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2024

Bridging the Gap: Expanding Medical “Aid” in Dying for ALS Patients

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INTRODUCTION

When individuals contemplate constitutional concepts about the United States, it is likely that their line of thinking will immediately proceed to the pre-conceived notion that America is the "land of the free," where citizens are guaranteed rights to their personal dignity and bodily autonomy. However, Americans have fewer protected rights to bodily autonomy than a layperson may think, especially when it comes to a physically handicapped, terminally ill patient's right to choose how and when they die. Lawmakers have made significant strides in implementing legislature in their states that allow physically able, terminally ill patients to painlessly end their own lives with the help of physician-prescribed lethal doses of medication. These legislatures are collectively called Medical Aid in Dying ("MAID"). While many patients are reaping the benefits of MAID, not all patients who need more inclusive access to MAID are afforded such an opportunity. This is especially true for patients diagnosed with Amyotrophic Lateral Sclerosis ("ALS").

The horrors of ALS can only be truly appreciated by those who live with it, followed closely only by those who have to watch their loved one progress through the disease. These patients become prisoners in their bodies, as was the case for Ken Smith.¹ Ken was a hard-working father of two whose life took a tragic turn when he was diagnosed with ALS. For Ken, the onset of his ALS started with a seemingly natural episode of numbness in his foot and slight tingling in his fingers, symptoms he simply attributed to his physically demanding trade profession. It was not until after Ken needed his leg amputated that the doctors believed that something more sinister was causing these issues. It was shortly after his procedure that he was officially diagnosed with ALS.

¹ Ken Smith is a family member of the author whose name has been changed for the purposes of this paper. His story is recounted from personal experience.

Ken's health declined at a relatively rapid pace over approximately three years. Before long, he became paralyzed from the waist down, unable to do any activities he once enjoyed. He could no longer walk, drive, or do his daily activities. Shortly after, he lost his ability to use his arms and hands. With that loss of movement, he could no longer do something as simple as changing the channel on the television or adjusting his position in bed. At this point, Ken was moved into a family member's home, and his family stepped up to the plate to take care of him with the help of a home health aide. Ken's sister, Mary-Anne, and her husband, Garrett, dedicated about a year and a half of their time to ensuring that Ken was cared for. They fed, bathed, and helped him use the restroom, just to name a few of the countless tasks they undertook. Towards the end, Garrett was essentially on-call 24/7, receiving multiple calls a day to help Ken, and in many instances, needed to help the health aide in the middle of the night.

All the while, Ken's body continued to waste away faster than he could have ever imagined. At this point, he could no longer breathe on his own. Instead, he relied on oxygen tanks for air and breathing treatments to expel the fluid from his lungs. Worst of all, mentally, Ken was still as sharp as a tack and as stubborn as he had always been. With that stubborn streak came a prolonged grieving of the loss of his own life. Earlier in his disease, when he had formally been determined to be in the terminal stage of ALS by his physician, Ken was given the choice of partaking in physician-assisted death pursuant to New Jersey's MAID legislation that would have allowed him to end his own life through the self-injection of a lethal dose of medication prescribed by his physician. However, until the last couple of months of his life, Ken was in denial that he was genuinely going to pass away, and, in some small part of his mind, he still had hope that he would get better.

By the time Ken finally came to terms with his inevitable passing, he was no longer eligible to utilize MAID, as he had lost the ability to self-administer the medication. All he could do was lay in his bed and wish for the pain to stop. Nothing could be done, as his physician could not administer the medication for him. Ken would have had to take the lethal dose several months prior, long before he had grieved the life he was losing. Sadly, Ken passed away from ALS in September 2020.

For patients like Ken, the self-administration requirement continues to act as a barrier to access to MAID, as the hallmark symptom of the condition is total body paralysis. Allowing a narrow exception for these physically disabled patients to seek help from a willing physician in administering the lethal dose of medication would provide invaluable accessibility for these patients. Achieving the goal of allowing a narrow exception in the "self-administration" requirement in MAID states is likely best achieved through legislative action. This is because the Supreme Court has been reluctant to hold that citizens have a constitutionally protected right to physician-assisted death. However, they have opined that States could implement MAID programs as they see fit. In fact, the Supreme Court has encouraged states to allow the democratic process to dictate how states implement MAID. Further, states' legislative ability to be more flexible would allow experimental expansions to MAID to be adjusted as necessary.

Enacting such an accommodation through the legislature would circumvent the issue of the Supreme Court determining that physician-assisted death is a fundamental right, therefore avoiding several issues cited as *legitimate state interests*. Further, recent research has revealed a substantial change in attitudes surrounding MAID, suggesting that the public and physicians themselves believe such an option may be necessary. Additionally, advancements in medical technology will allow effective communication between patients and their doctors, which is a

crucial necessity for the proposed accommodation discussed later in this paper. Lastly, of the states that have legalized MAID, Montana may have the necessary seeds planted to allow experimental legislation that would make MAID more accessible for physically disabled ALS patients while sheltering physicians from criminal liability as new data is collected on the implementation and functionality of the narrow expansion. Assuming that Montana would allow this accommodation, the goal is as new data becomes available, other states will follow in Montana's footsteps as they become assured that the expansion will not open the door to program abuse.

The body of this paper will examine a number of issues related to MAID and, specifically, how MAID applies to patients with ALS. In Section I, ALS will be introduced and a real case involving the issue presented will be discussed. Additionally, section I will discuss the history and legal landscape of MAID. Section II will discuss how new and relevant empirical data indicates that an expansion of MAID for ALS patients is ripe for legislative action. Section III will introduce the methods of MAID utilized in Montana. Lastly, Section IV will analyze how the existing MAID framework in Montana can be used as a starting point for the introduction of an experimental MAID legislation that would provide invaluable access to MAID for physically disabled, but mentally competent ALS patients, and hopefully kickstart a movement towards country-wide implementation.

SECTION I: BACKGROUND

A: Background on ALS

As of 2022, most participants in MAID are patients with terminal cancer diagnoses, at approximately 71.7%.² However, the second largest percentage of participants are those diagnosed with terminal neurological diseases (11.5%), followed by respiratory diseases (5.9%), heart conditions (6.15%), and other miscellaneous conditions (4.9%).³ Out of any of these diagnoses, patients with Amyotrophic Lateral Sclerosis (“ALS”) are subjected to unique hurdles that generally are not experienced by those with other conditions.

ALS is an incurable and untreatable neurodegenerative disease that causes irreversible breakdown of the body's motor neurons.⁴ Motor neurons function to initiate and control voluntary muscle movement.⁵ Approximately two out of every one-hundred-thousand people are diagnosed with ALS annually.⁶ ALS is unlike other terminal neurodegenerative diseases such as Parkinson's, Alzheimer's, and Multiple Sclerosis in that ALS patients rarely lose their cognitive ability. Instead, the hallmark symptom of ALS is that, as the condition progresses, patients will lose all control of their muscles, leading to difficulty or inability to move, talk, breathe, and swallow.⁷

² *FINAL MAID Data Across Authorized States*, Compassion and Choices (Jan. 5, 2022), https://www.compassionandchoices.org/docs/default-source/default-document-library/final-maid-data-across-authorized-states-01.05.22.pdf?sfvrsn=ad811300_1.

³ *Id.*

⁴ *The Stages of ALS: Framing the Progression of a Nonlinear Disease*, Target ALS <https://www.targetals.org/2022/01/04/the-stages-of-als-framing-the-progression-of-a-nonlinear-disease/>.

⁵ *Id.*

⁶ *Id.*

⁷ *Id.*

This condition gets more complicated than others because ALS is a highly variable condition with no progression timeline.⁸ Research has shown that ALS cases will progress over two to five years, meaning that some cases of ALS progress faster than others.⁹ Living past five years or more with ALS is rare, as only about twenty percent of patients live to the five-year mark, and only about five percent will live for twenty years or more.¹⁰

Early-Stage ALS can manifest in one of two ways, either "limb onset" or "bulbar onset."¹¹ Limb onset is more common and is characterized by weakness beginning in the hands and feet.¹² Conversely, the bulbar onset begins with difficulty speaking and swallowing.¹³ Additional early symptoms include muscle weakness, tightness, cramping, and twitching.¹⁴

In Middle-Stage ALS, symptoms worsen, and muscle atrophy spreads to other body parts, with some areas completely paralyzed.¹⁵ Further, patients have more difficulty swallowing, walking, performing daily activities, and driving.¹⁶

In Late-Stage ALS, most of the patient's muscles are completely paralyzed, including those in the mouth and throat, leading most patients to need a ventilator to breathe and a feeding tube for nutrient intake.¹⁷ Patients are, therefore, mostly paralyzed at this time.

In Final-Stage ALS, the patients are determined, by their physician, to be in the "terminal" stage of the disease and are then eligible for hospice care.¹⁸ Patients in this stage will have respiratory failure, their speech will be unintelligible or physically impossible, and they will

⁸ *Id.*

⁹ *Id.*

¹⁰ *Id.*

¹¹ *Id.*

¹² *Id.*

¹³ *Id.*

¹⁴ *Id.*

¹⁵ *Id.*

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ *Id.*

entirely rely on someone else for care.¹⁹ No treatment is available other than palliative care to relieve discomfort and sedate the patient.²⁰ In states where MAID is legalized and pursuant to the current overarching MAID framework discussed above, the terminal stage is when patients become fully eligible to participate in MAID, so long as they are mentally competent adults and can self-administer the lethal dose of medication.

The most glaring issue is that, by the time an ALS patient reaches this stage, many no longer have sufficient voluntary muscle control and mostly rely on the care of others. This leads to a significant issue with the self-administration requirement in all MAID frameworks. Essentially, these patients trade one eligibility factor for another or, at the very best, have a minimal window in which they still retain the minimum level of voluntary muscle control that would allow them to self-administer the medication. Therefore, in reality, patients with ALS must make the difficult decision of whether to self-administer the lethal dose of medication within this limited "terminal" period before they are ready to end their lives or to take the substantial risk of waiting until they are ready, but potentially losing the ability to self-administer the medication at all, subjecting them to significant pain and suffering until they eventually succumb to death.

B. The Case of Sandy Morris

This is no mere speculation of the profoundly personal choice ALS patients may ponder regarding their end-of-life wishes. For many, like fifty-five-year-old Sandy Morris, it was and is a terrifying reality.²¹ Sandy was first diagnosed with ALS in January 2018 and, as of December

¹⁹ *Id.*

²⁰ *Id.*

²¹ Esmé E Deprez, *A Fight to Die*, Bloomberg.com (Dec. 17, 2012), <https://www.bloomberg.com/news/features/2021-12-17/death-with-dignity-right-to-die-laws-leave-patients-with-impossible-choice>.

2021, spent most of her days in bed, unable to move below her chin. She could no longer ride her horses, cross-country ski, or run.²² She relied on home health aides to help with basic hygiene, eating, drinking, and getting into her motorized wheelchair.²³ She could not breathe on her own without the help of a ventilator forcing air into her nose.²⁴

However, while Sandy's physical health was failing, her cognitive ability remained in full force.²⁵ She understood what was happening to her and that her death was looming in the near future. With this in mind, she intended to use California's MAID law.²⁶ She was eligible to participate, and her case "embodied the spirit of the law's aim: to offer agency and autonomy at the end of life in lieu of suffering, indignity, and shame."²⁷ However, Sandy's dilemma began regarding her decision of when the right time would be for her to pass, keeping in mind that patients partaking in MAID must self-administer the lethal dose of medication.²⁸ This left Sandy with the horrifying choice of whether to ingest the medication while she was still physically able to but emotionally unprepared to leave her husband and three children behind or to wait and lose the ability to act altogether and succumb to the slow death-by-suffocation she knew waited for her.²⁹ While the requirement's basis is steeped in good intentions, the issue remains that, for patients like Sandy with severe neurodegenerative conditions that cause extreme physical disability, it acts as a barrier to utilization.³⁰ The issue is, because the topic of MAID has long been controversial and has been subjected to substantial push-back since its debut in the United

²² *Id.*

²³ *Id.*

²⁴ *Id.*

²⁵ *Id.*

²⁶ *Id.*

²⁷ *Id.*

²⁸ *Id.*

²⁹ *Id.*

³⁰ *Id.*

States, it is unlikely that any progress will be made towards expansion of MAID accessibility, at least through judicial mean.

C. History of MAID

MAID is not a novel concept; rather, the idea of physician-assisted death predates the implementation of Oregon's Death With Dignity Act in 1997. Physician-assisted death became widely publicized, beginning with the highly controversial case of Doctor ("Dr.") Kevorkian in 1990.³¹ After traveling to the Netherlands, where MAID is nationally legalized, and learning about the practice of physician-assisted death there, Dr. Kevorkian developed his plan to implement a similar practice here in the United States.³² As a means of protecting himself from criminal liability, he ensured that his patients expressly consented to participation, required patients to seek consultation with family and mental health providers, allowed a month-long waiting period in which patients contemplated their decision, and videotaped interviews with the patient, their families, and the ultimate suicide which he termed "medicide."³³

The first patient to avail herself to Dr. Kevorkian's practice in 1990 was Janet Adkins, a fifty-four-year-old teacher from Oregon diagnosed with Alzheimer's disease. Immediately after her death, Dr. Kevorkian notified the police. He was briefly detained until Mr. Adkins and his two sons held a public press conference to read Mrs. Adkins' suicide note. In his first publicized interview, Dr. Kevorkian stated that his goal was "to make euthanasia a positive experience" and

³¹ Keith Schneider, *Dr. Jack Kevorkian Dies at 83; A Doctor Who Helped End Lives*, The New York Times, (June 3, 2011). <https://www.nytimes.com/2011/06/04/us/04kevorkian.html>

³² *Id.*

³³ *Id.*

stated that he was "trying to knock the medical profession into accepting their responsibilities and that those responsibilities include assisting their patients with death."³⁴

According to Dr. Kevorkian, he assisted over a hundred patients across the country with their suicides using the machine that he invented himself.³⁵ This machine he called the "Thanatron" worked in the following fashion:

“The device consisted of a board to which one's arm is strapped to prevent movement, a needle to be inserted into a blood vessel and attached to IV tubing, and containers of various chemicals that are to be released through the needle into the bloodstream. Strings are tied to two of the fingers of the person who intends to die. The strings are attached to clips on the IV tubing that control the flow of the chemicals. As explained by one witness, the person raises that hand, releasing a drug called methohexital, which was described by expert witnesses as a fast-acting barbiturate that is used under controlled circumstances to administer anesthesia rapidly. When the person falls asleep, the hand drops, pulling the other string, which releases another clip and allows potassium chloride to flow into the body in concentrations sufficient to cause death.”³⁶

Dr. Kevorkian received extensive backlash from the public and the medical community for his actions, ultimately earning him the moniker "Doctor Death."³⁷ Regardless of this backlash, he continued in his crusade, remaining the ever-zealous advocate for a patient's right to choose death in the event of a terminal illness and a devout supporter in assisting his patients act on that choice.³⁸ However, Dr. Kevorkian was ultimately arrested and convicted for second-degree murder. After spending a few years in prison and losing his medical license, Dr. Kevorkian still advocated for physician-assisted death.³⁹ In fact, on his deathbed in 2011, he

³⁴ *Id.*

³⁵ *Id.*

³⁶ People v. Kevorkian, 527 N.W.2d 714, 733 (Sup. Ct. MI. 1994).

³⁷ *Schneider*, supra note 31.

³⁸ *Id.*

³⁹ *Id.*

expressed that he would have wanted the same option available to him as he had provided for his patients.⁴⁰

Medical Aid in Dying ("MAID") was first officially introduced in the United States in Oregon, beginning with the first legislative bill for the Death With Dignity Act in 1989.⁴¹ Oregon's official Death With Dignity Act was enacted on October 27, 1997.⁴² Oregon's death with dignity laws allows eligible terminally ill patients to end their lives through a voluntary self-administration of a lethal dose of medication that their physician prescribes.⁴³ It is not a state program; instead, qualified patients must seek out participating physicians to partake.⁴⁴ Physicians are not required to provide the service but are free to do so if they wish.⁴⁵

Eligibility for MAID generally requires that patients seeking participation must be: (1) eighteen years of age or older; (2) capable of making and communicating healthcare decisions for themselves; and (3) diagnosed with a terminal illness that will lead to death within six months.⁴⁶ Further, these patients must be willing and physically able to self-administer the medication when they are ready to end their lives.⁴⁷ The patient's physician is the one that determines the patient's eligibility. In order to then get a prescription from the physician, patients must take additional steps such as written and oral requests, satisfy waiting periods, get an additional doctor to confirm their diagnosis, satisfy the requirement that they are mentally competent to participate, and confirm that they were advised on all possible alternatives to

⁴⁰ *Id.*

⁴¹ *Our History*, deathwithdignity.org <https://deathwithdignity.org/history/>.

⁴² *Id.*

⁴³ *Oregon's Death With Dignity Act (DWDA)*, Oregon Health Authority <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/faqs.aspx>.

⁴⁴ *Id.*

⁴⁵ *Id.*

⁴⁶ *Id.*

⁴⁷ *Id.*

physician-assisted death.⁴⁸ Each requirement ensures that patients can make a fully informed decision and change their minds until they self-administer the medication.

Since the official outset of Oregon's MAID legislation, nine states and one district have followed in Oregon's footsteps, including Washington, California, Hawai'i, Montana, Colorado, New Mexico, New Jersey, Vermont, Maine, and Washington D.C.⁴⁹ Each of these states, other than Montana, have implemented MAID through ballots or legislation.⁵⁰ Although varying slightly in their intricacies, each of their MAID laws contains the exact four boilerplate requirements introduced by Oregon. Therefore, in these states, the self-administration requirement is a significant barrier to physically disabled, terminally ill patients who want to participate in MAID. Further, legal landscape surrounding physician-assisted death has been a consistent roadblock for those seeking state implementations of MAID and expanding existing MAID programs.⁵¹

D. The Legal Landscape of MAID

The prevailing legal precedent on physician-assisted death was established in the Supreme Court case of Washington v. Glucksberg.⁵² In Washington v. Glucksberg, the Supreme Court of the United States ("the Court") examined whether Washington's ("the State") prohibition against "caus[ing]" or aid[ing]" a suicide offended the Fourteenth Amendment to the United States Constitution.⁵³ The plaintiffs in the case contended that there was "a liberty interest protected by the Fourteenth Amendment that extended to a personal choice by a mentally

⁴⁸ *Id.*

⁴⁹ *States Where Medical Aid in Dying is Authorized*, Compassion and Choices <https://compassionandchoices.org/resource/states-or-territories-where-medical-aid-in-dying-is-authorized>.

⁵⁰ *Id.* Montana will be discussed later in this paper.

⁵¹ *Id.*

⁵² Washington v. Glucksberg, 521 U.S. 702 (1997).

⁵³ *Id.* at 705, 706.

competent, terminally ill adult to commit physician-assisted suicide."⁵⁴ The plaintiffs primarily relied on the cases of Cruzan v. Director of Mo. Dept. of Health and Planned Parenthood v. Casey.⁵⁵

In Cruzan, the petitioner had sustained substantial injuries after an automobile accident and was in a persistent vegetative state.⁵⁶ The petitioner's parents informed the hospital that the petitioner had previously expressed that she did not want to be on life-sustaining treatment in the event of an accident, but the hospital refused to terminate the treatment.⁵⁷ The Supreme Court held that a competent person has a liberty interest under the Due Process Clause in refusing unwanted medical treatment because, based on the Nation's history and traditions, forcing treatment and medication on a patient without their consent was considered battery.⁵⁸ However, the State had the ability to require that there be clear and convincing evidence of the petitioners end-of-life wishes, usually in the form of an advanced directive.⁵⁹ Further, in Planned Parenthood v. Casey, the Supreme Court reaffirmed the holding in Roe v. Wade that granted women a constitutional right to privacy regarding their choice to have an abortion.^{60 61}

The petitioners in Glucksberg therefore argued that physician-assisted death and the right to refuse unwanted medical treatment established in Cruzan were synonymous. Further, they argued that the Constitutional right to privacy established in Roe and reaffirmed in Casey extended to a mentally competent terminally ill patients right to physician-assisted death.

⁵⁴ *Id.* at 708.

⁵⁵ *Id.* at 708.

⁵⁶ Cruzan v. Director, Missouri Dept. of Health, 497 U.S. 261, 261 (1990). Condition in which a person exhibits motor reflexes but evinces no indications of significant cognitive functions.

⁵⁷ *Id.* at 261

⁵⁸ *Id.*

⁵⁹ *Id.*

⁶⁰ Planned Parenthood of Southern Pennsylvania v. Casey, 505 U.S. 833, 834 (1992)

⁶¹ In the 2022 case Dobbs v. Jackson Womens Health Org., 142 S.Ct. 2228, 2234 (2022) the Supreme Court overruled Roe and Casey, holding that there is no constitutional right to abortion. This ruling may act as a continuing barrier to expansion of MAID, as many MAID arguments are based in privacy and personal autonomy. But, not enough is known right now for what those barriers will look like.

After a thorough analysis, the Court disagreed.⁶² As with any claim pertaining to due process, the Court began by examining the Nation's history, legal traditions, and practices.⁶³ The Court was unpersuaded by the petitioners' argument that Cruzan and the instant case were synonymous, as the right to refuse unwanted treatment was not deduced from abstract concepts of personal autonomy, but rather the common law rule that such treatment without consent was battery.⁶⁴ Therein lies the key distinction between Cruzan and the instant case. Here, it stated that under Anglo-American common law, the practice of suicide and assisted-suicide has always been prohibited or otherwise disapproved.⁶⁵ Further, suicide and assisted suicide were still statutorily prohibited in a majority of States.⁶⁶ The Court also elaborated that there have never been any exceptions to these rules for people who were near death.⁶⁷ It was also unpersuaded by the petitioners argument that under Casey, a patient has a fundamental liberty interest in privacy that encompasses their right to choose how they die. The Court states that although Casey recognized many rights and liberties protected by the Constitution, it did not follow that all important personal decisions are so protected.⁶⁸ Therefore, the Court determined that there is no fundamental liberty interest to physician-assisted death.⁶⁹

Because physician-assisted death is not a Constitutionally protected right, any State ban on the practice must only be rationally related to a *legitimate government interest*. Here, the State had an "unqualified interest" in the preservation of human life from beginning to end, regardless

⁶² *Glucksberg*, *supra* note 93 at 709.

⁶³ *Id.* at 710.

⁶⁴ *Id.* at 725.

⁶⁵ *Id.* at 711.

⁶⁶ *Id.* at 710.

⁶⁷ *Id.* at 702.

⁶⁸ *Id.* at 728.

⁶⁹ *Id.*

of physical or mental condition, which the Court has affirmed that "the States' may properly decline to make judgments about the "quality" of life that a particular individual may enjoy'."

However, the Court noted that "public concern and democratic action are therefore sharply focused on how best to provide dignity and independence at the end of life, with the result that there have been many significant changes in state laws and in the attitudes these laws reflect."⁷⁰ The most substantial deterrence to allowing physician-assisted suicide is the belief that "legalizing assisted suicide and euthanasia would pose profound risks to many individuals who are ill and vulnerable."⁷¹ For this reason, the Court stated that, by extending a constitutionally protected right to assisted suicide, it feared that doing so would place the matter outside the arena of public debate and legislative action, and therefore it would need to "exercise the utmost care."⁷² The Court added that "[t]hroughout the Nation, Americans are engaged in an earnest and profound debate about the morality, legality, and practicality of physician-assisted suicide. Our holding permits this debate to continue, as it should in a democratic society."⁷³ Further, Justice Souter, in his concurring opinion, added that "[t]he day may come when we can say with some assurance which side is right, but for now, it is the substantiality of the factual disagreement, and the alternatives for resolving it, that matter."⁷⁴

SECTION II: EMPIRICAL DATA

In the twenty-five years since Washington v. Glucksberg, a wealth of data has been collected on topics surrounding MAID. First, there have been substantial changes in attitude regarding physician-assisted suicide. For instance, a Gallup poll administered in 2018 indicated

⁷⁰ *Id.* at 716.

⁷¹ *Id.* at 719.

⁷² *Id.* at 720.

⁷³ *Id.* at 735.

⁷⁴ *Id.* at 786.

that a broad majority of Americans (72%) believe that doctors should be legally allowed, at the patient's request, to end a terminally ill patient's life using painless measures.⁷⁵ This support is for euthanasia rather than physician-assisted suicide.⁷⁶ The poll's author believes that physician-assisted suicide garners less overall support due to the negative connotation around the word "suicide," though the statistical difference is not significant.⁷⁷

Further, in a national study conducted by Hetzler, Nie, Zhou, and Dugdale in 2019⁷⁸, the researchers sought to assess the beliefs of United States physicians regarding the national legalization of physician-assisted suicide.⁷⁹ The researchers sent surveys to one thousand randomly chosen physicians around the country.⁸⁰ Half of the sample comprised physicians from all specialties, and the other half comprised specialties more likely to deal with end-of-life care.⁸¹

The survey included definitions for "physician-assisted suicide ("PAS)," "physician aid in dying (AID)," and "euthanasia" (physician directly administers a drug or drugs intending to end the patient's life).⁸² The first section of the study asked physicians to express their attitudes regarding concepts such as PAS legality, decriminalization of PAS/AID, and willingness to participate in PAS and AID actively.⁸³ In another section, physicians were asked to what extent they agree with statements regarding patients' reasons for seeking PAS/AID, the safety and efficacy of current safeguards for the program, social, professional, and economic implications

⁷⁵ Megan Brenan, *Americans' Strong Support for Euthanasia Persists*, Gallup, (May 31, 2018).

⁷⁶ "Euthanasia" means that the physician would be the one administering the lethal dose of medication, as opposed to "physician-assisted death" meaning that the physician is only supplying the prescription for the medication.

⁷⁷ *Id.* *Supra* note 112.

⁷⁸ Peter T Hetzler 3rd et al., *A Report of Physicians' Beliefs About Physician-Assisted Suicide: A National Study*, 924 *The Yale journal of biology and medicine* 575–585 (2019).

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6913834/>.

⁷⁹ *Id.*

⁸⁰ *Id.*

⁸¹ *Id.*

⁸² *Id.* PAS and AID are synonymous.

⁸³ *Id.*

of national legalization, and ethical and moral statements.⁸⁴ Additionally, physicians were asked to what extent they agree with statements about patients' reasons for seeking PAS/AID and the safety and efficacy of current safeguards for the program.⁸⁵ Lastly, they were asked about their level of experience dealing with end-of-life care, their willingness to actively participate in PAS/AID, and demographic information about their practice.

The results of the first section revealed that about 60% of physicians believe that PAS should be legalized, and approximately 69% think that PAS should be decriminalized.⁸⁶ However, the results indicated that only 9% of physicians would unequivocally perform PAS themselves.⁸⁷ The physicians indicated that lack of training, religious or spiritual beliefs, supporting patient choice, and legal implications were reasons for their unwillingness to participate actively.⁸⁸ The reasons least chosen were ethical or moral opposition (5%), inappropriateness (5%), and inherent severity of PAS (4%).⁸⁹ The researchers found that religion and spiritual teachings played a role in physicians' decisions, as did physicians' Hippocratic oath to "do no harm" and fear of legal implications.⁹⁰ These results then suggest that there are various reasons physicians may not actively participate in providing PAS services but, nonetheless, may believe that the practice should be allowed.⁹¹ Each practitioner's reasons for non-participation are valid; however, they should not be used to preclude the practice of PAS/AID.

⁸⁴ *Id.*

⁸⁵ *Id.*

⁸⁶ *Id.*

⁸⁷ *Id.*

⁸⁸ *Id.*

⁸⁹ *Id.*

⁹⁰ *Id.*

⁹¹ *Id.*

Further, in section two, the results indicated that most physicians in the study believed that patients' physical pain was the main motivational factor in their decision to seek PAS/AID. However, this is not the case, nor is physical pain in the top five reasons patients seek PAS/AID. The results show that there is general misinformation among physicians that pain is a primary contributing factor in patients' decisions to seek PAS.⁹² Lastly, many physicians agreed that the safeguards in place are adequate.⁹³

Not only have there been significant changes in attitude regarding MAID, but advances in medical technology have made it possible for ALS patients to communicate effectively even when they may not be able to do so verbally or through the written word.⁹⁴ This technology, called Eye-Gaze technology, tracks patients' eye movements to activate letters, words, or phrases on a screen that are then read aloud by the system.⁹⁵ To take advantage of this device, patients must only be able to control muscle movement in their eyes.⁹⁶ Such technology would make it possible for these patients to effectively communicate their wishes much later into the "terminal" stage of ALS than they had been previously without this device. The importance of this device will be discussed further in a subsequent section; however, the most substantial implication of the sought expansion would be that patients could give affirmative consent until the time of death, regardless of their ability to self-administer the medication.

This empirical evidence provides vital information regarding the changing attitudes towards physician-assisted death and advances in medical technology that would now arguably combat the fears noted in Washington v. Glucksberg. However, due to the existing legal

⁹² *Id.*

⁹³ *Id.*

⁹⁴ *Augmentative and Alternative Communication*, ALS.org <https://www.als.org/navigating-als/living-with-als/therapies-care/augmentative-alternative-communication>.

⁹⁵ *Id.*

⁹⁶ *Id.*

landscape, it is improbable that there will ever be a judicial vehicle for ALS patients to seek an expansion of MAID in the manner necessary. In fact, only one State has implemented MAID through judicial ruling, determining that their criminal defense of consent allowed doctors to prescribe the lethal dose of medication without fear of criminal liability, giving patients access to the medication to self-administer was not against public policy.

SECTION III: SEEDS FOR EXPANSION ARE PLANTED IN MONTANA

For any progress to occur regarding the proposed expansion to MAID, advocates and lawmakers must first identify a foothold that allows the process to begin. That foothold may exist in Montana, making it the perfect entry point for the trek to accessibility for ALS patients. In Baxter v. State of Montana, a terminally ill patient and physician brought an action challenging the constitutionality of a Montana homicide statute that penalized physicians for providing aid-in-dying services to terminally ill patients.⁹⁷ The case involved Mr. Baxter, a retired truck driver with terminal lymphocytic leukemia.⁹⁸ Due to his condition, he experienced many severe symptoms, including "infections, chronic fatigue, weakness, anemia, night sweats, nausea, swollen glands, significant ongoing digestive problems, and generalized pain and discomfort."⁹⁹ Each symptom increased in severity as the chemotherapy treatments became less effective.¹⁰⁰ There is no cure for terminal lymphocytic leukemia, nor was there any prospect of recovery for Mr. Baxter, so he wanted to avail himself to physician-assisted death.¹⁰¹

However, MAID was not legal in Montana at the time of this case. In fact, Montana's criminal law statutes provided that physicians who provided aid-in-dying to mentally competent,

⁹⁷ Baxter v. State of Montana, 224 P.3d 1211 (Sup. Ct. MT, 2009).

⁹⁸ *Id.* at 1214.

⁹⁹ *Id.*

¹⁰⁰ *Id.*

¹⁰¹ *Id.*

terminally ill patients would be penalized for homicide.¹⁰² The Montana district court concluded that this Montana homicide law was unconstitutional and determined that the Montana State Constitution provided rights of individual privacy and human dignity, including the right for a mentally competent, terminally ill patient to seek aid-in-dying.¹⁰³ The State of Montana appealed the district court's decision.

On appeal, the Montana Supreme Court resolved the case without addressing the constitutional question, opting to use legislative action instead.¹⁰⁴ The Court approached the issue from the standpoint of criminal culpability for physicians providing aid-in-dying.¹⁰⁵ Specifically, they analyzed whether a patient's consent to receiving the aid-in-dying constituted a statutory defense to homicide charges.¹⁰⁶ This defense would shield physicians from criminal liability when providing aid-in-dying services to terminally ill patients.¹⁰⁷

According to Montana law, consent is a valid defense except when it would be against public policy.¹⁰⁸ The Montana Supreme Court concluded that conduct violates public policy when said conduct "disrupts public peace and physically endangers others."¹⁰⁹ Here, the Court distinguished aid-in-dying in that "handing medicine to a terminally ill patient, and the patient's subsequent peaceful and private act of taking medicine, are not comparable to violent, peace-breaching conduct that [the courts] have found to violate public policy."¹¹⁰ The Court concluded that there "was nothing to suggest that a patient's private interaction with their physician, and subsequent decisions regarding whether to take medication provided by a physician, violate

¹⁰² MCA 45-5-102(a).

¹⁰³ *Baxter*, supra note 160 at 1214.

¹⁰⁴ *Id.* at 1215.

¹⁰⁵ *Id.*

¹⁰⁶ *Id.*

¹⁰⁷ *Id.* at 1215.

¹⁰⁸ *Id.*

¹⁰⁹ *Id.*

¹¹⁰ *Id.* at 1216.

public policy."¹¹¹ They reasoned that each stage of the process between the physician and the patient is private, civil, and compassionate and that they work together to create a means by which the patient can control their mortality.¹¹²

Next, the Court turned to the examination of Montana's Terminally Ill Act, the proposed legislation that implemented MAID in Montana, the Court noted that the Act is a statutory starting point for understanding the legislative purpose of availing aid-in-dying to terminally ill patients.¹¹³ The Court concluded that it is clear that the legislature had carefully constructed the Terminally Ill Act to carve out a statutory scheme that gave terminally ill patients in Montana the right to decide what happens to them come the end of their lives. Moreover, physicians would not be prosecuted for assisting patients by providing them with the lethal dose of medication, as doing so was not against public policy.¹¹⁴

Further, the Act provides that the Attorney General must establish and maintain a state registry as well as an education and outreach program regarding "advance health care planning and end-of-life health care decision making," which would express the importance of "the need for readily available legal documents that express an individual's health care wishes."¹¹⁵ This provision intends to memorialize the legislature's intent to honor terminally ill patients' end-of-life decisions, and nothing regarding aid-in-dying would be against this purpose.¹¹⁶

SECTION IV: ANALYSIS

Considering the long-standing legal precedent outlined in Washington v. Glucksberg, it is unlikely that patients like Sandy will successfully seek a reasonable expansion to MAID using

¹¹¹ *Id.* at 1217.

¹¹² *Id.*

¹¹³ *Id.*

¹¹⁴ *Id.* at 1221.

¹¹⁵ *Id.* at 1220.

¹¹⁶ *Id.*

Judicial avenues, as any MAID legislature, either in favor or against expansion, must only be rationally related to a legitimate state interest. Without determining that a patient has a fundamental right to die, the Judiciary is extremely limited in its ability to grant expansion. However, the Judiciary is not the only vehicle for patients and lawmakers to seek expansion.

Justice Souter made a compelling argument in Washington v. Glucksberg that legislatures have the superior ability to obtain the facts necessary to make a judgment about the physician-assisted suicide controversy.¹¹⁷ He argued that not only does the legislature function with more flexibility for factfinding, but they also have the power to experiment, making adjustments to their programs as new information becomes available in their jurisdictions.¹¹⁸ This would leave the legislature the proper avenue to pursue the implementation of MAID in general and reasonable expansion for ALS patients moving forward. While this is not by any means binding precedent, it is, however, largely persuasive in states that seek expansion.

The first hurdle that needs to be addressed is finding a state with an initial willingness to implement an expanded program. Without a willingness to be the first to step off the edge into the realm of expansion, states will likely remain hesitant to enact an exception because of *legitimate state interests*. While this is true at the moment, the attitude of Justice James Nelson's concurring opinion in Baxter v. State of Montana suggests that there may be a ray of hope for expansion of Montana's MAID legislature that could eventually be the key to country-wide expansion to MAID to include reasonable accommodation for ALS patients. While the majority opinion in Baxter addressed the case from the standpoint of criminal liability instead of answering the question of the constitutionality of MAID, Justice Nelson believed that addressing constitutionality was extremely important.

¹¹⁷ Glucksberg, supra note 93 at 2293.

¹¹⁸ *Id.*

Justice Nelson believes that when one simply applies the principles of individual dignity, it is clear to see that terminally ill patients' arguments have merit. While the overall question of constitutionality in the case was avoided in the opinion, Justice Warner felt the need to address it. Montana's 1972 Constitution Article II, Section 4 provides that:

"the dignity of the human being is inavoidable. No person shall be denied equal protection of the laws. Neither the State nor any person, firm, corporation, or institution shall discriminate against any person in the exercise of his civil or political rights on account of race, color, sex, culture, social origin or condition, or political or religious ideas."¹¹⁹

He concluded that the Dignity Clause, regarding the fact that the dignity of the human being is inavoidable, stands as its own provision as a fundamental constitutional right.¹²⁰ He further noted that the Montana Supreme Court has previously held that:

"[r]espect for the dignity of each individual...demands that people have for themselves the moral right and moral responsibility to confront the most fundamental questions about the meaning and value of their own lives and the intrinsic value of life in general, answering their own consciences and convictions."¹²¹

He opined that we, as humans, understand that when people are stripped of their dignity, the human no longer exists. This is why we are also horrified by accounts of fellow humans being forced to endure humiliating, degrading, and painful deaths caused by terminal illnesses.¹²² Justice Nelson further believed that the State's assertion that it had a compelling interest in preserving life and protecting vulnerable groups from potential abuse was entirely inadequate to justify the State's opposition to aid-in-dying.¹²³ He explained that, in these cases, these patients

¹¹⁹ M.T. Const. II, § 4.

¹²⁰ *Baxter*, *supra* note 160 at 1229.

¹²¹ *Baxter v. State of Montana*, 224 P.3d 1211, 1230 (Sup. Ct. MT, 2009). (quoting *Armstrong v. State*, 989 P.2d 364, 389 (Sup. Ct. MT, 1999).

¹²² *Baxter*, *supra* note 160 at 1231.

¹²³ *Id.* at 1232.

are mentally competent, incurably ill, and expect death within a relatively short time. The government could have no legitimate purpose in forcing these patients to suffer through slow physical deterioration until the last possible moment.¹²⁴

He continues that the human right to dignity remains absolute, even at the time of death, and that a paternalistic government fueled by political ideology or religious belief may not strip an individual of these rights.¹²⁵ Lastly, he reiterated that:

"[d]ignity defines what it means to be human, It defines the depth of individual autonomy throughout life and, most certainly, at death," and that "[u]surping a mentally competent, incurably ill individual's ability to make end-of-life decisions and forcing that person against [their] will to suffer a prolonged and excruciating deterioration is, at its core, a blatant and untenable violation of the person's fundamental right of human dignity."¹²⁶

While it is true that Justice Nelson's concurrence is not a binding precedent, it does get to the heart of the issue experienced by patients with ALS who are ineligible to participate in MAID solely because they lose the voluntary muscle control necessary to self-administer the medication. Justice Nelson's views are perfectly aligned with the spirit of MAID, and his openness to the concept of a fundamental right to human dignity may indicate that others in Montana would be willing to enact the proposed expansion.

Further, States would likely want reassurance that the public is interested in expanded MAID accessibility. Additionally, they would need to know that physicians are open to the idea and are willing to participate actively. The empirical data discussed previously indicates that the public wants an expansion of MAID and that physicians are receptive to the idea of actively

¹²⁴ *Id.*

¹²⁵ *Id.* at 1233.

¹²⁶ *Id.*

assisting in administering the medication to ALS patients who are physically unable to do so themselves.¹²⁷

Finally, for a reasonably streamlined implementation of the proposed accommodation for these patients, there needs to be an existing framework with flexibility for modification that would also not open the door to potential abuse. While the self-administration requirement is steeped in good intentions, the fear that these patients could change their minds as the physician injects the medication could be mitigated in practice by implementing a few reasonable safeguards. Here, building off of the existing Montana process of using the consent defense, a very narrow exception could be carved out that would allow a mentally competent, terminally ill patient to consent to receive a physician-administered lethal dose of medication in the event the patient becomes physically disabled before they can administer the medication themselves. Moreover, it is entirely possible that, with physicians being aware that their actions could cause a criminal indictment, physicians seeking to abuse MAID laws could be deterred from doing so. So long as each step is taken correctly, physicians would have little reason to fear prosecution.

As discussed previously, the consent defense is unambiguous and states that it is valid as long as the Act does not violate public policy.¹²⁸ Here, the Act of a physician respecting a patient's end-of-life wishes should not rise to the level of violent, peace-breaching conduct that has been found to violate public policy. Again, each stage of the process between the physician and the patient is private, civil, and compassionate as they work together to create a means by which the patient can control their own mortality.¹²⁹ Simply changing who administers the medication, with fully informed consent to respect the wishes of a dying patient, does not put the

¹²⁷ *Hetzler*, *supra* note 130.

¹²⁸ *Supra* note 159.

¹²⁹ *Supra* notes 160, 161.

public good at risk when done correctly, mainly because receiving fully informed consent is entirely possible.

These patients, using advanced medical technology implemented in the eye-gaze systems, could still give full and informed consent until the end so long as they can still move their eyes. To ensure that there is no doubt as to what the patient consents to at their time of death, an unbiased witness should be present to sign off that the patient's consent was freely given.

Additionally, Montana could require patients to go through an additional approval process that requires a rigorous psychiatric consultation and a case-by-case eligibility determination by a qualified board of physicians. This would eliminate any uncertainty regarding competency and mitigate the potential for individual physician abuse. This is an entirely feasible option considering the reasonable number of patients this would affect.¹³⁰

Furthermore, Montana's Terminally Ill Act already provides that patients utilizing aid-in-dying must have advanced directives on file that clearly and unambiguously express their end-of-life wishes.¹³¹ Requiring ALS patients eligible for services pursuant to the narrow exception to provide an additional provision in their directives regarding their wish to receive a physician-administered injection in the event of total physical disability would provide an added safeguard that would memorialize patient wishes without adding any extra administrative burdens.

By enacting the narrow exception in this fashion, the legislature could adjust this MAID exception as necessary until the program functions in its intended fashion, without having to expand MAID as a whole right off the bat. With some time, Montana would find that either the consent defense is necessary or that this method works just fine as a general exception without

¹³⁰ *Supra* note 4. Two out of every one-hundred-thousand people are diagnosed with ALS annually, which is a relatively low number of patients annually. This number could also be much lower depending on how many would want to use MAID.

¹³¹ *Supra* note 168.

opening the door for potential physician abuse from the beginning. This process could eventually assuage the fear that MAID expansion in this form would act as the *slippery slope* toward voluntary euthanasia, while also acting as a workable model for country-wide expansion.

CONCLUSION

In conclusion, for patients like Ken and Sandy, the self-administration requirement continues to act as a barrier to accessibility to MAID. Thus, allowing a narrow exception for these physically disabled patients to seek help from a willing physician in administering the lethal dose of medication would provide invaluable accessibility for these patients.

Enacting such an accommodation through the legislature would circumvent several issues cited as *legitimate state interests*. Further, recent research has revealed a substantial change in attitudes surrounding MAID, suggesting that the public and physicians themselves believe such an option may be necessary. Additionally, advancements in medical technology will allow effective communication between patients and their doctors. Lastly, of the states that have legalized MAID, Montana has the necessary seeds planted that would provide a flexible framework for experimental legislation that would make MAID more accessible for physically disabled ALS patients while sheltering physicians from criminal liability as new data is collected on the implementation and functionality of the narrow accommodation. The goal is that, if Montana were to adopt the suggested accommodation, as new data becomes available, this implementation would act as a catalyst for country-wide expansion. Montana can and should consider this proposal.