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TARGET ARTICLE

Neurologic Diseases and Medical Aid in Dying: Aid-in-Dying Laws Create an Underclass of Patients Based on Disability

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ABSTRACT
Terminally ill patients in 10 states plus Washington, D.C. have the right to take prescribed medications to end their lives (medical aid in dying). But otherwise-eligible patients with neuromuscular disabilities (ALS and other illnesses) are excluded if they are physically unable to "self-administer" the medications *without assistance*. This exclusion is incompatible with disability rights laws that mandate assistance to provide equal access to health care. This contradiction between aid-in-dying laws and disability rights laws can force patients and clinicians into violating one or the other, potentially creating an underclass of patients denied medical care that is available to those with other (less physically disabling) terminal illnesses. The immediacy of this issue is demonstrated by a lawsuit in Federal court filed in August 2021, requesting assistance in self-administration for terminally ill patients with neuromuscular diseases. This paper discusses the background of this conflict, the ethical issues at the heart of the dilemma, and recommends potential remedies.

KEYWORDS
Medical aid in dying; MAID; amyotrophic lateral sclerosis; ALS; euthanasia; assisted suicide; death with dignity

BACKGROUND

The right of terminally ill patients to take clinician-prescribed medications to end their lives, commonly referred to as "medical aid in dying" (MAID), is now legal in eleven U.S. jurisdictions.[1] These laws cover 22 percent of the U.S. population.[2] But they require self-administration of the aid-in-dying medications *without assistance*. This excludes otherwise eligible terminal patients whose physical disabilities render them unable to meet that requirement. This particularly applies to patients with amyotrophic lateral sclerosis (ALS).

Terminally ill patients with ALS comprise roughly 10 percent of patients completing medical aid in dying.[3] This is second only to cancers (about 70 percent of aid-in-dying deaths). The 10 percent rate of ALS deaths from aid in dying constitute a much higher percentage than the U.S. per capita deaths from ALS of only 0.3 percent (Centers for Disease Control 2021).[4] So ALS is among the most significant of illnesses that lead to completion of medical aid in dying. Some ALS patients, however, lose the required ability to self-administer the medications *without assistance*: They

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[1] California End of Life Option Act, Cal. Health & Safety Code §§ 443.1–.22;
Colorado End of Life Options Act, Colo. Rev. Stat. §§ 25-48-101 to -123;
District of Columbia Death with Dignity Act, D.C. Code §§ 7-661.01–.16;
Hawaii Our Care, Our Choice Act, Haw. Rev. Stat. §§ 327L-1 to -25;
Maine Death with Dignity Act, Me. Stat. tit. 22, § 2140;
New Jersey Aid in Dying for the Terminally Ill Act, N.J. Stat. §§ 26:16-1 to -20;
New Mexico Elizabeth Whitefield End of Life Options Act, N.M. Stat. Ann. §§ 24-7C-1 to -8, 24-1-43, 30-2-4.
Oregon Death with Dignity Act, Or. Rev. Stat. §§ 127.800–.897;
Vermont Patient Choice and Control at End of Life Act, Vt. Stat. Ann. tit. 18, §§ 5281–93;
Washington Death with Dignity Act, Wash. Rev. Code §§ 70.245.010-.220–.904.;
Baxter vs. Montana, 224 P.3d 1211, (Mont. Dec. 31, 2009)

[2] United States Census Bureau. The population of these eleven states totals 73 million = 22% of the U.S. population, 330 million. https://www.census.gov/quickfacts/fact/map/US/PST045219

[3] California Department of Public Health 2022; Colorado Department of Public Health & Environment 2022; Maine Department of Health & Human Services 2022; New Jersey Department of Health 2022; Oregon Health Authority 2022; Vermont Department of Health 2022; Washington State Department of Health 2021). There is insufficient data from Montana, New Mexico and Washington DC.

[4] Total deaths in U.S. ≈ 700/100,000 population.
ALS Foundation for Life: https://www.alsfoundation.org/learn/facts.htm
ALS deaths ≈ 2/100,000 population.

may be unable to swallow, place a straw in their mouth, or completely press a syringe plunger to release all the medications into a feeding or rectal tube. Such difficulties apply to more than a dozen other common neurologic diseases and movement disorders, including Parkinson's, strokes, and multiple sclerosis.[5]

These terminally ill, physically disabled patients and the clinicians who care for them face an ethical and legal dilemma. While aid-in-dying laws require *unassisted* self-administration, disability rights laws require the exact opposite. Disability laws mandate assistance and equal access to health care. They stress that a disability must not bar access to services where reasonable accommodation is possible.

The tension between these opposing requirements poses significant dilemmas for movement-impaired patients and their caregivers. Patients dying from neuromuscular diseases may be able to physically *initiate* self-administration, but not *complete* it unless they have some assistance. That creates an underclass of terminally ill patients who, due to their substantially impaired motor function, cannot access a medical procedure legally provided to more-able-bodied terminally ill patients. Yet little has been written about how to resolve these dilemmas, leaving clinicians and patients in the dark. This article considers the conflicts between aid-in-dying laws and disability rights laws. It then offers several solutions for resolving these conflicts.

WHAT THE OPPOSING LAWS REQUIRE

To concretely illustrate the conflict between the no-assistance prohibition in aid-in-dying laws and the affirmative duty to assist under disability laws, we contrast the California End of Life Option Act with the Americans with Disabilities Act.

California End of Life Option Act

For simplicity, we cite the self-administration without assistance requirement in California's End of Life Option Act, since it applies to the largest population of all aid-in-dying jurisdictions.[6] Similar restrictions, with different wording, are included in other U.S. aid-in-dying laws[7] (New Mexico's aid-in-dying law, however, in response to the difficulties noted above, eliminates the "no assistance" clause).[8] The California law requires that the patient herself ingest the medication, whether by swallowing, stomach or intestinal feeding tubes, or rectal administration.[9]

> A person shall be considered a "qualified individual" only if "the individual has the physical and mental ability to self-administer the aid-in-dying drug."
>
> "Self-administer means a qualified individual's affirmative, conscious, and physical act of administering and ingesting the aid-in-dying drug to bring about his or her own death."
>
> "A person who is present may, without civil or criminal liability, assist the qualified individual by preparing the aid-in-dying drug so long as the person does not assist the qualified person in ingesting the aid-in-dying drug."

Americans with Disabilities Act

While many state laws prohibit discrimination based on disability, for simplicity we focus on the key federal statute, the Americans with Disabilities Act.[10] The ADA requires clinicians to make reasonable accommodations so that healthcare services are available to qualified individuals with disabilities.[11]

> "No qualified individual with a disability shall … be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by any such entity" when reasonable accommodation can be provided."

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[5] Terminal neuromuscular diseases include but are not limited to: (1) ALS – amyotrophic lateral sclerosis, (2) MS – multiple sclerosis, (3) PSP – progressive supranuclear palsy, (4) MSA – multiple system atrophy, (5) Huntington's disease, (6) Muscular dystrophies (varying types), (7) Cerebral palsy, (8) Paralysis from strokes and brain cancers, (9) Parkinson's disease and related disorders, (10) Myasthenia Gravis, (11) SMA – Spinal muscular atrophy (types 2, 3 and 4 can live to adulthood), (12) Mitochondrial and other myopathies, (13) Ataxias.

[6] California End of Life Option Act, 2015 Cal. Health & Safety Code §§ 443.1–.22.

[7] Colorado End of Life Options Act, 2016. Colo. Rev. Stat. §§ 25-48-102(15) ("Self-administer means a qualified individual's affirmative, conscious, and physical act of administering the medical aid-in-dying medication to himself or herself to bring about his or her own death.")

Hawaii Our Care, Our Choice Act, 2021. Haw. Rev. Stat. §§ 327L-1 (same)

New Jersey Aid in Dying for the Terminally Ill Act, 2019. N.J. Stat. §§ 26:16-3 ("Self-administer means a qualified terminally ill patient's act of physically administering, to the patient's own self, medication that has been prescribed.")

[8] New Mexico Elizabeth Whitefield End of Life Options Act, N.M. Stat. Ann. §§24-7C-1 to -8, 24-1-43, 30-2-4

"This act allows assistance in the self-administration of aid-in-dying medications." Personal communication from the lead author, Deborah A. Armstrong, to Thaddeus Pope and Lonny Shavelson.

[9] Kirchmeyer, Kimberly, 2016. Email. Executive Director, Medical Board of California (Sept. 6, 2016) ("So long as the patient is self-administering the drug whether it is into a nasogastric or other stomach/small bowel feeding tubes of the rectal route would be acceptable.").

[10] Americans with Disabilities Act, 1990. 42 U.S.C. §§ 12101 *et seq.*

[11] Americans with Disabilities Act, 1990. 42 U.S.C. § 12132.

PATIENT VIGNETTES

To clarify the dilemma faced by physicians and their patients, we present a series of four increasingly complex patient vignettes derived from actual circumstances. In each situation, we consider the requirement of unassisted self-administration of aid-in-dying medications.

In practice, most aid-in-dying deaths are attended by a clinician or one or more family members (Oregon Health Authority 2022)[12]—all of whom have the same requirements and limitations under the End of Life Option Act. The law does not regulate who can or must attend the death, nor does it distinguish different responsibilities for a clinician or family member. Thus, the actions described below could be performed by a family member (as portrayed in these vignettes), an assistant to the physically impaired patient, or a physician, nurse, or other health practitioner.

Vignette 1

Imani is a 59-year-old female with advanced ALS. She is terminally ill and has decision-making capacity. Imani maintains swallowing function but has minimal movement of her hands and cannot hold a glass. She can manipulate a straw with her own hand movements. Her mother mixes the aid-in-dying medications, fills the glass, and places a straw in it. She then places the glass near Imani's mouth. Imani moves the straw to her lips and sucks all of the medications down. She is asleep at 4 minutes and dies at 20 minutes.

Vignette 2

Imani has lost the ability to manipulate the straw on her own. Her mother places the glass near Imani's mouth, then holds the straw to her lips while Imani sucks all of the medications down. She dies.

Vignette 3

Imani has lost her ability to swallow effectively, but she maintains some function in her hands. For nutrition, she has a feeding tube that has been surgically placed into her stomach. Typically, her mother prepares the nutritive liquids, then fills a large syringe and attaches it to the feeding tube. Imani administers the feedings into her stomach by pushing on the plunger of the syringe (Illustration 1). On the aid-in-dying day, Imani's mother prepares the medications, puts them in the syringe, and attaches the syringe to the feeding tube. Imani pushes the plunger, all of the medications enter her stomach, and she dies.

Vignette 4

As in Case 3, Imani pushes the plunger on the syringe, initiating the self-administration of the lethal medications. But her hand strength fatigues (or is inadequate) and she *cannot complete the dose*. Imani panics, worried that she will be physically and cognitively damaged by this partial dose of medications, but not die. She asks her mother for help. Imani maintains pressure on the syringe, thus continuing to participate in the self-administration, and her mother gently adds the minimal amount of pressure/assistance needed in addition to Imani's pressure so that medications continue to flow into Imani's stomach. The full dose of medications is completed and Imani dies.

Patient Vignette Summaries

In all cases Imani has decision-making capacity and has made an informed decision for medical aid in dying. "Self-administration" and "Assistance" are noted (Table 1).

DISCUSSION

Aid-in-Dying Laws Conflict with Disability Rights Laws

Prohibiting assistance in the self-administration of aid-in-dying medications is problematic when viewed through the lens of the federal Americans with Disabilities Act (ADA).[13]

Note that by "assistance" we do not mean taking over the entire act of administering the medications—which would violate the self-administration clause of the law, which we are not questioning. The patients themselves would physically initiate the self-administration of the medications and continue that action to the best of their abilities. Assistance would be provided only if the patient is unable to fully complete the self-ingestion of the medications without assistance.

The ADA requires that state governments, private entities and individuals that afford public accommodations provide those with disabilities an equal opportunity to participate in the enjoyment of services.[14] Those organizations must make reasonable modifications in practices and procedures to avoid

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[12] For details from all aid-in-dying states, see: https://www.acamaid.org/attendants/ Clinician, for the purposes of this paper and in the aid-in-dying context in general, includes: MD, NP, PA, nurse, social worker, hospice chaplain, trained volunteer, aid-in-dying experienced end-of-life doula.

[13] Footnote 10, Op.Cit.

[14] Americans with Disabilities Act, 1990. 42 U.S.C. § 12132; 42 U.S.C. § 12182(b)(1)(A)(i); https://www.law.cornell.edu/uscode/text/42/12182#:~:text=No%20individual%20shall%20be%20discriminated,a%20place%20of%20public%20accommodation.

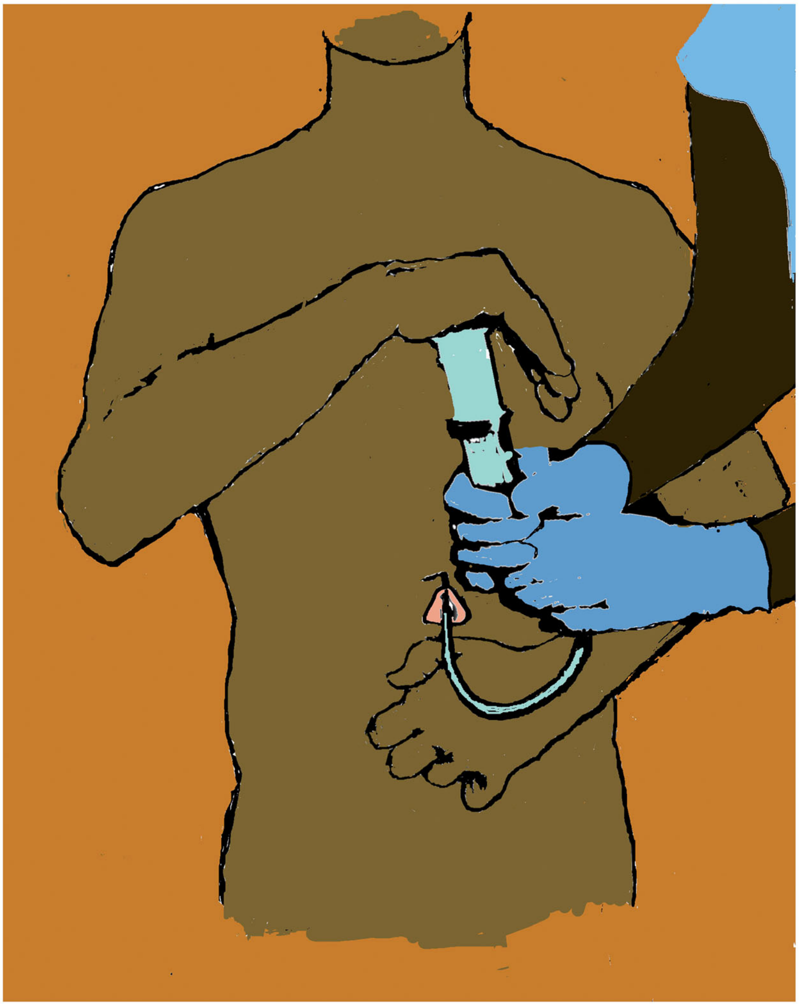

Illustration 1. Syringe feeding.

Table 1. Case summaries.

Case #	Imani's physical ability	Imani's physical participation	Mother's participation	Self-administration	Assistance	Legality (by present End of Life Option Act)
1	Swallowing. Some hand movement.	Puts straw in her mouth, sucks medication down.	Puts medication in glass, inserts straw in glass.	√	X	√
2	Swallowing. No hand movement.	Sucks medication down.	Moves straw to Imani's mouth.	√	X	√
3	No swallowing. Has hand movement. Has feeding tube.	Pushes syringe plunger to administer medications.	Puts medications in syringe and attaches it to feeding tube	√	X	√
4	As in case 3	Pushes syringe plunger and continues to push, but is too weak to complete the dose	Places her hand on Imani's, notes Imani's continued push, adds the pressure needed to complete the dose.	√	√	X

discrimination on the basis of disability. Reasonable accommodations may require assistive devices and human assistance when necessary to ensure access to services for individuals with disabilities (Iezzoni et al. 2022). Patients disabled by neurologic disease are protected by the ADA.

But aid-in-dying laws require the *unassisted* self-administration of medications. This prevents competent, terminally ill people with neurologic diseases from accessing aid in dying because they cannot physically fully administer the medications. The *unassisted* self-administration requirement creates a barrier to health services available to people without those disabilities. Unless accommodated, this barrier runs contrary to disability rights laws. Although yet untested in court, the analysis is straightforward.

It is immaterial that some disabled individuals can participate in aid in dying. The ADA prohibits disability-based discrimination against any individuals or classes of individuals (Iezzoni et al. 2022). The patient vignettes above illustrate how assistance prohibitions discriminate based on disability. Able to swallow in Vignette 1 and 2, and use her hands in Vignette 3, Imani can legally benefit from aid-in-dying laws, controlling the time and manner of her death. In Vignette 4, however, Imani has lost the ability to complete the process by her own strength alone, rendering her unable to control her death as in the other vignettes and the realm of more-able-bodied terminally ill patients.

The only difference between Imani in Vignettes 1, 2, and 3 and Imani in Vignette 4 is the degree to which she is disabled. Only the extent of Imani's disability excludes her from the benefits of the aid-in-dying statutes, a form of discrimination prohibited by the ADA. ADA-mandated reasonable accommodations, such as providing assistance by a caregiver, would ensure her inclusion. Such assistance, however, is prohibited by the aid-in-dying statutes.

This is demonstrated clearly in a court case we discuss more fully below. Briefly, one plaintiff, Sandra Morris, is a fifty-two-year-old mother of three adult children, suffering from advanced ALS. She has lost all strength other than very slight movements of one hand, which she could use to initiate the self-administration of aid-in-dying medications by pushing on a syringe attached to a rectal catheter. But she would be unable to complete the action, risking a partial dose of the medications. Ms. Morris is requesting relief from the court so that she may have assistance to complete the action which she will initiate. If she is not granted that relief, she will be denied the choice of an aid-in-dying death, which is her requested route to her rapidly approaching demise.

Aid-in-dying laws thus create an underclass of terminally ill patients with neurologic diseases who are denied the same right to choose how they will die that is provided to more-able-bodied patients.

The Supposed Bright Line of Euthanasia

Aid-in-dying laws clearly indicate that patients themselves must cause their own deaths by *unassisted* self-administration because legislators tried to avoid crossing a conceptual bright line that separates medical aid in dying from euthanasia (Pope 2020).[15] But there are multiple linguistic, ethical, and legal challenges to this distinction.

Linguistic Concerns

In contexts related to medical aid in dying in the U.S., "euthanasia" is commonly defined as the intentional administration by another person of a lethal agent to end the life of a terminally ill person. With euthanasia, someone other than the patient performs the action that brings on death.

There is a long history of considering this distinction to be essential. For example, in 1996 Baron et. al. defended legalizing what was then referred to as "physician assisted suicide" (now medical aid in dying), distinguishing it from "voluntary active euthanasia." In physician assisted suicide, the physician provides the medications for the patient to take. In voluntary active euthanasia, the physician administers the drug to the patient. Baron et al. concluded that only physician assisted suicide/medical aid in dying would be safe and ethical, considering "the voluntariness of the patient's act to be critical" (Baron et al. 1996).

But in deciding that self-administration was essential, what they did not consider—since the actual practice of medical aid in dying in the U.S. had not yet provided bedside experience—was a third variation for those too disabled to self-administer the medications without assistance. In this middle ground, the motor-impaired patient physically initiates the self-administration, but upon inability to fully complete the act they could have assistance (by the clinician or another in attendance). This falls in rarely described territory between just providing the medications for the patient to take (medical aid in dying), versus *fully* administering the medications for the patient (voluntary active euthanasia). Since 1997 the active practice of medical aid in dying has shown this third

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[15] State legislatures and courts in states where the practice is authorized recognize medical aid in dying as differing from suicide, assisted suicide or euthanasia. Euthanasia and assisted suicide are both illegal in jurisdictions where medical aid in dying is authorized. Medical-aid-in-dying laws on the books in California, Colorado, the District of Columbia, Hawai'i, Oregon, Maine, New Jersey, New Mexico, Vermont and Washington expressly state: "Actions taken in accordance with [the Act] shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide." And in Montana, where assisted suicide is specifically illegal, the Montana Supreme Court ruled in *Baxter v. Montana* that medical aid in dying provided to terminally ill, mentally competent adult patients in no way violates established state law [including Montana's assisted suicide statute] or the principles of public policy." https://tinyurl.com/55xpvupn

possibility to represent a significant population and need. Yet the historical hesitation between the binary choice of *providing* the medication or *administering* the medication persists. Considering the middle ground of "assisted self-administration" is relatively new and based on recent clinical experience.

The term "euthanasia" is accepted in many countries where medical aid in dying is legal. In the Netherlands, for example, physician-administered aid in dying is called euthanasia, understood in the sense of its Greek roots, *eu-thanatos*, for "good dying." Indeed, in eight of the ten non-U.S. countries where medical aid in dying is legal, terminally ill patients have a choice to self-administer oral medications to die, versus death brought on by a physician-administered injection (usually into an intravenous line) (Battin and Pope 2022). In Canada, for example, only 13 of 21,589 aid-in-dying patients since legalization opted for self-administration (Government of Canada 2021). Terminally ill patients in those countries see no bright line between self-administration and clinician-administration of medications—they simply choose the most efficient, secure and certain route to death.

In contrast, the term "euthanasia" is stigmatized in the United States. It is more frequently associated with the atrocities of Nazism—politically motivated mass murder (Battin 1992). But mandating self-administration *without assistance* to avoid historically negative associations would be the moral equivalent of prohibiting tubal ligations because of a long history of forced sterilizations.[16] The answer to historical horrors is to safeguard against repeating them, not to prohibit valuable medical procedures. Mandating unassisted self-administration to avoid the contemporary stigma of the term "euthanasia" creates a very real inequality in end-of-life care for patients with neurologic diseases, to resolve a theoretic linguistic dilemma.

Ethical Concerns

Some disability advocacy groups, notably including Not Dead Yet, warn that legalization of medical aid in dying for people with disabilities, a group highly susceptible to abuses, is tantamount to euthanasia, in the odious Nazi sense.[17]

But while disability rights advocacy organizations have been responsible for many advances in the lives of people with disabilities, those groups which oppose medical aid in dying do not represent a uniform opinion. Multiple disability rights advocacy organizations have taken a forceful position against California's prohibition of assistance in aid in dying, including The Golden West Chapter of the ALS Association; CripJustice; the Disability Justice Law and Organizing Project.[18] Opposition to medical aid in dying is not a monolithic position by disability rights organizations. And since 10 percent of all aid-in-dying deaths are accessed by patients with ALS, there is significant personal opposition to the platforms of disability organizations which oppose medical aid in dying.

All patients who qualify for aid in dying, including those with neurologic disabilities, must equally comply with the legal safeguards included in aid-in-dying laws: A verifiable terminal condition with fewer than six months to live, with confirmation by two independent clinicians; the mental capacity to make their own medical decisions; the ability to clearly communicate the above to the evaluating clinicians; two separate requests for medical aid in dying with a waiting period between them (the time varies among states, from 48 hours to 20 days); a written, signed and witnessed request; the understanding of the alternative routes to death and other care that can be provided; a statement from the patients, obtained in private, that they are not being coerced into this decision by others.

Aid-in-dying laws thus include multiple safeguards to assure that the aid-in-dying request comes fully at the behest of the dying patient alone. And aid-in-dying laws explicitly prohibit qualifying a person for reasons of disability alone, accepting only those whose illness has become verifiably terminal.[19]

When a state declares in its aid-in-dying laws that the right to autonomous and inclusive choices at the end of life must be provided to its citizens, the law and ethics should apply equally for people with neurologic diseases and for those without. Individuals with neuromuscular disabilities who are now terminally ill have every right to make autonomous decisions about their route to death, the same decisions available to more-able-bodied people.

Legal Concerns

Another stated reason for mandating self-administration without assistance is that denying

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[16] ThoughtCo. "Forced Sterilization in the United States." https://tinyurl.com/5c9anx72

[17] Not Dead Yet https://notdeadyet.org/

[18] Motion of the Golden West Chapter of the ALS Association, End of Life Choices California, CripJustice, and the Disability Justice Law and Organizing Project for Leave to File Brief as Amici Curiae. Shavelson V. California, No. 3:21-cv-06654-VC.

[19] California Health & Safety Code § 443.2(b) ("A person shall not be considered a 'qualified individual' under the provisions of this part solely because of age or disability.").

assistance provides a safeguard against abuse, since patients indicate complete and final consent by doing the procedure fully on their own.

But such a safeguard is singularly without precedent in healthcare. Crucial life-sustaining and life-ending informed consent is something physicians and patients work through every day. If a patient decides to end her life by having her ventilator turned off, we don't ask her to disconnect the tubing herself—without any help—so we can be sure she is certain. Patients sign informed consent forms for everything from heart transplants to brain surgery, yet no surgeon says, "To be sure you're fully consenting, here's the scalpel, please make the first cut."

Arguments that unassisted self-administration is needed to protect against aid-in-dying abuses ring hollow to experienced clinicians. As noted above, aid-in-dying laws are already replete with safeguards. Requiring *unassisted* self-administration adds nothing to safeguard the procedure against abuse. Rather, the requirement excludes a significant number of terminally ill patients with neurologic diseases from accessing the same options available to those more physically able.

The tension between freedoms and safeguards is common in law. For aid in dying, safeguards are achievable without such a significant limit as denying severely disabled terminally ill patients their right to assistance. Autonomy is a primary societal principle. Denying equal autonomy to patients with neurologic diseases compared to, say, patients with cancer, must be considered a fundamental violation of their rights, without providing significant additional safeguards against abuse.

The right to assistance for people with disabilities is so fundamental that it has been enshrined by Congress in the Americans with Disabilities Act. And Article VI, Paragraph 2 of the Constitution (the Supremacy Clause) states that federal law overrides state law. Aid in dying is now legal due to the votes of the public and legislators in 9 states and Washington DC (and by the courts in Montana). The federal ADA is clear, we believe, that such state health rights must be provided to all residents who qualify, not just the more-able-bodied.

Regardless of the above analyses, however, aid-in-dying legislative language in the U.S. limits the practice to unassisted self-administration.[20] So in a distinction that seems to defy logic, Imani's mother can legally fill a glass with aid-in-dying medications, then place a straw in the glass and hold the straw to Imani's lips while she sucks the medications down. But if Imani's disability has rendered her unable to swallow and she has a feeding tube, her mother cannot aid Imani's own efforts to push the medications into her stomach. Applying any pressure at all to the syringe plunger could potentially land Imani's mother in prison.

A fundamental principle of law and ethics is that we are required to treat similar cases similarly. Yet the very same Imani who does not depend on a feeding tube is treated entirely differently than the Imani who does require a feeding tube. Of even greater concern is that an Imani who can apply, say, 3 pounds per square inch of pressure to a syringe plunger and thus self-administer all of the medications, has full legal access to the death of her choice. But if she has, say, only 1 pound per square inch of strength to apply to the plunger, she has no right to assistance and cannot access that same manner of dying.

Present aid-in-dying laws also discourage clinicians from considering requests from neurocompromised patients. A significant side effect of the limitations of how aid-in-dying laws pertain to patients with neurologic diseases may result in clinicians opting out of taking aid-in-dying requests from neurologically impaired patients. This relative scarcity of participating doctors, as observed by the two authors of this paper who are physicians, creates another access barrier to a choice more readily available to terminally ill patients with more certain physical abilities.

Regrettably, there are circumstances where loved ones or clinicians at the bedside are trapped between accepting body and brain damage that may occur to the patient from partial doses of lethal medications if they do not assist, versus legal liability if they do assist. For people with ALS and other neurologic diseases, aid-in-dying laws as written can convert a death with dignity into a death with disaster. Imani's mother (or a supervising clinician), for example, had to make a split-second decision when Imani's unassisted self-administration failed before the full dose was administered (Vignette 4). Her mother was torn between potential legal culpability if she assisted to complete the dose, versus the guilt and anguish of witnessing brain and body damage to her daughter if she did not assist.

RECOMMENDATIONS

U.S. aid-in-dying laws prevent certain terminally ill patients with neurologic diseases from achieving their chosen method of death—an option available to still-able patients. This violates their rights as disabled persons.

We recommend remedies to bring the End of Life Option Act's "no assistance" clause into compliance

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[20] Footnote 1, *Op. Cit.*

with the ADA's requirement of "reasonable accommodations" for access to medical care.

Note that we are not asking to eliminate or modify the self-administration requirement, defined in the law as an "… affirmative, conscious, and physical act of administering and ingesting the aid-in-dying drug… " Rather, we are asking for a modified interpretation of "assistance" for patients who can initiate a physical act that is not adequate to fully complete the self-administration without assistance.

At present, the line between assistance and no assistance in aid in dying is arbitrary and confusing. In Vignette 2, Imani has lost the ability to bring the straw to her mouth, but when Imani's mother brings the straw to her mouth that is not assistance (since Imani herself is ingesting the medications). Yet in Vignette 4, when Imani pushes on the syringe plunger and initiates the dose into her feeding tube, but with inadequate strength to complete the dose, if Imani's mother provides the additional pressure needed while Imani continues to assert her own pressure—that constitutes assistance (which is subject to civil, criminal, and disciplinary liability).

What, then, would constitute a reasonable accommodation for patients with neuromuscular disabilities who cannot successfully take aid-in-dying medications without assistance? The following summarizes our recommendations.

First, if a patient can reliably swallow on their own, no assistance is needed with the self-administration of medications. Assistance in mixing and delivering the medications is already legal.

Second, if a patient's swallowing is impaired by their neurologic illness, then the medications are typically self-administered through a feeding tube into their stomach (already present and used for nutrition), or through a rectal catheter (enema). The medications are placed (by any assistant) in a catheter-tip syringe attached to the tube, and the patient self-administers the medications by pushing on the plunger of the syringe. The patient must initiate and continue a physical act of pushing on the plunger to comply with the self-administration requirement. If the patient can complete that action on their own and all the medications are taken into their body, no assistance is needed.

But if the patient lacks the strength to complete the self-administration of all the medications in the syringe, the procedure should be as follows.

1. The patient will physically initiate the action, beginning self-administration of the medications by either pushing on the plunger with their hand or finger, or if they lack hand-arm strength, by pushing on the plunger using their forehead or jaw, physically initiating the self-administration of the medications while the potential assistant observes.
2. If the patient completes self-administration of all the medications in this manner, no assistance is needed.
3. But if the patient becomes unable to complete the action in the middle of self-administration, assistance would be provided by the attendant's hand aiding the push on the plunger.
4. At no time would the assistance be the entire act of administration; rather it would be the minimal necessary assistance to aid the patient in the already-initiated self-administration.

Three routes could achieve the above recommendations to modify the "no assistance" clause of the law: (1) bringing test cases under the ADA, (2) clarifying the standard of care, and (3) amending aid-in-dying laws.

Test Cases

Ultimately, the conflict between aid-in-dying and disability rights laws may be resolved by the courts. Such a case was filed in federal court in Northern California in August 2021.[21] The case was brought on behalf of three terminally ill patients with neuromotor disabilities (two of whom have since died), and four aid-in-dying physicians. If denied any assistance with their self-administration of aid-in-dying medications, the patient plaintiffs stated they would need to end their lives sooner than they wish, fearing that without assistance they would lose the ability to self-administer the medications. In essence, they are being forced to die sooner by medical aid in dying, or to forego their right to medical aid in dying entirely and die at a later date by suffocation (the usual cause of death in ALS), or other "natural" means.

Interestingly, in light of our discussion of language concerns, Judge Vince Chhabria, who is presiding over the case, has repeatedly referred to aid in dying as "assisted suicide."[22] But the very aid-in-dying law he is considering exclusively uses the term medical aid in dying, and clearly declares that "… the law states that actions taken in accordance with this law shall

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[21] Shavelson v. California, No. 3:21-cv-06654-VC (N.D. Cal. Aug. 27, 2021) (Complaint).

[22] Shavelson v. California, No. 3:21-cv-06654-VC (N.D. Cal. Sept. 20, 2021) (Order denying preliminary injunction).

not, for any purposes, constitute suicide, assisted suicide, homicide, or elder abuse … "[23]

Additionally, Judge Chhabria wades into the linguistic swamp of "euthanasia," assuming that the plaintiffs are requesting "voluntary active euthanasia" for patients with neuromuscular disorders, while ignoring the new ground of "assisted self-administration" that is the focus of the lawsuit. This traditional binary between aid in dying and euthanasia denies the experience of many years of clinical practice which has made it clear that there is a third, distinct option, that of assisted self-administration. Of note, the California End of Life Option Act uses the word "euthanasia" only once, only in the context of prohibiting "active euthanasia." Neither the courts nor the legislature, then, have yet commented on the third path the plaintiffs are requesting: Assisted self-administration. As the case is winding through the court, the plaintiffs are arguing for that third, distinctive route.

On June 22, 2022, Judge Chhabria dismissed the lawsuit,[24] concluding, in essence, that the request for relief on the part of the plaintiff patients and physicians would change the permissions granted by California's End of Life Option Act from medical aid in dying to euthanasia. "The accommodation that the plaintiffs seek—to permit physicians to administer aid-in-dying medication—would traverse this boundary… it would transform the benefit under the act into something else entirely."

Judge Chhabria compassionately wrote of the plaintiffs: "Each has witnessed the way that the Act's prohibition on assistance places many people in a gut-wrenching position, forced to choose between acting sooner, while they are physically able to administer the medication on their own, or waiting, and risk losing the ability to take the medication and enduring the prolonged sort of death they wished to avoid. The plaintiffs argue that the Hobson's choice presented to Morris and people like her is not just excruciating—it is unlawful."

Nonetheless, the judge concluded that modifying the law to accommodate neurologically compromised patients who have lost the ability to ingest the medications without assistance would fundamentally alter the End of Life Option Act, thus making the requested accommodation under the Americans with Disabilities Act unreasonable. So he dismissed the case. The plaintiffs are considering an appeal.[25]

The dismissal of this case demonstrates the intense struggles between legislative, legal, ethical and clinical needs in the realm of aid in dying. Additional legal challenges are likely to follow, either through appeals of this case or new cases in additional states. Future legal decisions could establish the right of individuals compromised by neurologic disease to reasonable accommodation—assistance—when participating in medical aid in dying.

Standard of Care: Maximizing Safeguards While Maintaining Disability Rights

Without a test case adjudicating whether current aid-in-dying laws violate the ADA, the present self-administration mandate traps clinicians between violating aid-in-dying laws or violating disability rights laws. Developing a recognized standard of care can be an essential factor in interpreting the law and establishing precedent. "Standard of care" and "best practices" are commonly applied means to evaluate the appropriateness—and even legitimacy—of medical procedures and practices.

The concept of medical standard of care evaluates medical negligence based on the hypothetical practices of a reasonably competent health care professional under the same or similar circumstances. The standard does not override law but can help establish clarity in the face of ambiguity.

In the case of aid in dying, there is a discrete community of clinicians for whom aid-in-dying care is a significant part of their medical practice (estimated nationally to be in the high-hundreds). More than 300 of these clinicians were brought together for the first time at the National Clinicians Conference on Medical Aid in Dying at the University of California, Berkeley, in 2020, which resulted in the formation of the American Clinicians Academy on Medical Aid in Dying (the Academy). Among other educational activities, the Academy sponsors an active discussion Listserv including more than 700 aid-in-dying clinicians.

While the Academy is newly founded and some might accuse it of hubris or prejudice in recommending standards, it is following the hallowed traditions of medicine wherein the most experienced clinicians do indeed recommend the standards in their fields. For example, the American Society of Transplant Surgeons weighs in on ethical guidelines and clinical standards related to organ transplants.[26]

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[23] Cal. Health & Safety Code § 443.18.

[24] Shavelson v. California, No. 3:21-CV-06654 (N.D. Cal. June 22, 2022) (Order granting motion to dismiss).

[25] Shavelson v. California, No. 3:21-CV-06654 (N.D. Cal. July 12, 2022) (Second amended complaint).

[26] American Society of Transplant Surgeons. https://asts.org/advocacy/resources-for-transplant-professionals

The Academy, then, is positioned to investigate and weigh in on aid-in-dying standards of care for patients with neurologic diseases. A difficulty with this approach is that many clinicians now restrict their practices due to fear of the difficult-to-interpret and contradictory laws. Nonetheless, while a survey of clinical practices and opinions would not be legally binding, it would be highly instructive, especially to state medical boards that may in the future confront this question. The Academy is also filing an amicus brief in the court case outlined above, recommending that self-administration with assistance be permitted for motor-impaired patients. If the court should grant this right, the Academy will be instrumental in establishing standards of care for its clinical implementation.

A complaint to a state medical board, and their conclusions, would be likely to shape the standard of care for medical aid in dying. State medical boards would give serious consideration to an alleged violation of the standard of care based on what a community of similar clinicians would do. An Academy-recommended standard of care would be highly relevant to a medical board's deliberations.

Refining U.S. Aid-in-Dying Laws

The third route for removing the obstacle for patients with neurologic diseases is to amend the "without assistance" requirement in aid-in-dying laws. There is significant precedent for updating aid-in-dying laws in the U.S. to remove other barriers to access. For example, in 2019, Oregon amended its 1997 statute, allowing a doctor to bypass the originally required 15-day waiting period for a patient who has requested aid in dying but will not live through that waiting period.[27] The required wait is maintained for other patients. Similarly, in 2021, California amended its 2015 statute to reduce the waiting period.[28] New Mexico also shortened the waiting period in its new aid-in-dying law.[29] Hawaii, Vermont, and Washington are seeking to modify their aid-in-dying laws as well.[30]

A bit further afield, Australia might serve as a model for future judicial or legislative action in the United States. Medical aid in dying is legal or pending implementation in all six Australian states.[31] While self-administration of aid-in-dying medications is required in most states—as in U.S. aid-in-dying laws—those Australian laws provide for "practitioner administration permits" for patients who cannot complete unassisted self-administration.

This option was judged legally necessary to comply with human rights laws, such that terminally ill patients with movement disorders would not be excluded from legal aid in dying (Victoria State Government 2017). For still-able patients, the requirement of unassisted self-administration is maintained. Australian law thus maintains safeguards without running afoul of its legal equivalent of the Americans with Disabilities Act. Aid-in-dying laws in the U.S. could be modified to similar ends.

A future legislative remedy to the conflict between aid-in-dying and disability rights laws, and the most feasible politically, would model Australia: bypassing the unassisted self-administration rule only for those patients who otherwise qualify for aid in dying but are unable to physically comply. Aid-in-dying laws would remain unchanged for others capable of complying (including motor-impaired individuals who still have the strength to comply). This approach maintains all legislative intents and safeguards for the vast majority of cases, while providing equal access to those with diseases that make unassisted self-administration impossible.

CONCLUSION

We hope that careful exploration of circumstances such as those faced by Imani will provide future guidance in evaluating and understanding the complexity of this issue. Legal medical aid in dying is a relatively new aspect of medicine and, like all new fields, best practices and legal precedents must be established. But today's aid-in-dying laws unjustly disenfranchize terminally ill patients with advanced neurologic diseases that impair movement and strength. As they rapidly approach their deaths, these patients deserve equal rights to all end-of-life options.

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[27] Oregon Legislative Assembly. 2019. S.B. 579, 80th Legis. (2019), codified at Or. Rev. Stat. §§ 127.840(2) & 127.850(2).

[28] California Legislative Information. 2021. Cal. S.B. 380 (2021).

[29] New Mexico Elizabeth Whitefield End of Life Options Act, N.M. Stat. Ann. §§24-7C-1 to -8, 24-1-43, 30-2-4.

[30] Washington State Legislature. 2021 HB 1141; Hawaii State Legislature, 2021, HB 487; Vermont General Assembly, 2021, S.74.

[31] QUT. "End of Life Law in Australia: Voluntary Assisted Dying" https://end-of-life.qut.edu.au/assisteddying; New South Wales Voluntary Assisted Dying Bill 2021, https://www.parliament.nsw.gov.au/bills/Pages/bill-details.aspx?pk=3891; Wikipedia.

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