Have Arguments For and Against Medical Aid in Dying Stood the Test of Time?

DOI: 10.52214/vib.v9i.12079

David N. Hoffman & Emily Beer*

ABSTRACT

It has been 26 years since medical aid in dying ("MAiD") was first legalized in Oregon, and today, about 20 percent of people in the US live in jurisdictions that permit MAiD. The New York State legislature is currently considering a bill that would permit Medical Aid in Dying for terminally ill patients in certain defined circumstances. Those states now benefit from decades of experience, evidence, and reporting from MAiD jurisdictions. This demonstrates that legislation can simultaneously grant terminally ill citizens the civil right to access MAiD while also aggressively protecting all patients from coercion, manipulation, and harm. Given the copious evidence gathered in the past decades, concerns about abuse can no longer be credited as grounds for opposing the passage of legislation that is demonstrably both effective and safe.

Keywords: Medical Aid in Dying, Terminally Ill, Coercion, Harm, Legality, Treating Pain, Morality

INTRODUCTION

It has been 26 years since medical aid in dying ("MAiD") was first legalized in Oregon, and today, about 20 percent of people in the US live in jurisdictions that permit MAiD. Other jurisdictions, including New York, are actively considering adopting MAiD laws. Those states now benefit from decades of experience, evidence, and reporting from MAiD jurisdictions, demonstrating that legislation can permit MAiD while also aggressively protecting all patients from coercion, manipulation, and harm. The data should allay the concerns of those who oppose MAiD due to the risk of abuse, coercion, and a hypothetical slippery slope. We, as a society, as clinicians, and as ethicists, must remain vigilant and prevent abuse of MAiD, given the potential risks in the community and in congregate care settings and the risk of patient exploitation by family members. However, given the copious evidence, concerns about abuse do not justify opposition to legislation that is effective and safe.

* David N. Hoffman, JD University of Buffalo School of Law, Professor Columbia University
Emily Beer, JD Cornell University, MS Columbia University

© 2023 Hoffman & Beer. This is an open access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction, provided the original author and source are credited.
I. New York’s MAiD Bill

The New York State legislature is currently considering a bill that would permit MAiD for terminally ill patients in defined circumstances. The bill applies only to adults with a terminal illness or condition that is “incurable and irreversible” and “will, within reasonable medical judgment, produce death within six months.” The bill contains numerous protective requirements:

- MAiD requests can only be made by the patient themself; requests cannot be made by healthcare agents, surrogates, or anyone else;
- MAiD requests must be made both orally and in writing to the patient’s attending physician;
- No person is eligible for MAiD solely because of age or disability;
- The patient’s attending physician must determine the patient has a qualifying terminal illness, has decision-making capacity, and has made a voluntary, informed decision to request MAiD, in the absence of coercion;
- These determinations must be confirmed by a second consulting physician in writing;
- If the attending physician has any concern that the patient may not have decision-making capacity, the patient must be referred to a mental health professional;
- The attending physician has additional duties to the patient, including ensuring the decision is informed, by discussing the patient’s condition and prognosis; discussing the MAiD process, and treatment alternatives like palliative and hospice care; offering referrals to other appropriate treatment, like palliative and hospice care; and educating the patient that their request can be rescinded at any time and offering them an opportunity to do so;
- The written request must be witnessed by at least two adults who cannot be (i) related to the patient, (ii) entitled to any portion of the patient’s estate, (iii) employed by a healthcare facility where the patient is receiving treatment or residing, (iv) or the attending physician, consulting physician, or mental health professional determining decision-making capacity; and
- MAiD medication must be self-administered by the patient, and it must be voluntarily ingested.

ARGUMENTS FOR AND AGAINST MAiD

II. No Evidence of Abuse of Existing MAiD Laws

MAiD supporters and critics alike have a concern about the abuse of MAiD. For this reason, MAiD laws throughout the US incorporate strict eligibility criteria and protective procedural requirements. For instance, patients are eligible only if they are terminally ill with six months or less to live, more than one physician must be involved, and requests must be witnessed (by individuals unrelated to the patient who will not profit from the patient’s estate). MAiD requests have been closely examined in the 27 years since Oregon became the first state to legalize the practice. The results show that these compassionate and protective measures have worked.

There have been no documented or substantiated incidents of MAiD abuse since Oregon became the first to implement a MAiD law in 1997. In 2019, the executive director of Disability Rights Oregon (DRO), an organization mandated by federal law to investigate complaints of abuse or neglect of people with
disabilities, reported that DRO has never received a complaint that a person with disabilities was coerced into obtaining a prescription for MAiD drugs.\textsuperscript{6}

A recent study of aggregated data from all nine of the US jurisdictions with publicly available MAiD records from 1998 to 2002 found that 95.6 percent of those who died by MAiD were non-Hispanic white individuals, and 53.1 percent were male.\textsuperscript{7} 72.2 percent of these individuals had at least some college education, 74 percent had a cancer diagnosis, and the median age of MAiD death was 74 years old. Only 11 percent of patients were uninsured. MAiD users tend to be white, older, educated, diagnosed with cancer, and insured. Fears that MAiD would overwhelmingly be used by (or on) the poor, the uninsured, the uneducated, or racial and ethnic minorities have not materialized. This data has actually raised a converse concern: that MAiD may, inequitably, not be readily available to less privileged populations or those with a diagnosis other than cancer.\textsuperscript{8}

Opponents of MAiD may argue that the recent relaxation of certain legal restrictions in some jurisdictions is evidence that the slippery slope to unrestricted euthanasia has begun. This is a mischaracterization. Certain restrictions have been adjusted. For instance, Oregon and Vermont removed the residency restriction that previously excluded non-residents from eligibility.\textsuperscript{9} Both states changed the residency requirement due to lawsuits challenging the constitutionality of requiring residence.\textsuperscript{10} New Jersey’s law will likely change soon, as well.\textsuperscript{11} Initial MAiD laws were drafted to be highly restrictive out of concern about unintended and unforeseeable consequences. Given the gravity of the subject, decades ago, it was better to err on the side of caution, even if that meant excluding from eligibility people who ought to, ethically or legally, be included. Now, with nearly 30 years of experience and data, we can better determine which requirements are necessary to appropriately protect patients, clinicians, and society. Restrictions proven to be unnecessary can now be modified. The core purposes of MAiD laws and the rights and protections they provide are not changing. Rather, a few aspects of the regulations are being adjusted so they are not more restrictive than necessary to achieve their purpose.

The ever-growing body of evidence that MAiD laws can adequately protect against abuse and the mythic slippery slope has assured many that their fears will not materialize.\textsuperscript{12} For example, NYU bioethicist Arthur Caplan was once a vigorous opponent of MAiD. He worried that MAiD laws would lead to the abuse of the poor, uninsured, and disabled in service of cost-saving or the convenience of others.\textsuperscript{13} But, after closely following the empirical evidence from MAiD early-adopters, Oregon and Washington, Caplan changed his mind. In 2018, he argued in favor of the NY MAiD bill before the New York State Assembly Standing Committee on Health.\textsuperscript{14} Discussing his review of evidence from these states, Caplan stated:

I found no cause for my concerns, none with respect to the slippery slope. There isn’t solid evidence of coercion or duplicity being exercised with respect to people who choose assistance in dying in either state. The police, government officials, families of those who have chosen to use the legislation and the general citizenry find no causes or basis for changing the laws due to abuse or misapplication . . . These slippery slope arguments are just not true . . . there is no current factual support for this slippery slope argument that vulnerable individuals are at risk for being coerced into using the law.\textsuperscript{15}

Decades of evidence has shown that legislation can simultaneously grant terminally ill patients access to MAiD while also protecting against coercion and abuse. In the face of this evidence, continuing to deny access to MAiD because of hypothetical abuse is unjust and unethical.
III. Views of Opponents are Neither Grounded in Fact nor Consistent with Current End-of-Life Practices
   a. Risk of coercion

One common argument heard today from some disability advocates who oppose MAiD goes something like this: *Everybody who would qualify for and use MAiD is (or will become) a disabled person, so MAiD only kills people with disabilities. The most common reasons people choose to end their lives via MAiD are disability issues, like loss of autonomy, less ability to engage in activities, and loss of dignity. They argue that, instead of making it easier for disabled people to die, we should make sure that proper services and support exist so that disabled people do not choose to die.* Such disability-rights-based arguments tend to assert that to avoid abuse, we must prohibit MAiD altogether.

They argue that legalizing MAiD will inexorably lead to abuse and coercion, and disabled people will be pressured into suicide. Some even argue that MAiD laws are the first step to euthanasia, noting the path in other jurisdictions. As an initial matter, people with disabilities deserve adequate support and services, and these are not always available to them. People with disabilities have faced tremendous discrimination in the healthcare system and have been historically prevented from accessing proper care and asserting their autonomy. Ensuring that all can access adequate end-of-life care, like palliative or hospice care, is an ongoing battle that ought not be abandoned. But fighting for adequate end-of-life care and legalizing MAiD are not mutually exclusive. In Oregon, 90 percent of those who access MAiD are enrolled in hospice and states with MAiD laws tend to have better access to palliative care than states without. MAiD proponents seek only to add another choice for the dying, not to diminish any other options. This is reflected in the text of New York’s pending bill, which explicitly requires patient education and referrals to appropriate end-of-life services, like palliative care and hospice. No one has openly argued that society should hold terminally ill patients hostage in order to obtain broader support and funding for palliative care, but that is the practical effect.

Beyond the need for supportive services and proper access to the full range of end-of-life care options, the disability argument fails. First, the assertion that MAiD laws will be abused and disabled people will be coerced into suicide is not grounded in fact. To the contrary, real-life evidence gathered in over two decades of legal MAiD has shown no documented or substantiated incidents of abuse, as discussed above. The slippery slope has simply not materialized.

Advocates for people with disabilities who are opposed to MAiD have not clearly articulated exactly who is vulnerable to being coerced into obtaining a MAiD prescription or even how such coercion could logistically occur. Most people with disabilities are not vulnerable to MAiD abuse, as they do not have a qualifying terminal illness or lack decisional capacity due to a developmental disability and are therefore not eligible.

MAiD opponents appear to be claiming that all those who qualify for MAiD are vulnerable and seek protection from MAiD laws. But this would include many of the people that, over the past decades, have aggressively and publicly advocated for access to MAiD – terminally ill people, like Brittany Maynard, many of whom lobbied hard for the passage of MAiD laws while knowing that they themselves would die before the laws passed. Opponents of MAiD from a segment of the disability rights community are telling individuals who they claim, without permission, as members of the MAiD opposition community, that they must all endure unimaginable suffering without a MAiD option because they must be protected from theoretical coercive harm. People with disabilities should be allowed to make their own choices. No one,
not even the most well-meaning advocate, should be allowed to obstruct a patient’s end-of-life choices – those choices belong to the patient alone.

b. Argument That the Demand for MAID is a Result of Poor Disability Services

Second, the argument that terminally ill patients would decline MAID if only they had better disability services or support is disingenuous to the extent that it ignores the fact that people choosing MAID are *actively dying*. No provision of supportive services can change this. And it is perfectly reasonable for someone who knows that *they will die in less than six months* to want some control over the manner of their death and to avoid the deterioration, indignity, and suffering that could come with it. The argument construes a MAID death as a choice to die rather than live with a disability. But individuals choosing MAID are not choosing death – death is coming and coming quickly. MAID simply offers some control over this reality, giving patients an option that is safe, certain, and painless. Certainly, supportive hospice services should be available for these individuals. But there is no evidence demonstrating that any amount of service would eliminate the need and desire for the MAID option.

c. Inconsistent Positions on MAID and Other Ending Life Care Options: Palliative Sedation and VSED

MAID opponents who are concerned about abuse and coercion often hold inconsistent views on other currently available ending life care options. For example, some argue that palliative sedation renders MAID unnecessary and does not present the same ethical problems. However, whereas MAID can only be chosen by the patient themselves (and the patient must have decision-making capacity), the same is not true for palliative sedation. Palliative sedation, a valuable modality of end-of-life care, does not have to be initiated by the patient. If the patient is deemed not to have decision-making capacity to make that decision, their healthcare proxy can decide to initiate the process and continue it until the patient dies. Individuals other than patients often choose to begin palliative sedation and continue it to its inevitable conclusion. And because palliative sedation does not require enabling legislation, none of the protective safeguards incorporated in MAID legislation are available to protect those who receive palliative sedation.

Some may try to differentiate between palliative sedation and MAID by saying that once started, palliative sedation can always be discontinued – it need not end in the patient’s death. This is true, but the very process of palliative sedation will inevitably make the patient insensible or unconscious or otherwise unable to exercise a choice to stop sedation. With MAID, the patient must self-administer and ingest the medication on their own, with death following quickly. The patient can choose to forgo MAID up until the very moment of self-administration. Considering MAID’s procedural safeguards, including that only the patient may choose and administer MAID, MAID patients are offered more protection from potential abuse than patients who receive palliative sedation.

While some have vocally opposed MAID for decades, there has not been similar opposition to the option of voluntarily stopping eating and drinking (VSED). With VSED, adults with decision-making capacity make a voluntary decision to refuse nutrition and hydration to die more quickly. People choosing VSED are, essentially, making the same choice that people choosing MAID do. But VSED is a less predictable process that takes much longer to complete. Unfortunately, the process also carries a risk of unpleasant side-effects, though proper care can help mitigate them. Additionally, the practice of VSED is not constrained by statutorily defined protective measures, as is the case with MAID – one does not even need to have a terminal illness to choose VSED.
It is logically inconsistent for those who oppose MAiD because of the perceived potential of abuse to hold different views about VSED. If malevolent actors can unethically pressure or coerce patients into MAiD, they can also coerce them to stop eating and drinking. As with palliative sedation, it could be argued that an important difference is that VSED can be stopped, unlike MAiD. This argument fails clinically and ethically. As with palliative sedation, the VSED process eventually results in the patient losing consciousness and decision-making capacity. The patient generally becomes unarousable for a period that could last for days or even weeks. For this reason, it is crucial for VSED patients to express their choice in writing (or preferably in video recording) to ensure that they will not be given nutrition or hydration when they are no longer able to enforce their refusal (or if they begin asking for nutrition or hydration). Therefore, there is a period in which the patient cannot decide to end the process, just as with palliative sedation. To the extent that someone is so concerned with potential abuse of MAiD that they seek to ban it but have not expressed similar concerns with VSED, these positions are inconsistent.

At a NYS Bar Association-sponsored conference on MAiD in 2019, David Hoffman asked a MAiD opponent whether, “as someone who is looking out for the interests of a segment of the disability population,” she supports palliative sedation and VSED. Kathryn Carroll, who represented the Center for Disability Rights (“CDR”), confirmed that CDR did not oppose palliative sedation and did not offer a position on VSED. She noted the subtle difference in intention:

I don’t believe the Center for Disability Rights has taken issue with palliative sedation. And my understanding is that there is a key difference between palliative sedation and assisted suicide, particularly in that palliative sedation, the point is not to bring about the death of the person, but to relieve the pain that they are experiencing. And so the death is more of a side effect rather than the intended outcome.

During the questioning, she provided no explanation as to why the potential for abuse would be different among palliative sedation, VSED, and MAiD. The other MAiD opponent on the panel, Dennis Vacco, of Vacco v. Quill fame, interjected but could not explain any ethically significant difference between VSED and MAiD. Instead, he focused solely on palliative sedation, stating that the relevant difference is that palliative sedation can be stopped:

. . . treating the pain including what you referred to as terminal sedation, is not moral and legally and ethically the same as physician-assisted suicide . . . The fact of the matter is – the difference is you can terminate that treatment, and it’s the permanent aspect of physician-assisted suicide that goes back to what I said 20 minutes ago. You can’t put the bright line anyplace else other than where it is.

But, as discussed above, that difference is of little import, given that palliative sedation results in patients without the ability or capacity to make the choice to stop treatment. Vacco then reverted to his concerns about the potential for coercion and the elusive slippery slope, referencing his primary argument that the only way to ensure there is no abuse of a MAiD law is not to have one at all:

The bright line that is created by the law in the state of New York, which makes physician-assisted suicide a manslaughter in the second-degree, or assisting suicide by anybody, manslaughter in the second degree . . . is unfortunately the only place that line can be. That line should not move further toward accommodation. And we see here in the context of . . . all of the so-called protections in the statute. With every protection that is not
prohibition, with every protection, you raise the possibility of abuse. You raise the possibility with every protection.\textsuperscript{32}

Neither Vacco nor Carroll addressed the fact that many common practices today can be the result of coerced decisions. These practices have none of the safeguards contained in MAiD legislation. As another panelist, David Leven, stated:

consider that people who want to have life-sustaining treatment withdrawn, whether it’s a ventilator or feeding tube, they can also be coerced by family members. That can happen even more often, of course, because that process takes place more and more often, and there are none of the safeguards that we’re talking about here . . . there are risks involved in any process which might result in a hastened death. But there seems to be very little risk involved with medical aid in dying based on the experience in 40 years and the nine states which now permit medical aid in dying based on the experience in 40 years and the nine states \textsuperscript{33}

There is an inescapable inconsistency within the disability argument: one cannot logically be so concerned about the abuse of legalized access to MAiD to justify opposing all MAiD legislation while simultaneously supporting options like palliative sedation or VSED as abuse-free alternatives.

d. Argument Against Speaking for a Community with Diverse Views

Finally, while some disability advocates opposing MAiD will claim terminally ill patients as part of their community, they have no right or authorization to speak for the extremely heterogeneous group of terminally ill patients or the disability community\textsuperscript{34} as a whole. The disability community is not homogenous; while some members oppose MAiD, others support it.\textsuperscript{35} Recent polling indicates that MAiD may have broad support across the disability community.\textsuperscript{36}

e. MAiD Opponents Hold the Rights of the Terminally Ill Subordinate to Their Personal Morality and Unsubstantiated Theoretical Concerns

The argument that does not get much attention, the one that is the simplest and perhaps even the most compelling, is that all killing is wrong, and the government ought not to be in the business of enabling it. That is certainly a compelling religious and moral argument against individuals engaging in any form of acts that result in ending a human life. But such an ethical or theological position does not dictate that individuals who hold different views on personal morality should be precluded by the state from accessing the most safe, certain, and painless means of addressing an invariably terminal illness.

Arguments like the one described above by Vacco (that the only way to completely avoid potential MAiD abuse is to prohibit MAiD) are essentially claiming that the safest thing to do is to subordinate the suffering of the terminally ill to avoid the more subtle task of balancing the interests of two different groups of New York state citizens. But surely, that is the role of the legislature every day. And we should expect no less from the legislature on this issue. The best way to ensure no one dies in car accidents is to prohibit driving. But instead of doing so, we implement safety regulations (like speed limits) to balance the right to travel with the right of everyone else not to be killed in the process. Evidence demonstrates that MAiD legislation can also strike a balance between the rights of the terminally ill and the need to prevent harm. It is not justifiable to support a blanket prohibition of MAiD.
CONCLUSION

Opponents of MAiD have had decades to cite problematic case studies or formulate a compelling moral argument against it that is grounded in data rather than an assertion of their personal morality. Plainly, no one on either side of the MAiD legislative discussion wants to see anyone subjected to involuntary euthanasia or coerced into MAiD as a better alternative to palliative care when such a plan of care is a viable alternative to “ending life care.” However, enough time has passed, and the risk of coercion has been given sufficient study and debate that we can now conclude, as a society, that the rights of the terminally ill and the rights of persons committed to living their best and longest life with a disability are wholly compatible. It is time for the legislature to strike the appropriate balance and give the terminally ill a well-regulated, responsible pathway to obtaining medication that can relieve their suffering in a manner that is safe, certain, and painless.


4 Id.


8 Id.


14 Id.

15 Id.


19 See also, Ben Colburn, Disability-based Arguments against Assisted Dying Laws, 36 BIOETHICS 680 (2022) (cataloging research in multiple countries and concluding that “there is no evidence that assisted dying laws have a disproportionate effect on people with disabilities”). https://doi.org/10.1111/bioe.13036

20 Eyder Peralta, As Planned, Right-To-Die Advocate Brittany Maynard Ends Her Life, NPR (Apr. 3, 2014), https://www.npr.org/sections/thetwo-way/2014/11/03/361094919/as-planned-right-to-die-advocate-brittany-maynard-ends-her-life (Activist Brittany Maynard moved to Oregon after she was diagnosed with a malignant brain tumor, because her home state did not permit MAID at the time).

21 Ending life care is defined as the final stage of the end-of-life care continuum, where the patient chooses to end their life as a means to end their suffering or unacceptable quality of life.

22 Palliative sedation is defined as “the use of medications to induce decreased or absent awareness in order to relieve otherwise intractable suffering at the end of life,” and it carries a risk of hastening death. Molly L. Olsen, Keith M. Swetz & Paul S. Mueller, Ethical Decision Making With End-of-Life Care: Palliative Sedation and Withholding or Withdrawing Life-Sustaining Treatments, 85 MAYO CLIN PROC 949 (2010). https://doi.org/10.4065/mcp.2010.0201

25 This is not to say that MAiD and VSED are ethically identical. Different writers have articulated various reasons why MAiD and VSED are meaningfully different and meaningfully similar. Here we distinguish the potential for abuse, as this is the argument that persists among MAiD opponents. For a broader discussion on the ethics of VSED and how it compares to MAiD, see VOLUNTARILY STOPPING EATING AND DRINKING: A COMPASSIONATE, WIDELY-AVAILABLE OPTION FOR HASTENING DEATH, (Timothy E. Quill et al. eds., 2021). https://doi.org/10.1093/med/9780190080730.001.0001
26 Id.; see also David N. Hoffman and Judy Schwarz, Can Patients Choose to Stop Eating—Even If They Have Dementia—and Can Health Care Facilities Get Paid for Taking Care of Them? Ethics and Reimbursement at the End of Life (Am. Health L. Ass’n Conf. on Long Term Care and the Law 2020).


28 Id.

29 CDR still does not appear to have articulated a position on VSED. CDR is a major and vocal opponent of MAiD legislation in NY with considerable resources (they state their projected 2010 budget was approximately $29,000,000). About Us, CENTER FOR DISABILITY RIGHTS, https://cdrnys.org/about/.


31 Health Law Section: Duties, Rights & the Law at the End of Life (2019), supra note 5.

32 Id.

33 Id.

34 Ben Colburn, Disability-based Arguments against Assisted Dying Laws, 36 BIOETHICS 680 (2022) (providing evidence that “that people with disabilities, and disability rights organizations, have diverse views on the question of whether assisted dying should be legal”). https://doi.org/10.1111/bioe.13036
