

**Dementia and Physician-Assisted Suicide: Why Death with Dignity Acts Should Include
People with Dementia and How it Can be Accomplished**

by

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Dementia and Physician-Assisted Suicide: Why Death with Dignity Acts Should Include People with Dementia and How it Can be Accomplished

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This thesis argues that patients with dementia should be given access to physician-assisted suicide in U.S. jurisdictions where this practice has already been legalized. Death with Dignity Acts are currently structured with a terminal illness provision that only allows patients with six-months left to live to participate in physician-assisted suicide. This necessarily excludes patients with dementia from participating in physician-assisted suicide because it is likely that they will be incompetent and unable to choose to participate when they have six months left to live. Dementia is a terminal illness that results in death anywhere from eight to twelve years after diagnosis. Some patients who are diagnosed with dementia want the ability to access physician-assisted suicide, but are excluded for the reason noted above. The addition of a supported decision-making model will reinforce the patient's decision-making capacity in that it helps convey to other's that the patient has decision-making capacity and provides additional guidance and structure to the decision-making process. This thesis argues that removing the six-month requirement from and adding a supported decision-making component to the laws will allow patients with dementia the option of participating in physician-assisted suicide in jurisdictions with Death with Dignity Acts.

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Preface

I dedicate this project to Zach Mace, Dr. Lingler, and Dr. Thurston.

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1.0 Introduction

Physician-assisted suicide, as a state-sanctioned act, began in the Netherlands under the State Commission of Euthanasia in 1985. On October 27th, 1997 Oregon's Death with Dignity Act went into effect, making Oregon the first jurisdiction in the United States to legalize physician-assisted suicide.¹ Oregon was then followed by seven states and the District of Columbia, which all passed Death with Dignity Acts. Montana's Supreme Court ruled that physician-assisted suicide is allowed in the state, but did not explicitly enact a Death with Dignity Act. In spite of growing support, physician-assisted suicide is still a highly controversial topic both because of what it entails and who is denied access to it. Exclusions are due in large part to the requirement that a person seeking physician-assisted suicide must have a terminal condition and must be expected to die from that condition in six months or less.

Though dementia is a terminal condition, the time from diagnosis to death is eight years on average.² Given that the last six months of the disease will consist of late-stage dementia, it is highly unlikely that anyone at this point in the disease's progression would have the decision-making capacity required to access physician-assisted suicide.³ Death with Dignity Acts are currently structured in a way that excludes many patients who would benefit from and who would like to have access to physician-assisted suicide. I will argue that Death with Dignity Acts should

¹ "Oregon's Death with Dignity Act." *Oregon Health Authority: Oregon's Death with Dignity Act: Death with Dignity Act: State of Oregon*. 1995.

² de Beaufort, Inez D, and Suzanne van de Vathorst. "Dementia and Assisted Suicide and Euthanasia." *Journal of neurology*. National Institute of Health, March 26, 2016.

³ Reisberg, B., Ferris, S. H., de Leon, M. J., & Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *The American Journal of Psychiatry*, 139(9), 1136-1139.

include provisions allowing patients with dementia to participate in physician-assisted suicide. One such provision would allow patients with dementia to designate a supporter to help them in their decision-making process as described in the Supported Decision-Making Model section. I will argue that Death with Dignity Acts should include provisions allowing patients with dementia to participate in physician-assisted suicide through a supported decision-making model.

2.0 Aid in Dying

Physician-assisted suicide laws were first enacted in The Netherlands as the result of the State Commission of Euthanasia, which concluded that euthanasia was technically illegal but that, if physicians were to adhere to three outlined criteria, they would not be prosecuted in a court of law for providing euthanasia and physician-assisted suicide.⁴ The Dutch Euthanasia Acts allows patients with an array of diseases to participate in euthanasia and physician-assisted suicide, providing that physicians follow the following criteria: voluntariness, unbearable suffering, and consultation.

“Voluntariness” means that the patient has asked to participate in euthanasia or physician-assisted suicide of their own volition, without coercion, and have sufficient decision-making capacity to do so. “Unbearable suffering” means that the patient will not recover from their illness and the condition cannot be ameliorated. “Consultation” means that the attending physician must discuss the patient’s condition as well as their request with another physician who then consults on the patient’s case to see if they meet the criteria to participate in euthanasia or physician-assisted suicide.⁶ After physician-aid in dying cases conclude, they are presented to Euthanasia Review Committees (ERC’s), which review physician action and patient disease to determine whether or not a case has been carried out with “due care.”

⁴ de Wachter, Maurice A.M. "Euthanasia in the Netherlands. " *The Hastings Center Report*. Mar.-Apr. 1992: 23+. Business Insights: Global. Web. 12 July 2019.

⁵ de Beaufort, Inez D, 2016.

⁶ de Wachter, Maurice A.M., 2019

The ERC's use the following criteria to determine whether or not a case should be prosecuted in a court of law:

1. The ERC must be convinced that the case concerned a voluntary and well-considered request.
2. The ERC must be convinced that the case concerned unbearable and hopeless suffering of a patient.
3. The ERC must know that the physician informed the patient about the medical condition and other treatment options.
4. The ERC has concluded that the physician and the patient determined that there were no reasonable alternatives to physician-assisted suicide and euthanasia for the patient's situation.
5. The ERC determines that the physician consulted with at least one other physician independent of the case, who has seen the patient and has given his/her conclusions in writing with respect to the above conditions and agreed with the attending's determinations.
6. The ERC determines that the physician has carried out the life-ending intervention or assisted suicide in a medically correct way.

These criteria serve as the basis for the review of the patient's case to determine if their physician acted in a medically permissible way that exempts them from prosecution.⁷

Before proceeding, it is important to note the difference between euthanasia and physician-assisted suicide. Euthanasia is defined in the Netherlands as the "...active termination of a patient's life, at his or her request, by a physician."⁸ In this thesis, I will be discussing physician-assisted suicide, which is defined as, "...ending one's own life through the voluntary self-administration of lethal medications, expressly prescribed by a physician for that purpose."⁹ The distinction lies in the separation between self-administration and physician-administration of the lethal medication. I will only be discussing physician-assisted suicide and will be arguing that patients with dementia should be able to participate in the self-administration of lethal medication provided that they are competent to make the decision and that they meet the requirements in the relevant jurisdictions. The guidelines for physician-assisted suicide in the United States are similar to those of the State Commission of Euthanasia, though they are worded differently and based on United States law.¹⁰

The documentation of physician-assisted suicide in the United States began between the 1860's and the 1930's during the Progressive movement, which allowed for more open conversations surrounding death leading to American's wanting the "natural right to a natural death."¹¹ This idea grew from the long-held ancient practice of euthanasia, in which a physician would administer lethal amounts of poison to suffering patient upon the latter's request. The

⁷ Kimsma, G K. "Death by Request in The Netherlands: Facts, the Legal Context and Effects on Physicians, Patients and Families." *National Center for Biotechnology Information* 13 (July 29, 2010): 1–7.

⁸ de Wachter, Maurice A.M., 2019

⁹ "How to Access and Use Death with Dignity Laws." *Death With Dignity*.

¹⁰ "How to Access and Use Death with Dignity Laws." *Death With Dignity*.

¹¹ Dowbiggin, Ian. *A Merciful End: the Euthanasia Movement in Modern America*. Oxford: Oxford University Press, 2003. 23.

practice was one that allowed for a “good death”.¹² Euthanasia was thought to be a way of giving patients an “easy death”, one that avoided unnecessary pain and suffering. A physician named William Duncan McKim took this concept of “easy death” and equated it to “active” euthanasia as a way to relieve patient suffering. His ideas about active euthanasia coupled with the formation of the Progressive Era’s more open thinking regarding death, led to what we now consider the modern day right to die movement.¹³ In the United States today, physician-assisted suicide is governed by acts and court rulings that outline who is able to participate in physician-assisted suicide. While physician-assisted suicide is legal in nine jurisdictions, there are still those who oppose it.

One of the strongest criticisms of my position, regarding expanding access to physician-assisted suicide, stems from the ethical debate regarding physician-assisted suicide generally: the practice of medicine endeavors to make lives better, not to end them.¹⁴ To this I respond that citizens in jurisdictions that have passed Death with Dignity Acts have already determined that physician-assisted suicide is morally and legally permissible. I am suggesting changes in the provisions that will allow patients with dementia to participate in a process that has already been legalized in certain jurisdictions.

¹² Hooff, Anton J.I Van. “Ancient Euthanasia: ‘Good Death’ and the Doctor in the Graeco-Roman World.” *Social Science & Medicine* 58, no. 5 (March 2004): 975–85.

¹³ Dowbiggin, Ian. 22-23.

¹⁴ Lagay, Faith. “Physician-Assisted Suicide: The Law and Professional Ethics.” *AMA Journal of Ethics*, vol. 5, no. 1, 2003.

3.0 Physician-Assisted Suicide in the United States

The Supreme Court of the United States decided in two court cases, *Vacco v. Quill* and *Washington v. Glucksberg*, that the United States Constitution does not uphold a citizen's right to die with physician assistance. In *Vacco v. Quill*, the Supreme Court ruled that it is up to each state to determine whether or not its residents can participate in physician-assisted suicide.¹⁵ The ruling in *Washington v. Glucksberg* bolters this decision: the United States Supreme Court determined that Washington's ban on physician-assisted suicide was not unconstitutional.¹⁶ These rulings set the precedent that each U.S. jurisdictions may determine whether it will allow physician-assisted suicide.

As was previously mentioned, Oregon was the first state to legalize physician-assisted suicide, defining the act as a medical intervention which, "...allows terminally-ill Oregonians to end their lives through the voluntary self-administration of lethal medications, expressly prescribed by a physician for that purpose."¹⁷ Other U.S. jurisdictions that currently allow physician-assisted suicide include California, Colorado, Maine, New Jersey, Vermont, Washington, D.C., and Hawaii. In *Baxter v. Montana* (2009), The Montana Supreme Court concluded that the practice was not prohibited, meaning that the practice is permitted until such time as laws are enacted prohibiting it.¹⁸

¹⁵ Coleson, Richard E. "Vacco v. Quill." *Issues in Law and Medicine* 13, no. 3 (June 26, 1997): 323–29.

¹⁶ Coleson, Richard E. "Washington v. Glucksberg ." *Issues in Law and Medicine* 13, no. 3 (June 26, 1997): 315–324.

¹⁷ "Oregon's Death with Dignity Act." *Oregon Health Authority: Oregon's Death with Dignity Act : Death with Dignity Act : State of Oregon*. 1995.

¹⁸ "Oregon's Death with Dignity Act." 1995.

Death with Dignity Acts require a person seeking physician-assisted suicide to have decision-making capacity and to make the request for him/herself. They also require that the patient making the request be a resident of the jurisdiction in which the lethal medication will be provided and that the patient make three requests - two oral at no less than 15 days apart and one written.¹⁹ The requestor must also have been given a terminal diagnosis in which they have no more than six months to live, which is determined by an attending physician and confirmed by a consulting physician. There are also reporting requirements that allow for deaths to be tracked yearly to ensure that the medication is being prescribed for its intended use.²⁰

Other jurisdictions' Death with Dignity Acts are structured similarly to Oregon's; however, there are variations.²¹ The differences between the acts are minimal and all require the provisions listed above with some additions. California's Act, for example, has the additional requirement that patients must be informed of feasible alternatives including, but not limited to, hospice and palliative care. This means that a patient must be aware of their option to enroll in hospice or receive palliative care to aid in symptom management and to alleviate suffering.²² Washington, D.C. also has a "feasible alternative clause", which states that patients must be informed of other

¹⁹ [1995 c.3 s.3.06]

²⁰ "Oregon Revised Statute: Oregon's Death with Dignity Act." *Oregon Health Authority : Oregon Revised Statute: Oregon's Death with Dignity Act : Death with Dignity Act : State of Oregon*, 1999.

²¹ California End of Life Options Act (2016), Colorado End of Life Options Act (2016), Hawaii Our Care, Our Choice Act (2019), Vermont Patient Choice and Control at the End of Life Act (2013), New Jersey Aid in Dying for the Terminally Ill Act (2019), and Washington Death with Dignity Act (2008), Maine Death with Dignity Act (2019), Montana allows for physician-assisted suicide as of 2009, however they have not passed an explicit Act.

²² SB-128 End of life.(2015-2016) *California Legislative Information*. Legislative Counsel Bureau, 2019.

alternatives; however, they are not required to participate in them before asking for the lethal prescription.²³

One of the concerns for states that have physician-assisted suicide laws is that the law can be abused. States have attempted to overturn some of the acts and legislation passed, however, all of the attempts have failed. As published in the yearly Death with Dignity Act Reports, deaths from physician-assisted suicide make up only 45.9 of every 10,000 deaths in Oregon, and the number of deaths has been relatively stable for the past four years.²⁴ These statistics provide evidence that concerns about abuse are unfounded. Another notable concern could be that, because I am suggesting removing the six-month terminal illness requirement, more people will have access to physician-assisted suicide and therefore there will be less control over access. To address this criticism, I would draw attention to physician-assisted death in the Netherlands. The Netherlands has been practicing physician-assisted death since before the 1990's and reports of physician-assisted deaths have remained fairly stable, with reports of deaths from euthanasia and physician-assisted suicide from 1990 to 2005 remaining fairly steady.²⁵ The Netherlands does not have a terminal illness requirement in their act, so this suggests that the numbers in the United States should also remain fairly stable if the six month requirement were eliminated. While physician-assisted suicide laws in the United States' are loosely based on those in the Netherlands, significant differences remain.

²³ B21-0038, the Death with Dignity Act of 2015. 2015.

²⁴ Center for Health Statistics, Public Health Division. "Oregon Death with Dignity Act 2018 Data Summary ." *Oregon Health Authority* , February 15, 2019, 1–16.

²⁵ Heide, Agnes Van Der, Bregje D. Onwuteaka-Philipsen, Mette L. Rurup, Hilde M. Buiting, Johannes J.m. Van Delden, Johanna E. Hanssen-De Wolf, Anke G.j.m. Janssen, et al. "End-of-Life Practices in the Netherlands under the Euthanasia Act." *New England Journal of Medicine* 356, no. 19 (October 2007): 1957–65.

The way Death with Dignity Acts are structured necessarily excludes patients with dementia who may be seeking to participate in physician-assisted suicide because they may no longer be able to make that medical decision for themselves at the time they are diagnosed with six months to live. The problem is also exacerbated by the fact that it is also sometimes (erroneously) presumed that people with dementia totally and automatically lack decision-making capacity even if they are at an early stage in their diagnosis.²⁶

3.1 Baxter v. Montana

The ruling in *Baxter v. Montana* allowed for physician-assisted suicide in the state of Montana. Robert Baxter was a retired truck driver who was diagnosed as terminally ill with lymphocytic leukemia. He had undergone multiple rounds of chemotherapy and suffered serious side effects such as infections, chronic fatigue, anemia, nausea, pain, and digestive problems. Mr. Baxter had no hope for recovery and there was no cure for his disease, so he wanted the option of taking a lethal dose of medication prescribed by his doctor.

Mr. Baxter, along with four physicians and a non-profit called Compassion and Choices, brought action to the District Court of Montana. They challenged the “constitutionality of the application of Montana homicide statutes to physicians who provide aid in dying to mentally competent, terminally ill patients.” Based on the findings in Mr. Baxter’s case, the District Court ruled that “a patient may use the assistance of his physician to obtain a prescription for a lethal

²⁶ Wright, Megan, “Dementia, Autonomy, and Supported Healthcare Decision Making.” March 18, 2019.

dose of medication.” The court based its decision on the pre-existing statute called the Montana Rights of the Terminally Ill Act. This act states that, “an individual of sound mind and 18 years of age or older [has the right] to execute at any time a declaration governing the withholding or withdrawing of life-sustaining treatment.”²⁷ The court concluded that part of the rights outlined in the Montana Rights of Terminal Ill Act say that terminally ill patients have the right to their end of life wishes being followed even if it requires direct participation by a physician.²⁸ The Court said,

“The Rights of the Terminally Ill Act very clearly provides that terminally ill patients are entitled to autonomous, end-of-life decisions, even if enforcement of those decisions involves direct acts by a physician. Furthermore, there is no indication in the Rights of the Terminally Ill Act that an additional means of giving effect to a patient’s decision—in which the patient, without any direct assistance, chooses the time of his own death—is against public policy.”

From this the court determined that physician-assisted suicide is legally permissible.

An important piece of this court case for dementia patients is the Montana Rights of Terminally Ill Act’s definition of terminal. The Act says,

“The scope of the Act is narrow. Its impact is limited to treatment that is merely life-prolonging, and to patients whose terminal condition is incurable and irreversible, whose death will soon occur, and who are unable to participate in treatment decisions. Beyond its narrow scope, the Act is not intended to affect any existing rights and responsibilities of persons to make medical treatment decisions. The Act merely provides

²⁷ Section 50-9-103, MCA

²⁸ Section 50-9-103, MCA

alternative ways in which a terminally-ill patient's desires regarding the use of life-sustaining procedures can be legally implemented.”²⁹

The definition of “terminal” the Act uses does not contain a specific timeline, such as the six-month requirement found in Death with Dignity Acts. Instead it only says that the condition is incurable, irreversible, and will “soon” result in death. While patients with dementia can have anywhere from 6-12 years to live after diagnosis, the disease is still a terminal one. A law permitting physician-assisted suicide could be passed that is consistent with the Montana Rights of the Terminally Ill Act cited in *Baxter v. Montana*.

²⁹ Uniform Rights of Terminally Ill Act (1989), 9C U.L.A. at 312.

4.0 Decision-making Capacity

Decision-making capacity is an important concept for dementia patients who want to participate in physician-assisted suicide because their ability to participate is predicated on whether or not they have decision-making capacity. A thorough explanation of the concept and how it is assessed in practice is necessary to show how a physician determines if a patient has capacity to make the choice to end their own life. Decision-making capacity is the ability of a patient to make an informed decision about their medical care.³⁰ Competency is the ability to perform a task and can vary over time and may be intermittent; in other words, someone can be competent to perform a task at one point in time but at another point in time they may not be able to perform that same task.³¹ Although Competency and decision-making capacity have distinct definitions they can be used interchangeably.

In their book *Assessing Competence to Consent to Treatment*, Appelbaum and Grisso outline maxims that have practical implications for the assessment of decision-making capacity. They are specifically addressing legal competence/incompetence and address how legal competency can be determined. These maxims highlight that functional deficits can impact a person's decision-making capacity and that this has practical implications for the assessment of the decision-making capacity of patients with dementia.

³⁰ Charland, Louis C. "Decision-Making Capacity." *Stanford Encyclopedia of Philosophy*, June 20, 2011, 1–20.

³¹ Beauchamp, Tom L., and James F. Childress. *Principles of Biomedical Ethics*. New York: Oxford University Press, 2009.

If a physician is to assess the decision-making capacity of a patient with dementia, they must look at the functional abilities the person possesses based on the stage of disease the patient is in, what deficits might present at that stage of the disease, determine what functional demands the decision to participate in physician-assisted suicide might place on the patient, and understand that, because the disease has a progressive nature, the patient's ability to make this decision could change. These concerns are considered and weighed against each other to determine whether or not a person is capable of making a decision. In order to look at capacity holistically the physician must also assess the practical implications of the maxims which are, "functional abilities, psychopathology, task demands, consequences and then reassessment of that functioning."³²

These concepts explain some of the necessary conditions to be considered a competent person and therefore to be someone whose decisions should be respected by others. While sometimes these concepts are interchangeably used, they do possess distinct legal definitions. An adult in the United States is presumed to be competent until prove otherwise. This proof would consist of demonstrating that the adult lacks at least one of the four abilities related to legal competence. As stated above, competency and decision-making capacity are related because if a patient is deemed competent then they will also have decision-making capacity. In order to be found competent, a patient must possess the same abilities that are necessary to be found to have decision-making capacity. These four functional abilities are: the ability to express a choice, the ability to understand the information relevant to the treatment decision, the ability to appreciate the significance of this information for one's own situation, and the ability to reason through the relevant information to weigh the treatment options in light of one's own values.³³

³² Grisso, Thomas, and Paul S. Appelbaum. 30.

³³ Grisso, Thomas, and Paul S. Appelbaum. 31.

Knowing the implications for clinical assessment which follow from these maxims regarding competence as well as the abilities related to competence can certainly help a physician in assessing whether a patient is competent to consent to treatment. There will, however, be borderline cases that are difficult to judge even with the thorough assessment mentioned above. It can be helpful in these cases for a clinician to consult colleagues with relevant expertise, such as, geriatric psychiatrists or neurologists to determine whether or not the patient has capacity. In the case of depression, a consultation would be especially useful to determine whether or not the depressive episode could be impacting the patient's decision-making capacity and whether or not they are capable of choosing to participate in physician-assisted suicide. In the cases where true doubt remains about a patient's decision-making capacity, a physician could wait and reassess the patient at a later time, since capacity can vary over time and as the disease progresses. If a patient's decision-making capacity is still in question, access to physician-assisted suicide should be denied.

In the case of patients with dementia who are looking to participate in physician-assisted suicide, the physician would need to assess the patient's functional abilities, with a focus on the potential deficits associated with dementia. The physician would also have to look at whether or not the patient understands the gravity of the decision he or she is making, ensuring that they account for the other treatment options that are available. Part of the informed consent process would be explaining that participating in physician-assisted suicide may result in missing out on a possible cure and therefore an extended life of acceptable quality from the patient's perspective. In order to avoid later discrepancies regarding patient wishes, the physician, at the time of the patient's request, should ask the patient what they would want to do if a cure came along after they were prescribed the medication. This would avoid any presumptions that the patient would want

the “cure” and that all parties would be abiding by the patient’s wishes. The answer to this question should also be documented in the patient’s medical records and in the patient’s advanced directive.

To successfully request to participate in physician-assisted suicide, the patient would have to exhibit a sufficient understanding of their disease, such as the fact that it is progressive and terminal and that just because their disease is progressive and terminal does not mean that they will not have some “good” years left, and the possibility of a cure coupled with the understanding that there are alternatives, such as hospice and palliative care.

A dementia diagnosis does not automatically render the newly diagnosed person incapable of making their own decisions, however, depending on the stage of disease progression and when they are diagnosed, they may no longer be able to make decisions. Therefore, decision-making capacity needs to be assessed on a case-by-case basis because it needs to be determined whether the deficits associated with the diagnosis render the person incapable of making a decision for him or herself.

5.0 Dementia

Dementia is the loss of cognitive functions, such as thinking, remembering, reasoning, and behavioral abilities to such an extent that it interferes with daily life. These cognitive capacities include memory, language skills, visual perception, problem solving, self-management, and the ability to focus.³⁴ This loss of cognitive function and functional abilities can be measured on a seven-part scale that explains what happens at each stage of decline. The stages provide one useful way of thinking about the progression of dementia, though many physicians may prefer to simply classify the disease as either, mild, moderate, or severe. Stages one through three begin at no cognitive impairment to mild cognitive decline, which includes memory problems and changes that are noted by family and friends. Stages four and five show a marked to moderate decline in function that results in an inability to complete tasks and notable changes upon medical assessment, such as when a Montreal Cognitive Assessment (MoCA) is performed.³⁵ Patients can also seem withdrawn and may be unable to make certain decisions on their own. At stages six and seven there is a major decline with severe loss of cognitive function. Patients may no longer be able to complete tasks on their own, resulting in a need for constant supervision. This may even

³⁴ “What Is Dementia? Symptoms, Types, and Diagnosis.” *National Institute on Aging*, U.S. Department of Health and Human Services, 31 Dec. 2017.

³⁵ Freitas, Sandra, Mário R. Simões, Lara Alves, Margarida Vicente, and Isabel Santana. “Montreal Cognitive Assessment (MoCA): Validation Study for Vascular Dementia: Journal of the International Neuropsychological Society.” Cambridge Core. Cambridge University Press, June 8, 2012.

progress to the complete inability to interact with their environments, up to and including catatonia.³⁶

There are several different types of dementia and diseases that may include dementia, such as Alzheimer's Disease, Parkinson's disease, Huntington's disease, Lewy-body dementia, frontotemporal dementia, vascular dementia, and AIDS. The characteristics of dementia differ depending on the type, and also shortens life-expectancy anywhere from three to twelve years.³⁷

5.1 Dementia and Decision-making Capacity

The importance of the dementia scale is its potential to distinguish between stages as well as its definition based on objective criteria that can be observed by a clinician; however, this does not mean that the scale applies to every patient in the same way. The stages provide a guide for how the disease may progress, but this does not mean that dementia will progress at the same rate with the same symptoms in the same order for each individual. With that being said, the latest stages of the disease are characterized by deficits that will almost always result in a loss of decision-making capacity. One such deficit found in late-stage dementia is the loss of the ability to reason associated with a loss of executive function. This loss significantly undermines a key ability to competently reason, which, as was described in Grisso and Appelbaum's model above, renders the affected person incompetent. Executive function includes a number of abilities such

³⁶ Reisberg, B., Ferris, S. H., de Leon, M. J., & Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *The American Journal of Psychiatry* 139(9), 1136-1139.

³⁷ de Beaufort, Inez D, 2016.

as initiation of tasks, volition, working memory, selective attention, set shifting, task setting, and task maintenance. It also includes response inhibition, monitoring and goal directed behavior.³⁸

When a person with dementia is deciding whether to participate in physician-assisted suicide they will have to use reasoning their working memory, selective attention, the ability to task set and to maintain that task setting. This might not be possible depending on what stage in the disease process a patient is as people with dementia are at an ever-increasing risk of losing these abilities as their diseases progress. The notion that patients with dementia are incapable of making this decision because they lack the relevant abilities is a reasonable concern. Decision-making capacity should be assessed on a case-by-case basis for every person asking to participate in physician-assisted suicide. The assessing physician must keep in mind that the disease is relevant only insofar as it impairs a person's ability to reason, understand and appreciate relevant treatment information, and to express a choice regarding treatment. The physician and consulting physician are essentially the gatekeepers who ensure only competent patients get access to physician-assisted suicide. They ensure that if a patient does not have decision-making capacity that they are prevented from having access to lethal medication.

³⁸ Darby, R Ryan. "Dementia, Decision-Making, and Capacity". *Harvard review of psychiatry* (1067-3229), 25 (6), (2017). 270.

5.2 Dementia as a Terminal Illness

In addition to putting people at risk of losing decision-making capacity, dementia is also a terminal disease with a high mortality rate.³⁹ According to a study published in the *New England Journal of Medicine*, data suggests that patients with advanced dementia had a median survival rate of 1.3 years. The study followed 323 nursing home residents with advanced dementia for 18 months in 22 nursing homes. They then collected data to characterize the residents' survival, clinical complications, symptoms and treatments to understand prognosis and complications in people with advanced dementia. The researchers found that over the 18-month time period 54.8% of the residents they followed died. The patients died from a variety of complications such as pneumonia and fever, but the largest number (85.8%) died from eating problems. From this data researchers determined that pneumonia, fever, and eating problems are common complications in patients with advanced dementia and they are commonly associated with a high six-month mortality rate. The authors give further evidence for dementia being a terminal disease based on the fact that none of the patients studied died of acute devastating events, or from other chronic conditions that normally result in decompensation.⁴⁰

³⁹ Mitchell, Susan L., Joan M. Teno, Dan K. Kiely, Michele L. Shaffer, Richard N. Jones, Holly G. Prigerson, Ladislav Volicer, Jane L. Givens, and Mary Beth Hamel. "The Clinical Course of Advanced Dementia." *New England Journal of Medicine* 361, no. 16 (2009): 1529–38.

⁴⁰ Mitchell, Susan. 1536

6.0 Supported Decision-making Model

Megan Wright proposes a practical solution to the problem of physicians assuming that a patient is incompetent merely because they carry a dementia diagnosis in “Dementia, Autonomy, and Supported Health Care Decision Making”. In her article, Wright discusses the problem of presumed incompetence in dementia patients and suggests implementing a supported decision-making model as a potential solution. The supported decision-making model (SDM) she includes promotes patient autonomy by allowing patients to rely on others to help them process and understand the information relevant to the decisions they need to make. Wright’s proposed model recognizes that people often consult with others when making important decisions and simply puts these pre-existing decision-making relationships into a legal framework.⁴¹ This model has major benefits for patients with dementia, two of which are that it gives patients more opportunities to have relevant information clarified, and it improves a person’s ability to make his or her own decisions by serving as a safeguard against the presumption of incompetence made solely on the basis of a dementia diagnosis.

In practice, the supported decision-making model would look something like this: A patient would fill out a supported decision-making form, which can be witnessed by an attorney, designating their supporter. This form could then be given to their physician explaining that their supporter would attend doctor’s appointments, help reframe information in a way that the patient better understands, and generally be there as an additional support for the patient. The form would explain to the physician that the supporter cannot make any decisions for the patient and that if the

⁴¹ Wright, Megan, 2019.

patient were no longer able to make decisions for themselves, then the patient's designated surrogate would take over.

Turning the focus to how the supported decision-making model would work when a patient requests to participate in physician-assisted suicide, the supporter would attend the appointment where the patient would ask for the lethal medication. The supporter would sit with the patient and the physician and could ask questions that they think might be relevant to the patient's decision-making process, they could take notes, and reframe any medical wording that might be difficult for the patient to understand. They could help the physician understand how the patient is communicating if the patient communicates in a different way because of their disability. The supporter could also assist the patient in writing the written request to participate in physician-assisted suicide.

Maintaining a person's autonomy for as long as possible is the goal of applying the supported decision-making model to persons with dementia. Though autonomy and competence are related, they are not identical.⁴² The right of a competent person to make an informed choice regarding medical care is part of common law. Take, for example, *Schloendorff v. Society of New York Hospital* and *Mohr v. Williams*. In *Schloendorff v. Society of New York Hospital*, the court determined that, because the plaintiff was cut open and had a tumor removed without her consent, she was wronged because her consent was not sought out and should have been. The court therefore concluded that patients have the basic right to be a part of their medical care and give explicit consent to treatment. The court decided that every adult of "sound mind" has a right to

⁴² Levin, and Sander M. "Text - H.R.4449 - 101st Congress (1989-1990): Patient Self Determination Act of 1990." Congress.gov, July 2, 1990.

determine what happens to their body and therefore that competence is a necessary condition for a patient to exercise autonomy.⁴³

In *Mohr v. Williams*, Mrs. Mohr went to Dr. Williams to have an operation on her right ear. During the operation Dr. Williams determined that her right ear was fine and that her left ear needed to be operated on instead. He proceeded to fix a non-emergent issue in her left ear. When Mrs. Mohr discovered this, she sued Dr. Williams for battery. The Supreme Court of Minnesota determined that if a doctor has received a patient's consent to perform a particular operation, he or she cannot then perform a different operation. This case set precedent by showing that a surgeon has to respect a patient's right to make an informed decision regarding his or her care.⁴⁴ Patients have a right to make an informed decision about their medical care and physicians have a corresponding obligation to respect those informed decision.

However, in the case of patients with dementia, because it is a neurodegenerative disorder that can affect decision making, having someone who the patient trusts, who understands the patient's wishes, and who can help the patient to make decisions with their physician could be the best way to maintain autonomy until they are no longer capable of making such decisions.⁴⁵

Mary Donnelly, in her article "Deciding in Dementia: The Possibilities and Limits of Supported Decision Making", agrees that supported decision-making can be a valuable tool for patients with dementia. There are several legal acts that have been passed which create alternatives to guardianship for persons with dementia. One of these acts, from British Columbia, is called The

⁴³ *Schloendorff v. Society of New York Hospital*, 211 N.Y. 125, 105 N.E. 92 (1914).

⁴⁴ *Mohr v. Williams*, 104 N.W. 12 (Minn. 1905)

⁴⁵ Keeling, Amanda. "Supported Decision Making: the Rights of People with Dementia." *National Center for Biotechnology Information*, U.S. National Library of Medicine, 23 Mar. 2016.

Adult Guardianship and Co-Decision-making Act. This Act intends to operate alongside guardianship acts in terms of representing patient interests if they have a disability and have trouble making, or are unable to make, decisions themselves.

The Act defines the scope of guardianship and of the co-decision-maker's role. The co-decision-maker is appointed by the patient to help the patient with some decisions but the patient is making all the decisions. Guardianship is legally defined as, "...the state law process by which a court appoints a surrogate to make decisions for an adult who is deemed 'incapacitated,' frequently by virtue of intellectual disability, mental illness, or cognitive impairment."⁴⁶ Co-decision making allows for the patient with capacity to make their own decisions with the assistance of others. The term "co-decision maker" may imply a joint decision-making effort and is equivalent to "supporter", but it is important to note that all final decisions rest with the patient.

The court determines the scope of that co-decision-making power depending on what the co-decision-maker is helping decide. The co-decision-maker can assist in making decisions but must abide by what the competent patient says.⁴⁷ In the case of dementia, Donnelly says that it can be useful in terms of keeping patients with dementia "at the center of their care."⁴⁸ This means that the patient is making all of his or her decisions with the assistance of a supporter.

Donnelly suggests that, based on the forms of supported decision-making described in the legal acts, the following are the ways in which supported decision-making can be useful to patients

⁴⁶ Diller, Rebekah. "Legal Capacity for All: Including Older Persons in the Shift from Adult Guardianship to Supported Decision-Making." *Fordham Urban Law Journal* 43, no. 3 (April 1, 2016): 1–44.

⁴⁷ The Adult Guardianship and Co-Decision-making Act. *Statutes of Saskatchewan, 2000. Chapter A5-3.*

⁴⁸ Donnelly, Mary. "Deciding in Dementia: The Possibilities and Limits of Supported Decision-making." *Internal Journal of Law and Psychology* 66 (September 2019): 1-7.

with dementia: "...life planning (choosing priorities in the context of values); independent advocacy (helping the person express his or her will and preferences); communicational and interpretative supports (representing the person's often unique forms of communication)..."⁴⁹

I think that, as Donnelly describes it, supported decision-making can assist patients in the medical decision-making process by providing them an additional perspective on the relevant medical information. Because the patients that I am suggesting should be able to participate in physician-assisted suicide are competent to make their own decisions, this is a reasonable alternative to guardianship. I am not suggesting that supported decision-making be mandated for patients with dementia to participate in physician-assisted suicide, only that it can be helpful as a second set of ears and as a someone who could possibly help explain complicated medical information.⁵⁰ The capacity assessment that is done with the patient is performed directly between the patient and physician alone. The supporter, of course, could help with the nuances of the decision at hand, but the capacity assessment is between the patient and physician only.

⁴⁹ Donnelly, Mary. pg. 6

⁵⁰ Donnelly, Mary. pg. 5

7.0 Moral Argument for Allowing Patients with Dementia to Access Physician-Assisted Suicide

In a study conducted at the University of Pennsylvania, researchers looked at cognitively intact, healthy older adults with a biomarker called amyloid- β , that tends to suggest Alzheimer's will develop later in life. The participants were interviewed several times, with the last interview occurring 12 months after the markers were found. During the last interview, interviewers asked participants if they would want to participate in physician-assisted suicide due to the nature of the markers and the impending likelihood of a terminal disease. Of the 80 healthy adults interviewed, one in five said they would pursue physician-assisted suicide if they were to become cognitively impaired, were suffering, or were becoming a burden. Most of the interviewees who said they would seek physician-assisted suicide had already expressed this desire in previous interviews without prompting from the researchers.

In recent years, patients with dementia have been granted access to physician-assisted suicide in the Netherlands. A total of 25 cases of patients with dementia participated in physician-assisted suicide and euthanasia in 2010.⁵¹ This statistic further shows that patients with dementia do want access to physician aid in dying.

The yearly report published by the Oregon Public Health Division, as required by the Death With Dignity Act, shows that most individuals choose to participate for the following reasons: so they are no longer a burden on their families, to maintain autonomy and sense of self, avoiding

⁵¹ Gather, Jakov, and Jochen Vollmann. "Physician-Assisted Suicide of Patients with Dementia. A Medical Ethical Analysis with a Special Focus on Patient Autonomy." *International Journal of Law and Psychiatry* 36, no. 5-6 (2013): 444–53.

loss of dignity, and because of an inability to participate in activities that make life enjoyable.⁵² Dementia can cause the loss of autonomy, sense of self, dignity, the inability to participate in activities that make life enjoyable, and can result in persons with dementia feeling as though they are a burden to their families. This is why some patients with dementia may want to participate in physician-assisted suicide.⁵³ This shows that dementia patients want to participate in physician-assisted suicide for the same reason patients who currently are allowed to access physician-assisted suicide do in fact participate.⁵⁴

7.1 Provision for Patients with Dementia Accessing Physician-Assisted Suicide

The “six month” component of the definition of terminal illness in the Death with Dignity Acts is problematic because persons dying from dementia will not have decision-making capacity when they only have six months to live. Dementia progresses at different rates depending on the person, therefore assessing capacity at the time of the request, instead of mandating that each person requesting have six months to live, should be how physicians determine eligibility to participate.

⁵² Center for Health, Public Health Division. “Oregon Death with Dignity Act 2018 Data Summary.” Oregon Health Authority, February 14, 2019.

⁵³ de Beaufort, Inez D, 2016.

⁵⁴ Largent , Emily A, Melanie A Terrasse, and Kristin Harkins. “Attitudes Toward Physician-Assisted Death From Individuals Who Learn They Have an Alzheimer Disease Biomarker.” *Journal of American Medical Association* 76, no. 7 (April 29, 2019): 1–6.

Furthermore, physicians are notorious for predicting the amount of time left in someone's life and being wrong.⁵⁵ In a study published in the British Medical Journal designed to review clinical predictions of survival rates in cancer patients, it was found that physicians "consistently overestimate patient's survival rates." These over-estimations can significantly impede a patient's ability to have a "good death."⁵⁶ There are similar studies of dementia patients; one shows that physicians cannot predict when a patient will exhibit late stage Alzheimer's signs and that each stage is different depending on the person. Therefore, there is an ambiguous timeline for death from dementia.⁵⁷

People who are currently allowed access to physician-assisted suicide are allowed to participate to avoid avoidable suffering, but that should not be limited to those who are going to die within six months. Dementia patients want access to physician-assisted suicide to avoid suffering, which is why some patients have access to physician-assisted suicide now; justice therefore demands that we should eliminate the six-month rule to grant access. By passing acts permitting physician-assisted suicide, jurisdictions are showing that they have an interest in allowing residents to avoid the suffering of a terminal disease. Suffering does not have a timeline and therefore access to physician-assisted suicide should be granted to those who are suffering from a terminal illness, regardless of how long they have to live. It should be noted that removing the six-month provision will allow for patients with other terminal illnesses to participate in

⁵⁵ Glare, Paul, Kiran Virik, Mark Jones, Malcolm Hudson, Steffen Eychmuller, John Simes, and Nicholas Christakis. "A Systematic Review of Physicians' Survival Predictions in Terminally Ill Cancer Patients." *The BMJ*. British Medical Journal Publishing Group, July 24, 2003.

⁵⁶ Glare, Paul, 2003.

⁵⁷ Cutler, N. R. "Clinical History, Brain Metabolism, and Neuropsychological Function in Alzheimer's Disease." *Annals of Neurology* 18, no. 3 (September 1985): 1-12.

physician-assisted suicide, however, in this paper, I am only discussing patients with dementia because of the eventual lack of decision-making capacity. I am not suggesting that patients with dementia are the exception, only that they should be granted access to physician-assisted suicide by removal of the six-month provision.

Under the Death with Dignity Act, as with any other patient asking to participate in physician-assisted suicide, patients with dementia will undergo a capacity assessment. If deemed to have decision making capacity, they should then have access to physician-assisted suicide, assuming they meet all other criteria. To address the presumption of incompetence, providing patients with the legal option of having a supporter can serve as a practical barrier to physicians making the presumption that the patient with dementia is incompetent. They do not need someone to make decisions for them, rather, they only wish to have someone to be there with them. The physicians who determine whether patients should have access to physician-assisted suicide will need to be educated on how the supported decision-making model works in theory and what it looks like in practice.

Given the information above, and by way of example, I would change the Oregon statute at line 12 from, "Terminal disease means an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months."⁵⁸ to "Terminal disease means an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgement, produce death." I will simply

⁵⁸ [1995 c.3 §1.01; 1999 c.423 §1]

be removing the six-month requirement to redefine who is considered to be a terminal patient according to the law.⁵⁹⁶⁰

⁵⁹ A notable concern (that will not be addressed here) could be that, because I am suggesting removing the six-month terminal illness requirement, more people will have access to physician-assisted suicide and therefore there will be less regulation. The removal of the six-month provision may in fact result in the need for more regulations, but the larger concern would be that it would be more difficult to prevent abuse and even maintain the “terminal illness” provision once so many have access.

⁶⁰ In the case of *Baxter v. Montana*, because it is a court case, this would require the state to pass legislation enacting laws specifically allowing physician-assisted suicide that could be similar to provisions passed in jurisdictions with death with dignity acts. In that case, if Montana passed something similar to a Death with Dignity Act, the provision could read the same as the provision above in order to include patients with dementia.

8.0 Provision for Supported Decision-Making Model

I would also include a provision that provides patients with the right to have a supported decision maker. This would be based on current laws that allow for a supported decision maker. My provision will read, “A supporter is allowed for patients with cognitive challenges, ensuring that they are the ultimate decision-maker but are provided support from another, giving them the assistance they need to make decisions for themselves.⁶¹ This provision outlines the capacity in which a supporter may act and allows for the presence of one when a person with dementia may be deciding to participate in physician-assisted suicide.

The supporter relationship will be legally outlined following a document similar to the one used in Texas⁶². The state of Texas has an alternative legal model to that of guardianship that outlines what someone who needs support will require from their supporter and a legal document that the supporter fills out showing they are in agreement that they cannot make decisions for the person they are supporting. Texas defines supported decision-making as follows:

“A process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self-determination of the adult.”⁶³

⁶¹ Kohn, Nina A., Jeremy A. Blumenthal, and Amy T. Campbell. “Supported Decision-Making: A Viable Alternative to Guardianship?” SSRN Electronic Journal, 2012. 4

⁶² See appendix A

⁶³ Texas Estates Code § 1357.002(3)

The idea is that a person who needs some extra help can legally appoint a supporter to help them get information to make medical decisions, understand risks, and communicate their decisions. The person can be a family member, relative or friend.

8.1 Potential Concerns

A concern could be that a supporter for a patient with dementia might be manipulating the patient into making the decision to participate in physician-assisted suicide since the latter may be vulnerable to such influence and the former could be benefitted by such an outcome. In response to this legitimate concern, I would argue that the physician overseeing and prescribing a patient the lethal medication has a responsibility to ensure that the supporter is acting in the patient's best interests - the patient's ability to be given the information he or she needs to make an autonomous decision and to have that decision respected by others. If a physician believes that the supporter is not acting in the patient's best interests, the physician can suggest that the patient bring someone else to the appointments and explain the guidelines that must be followed for someone to be the supporter. This will require additional physician education, with the supported decision-making requirements used as a guideline to inform them about whether or not the supporter should in fact be the supporter. The supported decision-making form would be helpful in this regard since it outlines why the person providing support should be supporting and what their duties entail.⁶⁴

This means that if there were to be a medical decision that had to be made the medical decision maker (i.e., the patient) would make that decision, not the supporter. Second, it reaffirms

⁶⁴ See Appendix

that the person with dementia still retains decision-making capacity.⁶⁵ This document can be used in conjunction with an advance directive and would not, necessarily, interfere with the medical decision-making process since there is no inherent conflict between the supported decision-making model and advance directives because when the latter goes into effect the former is no longer valid. If it were to become unclear that the patient in question had decision-making capacity, another, possibly more formal, capacity test could be conducted to determine whether or not the patient is still capable of choosing to participate in physician-assisted suicide. As stated earlier, if a patient's capacity is still in question, specialist, such as a geriatrician or a psychiatrist could be consulted or a capacity assessment could be performed at a later time.

⁶⁵ A physician can determine that a patient with a supporter is incompetent to make the decision to participate in physician-assisted suicide.

9.0 Conclusion

Death with Dignity Acts are currently structured in a way that excludes patients who would benefit from and who would like to have access to physician-assisted suicide. Patients with dementia want to participate in physician-assisted suicide for the same reasons patients who have access to physician-assisted suicide want to participate; they do not want to be a burden, they do not want to lose their dignity or sense of self, and because they can no longer participate in the activities that make life enjoyable.

I would like to make it clear that I am not excluding patients who want to participate that have other terminal diseases. Of course, given my redefinition of terminal illness, people with other conditions will qualify to participate in physician-assisted suicide. I am simply arguing that due to the presumption of incompetence, among other things, that is too often made regarding patients with dementia, and because of the terminal nature of their disease, they should have access to physician-assisted suicide.

Removing the six-month terminal diagnosis provision will allow for patients with dementia to begin the process for participation in physician-assisted suicide. When a patient asks their attending physician to participate in physician-assisted suicide, a capacity assessment is performed to determine whether or not the patient is capable of making such a decision, therefore hesitation about capacity, just because of a dementia diagnosis, may be unwarranted.

Changing the current definition of “terminal patient” in Death with Dignity Acts makes the laws more equitable. In allowing for supported decision-making, patients with dementia will be able to make their own medical decisions without the automatic presumption of incompetence. Because access can be granted to patients with dementia in an ethically justifiable manner, the

laws should be changed to grant patients with dementia access to physician-assisted suicide in jurisdictions with Death with Dignity Acts.

Appendix A Texas Supported Decision-Making Model

Supported Decision-Making Agreement

This agreement is governed by the Supported Decision-Making Act, Chapter 1357 of the Texas Estates Code. This supported decision-making agreement is to support and accommodate an individual with a disability to make life decisions, including decisions related to where and with whom the individual wants to live, the services, supports, and medical care the individual wants to receive, and where the individual wants to work, without impeding the self-determination of the individual with a disability. This agreement may be revoked by the individual with a disability or his or her supporter at any time. If either the individual with a disability or his or her supporter has any questions about the agreement, he or she should speak with a lawyer before signing this supported decision-making agreement.

Appointment of Supporter:

I (Name of Adult with Disability), _____ am entering into this agreement voluntarily.

I choose (Name of Supporter) _____ to be my Supporter.

Supporter's Address: _____

Phone Number: _____

E-mail Address: _____

My Supporter may help me with life decisions about:

Yes ___ No ___ obtaining food, clothing and a place to live

Yes ___ No ___ my physical health

Yes ___ No ___ my mental health

Yes ___ No ___ managing my money or property

Yes ___ No ___ getting an education or other training

Yes ___ No ___ choosing and maintaining my services and supports

Yes ___ No ___ finding a job

Yes ___ No ___ Other: _____

My Supporter does not make decisions for me. To help me make decisions, my Supporter may:

1. Help me get the information I need to make medical, psychological, financial, or educational decisions;
2. Help me understand my choices so I can make the best decision for me; or
3. Help me communicate my decision to the right people.

Yes ___ No ___ My Supporter may see my private health information under the Health Insurance Portability and Accountability Act of 1996. I will provide a signed release.

Yes ___ No ___ My Supporter may see my educational records under the Family Educational Rights and Privacy Act of 1974 (20 U.S.C. Section 1232g). I will provide a signed release.

This agreement starts when signed and will continue until _____ (date) or until my Supporter or I end the agreement or the agreement ends by law.

Signed this _____ (day) of _____ (month), _____ (year)

(Signature of Adult with Disability)

(Printed Name of Adult with Disability)

CONSENT OF SUPPORTER

I (Name of Supporter), _____ consent to act as a Supporter under this agreement.

(Signature of Supporter)

(Printed Name of Supporter)

This agreement must be signed in front of two witnesses or a Notary Public.

(Witness 1 Signature)

(Printed Name of Witness 1)

(Witness 2 Signature)

(Printed Name of Witness 2)

OR

Notary Public

State of _____

County of _____

This document was acknowledged before me on _____ (date)

By _____ and _____

(Name of Adult with a Disability)

(Name of Supporter)

(Signature of Notary)

(Printed Name of Notary)

(Seal, if any, of notary)

My commission expires: _____

WARNING: PROTECTION FOR THE ADULT WITH A DISABILITY

If a person who receives a copy of this agreement or is aware of the existence of this agreement has cause to believe that the adult with a disability is being abused, neglected, or exploited by the supporter, the person shall report the alleged abuse, neglect, or exploitation to the Department of Family and Protective Services by calling the Abuse Hotline at 1-800-252-5400 or online at www.txabusehotline.org.

DUTY OF CERTAIN PERSONS WITH RESPECT TO AGREEMENT

A person who receives the original or a copy of a supported decision-making agreement shall rely on the agreement. A person is not subject to criminal or civil liability and has not engaged in professional misconduct for an act or omission if the act or omission is done in good faith and in reliance on a supported decision-making agreement.

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