore, the *Integrity View* does not provide justification for a right to autonomy for a person with advanced dementia.[81]

This leads to Dworkin introducing his concept of *precedent* autonomy which proposes that we should respect the decisions a person made when they were competent as regards what to do for them when they are in a state of advanced dementia.[82] As previously mentioned, neither the *Evidentiary View* nor the *Integrity View* of autonomy can provide a right to autonomy for the person *while they are in the stages of advanced dementia*. However, the *Integrity View* can provide a right to *precedent* autonomy for the

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[81] Dworkin, "Life's Dominion," 226.
[82] Dworkin, "Life's Dominion," 226.

person drafting the advance directive.[83] This can only be overturned by a future autonomous decision. If a person still has capacity, they can overturn their previous autonomous directive. However, if they lack capacity due to advanced dementia, they cannot overturn their previous autonomous decision.

This leads to the apparent conflict between precedent autonomy and current considerations of beneficence. Typically, the Substitute Decision-Maker (SDM) for the person with advanced dementia has an expectation to maintain a happy life for that person but the directive founded on a right to precedent autonomy may dictate otherwise.[84] This leads to the apparent conflict between experiential interests and critical interests that will become central to the debate.[85] The respect for (precedent) autonomy may emphasize the critical interests while the considerations of beneficence may emphasize the current experiential interests. I return to the modified-Margo case from Chapter 1. This case draws out the tension between critical interests and experiential interests.

In our modified-Margo case, Margo is a pleasantly confused woman with advanced dementia who created an advance request for MAiD when she still had capacity. There are many reasons why she may have done this: Maybe she saw her parents suffer through advanced dementia and does not want to suffer through that same fate; maybe she has seen the burden on families that occurs when a loved one reaches the advanced stages of dementia; maybe she does not want her friends and family to have

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[83] Dworkin provide arguments to disregard the *evidentiary view* altogether in the setting of dementia. However, a full exploration of this is outside the scope of this thesis. The important factor at this stage of Dworkin's arguments is that *precedent* autonomy can find justification under at least one view.

[84] As noted earlier in this thesis, legislation has emphasized that the SDM has a primary obligation to do what is in keeping with the person's wishes and secondarily to maintain a happy. For the purposes of explaining Dworkin's arguments, I am simply focusing on the secondary expectation here.

[85] Dworkin, "Life's Dominion," 230.

their memories of her "tarnished" by her advanced dementia behaviour. Regardless of the reason, Margo has now reached a state of advanced dementia and seems to be very happy in her current life. She also has an advance request for MAiD when she reaches this stage of her disease.

The SDM for Margo may argue that she is clearly happy in her current life and should not receive MAiD so that she can continue enjoying her experiential interests such as the repeated paintings and peanut butter & jelly sandwiches. The defender of the advance request will argue that she must be provided MAiD as requested in order to uphold the critical interests that defined what brought her life meaning and value.

Dworkin argues that the critical interests take precedence in this conflict because *only* the critical interests provide value in establishing the right to *precedent* autonomy (as was determined by the *Integrity View* regarding value to autonomy). Therefore, the experiential interests that are currently being considered by the SDM should not influence the decision to respect the advance request.[86] While considerations of beneficence might point us towards allowing our modified-Margo to live and enjoy her peanut butter sandwiches, respect for autonomy should take priority. For Dworkin, the only autonomy to consider for patients with advanced dementia is *precedent* autonomy which is founded on critical interests. Therefore, from respect of autonomy we ought to respect the advance requests and provide MAiD.[87]

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[86] Dworkin, "Life's Dominion," 232.

[87] Dworkin's original arguments focused on a modified-Margo case where Margo had created an advance directive to withhold potentially life-saving therapies once she reached a stage of advanced dementia in order to hasten her death. However, he also felt his arguments would extend to withdrawing life-sustaining interventions and even MAiD. See Dworkin, "Life's Dominion," 231.

Dworkin takes this a step further and argues that we need not rely solely on respect for autonomy to push us to adhere to the advance directive. Dworkin argues that considerations of beneficence also push us to adhere to the advance request. If the SDM wishes to do what is in Margo's *true* best interests, they should give priority to Margo's critical interests over her experiential interests. As mentioned previously, Dworkin places priority on critical interests over experiential interests. Dworkin argues that it would be an error to believe that beneficence would lead us to prioritize the peanut butter & jelly sandwiches over Margo's critical interests which have given her life meaning. If we want to act from a place of beneficence, we should still respect the advance request which was drafted with critical interests in mind. For Dworkin, both beneficence and respect for autonomy ought to be guided by critical interests and therefore support the advance request. Under this Critical Interests Approach, critical interests are seen as overarching guiding concept that harmonize autonomy and beneficence in such a way that they are no longer in conflict.

Criticisms of this approach

Critics of this outcome may cite the intuitive disgust of ending Margo's happy existence. Aside from the consideration of the loss of the potential future enjoyments, there is also the potential distress she would experience during the procedure itself in terms of placing an IV and administering medications, potentially against her efforts to stop the procedure. However, we should not appeal to simple intuitive feelings when trying to develop ethical positions. For many, the image of a fetus being destroyed during a therapeutic abortion instils a similar intuitive disgust, yet we often require more sophisticated ethical arguments when approaching ethical debates surrounding abortion. We should seek similar grounds when discussing end-of-life issues.

Looking to more philosophic grounds regarding criticisms of the Critical Interests Approach, we ought to look at the grounds for the priority of the critical interests themselves. For starters, the line between critical interests and experiential interests is far from clear. Dworkin himself acknowledges this. Dworkin would readily admit that a fine-dining chef may place culinary enjoyment of fine meals as a critical interest. Yet, Margo's enjoyment of peanut butter & jelly sandwiches would be designated an experiential interest. I spent nearly a decade of my life working in restaurants and continue to place a high value on the enjoyment of a nice meal. Could I qualify this as a critical interest for me? Such meals hold an important place in my memories but don't exactly enter into my current career trajectory nor do they compare with the importance I place on my family and friends.

Dworkin and supporters of the Critical Interests Approach could counter that such concerns are simply technical nuances of the approach and do not undermine the overall approach. However, critics often point towards the priority placed on the *whole life narrative* and propose alternative for the priorities of human life. I will explore a few of these alternatives in the coming sections.

The Critical Interests Approach also relies on the *whole life narrative* as the foundation for the persistence of personal identity. In order to invoke the advance request for MAiD, the proponents of the Critical Interests Approach rely on the *whole life narrative* and associated critical interests of the pre-dementia person to hold sway over the life of the advanced dementia person. However, the metaphysics of this narrative view of personal identity have substantial problems which I will explore in depth in Chapter Four.

Best Interests Approach: Dresser

In her 1995 paper, *Dworkin on Dementia*, Rebecca Dresser provides one of the most important responses to Dworkin's Critical Interests Approach. As noted in the previous section, Dworkin argued that both the principle of autonomy and principle of beneficence favour his approach; Dresser provides philosophical arguments against both of Dworkin's claims.[88]

In her 1995 paper, Dresser borrows from work by Derek Parfit and challenges the notion of personal identity as a fixed and permanent entity. Dresser argues that after the extreme psychological changes a person undergoes in the progression to the advanced stages of dementia, they may become a different person altogether.[89] If this is the case, then the pre-dementia Margo would have no more right to create a directive regarding advanced dementia Margo than I would have to create a directive about you.[90]

While pre-dementia Margo and advanced dementia Margo may not be the same person, Dresser asserts that Margo is still a person with moral standing – by contrast, Dworkin asserted that a person with advanced dementia did not hold moral standing as a person capable of autonomous decisions and, therefore, argued that their moral standing

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[88] Dresser also provides a variety of practical arguments. However, these practical arguments do not counter Dworkin's position – rather they simply draw caution and attention to important considerations regarding the position if we were to enact it into policy. An analysis of these arguments is outside the scope of this thesis.

[89] Dresser, "Dworkin on Dementia," 35.

[90] This is a critical step in Dresser's arguments which warrants much further discussion. However, my purpose in the sub-section is to provide a summary of Dresser's approach. Despite the importance of this step in her arguments, Dresser does not provide an in-depth analysis of persistence of personal identity nor provide arguments directly against Dworkin's assumption of a narrative view of personal identity. As I will discuss at the close of this chapter, the central tension between Dworkin and the various responses to Dworkin surrounds a lack of resolution of this issue.

was like a person in a vegetative state.[91] Dresser argues that an advanced dementia Margo still has sentience and therefore a moral standing that should lead us to protect Margo.[92] Given that Margo cannot express her wishes regarding life-or-death decisions under standard assessments of capacity, Dresser argues we ought to look to her current *best interests*.[93] By challenging the notion that pre-dementia Margo and advanced dementia Margo are the same person and also asserting that advanced dementia Margo holds moral standing as a person, Dresser challenges Dworkin's arguments regarding autonomy.

Dresser also provides complementary arguments against Dworkin's position on beneficence by challenging the priority placed on critical interests as derived from our whole life narrative. Dresser points out that Dworkin provides no empirical evidence to show that people *actually* put priority on the whole life narrative. To the contrary, Dresser argues that most people take life one day at a time rather than focusing their decisions on their whole life narrative.[94] She also points out the fuzzy line between critical and experiential interests and highlights that many of the critical projects that people undertake, are undertaken for the experiential interests that those projects will provide.[95] For example, many people, who are not professional musicians, place high importance on music and go to great measures to attend live concerts or music festivals.

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[91] Dworkin, "Life's Dominion," 228.

[92] Dresser points to arguments Dworkin makes regarding the connection between sentience and moral standing in other parts of his book, *Life's Dominion*. In Chapter 2 of *Life's Dominion* Dworkin has argued that abortion should be greatly limited once the fetus has developed to a point where it can achieve sentience (which Dresser and Dworkin attribute to being roughly around viability). When discussing abortion, Dworkin argues that the sanctity of life derives from our sentience and therefore provides the increased moral standing of the fetus once it can achieve sentience.

[93] Dresser, "Dworkin on Dementia," 36-37

[94] Dresser, "Dworkin on Dementia," 36.

[95] Dresser, "Dworkin on Dementia," 35-36.

Is the experience of such live performances to be regarded as a critical or experiential interest. Being a parent fits quite prominently in my life narrative, however, even in the absence of a life narrative, time spent with my children is of high value. Dworkin's definitions of critical and experiential interests do not provide a clear boundary between the two. Taken as a whole, these arguments challenge Dworkin's assertion that critical interests should guide considerations of beneficence. For Dresser, beneficence ought to be guided by the current *best interests* of the person who is currently in front of us.

Applying the Best Interests Approach to Modified-Margo

Under Dresser's approach, given that Margo still has enjoyment and apparent interest in her day-to-day activities, decisions should be made placing priority on her current best interests. It seems that Margo has an interest in continuing to listen to repeated songs, and eating peanut butter & jelly sandwiches. While these are experiential interests, they are her current best interests. To fulfil these interests, Margo must go on living. Therefore, we ought to disregard the advance request for MAiD.

It is worth noting that this approach acknowledges that denying the advance request is denying an autonomous decision that was made by pre-dementia Margo. That decision was made by the then-current-best-interests of pre-dementia Margo. However, denial of those interests in favour of these interests is logically consistent because the Best Interests Approach assumes that pre-dementia Margo and advanced-dementia Margo may be different people. Dresser contends that we are not denying the then-current-best-interests of pre-dementia Margo (who wanted MAiD for herself if she had advanced dementia) because that Margo no longer exists, therefore, there is no way to fulfil this wish. We can only consider the current Margo who has her own best interests distinct from those of the pre-dementia Margo.

Criticisms of this approach

If the current best interests of the individual should take priority, why not respect the decisions of persons who are intoxicated, delirious, or impaired by mental health conditions? A proponent of the Best Interests Approach may argue that, when impaired in these ways, a person can not make a decision in their best interests. However, opponents of the Best Interests Approach will ask the proponents to explain why a person impaired by dementia can determine their best interests, but a person impaired by alcohol cannot. We commonly feel that requests made when intoxicated do not get to a person's *true* wishes. Similarly, a person in the midst of an acute, clinical depression, who has never before espoused an interest in suicide, would be prevented from attempting suicide until such time that we could ascertain the depth of their wish to end their lives.[96] In Chapter 4, I will explore these arguments in more detail.

In a similar vein, proponents of this approach need to differentiate between the best interests of the person with advanced dementia and the best interests of a child. We would deny the child the right to follow their self-declared best interests to eat cake for every meal. We make decisions for children based on the larger life trajectory we anticipate they will follow rather than the best interests they assert for themselves in the moment. We take a paternalistic approach with children because we believe they are not competent to make decisions for themselves with considerations beyond the moment in

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[96] Please note, this example is as regards an acute depression and fluctuating desire to end one's life. This is not meant to indicate that people with depression are incapable of making decisions to end their lives.

question or, at least, not considering a long enough life trajectory. Why not apply the same standard for persons with advanced dementia.

Finally, there is an important metaphysical implication from the Best Interests approach: The Best Interests approach is built on the belief that the person with advanced dementia is a different person from the person who drafted the advance directive. Proponents of the Best Interests Approach ought to define how and when this difference occurs: At what point does the person become a different person? Is it an issue of loss of their personal life narrative? A change in personality? At what point do they change enough to say they are a different person? We will explore these questions in more detail in Chapter 4

Values-Based Approach: Jaworska

In her 1999 article, *Respecting the Margins of Agency*, Agniesza Jaworska provides an alternative to Dresser and Dworkin's approaches. Like Dresser, Jaworska focuses on the current interests of persons with dementia but for different reasons. Whereas Dresser focuses on the experiential interests of the current person, Jaworska focuses on their current *values*. For Jaworska, so long as a person is capable of having *values* (i.e., they are a *valuer*), they have capacity for autonomy and therefore maintain authority regarding their well-being. Jaworska contends that a person with dementia will maintain their capacity to *value* even after they may have lost their ability to consider their whole life narrative. Therefore, there will be a portion of people with dementia who may have autonomy per Jaworska but not have autonomy per Dworkin.

Jaworska challenges Dworkin's position on two fronts: Her 'reconceiving well-being' arguments target Dworkin's arguments regarding beneficence and her 'rethinking autonomy' arguments target Dworkin's arguments regarding autonomy. [97]

Reconceiving Well-Being

In terms of reconceiving well-being, Jaworska accepts Dworkin's prioritization of critical interests over experiential and critical interests; however, she defines critical interests differently from Dworkin.[98] Jaworska argues that critical interests need not make reference to our whole life narrative. Rather, critical interests ought to reference what we *value* as good.[99] However, defining what counts as a *value* (and not merely an experience) is hard to tease apart. While it may seem intuitive that *values* are distinct from simple physical pleasures, cravings, and desires, drawing the defining lines is quite difficult. Jaworska acknowledges the difficulty in defining her conception of *values* but does provide three aspects which she feels helps capture her concept of *values*:

1) The person feels that they are correct to want what they want,
2) The want is tied up in the person's sense of self-worth,
3) This want is independent of their personal experience.[100,101]

Jaworska points to real-life cases where a patient with dementia makes a decision that seems to be clearly dependent on a *value,* yet the patient is unable to consider their whole life narrative. Jaworska cites examples of a people with dementia who have lost the grasp of their life narrative yet continue to participate voluntarily in research studies

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[97] Jaworska, "Respecting the Margins of Agency," 109-110.
[98] Jaworska, "Respecting the Margins of Agency," 110.
[99] Jaworska, "Respecting the Margins of Agency," 113-114.
[100] Jaworska, "Respecting the Margins of Agency," 116.
[101] It is worth noting that the classic Margo example may not have the capacity to *value* as defined by these criteria provided by Jaworska.

and can also provide their rationale for doing so in a way that articulates the *value* of how research may benefit others.[102] Jaworska notes a specific example of a patient who could only just grasp that the research study was different from the other recreational activities he was participating in. Yet, the patient was able to communicate that he felt much more engaged in the research study activities because he grasped there was some larger purpose. As the patient put it "I feel that this is a real good, big project, and I'm sure you do too. This project is a sort of scientific thing."[103] Jaworska argues that this person is expressing a *value* that supports their critical interest in participating in this study even though the person was no longer capable of understanding how such an interest would be relevant to their whole life narrative.

Jaworska notes that a person with dementia need not place value on higher-order concepts like the importance of science and research. A person may place *value* on simpler pleasures and living in the moment. Critical interests and experiential interests need not be a dichotomy. Critical interests can be focused on experiential interests. According to Jaworska, many patients with dementia may maintain *value*, and therefore critical interest, in the simple pleasures of day-to-day life.[104,105] By reconceiving well-being to focus on *values* rather than the whole life narrative, Jaworska aims to undermine Dworkin's assertion that prioritizing a patient's critical interests best respects the principle of beneficence in the setting of advanced dementia.

Rethinking Autonomy

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[102] Jaworska, "Respecting the Margins of Agency," 118.
[103] Jaworska, "Respecting the Margins of Agency," 118.
[104] Jaworska, "Respecting the Margins of Agency," 120.
[105] For Jaworska, having the ability to *value* indicates a person has capacity for making their own decisions and therefore their autonomy ought to be respected. This is a very controversial claim as it challenges the standard if comparative decision-making capacity as laid out in Chapter 1.

Dworkin argued that the only way to respect a person's autonomy was to respect their previous ability to make autonomous decisions (i.e., their precedent autonomy). If those previous decisions are currently satisfiable and the person is now in a state of advanced dementia, then we ought to respect those previous decisions because the person no longer has capacity for autonomy. However, Jaworska proposes that the person with dementia may maintain some capacity for autonomy even if they cannot see how their decisions fit into their larger life narrative or even know how to effectively enact those values. Jaworska provides the example of a person with dementia who *values* their independence yet is not aware of what functions they are capable of doing independently. The person's family may recognize the *value* the person with dementia places on independence and helps to structure their day-to-day life to maximize their independence. In such a way, Jaworska believes the family is respecting the individual's autonomy.[106]

These arguments would suggest that Dworkin's approach only considers the margins between full autonomy and the initial stages of diminishing autonomy. Jaworska would argue that Dworkin's approach is not actually getting at the essential aspects of the capacity for autonomy. Jaworska does not see autonomy as an all-or-none phenomenon. Higher cognitive faculties that would allow us to also assess our *values*, place them under critical scrutiny, and revise them after careful evaluation, would provide a more robust level of autonomy. The capacity to *value* is the minimal requirement, in her view, on what is needed for the most basic capacity for autonomy. However, importantly for Jaworska, the capacity to *value* does render a person capable of autonomy.[107]

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[106] Note, this respects autonomy as Jaworska is defining it. This definition of autonomy and capacity differs from standard medical capacity assessments. This will be discussed later in the chapter.

[107] Jaworska, "Respecting the Margins of Agency," 130.

Jaworska notes that in order to respect the contemporaneous autonomy of a person with dementia, caregivers will need to take measures to enhance their autonomy.[108] Such measures, often-referred to as supported decision-making, have been described by other authors in the disability literature and there has been a recent emphasis on bringing this approach to patients with dynamic impairments such as Alzheimer's dementia.[109] Under supported decision-making models, an individual whose decision-making capacity is expected to diminish enters an agreement with a support-person or network of supporters who agree to support the person with diminishing capacity to make their own informed decisions. These supporters can then act as cognitive prostheses for the person with diminished capacity. They may take written notes at medical appointments or may assist in simplifying complex conversations in a way that they know will be familiar to the patient.[110,111] Such supported decision-making models would be complementary to helping determine the contemporaneous *values* of a person with dementia in a way to help support Jaworska's Values-Based Approach.[112,113]

For most cases, Jaworska and Dworkin are likely to agree. At the early stages of dementia, a patient is likely able to both express their *values* and be able to consider their whole life narrative. Likewise, at the end-stages of dementia, a patient is unlikely to express *values* as conceived by Jaworska, nor be able to consider their whole life

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[108] Jaworska, "Respecting the Margins of Agency," 133-134.

[109] Peterson, Karlawish & Largent, "Supported Decision Making With People at the Margins of Autonomy," 4-5.

[110] Peterson, Karlawish& Largent, "Supported Decision Making With People at the Margins of Autonomy."

[111] Appelbaum& Trachsel "The Doctrine of Informed Consent Doesn't Need Modification for Supported Decision Making," 28.

[112] Jaworska Chiong, "Supported Decision-Making for People with Dementia Should Focus on Their Values."

[113] Veit et al, "Evaluating Tradeoffs between Autonomy and Wellbeing in Supported Decision Making."

narrative.[114] However, teasing out this fuzzy middle ground between moderate to advanced dementia is where the tension lies between Jaworska's values and Dworkin's emphasis on whole life narratives.[115] Within this middle ground between moderate to advanced dementia, there could easily arise conflict between previously made advance directives and current conflicting *values*. The advance directive may have been drafted when the person was capable of a higher-level of robust autonomy but may be in direct conflict to the person with dementia's current *values*. Therefore, their previous robust autonomy conflicts with the contemporary more limited autonomy.

It is important to note that this 'limited autonomy' challenges the standard model of comparative decision-making capacity (DMC) as described in Chapter 1. Comparative DMC requires the higher-level cognitive abilities often associated with higher-level autonomy. When Jaworska is arguing that the capacity to *value* provides a degree of autonomy (albeit minimal), she is challenging the priority placed on comparative DMC. Jaworska is not alone this challenge. Navin, Brummett, and Wasserman have argued that in the absence of comparative DMC, patients may still have capacity to refuse treatment. Specifically, these authors describe two ways a patient could have capacity for refusal of treatment even if they do not meet the traditional criteria for capacity as defined by comparative DMC: burdens-based refusals and goals-based refusals. A patient may have

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[114] Jaworska, "Respecting the Margins of Agency," 134-135.

[115] Jaworska readily admits that her proposal does not lead to a simple method to determine how to act on a person with dementia's behalf. Recognition of the capacity for autonomy as deriving from a capacity for *values* raises many difficult conflicts. Merely looking at contemporary values can lead to conflicts. A person with dementia may want to avoid bathing and dressing and *value* their ability to make their own decisions in that regard. They may also *value* the time spent with grandchildren who may not visit if the person with dementia is dishevelled and smells bad. Therefore, there is a clear conflict in *values* that the person with dementia may have lost the capacity to balance. According to Jaworska, we must do our best to respect these *values* and balance them out on their behalf. This draws in further questions and potential criticisms regarding Jaworska's conceptualization of autonomy, some of which are beyond the scope of this project, some of which will enter the discussion in Chapter 4.

an overriding objection to a burden involved in all possible treatments (e.g., the burden of being alive and subjected to medical interventions), or an important goal may not be possible if the patient underwent any of the possible treatments (i.e., the goal to be at home). The patient may lack the cognitive capacity to compare all potential treatments but still be able to express their decision to avoid a specific burden at all costs or prioritize a specific goal despite any consequences.[116] A full analysis of the alternatives to comparative DMC is beyond the scope of this thesis. My goal in this paragraph is to highlight that the standard definition of capacity is not universally accepted and is open to critique. Jaworska argues that a person may lack the higher-cognitive abilities needed for comparative DMC and yet still have capacity for (limited) decision-making so long as they are capable of *valuing*.

Jaworska notes that this scenario is very different from the scenario where an advance directive exists for a person who no longer has consciousness. In this scenario where the patient no longer has consciousness, there is no current person with *values* or any agency whatsoever. Therefore, the previous autonomy has no current autonomy to contend with. However, if we are to assert that a person with dementia, who is a *valuer*, has autonomy then we find ourselves in a different position. Jaworska likens this to a “Ulysses” contract. While she does not come down with a clear answer as to how to contend with this scenario, she does argue that we should see this in a similar vein as we might see a person who, foreseeing their later weakness of will or change in character,

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[116] Navin, Brummett & Wasserman. "Three Kinds of Decision-Making Capacity for Refusing Medical Interventions," 1-3.

decides to make a contract with another person to counter their future decisions.[117] This is an important point, which I will discuss further in Chapter 4 and 5.

In summary, Jaworska argues that her *values* can be used as an overarching guiding concept for both beneficence and autonomy. Jaworska asks us to reconceive of well-being such that our considerations of beneficence for a patient be founded on *values* as defined by that current patient. According to Jaworksa, our best interests are those we *value*, not critical interests reflective of our whole life narrative. She also asks us to rethink autonomy such that a patient could be considered to have autonomy so long as they have capacity for *valuing*. This line of argumentation is meant to counter Dworkin's arguments regarding *precedent* autonomy. For Dworkin, critical interests should be the overarching guiding concept for both autonomy and beneficence. For Jaworska, *values* should be the overarching guiding concept for considerations of autonomy and beneficence.[118]

Applying the Values-Based Approach to Modified-Margo

By standard medical capacity assessments, Margo would be deemed incompetent to make a decision regarding MAiD. This would be in line with the Critical Interests Approach which contends that she does not have autonomy because she can not appreciate her whole life narrative. However, under the Values-Based Approach, autonomy may still exist so long as a person is a *valuer*. Margo may lack the ability to reflect on her whole life narrative but still possess *values*. While Margo's ability to communicate her *values* is obviously quite limited, we can work with her through

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[117] Jaworska, "Respecting the Margins of Agency," 136-138.
[118] Throughout this thesis, I will use the italicized *values* when referring to *values* as defined by Jaworska. When using the term value in the more general sense, I will not italicize the word.

supported decision-making to determine if she has *values*. This would assist us in determining whether to uphold the advance request for MAiD.

After careful and deliberate inquiry, we may determine that Margo has embraced a *value* for the simple pleasures in life. While the day-to-day pleasures that she enjoys on their own would be characterized as experiential interests, she may have a second-order *value* on a life that appreciates the experiential interests that life has to offer. She may communicate this by saying that life's primary meaning is enjoying the simple pleasures in life or some similar endorsement of this principle. She may also relay that she *values* herself because she is a person who can appreciate the simple pleasures in life. In these ways, she is expressing a *value* in a way that provides her a degree of autonomy under the Values-Based Approach. As such, she has capacity for decisions based on these *values*. If we wish to respect her current capacity for autonomy, we must attempt to make decisions for her in light her current *values*. Her ability for self-determination is reliant on her capacity for *values*. If we feel she is a *valuer* and the advance request for MAiD is not in line with her current *values*, then we should overturn the advance directive.

By contrast, it could also be the case that Margo is simply enjoying her repeated songs and peanut butter & jelly sandwiches as mere experiential interests with no evidence of her *valuing* these experiential interests (e.g., she does not communicate a second-order preference for these experiential interests or meet the other criteria for *value* as laid out by Jaworska). If this is the case, she may lack any capacity for autonomy and therefore cannot overturn the advance request and, therefore, MAiD should be provided.

Criticisms of this approach

Much as the Critical Interests Approach faced criticism due to the fuzzy boundary between critical and experiential interests, it is difficult to ascertain the boundary of what counts as a *value*. As seen in this case, it is difficult to ascertain when Margo is simply enjoying experiential interests and when she *values* enjoying her experiential interests. Likewise, in the scenarios described by Jaworska where a person with advanced dementia was expressing a *value* for research when participating in a study, it would be hard to tease out if they truly have a *value* in the research versus when they are enjoying the feeling on being part of something that feels important. The boundary between *value* and experiential enjoyment seems tricky to parse.

Like Dresser, Jaworska's approach endorses indeterminacy of persistence of personal identity. This is a controversial claim. The question of persistence of personal identity will be the primary subject of Chapter 4.

The Authenticity Approach: Carter

In her 2022 article, *Advance Directives*, Matilda Carter proposes an approach that is similar to Jaworska's Values-Based Approach with some important differences. To introduce her position, she highlights the tension at play between respect for autonomy and beneficence in cases like our modified-Margo. If a patient has only temporarily lost capacity (e.g., they are in a state of delirium due to sepsis or lost consciousness temporarily due to intoxication) we will invoke respect for autonomy and attempt to make treatment decisions based on what the person would have wanted – respect for autonomy is paramount. If the person has never had capacity for autonomy (they were born with a severe congenital cognitive disability) then we do what we believe is in their best interests – we rely on beneficence. In keeping with the previous debate, Carter notes that cases like those of modified-Margo create a special tension between these principles as it is not as clear whether autonomy or beneficence should play the central role.[119]

As mentioned previously, Dworkin, Dresser and Jaworska attempt to sidestep this tension by pointing to an overarching concept that guides both autonomy and beneficence (i.e., critical interests, best interests, or *values*). Carter similarly believes that her proposed *principle of authenticity* invokes both respect for autonomy and beneficence and therefore sidesteps this tension:

> "I argue that there need be only one principle in substitute decision-making: that of determining authenticity. This principle favours a substituted judgment standard in all cases and instructs decision-makers to determine what the patient would authentically prefer to happen—not merely in light of their past decisions but also in light of their present settled dispositions."[120]

She refers to this approach as the principle of determining authenticity; however, I will refer to this as the Authenticity Approach within this thesis. In defence of this Authenticity Approach, Carter argues that people with advanced dementia still retain the potential to generate a present state of character and dispositions and therefore are still able to make autonomous decisions.[121] This character and disposition can still reflect values[122] and interests that are deeper than experiential interests. Dworkin would counter and contend that such values and interests are not reflective of critical interests because the person is not capable of critical reflection over the entirety of their life. In the same vein as Jaworska and Dresser, Carter points out that our values and interests regularly

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[119] Carter, "Advance Directives," 32-33.
[120] Carter, "Advance Directives," 33.
[121] Carter, "Advance Directives," 35.
[122] Recall, that I will italicize the word *value* when it refers to Jaworska's concept. It is not italicized here as Carter is using value in the more general fashion and not the specific concept described by Jaworska.

change as our life changes and our understanding of our life narrative may be very different from one age to another.[123] However, these values and interests will be stable and consistent at any given age. Carter argues that we need to determine what these values, interests, goals, preferences, and commitments are for the current person we are working with. Borrowing from John Christman, Carter states, "authentic mental elements are those that a person would not deeply repudiate upon a hypothetical or actual reflection over a variety of circumstances."[124] If the advance directive is not aligned with these 'authentic mental elements', Carter proposes the advance directive may be defeasible.[125]

Carter brings in the concept of *Authenticity as nonalienation* to help outline when an advance directive may be defeasible. An advance directive is defeasible if it alienates the current person's authentic self as defined by their settled disposition as regards their values, interests, goals, preferences, and commitments. Overturning the advance directive when it alienates the patient's current authentic self, respects the patient's right to self-determination. In this way, her position is quite similar to Jaworska's values-based approach.[126]

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[123] Carter, "Advance Directives," 36.

[124] Carter, "Advance Directives," 37.

[125] It is worth noting that Christman proposes that autonomy requires both authenticity and competence and Christman's requirements for competence seem to be higher than would be achieved by cases of patients with advanced dementia – Christman, "The Politics of Persons," 155.

[126] It is worth teasing out a subtle nuance in Carter's approach. Carter does not ground her position on a respect for autonomy, per se. Rather it is a respect for authenticity. According to Carter, respect for autonomy calls on us to respect a freedom from interference. If a smoker decides they want to continue to smoke cigarettes despites it being terrible for their health, I respect their autonomy and do not interfere with their smoking cigarettes. However, Carter wishes to ground respect for authenticity in the idea of freedom from nondomination: a person is free as long as, "they are not exposed to the arbitrary will of another." In this concept of freedom, interference is allowed so long as it tracks a person's own authentic interests. See Carter, "Advance Directives," 38.

This approach does not require that we reject advance directives simply because a person has developed advanced dementia. Instead, they can be an important source of information as we try to determine the authentic preferences of the current person with advanced dementia. However, if we see other contemporary evidence that indicates that the preferences expressed in the advance directive are no longer authentic then the advance directive could be seen as defeasible. As such, the more information and context that can be provided in the advance directive, the better it can assist us in determining whether the advance directive remains authentic to the person with advanced dementia.[127] To summarize Carter's approach:

> "The principle of determining authenticity is intended to replace respect for autonomy and beneficence as the standard for substitute decision-making. To adhere to it, the decision-maker must consider all evidence of values and preferences they have, including the advance directive and any more recent information that contradicts it, to construct a set of preferences that can be deemed authentic, in the sense of being nonalienating."[128]

In keeping with Dworkin, Dresser, and Jaworska, Carter proposes an overarching concept (i.e., *authenticity*) that will overcome the tension between beneficence and autonomy and provide guidance when considering advance directives in the setting of dementia.

Applying the Authenticity Approach to Modified-Margo

The Authenticity Approach seeks to ensure that the advance request does not alienate the current person's authentic self. In the current case regarding Margo, we would hope that the advance request provided some context behind pre-dementia

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[127] Carter, "Advance Directives," 39.
[128] Carter, "Advance Directives," 40.

Margo's decision to draft the request for MAiD. This would help us determine if the advance request remains valid for current advanced dementia Margo. If the advance request for MAiD was a drafted because Margo believed that a person could not possibly be happy when she had advanced dementia, then the advance request would not hold. Current Margo is clearly someone who is living a happy life and her authentic self is in keeping with the belief that a person with advanced dementia can live a happy life. Therefore, that belief expressed in pre-dementia Margo's decision to draft an advance request for MAiD alienates advanced dementia Margo's current self and that advance request should be overturned.

We could add in some extra features to the case to show how an advance request for MAiD may still hold under the Authenticity Approach. Let's imagine the advance request for MAiD was drafted because pre-dementia Margo did not want to be a burden on her family once she had advanced dementia. She acknowledged that a person with advanced dementia may enjoy the simple things in life, but such enjoyments are trivial to her compared to the thought of being a burden on her family. Now, as Margo is moving from the moderate to advanced stages of dementia, Margo's family members find themselves incredibly busy with Margo's care. They don't mind caring for her, but Margo is clearly upset whenever they attempt to assist her with cleaning herself, toileting, or getting dressed. She constantly notes that she does not want to be such a bother. She enjoys her books and sandwiches, but she is clearly upset whenever her family must help her with such tasks. However, she also realizes she needs assistance and does not want to be left unclean or dishevelled. In such a scenario, the advance request for MAiD may very well be in keeping with Margo's authentic self and should be upheld.

Criticisms of this approach

Understanding what counts as 'authentic' will face similar challenges as what will count as a *value* or what will count as a critical interest. Further, why the present authentic preferences, values, and desires warrant priority will face similar criticisms as to why the current bests interests of the Best Interests Approach warrant priority. The Authenticity Approach seeks to call on the consistent preferences, values, and desires of the current person with advanced dementia. However, the Critical Interests Approach attempted to do the same thing on a larger scale – consistency over the lifetime. If consistency is the measure to determine authenticity, then why not draw that out over a larger range of consistency and pull in the whole life narrative. Even if Carter's *Authenticity Approach* can be applied to specified "just right" timeframe (i.e., not as short as mere experiential interests but not as long as critical interests), the approach still faces the challenge of determining why it would be applied only in the setting of dementia and not to children or situations of intoxication, mental health conditions, or delirium. Carter does provide arguments to border off her approach to just dementia, however, I believe these arguments are not successful. A full exploration of these arguments will be provided in Chapter 4.

Common Themes within the Approaches

Among this array of conflicting perspectives, there are two important common themes that emerge:

1. All authors propose an overarching guiding concept that can overcome the tension between autonomy and beneficence when considering advance directives in the setting of dementia;[129] and,
2. These overarching guiding concepts are focused on the subjective perspective of the patient: They are focused on both determining what that person would choose for themselves (autonomy), and what would be the greatest benefit for the person based their self-determined interests, preferences, or values (beneficence). There is a consistent attempt to take on the self-perspective of the patient themselves.

There is conflict about *who is the self* that gets to make those choices and determine what they value, and disagreement about which decisions are most true to that *self*. However, there seems to be general agreement that we are trying to get at the choices that the person would make and what that person would consider to be their most important interests – even if the authors can't agree who the relevant person really is.

Specifically, Dworkin argues that our autonomy relies on our ability to consider our critical interest and argues that considerations of beneficence ought to prioritize those critical interests. Critical interests are determined by the person themselves when they consider their whole life narrative. Dresser focuses on what the current person with dementia would consider to be their most important interests. While she disagrees on who gets to determine which are the most important interests (the pre-dementia person or the advanced dementia person), both she and Dworkin emphasize the importance of the

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[129] It could be argued that the authors are not truly harmonizing the tension with an overarching guiding concept. Rather, the authors may be prioritizing autonomy over beneficence. I do believe there is merit to this line of argumentation. However, in the authors' writing they do seem to see their arguments as harmonizing this tension rather than simply prioritizing autonomy over beneficence. For the purposes of this thesis, I will grant them the benefit of the doubt and reference their overarching guiding concept as harmonizing this tension

interests determined by the person of relevant moral standing. Jaworksa provides an emphasis on *values* underlying considerations of autonomy and beneficence. The *values* are those determined by the *valuer* themselves. Carter proposes that her principle of authenticity can guide both autonomy and beneficence. This Authenticity Approach focuses on the *person's* values, preferences, and goals to ensure that they are in keeping with the advance directive. If the advance directive alienates their current authentic self, then the advance directive is defeasible. Dworkin's critical interests, Dresser's best interests, Jaworska's *values*, and Carter's authentic self, are all concepts that attempt to harmonize beneficence and autonomy. Further, these concepts all focus on the choices the person would make for *themselves* and what the person would determine are *their* values, preferences, or goals.

When trying to bring autonomy in line with their overarching guiding concept, the authors will all declare that we ought to respect the person's ability to choose for themselves. However, they disagree about whether the morally relevant person is the pre-dementia person or the advanced dementia person. Amongst those authors that propose that the advanced dementia person is the morally relevant person, there is subtle disagreement about how we determine what that person's choices would be. However, all agree that we ought to respect the choices that the morally relevant person would make for themselves.

When trying to bring beneficence in line with their overarching guiding concept, the authors will declare that we ought to maximize the appropriate interests, values, or preferences of the person as determined by the person. None of the authors propose that we ought to consider some objective assessment of interests, values, or preferences (i.e., no author is suggesting doing a third person perspective calculus of pleasure and pain). The authors may disagree whether we should consider the interests, values, and preferences of the pre-dementia person or the advanced dementia person. Amongst those authors that propose that the advanced dementia person is the morally relevant person, there is disagreement about which interests, values, or preferences should be maximized. However, all authors agree that the person *themselves* determines which interests, values, or preferences are most important for them.

Collectively, I would consider this a focus on self-determination: Self-determination as regards choices and self-determination of interests, values, or preferences. I recognize that self-determination is usually used synonymously with autonomy. The principle of autonomy is usually invoked in defence of a person's right to choose for themselves. While these authors want to respect a person's right to choose for themselves, they are also suggesting that we ought to try to maximize a person's interests, values, and preferences when they can no longer choose for themselves. However, in doing so, we ought to maximize on the interests, values, and preferences that that person had determined were most important for themselves. The maximization is still based on self-determination, however, this focus on beneficence-based self-determination is not as focused on *choice* in the way that the principle of autonomy is typically invoked.[130] Despite the usual practice of using autonomy and self-determination synonymously, I will use them in a slightly different fashion moving forward in this thesis. When using autonomy, I will be referring to the usual use of the term as regards a person's right to

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[130] Once could argue that the strategy these authors are using to harmonize autonomy and beneficence is simply bringing beneficence under autonomy. A full exploration of this argument would require an in-depth exploration of the concept of autonomy which is beyond the scope of this thesis.

choose for themselves. When using self-determination, I will be capturing both a person making their own choices and a person's self-determined interests, values, and goals.

One final common thread is worth noting: None of these approaches deny advance requests for MAiD altogether. Dresser, Jaworska, and Carter all propose cautions against Dworkin's endorsement of advance requests for MAiD. However, these cautions will still permit advance requests for MAiD so long as the relevant features of the case are conducive to upholding the advance request. If a person's current best interests, *values*, or authentic self are still in line with the advance request, then the advance request holds, and MAiD would be permitted. As such, there is no approach that denies advance requests for MAiD simply because advance requests for MAiD should not exist. Rather, the approaches all aim to determine how we should institute such advance requests. As such, I will not enter any ethical arguments in favour of advance requests overall. Rather, I will focus my discussion to *how* such advance requests ought to be implemented.

Chapter Summary

In this chapter, I reviewed the literature on advance directives for life-or-death decisions in the setting of dementia. Dworkin's Critical Interests Approach is generally supportive of upholding advance requests for MAiD or advance directives that would hasten death even in the modified-Margo case from Chapter 1. Dresser's Best Interests Approach, Jaworska's Values-Based Approach, and Carter's Authenticity Approach generally deny advance requests for MAiD or advance directives that would hasten death in cases like our modified-Margo case. Dresser, Jaworska, and Carter point to different overarching guiding concepts with their approaches, however, they all agree that the morally relevant person is the current advanced dementia Margo. By contrast, Dworkin believes the morally relevant person is pre-dementia Margo who drafted the advance request. An exploration of this tension will be the central focus of the next two chapters.

Despite the disagreement on whether to respect the advance request for MAiD, all authors utilize a similar strategy when facing the apparent tension between autonomy and beneficence in the modified-Margo case. All authors point to some overarching guiding concept that can harmonize beneficence and autonomy (critical interests, best interests, *values*, or authenticity). It is also worth noting that all these overarching guiding concepts place priority on *self-determination:* Self-determined choices and self-determined interests, values, or preferences. The primary tension between Dworkin and the other authors lies in determining which *self* ought to be making choices and which self ought to be determining which interests, values, or preferences are most important. This disagreement about which *self* is morally relevant is founded in a disagreement on the metaphysical foundations of persistence of personal identity. In the next chapter, I will explore the competing views of persistence of personal identity in the hopes of providing a deeper understanding of this tension.

Chapter 4

In Chapter 3, I described various approaches to advance directives/requests for life-or-death decisions. Specifically, I provided a summary of Dworkin's Critical Interests Approach, Dresser's Best Interests Approach, Jaworska's Values-Based Approach, and Carter's Authenticity Approach. I noted some common themes between these approaches. These approaches note the apparent tension between autonomy and beneficence when considering advance directives/requests for life-or-death decisions for patients with advanced dementia. To overcome this apparent tension, these approaches tend to point toward some overarching guiding concept that helps overcome the tension such as critical interests for Dworkin or authenticity for Carter. In all approaches, the overarching guiding concept emphasizes *self-determination*[131] as a paramount consideration. Even when recognizing considerations of beneficence, the authors focus on how the patient would define best interests *for themselves* - as opposed to best interests in a more general sense from the perspective of an objective observer.

At the close of Chapter 3, I noted that the primary tension between these authors lies in their approach to personal identity. On one side, Dworkin argues that our life narrative creates a foundation for persistence of personal identity. On the other side, Dresser, Jaworska, and Carter follow Parfit's account of personal identity and note that personal identity is indeterminate and therefore may not persist in some cases of advanced dementia. They claim that if personal identity is not persistent, then the pre-dementia person's advance request may not hold for the advanced dementia person

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[131] Recall, I am using self-determination to collectively capture both the normal use of the term (e.g., autonomy, choosing for oneself), and the strategy of prioritizing self-determined interests, values, and preferences when considering beneficence.

because they are not necessarily the same person. According to Dresser, Jaworksa, and Carter, even if an advance request exists, we must take measures to ensure that the current advanced dementia person would want the advance request to be enacted even if they lack capacity under the standard medical model of comparative decision-making. For Dresser, we ought to look at their current best interests, for Jaworska we ought to look at their current *values*, for Carter we ought to look to their current authentic self. While these authors all point towards a slightly different factor to determine if the current advanced dementia person would want the advanced request enacted, they all rely on an interpretation of indeterminacy of identity that emphasizes the current person's wishes. From here on, I will call this interpretation to personal identity the D-J-C interpretation of personal identity. While their approaches are different, the underlying interpretation of personal identity is the same for all three approaches.

In this chapter, I will first explore Dworkin's narrative view of personal identity and argue that it does not provide sufficient metaphysical grounds for persistence of personal identity. In the second section of this chapter, I will provide a summary of Parfit's work on personal identity and draw out some conclusions from this work that are of special relevance to advance requests for MAiD. I will then explore the D-J-C interpretation of personal identity. I will argue that the approaches of Dresser, Jaworksa and Carter fail because they rely on an interpretation of personal identity that endorses the extreme claim described by Parfit. In Chapter 5, I will propose an approach to advance requests for MAiD that relies on the moderate claim described by Parfit.

Dworkin's Narrative View of Personal Identity

Personal identity poses several important questions for philosophy of mind. The personhood question asks, "What does it mean to be a *person*?" The characterization question asks, "Who am I?" The evidence question asks, "What evidence supports you being the same person?" While these are all important questions that touch on the project at hand, the most relevant is the persistence question which asks, "What maintains your persistence as the same being over time?"[132] The debate surrounding advance requests for MAiD centres around scenarios like our modified-Margo case, and I believe the resolution to that debate resides in the persistence question. If pre-dementia Margo who drafted the advance request for MAiD is the same person as advanced dementia Margo, it is far easier to argue in favor of the advance request for MAiD. However, if personal identity is indeterminate and Alzheimer's dementia provides sufficient change to personal identity such that pre-dementia Margo and advanced dementia Margo ought to be considered different people then it becomes much harder to argue in favor of the advance request for MAiD.

I believe a link does exist that can provide grounds for the advance request to hold, and this link is overlooked in the D-J-C interpretation of personal identity. The link that I will describe has similar metaphysical foundations as the D-J-C interpretation and avoids the metaphysical problems that Dworkin's approach. However, prior to

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[132] Note that the evidence question asks what evidence can be provided to show a being persists, while the persistence question examines the very nature of the persistence: I may persist and still not be able to provide evidence to support that persistence. The personhood question asks what it means to be a person, but the persistence question need not be contained to being a person: I may persist as a being and no longer be a *person*. The characterization question is most closely linked to the persistence question as the very nature of "Who I am?" likely needs to be answered to understand how I could persist. A full exploration of these important questions is beyond the scope of this paper. I introduce them here to acknowledge their importance and existence. However, the persistence question will be the only question regarding personal identity that I will examine in detail.

constructing my arguments in defence of this claim, I will first provide a summary of the most common approaches to answering the persistence question. There are three categories of answers to the persistence question that are worth considering:[133]

1. Psychological criterion views: Our persistence lies in some aspect of the persistence of our psychology. In its most simple form, my memories connect current me to the past me. However, this memory criterion alone is likely insufficient, and this view is often expanded to include other aspects of my psychology such as intentions, beliefs, desires, values, and preferences.[134]
2. Physical criterion views: Our persistence depends on the continuity of our physical bodies. This perspective is far less popular than the psychological criterion views. However, some philosophers contend that you need both psychological criterion and physical criterion or take an either-or approach.[135]
3. Narrative view: Our persistence has to do with the stories we tell about ourselves. Under this view, my narrative is more than just my way of answering the characterization question, "Who am I?" but also determines when I begin and when I end. A future being is me, if the narrative he has identifies him with me, and vice versa.[136]

Later in this chapter when discussing Parfit's approach to personal identity, I will examine the psychological criterion and physical criterion views in detail. For now, I

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[133] The Stanford Encyclopedia of Philosophy also describes a fourth view, anticriterialism. Whereas the three approaches listed above contend that there are "informative, nontrivial necessary and sufficient conditions for a person existing at one time to exist at another time," anticriterialism denies this. I have not included a full exploration of this view as, above and beyond what is included in Parfit, I do not feel it adds anything of significant relevance to the project at hand.

[134] Olson, "Personal Identity," *The Stanford Encyclopedia of Philosophy*.

[135] Olson, "Personal Identity," *The Stanford Encyclopedia of Philosophy*.

[136] Olson, "Personal Identity," *The Stanford Encyclopedia of Philosophy*.

would like to focus on the narrative view as it is central in Dworkin's Critical Interests Approach to advance requests/directives.

There is an intuitive appeal to the narrative view of persistence of personal identity. If the narrative view was correct, and it was true that our personal identity was metaphysically dependent on our life narrative for existence, then Dworkin's Critical Interests Approach would be a logical consequence. However, I do not believe the narrative view stands up to metaphysical scrutiny. Consider the following thought experiments that challenge the narrative view:

> *Jamal grew up in Halifax and lived a 'normal' life per Nova Scotian standards. At the age of twenty-one, he developed symptoms of schizophrenia including delusions that he is Xerxes the Great. He has no memories of his life as Jamal, and insists he is Xerxes and has clear memories of his father Darius and describes invading Greece with first-person oriented details. He was a successful history student at Dalhousie so it is not unusual that he may have had knowledge of these facts, however, he now recalls such facts in the form of personal memories. When challenged as to his current existence in Halifax, Jamal-Xerxes believes that he has been resurrected in Halifax after centuries lived in the afterlife. He describes this reincarnation story in a first-person perspective and the details are in keeping with the cultural beliefs of the historical era of the historical figure Xerxes.*

It would be absurd to say that Jamal is now the historical figure, Xerxes. At most, it could be argued that Jamal no longer exists and there is a new person that exists that believes he is Xerxes. However, the narrative being told by this current person clearly connects to the narrative of Xerxes. This example shows that the narrative view does not seem to be *sufficient* for persistence of personal identity.[137]

> *Fatima is the 40-year-old mother of two children and happily married to her husband, Hassan. While doing repairs on her home, she fell off a ladder and suffered a major head injury. She lost all memories of the past 15 years. She does not remember her marriage or the birth of either of her children. She does maintain other aspects of her personality, such as her sense of humor and sense of compassion. She still enjoys the same songs, although she does not remember where she first heard the more recent ones. She values family and still desires to have children. She maintains all her usual cognitive skills and abilities. Aside from her memories, she is essentially the same person. Upon waking from the accident, she is surprised to hear that she is married with children. While her husband and children find it very unsettling that their mother does not remember them, they still see her as their mother. They continue as a family and support Fatima in her recovery.*

Over time, Fatima and her family will develop a new narrative about Fatima's life that incorporates the fall, head injury, and memory loss. However, in the immediate aftermath of the fall, Fatima does not have a narrative that connects her to the person who existed just prior to the fall. However, given the other similarities, her family sees her as the

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[137] There are potential rebuttals to this scenario that argue that the narrative view could be sufficient if other criteria are met. For example, the fact that Jamal is suffering from a mental illness could be seen as lacking the criteria of the narrative functioning in 'non-pathological' or 'ordinary' fashion. The main point here is that the narrative view (on its own) as proposed by Dworkin is not sufficient for personal identity. Additional criteria are needed. An exploration of those criteria is beyond the scope of this thesis. However, I believe that the literature surrounding those additional criteria inevitably lead towards the more robust psychological criteria that are proposed by Parfit (which include narrative alongside other features of our psychology). I will describe this view in more detail later in this chapter.

same person, and they continue as a family. This scenario indicates the narrative link is not *necessary* for persistence of personal identity.[138]

Given that a life narrative is neither necessary nor sufficient for the persistence of personal identity, the narrative view cannot be the answer to the persistence of personal identity question.[139] This creates a problem for Dworkin's Critical Interests Approach which I believe cannot be overcome. Dworkin argues that a person's critical interests take priority when considering whether or not to respect an advance directive. Even if the current person can no longer understand their critical interests, those critical interests apply to them because that current person is still part of the whole life narrative from which those critical interests arise. However, if the life narrative is neither necessary nor sufficient grounds to connect the current person to the previous person who drafted the advance request, then there are also no grounds for the advance request to hold.[140] For an advance request to hold, some other source of persistence of personal identity must be identified. This leads us to consider the other two potential answers to the persistence question: The psychological criterion view and the physical criterion view. In the next section, I will turn to Parfit's work on the persistence question and his exploration of

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[138] Alternatively, it could be argued that Fatima is now a different person, and the narrative view still holds as necessary. However, if the narrative view is to hold this strictly, then Dworkin's Critical Interests Approach faces challenges in settings where the person with advanced dementia has no memory of their previous life as we would then them a different person (even if the previous person drafting the advance directive would have seen them as a future self). A full discussion surrounding this challenge is beyond the scope of this thesis.

[139] Please note that there are extensive arguments against the Narrative View. For the sake of brevity, I have included the most simple and straightforward arguments.

[140] As I will show later in the chapter, even though our life narrative is not sufficient nor necessary grounds for persistence of personal identity, it is still a component of our psychology. Our narrative involves memories, dispositions, goals, and many other features that fall under the Psychological Criterion which we will explore in a moment.

psychological criterion and physical criterion as potential answers to the persistence question.

Parfit and the Persistence of Personal Identity

Derek Parfit's 1984 book, *Reasons and Persons*, provides one of the most influential analyses of personal identity in the history of philosophy. While a full review and defence of Parfit's arguments are beyond the scope of this project, I will provide a summary of the aspects that are most relevant to the question at hand. Parfit's arguments focus on the psychological criterion and physical criterion views for persistence of personal identity. Parfit divides the psychological criterion into two important subsets: psychological connectedness and psychological continuity. Psychological connectedness means holding of the same psychological connections (i.e., features) such as memories, dispositions, intentions, and preferences. From day-to-day, I maintain almost all the same psychological connections. Therefore, from day-to-day, I can be easily seen to be the same person from a psychological connectedness perspective. However, over an extended period, most of my psychological connections may be different.[141] Psychological continuity means holding a chain of overlapping strong psychological connections. The person I was at age 3 has vastly different psychological connectedness from my current self. However, the changes in connectedness happened slowly such that between any given day, the majority of psychological connections were the same (i.e., strong connections) and therefore there is psychological continuity from me at age 3 to me today. [142,143] Parfit uses the term relation *R* to refer to psychological connectedness and/or

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[141] Parfit, "Reasons & Persons," 206.

[142] Parfit, "Reasons & Persons," 303-306.

[143] If the reader requires more clarity on the definitions of psychological continuity and connectedness, consider the following: 15-year-old me may seem to be a different person from 80-year-old me, from a

continuity, collectively.[144] With this definition of *R* in mind, Parfit considers the possible answers to the persistence questions. According to Parfit, "Here are the simplest answers:

> (1) Physical continuity,
>
> (2) Relation *R* with its normal cause,
>
> (3) *R* with any reliable cause,
>
> (4) *R* with any cause."[145]

Parfit determines that option (4) is the only viable candidate. His arguments involve a systematic exclusion of the first three options. I will provide a summary of these arguments in the next sub-section. These arguments do involve some strange thought experiments which seem to take us far afield from the real-world task at hand regarding advance requests for MAiD. However, these thought experiments do allow us to derive a clear focus on *what matters* when considering persistence of personal identity. When Parfit uses the term, '*what matters,*' he is referring to what is important to us at an existential level. I believe that this clear focus on *what matters* will then provide us the

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psychological connectedness perspective. Between age 15 and 80, I would anticipate that my memories, dispositions, intentions, and preferences will have changed vastly. 15-year-old me and 80-year-old me may only hold 10% of the same connections. However, 15-year-old-me may hold 70% of the same connections as 25-year-old me, who holds 70% of the same connections as 35-year-old me, who holds 70% of the same connections with 50-year-old-me, who holds 70% of the same connections with 80-year-old me. From a psychological connectedness perspective, it may be hard to argue that 15-year-old me and 80-year-old me are the same person given that we only share 10% psychological connectedness. However, there exists a chain of interval me's that hold strong connectedness to each other. With this overlapping connectedness in place, 15-year-old me can be seen as the same person as 80-year-old me from a psychological *continuity* perspective. This could be pushed even further in the theoretical example of a person with eternal life. For an immortal person, there may be 0% psychological connectedness between their current self and their self one million years ago but there may be a series of overlapping interval persons who had strong psychological connectedness, and this creates a psychological continuity between the immortal selves that exist one million years apart.

[144] Parfit specifically defines R as "psychological connectedness and/or continuity, with the right kind of cause." I have omitted the qualifier in this explanation as it is only important when considering certain counterarguments which are beyond the scope of this project.

[145] Parfit, "Reasons & Persons," 283.

foundation to approach the tension between Dworkin and the D-J-C interpretation of personal identity.

What Matters

When answering the persistence question, Parfit poses a variety of thought experiments that lead us to reflect on *what matters* as regards our continued existence. Parfit's approach begins with an exploration of what matters in persistence of our personal identity. However, in the attempt to answer this question, he shows a much deeper truth, which is that personal identity does not matter to our continued existence – at least not in the way it is often conceived. This leads to a conclusion regarding what matters about our continued existence which in turn speaks to what matters as regards our very existence as beings in any sense. In this way, *what matters* in Parfit's work captures a concept that is much larger than just what matters for persistence of personal identity. Collectively, I will capture this concept with the italicized *what matters* in this project. Parfit's conclusions regarding what matters will be of critical importance for my approach to advance requests for MAiD.

When considering *what matters*, the first possible answer to the persistence question (as listed previously), (1) Physical continuity, is easily excluded. While there are many different arguments against physical continuity as the grounds of persistence of personal identity, for the purposes of the project at hand, I will simply provide Parfit's famous teletransportation thought experiment:

> *"I enter the Teletransporter. I have been to Mars before, but only by the old method, a space-ship journey taking several weeks. This machine will send me at the speed of light. I merely have to press the green button. Like others, I am nervous. Will it work? I remind myself what I have been told to expect. When I press the button, I shall lose consciousness, and then wake up at what seems a moment later. In fact I shall have been unconscious for about an hour. The*

> *Scanner here on Earth will destroy my brain and body, while recording the exact states of all of my cells. It will then transmit this information by radio. Travelling at the speed of light, the message will take three minutes to reach the Replicator on Mars. This will then create, out of new matter, a brain and body exactly like mine. It will be in this body that I shall wake up. Though I believe that this is what will happen, I still hesitate. But then I remember seeing my wife grin when, at breakfast today, I revealed my nervousness. As she reminded me, she has been often teletransported, and there is nothing wrong with her. I press the button. As predicted, I lose and seem at once to regain consciousness, but in a different cubicle. Examining my new body, I find no change at all. Even the cut on my upper lip, from this morning's shave, is still there."*[146]

An important aspect in following along with Parfit's arguments regards the simple question: Would *you* press the button? I certainly would.[147] This intention is founded on the scientific evidence that, overwhelmingly, indicates that our mind[148] and consciousness arise from the physical manifestation of the configuration of our brain and associated nervous system. If this configuration can be replicated, as is illustrated in this thought experiment, I would expect that my mind and consciousness would be replicated. Therefore, the *physical* continuity of my brain is not needed. At best, materialists could argue that a physical configuration of a brain is needed but not the physical continuity of the current brain sitting in my head here on Earth. Therefore, the first answer, (1) Physical continuity, is not *what matters*.

The teletransporter thought experiment points us clearly to accepting that relation *R* is what matters. Further, it also discounts the second answer, (2) Relation *R* with its normal cause, because teletransportation or any replication of our brain aside from the

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[146] Parfit, "Reasons & Persons," 199.

[147] If you wouldn't press the button, it is important to define why. Parfit provides compelling arguments against a myriad of potential reasons why a person may not push the button. These are complex metaphysical arguments that are too lengthy to summarize here. For the purposes of this project, I will assume that the reader *would* press the button and activate the teletransporter to Mars.

[148] Within this thesis, I will use the term 'mind' to mean our collective psychological features which includes our conscious experience, perceptions, memories, preferences, dispositions, intentions, etc. For purposes that will become apparent later in this chapter, when I use the term 'mind,' I am not referring to a distinct entity like a soul or Cartesian ego.

normal physical continuity is not the normal cause. This leaves us with the last two options, (3) *R* with any reliable cause, and (4) *R* with any cause. Intuitively, it seems that a *reliable* cause would be needed. However, imagine you were facing certain death and the only escape was to enter a teletransporter that had a 50% failure rate. Between certain death and a 50% chance of survival, the teletransporter seems like a good option. [149] If I awoke as the replication of my current body, I would consider that *I* have survived. Therefore, what matters is the final answer proposed by Parfit: (4) *R* with any cause. [150] The primary purpose of establishing the qualifier 'with any cause' is because this indicates that the cause itself is not relevant, therefore all that matters is relation *R*. This has some important implications that can be applied to the question of advance requests for MAiD. Namely, if we accept that *what matters* is relation *R* (regardless of cause), it leads us to the following conclusions:

- We ought to adopt a *reductionist* view of personal identity.
- Personal identity is *indeterminate*.
- Personal identity is not *what matters*, rather, relation *R* is what matters.

In the remainder of this section, I will provide a brief explanation of these three bullet points. I will then consider the D-J-C interpretation of personal identity considering these conclusions. As I will argue, while the D-J-C interpretation of personal identity is in line with Parfit's account of personal identity, it implies acceptance of the extreme claim that could flow from these conclusions. I will argue that the moderate claim that flows from these conclusions is better suited to the question of advance requests for MAiD. In

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[149] Modified example from Parfit, "Reasons & Persons," 286-287.

[150] In later work, Parfit acknowledged that this qualifier, also know as the *wide psychological criterion*, need not be specifically adopted. For more details see Sauchelli, "Derek Parfit's Reasons & Persons: An introduction & Critical Inquiry," 51.

Chapter 5, I will then propose an approach to advance requests to MAiD which endorses the moderate claim.

Reductionist View of Personal Identity

As soon as a person decides they would press the button of the teletransporter, they have implicitly accepted a *reductionist view* of personal identity. Under a reductionist view, we are nothing more than the psychological and/or physical states and the relations between these states. This is contrasted with a *non-reductionist* view which states that we are more than simply our psychological and/or physical states; our existence depends on the existence of something extra like a Judeo-Christian soul, a Hindu atman, a Cartesian ego, or some further fact. A non-reductionist may assert that the soul, atman, or ego is all we need for our existence, or may agree that some psychological and/or physical feature is needed *and* some further fact. [151] The teletransporter merely scans, transmits, and replicates the exact features of my body and brain. Scientific evidence overwhelmingly indicates that my psychological features, including my mind[152] and consciousness, arise from the physical configuration of the neural networks of my brain. However, no similar evidence indicates that there is anything like a soul or Cartesian ego that arises from those physical configurations.[153] Therefore, pressing the button of the teletransporter is an endorsement of a reductionist view.[154]

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[151] Parfit, “Reasons and Persons,” 210.

[152] Recall that I am using mind to refer to psychological connections and not a determinate entity. This sub-section makes clear why that disclaimer is important.

[153] Parfit, “Reasons and Persons,” 210.

[154] It is worth noting that pressing the button in the teletransporter thought experiment is not merely an endorsement of a science fiction technology but also meant to be an endorsement of modern scientific understanding of how our minds arise from our brain. Various scientific disciplines, including psychology, neuroscience, and biology, all accept that the brain gives rise to the mind. We need not accept a strict materialist perspective that equates the brain and the mind. Various dualist theories of mind, such as

Personal Identity is Indeterminate

According to Parfit, acceptance of a reductionist view of personal identity entails acceptance that personal identity is indeterminate. Parfit's arguments in this regard are even stronger if we accept that '(4) *R* by any cause' is the answer to *what matters*. To highlight this, I will return to our teletransporter thought experiment:

> *I have been using teletransportation for my trips to Mars for many years. However, this morning when I enter the teletransporter and press the button, nothing happens. I leave the teletransporter to seek help from the staff operating the device. When I complain that the teletransporter has failed to send me to Mars, the staff assure me that I have certainly made it to Mars. However, the disintegration feature was accidentally disabled. They ask me to re-enter the teletransporter so they can complete the disintegration. To assuage my concerns, they wait until my replica is rebuilt on Mars and they turn on an interplanetary communication device and allow me to see and speak to myself on Mars. The 'me' on Mars assures me that the process has worked, and 'I' am safely on Mars. The 'me' on Mars encourages me to enter the teletransporter and complete the disintegration. I feel an understandable unease about disintegration at this point.*[155]

This is an example of what Parfit calls a *branch line*. Such branch lines indicate that personal identity is not always determinate. Who is *me*? The *me* on Mars who will continue with the remainder of my life or the *me* on Earth suffering a delayed disintegration error? I may say that both are *now* unique individuals. However, which one is contiguous with the *me* just prior to pushing the button in the teletransporter? If I have accepted a reductionist view of personal identity where what matters is *R* by any cause,

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functionalism or epiphenomenalism, can avoid a strict materialist view while still acknowledging that the brain gives rise to the mind. By theoretically pressing the button in the teletransporter in the thought experiment, we endorse this modern scientific understanding of the relationship between brain and mind and therefore a reductionist view of personal identity.

[155] Modified example from Parfit, "Reasons and Persons."

and pressed the teletransporter button, then I must also accept the indeterminacy of personal identity.[156]

Personal Identity is Not What Matters

Parfit's work provides a third conclusion that is of relevance to advance requests for MAiD: Personal identity is not *what matters*. As noted earlier in this chapter, when considering the persistence of personal identity, *what matters* is (4) *R* by any cause. This leads to Parfit's other conclusions supporting a *reductionist* view of personal identity and the *indeterminate* nature of personal identity. If these arguments are accepted, then it entails that personal identity is not *what matters*. *What matters* is relation *R*. Personal identity often coincides with relation *R*, however, if personal identity diverges from relation *R*, it becomes apparent that relation *R* is *what matters*. The thought experiments that draw the indeterminacy of personal identity (such as the branch-line case described above) are intended to draw our attention to this potential divergence between personal identity and relation *R*.

In Parfit's book, "Reasons & Persons," there are extensive compelling arguments regarding this point.[157] My summary of these arguments does not do justice to Parfit's account, and any further elaboration would take us further afield from the purpose of this thesis.[158] If my summarized arguments are not considered to be sufficiently convincing, it is worth noting that Dresser and Jaworksa specifically endorse Parfit's account of

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[156] This is an incredibly condensed and overly simplified explanation of the indeterminacy of personal identity. However, a full exposition on this concept would be quite lengthy and diverge quite far from the purpose of this thesis. For a full account, please see Parfit, "Reasons and Persons," 199-306.
[157] Parfit, "Reasons & Persons," 245-272.
[158] For a full account of the importance of relation *R* see Parfit, "Reasons & Persons," 199-306.

personal identity[159,160] and, I would argue, Carter does so implicitly when she endorses both Dresser and Jaworska's views.[161] Even if the reader does not accept Parfit's account overall, I believe that Parfit's conclusions can still be justifiably assumed in the counterarguments to the D-J-C interpretation of personal identity given that Parfit's account is endorsed by these authors within the development of their approaches.

In summary, relation *R* is *what matters* as regards our continued existence. Personal identity is better conceptualized as a social construct that is founded on relation *R*. Personal identity *seems* to be *what matters* for our continued existence, however, this is simply because personal identity often coincides with relation *R*.[162] This reframes the question about *what matters* in an especially important way. I began this chapter by pointing towards the importance of the persistence question. I argued that addressing the persistence of personal identity was critical to addressing advance requests for MAiD. Likewise, Parfit begins his account of personal identity by asking *what matters* as regards the persistence of personal identity. However, in answering this question, we discover that persistence of personal identity does not matter at all. What matters for our continued existence is persistence of relation *R*.[163,164] This is of critical importance to advance requests. As I will discuss in the next section, I believe the D-J-C interpretation of personal identity overlooks the special regard that is usually granted to relation *R*. In

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[159] Dresser, "Dworkin on Dementia," 35.
[160] Jaworska, "Respecting the Margins of Agency," 105.
[161] Carter, "Advance Directives," 34-37.
[162] Parfit, "Reasons & Persons," 256-260.
[163] Parfit, "Reasons & Persons," 282.
[164] Recall that relation *R* captures both psychological connectedness and psychological continuity. It is worth noting that Parfit sees these both as *what matters*. According to Parfit, there is no argument to give priority to either connectedness or continuity; there is also no reason to consider them as equal either. While there is no way to argue for their relative value to each other, both connectedness and continuity are *what matters.* See Parfit, "Reasons & Persons," 301.

order to understand how these authors overlook this special regard, I must first define two final concepts from Parfit: the extreme claim and the moderate claim.

Extreme versus Moderate Claim

As explained above, we ought to assume a reductionist view of personal identity which is indeterminate and only ever coincidentally aligned with *what matters*: Relation *R.* Acceptance of these arguments leads to two possible claims:

1. Extreme claim: We have no reason to care about what will happen to ourselves in future. If there is no further fact, soul, ego, or self beyond relation R, then we have no reason to care about our future. Continuity of relation R does not do enough to make us care.[165]
2. Moderate claim: Relation *R* provides enough reason to care about what happens to ourselves in the future.[166]

Parfit acknowledges that acceptance of his reductionist arguments could lead to either claim but knows of no argument to accept one claim over the other. As Parfit puts it, "There is a great difference between the Extreme and Moderate Claims. But I have not yet found an argument that refutes either."[167]

If one wishes to apply Parfit's philosophy to advance requests for MAiD, it is critical to be clear as to whether the approach endorses the extreme claim or the moderate claim. As noted by Parfit, following the extreme claim entails no special regard to our future selves because relation *R* does not provide sufficient grounds for any connection of concern. I believe that this would also apply to past selves. Relation *R* is our only

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[165] Parfit, "Reasons & Persons," 307-311.

[166] Parfit, "Reasons & Persons," 311.

[167] Parfit, "Reasons & Persons," 312.

connection to our future self *and* our only connection to our past selves. If relation *R* is sufficient grounds for any connection of concern to our future selves, then that would apply equally to our past selves.

In the next section, I will argue that the D-J-C interpretation of personal identity denies any special regard to our past selves and therefore endorses the extreme claim. While there may be no reason to refute the extreme claim or moderate claim outright, I will argue that, within the context of advance requests/directives, any approach that endorses the extreme claim leads to intuitively unacceptable results, logical inconsistencies, and significant pragmatic concerns. Later, in Chapter 5, I will describe an approach to advance requests that relies on the moderate claim.

D-J-C Interpretation of Personal Identity

In the previous section, I drew out three conclusions from Parfit's account of personal identity: Existing evidence supports a *reductionist view* of personal identity, personal identity is *indeterminate*, and personal identity is not *what matters* for our continued existence, rather, relation *R* is *what matters*. These conclusions all have direct bearing on advance requests for MAiD. However, they lead to two possible claims: The extreme claim that relation *R* provides insufficient connection for any special regard for our past or future selves, or the moderate claim that relation *R* provides sufficient connection for special regard for our past or future selves.

Dresser, Jaworksa, and Carter's approaches endorse Parfit's account of personal identity (either explicitly or implicitly).[168,169,170] Parfit's account proposes that personal

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[168] Dresser, "Dworkin on Dementia," 35.

[169] Jaworska, "Respecting the Margins of Agency," 105.

[170] Carter, "Advance Directives," 34-37.

identity is indeterminate and therefore not always persistent. Dresser, Jaworska, and Carter argue that the advance request may be defeasible if the pre-dementia person who created the advance request is sufficiently different from the current advanced dementia person. While the D-J-C interpretation of personal identity does not explicitly state that the previous person and the current person are completely different people, it does place paramount importance on the current person. I will argue that the degree of priority they place on the current person requires endorsement of the extreme claim. To illustrate this, I will apply their approaches to loss-of-capacity cases such as delirium and intoxication.[171] Consider the following example:

> *Siti is a 52-year-old lawyer who is passionate about music and spends her weekends playing drums in a local band. She presents to the emergency department in a sepsis-induced delirium. Her medical team is worried she may die if antibiotics and intravenous fluids are not provided in an intensive care setting. Amid her delirium, she declares that she must go home to practice for her upcoming gig this weekend. She says the medical team is impeding on her liberty and she does not want to be poked with needles and refuses placement of an IV. When told she could die, she says she's totally fine with that risk, music is her life, and she would rather risk death than not be ready for the upcoming gig with her band this weekend.*

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[171] It is worth noting that these authors would not want their approaches applied to such cases. As I will show, if their approaches are applied in these cases, we come to intuitively unacceptable and logically contradictory results. These authors are aware of this problem and provide arguments as to why their approaches ought not be applied in such cases. In the latter half of this section, I will show that these arguments fail and as such there is no differentiating criterion between dementia cases and other loss-of-capacity scenarios. If there is no differentiating criterion between these cases, then logical consistency requires that their approaches be applied in both types of cases - which leads to unacceptable results.

In her delirious state, she would not be competent to make decisions about leaving the hospital under standard medical assessments of capacity. What would Dresser, Jaworksa, or Carter say about such a case? They would refuse to analyze it using their approaches, because they wish to restrict their approaches to dementia-type cases. But what happens if we apply their approaches in this case? Siti's current best interests are to play music and avoid the pain and confinement of the hospital.[172] Siti has stated that her primary *value* is music and playing at her upcoming gig; staying in hospital will prevent her from attending that gig. Siti's authentic self is currently focused on music and being liberated from the hospital. If we applied Dresser's Best Interests Approach, Jaworska's Values-Based Approach, or Carter's Authenticity Approach to the current situation, Siti ought to be allowed to leave the hospital.

As noted, Dresser, Jaworska, and Carter would not want to apply their approach in situations like Siti's because they believe their approaches only apply to dementia-type cases. In order to limit their approaches to dementia-type cases, these authors must provide some criteria to differentiate between cases where their approach ought to be applied (e.g., dementia cases) and cases where their approaches ought not to be applied (e.g., delirium or intoxication). If no differentiating criteria can be established, then their approaches warrant re-examination. I argue that there is nothing inherent in their approaches that can provide differentiating criteria. The authors propose two categories of differentiation criteria:

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[172] It could be argued that a forced ICU admission reflects Siti's current focus on music. By staying in hospital, Siti survives and is therefore able to play more music in the long run. For the purposes of the point that I am trying to make with this example, I could add that Siti, in her current delirious state, considers the upcoming gig to be of paramount importance and the pinnacle of her musical journey and life.

1. Lack of future self with capacity: So long as there is no possible future self that will have capacity, the approach may be applied. Margo will never become undemented, whereas Siti will return to her previous self after treatment with antibiotics and clearance of the infection.[173]
2. The current self has a settled disposition: This argument is used specifically by Carter's Authenticity Approach. Under this argument, Siti's current state is not a settled disposition and therefore does not express her authentic self. However, Margo has entered a settled disposition and therefore has an authentic self that is distinct from the pre-dementia Margo.[174]

In the next two sub-sections, I will deal with these two categories of differentiation criteria.

Lack of Future Self with Capacity

Margo will never be 'undemented' whereas Siti could return to her previous self – intuitively, this seems like a reliable criterion for differentiating between these types of scenarios. If there was a cure for Alzheimer's dementia, that would dramatically impact how advance requests are drafted and interpreted. However, I contend that there are no principled reasons to accept this differentiation criterion. There is nothing logically inherent in Parfit's arguments regarding personal identity, nor in Dresser's, Jaworska's, or Carter's approaches that provides support for the idea that the potential states of future selves ought to impact the defeasibility of advance requests. Further, even if the D-J-C interpretation of personal identity could supply a principled reason to accept this

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[173] Carter, "Advance Directives," 38.
[174] Carter, "Advance Directives."

differentiation criterion, it would still not create the boundaries that Dresser, Jaworksa, and Carter require. Consider the following thought experiment:

> *Kyoko is a 35-year-old CEO of a successful tech firm. She has been diagnosed with a fatal but highly predictable disease. She has been told she has 6 months to live. She drafts her advance directive, updates her will, establishes her durable power of attorney, and ensures her wishes are known. She has acquired an immense fortune and plans to donate half to charity and half towards enjoying the final months of her life. Once these plans are in place, she purchases a recreational drug that will place her in a pleasant, irreversible, and confused psychedelic state for the remainder of her life. Kyoko is aware that after she takes the drug, she will lose capacity*[175] *and no longer appreciate the importance of her donation to charity. She has given explicit instructions not to allow high-Kyoko to spend the second half of the fortune. After taking the drug, she approaches her power-of-attorney and requests she be given access to the other half of her fortune to spend on enjoying her final months.*

In this scenario, Kyoko will never become un-high. If we apply Dresser's Best Interests, Jaworska's Values-Based Approach, or Carter's Authenticity Approach to the scenario at hand, current high-Kyoko would get her way and spend the fortune in a way her previous self would not have wanted. Allowing high-Kyoko to overturn the wishes of sober-Kyoko seems to be an intuitively unacceptable result; it would go against our social norms and typical moral intuitions. While social norms and moral intuitions often warrant

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[175] In these examples, when referring to capacity, I am referring the standard medical model of comparative decision-making capacity.

being overturned in the face of solid ethical arguments, this discrepancy ought to give us pause to examine those ethical arguments for logical consistency.

Dresser, Jaworska, and Carter all express that they believe that their approach ought to apply in advanced dementia cases but not in cases of intoxication or delirium. However, this case shows how their arguments cannot prevent their view from being applied to cases of intoxication.[176] Therefore the 'lack of future self with capacity' criterion does not suffice to limit Dresser, Jaworska, and Carter's approaches to dementia-type cases. In the next sub-section, I will argue against Carter's second proposed differentiation criterion. If neither of these criteria provide sufficient grounds for differentiating between dementia cases and cases of intoxication or delirium, Dresser, Jaworksa, and Carter's approaches result in intuitively unacceptable results.

Current Self has a Settled Disposition

Carter's Authenticity Approach points to a second possible criterion for differentiating between a patient with advanced dementia and a patient with intoxication or delirium. As discussed in Chapter 3, Carter proposes that an advance request is defeasible if it alienates the current person's authentic self. The authentic self is determined by looking at the person's settled disposition regarding things such as values, preferences, or goals. Even if the person lacks capacity, the advance request may be

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[176] Dresser, Jaworska, and Carter could argue that this example merely displays how their approach would work in an extended intoxication. In doing so, they could 'bite the bullet' in this case and say that this would not be a truly unacceptable result in extended intoxication but still try to hold their view in other cases. However, with a little imagination, this example can be tweaked to provide a myriad of possible consequences. I could provide slight variations on the thought experiment that could further pull apart the logical inconsistencies of this approach. Imagine the medical team discovers their prediction is off regarding Kyoko's life expectancy. It turns out she will live 10 seconds longer than the drug's high and regain capacity for 10 seconds. Does this impact her request for the second half of her fortune? Or it turns out she has a 50% of surviving due to a new treatment, does this impact her request?

overturned if their current settled values, preferences, or goals are not in line with the substance of the advance request.

If this Authenticity Approach is applied to our modified-Margo scenario (where Margo has an advance request for MAiD), the advance request might be overturned. This would be a welcome possibility for Carter and the scenario where her approach is meant to be applied. However, if the Authenticity Approach is applied to our delirious Siti scenario, the result is that Siti would be permitted to leave the hospital. If Carter wishes for her Authenticity Approach to be applicable in advanced dementia but not in other cases of lost capacity, such as delirium or intoxication, she needs to provide criteria to differentiate these cases. To differentiate between these scenarios, Carter's approach can point at the requirement of a *settled* disposition. A person in a sepsis-induced delirium is not in a settled disposition in the same way that a person with advanced dementia.[177]

However, Carter does not provide clear delineation to the boundaries of *settled*. For Carter's approach to work, *settled* needs to be narrow enough to avoid incorporating Dworkin's critical interests, yet broad enough to avoid incorporating frivolous desires, periods of intoxication, and delirious states. Dispositions, such as preferences, desires, values, and goals, can be viewed on a spectrum such that some span momentary periods, while others span a lifetime. A craving for a cigarette could be a momentary desire, while the goal of raising healthy, independent children would be a lifelong goal. If *settled* covers very narrow time periods, cravings for cigarettes would have to be considered and Carter clearly wants to avoid inclusion of such quickly changing desires. If *settled* covers

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[177] Jaworska's Values-Based Approach could follow a similar strategy. While Jaworska doesn't explicitly state it, values could be characterized as having a more long-standing character and Jaworska could require that values have a settled disposition. The arguments I make in this sub-section could apply equally to considerations of values as settled dispositions.

an overly broad period, then Dworkin's critical interests should be considered. To avoid placing value on brief cravings, Carter needs to propose that inclinations over a longer period are *more* important. However, if she proposes inclinations over a longer period are *more* important, than Dworkin's critical interests are the *most* important. Suddenly, Dworkin's Critical Interests Approach becomes the approach to determining maximum authenticity. Carter may contend that the current person no longer holds those interests. However, in any given moment, a person may not hold more mid-range preferences, desires, or values. Margo could be said to hold the value of enjoying the simple pleasures in life. However, it is doubtful she holds that value in mind every moment of the day. It is quite imaginable that she may have brief periods of sadness or anger. In those moments, she is not expressing the value of enjoying the simple things in life. Carter's authenticity approach requires that this authentic self holds even in moments where those values are not immediately present. She may contend that on average Margo holds the value of enjoying the simple pleasures in life. How long a period is considered to work out that average? If a long enough period is considered (e.g., over 50 years), then critical interests will take priority. If too short a period is considered, brief desires become important. Carter's approach does not offer an argument in defence of a period that is *just right*.

Median survival with advanced Alzheimer disease is 1.3 years[178] and so I take it that Carter's *settled* disposition is intended to cover somewhere in this window. While Carter provides no arguments to establish this as the *just right* period under consideration, even if she could provide arguments for a *just right* period, I can propose thought

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[178] Mitchell, "Care of patients with advanced dementia."

experiments that challenge using *settled disposition* as a differentiating criterion for other loss of capacity states such as intoxication or delirium. Consider the following:

> *Miraculously, Kyoko has survived her illness and the drug wears off. She is incredibly happy to see that half her fortune was not spent on her party. She learns of a new drug that lasts two years and decides to embark on a two-year high vacation. When on this new drug, people are known to develop the strong desire for the experience of childbirth. She does not want children and has an intrauterine device (IUD) placed so that she will have active contraception for the next five years. She drafts an advance directive explicitly stating that the IUD must not be removed even if she expresses the desire to do so. A year after taking the drug, she requests removal of the IUD because she wants to experience childbirth. She lacks the cognitive capacity to fully understand the consequences of childbirth such as the subsequent task of raising children, however, she can express a settled disposition that values a preference to be pregnant and give birth.*

Kyoko is in a settled disposition just as much as Margo. However, removing the IUD would undermine her previous self-determined wishes. The supporter of Carter's position could then retort that Kyoko is not in a *settled disposition* because she will return to her sober state eventually. This is a return of the argument I dealt with in the previous sub-section: 'Lack of future self with capacity.' Even if these two arguments are combined, the thought experiment can be altered to challenge these as criteria for differentiating between advanced dementia and other loss of capacity scenarios:

> *Just before she enters her two-year high, Kyoko learns that her disease has returned. She will die just days before her two-year high ends. Learning this, she emphatically reminds her doctors, friends, family, and lawyers that the IUD must not be removed. She has never wanted children and the thought of having a child while high and then potentially leaving behind an orphan child even further strengthens the desire not to have children. One year after taking the drug, she requests the IUD be removed so she can experience childbirth.*

Let me reiterate that Kyoko currently does not have capacity to understand the consequences of having children and therefore does not have comparative decision-making capacity which is the current standard in medicine. Rather, she has the desire to become pregnant and give birth. She could voice this as a *value* such as "I believe that the experience of giving birth is an experience that will enrich my life and something I must experience before I die." She can consistently describe this as being in her best interests in a stable way that is *settled* over the two-year period. However, I would contend that removing the IUD is the wrong thing to do for Kyoko – or at least intuitively unacceptable.

Neither of the two proposed differentiation criteria provide ample justification for overturning modified-Margo's advance request for MAiD but maintaining Kyoko's advance directive to leave the IUD in place. It seems as if there is something missing. In the next section, I will argue that the missing element is an endorsement of the moderate claim that stems from Parfit's conclusions regarding personal identity. The reason that Dresser, Jaworska, and Carter cannot provide differentiation criteria between scenarios of loss of capacity is because the D-J-C interpretation of personal identity implicitly relies on the extreme claim. Any approach that relies on the extreme claim will inherently have to focus on the current person regardless of what reason they have lost capacity. As I will explain in the next section, endorsement of the extreme claim would entail removal of Kyoko's IUD, allowing delirious Siti to leave the hospital, and overturning modified-Margo's advance request for MAiD. These intuitively unacceptable results should give us pause regarding the approaches of Dresser, Jaworska, and Carter. I will then argue that if these approaches endorse the extreme claim, they lead to a logical inconsistency that provides another reason to reject these approaches. I will then also highlight the pragmatic concerns regarding an endorsement of the extreme claim within the medical environment. Taken together, the intuitively unacceptable results, logical inconsistencies, and pragmatic concerns ought to lead us to reject the use of the extreme claim and D-J-C interpretation of personal identity when developing an approach to advance requests for MAiD. Therefore, endorsing the moderate claim will be necessary if we are to develop an approach to advance requests.

The Extreme Claim versus the Moderate Claim

In the previous section, I noted that the D-J-C interpretation of personal identity cannot provide criteria for differentiating between loss of capacity scenarios. Therefore, if Dresser, Jaworksa, or Carter's approach is applied in the setting of advance dementia, it ought to be applied in any scenario of loss of capacity, including intoxication, or sepsis-induced delirium - where application of the approach would have intuitively unacceptable results. I believe that the reason their approaches cannot be restricted to cases of dementia is because their approaches implicitly endorse the extreme claim: Relation *R* provides insufficient connection for any special regard for our past or future selves. In this section, I will provide further support for my assertion that their approaches endorse the extreme claim. I will then describe two further problems that follow from their endorsement of the extreme claim: logical inconsistency, and pragmatic concerns. I will then describe how endorsement of the moderate claim can provide clarity regarding advance requests that is lacking in the D-J-C interpretation of personal identity.

Dresser, Jaworska, and Carter all propose approaches that allow us to determine what the current person with advanced dementia would want. Dresser focuses on *their current* best interests; Jaworska tries to determine *their current* values; Carter emphasizes *their current* authentic self. The advance request (or directive) can be used to help inform us about what the current person might want, however, no special regard is given for the person who drafted the advance request. The author of the advance request is simply providing a data point to determine what the current person would want. All three authors focus on self-determination for the current person. There is no special regard for the past person, therefore the extreme claim is being endorsed. To help draw out this point, I will return to our modified-Margo case from Chapter 1 with a few added nuances:

> *When Margo was diagnosed with early Alzheimer's dementia, she drafted an advance request to receive MAiD once she reached the advanced stages of dementia and could no longer care for herself at home. She lives in a small rural town and the nearest nursing home is two hours away. Leaving her small town seems a fate worse than death for her. She has spent her life saving up money to send her grandchildren to university and does not want this money being spent on private in-home care. Further, she is incredibly proud of her children's careers, and nothing makes her happier then considering the wonderful lives that she has*

> *helped create for them. She would rather die then see them leave those lives to move home to care for her. Her family loves her dearly and would gladly leave their careers and forego the possibility of university education to care for her so there is no concern regarding coercion. However, Margo sees little value in living a few extra years in a state of advanced dementia. The mere thought of being a burden to her family and having her lifelong efforts go to waste causes Margo intolerable psychological and existential suffering.*
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> *Years later, Margo has reached the state of advanced dementia. She is unable to care for herself. She often leaves the stove on unattended, goes without eating or washing for days, and leaves her home and gets lost. After one such episode of getting lost, adult protection becomes involved and recommends placing her in a nursing home or hiring a private in-home caregiver. Margo clearly states that she wants to remain in her home and reiterates that she would rather die than leave her home. Despite her inability to care for herself, she is happy and enjoys the simple things in life. Her physician notes the advance request and tries to discuss MAiD with Margo and remind her about the reasons that led Margo to draft the advance request in the first place. When her physician mentions Margo's previous intention to pay for her grandchildren's university costs, Margo looks surprised and tells her physician that she has no memory of ever having children, let alone grandchildren.*

Dresser's Best Interests Approach, Jaworska's Values-Based Approach, and Carter's Authenticity Approach would all lead us to overturn the advance request for MAiD in this scenario. However, doing so completely disregards Margo's most deeply held values, preferences and goals as stated just a year or so earlier: To not be a burden on her family and send her grandchildren to university. There is nothing in these three approaches that provides any special regard for previous Margo. Previous Margo only serves to help inform us about what current Margo would want. Therefore, these approaches and the coinciding D-J-C interpretation of personal identity endorse the extreme claim: Relation *R* provides insufficient connection for any special regard for our past or future selves.[179]

As noted earlier, Parfit acknowledges that there are no arguments to accept the moderate claim over the extreme claim and vice versa.[180] However, within the specific context of advance requests and directives, I believe there are reasons to refute the extreme claim. As described in the previous section, the D-J-C interpretation's endorsement of the extreme claim led to intuitively unacceptable results. As I will describe below, an endorsement of the extreme claim in this setting will also lead to logical inconsistency and significant pragmatic concerns.

Logical Inconsistency

The very act of creating an advance request or directive is an acknowledgement that we have some special regard for our future selves. An endorsement of the extreme claim entails that we have no special regard for our future selves. Therefore, any approach that endorses the extreme claim must also reject the value of advance requests/directives outright; they would not simply be defeasible, they would be

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[179] If the D-J-C interpretation of personal identity provides any special regard, the authors make no note of this, and their approaches are created in such a fashion that this special regard can hold no influence. Therefore, even if the authors may assert that a special regard exists, their approaches provide no possible recognition of the special regard.

[180] Parfit, "Reasons & Persons," 312.

completely meaningless. Therefore, it would be logical inconsistent to create an approach to advance requests that endorsed the extreme claim because the very act of drafting an advance request entails some special regard for your future self. Consider the following:

A = the act of drafting an advance request/directive is meaningful

B = the extreme claim is true

C = we hold special regard for our future selves

1: The act of drafting an advance request/directive is meaningful, only if we hold a special regard for our future self = $(A \supset C)$ [181]

2: If the extreme claim is true, then we do not hold special regard for our future selves = $(B \supset \sim C)$

To develop an approach to advance requests/directives, you would have to first believe that drafting an advance request/directive is meaningful (A). If that approach then also endorses the extreme claim $(A \wedge B)$, you run into a logical inconsistency:

$(A \wedge B)$

$(A \supset C)$

$\underline{(B \supset \sim C)}$

$(C \wedge \sim C)$

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[181] In the modified-Margo case, it could be argued that pre-dementia Margo did not have any special regard for her future self when she drafted the advance request for MAiD. Instead, she drafted the advance request for special regard for her family. However, this would need to be special regard for her family's future selves, which would then entail endorsement of the moderate claim. If the extreme claim were true, Margo would have no reason to hold any special regard for the future selves of her family which would undermine her motivation for drafting the advance request. Any attempt to derive meaning for an advance request/directive will require holding a special regard for future selves. Theoretically, we could attempt to motivate the advance request from a position of an objective third party who was determining what was in the best interests of the person in a paternalistic way. However, I believe endorsement of that ethical argument entails an entirely different application of advance requests where they need not be drafted by the person who would be the recipient. Instead, we could begin to draft advance requests for other people if we could argue we knew what was in their best interests. A full exploration of this line of argument is beyond the scope of this thesis.

If my arguments that the D-J-C interpretation of personal identity endorses the extreme claim are accepted, that implies that Dresser, Jaworska, and Carter's approaches cannot be applied to advance requests/directives because they inherently imply advance requests/directives are meaningless or face a logical inconsistency. Therefore, the use of the D-J-C interpretation of personal identity in advance requests/directives leads, not only to intuitively unacceptable results, but also to a logical inconsistency.

Pragmatic Concerns

I can also expand these arguments from the focused logical inconsistency with advance requests/directives to a broader pragmatic perspective. Even though I can provide no compelling argument to refute the extreme claim outright, I do believe that we must endorse the moderate claim in order to live our lives. When I put on my watch in the morning, I spend time adjusting the tightness of the watchstrap such that it will be comfortable for the whole day. I may pull to a certain tightness that is not uncomfortable in the moment, but I can predict will become uncomfortable after a few hours and loosen the watchstrap ever so slightly. When I do this, I endorse the moderate claim. I would also argue that the entire enterprise of medicine would have to be radically changed if we endorsed the extreme claim. Treating hypertension, diabetes, or encouraging exercise all clearly endorse a special regard for our future selves. Even taking an antibiotic to treat an infection endorses the moderate claim as the results will be seen in the future. Pushing this even further, if I receive an analgesic for current pain, the relief will still take minutes to take effect and therefore this treatment is done for a future self. If we were to endorse the extreme claim, it would entail completely changing how the medical world operates and how we live our everyday lives. Even though I can provide no compelling argument to refute the extreme claim outright, from purely pragmatic grounds, I can argue we ought to avoid the extreme claim.

Taken together, I have provided three reasons that we ought to avoid the extreme claim in the setting of advance requests and directives:

1) It will lead to intuitively unacceptable results,
2) It leads to logical inconsistencies, and
3) It leads to significant pragmatic concerns.

If we must avoid the extreme claim within the setting of advance requests/directives, then we only have one other option to consider when developing an approach to advance requests for MAiD: endorsing the moderate claim.

Endorsing the Moderate Claim

If I endorse the moderate claim when considering the latest version of the modified-Margo example, I now face an interesting tension between previous Margo who drafted the advance request for MAiD and current Margo with advanced dementia. A Best Interests, Values-Based, or Authenticity Approach would lead to overturning the advance request for MAiD out of respect for current Margo's best interests, *values*, or authentic self. However, this goes against the wishes of previous Margo. This is a tension between the previous Margo's right to self-determination and current Margo's right to self-determination[182] (which Dresser, Jaworska and Carter believe is derived from her best interests, *values*, or authentic self).

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[182] Recall that I am using the term self-determination in a special fashion here to capture both the usual use of the term (a person choosing for themselves) and the added self-determining of values or interests that would be maximized under considerations of beneficence – see Chapter 3.

Typically, when facing a disagreement between a past self and a current self, the current self takes priority. If I draft an advance directive against organ donation, and then, 10 years later, change my mind on the matter, I am permitted to change that advance directive in favor organ donation.[183] However, such cases do not have the direct tension that is seen in the current modified-Margo case. As regards organ donation, my previous self did not want their organs to be donated on their current understanding of the matter. This previous self did not say, I do not want my organs donated *and* if I change my mind on the matter, I still do not want my organs donated. [184]In the modified-Margo case, this is the situation. Previous Margo drafted an advance request for MAiD knowing that she would lose capacity and knowing that at that stage she may express an opposition to MAiD. The previous person's knowledge of the anticipated change of mind and request to ignore the change of mind is what creates the special tension here. Consider a simpler scenario to draw out this tension more clearly:

> *Isabella is a 27-year-old gun enthusiast with bipolar disorder. She can tell that she is at the early stages of an acute depressive episode. She knows this depressive episode will worsen and she will turn to alcohol to cope. Once she starts drinking, she will become suicidal. She approaches her friend, Bob, to hold on to her guns for her until the depression passes. She tells Bob that she will likely visit him while drunk during the depths of the depression and ask for her guns back so she can end her life. She advises Bob, in no uncertain terms, not to*

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[183] In this example, I assume that I have capacity at both time points.

[184] Theoretically, I could say "I do not want my organs donated *and* if I change my mind on the matter, I still do not want my organs donated." However, this is not what typically happens with consent. An exploration of this possibility is outside the scope of this thesis. My purpose here is to emphasize that the current person typically has priority if they have capacity.

> *give her back her guns. As expected, two weeks later, Isabella knocks at Bob's door late in the evening, clearly intoxicated, and asking for her guns so she can kill herself.*

The same tension is at play here as with our modified-Margo case. Previous Isabella's wishes are in direct conflict with current Isabella. Further, previous Isabella's wishes clearly stated not to give back the guns even if she changed her mind. If the extreme claim is endorsed, relation *R* provides insufficient connection between previous and current Isabella for any special regard between the two people. Assuming the extreme claim, if Bob wants to do right by his friend, Isabella, the only Isabella he can consider is the drunk Isabella at his door. The previous Isabella's wishes ought not to hold any sway over current Isabella – likewise, Bob cannot look to the future as there is no special regard under the extreme claim for future Isabella who is sober and no longer depressed.[185]

By contrast, under the moderate claim, previous Isabella, through relation *R*, does hold some connection worthy of special regard and Bob can consider his promise when facing drunk Isabella at his door.[186] Intuitively, it seems clear that Bob should not give the guns back but let's consider why: The intuitive response is that Isabella is currently

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[185] Taken to its logical conclusion, the extreme claim threatens any usual conception of friendship or relationship that persists through time. Therefore, this entire scenario seems to entail a logical contradiction under the extreme claim in a similar fashion as using the D-J-C interpretation of personal identity in advance requests/directives.

[186] One could argue that even if the extreme claim nullifies the promise to previous Isabella, Bob ought not to give the guns to current Isabella because letting her kill herself would be wrong all on its own. However, this argument would imply that a person ending their own life through a prescribed medication would also be wrong which calls into question the very practice of MAiD. A full exploration of this line of argumentation is beyond the scope of this thesis. However, I believe that the only way a person can assert that MAiD is permissible while also asserting that we ought to take measures to prevent an intoxicated person from attempting suicide is by invoking responsibilities to past or future selves which requires endorsement of the moderate claim.

drunk and depressed and ‘not in her right mind.’[187] I believe there is merit in this intuition and that exploring this intuition provides an answer that can then inform how we ought to approach advance requests for MAiD.

When we say Isabella is ‘not in her right mind,’ the initial thought is that she currently lacks capacity. However, Isabella could be depressed and drunk and still have capacity under the standard model of comparative decision-making capacity. She could be able to understand and appreciate the consequences of taking a gun to end her life or continue living. She may voice a clear understanding of her bipolar disorder and provide a reasonable assessment that results in dying being preferable to living based on her current values, preferences, and interests. While a *severely* intoxicated person may not be able to provide such a comparative analysis, there is a level of intoxication where there is insufficient alcohol to remove a person’s cognitive capacity for comparative decision-making, but there is sufficient alcohol to alter their balance of their values, preferences, and interests. Isabella finds herself in such a situation: She has capacity, but the balance of her values is sufficiently different such that she wants to end her life whereas she did not have such a wish while sober.

So, a lack of capacity is not sufficient grounds to say Isabella is ‘not in her right mind.’ Instead, I believe the key question to consider when exploring this intuition is *whose* right mind are we talking about when we say, ‘Isabella is not *her* right mind.’ I would argue, we are not talking about the current Isabella’s mind. When considering a person’s mind, we have argued for a reductionist view which would strip away any

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[187] A more sophisticated response could be that Isabella currently lacks capacity. However, Dresser, Jaworska, and Carter’s approaches are meant to deal in situations of lack of capacity. While they would not want their approaches to apply in cases of intoxication, I have already argued that there is no differentiation criterion that allows them to restrict application of their approaches in this way.

appeal to soul, Cartesian ego, or some further fact. Therefore, if we refer to Isabella's mind, we can only refer to features of her psychology such as memories, preferences, dispositions, or intentions. Alcohol and depression impact our psychology; however, the impacted psychological features are *all that is present* and are part of the psychological features that *are* current Isabella. What caused the existence of the current psychological features cannot be considered without invoking some further fact to differentiate certain psychological features from others. So, current Isabella is in the only mind that current Isabella has. There is no other *right mind* to appeal to. Therefore, when referring to *her* right mind, it would seem I am referring to some other Isabella aside from the current Isabella – likely I am referring to the previous Isabella who provided instructions not to give her back her guns.

This previous Isabella predicted that a future self would be afflicted by alcohol intoxication and anticipated this would change aspects of her psychological features in ways that the sober Isabella did not want and saw as external to her current understanding of herself. Previous Isabella and current Isabella are connected by relation *R*: Previous Isabella and current Isabella share both psychological continuity and a large portion of psychological connectedness, however, there are important differences that currently exist because of the intoxication of alcohol.[188] Psychological connectedness changes over time and is a natural and unavoidable part of our existence. However, the changes from alcohol are changes that sober Isabella is opposed to and sees as external to herself. Current/drunk Isabella is not in 'her right mind' as was explicitly defined by

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[188] For the sake of simplicity, I am focusing on the changes related to alcohol as it is more clearly an external influence on previous Isabella. The acute mental health issues could also be considered as unwanted influences. However, for the moment, I will focus on the alcohol for the purposes of introducing my arguments.

previous/sober Isabella. When Bob decides not to give the guns back to current Isabella, he does so because it is previous/sober Isabella who is his friend, and he wishes to do right by her. Previous/sober Isabella has instructed him that the changes that will be present in the current/drunk Isabella are changes that previous/sober Isabella does not want to occur and sees as external to herself.

Under the extreme claim, there is no connection between previous Isabella and current Isabella that is worthy of special regard. Bob may wish to do right by his old friend, previous/sober Isabella, however, he recognizes that previous Isabella has no special claim to what happens to current Isabella. Under the extreme claim, if he wishes to withhold the guns, he will have to do so from paternalistic grounds. There is merit to that claim, however, Dresser, Jaworksa, and Carter all claim that their approaches avoid paternalism and endorse self-determination (in slightly different ways).

Under the moderate claim, there is a connection between previous Isabella and current Isabella that is worthy of special regard. Parfit explicitly states he has no advice to provide on how to interpret the weight of special regard if the moderate claim is endorsed, however, at least there is some footing for Bob to deny current/drunk Isabella the guns out of respect of the special regard between previous and current Isabella. He is still siding with his old friend's wishes over the wishes of the drunken person in front of him. However, he has grounds to do so under the moderate claim that do not exist in the extreme claim.

In this scenario, previous Isabella identified the future alcohol intoxication as an anticipated influence on her psychological connections that she identified as unwanted and external to her. The moderate claim provides us grounds to respect the wishes of the previous person in these situations. In general, the changes that happen to our psychological connections are not anticipated, unwanted, or regarded as external to ourselves. As I age, I develop new memories, foster new preferences, and develop new intentions. This is part of our usual existence. A young rebellious teen who loves punk music may hate to learn that they would later become a corporate lawyer who listens to soft rock, however, there is no predictable, unwanted, external influence that the teen can point to in the same way that previous Isabella can point to the alcohol.[189] To drive this point home, lets consider one last thought experiment:

> *Planet Earth is under threat from an alien race that can alter our psychological connections in subtle but important ways – which is referred to as mind control. The alien mind control leaves almost all our psychological features intact: Memories, dispositions, intentions, and preferences are almost all identical before and after mind-control. The only changes are the creation of two preferences: A mind-controlled human wants to be mind-controlled and wants the aliens to rule humans. Any psychological connections that need to be altered to provide consistency with these preferences are made but otherwise the human has the same psychological connections as before. Thankfully, human scientists have developed an easy cure for mind control. I have signed an advance directive to be given the cure if I suffer from mind-control. Soon after signing the advance directive, I become a victim of alien mind-control. I now have the settled*

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[189] Arguably, the rebellious teen may be able to point to concerted influence of social media, advertising, and societal norms, as an external force that has predictable and unwanted influence. However, this line of argument does not undermine my approach.

> *disposition, values, and expressed best interests in favor of alien mind-control and preference for the aliens to become our overlords.*

Under Dresser, Jaworska, or Carter's approaches, the advance directive should be overturned, and I would live the rest of my life under mind-control, supporting alien domination. However, under the moderate claim, my previous self does have some moral connection to my current self. They are psychologically continuous and share the majority of psychological connectedness. However, there is a tension between the self-determination of my previous self and current self. My previous self saw the mind-control as an anticipated, unwanted, and external influence on his psychological connections. That previous self would see themselves as still existing within the current self. However, the current self is a conglomeration of the previous self (the relation *R* that they considered to be them) *and* these unwanted psychological connections (those caused by the alien mind-control). If we have a moral duty to the previous self, then we ought to provide the cure for mind-control.

I believe we could consider intoxication, sepsis-induced delirium, and Alzheimer's dementia in the same light as the alien mind-control. Intoxication and sepsis-induced delirium are much easier to see in this light. The alcohol and infectious agents are more clearly seen as external. Alzheimer's dementia is more difficult to characterize in this way. The changes that occur in Alzheimer's dementia happen much more gradually and more closely mimic the personality changes that happen during healthy aging. However, it is a disease under almost any possible definition of disease. During the early stages, it can seem like variation on usual biological functioning, but this is not the case. Autopsied brains reveal amyloid deposits and have characteristic histopathological findings. While the pathophysiology of Alzheimer's dementia is poorly understood, there is a standard pathophysiological process that is occurring where a physical disorder in the brain leads to the psychological changes that are characteristic of the disease. Likewise, disordered physical underpinnings can be pointed to in other dementias like Lewy-Body and vascular dementia.[190]

When pushed on the point, I readily admit that there is a no clear metaphysical distinction as to what should be considered an external influence on my psychological connections. Hence, I have been stating that it is an external influence as determined by the person in question. It is quite possible that someone may be diagnosed with Alzheimer's dementia and consider that this disease is now part of who they are. However, a person could equally be diagnosed with this disease and squarely consider it to be an anticipated external and unwanted influence on their psychology. While the self, as discussed by Parfit, does not exist the way it is commonly considered to exist, there is still something present that is *me* even if we accept Parfit's account. That *me* can only be constituted by relation *R*. Parfit's philosophy entails that I *am* relation *R*. If I see myself as my current relation *R* and then look to the potential impacts of alien mind-control as not being *me*, then I can argue that the future mind-controlled person is part *me* and part *something else.* There will be a future being that will be me *and* the influence of alien mind-control.[191] Likewise, if I am diagnosed with Alzheimer's dementia, I can consider that there will be another future being who is a conglomeration of the future me *and* the psychological influence from the Alzheimer's. However, when creating the advance

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[190] Keene, Montine & Kuller, "Epidemiology, pathology, and pathogenesis of Alzheimer disease."

[191] So far in this chapter, I have been primarily using the term 'person' in these descriptions but will shift to broader term 'being' for the remainder of this sub-section. Arguably, the conglomeration entities, as I conceptualize them here, ought not to be considered persons

request, I can do so with thought to the future *me* component of that future conglomeration and design advance requests in such a fashion to oppose that influence that I see as unwanted and external to the aspects of relation *R* that I see as being *me*. If I endorse the moderate claim, I can claim special regard over this future *me*; my wishes, as the being drafting the advance request, ought to have some special regard when considering the advance request in question.

It is worth noting that this special regard is founded on relation *R* which will diminish over time. While psychological continuity will likely hold, psychological connectedness will diminish over time. The psychological connectedness between current-me and tomorrow-me is much stronger than between current-me and 90-year-old me. Therefore, the special regard is stronger between current-me and tomorrow-me as compared to current-me and 90-year-old me.

In this section, I argued that by endorsing the moderate claim we can give some special regard to the previous being who drafted the advance request even when the current being has best interests, *values*, or authenticity that opposes the advance request. I argued that if we have a moral obligation to the previous being, we can side with that being so long as the opposition that arises from the current being is due to an anticipated influence that the previous being considered external and unwanted. In the next chapter, I will apply these implications from the moderate claim and the other three conclusions drawn from Parfit to advance requests for MAiD.

Chapter Summary

In the first section of this chapter, I argued that the narrative view provides neither necessary nor sufficient grounds for the persistence of personal identity. Dworkin's

Critical Interests Approach relies on the narrative view and therefore Dworkin's Critical Interests Approach lacks the necessary metaphysical foundation to provide a moral framework for advance requests for MAiD.

In the second section of this chapter, drawing largely from Parfit, I provided conclusions that would need to be incorporated into any metaphysically sound approach to advance requests for MAiD. In the third section, I noted that, unlike Dworkin, Dresser, Jaworksa, and Carter all rely on this necessary metaphysical footing. However, their approaches lack any reliable differentiation criteria to restrict them from being applied to all lack-of-capacity scenarios. Therefore, endorsement of their approaches would entail application of those approaches in scenarios where their approach would lead to intuitively unacceptable results. I argued that this occurs because their approaches rely on an interpretation of personal identity that endorses the extreme claim: Relation *R* does not provide grounds for any special regard for our past or future selves. If these approaches endorse the extreme claim, this also leads to a logical inconsistency:

1) For an advance request to be meaningful, we must hold special regard for our future selves, and
2) If the approach to advance requests endorses the extreme claim, we do not hold special regard for our future selves.

Therefore, it would be logically inconsistent to apply their approaches to advance requests/directives. I then provided a third line of argument against the endorsement of the extreme claim by highlighting some pragmatic concerns in the setting of advance requests, the medical environment, and our everyday lives. I then explored the moderate claim and argued that an endorsement of this claim may allow us an approach to advance requests that rests on solid metaphysical footing and overcomes the challenges of the D-J-C interpretation. In the next chapter, I will take this exploration a step further and propose my Moderate Approach to advance requests for MAiD.

Chapter 5

Moderate Approach to Advance Requests for MAiD

In the previous chapter, drawing from Parfit, I drew out the following conclusions to consider when developing an approach to advance requests for MAiD: We ought to adopt a *reductionist* view of personal identity, personal identity is *indeterminate*, and personal identity is not *what matters* – rather, what matters is relation *R*.[192] I also argued that any approach to advance requests/directives that endorses the extreme claim would lead to intuitively unacceptable results, logical inconsistency, and significant pragmatic concerns. Therefore, we ought to consider the moderate claim when developing an approach to advance requests for MAiD. Recall that the moderate claim states that relation *R* provides sufficient connection for special regard for our past or future selves. By contrast, the extreme claim states that we have no reason to care about what will happen to ourselves in future.

I argued that Dworkin's Critical Interests Approach fails due to a lack of sufficient metaphysical footing. While Dresser, Jaworska, and Carter's approaches have adequate metaphysical footing, their interpretation of personal identity implicitly endorses the extreme claim. Endorsement of the extreme claim leads to intuitively unacceptable results, logical inconsistency, and significant pragmatic concerns. If we could somehow overlook these problems, the approaches proposed by Dresser, Jaworska, and Carter *could* result in an advance request for MAiD being overturned *even if* the current person lacks capacity for a decision regarding MAiD. Under their approaches, the

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[192] Recall that relation *R* is a term Parfit uses to collectively capture both psychological connectedness and psychological continuity.

advance request is overturned if there is opposition due to considerations of best interests, *values*, or authenticity.

If the moderate claim is endorsed, I argued that the previous person who drafted the advance request can be given special regard when considering the current person's opposition as expressed through best interests, *values*, or authenticity.[193] This may result in a tension between the self-determination of the previous and current person even though the previous person no longer exists and the current person lacks capacity.[194] To resolve this tension, I propose that the previous person's wishes ought to be respected when the opposition is due to anticipated psychological influence that is seen as external and unwanted by the previous person. Central to my approach to advance requests for MAiD will be determining whether that opposition is due the usual evolution of psychological connections or is the opposition due to an unwanted, external influence: Has the person merely changed their mind or is the disease speaking for the person.

So far in this thesis, my analysis has been focused on ethical theory and the metaphysics of personal identity. In this section, as promised, I will show how the lessons learned through this analysis would play out in real-life as regards advance requests for MAiD. Based on these theoretical underpinnings, I propose the following guiding principles for advance requests for MAiD:

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[193] I will shift back to the term 'person' in this section as it is more focused on real-world application and therefore the term person provides greater clarity in the application of these recommendations. However, it is worth keeping in mind that it may be incorrect to apply the term 'person' to the conglomeration entities as I have conceptualized them.

[194] In the standard medical model of comparative decision-making capacity.

1. We ought to **maximize the psychological connectedness** between the person creating the advance request and the person who will be the subject of the advance request.
2. We ought to **anticipate potential tensions** between the wishes of the person creating the advance request and the best interests, *values*, or authenticity of the person who will be the subject of the advance request.
3. If this tension occurs, we ought to **resolve this tension** by determining if the opposition is due to a change of mind, in the usual sense, or due to an anticipated influence from the disease that is external and unwanted, as defined by the person who created the advance request.

1. Maximizing Psychological Connectedness

The most important implication of the reductionist view is that there is no *self* that exists above and beyond our physical and/or psychological states. There is no Judeo-Christian soul, Cartesian ego, Hindu atman, or some further fact. This entails that there is no constant *me*. Therefore, I cannot draft an advance request and anticipate it will hold for all time across all scenarios. As well, personal identity is not *what matters*, relation *R* is what matters. While psychological continuity will likely hold throughout dementia, psychological connectedness will change. To maximize the probability that the person creating the advance request is most closely connected to the person who will be the recipient of the advance request, the advance request should be drafted by a person most like that recipient. Therefore:

a) The advance request ought to be drafted after the diagnosis of the disease and the person has had time to consider the diagnosis and incorporate these considerations into their psychology.[195] Considerable psychological change happens after the diagnosis of a dementia-causing disease. As well, once the diagnosis is made, a person can better predict how they will change as the disease progresses,

b) The advance request ought to be updated at regular time intervals, while the person maintains capacity, to ensure that the advance request still fits with the person as they change over time,

c) So long as the person maintains capacity, the advance request ought to be updated after any major change in circumstances, such as change of health status or death of a loved one, as such changes could lead to changes in the person's psychology that could impact the advance request.

2. *Tensions between Temporally Distinct Selves ought to be Anticipated*

When drafting the advance request for MAiD, the person drafting the advance request ought to draft the advance request with anticipation of possible tension between their current wishes and their future self's wishes. Under the moderate claim, the future advance request will need to balance these tensions and resolve between them – this will be discussed in the next sub-section. Under Dworkin's Critical Interests Approach, the creator of the advance request for MAiD would have priority over the future person with advanced dementia. Under Dresser, Jaworska, and Carter's approaches, the future person with advanced dementia is likely to have priority in this tension. However, under the Moderate Approach, dealing with this tension is much more difficult. By anticipating this tension, the advance request can be written in a way that may avoid such tension:

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[195] This would only be possible if the dementia causing disease was diagnosed in the early to moderate stages of the disease. However, there are diagnostic tools and strategies that allow for diagnosis at these stages with sufficient reliability to allow for the drafting of an advance request.

a) The rationale behind the advance request for MAiD should be explored when drafting the advance request. The person should be aware that their disease process could follow many different variations and they may wish to nuance the advance request to fit with the various possible outcomes. For example, they may wish to provide qualifiers that the advance request for MAiD be postponed if they are in a happy Margo-like state during the advanced stages of dementia,

b) The person drafting the advance request for MAiD should include the rationale behind their decision for MAiD in the advance request. While they may consider various permutations of how the disease could impact their psychology, not all permutations can be considered. By providing their rationale, their future friends, family, and health-care team can assess the future tension and try to find a resolution that fulfills the wishes of the person who created the advance request for MAiD and the future person with advanced dementia.

3. Resolving Tension between Temporally Distinct Selves

For the vast majority of advance requests for MAiD, so long as they are drafted after the diagnosis is made, updated at regular intervals, and the rationale behind the advance request was explored and documented, I anticipate that it would be quite rare that a tension would occur between the pre-dementia person and the advanced dementia person. In most cases, a person with advanced dementia is not living a pleasant life like our Margo case. Further, I believe that most people drafting an advance request for MAiD would not want MAiD to occur while they were in a pleasantly confused state like Margo. I can imagine that the concerns of being a burden on family would be the primary cause for a person to draft an advance request to provide MAiD even if they are in a

Margo-like state. However, if our society can provide appropriate nursing home care or publicly funded in-home care, this could be avoided.[196] Regardless, there could arise a scenario where an advance request for MAiD exists and the person who created the request clearly wanted MAiD to occur once the person reached the advanced stages of dementia even if they were in a pleasantly confused state like Margo. This is the crux of the debate and resolution of this situation is the primary purpose of my in-depth analysis of personal identity.

Personal identity is *indeterminate* therefore I cannot assume that previous person's advance request ought to hold over current person because they are not necessarily the *same* person. Therefore, I cannot apply Dworkin's Critical Interests Approach. However, unless I endorse the extreme claim flowing from Parfit's conclusions, I cannot use the approaches of Dresser, Jaworska, or Carter because their approaches rely on an interpretation of personal identity that endorses the extreme claim.[197] An endorsement of the extreme claim entails that we have no special regard for our past or future selves, and the very act of drafting an advance request requires us to hold a special regard for our future self.

On the other hand, the moderate claim does allow me to give special regard for my future self so the act of drafting an advance request is consistent with an endorsement of the moderate claim. If I have endorsed the moderate claim (as is required to meaningfully draft and advance request), then I also have a special regard for the

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[196] Such considerations of justice are important. The less resources dedicated towards nursing homes and end-of-life care, the more 'tough' cases that will arise. This should be seen as a call for our society to do more for the people living those 'tough' cases. However, a person should not be denied MAiD because our society should have done more. A full exploration of these issues are beyond the scope of this thesis.

[197] See my arguments in Chapter 4 for more details.

previous person who drafted the advance request when I am currently facing the person with advanced dementia.[198] However, the moderate claim does not state how that special regard is applied or what weight we give. The closer the psychological connectedness, the stronger the special regard. If we followed the previous suggestions, the advance request has been drafted by a person with maximal psychological connectedness. The question at hand is the merit we give the changes in psychological connections that have led to the opposition to the advance requests.

For clarity, this is a scenario of advanced dementia where capacity is in question. A person at Margo's stage of dementia may lack comparative decision-making capacity (DMC) for a decision regarding MAiD but have capacity to refuse MAiD under burdens-based or goals-based DMC.[199] To resolve the question of capacity in this scenario, we must also consider autonomy and self-determination. Specifically, who is the relevant *self* whose autonomy we ought to respect.[200] I proposed earlier that if the previous person identified an **anticipated** influence on their psychology that they considered to be **unwanted** and **external** then the psychological changes that stem from that influence may be disregarded as being distinct from the person themselves. The impact from the disease should not be seen as part of the person (assuming the person saw the influence of the disease as something distinct from themselves).[201] The conglomeration of the

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[198] Note, this does not negate any special regard that exists for the current person.

[199] See Chapter 3, page 45 for an explanation of burdens-based and goals-based DMC

[200] In Chapter 3, I proposed the use of the term self-determination to encompass both the usual sense of the term as synonym for autonomy and the self-determined values, interests, and preferences we should consider under the principle of beneficence. I could also add the considerations of beneficence here and say which *self* is the relevant *self* when determining the values, interests, and preferences we should consider under the principle of beneficence.

[201] This is similar to Kant's perspective of true autonomy being the choices of the rational self and all other influences being heteronomous influences. However, in my approach, the desires, preferences, and inclinations are part of our *selves,* whereas Kant saw these influences external to our true rational selves. In my approach, the external influences are from the dementia-causing disease.

underlying person and the influence from the Alzheimer's dementia should not be seen as the relevant *self*. Instead, we ought to strip away the influence of the Alzheimer's dementia to get at the morally relevant *self* whose autonomy is worthy of our respect. If we can get at this relevant underlying person's autonomous wishes, then the person has capacity. However, if the influence of the Alzheimer's dementia prevents us from getting at the underlying person, then the person no longer has capacity. This assumes that the pre-dementia person had identified the disease process as an external and unwanted influence on their psychology. This leads to the following recommendations when trying to resolve the tension:

a) Can the current person with advanced dementia understand the reasons that the previous person provided for the advance request for MAiD?
    i. If they cannot understand these reasons, this is likely due to the disease process. If their disease has caused a cognitive deficit that has led them to be unable to understand these reasons, then the change in psychology that is causing the tension is due the disease. If the previous person considered that disease to be external and unwanted, then the opposition to MAiD is coming from the disease, not the person.[202] The advance request should be respected.
    ii. If they can understand the reasons that the previous person provided for the advance requests, their opposition to MAiD is likely due to a change of mind, rather than due to the disease.

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[202] Previously, I noted that the line between person and external sources is not completely clear. However, it is worth noting that the concept of *person* is a social construct and not a true metaphysically real thing beyond social constructs. To enact laws, advance requests, and allow society to function, we must rely on this social construct. A full exploration of this consideration is beyond the scope of this thesis.

I believe this recommendation is the most important result from this project so I would like to provide a brief example of how this would play out in real-life. For this example, I return to the most recent version of the modified-Margo scenario and apply my strategy for resolving the tension between the previous person's wishes and the current person's opposition as expressed through best interests, *values*, or authenticity.

In the most recent modified-Margo case, Margo's physician was struggling to determine if the advance request for MAiD ought to be respected. Previous Margo wanted to receive MAiD if she was no longer able to care for herself at home because she did not want to be a burden to her family and wanted her grandchildren to go to university. Due to the advancement of her disease, she no longer knows she has any family and, therefore, cannot understand the primary rationale behind her decision to have MAiD. She is happy in her home but cannot remain there without private in-home support or having her adult children move in with her. She does not want to go to a nursing home and still reports that she would rather die than go to a nursing home. However, due to her advanced disease she cannot understand the consequences of remaining at home. She does not understand that she cannot care for herself, and she cannot appreciate the consequences on her family if they set up the needed care to keep her at home. Her disease has impacted her psychology in the exact unwanted way that previous Margo anticipated and saw as external to her. In this scenario, the opposition to the advance request is due the disease and not due to an evolution of Margo (as Margo defined herself). MAiD ought to be performed.

Performing MAiD in these circumstances would entail challenges. Doing so in a way that was not distressing to Margo would be difficult. Further, I would anticipate emotional distress on the family, MAiD provider, and other people in Margo's life.[203] However, I believe it is the right thing to do. Intuitively, I feel distress that the current Margo would have her happy life cut short and that this is a moral harm to a vulnerable person. However, previous Margo is equally vulnerable. While previous Margo is no longer in existence, denial of the option of advance requests for MAiD would have caused harm to Margo when she did exist. Previous Margo would have chosen to die at a much earlier stage in her disease when she still had capacity to consent to MAiD. In doing so, she cuts her life much shorter and current Margo would never exist. Contrast this with a final modified-Margo example:

> *At the early stages of dementia, Margo drafted an advance request for MAiD to occur when she reached the advanced stages of dementia. She did so because she thought that anyone at such a stage would have intolerable suffering in terms of agitation, paranoia, and constant fear. Unfortunately, serial assessments do not occur. Years later, Margo has entered a pleasantly confused state in her advanced dementia. She lives at a nursing home and enjoys her peanut butter & jelly sandwiches and art classes. Her advance request triggers a request for MAiD and the medical team assesses her along with her family. While she cannot understand the proposed procedure, nor why this medical team is interviewing her, when she is asked if she is suffering, she can clearly advise them that she is*

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[203] The emotional distress on the family may lead them to want to overturn the advance request as substitute decision-makers (SDM). However, SDMs are expected to make decisions regarding what the patient would have wanted and not based on their own emotional distress. The Moderate Approach is intended to assist SDMs in determining what the patient would have wanted. Therefore, the Moderate Approach has indicated the advance request ought to be respected, then it would entail that it is what the patient would have wanted and would be the decision the SDM ought to endorse.

> *not suffering. She can also voice that she enjoys her current life and would like to continue living.*

There is an apparent conflict between the advance request for MAiD and the current best interests of Margo.[204] The advance request instructs us to end Margo's life, however, this would cut short the pleasure that she is currently experiencing. This returns us to the tension between autonomy and beneficence that was the central to Chapter 3. Current advanced dementia Margo does not have the cognitive abilities required for comparative DMC. However, she may have capacity for refusal under other models such as burdens-based DMC or goals-based DMC. An approach to advance requests for MAiD will require a way to deal with the uncertainty in these cases.

A change has occurred between when Margo drafted the advance request for MAiD and reaching her current state of advanced dementia. Previous Margo wanted MAiD to occur when she reached the advanced stages of dementia because she would not want to suffer in that state and current Margo reports she is not suffering. While current advanced dementia Margo does not have comparative DMC regarding MAiD, she does have capacity to tell us that she is not suffering. Determining the nature of this change is important in order to resolve the tension between previous Margo and current Margo. Recall that the moderate claim does provide special regard for our past selves so we cannot outright disregard the advance request in favor for the current person. I argued that anticipated, unwanted changes that happened due to an external influence ought to be disregarded when attempting to resolve the tension.[205] In this situation, previous Margo anticipated the disease was going to lead to agitation, paranoia, and suffering. This is not

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[204] Depending on which approach we adopt, we could also say current *values* or authentic self.

[205] Recall that this is external and unwanted as defined by the person themselves.

the case. In this case, we have no reason to believe that her pleasant confusion is unwanted. It is hard to determine if she would have considered it external. It could be that the dementia has reduced cognitive abilities in such a way that all that is left is sensory enjoyment or she may have developed her own focus on the simple pleasures in life as often happens as humans age. In the absence of serial assessments, it is hard to know. However, based on the information we do have in the case, it would seem the change that has occurred cannot be attributed to the disease itself and could be reflective of a natural change that occurred in Margo within the setting of other disease-related changes.

While Margo lacks the comparative DMC to refuse MAiD, she does have capacity to inform us that the rationale behind her previous decision for MAiD is no longer accurate. Recall, in this case pre-dementia Margo wanted MAiD when she reached the advanced stages of dementia because she thought that she would be suffering. Current advanced dementia Margo can tell us that she is not suffering. Therefore, when trying to resolve the tension between pre-dementia Margo's advance request and current advance dementia Margo's enjoyment of life, we can overturn the advance request for MAiD and still feel confident that we have given the appropriate special regard for pre-dementia Margo. In this way, the Moderate Approach still endorses the moderate claim.

The Moderate Approach provides a result in this case that appeals to a common intuition. If the clinicians for this latest Margo turned to the family and asked if they should proceed with MAiD, the family would likely say, "No, I don't think Margo would have wanted MAiD if she had known she was going to be so happy at this stage of her life." The pre-dementia Margo they knew was worried about suffering (as opposed to being a burden on her family or a loss of dignity). The reason this intuitive result occurs is because the family is thinking back to what pre-dementia Margo would have wanted.[206] They are providing special regard to her past self in keeping with the moderate claim.

Contrasting the Moderate Approach to Dworkin, Dresser, Jaworksa, and Carter

This approach varies from Dworkin's Critical Interests because it denies that our life narrative is the foundation of our personal identity and denies that critical interests hold priority. Under Dworkin, the whole life narrative creates a binding force across our lifetime that creates persistent and determinate *self*. If this determinate *self* exists, then it gives much greater force to an advance request for MAiD. However, as noted in Chapter 4, this position does not have solid metaphysical footing. Instead, our *self* is likely indeterminate. The Moderate Approach recognizes this and therefore advance requests hold less strictly. In terms of real-world application, this means that a person can still 'change their mind' even if they can no longer consider their whole life narrative.[207]

The Moderate Approach varies from Dresser, Jaworska, and Carter because it does not place absolute priority on the current person. While each approach focuses on a different consideration, in all approaches if the current person's consideration of interest stands in opposition to the advance request, the advance request may be overturned. The previous person's wishes only serve to inform about current person's best interests, *values,* or authentic self. This endorses the extreme claim which entails that relation *R* does not provide grounds for special regard for our future or past selves. The Moderate

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[206] Note, this does not mean that the advance request for MAiD is completely nullified. The advance request for MAiD could become relevant later in Margo's disease if she begins to suffer in the way she feared.

[207] It is worth noting that a person could have comparative DMC and therefore have capacity under the standard medical model and *not* be able to conceive of their whole life narrative. In this way, Dworkin's requirements for capacity for autonomous decisions is stricter even than the current medical model.

Approach endorses the moderate claim such that our past self can have some special regard for our current self. Therefore, when a tension exists between the wishes of the previous person who created the advance request and the current person with advance dementia, the current person does not trump the previous person. Instead, I propose we ought to aim to resolve this tension because both the current *and* past persons hold special regard.

In Chapter 4, I argued that there was nothing inherent in Dresser, Jaworska, and Carter's approaches that prevented their approach from being applied to non-dementia cases. It is worth noting that there is nothing inherent in the Moderate Approach that prevents it from being applied outside dementia cases, either. However, the fact that the Moderate Approach endorses the moderate claim leads to vastly different results as compared to the Best Interests, Values-Based, or Authenticity Approaches. A full exploration of how the Moderate Approach would apply to all loss-of-capacity scenarios is beyond the scope of this thesis. However, I will return to one example from Chapter 4 to quickly elucidate how the Moderate Approach avoids the problems faced by those other approaches.

Recall Siti, the musician suffering from sepsis-induced delirium, who wants to leave the hospital to practice for her upcoming gig. Under the Moderate Approach, pre-sepsis Siti still warrants special regard. We can reasonably assume that pre-sepsis Siti would have wanted to remain in hospital to receive the potentially life-saving therapies. There has been a change of mind and current-sepsis Siti wants to leave. This change is due to a confusion that is an anticipated result from the sepsis. Pre-sepsis Siti would have seen this as unwanted and external to her. Therefore, the change is due to the disease and not due to a change in Siti. Therefore, we respect the underlying Siti when we ignore her desire to leave the hospital.

Chapter Summary

In this chapter, I described the Moderate Approach to advance requests for MAiD. This approach endorses the moderate claim that relation *R* provides sufficient connection for special regard for our past or future selves. This can lead to a tension between the previous person that created the advance request and the current advanced dementia person who may 'express' opposition in the form of best interests, *values*, or authenticity. I argue that this tension can be overcome if the opposition stems from an anticipated influence on the previous person's psychology that they considered to be unwanted and external. I described how the proposed Moderate Approach would provide real-world recommendations for advance requests for MAiD. These recommendations rely on reliable metaphysical foundations that are lacking in Dworkin's Critical Approach. Unlike Dresser, Jaworksa, and Carter's approaches, the Moderate Approach remains logically consistent when applied to advance requests/directives because it endorses the moderate claim rather than the extreme claim.

In the final chapter, I will provide a summary of the arguments laid out in this thesis. I will briefly consider implications of my arguments for legislation and practice standards and compare my proposed approach to some of the ways that advance requests for MAiD have been implemented internationally. I will close by describing some limitations of this thesis and propose some future directions for research in this area.

Chapter 6: Conclusion

In Chapter 1, I laid out the purpose of this thesis: To provide a metaphysically sound, ethical approach to advance requests for MAiD in the setting of dementia. I also discussed some considerations regarding the concepts of capacity, autonomy, and self-determination that must be kept in mind when approaching advance requests in the setting of dementia. While comparative decision-making capacity is the current standard in medicine there are other models that hold merit.

In Chapter 2, I reviewed the legal standing of MAiD in jurisdictions where advance requests for MAiD are permitted. I noted that these jurisdictions had quite variable approaches to advance requests for MAiD which ought to prompt further exploration of the topic. Within the Canadian context, I also contrasted the legal standing of advance requests for MAiD and advance directives for other life-or-death medical decisions. At the close of the chapter, I argued that there was no ethical distinction between a patient's decision regarding MAiD, withholding therapy, or withdrawing intervention so long as all other relevant factors are the same. If there is no ethical distinction between these life-and-death decisions, then it is odd that the legal standing of these decisions is so different.

In Chapter 3, I described various approaches to advance directives for life-or-death decisions. Specifically, I provided a summary of Dworkin's Critical Interests Approach, Dresser's Best Interests Approach, Jaworska's Values-Based Approach, and Carter's Authenticity Approach. I noted some common themes between these approaches. The authors of these approaches note the apparent tension between autonomy and beneficence when considering advance directives for life-or-death decisions for patients with advanced dementia. To overcome this apparent tension, these approaches tend to point towards some overarching guiding concept that helps overcome the tension. In all approaches, the overarching guiding concept emphasizes *self-determination*[208] as a paramount consideration. I noted that the primary tension between these authors lies between their approach to personal identity. On one side, Dworkin argues that our life narrative creates a foundation for persistence of personal identity. On the other side, Dresser, Jaworska, and Carter endorse Parfit's account of personal identity and note that personal identity is indeterminate and therefore may not persist in some cases of advanced dementia. According to Dresser, Jaworksa, and Carter, even if an advance request exists, we must take measures to ensure that the current advanced dementia person would want the advance request to be enacted even if they lack capacity for the decision in the standard medical sense. For Dresser, we ought to look at their current best interests, for Jaworska we ought to look at their current *values*, for Carter we ought to look to their current authentic self. While these authors all point towards a slightly different factor to determine if the current advanced dementia person would want the advanced request enacted, they all rely on an interpretation of indeterminacy of identity that emphasizes the current advanced dementia person's wishes.

In Chapter 4, I explored the issues around persistence of personal identity in more depth. First, I argued that Dworkin's narrative view of personal identity does not have sufficiently solid metaphysical grounding to support his Critical Interests Approach. I then explored other views of persistence of personal identity. Drawing from Parfit, I

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[208] Recall, I am using self-determination to collectively capture both the normal use of the term (e.g., autonomy, choosing for oneself), and the strategy of prioritizing self-determined interests, values, and preferences when considering beneficence.

proposed the following conclusions to consider when developing an approach to advance requests for MAiD: We ought to adopt a *reductionist* view of personal identity, personal identity is *indeterminate*, and personal identity is not *what matters* – rather, what matters is relation *R*. I also argued that any approach to advance requests/directives would have to endorse the moderate claim or else would be logically inconsistent.

In the latter half of that chapter, I argued that Dresser, Jaworska, and Carter have difficulty restricting their approaches to just cases of dementia. However, if their approaches are applied to other loss-of-capacity scenarios (e.g., delirium, intoxication, mental illness), they provide intuitively unacceptable results. I argued that the reason that their approaches are unable to partition themselves to only dementia cases is because they implicitly endorse the extreme claim. Therefore, there are also logically inconsistent.

In the Chapter 5, I proposed that the Moderate Approach as a metaphysically sound, ethical approach to advance requests for MAiD. The Moderate Approach relies on the following guiding principles, primarily drawn from Parfit's view of persistence of personal identity:

1. Following Partfit's *reductionist* view of an *indeterminate* self, we recognize that the author of the advance request (the person who drafts the advance request) and subject of the advance request (the person who may receive MAiD because of the advance request) cannot be assumed to be the same person in a definitive and absolute sense. Therefore, the advance request cannot hold in an absolute sense.
2. The only connection that matters between the author and subject (of the advance request) is relation *R*: psychological connectedness and psychological continuity.

Therefore, the stronger the connection via relation *R* between author and subject, the greater the authority of the advance request.

3. Logical consistency requires us to endorse the moderate claim when approaching advance requests, therefore relation *R* provides sufficient grounds for special regard for our past and future selves, therefore we must consider both the author and the subject when approaching an advance request.
4. A dementia-causing disease can influence relation *R* in ways that could be considered external to a person's self-defined boundaries of *self*. If the author anticipated the changes due to this external influence and deemed them unwanted, those changes ought to be attributed to the disease and not the person themselves.

These guiding principles can provide the following real-world safeguards and considerations:

1. To maximize the psychological connectedness between the author and subject, the advance request ought to be drafted after the diagnosis of the disease and the person has had time to consider the diagnosis, updated at regular time intervals or after any major change in circumstances (assuming the person maintains capacity).
2. We ought to anticipate potential tensions between the wishes of the author and the subject when drafting the advance request. The person should be aware that their disease process could follow many different variations and they may wish to nuance the advance request to fit with the various possible outcomes. The person drafting the advance request for MAiD should document the rationale behind their decision. This will assist their family and healthcare team in determining if the

tension between the author and the subject is due to a true change in the *self* or the disease process.[209]

3. If a conflict between the author and subject's wishes occurs, this tension ought to be resolved by determining if the opposition is due to an actual change of mind of the person who created the advance request or due to an anticipated influence from the disease that is considered to be external and unwanted. Can the current person with advanced dementia understand the reasons that the previous person provided for the advance request for MAiD?
   a) If they cannot understand these reasons, this is likely due to the disease process. If their disease has caused a cognitive deficit that has led them to be unable to understand these reasons, then the change in psychology that is causing the tension is due the disease. If the previous person considered that disease to be external and unwanted, then the opposition to MAiD is coming from the disease, not the person. The advance request should be respected.
   b) If they can understand the reasons that the previous person provided for the advance requests, their opposition to MAiD is likely due to a change of mind, rather than due to the disease. In which case, the advance request for MAiD may be overturned.

Legislation, Practice Standards & Guidelines

I believe that these recommendations could provide clear guidance for families and healthcare professionals when facing an advance request for MAiD. I also believe that they could be drafted into the format of a usable clinical practice guideline or

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[209] Recall, the disease process is defined from the patient's perspective as an anticipated influence that they have deemed external and unwanted.

practice standard. In Canada, regulations concerning MAiD have been primarily founded in legislation and, to a lesser extent, the practice standards of provincial medical regulatory bodies.[210] However, there is a growing push to implement regulations concerning MAiD to be founded in practice standards rather than legislation.[211,212] Practice standards can be drafted in the language that is more relevant to healthcare professionals; such standards also have greater flexibility in the face of evolving medical knowledge and practices. Legislative changes will be required to allow advance requests for MAiD in the way suggested by the Moderate Approach. However, the Moderate Approach's safeguards and considerations would be best captured under practice standards or guidelines rather than legislation.[213]

Practice standards could draw on the guiding principles of the Moderate Approach when determining the logistics of the actual MAiD procedure. For example, practice standards ought to describe how the procedure is explained to a person who is still conscious but lacks capacity to understand the decision regarding MAiD. Likewise, standards should advise around the use pre-emptive sedatives, and whether their administration should be explained to the patient. A full exploration of these logistics is beyond the scope of this thesis.

While the Moderate Approach is founded on lengthy and complex metaphysical and ethical arguments, I believe the proposed safeguards and considerations can be understood and appreciated in the absence of the background arguments. If I am correct

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[210] These have generally been the practice standards of provincial regulatory colleges for physicians, nurses, and pharmacists.

[211] Health Canada, "Final Report of the Expert Panel on MAiD and Mental Illness," 48-53

[212] Canadian Medical Association, "Committee Appearance – Justice and Human Rights."

[213] Practice standards could be developed under the auspices of provincial medical regulatory organizations, such as the regulatory colleges, or practice guidelines could be developed by medical organizations such as the Canadian Association of MAiD Assessors and Providers.

in that assumption, then the Moderate Approach could assist MAiD assessors facing cases of advanced dementia. There is growing support for advance requests for MAiD among Canadian physicians. One study recently showed that the majority of physicians in Quebec are in favor of extending advance requests for MAiD to patients at the terminal stage of dementia; however, there was much less support in the setting of advanced dementia.[214] I believe that the decreased support may lie in the ethical uncertainty in cases like our modified-Margo. The Moderate Approach could assist physicians and nurse practitioners in facing that uncertainty.

International Comparison

The Moderate Approach would permit advance requests for MAiD in the setting of advanced dementia so long as the appropriate safeguards and considerations were met. This is also the case in other jurisdictions where advance requests for MAiD are permitted (i.e., Belgium, Luxembourg, the Netherlands, and Colombia). The Moderate Approach would permit the provision of MAiD in both conscious and unconscious patients, whereas Belgium and Luxembourg only allow advance requests in unconscious patients and the Netherlands only allows advance requests in conscious patients.[215]

The Moderate Approach also diverges from other jurisdictions with its complete emphasis on the patient's subjective perspective. While the Moderate Approach may shift which *self* we should be considering when interpreting the advance request for MAiD, it is always a *self* of the patient and never requires an objective observer to determine whether the suffering is intolerable or the acceptability of potential treatments. That said,

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[214] Bravo et al, "Quebec physicians' perspectives on medical aid in dying for incompetent patients with dementia," 738.

[215] Colombia makes no specific mention of consciousness vs unconsciousness. However, I found no evidence of any case of an advance request for MAiD in a conscious patient in Colombia.

this emphasis on the subjective perspective of the patient has been a common theme in all previous Canadian legislation surrounding MAiD. While it may be a divergence from other international jurisdictions, this divergence has been the case since Bill C-14 and was further emphasized in Bill C-7. Among jurisdictions that permit advance requests for MAiD, Canada may be alone with this patient-centred approach to MAiD; however, there are many other jurisdictions that permit MAiD, but do not permit advance requests (yet), that have adopted Canada's more patient-centred approach.[216]

Limitations

There are many issues that touch on the arguments contained within this thesis but, unfortunately, a full exploration of all these issues would be outside the scope of the thesis. I have tried to note these issues throughout this thesis. However, there are a few especially significant ones that warrant specific mention here.

First, a larger discussion of capacity, autonomy, and self-determination would likely augment clarity around both the ethical and metaphysical aspects of this thesis. As noted in Chapter 1, autonomy can be defined in various formats. For Kant, any choice not driven by reason was not autonomous. By contrast, modern bioethics typically allows a choice to be considered autonomous even if those choices are influenced by desires and preferences outside what Kant would call pure reason. In this thesis, I have argued that if the anticipated psychological changes that have happened due to a dementia-causing disease were considered to be external and unwanted from the perspective of the pre-dementia person, then those changes ought to be attributed to the disease and not the person. Therefore, such influence is in opposition to the person's autonomy, and we

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[216] Ministère de la Santé et des Services sociaux, "L'aide médicale à mourir pour les personnes en situation d'inaptitude: le juste équilibre entre le droit à l'autodétermination, la compassion et la prudence," 73-95.

ought not to respect the choices formed from that influence. This is a controversial argument and I recognize that my proposed Moderate Approach would fail if this argument does not hold. However, a full defence of this argument would require an in-depth exploration of autonomy that is beyond the scope of this thesis.[217]

Second, when discussing Dresser, Jaworska, and Carter's view of persistence of personal identity, I collectively referred to their view as the D-J-C interpretation of personal identity. There are nuances to their approaches that have slightly different applications for persistence of personal identity and, therefore, also implications for capacity, autonomy, and self-determination. I must admit that dealing with these author's approaches collectively as the D-J-C interpretation glosses over some interesting nuances in their views. However, dealing with each author's view independently would have made this (already lengthy) thesis much longer without adding a lot of substance. I believe that these subtle nuances do not change the resulting conclusion: All author's approaches implicitly endorse the extreme claim that flows from Parfit's work on persistence of personal identity.

Finally, this thesis relies heavily on Parfit's work on personal identity. If Parfit's view is wrong, this would undermine many of my arguments. While I may feel confident that Parfit's approach to persistence of personal identity is sound, his approach is not without critics. While a full defence of his philosophy is beyond the scope of this thesis, I could argue that his approach need not have universal acceptance to inform an approach to advance requests for MAiD. In developing legislation or practice standards around

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[217] Despite the apparent controversy, this view of autonomy may be adaptable to other interpretations of autonomy such as Michael Garnett's negative social view of autonomy – see Garnett, "Taking the Self out of Self-Rule," 31-32.

advance requests for MAiD, we can acknowledge uncertainty regarding the correct philosophic approach to persistence of personal identity. We can then develop these regulations in a fashion that builds on our ‘best guess’ while allowing the opportunity to adapt these regulations as our understanding of persistence of personal identity evolves.[218]

Future Directions

Beyond Dementia

This thesis has focused on advance requests for MAiD in cases of dementia. However, there are many other medical conditions which pose ethical challenges for advance requests for MAiD. Dementia-causing diseases tend to progress in a relatively predictable fashion over the course of years. This lends itself to the Moderate Approach to advance requests for MAiD. However, patients who suffer strokes or sudden brain injury may find themselves in conditions that they would have deemed worse than death. The pre-stroke/head injury person may have wished to have MAiD in their post-stroke/head injury condition, however, they would not have had an opportunity to draft an advance request for MAiD given that they could not have predicted they were going to have a stroke or head injury; by contrast, a person diagnosed with early dementia can draft an advance request with knowledge of their future advanced dementia condition. Future work could explore if there is a way to maximize psychological connectedness between the person before and after the stroke/head injury in such a way to allow for reliable advance requests for MAiD. Similarly, there may be interesting applications for

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[218] Sneddon, "Indeterminacy of identity and advance directives for death after dementia."

the Moderate Approach in other conditions that can impact capacity such mental illness, or substance-use disorder.

Beyond MAiD

The safeguards and considerations proposed by the Moderate Approach are not required when drafting advance directives for withholding potentially life-saving therapies or withdrawing life-sustaining interventions. As argued in Chapter 2, advance requests/directives for these life-or-death decisions ought to be seen as ethically equivalent when all relevant considerations are kept constant. It should then seem odd that the Moderate Approach be applied to MAiD and not withholding therapies or withdrawing interventions. Future work could look at how the Moderate Approach could be applied to advance directives for withholding/withdrawing. While a full exploration of this topic is beyond the scope of this thesis, I suspect that the Moderate Approach would not lead to a significant change in *which* cases advance directives for withholding/withdrawing are permitted. Instead, I suspect it may provide greater clarity to the uncertain cases. By encouraging more of the rationale behind the advance directive and consideration of different prognosis directions, I suspect that advance directives for withdrawing/withholding would become more robust and provide greater clarity for families and healthcare professionals struggling to interpret advance directives for withholding therapies or withdrawing interventions.

Beyond Documented Advance Requests

Throughout this thesis, I’ve been working with the scenario where the patient has a clear, documented advance request for MAiD. However, the Moderate Approach could be applied to scenarios in the absence of a documented request. Even in the absence of a documented advance directive, families can often advise the healthcare team to withdraw life-sustaining interventions if they believe that the withdrawal would be what the patient would have wanted. This also happens for withholding therapies. Given my previous arguments regarding the ethical equivalence of MAiD and withdrawing/withholding, it is possible that MAiD may be permissible if a patient lacks capacity and it is clear that it is what the patient would have wanted, even in the absence of a documented advance request. This would be a highly controversial practice and a full exploration is beyond the scope of this thesis. However, the guiding principles of the Moderate Approach could be helpful in determining whether such a practice ought to be permitted or not.

Beyond the Patient and the MAiD Provider

A typical MAiD request will have two primary agents: The patient requesting MAiD and the clinician(s) who will assess if the patient meets criteria for MAiD and then provide MAiD as requested by the patient. Typically, the patient maintains capacity throughout this process and no other agents need to enter this requester-provider relationship. Obviously, friends, family, and other members of the healthcare team can provide information to assist the assessment and are also impacted by the provision of MAiD. However, these other agents do not enter the specific request-provision relationship. With advance requests for MAiD, these other agents enter as intermediaries of this request-provision process. Some friend, family member, or healthcare provider must recognize when the 'trigger' for the advance request has occurred (e.g., the patient has reached the advanced stages of their disease) and approach the MAiD provider. This entails a series of new ethical considerations. For example, it places a new onus on the friend or family member who is expected to recognize and act on the trigger for the advance request. I believe the Moderate Approach could be of use in navigating these considerations. However, a full exploration of this added dynamic is beyond the scope of this thesis.

Chapter Summary

The purpose of this thesis was to provide a metaphysically sound, ethical approach to advance requests for MAiD in the setting of dementia. This chapter provided a review of my proposed Moderate Approach to advance requests for MAiD, as well as a summary of the arguments in support of this approach. I also described how the Moderate Approach could be implemented into real-world practice by opening legislation to a broader application of advance requests and incorporating the safeguards and considerations of the Moderate Approach into practice standards. I also compared how implementation of this Moderate Approach would compare to implementation of advance requests for MAID in other international jurisdictions where such requests are currently permitted. Finally, I described some limitations of this thesis and possible directions for future work in this area.

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