END-OF-LIFE CHOICE FOR PEOPLE LIVING WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS: COMPARING AMERICAN AND CANADIAN APPROACHES

by
*Amy Subach**

This Note argues for an expansion of end-of-life choice for people diagnosed with Alzheimer's Disease and Related Dementias in the state of Oregon, using both Canadian waiver of final consent and Supported Decision-Making models, with additional proposed safeguards to prevent coercion and missed diagnoses of treatable conditions.

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* J.D., *magna cum laude*, Lewis & Clark Law School. I would like to thank Professor Barbara Safriet for her guidance and wit; Jess Pezley and Kevin Díaz for their patience and support; Sun, Michaela, Heather, Connor, Andrew, and Adam for always sharing their brilliant, beautiful minds; Lekadia for our Tabor Stairs walks and karaoke therapy; my sister Ruth for caring for our mom and being my biggest cheerleader; my mom for showing me how to live a life dedicated to service; the stellar team at LCLR; and my children Irma Anderson and Isaac Subach for their sacrifices and love while their mom went to law school. This Note is dedicated to all the people who, when discussing this topic with me, vulnerably shared their stories, fears, and hopes concerning end-of-life care.

INTRODUCTION

As the population of the United States ages, more people will be diagnosed with Alzheimer's Disease and other types of dementia (also referred to as Alzheimer's Disease and Related Dementias or ADRD).[1] Because people in the later stages of dementia are considered incompetent to make medical decisions, they are ineligible for Medical Aid in Dying (MAID) in the 11 U.S. jurisdictions where MAID is available, even if they otherwise meet the criteria of having a terminal prognosis of less than six months to live (either from Alzheimer's, which is fatal, or from another terminal condition).[2] The desire to avoid suffering and how we define suffering[3] at the end of life and access to end-of-life choices are issues of bodily autonomy—issues that the American and Canadian Supreme Courts have come to deeply different conclusions on.[4]

Currently, in the United States, there are limited options for people diagnosed with ADRD who do not want to live through an extended decline, or who have one

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[1] ALZHEIMER'S ASS'N, 2023 ALZHEIMER'S DISEASE FACTS AND FIGURES 20 (2023), https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf.

[2] Vincent Thériault, Diane Guay & Gina Bravo, *Extending Medical Aid in Dying to Incompetent Patients: A Qualitative Descriptive Study of the Attitudes of People Living with Alzheimer's Disease in Quebec*, 4 CAN. J. BIOETHICS 69, 70 (2021) ("Allowing MAID at the beginning of the disease while the person is still competent risks ending life prematurely, while at the terminal stage it may be impossible to ensure that the person really wants to die due to their inability to communicate clearly."); *Medical Aid in Dying*, COMPASSION & CHOICES, https://www.compassionandchoices.org/our-issues/medical-aid-in-dying (last visited Aug. 6, 2024).

[3] Suffering usually refers to physical pain in the MAID context, but there are good reasons to include non-physical suffering when considering the reasons people should be able to access MAID. "Many persons' greatest concerns about living long into dementia are losing the ability to recognize friends and loved ones and becoming unaware of their own existence." Gina Bravo, Lise Trottier, Claudie Rodrigue, Marcel Arcand, Jocelyn Downie, Marie-France Dubois, Sharon Kaasalainen, Cees M. Hertogh, Sophie Pautex & Lieve Van den Block, *Comparing the Attitudes of Four Groups of Stakeholders from Quebec, Canada, Toward Extending Medical Aid in Dying to Incompetent Patients with Dementia*, 34 INT'L J. GERIATRIC PSYCHIATRY 1078, 1083 (2019). In the Oregon Death with Dignity Act 2022 Data Summary, "[i]nadequate pain control, or concern about it" came in sixth place among the end-of-life concerns, with 31% of patients citing it as a reason they chose MAID. The top three reasons were: "[l]ess able to engage in activities making life enjoyable;" "[l]osing autonomy;" and "[l]oss of dignity" at 89%, 86%, 62%, respectively. PUB. HEALTH DIV., OR. HEALTH AUTH., OREGON DEATH WITH DIGNITY ACT 2022 DATA SUMMARY 14 (2022).

[4] *Compare* Washington v. Glucksberg, 521 U.S. 702 (1997) (holding that a law in Washington state that prohibited causing or aiding suicide did not violate the Due Process Clause of the U.S. Constitution), *and* Vacco v. Quill*,* 521 U.S. 793 (1997) (holding that a law in New York that prohibited assisting suicide did not violate the Equal Protection Clause of the U.S. Constitution), *with* Carter v. Canada (Att'y Gen.), [2015] 1 S.C.R. 331 (Can.) (holding that a law that prohibited physician-assisted death violated the Canadian Charter of Rights and Freedoms).

or more concurrent terminal diagnoses in addition to ADRD.[5] While some have the means and ability to travel to a country like Switzerland to access "accompanied suicide" from an organization like Dignitas, that is not possible for most people due to financial concerns, the desire to die at home with loved ones, and other considerations.[6] There is also the option to voluntarily stop eating and drinking (VSED), which involves the cessation of all food and liquids to hasten death, and possibly the cessation of certain medications.[7] VSED offers its own challenges, especially with caregiver compliance.[8]

The Canadian approach to end-of-life choice for people with ADRD offers another option for U.S. jurisdictions with MAID. In Canada, people with ADRD or other diseases that implicate a future decline in cognitive function can access MAID if they sign a Waiver of Final Consent while they are competent.[9] This document allows a person who meets the requirements for MAID in Canada who is in the earlier stages of ADRD to access MAID in a later, no-longer-competent state.[10] This option gives people with a diagnosis of dementia space and time to enjoy their life while relieving them of the stress, anxiety, and dread of being forced to live in a state of mental and/or physical decline that they deeply wish to avoid, perhaps because they have cared for a loved one through the end stages of dementia themselves.[11]

In this paper, I will briefly cover the recent legal history of MAID in the United States and Canada, and the current state of MAID and ADRD in both countries. Then I will discuss different types of dementia and their impacts on quality of life

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[5] Emily A. Largent, Jane Lowers, Thaddeus Mason Pope, Timothy E. Quill & Matthew K. Wynia, *When People Facing Dementia Choose to Hasten Death: The Landscape of Current Ethical, Legal, Medical and Social Considerations in the United States*, 54 HASTINGS CTR. REP. S18–S19 (2024).

[6] *Accompanied Suicide*, DIGNITAS, http://www.dignitas.ch/index.php?option=com_content&view=article&id=20&Itemid=60&lang=en (July 2, 2024). For a complex and compelling account of this scenario, see AMY BLOOM, IN LOVE: A MEMOIR OF LOVE AND LOSS (2022). The author recounts her husband's diagnosis with Alzheimer's, his decision to travel to Switzerland to use the services of Dignitas to end his life, and the process of navigating that decision with him. Interestingly, Dignitas requires that people "be of sound judgment," and Bloom spends a lot of time trying to find a psychiatrist who will override a previous diagnosis of depression in her husband's medical chart, because a diagnosis of depression disqualified him from using Dignitas. *Id.*

[7] *Voluntarily Stopping Eating and Drinking*, COMPASSION & CHOICES, https://www.compassionandchoices.org/our-issues/vsed (last visited Aug. 6, 2024); Thériault et al., *supra* note 2, at 69.

[8] Rob Kuznia, *In Oregon, Pushing to Give Patients with Degenerative Diseases the Right to Die*, WASH. POST (Mar. 11, 2018, 11:48 AM), https://www.washingtonpost.com/national/in-oregon-pushing-to-give-patients-with-degenerative-diseases-the-right-to-die/2018/03/11/3b6a2362-230e-11e8-94da-ebf9d112159c_story.html.

[9] Thaddeus Mason Pope, *Medical Aid in Dying and Dementia Directives*, 4 CAN. J. BIOETHICS 82, 83–84 (2021). Each province has its own form. *E.g.*, B.C. MINISTRY OF HEALTH, MEDICAL ASSISTANCE IN DYING WAIVER OF FINAL CONSENT (2022), https://www2.gov.bc.ca/assets/gov/health/forms/1645fil.pdf.

[10] Pope, *supra* note 9, at 84.

[11] Dawn MacKeen, *'What if This Is My Destiny?' Children of Alzheimer's Patients Sometimes Fear Future Diagnosis*, N.Y. TIMES (Aug. 5, 2022), https://www.nytimes.com/2022/08/02/well/mind/alzheimers-caregivers.html?smid=url-share.

and competency. Then I will overview the legal issues surrounding how to determine competency in a person with ADRD and introduce the option of supported decision-making (SDM) as a way to extend competency for a person with ADRD. I will discuss how voluntarily stopping eating and drinking is another option, an option that is perhaps more difficult for people with dementia and their caregivers than MAID. I will also address some concerns that surround offering MAID to someone with dementia, including coercion from loved ones and insurance companies, and existential questions.

I will make a series of policy suggestions to increase end-of-life choices for people with ADRD: (1) Oregon should amend its MAID statute to include a provision allowing for a "waiver of final consent" following the Canadian model; (2) Oregon should allow access to MAID for people with ADRD or other types of incapacity who use supported decision making; (3) Oregon should require a neuropsychiatric assessment to ensure that the person requesting MAID through a waiver of final consent or SDM is not suffering from treatable depression that is causing them to be suicidal and that there is no underlying and treatable cause of dementia; and (4) Oregon should require a doctor or nurse practitioner to be present at MAID administration for people using a waiver or SDM to ensure that the choice is truly voluntary at the time the patient desires to utilize MAID.

I. MAID IN OREGON (AND OTHER U.S. JURISDICTIONS)

There is no federal constitutional right to MAID in the United States.[12] The Supreme Court held that "[t]he decision to commit suicide with the assistance of another may be just as personal and profound as the decision to refuse unwanted medical treatment, but it has never enjoyed similar legal protection," and that therefore it was not "deeply rooted in our history and traditions, or so fundamental to our concept of constitutionally ordered liberty, that [MAID is] protected by the Fourteenth Amendment."[13] However, the Supreme Court left the door open for the states,[14] and MAID is currently available in 11 U.S. jurisdictions: Oregon, Washington, California, Vermont, New Mexico, New Jersey, Colorado, Hawai'i, Montana, Maine, and the District of Columbia.[15] Due to the number of excellent articles available on the topic of MAID in the United States,[16] I will focus my overview of the recent history of the laws and use the current Oregon statutory scheme as a stand-in for all U.S. jurisdictions for the sake of brevity.[17] Oregon was first in the nation to allow MAID, by passing ballot measures in 1994 and again in

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[12] Washington v. Glucksberg, 521 U.S. 702, 728 (1997); Vacco v. Quill*,* 521 U.S. 793, 797 (1997).

[13] *Glucksberg*, 521 U.S. at 725, 727.

[14] *Id.* at 735.

[15] *Medical Aid in Dying*, *supra* note 2.

[16] *See, e.g.*, Thaddeus Mason Pope, *Legal History of Medical Aid in Dying: Physician Assisted Death in U.S. Courts and Legislatures*, 48 N.M. L. REV. 267 (2018).

[17] Washington Post Editorial Board, *Oregon's Death with Dignity Act a Model for Other States*, OREGONIAN, (June 22, 2015, 4:00 PM), https://www.oregonlive.com/opinion/2015/06/oregons_death_with_dignity_act.html.

1997 for the Oregon Death with Dignity Act (DWDA).[18] Most states with a statutory scheme that provides for MAID modeled their MAID legislation after Oregon's Death with Dignity Act.[19]

For a person to be eligible for MAID in Oregon they need to be over 18, diagnosed with a terminal illness with a prognosis of less than six months to live, capable, and acting voluntarily.[20] Both their attending physician and a consulting physician must agree that the person meets the requirements.[21] If there is a concern that the person "may be suffering from a psychiatric or psychological disorder or depression causing impaired judgment, either physician shall refer the patient for counseling."[22] The residency restriction in the Oregon law was repealed by the state legislature after a case was brought by a local physician and Compassion & Choices sued and reached a settlement with the state to remove the residency restriction.[23] Vermont also removed its residency restriction, but the other states still retain theirs, for now.[24]

A person who meets the requirements for MAID must make two oral requests to their attending physician, fifteen days apart, and one written request signed by two witnesses before their physician can prescribe it.[25] If the person is believed to have less than fifteen days to live, the fifteen-day requirement can be waived.[26] The patient can rescind their request at any time.[27]

A. Oregon's Statutory Definitions of Capacity and Informed Consent

While there are differences across states, the language in the statutes surrounding capacity follows the Oregon model. In the Oregon Death with Dignity Act, a person is capable to access MAID if,

> in the opinion of a court or in the opinion of the patient's attending physician or consulting physician, psychiatrist or psychologist, a patient has the ability to make and communicate health care decisions to health care providers,

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[18] *Id.*; OR. REV. STAT. § 127.800 (2023).

[19] Amelia Templeton, *What Oregon's Death with Dignity Settlement Means for Terminally Ill Patients from Out of State*, OPB (Mar. 31, 2022, 5:00 AM), https://www.opb.org/article/2022/03/31/what-oregons-death-with-dignity-settlement-means-for-terminally-ill-patients-from-out-of-state/. In Montana, a district court found that the Montana Constitution provides a constitutional right for a terminally ill patient to die with dignity. Baxter v. Montana, 224 P.3d 1211, 1214 (Mont. 2009). However, on appeal, the Montana Supreme Court did not reach the constitutional question because the issues could be settled at the statutory level. *Id.* at 1221. The Montana Supreme Court went as far as vacating the lower court's ruling on the constitutional right to die with dignity. *Id.* at 1222.

[20] OR. REV. STAT. §§ 127.800, 127.805 (2023).

[21] OR. REV. STAT. §§ 127.815, 127.820 (2023).

[22] OR. REV. STAT. § 127.825 (2023).

[23] Complaint at 1–2, Gideonse v. Brown, No. 21-CV-1568 (D. Or. Oct. 28, 2021); Notice of Settlement, Gideonse v. Brown, No. 21-CV-1568 (D. Or. Mar. 28, 2022); *Medical Aid in Dying: Residency Restrictions*, COMPASSION & CHOICES, https://www.compassionandchoices.org/legal-advocacy/residency-restrictions (last visited Aug. 6, 2024).

[24] *Medical Aid in Dying: Residency Restrictions*, *supra* note 23.

[25] OR. REV. STAT. §§ 127.810, 127.805, 127.840 (2023).

[26] OR. REV. STAT. § 127.840(2) (2023).

[27] *Id.* § 127.840(3).

> including communication through persons familiar with the patient's manner of communicating if those persons are available.[28]

Additionally, a patient's physician must ensure that they are making an informed decision "[i]mmediately prior to writing a prescription for medication under ORS 127.800 to 127.897 . . . ."[29] "Informed decision" is defined as

> a decision by a qualified patient, to request and obtain a prescription to end his or her life in a humane and dignified manner, that is based on an appreciation of the relevant facts and after being fully informed by the attending physician of: (a) His or her medical diagnosis; (b) His or her prognosis; (c) The potential risks associated with taking the medication to be prescribed; (d) The probable result of taking the medication to be prescribed; and (e) The feasible alternatives, including, but not limited to, comfort care, hospice care and pain control.[30]

There is no additional language in the statute as to what it means to be capable, or what methods a court or a medical professional should use to make the determination of capacity in this situation.[31] The requirements point to three abilities required for a patient to be considered capable under the statute: to make health care decisions, to communicate health care decisions, and to be "fully informed" about their disease and the MAID process.[32]

II. MAID IN CANADA

Section Seven of the Canadian Charter of Rights and Freedoms (the Charter) reads, "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."[33] The Charter was signed in 1982 and granted Canada "full control over its Constitution."[34] The relative youth of the Charter in comparison to the U.S. Constitution is just the beginning of the many differences between the Canadian and American approaches to MAID.

In *Carter v. Canada*, the Canadian Supreme Court held that Section Seven of the Charter required that MAID be legal for any "competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition."[35] The case was brought by Gloria Taylor, a woman who was suffering from Amyotrophic Lateral Sclerosis (ALS), and Lee Carter and Hollis

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[28] OR. REV. STAT. § 127.800(3) (2023).

[29] OR. REV. STAT. § 127.830 (2023).

[30] OR. REV. STAT. § 127.800(7) (2023).

[31] *See* OR. REV. STAT. §§ 127.800–127.897 (2023).

[32] OR. REV. STAT. §§ 127.800(3) (2023).

[33] Canadian Charter of Rights and Freedoms § 7, Part 1 of the Constitution Act, 1982, *being* Schedule B to the Canada Act 1982, c 11 (U.K.).

[34] *Learn About the Charter*, GOV'T CAN. (Apr. 5, 2022), https://www.justice.gc.ca/eng/csj-sjc/rfc-dlc/ccrf-ccdl/learn-apprend.html.

[35] Carter v. Canada (Att'y Gen.), [2015] 1 S.C.R. 331, para. 127 (Can.).

Johnson, who had brought their mother/mother-in-law Kathleen "Kay" Carter (who suffered from spinal stenosis) to Switzerland to access MAID at Dignitas in Switzerland.[36] They argued, along with the Canadian Civil Liberties Association, that the Canadian laws against assisted suicide and consent to murder violated the Charter's guarantees to "life, liberty and security of the person . . . ."[37] The Court agreed, writing in the introduction to the case:

> It is a crime in Canada to assist another person in ending her own life. As a result, people who are grievously and irremediably ill cannot seek a physician's assistance in dying and may be condemned to a life of severe and intolerable suffering. A person facing this prospect has two options: she can take her own life prematurely, often by violent or dangerous means, or she can suffer until she dies from natural causes. The choice is cruel.[38]

The Court initially gave lawmakers one year to enshrine their decision into statute and granted an additional four-month extension.[39] Notably, MAID was already available "in Quebec under certain conditions since December 10, 2015."[40] In June of 2016, the Canadian Parliament passed Bill C-14, allowing eligible Canadians who met the requirements laid out by the Supreme Court access to MAID.[41] Parliament added an additional requirement, though. Bill C-14 required natural death to be reasonably foreseeable for a person to be eligible.[42] This requirement was challenged and found to violate the Charter in a case that went to the Superior Court of Quebec, *Truchon c. Procureur général du Canada*.[43] After *Truchon*, Parliament passed Bill C-7 in March 17, 2021, which created two tracks: one track for people with a reasonably foreseeable death, and a second track for people without a reasonably foreseeable death.[44] The new law meant that people suffering solely from a mental illness could qualify for MAID, which became a cause of concern for many Canadians, so Parliament passed Bill C-39 "to extend the temporary exclusion of eligibility in circumstances where a person's sole underlying

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[36] *Id.* at para. 11.

[37] *Id.* at para. 40.

[38] *Id.* at para. 1.

[39] Carter, 1 S.C.R. at para. 147; *Canada's Medical Assistance in Dying (MAID) Law*, GOV'T CAN. (July 31, 2024), https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html.

[40] Thériault et al., *supra* note 2, at 69.

[41] *Legislative Background: Medical Assistance in Dying (Bill C-14)*, GOV'T CAN. (Feb. 2, 2023), https://www.justice.gc.ca/eng/rp-pr/other-autre/ad-am/p2.html.

[42] *Id.*

[43] Truchon v. Att'y Gen. of Canada, 2019 CanLII 3792 (Can. Que. Super. Ct.), at paras. 533–35.

[44] *Infographic: Canada's New Medical Assistance in Dying (MAID) Law*, GOV'T OF CAN. (Jul. 7, 2021), https://www.justice.gc.ca/eng/cj-jp/ad-am/infograph.html.

medical condition is a mental illness for a period of one year, until March 17, 2024."[45] Parliament further extended the deadline to March 17, 2027.[46]

A. Accessing MAID in Canada for People with and without a Reasonably Foreseeable Natural Death

After *Truchon* challenged the requirement of a reasonably foreseeable natural death, Parliament created a two-track process for people who had a reasonably foreseeable natural death (Track One) and those who did not (Track Two). To be eligible for MAID for either track in Canada, a person must:

> be 18 years of age or older and have decision-making capacity; be eligible for publicly funded health care services; make a voluntary request that is not the result of external pressure; give informed consent to receive MAID . . ., meaning that the person has consented to receiving MAID . . . after they have received all information needed to make this decision; have a serious and incurable illness, disease or disability (excluding a mental illness until March 17, 2024); be in an advanced state of irreversible decline in capability; have enduring and intolerable physical or psychological suffering that cannot be alleviated under conditions the person considers acceptable.[47]

C-7 relaxed the safeguards for people with a reasonably foreseeable natural death (Track One) and created stricter safeguards for people without a reasonably foreseeable natural death (Track Two).[48] To request MAID in Track One, a person must make a request in writing that is signed by an independent witness after they are informed that they "have a serious and incurable illness, disease or disability."[49] Their condition and eligibility must be confirmed by two nurse practitioners or doctors.[50] Finally, they "must be given an opportunity to withdraw consent and must expressly confirm that their consent immediately before receiving MAID . . . (however, this 'final consent' requirement can be waived in certain circumstances)."[51] Track Two adds several additional requirements. The medical professionals assessing the patient's eligibility must consult with a medical provider that has "expertise in the medical condition that is causing the person's suffering" if they do not have that expertise.[52] Additionally,

> the person must be informed of available and appropriate means to relieve their suffering, including counselling services, mental health and disability

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[45] *Canada's Medical Assistance in Dying (MAID) Law*, *supra* note 39; Holly Honderich, *Who Can Die? Canada Wrestles with Euthanasia for the Mentally Ill*, BBC (Jan. 13, 2023), https://www.bbc.com/news/world-us-canada-64004329; Clancy Martin, *Medical Assistance in Dying Should Not Exclude Mental Illness*, N.Y. TIMES (Apr. 21, 2023), https://www.nytimes.com/2023/04/21/opinion/medical-assistance-dying-mental-illness-maid.html.

[46] *Canada's Medical Assistance in Dying (MAID) Law*, *supra* note 39.

[47] *Id.*

[48] C-7 removed the 10-day reflection period between the approval and the receipt of MAID for Track One. *Id.*

[49] *Id.*

[50] *Id.*

[51] *Id.*

[52] *Id.*

> support services, community services, and palliative care, and must be offered consultations with professionals who provide those services; the person and the practitioners must have discussed reasonable and available means to relieve the person's suffering, and agree that the person has seriously considered those means; the eligibility assessments must take at least 90 days, but this period can be shortened if the person is about to lose the capacity to make health care decisions, as long as both assessments have been completed . . . .[53]

Importantly, people in Track Two are not able to waive their final consent to MAID, but if they are at risk of losing capacity, the 90-day assessment period can be shortened.[54]

B. *Canadian Waiver of Final Consent*

Under the Canadian system, since the enactment of C-7, people who have a reasonably foreseeable natural death are able to sign a waiver of final consent. The waiver's purpose is "to permit dying persons who have been found eligible to receive medical assistance in dying and are awaiting its provision to obtain medical assistance in dying even if they lose the capacity to provide final consent, except if they demonstrate signs of resistance to or refusal of the procedure."[55] The waiver is a written agreement between a patient who has capacity to consent and the medical or nurse practitioner where the patient consents to the administration of MAID by the practitioner on a future date.[56] If the person loses capacity to consent before the agreed-upon administration date, and "the person does not demonstrate, by words, sounds or gestures, refusal to have the substance administered or resistance to its administration," also known as an "incapacitated veto," the practitioner is allowed to administer MAID to the person "in accordance with the terms of the arrangement."[57] Parliament acknowledges "the inherent risks and complexity of permitting medical assistance in dying for persons who are unable to provide consent at the time of the procedure . . . ."[58] Each province has its own form for the waiver.[59]

Canadian stakeholders, including people with mild dementia, their caregivers and families, and medical providers, have shown strong support for MAID for

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[53] *Id.*

[54] *Id.*

[55] An Act to amend the Criminal Code (medical assistance in dying), S.C. 2021, C-7, pmbl. (Can.); HEALTH CAN., FOURTH ANNUAL REPORT ON MEDICAL ASSISTANCE IN DYING IN CANADA 2022, 12 (2023), https://www.canada.ca/en/health-canada/services/publications/health-system-services/annual-report-medical-assistance-dying-2022.html#a5.

[56] Act to Amend the Criminal Code § 3.2(a) (Can.); HEALTH CAN., *supra* note 55, at 12.

[57] Act to Amend the Criminal Code § 3.2(b)–(d) (Can.). *See* Pope, *supra* note 9, at 84.

[58] Act to Amend the Criminal Code pmbl. (Can.).

[59] *See, e.g.*, CAN. MINISTRY OF HEALTH, CLINICIAN AID D-1 – WAIVER OF FINAL CONSENT (2022), https://www.dyingwithdignity.ca/wp-content/uploads/2022/07/Clinician-Aid-D-1-Waiver-of-Final-Consent.pdf (Ontario's waiver); ALTA. HEALTH SERVS., WAIVER OF FINAL CONSENT (2021), https://www.albertahealthservices.ca/frm-21806.pdf (Alberta's waiver); B.C. MINISTRY OF HEALTH, MEDICAL ASSISTANCE IN DYING WAIVER OF FINAL CONSENT (2022), https://www2.gov.bc.ca/assets/gov/health/forms/1645fil.pdf (British Columbia's waiver).

people with dementia. A Canadian study to ascertain the attitudes of people with early-stage Alzheimer's disease toward allowing MAID for people with advanced dementia before C-7 was enacted found that people with dementia (who still had capacity to consent to the study) had overwhelmingly positive feelings about MAID in general and MAID for people with dementia, specifically the ability to waive their final consent.[60] A 2019 study of physicians, nurses, people over 65, and informal caregivers of people with dementia found that around 70% of respondents were comfortable with requesting MAID in the case that they or a close family member had advanced dementia under certain conditions.[61]

C. Comparing Canadian and Oregonian MAID Demographics

In Canada, as opposed to in the United States where self-administration is a requirement for MAID, provider administration makes up the vast majority of MAID: In 2022, there were fewer than seven instances of self-administration in Canada.[62] Canada began tracking "information related to race, Indigenous identity, and disability of those seeking MAID" in 2023, so demographic information will not be available until 2024.[63]

Of the people in Oregon who accessed MAID in 2022, "most patients were age 65 years or older (85%) and white (96%). The most common diagnosis was cancer (64%), followed by heart disease (12%) and neurological disease (10%)."[64] There has been much fear-mongering that MAID would end up being accessed by people at risk for exploitation or harm, but those fears have turned out to be unfounded.[65] Ninety-five percent had a high school diploma or higher, and 55% had a college degree or higher.[66] The average age of MAID recipients in Canada was 77 years old, and 63% listed cancer as their main condition.[67] For people without a foreseeable natural death, the main conditions cited were neurological (50%), other (37%), and multiple comorbidities (24%).[68] Of the 13,241 people who died from MAID in 2022, only 463 (4%) of them did not have a reasonably foreseeable natural death.[69] Also, 2022 was only the second year that MAID was

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[60] Thériault et al., *supra* note 2, at 69 ("Every participant said that they would ask for MAiD at some point should it become available to incompetent patients and most wished that it would be legal to access it through a request written before losing capacity.").

[61] Bravo et al., *supra* note 3, at 1080, 1084.

[62] HEALTH CAN., *supra* note 55, at 21.

[63] *Id.* at 8.

[64] PUB. HEALTH DIV., *supra* note 3, at 3.

[65] Anne Marie Su, Note, *Physician Assisted Suicide: Debunking the Myths Surrounding the Elderly, Poor and Disabled*, 10 HASTINGS RACE & POVERTY L.J. 145, 175 (2013) ("Thirteen years of data from Oregon's experience with [MAID] and three years of data from Washington show that careful monitoring, and other safeguards, can address the government's interest in protecting patients from mistakenly and involuntarily deciding to end their lives.").

[66] PUB. HEALTH DIV., *supra* note 3, at 11.

[67] HEALTH CAN., *supra* note 55, at 5.

[68] *Id.* at 34.

[69] *Id.* at 5, 34.

available for people without a reasonably foreseeable death.[70] "In 2022, 2,144 individual[s] [(13%)] who requested MAID died of another cause."[71]

People in Oregon ranked their top three reasons for choosing MAID as follows: "decreasing ability to participate in activities that made life enjoyable (89%), loss of autonomy (86%), and loss of dignity (62%)."[72] Only 31% of people who chose MAID in Oregon did so because of "[i]nadequate pain control" or the fear of inadequate pain control.[73] Since the implementation of DWDA in Oregon, only 66% of people who received a prescription for MAID ended up using the medication.[74] People in Canada choose MAID because of "the loss of ability to engage in meaningful life activities (86%), followed by loss of ability to perform activities of daily living (82%) and inadequate control of pain, or concern about controlling pain (59%)."[75] A higher percentage (almost double) of Canadians cite inadequate control of pain than Oregonians, and only 31% of people in Oregon listing it as a reason.[76]

D. *Current Controversies Concerning MAID Administration*

Canada's approach to MAID has been widely criticized since its inception for several reasons, including that there are cases where people have died from MAID for reasons more related to lack of services than grievous and irremediable suffering.[77] The amount of people accessing MAID in Canada has also caused concern.[78] In 2022, 13,241 people accessed MAID in Canada, making up 4% of total deaths in the country.[79] For comparison, Canada and California have similar populations, but only 853 people accessed MAID in California in 2022.[80] What accounts for this difference? Opponents of MAID in Canada point to a lack of rigorous vetting, "[l]ack of oversight," poorly worded and "undefined terminology," "suicide contagion," and a general tendency to focus on MAID as a solution to societal and social problems.[81] However, it seems likely that the requirement of multiple oral and written requests, a reluctance among many U.S. practitioners to offer MAID, and the requirement of a terminal diagnosis of six months or less are large factors in the difference between California and Canada.[82] Doctors in Oregon

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[70] *Id.* at 20.

[71] *Id.* at 51.

[72] PUB. HEALTH DIV., *supra* note 3, at 8.

[73] *Id.* at 14.

[74] *Id.* at 6.

[75] HEALTH CAN., *supra* note 55, at 31.

[76] PUB. HEALTH DIV., *supra* note 3, at 14.

[77] Ramona Coelho, John Maher, K. Sonu Gaind & Trudo Lemmens, *The Realities of Medical Assistance in Dying in Canada*, 21 PALLIATIVE & SUPPORTIVE CARE 871, 872 (2023).

[78] *Id.*

[79] HEALTH CAN., *supra* note 55, at 5.

[80] CAL. DEP'T OF HEALTH, CALIFORNIA END OF LIFE OPTION ACT 2022 DATA REPORT, 5 (2023), https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/CDPH_End_of_Life%20_Option_Act_Report_2022_FINAL.pdf; Coelho et al., *supra* note 77, at 872.

[81] Coelho et al., *supra* note 77, at 872–76.

[82] For a robust discussion on the difference between how Canada and the States approach

can opt out of participating in MAID, but practitioners in Canada must refer people who request MAID to a participating provider.[83] Additionally, U.S. facilities can prohibit their providers from providing patients with access to MAID.[84] Another factor might be how MAID is administered in Canada, as the vast majority of people in Canada elect to have a doctor or nurse practitioner inject them with the medications,[85] whereas in the States people must self-administer the medication, requiring a complicated process of opening over a hundred capsules and drinking an extremely bitter solution.[86] Another factor might be that even when people in Oregon get access to MAID, around a third of them die from their terminal illnesses or other causes before they access MAID.[87] In Oregon in 2022, 278 people died by accessing MAID, out of 431 people who had received prescriptions, including 32 people who died using prescriptions from previous years.[88] Nineteen percent (84) of the people who received a prescription for MAID in 2022 died from other causes, and the ingestion status is unknown for 101 people, 43 of whom died in 2022.[89] Over the lifetime of the statute, from 1997 to 2022, only 66% of people who obtained a prescription "died from ingesting the medications."[90] In contrast, 13% of people who requested MAID in Canada in 2022 died before they could receive MAID.[91] That so many people die from natural causes before accessing MAID in Oregon suggests that the six-month prognosis might prevent at least some of them from getting the chance to access MAID, although people also might feel comforted

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the duties of conscientious objector medical providers, see Dov Fox, *Medical Disobedience*, 136 HARV. L. REV. 1030, 1078 (2023) ("Canadian courts condition conscience exemptions for refusers on their pointing patients to a specific willing provider." (citing Christian Med. & Dental Soc'y of Can. v. Coll. of Physicians & Surgeons of Ont., [2019] 147 O.R. 3d 398, paras. 2, 7–8 (Can. Ont. C.A.))).

[83] OR. REV. STAT. § 127.885(4) (2023); Fox, *supra* note 82, at 1076; Megan S. Wright, *Equality of Autonomy? Physician Aid in Dying and Supported Decision-Making*, 63 ARIZ. L. REV. 157, 165 (2021).

[84] Paula Span, *The New Old Age, Aid in Dying Soon Will be Available to More Americans. Few Will Choose It*, N.Y TIMES (July 8, 2019), https://www.nytimes.com/2019/07/08/health/aid-in-dying-states.html ("A recent survey of 270 California hospitals, published in JAMA Internal Medicine, found that 18 months after implementation of the state's End of Life Option Act, more than 60 percent—many of them religiously affiliated—forbade affiliated physicians to participate.").

[85] Igor Stukalin, Oluwatobi R. Olaiya, Viren Naik, Ellen Wiebe, Mike Kekewich, Michaela Kelly, Laura Wilding, Roxanne Halko & Simon Oczkowski, *Medications and Dosages Used in Medical Assistance in Dying: A Cross-Sectional Study*, 10 CMAJ OPEN E19, E19 (2022) ("However, it is clear that, across Canada, self-administered MAiD is rare, with fewer than 7 cases reported.").

[86] Joel Krinsky*, Embracing the End: A Comparative Analysis of Medical Aid in Dying in Canada and the United States,* 48 BROOK. J. INT'L L. 331, 342, 351 (2022). For an anthropological perspective of how this process plays out in Oregon, see generally ANITA HANNING, THE DAY I DIE: THE UNTOLD STORY OF ASSISTED DYING IN AMERICA (2022). In Oregon and Vermont, MAID medications can be administered into the G-tube of a patient who is unable to swallow, as long as the patient is still "self-administering" the medication. Mara Buchbinder, *Access to Aid-in-Dying in the United States: Shifting the Debate from Rights to Justice*, 108 AM. J. PUB. HEALTH 754, 756 (2018).

[87] COMPASSION & CHOICES, MEDICAL AID-IN-DYING UTILIZATION REPORT 3 (2024).

[88] PUB. HEALTH DIV., *supra* note 3, at 3.

[89] *Id.* at 7.

[90] *Id.* at 6.

[91] HEALTH CAN., *supra* note 55, at 7.

just by knowing that they do not have to suffer longer than they want to and are thus able to die without the fear of unnecessary suffering.[92]

One's perspective on the relative rates of people in Canada and the United States accessing MAID depends on one's feelings towards MAID in general.[93] One study found that psychiatrists' feelings about MAID can influence their assessment of patient competency, creating another potential barrier to accessing MAID.[94] Studies have shown that "there is a risk that the personal core values of the physician may influence his/her assessment of the competence of a patient and that patient autonomy may be restricted due to normative preconceptions on the part of the physicians."[95] In other words, both cultural perspectives and the political milieu influence providers. Also, providers' internalization of these perspectives impacts how they treat their patients, not only in whether they will prescribe or administer MAID, but also in whether a provider will find a patient competent to make that choice for themselves.[96]

Disability rights advocates are among some of the most vocal opponents of MAID, along with Catholics and other religiously affiliated right-to-life organizations.[97] Disability rights advocates have argued "that deep-rooted bias against disability, filtered through powerful professional cultures, prevents people from exercising true freedom of choice in making decisions regarding the treatment of infants with disabilities, assisted suicide, and prenatal testing and selective abortion."[98] They also argue that because of the disability paradox, many people who have a dementia diagnosis will adjust to their diagnosis over time.[99] It is important to note that not all disability advocates agree, and some argue that access to MAID is a disability rights issue and may have implications involving the Americans with Disabilities Act.[100] A recent poll of people living with a disability

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[92] *See* PUB. HEALTH DIV., *supra* note 3, at 6; HANNING, *supra* note 86; Dallas R. Lawry, *Rethinking Medical Aid in Dying: What Does It Mean to 'Do No Harm?'*, 14 J. ADVANCED PRAC. ONCOLOGY 307, 314 (2023) ("Still others report a sense of comfort and control just by 'having the option,' even if they never ingest the medication." (citing Kathy Black & Ellen L. Csikai, *Dying in the Age of Choice*, 11 J. SOC. WORK END-OF-LIFE & PALLIATIVE CARE 27, 27–44 (2015))).

[93] David Brooks, *The Canadian Way of Death: The Outer Limits of Liberalism*, THE ATLANTIC, June 2023, at 87–88, 95.

[94] Jakov Gather & Jochen Vollman, *Physician-Assisted Suicide of Patients with Dementia: A Medical Ethical Analysis with a Special Focus on Patient Autonomy*, 36 INT'L J. L. PSYCH. 444, 447 (2013).

[95] *Id.*

[96] *Id.* at 444, 446, 448–51; Janine Brown, *Health-Care Providers and MAID: The Reasons Why Some Don't Offer Medically Assisted Death*, THE CONVERSATION (Jul. 17, 2022, 9:26 AM), https://theconversation.com/health-care-providers-and-maid-the-reasons-why-some-dont-offer-medically-assisted-death-186625.

[97] Span, *supra* note 84; Ben Colburn, *Disability-based Arguments Against Assisted Dying Laws*, 36 BIOETHICS 680 (2022). *See generally* Pew Research Center, *Religious Groups' Views on End-of-Life Issues* (2013), https://www.pewresearch.org/religion/2013/11/21/religious-groups-views-on-end-of-life-issues/.

[98] Samuel R. Bagenstos, *Disability, Life, Death, And Choice*, 29 HARVARD J. L. & GENDER 425, 441 (2006).

[99] Cees M.P.M. Hertogh, *The Misleading Simplicity of Advance Directives*, 23 INT'L PSYCHOGERIATRICS 511, 513 (2011).

[100] *See* Amitai Heller, *Comment: Further Consideration on the Relationship between the Americans with*

found that 79% of people living with a disability believed that "medical aid in dying should be legal."[101] Although some people have voiced concerns that MAID would be disproportionately used by vulnerable populations,

> [r]ates of assisted dying in Oregon and in the Netherlands showed no evidence of heightened risk for the elderly, women, the uninsured (inapplicable in the Netherlands, where all are insured), people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations.[102]

An abundance of books and articles have been written in medical, law, and bioethics journals, as well as in the press about the legality and ethical implications of MAID.[103] There is a robust debate surrounding the issue.[104] However, in places where MAID is available, like in Oregon, I believe it should be available to people with ADRD, as long as they give advanced consent when they have legal capacity, even if they do not at that moment have less than six months to live. This would require a thoughtful restructuring of Oregon's Death with Dignity Act. To understand what might be required, I will discuss ADRD and how it impacts capacity, and discuss supported decision-making.

III. ALZHEIMER'S DISEASE AND RELATED DEMENTIAS AND COMPETENCY

The Centers for Disease Control defines dementia as "not a specific disease but . . . a general term for the impaired ability to remember, think, or make decisions that interferes with doing everyday activities."[105] Under the UN Convention on the Rights of Persons with Disabilities, persons with disabilities, such as persons with dementia, are required to be recognized as persons before the law with legal capacity, and states are obliged to support their ability to make decisions with legal effect.[106] There are multiple types of ADRD, with different causes and courses of

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Disabilities Act, Supported Decision-Making, and Medical Aid in Dying, 80 WASH. & LEE L. REV. 617 (2023).

[101] SUSQUEHANNA POLLING & RSCH. INC., NATIONAL PUBLIC OPINION SURVEY CROSS TABULATION REPORT 4 (2023), https://bit.ly/SPRNatDisabilityPoll2023.

[102] Margaret P. Battin, Agnes van der Heide, Linda Ganzini, Gerrit van der Wal & Bregje D Onwuteaka-Philipsen, *Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in "Vulnerable" Groups*, 33 J. L. ETHICS MED. 591, 591 (2007).

[103] *See, e.g.*, Katelyn John, *The Ethical Debate on Death with Dignity*, MARKKULA CTR. FOR APPLIED ETHICS AT SANTA CLARA UNIV. (May 17, 2023), https://www.scu.edu/ethics/healthcare-ethics-blog/the-ethical-debate-on-death-with-dignity/; Tavis Carpenter & Lucas Vivas, *Ethical Arguments Against Coercing Provider Participation in MAiD (Medical Assistance in Dying) in Ontario, Canada*, 21 BMC MED. ETHICS (June 2020).

[104] Alexander I.F. Simpson, *Medical Assistance in Dying and Mental Health: A Legal, Ethical, and Clinical Analysis*, 63 CAN. J. OF PSYCHIATRY 80 (2018); Carpenter & Vivas, *supra* note 103 ("This legal change resulted from extensive public debate and disagreement over many of the profound ethical and practical implications of euthanasia.").

[105] *About Dementia*, CDC (Apr. 5, 2019), https://www.cdc.gov/aging/dementia/index.html.

[106] Theresa S. Wied, Julia Haberstroh, Jakov Gather, Tarik Karakaya, Frank Oswald, Mishal Qubad, Matthé Scholten, Jochen Vollmann & Johannes Pantel, *Supported Decision-Making in Persons*

progression.[107] Alzheimer's is the most common type of dementia, accounting for 60%–80% of all cases, but there are several other types, including Lewy-Body dementia and Frontotemporal dementia.[108] Although there have been some recently approved drugs that may slow the progression of Alzheimer's, there is no known cure, and Alzheimer's is fatal.[109] Within each type of dementia, there can be wide varieties of a person's experience of the progression of the disease in terms of when the disease starts, how quickly it progresses, and which symptoms dominate.[110] Just as no two people are exactly alike, no two people with dementia experience the exact same symptoms and progression.[111] This fundamental unknowability can cause anxiety among patients and their caregivers and families.[112] This fundamental unknowability also makes it difficult to make blanket statements about the capacity of people with ADRDs to make their own medical decisions.

Although Alzheimer's is a terminal disease, unlike people with a terminal diagnosis of stage four pancreatic cancer, where the outcome over the next year is almost certain,[113] and thus allows for a terminal prognosis and access to MAID, people with a diagnosis of mild dementia or early Alzheimer's do not qualify for a terminal diagnosis under existing Oregon MAID statutes because of the fundamental unknowability of the progression of the disease and the large variation in life expectancy.[114] People in the later stages of ADRD, who might have less than

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with Dementia: Development of an Enhanced Consent Procedure for Lumbar Puncture, 12 FRONTIERS IN PSYCHIATRY 1, 2 (2021) (citing G.A. Res. A/RES/61/106, annex, Convention on the Rights of Persons with Disabilities (Dec. 13, 2006)).

[107] *Dementia vs. Alzheimer's Disease: What is the Difference?*, ALZHEIMER'S ASS'N, https://www.alz.org/alzheimers-dementia/difference-between-dementia-and-alzheimer-s (last visited Aug. 6, 2024). For the purposes of this Note, I will alternate referring to ADRD and dementia when speaking generally, but will refer to Alzheimer's when speaking specifically about Alzheimer's.

[108] *What is Alzheimer's Disease?*, ALZHEIMER'S ASS'N, https://www.alz.org/alzheimers-dementia/what-is-alzheimers (last visited Aug. 6, 2024); *Types of Dementia,* ALZHEIMER'S SOC'Y, https://www.alzheimers.org.uk/about-dementia/types-dementia (last visited Aug. 6, 2024).

[109] ALZHEIMER'S ASS'N, *supra* note 108; *Deaths from Alzheimer's Disease,* CDC (May 26, 2017), https://www.cdc.gov/aging/publications/features/alzheimers-disease-deaths.html.

[110] *Stages of Alzheimer's*, ALZHEIMER'S ASS'N, https://www.alz.org/alzheimers-dementia/stages (last visited Aug. 6, 2024); Gather & Vollman, *supra* note 94, at 449 ("There is a high variability among individuals and general uncertainty as far as the temporal prognosis is concerned.").

[111] *The Seven Stages of Alzheimer's*, U. PENN. MED. (Dec. 31, 2020), https://www.pennmedicine.org/updates/blogs/neuroscience-blog/2019/november/stages-of-alzheimers; Thériault et al., *supra* note 2, at 69.

[112] *Caregiver Stress*, ALZHEIMER'S ASS'N, https://www.alz.org/help-support/caregiving/caregiver-health/caregiver-stress (last visited Aug. 6, 2024). Additionally, anxiety might be an early symptom of ADRD. Honor Whiteman, *Anxiety May be an Early Sign of Alzheimer's,* MED. NEWS TODAY (Jan. 12, 2018), https://www.medicalnewstoday.com/articles/320604. Caregivers are often concerned about whether they too will develop Alzheimer's. MacKeen, *supra* note 11.

[113] *Pancreatic Cancer Prognosis*, JOHNS HOPKINS MED., https://www.hopkinsmedicine.org/health/conditions-and-diseases/pancreatic-cancer/pancreatic-cancer-prognosis (last visited Aug. 6, 2024).

[114] René J.F. Melis, Miriam L. Haaksma & Graciela Muniz-Terrerab, *Understanding and*

six months to live, are typically no longer considered competent to make decisions about their own care.[115] Even if a person in Oregon with a diagnosis of mild cognitive impairment has a co-morbidity with a terminal prognosis of less than six months, they would need to access the MAID prescription and take it before they were perceived to have lost decisional capacity.[116] This could lead to someone hastening their death before they were ready because of the worry that they would no longer be considered capable by the time they were ready to die.

The number of people living with ADRD in the United States is projected to reach 14 million by 2060, up from 6.7 million in 2023.[117] ADRD disproportionately impacts Black and Hispanic people.[118] There is also evidence that "[l]iving in a poor neighborhood may increase the risk for the brain changes characteristic of Alzheimer's disease."[119] In the interests of healthcare equity,[120] it is imperative to ensure that all people are able to access quality dementia care and meaningful end-of-life choices. I argue that this should include access to MAID.

A. Progression of ADRD and Competency

There are several types of dementia that vary in cause, symptoms, age of onset, and speed of progression.[121] The most common type of dementia is Alzheimer's Disease, which the World Health Organization estimates accounts for 60%–70% of all dementias.[122] In addition to Alzheimer's, dementia can also be caused by other health issues, like infection, alcohol use, repeated head injuries, and nutritional deficiencies.[123] One person can have multiple causes and forms of dementia, as

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Predicting the Longitudinal Course of Dementia, 32 CURRENT OP. PSYCHIATRY 124, 125 (Mar. 2019); OR. REV. STAT. §§ 127.800, 127.805 (2023). People with an Alzheimer's diagnosis can live more than 20 years after their diagnosis, but the more typical lifespan is four to eight years. ALZHEIMER'S ASS'N, *supra* note 108. All current MAID statutes in the United States require a terminal diagnosis of six months or less to live. *Medical Aid in Dying*, COMPASSION & CHOICES, https://www.compassionandchoices.org/our-issues/medical-aid-in-dying (last visited Aug. 6, 2024).

[115] Thériault et al., *supra* note 2, at 69.

[116] *Medical Professionals: Introduction to Oregon's Death with Dignity (DWD),* END OF LIFE CHOICES OR., https://eolcoregon.org/medical-professionals/ (last accessed July 12, 2024).

[117] ALZHEIMER'S ASS'N, *supra* note 1, at 31; *About Dementia*, *supra* note 105.

[118] *About Dementia*, *supra* note 105; Erica Kornblith, Amber Bahorik, W. John Boscardin, Feng Xia, Deborah E. Barnes, Kristine Yaffe, *Association of Race and Ethnicity with Incidence of Dementia Among Older Adults*, 327 JAMA 1421, 1488–1495 (2022).

[119] Nicholas Bakalar, *Living in Poverty May Increase Alzheimer's Risk*, N.Y. TIMES (July 28, 2020), https://www.nytimes.com/2020/06/22/well/mind/living-in-poverty-may-increase-alzheimers-risk.html.

[120] Rachel Nall, *Health Equity: Meaning, Promotion, and Training*, MED. NEWS TODAY (Sept. 8, 2020), https://www.medicalnewstoday.com/articles/health-equity; Kathy L. Cerminara & Barbara A. Noah, *Removing Obstacles to a Peaceful Death*, 25 ELDER L.J. 197 (2017).

[121] *The Progression, Signs and Stages of Dementia*, ALZHEIMER'S SOC'Y (Feb. 24, 2021), https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/progression-stages-dementia.

[122] *Dementia*, WORLD HEALTH ORG. (Mar. 15, 2023), https://www.who.int/news-room/fact-sheets/detail/dementia.

[123] *Id.*

"[t]he boundaries between different forms of dementia are indistinct and mixed forms often co-exist."[124] Alzheimer's Disease "is still incurable to this day and its progression gradually affects cognitive functions and the ability to carry out activities of daily living. In the advanced stage, patients can suffer greatly physically and/or psychologically and most are unable to consent to care."[125] In some medical frameworks, dementia is broken into categories of pre-clinical, mild, moderate, or severe cognitive impairment; in others, specifically Alzheimer's, there are seven stages.[126] No matter how it is compartmentalized, ADRD is a progressive process that results in increasingly reduced cognitive function.[127] The progression of ADRD is both unknowable and inevitable, and "there are people with dementia whose suffering cannot be alleviated even with optimal medical treatment and psychosocial care . . . [who] are painful witnesses to the inevitable loss of their intellectual capabilities and are aware that, in the near future, they will be almost wholly dependent on others for help."[128] However, many become accustomed to the new reality of their lives as their dementia progresses.[129]

B. *How Competency is Assessed: Medical and Legal Worlds Collide*

The Oregon Death with Dignity Act requires a court, doctor, psychiatrist, or psychologist to assess whether the patient is "capable" of deciding to access MAID.[130] The Act defines capable as "a patient has the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available."[131] The physician must also confirm "[i]mmediately prior to writing a prescription for [MAID] . . . that the patient is making an informed decision."[132] An informed decision is defined as

> a decision by a qualified patient, to request and obtain a prescription to end his or her life in a humane and dignified manner, that is based on an appreciation of the relevant facts and after being fully informed by the attending physician of: (a) His or her medical diagnosis; (b) His or her prognosis; (c) The potential risks associated with taking the medication to be prescribed; (d) The probable result of taking the medication to be prescribed;

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[124] *Id.*

[125] Thériault et al., *supra* note 2, at 69.

[126] *Alzheimer's Stages: How the Disease Progresses*, MAYO CLINIC (Jun. 7, 2023), https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/in-depth/alzheimers-stages/art-20048448; *The 7 Stages of Dementia: A Comprehensive Guide*, RIGHT AT HOME, https://www.rightathome.net/central-texas/blog/7-stages-of-dementia-comprehensive-guide-for-caregivers (last visited Aug. 6, 2024).

[127] Gather & Vollman, *supra* note 94.

[128] *Id.* at 446.

[129] *See* Linda Clare, Laura D. Gamble, Anthony Martyr, Catherine Quinn, Rachael Litherland, Robin G. Morris, Ian R. Jones, & Fiona E. Matthews, *Psychological Processes in Adapting to Dementia: Illness Representations Among the IDEAL Cohort,* 37 PSYCH. AND AGING 526, 527 (2022).

[130] OR. REV. STAT. § 127.800(3).

[131] *Id.*

[132] OR. REV. STAT. § 127.830 (2023).

> and (e) The feasible alternatives, including, but not limited to, comfort care, hospice care and pain control.[133]

In other words, the patient must be capable of understanding the gravity of their diagnosis, the risks and finality of MAID, and the available alternatives to MAID. The DWDA does not inform physicians or courts of the methods they can use to determine if the patient has capacity to make an informed decision.[134]

A diagnosis of ADRD does not necessarily mean that a patient has lost the capacity to make medical decisions: "[e]ven within the population of persons diagnosed as having a form of dementia, such as Alzheimer's Disease, 'there is sufficient heterogeneity such that one cannot simply equate dementia with incapacity.'"[135] In other words, it is possible that a person with cognitive impairment could be capable of making their own medical decisions. Doctors and medical practitioners are trained to evaluate a person's level of cognitive impairment as well as their capacity to make medical and sometimes other decisions.[136] "Competency and capacity are often used interchangeably, but the term 'decisional capacity' usually refers to the immediate medical decision to be made whereas 'competency' is understood as a legal determination that focuses on the overall status of the patient."[137]

Practitioners perform assessments to measure the level of cognitive impairment in people over 65 or who appear to be experiencing dementia symptoms.[138] Some assessments take as little as three minutes, while others, such as a neuropsychological exam performed by a neurologist, are more in-depth and can take several hours.[139] Assessments of cognitive function can be performed as part of an annual physical, but the neuropsychological exam is more adept at determining the cause and extent of cognitive impairment.[140] Some assessments place people on a scale from no cognitive impairment to severe cognitive impairment, and some

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[133] OR. REV. STAT. § 127.800(7) (2023).

[134] OR. REV. STAT. § 127.830 (2023).

[135] Lois A. Weithorn, *Psychological Distress, Mental Disorder, and Assessment of Decisionmaking Capacity under U.S. Medical Aid in Dying Statutes,* 71 HASTINGS L.J. 637, 679 (2020) (citing SCOTT Y. H. KIM, EVALUATION OF CAPACITY TO CONSENT TO TREATMENT AND RESEARCH 42 (2010)).

[136] *See* Soumya Hegde & Ratnavalli Ellajosyula, *Capacity Issues and Decision-Making in Dementia*, 19 ANN. INDIAN ACAD. NEUROLOGY S34, S35 (2016).

[137] Brenna M. Rosen, *Supported Decision-Making and Merciful Health Care Access: Respecting Autonomy at End of Life for Individuals with Cognitive Disabilities*, 80 WASH. & LEE L. REV. 555, 568 (2023).

[138] *Assessing Cognitive Impairment in Older Patients*, NAT'L INST. ON AGING, https://www.nia.nih.gov/health/health-care-professionals-information/assessing-cognitive-impairment-older-patients (last visited Aug. 6, 2024). The American Academy of Family Physicians suggests several tests to measure cognitive function, including the Mini-Cog, the Montreal Cognitive Assessment (MoCA), the AD8 Dementia Screening Interview, and the Rowland Universal Dementia Assessment Scale (RUDAS). *Cognitive Evaluation,* AM. ACAD. FAMILY PHYSICIANS, https://www.aafp.org/family-physician/patient-care/care-resources/cognitive-care/cognitive-evaluation.html (last visited Aug. 6, 2024).

[139] *Cognitive Evaluation*, *supra* note 138; *Neuropsychology Services/Frequently Asked Questions*, RENAISSANCE SCH. MED. STONY BROOK UNIV., https://renaissance.stonybrookmedicine.edu/neuropsychology/faq (last visited Aug. 6, 2024).

[140] *Assessing Cognitive Impairment in Older Patients*, *supra* note 138.

have a cut-off score below which a further assessment of cognitive impairment is suggested.[141] For example, the Mini-Cog scores people on a scale from 0–5, with a score of 0–2 "indicat[ing a] higher likelihood of clinically important cognitive impairment" and "[a] total score of 3, 4, or 5 indicates lower likelihood of dementia but does not rule out some degree of cognitive impairment."[142] The Standardized Mini-Mental State Exam (SMMSE) has severity gradings of "could be normal," mild, moderate, and severe cognitive impairment, and the Montreal Cognitive Assessment (MoCA) similarly has mild, moderate, and severe gradings, which correlate to the early, middle, and late stages of the SMMSE.[143]

An assessment of cognitive impairment does not necessarily translate into a lack of decisional capacity: "one cannot simply equate dementia with incapacity."[144] Crucially, the existence of "[i]mpaired cognition does not equate to impaired decision-making capacity."[145] Determinations of medical capacity are made by assessing "the patient's ability to understand the situation, communicate choice, appreciate the potential outcomes of an illness, generally reason or rationalize, and consider the pros and cons of treatment."[146] Medical practitioners trained in assessing competency are seen as making a binary decision: either the person is competent to make a decision about their own medical care or they are not.[147] And medical practitioners' attitudes towards MAID can impact their competency assessments.[148] However, this seemingly binary decision is made in relationship to the type of decision the person needs to make: a different level of competency is required for the decision to take an over-the-counter pain killer than is to consent to hip replacement surgery—and certainly, an even higher level of competency would be required to consent to stop life-sustaining medical treatments or to access MAID.[149] Additionally, for people with dementia, it has been shown that "the degree of their capacity tends to be subject to temporal fluctuations."[150] Additionally, "[i]n the clinical competence assessment by the physician there is . . .

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[141] The RUDAS test sets this score at 22 out of 30 total points or below. NSW HEALTH, ROWLAND UNIVERSAL DEMENTIA ASSESSMENT SCALE ADMINISTRATION AND SCORING GUIDE 24, https://www.dementia.org.au/sites/default/files/2023-12/RUDAS-admin-scoring-guide.pdf.

[142] *Scoring the Mini-Cog,* MINI-COG, https://mini-cog.com/scoring-the-mini-cog/ (last visited Aug. 6, 2024).

[143] B.C. MINISTRY OF HEALTH, STANDARDIZED MINI-MENTAL STATE EXAMINATION (SMMSE) (2014), https://www2.gov.bc.ca/assets/gov/health/practitioner-pro/bc-guidelines/cogimp-smmse.pdf; *FAQ*, MOCA COGNITION, https://mocacognition.com/faq/ (last visited Aug. 6, 2024).

[144] KIM, *supra* note 135, at 42.

[145] Meghan McCarthy, *An Instrument Heard Round the World: How the Assessment of Capacity for Everyday Decision-Making, or ACED, Launched a Revolution in the Elder Care*, PENN MEMORY CTR. (Sept. 5, 2023) https://pennmemorycenter.org/aced-tool-2023/.

[146] Rosen, *supra* note 137, at 568–69.

[147] Gather & Vollman, *supra* note 94, at 447 ("[T]he assessment of competence must ultimately be in relation to the particular decision situation.").

[148] *Id.*

[149] *Id.*; Jalayne J. Arias, *A Time to Step In: Legal Mechanisms for Protecting Those with Declining Capacity*, 39 AM. J. L. & MED. 134, 137–138 (2013) ("Capacity is a continuum and is context-specific."); Rosen, *supra* note 137, at 569.

[150] Gather & Vollman, *supra* note 94, at 448.

the problem of low inter-rater reliability."[151] This means that different clinicians can make different assessments about the same person's capacity. In other words, the results of competency assessments can be influenced by the assessor's personal beliefs, the assessor making the assessment, the assessor's training, and the fluctuations of competency that are consistent with ADRD. Finally, decisional capacity is context-dependent on the gravity of the decision.[152]

This assessment of competency is further complicated when the reality of how many people make decisions is taken into account. For many people, decisions about health care are not made in isolation but rather in concert with other people, including family and medical providers.[153] In other words, truly autonomous decisions are rare, and holding patients up to "the ideal of fully or completely autonomous decision making strips their acts of any meaningful place in the practical world, where people's actions are rarely, if ever, fully autonomous. [. . .]. Such consequential decisions must be *substantially* autonomous, but being *fully* autonomous is a mythical ideal."[154] This understanding is reflected in Oregon's definition of capacity in the DWDA, which allows "communication through persons familiar with the patient's manner of communicating if those persons are available."[155] Although that statute does not explicitly allow for supported decision-making, it does reflect the reality that some factors in determining competency—being able to communicate a decision—do not necessarily need to be entirely autonomous.[156]

C. Supported Decision-Making as a Potential Way to Extend Competency for People with ADRD

Supported Decision-Making (SDM) is a process that allows people with cognitive impairments or other intellectual or developmental disabilities the ability to make their own decisions in concert with trusted supporters.[157] It "allows people with impaired decisional abilities to retain their decision-making independence by choosing friends and family members who help them make choices rather than make the choices for them."[158] Supported Decision-Making is a means for people with "marginal" decision-making capacity to make decisions for themselves with support.[159] As of December 2023, fifteen states and the District of Columbia have

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[151] *Id.*

[152] Rosen, *supra* note 137, at 569.

[153] Wright, *supra* note 83, at 173 ("Research has demonstrated that many persons, regardless of disability status, prefer to make serious and late-life healthcare decisions relationally—in consultation or collaboration with others and perhaps after accounting for others' interests—and still view themselves as deciding autonomously.").

[154] Gather & Vollman, *supra* note 94, at 447 (citing T. L. BEAUCHAMP & J.F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS (6th Ed. 2009)) (alteration in original).

[155] OR. REV. STAT. § 127.800(3) (2023).

[156] OR. REV. STAT. § 127.800(3), (7) (2023). *See generally* Thériault et al., *supra* note 2.

[157] Wright, *supra* note 83, at 170.

[158] *Supported Decision Making*, PENN MEMORY CTR., https://pennmemorycenter.org/supported-decision-making/ (last visited Aug. 6, 2024).

[159] *Id.* ("When an individual has full decision-making capacity, they make their own

enacted Supported Decision-Making agreement statutes.[160] SDM is an alternative to traditional model of guardianships for people with intellectual or developmental disabilities.[161] Guardianships have been described as a "civil death" and the "American Bar Association has criticized guardianship as a commonly abused practice that 'deprives an individual of virtually all legal rights.'"[162] SDM is preferable to guardianships because it is less restrictive and allows more decisional autonomy to people with intellectual or developmental disabilities and cognitive impairments.[163] The ability to decide for oneself is "a dignitary good" that is "linked to increased wellbeing."[164] SDM is based on the belief "that everyone should have equal legal capacity or equal power to exercise legal rights, an ideal found in the Convention on the Rights of Persons with Disabilities."[165] Scholars have argued that Supported Decision-Making is a potential avenue to ensure that people with a mild to moderate dementia diagnosis can access MAID if they desire and are otherwise eligible.[166] This would enable patients with mild to moderate stage ADRD and a separate terminal prognosis to access MAID with the support of their decision-making partners. This has the potential to alleviate some of the anxiety that goes along with the unpredictability of dementia and the stress of a terminal prognosis.

However, in states where both MAID and SDM are available, SDM does not currently make it possible for a person whose only terminal diagnosis is Alzheimer's to access MAID, because by the time a person enters end-stage Alzheimer's, they will be experiencing severe cognitive impairment, meaning that they lack even the marginal capacity to make decisions, and SDM will no longer be an option.[167]

D. *Advance Directives for VSED*

One option for people with dementia who want to hasten their death is to Voluntarily Stop Eating and Drinking (VSED). In states where MAID is not legal,

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decisions. When an individual lacks capacity, a surrogate will make decisions for the individual. Marginal capacity describes individuals with some inefficiencies in decision-making. If an individual has marginal capacity, supported decision making can be used to make the decision.").

[160] *Supported Decision-Making Agreement Laws in the U.S.,* SUPPORTED DECISION-MAKING N.Y., https://sdmny.org/supported-decision-making-legislation/supported-decision-making-agreement-legislation-in-the-u-s-and-elsewhere/supported-decision-making-agreement-laws-in-the-u-s/ (last visited Aug. 6, 2024).

[161] *Less Restrictive Options*, ABA COMM. ON L. & AGING (Nov. 21, 2023), https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/supported-decision-making/.

[162] Rosen, *supra* note 137, at 577 (citations omitted).

[163] *Less Restrictive Options*, *supra* note 161.

[164] Wright, *supra* note 83, at 169.

[165] *Id.*

[166] *Id.* at 172–84 ("Indeed, supported decision-making can be seen as a reasonable accommodation under the ADA so that persons with decisional impairments can autonomously make their own healthcare, including end-of-life, decisions.").

[167] *Supported Decision Making, supra* note 158. *See* Kristen Fischer, *New Paths Could Allow for Medical Aid in Dying for People with Dementia,* MCKNIGHTS (Feb. 7, 2024), https://www.mcknights.com/news/new-paths-could-allow-medical-aid-in-dying-for-people-with-dementia/.

or where a person does not qualify for MAID, VSED is often the best option available for patients.[168] It entails the cessation of all food, liquids, and, occasionally, life-sustaining medications.[169] The VSED patient requires "24-hour care during this process, and ongoing hospice care or oversight by [a] physician."[170] This process can be harrowing for the caregivers of people with dementia because the person might request food and drink and their caregivers must remind them of their decision, and reaffirm that the patient still consents.[171] Because the VSED process requires the ongoing consent of the person, it is not available for someone with late-stage dementia.[172]

Executing an Advance Directive for VSED while in the earlier stages of dementia is a possibility for people faced with a dementia diagnosis. Advance Directives came to the forefront of end-of-life planning in the 1970s and "are rooted in the doctrine of informed consent."[173] Advance Directives allow for a person to refuse consent to medical treatments for their future self, based on the idea "that autonomy is the core value to guide medical decision-making. Respecting autonomy allows individuals to shape their lives according to their personal values and preferences."[174] In Oregon, an Advance Directive "is a legal document" executed by a "capable adult" that establishes a health care representative if and when a person becomes incapacitated and a set of instructions for that representative to follow if they become incapacitated.[175] Under Oregon law, a person is considered incapable and their Advance Directive comes into effect when:

> in the opinion of the court in a proceeding to appoint or confirm authority of a health care representative, or in the opinion of the principal's attending physician or attending health care provider, a principal lacks the ability to make and communicate health care decisions to health care providers,

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[168] VSED is often chosen by patients with "[a] non-time specific prognosis, [d]ifficulty swallowing, [i]nability to absorb and process medications, [g]astrointestinal obstruction, [or e]arly/moderate stage of dementia." *Voluntarily Stopping Eating and Drinking*, *supra* note 7.

[169] *Id.*

[170] Marcia Sloane, *Journal of my Mother's Death: A VSED Chronicle*, COMPASSION & CHOICES, 3 (2022), https://www.compassionandchoices.org/docs/default-source/default-document-library/vsed-journal-final-5.31.22.pdf/.

[171] For an overview of the experience of a wife helping her husband with Alzheimer's through the VSED process, see Phyllis Schacter, *VSED in 9 ½ Days*, https://phyllisshacter.com/the-vsed-choice/vsed-in-9-%c2%bd-days/4/ (last visited Aug. 6, 2024) ("He asks me for water twice. Each time I remind him why he is not eating and drinking. I say that I am happy to give him water. I also explain that it will take the process longer. I ask Alan: 'Would you like me to get you a glass of water, or would you prefer that I just spray mists of water into your mouth?' He understands, and he asked for the mists of water. I keep spraying his mouth until he is satisfied.").

[172] *Voluntarily Stopping Eating and Drinking*, *supra* note 7.

[173] Hertogh, *supra* note 99, at 511.

[174] *Id.*

[175] OR. REV. STAT. §§ 127.505–658 (2023); *Your Guide to the Oregon Advance Directive for Health Care*, OR. HEALTH AUTH. (Dec. 7, 2021), https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le3942.pdf; *Oregon Advance Directive for Health Care*, OR. HEALTH AUTH. (2022), https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le3905.pdf.

> including communication through persons familiar with the principal's manner of communicating if those persons are available.[176]

This language mirrors the definition of capable in the Oregon Death with Dignity Act.[177] So when a person is no longer capable of making and communicating their health care decisions to providers, they move from capable, and able to access MAID, to incapable, and their Advance Directive comes into effect.

Advance Directives grew in popularity in response to cases like those of Karen Ann Quinlan, who was in a permanent vegetative state and being kept alive on life support for years.[178] Quinlan was a real person whose end-of-life saga became a pop culture and legal phenomenon.[179] Advance Directives were seen as a legal way to avoid a protracted legal battle or being hooked up to machines after one's brain had ceased to function.[180] However, "advance directives were not designed with an exclusive focus on dementia and patients' fear of having to live through all its stages."[181] In fact, some scholars have criticized Advance Directives as a form of "'auto-paternalism' by denying [a person] the right to a change of mind at a later moment and subordinat[ing] the interests of the future incompetent person to her prospective autonomy."[182] There is a concern that respecting the wishes of the person who wrote the advance directive is "a kind of bias that risks lowering the moral standing of the patient in later years."[183] A person who is in a coma and will never regain consciousness looks different than a person with advanced cognitive impairment, but they are both considered legally "incapable."[184] Yet in both situations, consent can be withheld for life-sustaining medical care years in advance, through an advance directive.[185] A crucial issue with using an advance directive for VSED is that a person's "anticipatory beliefs often fail to recognize [one's] ability to adapt and that it is notoriously difficult to imagine how one's current preferences will hold in a given situation (such as dementia) that one has never experienced

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[176] OR. REV. STAT. § 127.505(14) (2023).

[177] A patient is "capable" under OR. REV. STAT. § 127.800(3) when "a patient has the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available."

[178] Hertogh, *supra* note 99, at 512.

[179] Robert D. McFadden, *Karen Ann Quinlan, 31, Dies: Focus of '76 Right to Die Case*, N. Y. TIMES (June 12, 1985), https://www.nytimes.com/1985/06/12/nyregion/karen-ann-quinlan-31-dies-focus-of-76-right-to-die-case.html ("Ordinary people found themselves wrestling with fundamental questions of life and death, as medical and legal issues blended into sociology and theology.").

[180] Hertogh, *supra* note 99, at 512.

[181] *Id.*

[182] *Id.*

[183] Sandeep Jauhar, *My Father Didn't Want to Live if He Had Dementia. But Then He Had It*, N.Y. TIMES (Oct. 23, 2023), https://www.nytimes.com/2023/10/23/opinion/alzheimers-dementia-advance-directives.html.

[184] *See* OR. REV. STAT. § 127.800(3).

[185] Hertogh, *supra* note 99, at 512.

before."[186] In other words, "contentment with life can be compatible with cognitive dysfunction—along with the prerogative to change one's mind about the care one wants at life's end."[187] Another issue with advance directives is that they are underutilized: less than half of Americans over the age of 50 have an advance directive or a medical durable power of attorney in place.[188]

The key to this is that a person choosing to hasten death with VSED must continuously consent to not eating or drinking; if they want to at any time, they are able to resume eating and drinking.[189] However, even in cases where someone explicitly refuses to be fed in their advance directive, there is no guarantee that caregivers will follow the directive, as happened to one woman in Oregon: "Though she had filled out an advance health-care directive instructing caregivers not to feed her if she lost the ability to feed herself, she was spoon-fed until two days before her passing."[190]

IV. COERCION, INSURANCE, EXISTENTIAL COHERENCE (WHOSE LIFE IS IT ANYWAY?)

Some of the previously discussed issues surrounding MAID for people with capacity become more complicated when MAID is available for people who choose MAID when they have capacity, but access it when they no longer have capacity, such as when using a waiver of final consent, or for people who choose MAID using supported decision-making. I will briefly address a few of the issues related to concerns about coercion, insurance, and existential coherence.

A. Coercion

Fear of coercion might be heightened in the instance of someone with ADRD choosing MAID either through SDM or a waiver, because there is often money at issue, and the person with ADRD might seem like a different person than they were before.[191] However, at least for MAID in Oregon, that fear has not turned out to be well-founded, as there has been no evidence of coercion since the DWDA was

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[186] *Id.* at 513.

[187] Jauhar, *supra* note 183.

[188] *National Poll on Healthy Aging: Advanced Care Planning*, UNIV. MICH. INST. HEALTHCARE POL'Y & INNOVATION (April 2021), https://deepblue.lib.umich.edu/bitstream/handle/2027.42/167012/NPHA-Advanced-Care-report-FINAL-04052021.pdf.

[189] *Alternative Options to Hasten Death*, DEATH WITH DIGNITY, https://deathwithdignity.org/resources/options-to-hasten-death/ (last visited Aug. 6, 2024). *See* Hope Wechkin, Robert Macauley, Paul T. Menzel, Peter L. Reagan, Nancy Simmers, & Timothy E. Quill, *Clinical Guidelines for Voluntarily Stopping Eating and Drinking (VSED)*, 66 J PAIN AND SYMPTOM MGMT. 626, 627, 630 (Nov. 2023).

[190] Kuznia, *supra* note 8.

[191] Wright, *supra* note 83, at 179 ("[U]nlike the case of a person who has always had decisional impairments, a person with an acquired disability may have accumulated significant assets prior to the onset of impairment; receive care from informal caregivers; or seem like a different person than they were prior to their decisional impairments. These factors may result in greater conflicts of interest with family members who may not care as much about overriding the supported person's current preferences.").

enacted in 1997.[192] There are several safeguards in the law to prevent coercion and to ensure that the person is voluntarily seeking MAID, and it is a "felony to coerce someone to request the medication or to forge a request."[193] With the appropriate additional safeguards that I discuss below, I believe that MAID can safely be expanded to people with dementia through Supported Decision-Making or a waiver of final consent.

There have been instances in Canada where people have sought MAID because of concerns unrelated to their physical health, such as poverty or isolation—this could be framed as societal coercion.[194] While widely publicized, these cases are rare, and in any event, the requirement of a terminal prognosis of six months in Oregon would avoid this issue.[195] Additionally, removing the option for MAID for people who need it would not solve the underlying societal problems.

Similarly, there have been a few allegations in America of insurance suggesting MAID while denying otherwise life-sustaining medication.[196] However, these instances are rare.[197] While there is much room for improvement in the American "health care" system, it is an unfounded fear that profit-driven insurance companies in the United States will solely offer MAID in place of life-sustaining treatment.[198]

B. Existential (In)Coherence: Whose Life Is It Anyway?

An important consideration when it comes to the waiver of final consent is who exactly has the moral authority to make this decision to die using MAID. Is it

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[192] Su, *supra* note 65, at 175 ("[T]he 'fear of coercion' rationale is problematic. Opponents have claimed that 'mistaken decisions may result from inadequate palliative care or a terminal prognosis that turns out to be in error; coercion and abuse may stem from the large medical bills that family members cannot bear.' The fact is, however, that these issues have not occurred in either Oregon or Washington."); *Fact: Medical Aid-in-Dying Laws Work to Protect Patients*, COMPASSION & CHOICES (Dec. 15, 2022), https://compassionandchoices.org/wp-content/uploads/2020/11/maid-laws-protect-patients_12_15_22.pdf ("There have been no documented or substantiated incidents of abuse or coercion across the authorized jurisdictions since Oregon implemented the first medical aid-in-dying law on Oct. 27, 1997.").

[193] *Fact: Medical Aid-in-Dying Laws Work to Protect Patients*, *supra* note 192; OR. REV. STAT. § 127.890 (2023).

[194] For a discussion of some of these cases, see Brooks, *supra* note 93, at 84, 87.

[195] *See* Mary C. Deneen, *Bioethics— "Who Do They Think They Are?": Protecting Terminally Ill Patients Against Undue Influence by Insurers in States Where Medical Aid in Dying is Legal*, 42 W. NEW ENG. L. REV. 63, 72 (2020).

[196] *Id.* at 64–65.

[197] *Id.*

[198] *Frequently Asked Questions: Medical Aid in Dying*, COMPASSION & CHOICES, https://www.compassionandchoices.org/resource/frequently-asked-questions#question-10 (last visited Aug. 6, 2024) ("This myth is further dispelled by the fact that 90.2% of people in Oregon who choose medical aid in dying are enrolled in hospice care and not receiving expensive or intensive treatment. Hospice enjoys nearly universal insurance coverage, and hospices have charitable funds to cover those who cannot afford it. Medicare and Medicaid fully cover hospice services, with no lag or delay in payment, as with some other services. Hospice is significantly less expensive than treatments meant to extend life, which occur before a person becomes eligible for medical aid in dying. In short, consideration of medical aid in dying comes at a time when the cost of care is low, and there is no financial incentive to encourage people to choose this option.").

ethically appropriate to follow a person's waiver to consent to MAID that was given before that person underwent a decline in cognitive function? Fundamentally, is it even the same person? Because "sometimes it may seem as if the person with decisional impairments for whom an end-of-life decision is being made is not the same person who wrote the advance directive" or who waives final consent.[199] This "raises questions about the moral authority of the advance directive" or waiver.[200] Respecting the past wishes and capacity of a person raises "the problem of personal identity, which often arises in the case of persons who acquire dementia and may experience personality change or such profound memory loss that they are no longer recognizable as the person they once were."[201] While this is an intriguing area of bioethics, when people with early-stage Alzheimer's have been asked about this dilemma, their answers show that this is not an issue for them:

> When the subject of taking a decision for a future-self that may not correspond to the present-self was brought up by the interviewer, that last participant made it clear that the medical team and her family should give priority to what she expressed in her advance request if she was no longer able to make a decision: "[. . .] when the disease is very advanced, that I am no longer myself and I change my mind. [. . .] they should listen to me now."[202]

Additionally, people are accustomed to the idea of advance directives, and that the past self can dictate what type of medical care they consent or refuse to consent to for a future incapacitated self.[203] Although many are comfortable with the withdrawal of life-supporting medicines or refusing to start life-sustaining treatments for a future incapacitated self, it is understandable that people might be less comfortable with the choice to hasten death through MAID for a future self.[204] Advance directives are often written with a future self who is unconscious in mind, not necessarily a future self who is conscious but cognitively impaired and able to express preferences.[205] While managing his father's dementia and advance directive, Doctor Sandeep Jauhar wrote that "it seems that a contemporaneous desire to live, even in a person with dementia, must be taken seriously, despite what that person might have previously written. We recognize that minds evolve and people change in every sphere of human life."[206] However, with the appropriate legal framework, I believe that MAID can be made accessible in an ethical manner that respects the contemporaneous desires of people with ADRD.

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[199] Wright, *supra* note 83, at 168 n.57 (citing Megan S. Wright, *Dementia, Autonomy, and Supported Healthcare Decision Making*, 79 MD. L. REV. 257, 314–19 (2020)).

[200] *Id.*

[201] *Id.*

[202] Thériault et al., *supra* note 2, at 72 (alterations in original).

[203] *See* ANNE WILKINSON, NEIL WENGER, & LISA R. SHUGARMAN, LITERATURE REVIEW ON ADVANCE DIRECTIVES 7–8 (2007).

[204] Is there really a difference between these options for a person who was less than six months to live? This is beyond the scope of this paper, but I would suggest that this might be a "distinction[] without a difference." ROBERT A. BURT, DEATH IS THAT MAN TAKING NAMES: INTERSECTIONS OF AMERICAN MEDICINE, LAW, AND CULTURE, 13 (2002).

[205] *See* Jauhar, *supra* note 183.

[206] *Id.*

V. RECOMMENDATIONS

In the interest of increasing end-of-life choices for people with ADRD and increasing bodily and decisional autonomy for people with cognitive and decisional impairments, I suggest that Oregon adopt the Canadian model of a waiver of final consent for people with ADRD. Further, to extend competency through the progression of ADRD, I suggest that Oregon should adopt legislation that explicitly allows supported decision-making for the Death with Dignity Act. Further, to ensure that only people who truly want the option of MAID are accessing it, I suggest that for cases of either supported decision-making or a waiver of final consent, the legislature adds two additional requirements: that the patient is assessed for depression and treatable causes of pseudo-dementia, and that a doctor or nurse practitioner be present at the time of self-administration.

A. Adopt the Canadian Model of a Waiver of Final Consent

The Canadian waiver of final consent model could work in Oregon with a few modifications. In cases where a person with a separate terminal prognosis of greater than six months and early or mild cognitive impairment, they could give advanced consent for MAID in the event that their prognosis is for less than six months (and thus would be eligible for MAID in Oregon) and they had lost the legal capacity to consent to MAID. The person could discuss with their physician and loved ones what would be the triggers for MAID for them. It could be the loss of ability to recognize loved ones, unmanageable pain, inability to take part in the activities they enjoy, or any combination of factors. Although the Canadian waiver requires a date set in advance,[207] the Oregonian waiver could set a triggering event, such as a terminal prognosis of less than six months, and then a recurring evaluation to determine if the person is meeting their own requirements. This could involve an interview, performed by a social worker or medical provider, with the person every couple of weeks to determine whether MAID is appropriate at that time. This interview would also serve as a welfare check of the person. As I suggest below, a doctor or nurse practitioner should be required to be present for the self-administration of MAID, to ensure that the person has the opportunity to refuse if they no longer desire MAID. The doctor or nurse practitioner should be required to interview the person in a private setting without other caregivers present to help ensure that the person has the opportunity to report any coercion and to voice their true wishes as to how they would like their life to end.

B. Allow Supported Decision-Making for MAID

In the interests of furthering disability rights and health care equity, Oregon should adopt supported decision-making generally, as well as specifically amend the Death with Dignity Act to state that people are considered capable under the Act when using supported decision-making. This would extend capacity for people with

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[207] An Act to amend the Criminal Code (medical assistance in dying), S.C. 2021, C-7, § 3.2(a)(ii) (Can.). *See, e.g.*, CAN. MINISTRY OF HEALTH, *supra* note 59; ALTA HEALTH SERVS., *supra* note 59.

ADRD into the moderate stages and allow them to sign a waiver of final consent or to access MAID if they have a terminal prognosis of six months. This would also allow people with other cognitive impairments with terminal prognoses to access MAID if that was their desire.

C. Require an Assessment for Depression and Treatable Causes of Dementia

To ensure that the patient is not requesting MAID because of a temporary bout of depression, which can sometimes happen as a reaction to the initial diagnosis and can often co-occur with Alzheimer's disease, I recommend that people seeking to use SDM or a waiver of final consent undergo an assessment to rule out depression or other mental illness that could be causing them to feel suicidal.[208] This assessment is also important to ensure that other treatable causes of dementia symptoms are discovered and addressed.[209] The requirements of the assessment would be decided by the legislature, but an extra safeguard would help protect people who might be suffering from depression who could adjust to their lives with dementia with the help of medication, and thus would not want to access MAID.[210]

D. Require Physician or Nurse Practitioner Presence at the Moment of MAID Administration in the instance of SDM or Waivers

In Canada, if a person with a waiver of final consent indicates to their provider at the scheduled time of administration that they do not consent, the provider will not administer MAID.[211] In other words, even if a person is not seen as capable of consenting to MAID, they are still seen as capable of refusing it.[212] In the rare case of self-administration, a medical practitioner is required to be there for the administration.[213] This is in contrast to general practice in Oregon where self-administration is the rule and the prescribing physician is only present for 13% of deaths, and another health care provider was present at an additional 13%.[214] I suggest that in order to allay concerns about coercion in instances of MAID when

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[208] Gather & Vollman, *supra* note 94, at 447.

[209] *Id.* at 446.

[210] *Id.* at 447.

[211] Criminal Code, R.S.C. 1985, c C-46, 241.2(3.2)(c) (Can.) ("the medical practitioner or nurse practitioner may administer a substance to a person to cause their death without meeting the requirement set out in paragraph (3)(h) if . . . the person does not demonstrate, by words, sounds or gestures, refusal to have the substance administered or resistance to its administration . . . ."); *id.* c C-46, 241.2(3.4) ("Once a person demonstrates, by words, sounds or gestures, in accordance with subsection (3.2), refusal to have the substance administered or resistance to its administration, medical assistance in dying can no longer be provided to them on the basis of the consent given by them under subparagraph (3.2)(a)(iv).").

[212] *Id.* c C-46, 241.2(3.4).

[213] *Id.* c C-46, 241.2(3.5)(a)(i) ("[B]efore the person loses the capacity to consent to receiving medical assistance in dying, they and the medical practitioner or nurse practitioner entered into an arrangement in writing providing that the medical practitioner or nurse practitioner would [] be present at the time the person self-administered the first substance . . . .").

[214] PUB. HEALTH DIV., *supra* note 3, at 9.

using either a waiver of final consent or supported decision-making, the Oregon legislature adds the additional requirement of the presence of a physician or nurse practitioner at the time of self-administration. This would act as an additional safeguard to ensure that the person is not accessing MAID against their will. In other words, even though they might not be seen as having the capacity to consent at the moment of administration, we would still be respecting their capacity to refuse, as they do in Canada. The presence of a third party who has no ulterior motives and is bound by a code of ethics would help to ensure that MAID would be available only to those who truly wanted that option.

CONCLUSION

Increasing access to end-of-life choice will continue to be controversial in a society where bodily autonomy is seen as a right by some and a sin by others. The reasoning the Supreme Court of the United States used to deny the right to MAID in *Glucksberg* was used almost a quarter of a century later to deny the right to abortion in *Dobbs*.[215] In America, the fight for bodily autonomy is fought in each state and territory.[216]

In Oregon, which has been at the forefront of the Death with Dignity movement,[217] we have the opportunity to make end-of-life choice more equitable by increasing access to MAID through supported decision-making and a waiver of final consent for people with dementia. Unfortunately, because we do not have a federal constitutional right to MAID, and because there are political concerns about expanding MAID to people with dementia before MAID is available nationwide, there is not currently support for expanding access from the national organizations that otherwise champion the increase of end-of-life choice in this country.[218] However, as a person who is at an increased risk of dementia, I hope that one day this option will be available to me and all people who desire it. As my Catholic grandmother used to pray, "may I be able to do for myself until the good Lord sees fit to take me." She died in a locked memory care unit, not able to recognize her husband, children, or grandchildren, at the age of 92.

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[215] Dobbs v. Jackson Women's Health Org., 142 S.Ct. 2228, 2242, 2246, 2247 (2022); Washington v. Glucksberg, 521 U.S. 702 (1997).

[216] *See, e.g.*, Sherronda J. Brown, *These US States are Protecting Gender-Affirming Care and Abortion Access,* PRISM (Mar. 28, 2023), https://prismreports.org/2023/03/28/states-protecting-gender-affirming-care-abortion/; *After Roe Fell: Abortion Laws by State*, CTR. FOR REPRODUCTIVE RTS., https://reproductiverights.org/maps/abortion-laws-by-state/ (last visited Aug. 6, 2024).

[217] Deneen, *supra* note 195.

[218] Kuznia, *supra* note 8 ("In particular, groups such as Compassion & Choices, the nation's largest right-to-die organization, and the Death With Dignity National Center, a main author of the original law, have little appetite for widening access to lethal drugs in the states where medically assisted suicide already is legal. Such meddling, they fear, could give ammunition to critics and frustrate their efforts to bring the narrowly defined statute to as many states as possible.").