

Refuting Arguments Against the Medical Aid in Dying Act

By David C. Leven

For almost two decades I have been working on health and end-of-life issues with End of Life Choices New York. The organization seeks to ensure that patients receive quality care at the end of life and that they have a wide range of choices available to enable them so that they may die on their own terms, when possible. I have worked as an advocate for vulnerable populations during my career, as a legal services attorney for 10 years and as the executive director of Prisoners' Legal Services for 20 years, seeking justice for poor people and prisoners. Seeking health justice for patients has become another passion. There is so much that needs to improve in our health care system, including at the end of life. Significant problems still need to be addressed regarding access to health care, quality health care, health care discrimination and disparities, ensuring that patient health care wishes are honored and that patients receive wanted but not unwanted care. However, as indicated below, those serious problems have no connection to medical aid in dying with regard to who accesses it. It is an option that should be available to patients at life's end.

It is important to keep in mind that only for the past three decades or so have patients had a clear legal right to make their own health care decisions and to accept or reject any care or treatment offered, including the right to stop treatment at any time, provided that they have decision-making capacity. And, when they lack decision-making capacity, health care agents in New York can make those decisions for patients either knowing the wishes of the patient or in their best interests. In the absence of a health care agent, surrogates are empowered to make these decisions under the Family Health Care Decisions Act when certain standards are met. These health care decisions often involve life-sustaining treatments and decisions are made every day by patients, health care agents and surrogates, to have such treatments never started or withdrawn, which ultimately results in the death of the patient.

In addition, hastened deaths occur when palliative sedation is used as a treatment option as well as when patients voluntarily stop eating and drinking.

It is important to clarify what medical aid in dying is, and what it isn't, as there has been confusion, and misunderstandings. It occurs when a terminally ill, mentally competent adult patient, who is likely to die within six months, takes prescribed medicines, which must be self-administered, to end suffering and achieve a peaceful death. The determination of capacity and terminal illness is made by two physicians after an oral and written request by the patient. The Medical Aid in Dying Act gives a clear

understanding of what the process entails. The bill is very comprehensive and contains numerous requirements, safeguards and guidance. It is quite similar to the laws enacted in 10 other U.S. jurisdictions, including our neighboring states, Vermont and New Jersey. About 20% of our nation's population are eligible for medical aid in dying.

Before there was experience with medical aid in dying (MAID), many arguments were made opposing it and various concerns were also raised, some understandable at the time. Unfortunately, many of these same arguments and concerns are still being expressed despite the fact that evidence shows that they no longer have validity, if ever they did. In fact, medical aid in dying laws have worked as intended and none of the problems expected by opponents have emerged. As a result, there have been no serious efforts to repeal MAID laws and many organizations, including medical organizations, have eventually taken either a supportive or neutral position. I am unaware of any organization that was either supportive of or neutral that has since become an opponent. There is continued strong opposition from some, primarily religions groups, most notably the Catholic Church hierarchy and some disability rights groups. Politically, virtually all Republican legislators have been opposed, despite polling, for example in New York, that consistently shows Republican voter support, mostly recently by a 2021 Marist poll, which showed that New Yorkers support MAID by a 58% to 37% margin. There was support across demographic groups: political party, age, race, region of the state.

And, in New York, it should be noted, physicians support the Medical Aid in Dying Act, by a 67% to 19% margin, according to a 2018 Medscape poll.

Opposition Arguments

Despite widespread support for MAID, based in part on evidence from states that authorize the practice, arguments are still being made in opposition that can be refuted. Below are some arguments against MAID and responses to them.

MAID is the same as assisted suicide and should not be permitted

Although court decisions have held that technically assisting a suicide and MAID are the same, in reality there are stark differences between typical suicides and MAID. People who die by suicide, usually have a mental illness. They could continue to live but choose not to; are done in isola-

tion, often impulsively and violently; and they are tragic. In contrast, MAID is available only to terminally ill patients who will soon die; their disease is killing them. The process usually takes at least several weeks from the time that a request is made for a prescription of life-ending medicines and they are taken, if at all. It occurs after consulting with two physicians and almost always with family support; and it is empowering. The term “assisted suicide” is rejected by the American Public Health Association, American Academy of Hospice and Palliative Medicine, American Medical Women’s Association, the American Psychological Association, American Academy of Family Physicians, and other highly respected health care organizations. In 2017, the American Association of Suicidology issued this statement: “Suicide is not the same as physician aid in dying.” <https://suicidology.org/wp-content/uploads/2019/07/AAS-PAD-Statement-Approved-10.30.17-ed-10-30-17.pdf>. The statement lists 15 points of differences. Three of them are quoted below:

2) In PAD, the person with a terminal illness does not necessarily want to die; he or she typically wants desperately to live but cannot do so; the disease will take its course. Suicide, by contrast, even when marked by ambivalence, typically stems from seemingly unrelenting psychological pain and despair; the person cannot enjoy life or see that things may change in the future. 3) In PAD, the individual who is already facing death often experiences intensified emotional bonds with loved ones and a sense of deepened meaning as life is coming to an end; in suicide, by contrast, the individual typically suffers from a sense of isolation, loneliness, and loss of meaning. 4) The term “suicide” may seem to imply “self-destruction,” and the act may be cast that way in some cultural and religious traditions. Ending one’s life with the assistance of a physician and with the understanding of one’s family is often viewed more as “self-preservation” than “self-destruction,” acting to die while one still retains a sense of self and personal dignity, before sedation for pain or the disease itself takes away the possibility of meaningful interaction with those around one.

Palliative or hospice care is enough to relieve the suffering of dying patients

There is no question that the provision of good palliative or hospice care effectively relieves the suffering of the vast majority of dying patients. That is the reason that the Medical Aid in Dying Act requires that the attending physician must “discuss with the patient” feasible alternatives or additional treatment options including hospice and pal-

liative care.” Those who die by MAID are far more likely to receive hospice care than others—over 90% on average in Oregon, where MAID has been legal for over 20 years, compared to a national average of about 50%. This means that even hospice care is unable to sufficiently relieve the suffering of some dying patients. As stated by Ann Jackson, the former CEO of the Oregon Hospice Association, who after indicating her initial opposition to MAID, “However, I came to realize that it was arrogant of me to believe that hospice and palliative care professionals could meet all the needs of the dying. Oregon is consistently rated among the best states for providing hospice and palliative care. Yet, even with the best care, some patients still suffer intolerably and want the option to take prescription medication to die painlessly, peacefully and quickly in their sleep.” (“Hospice care isn’t enough for all the dying,” Sacramento Bee, December 9, 2015).

Certainly, patients should not die prematurely by a hastened death, whether by MAID or by other means, if there are things that could be done to improve their quality of life, which they are willing to try. However, once desired treatment and care run their course, it should be up to the patient to decide how life will end. And, consider that the overarching goal of hospice and those who support the option of MAID is to ensure that patients have the best deaths possible. So those of us who work with dying patients want to ensure that this is what happens, that patients receive palliative care or hospice, as most MAID patients do, but again with the understanding that decisions about MAID, as with other hastening death options, should be left to the patient in consultation with doctors and loved ones.

We should not allow MAID until all patients have adequate access to quality palliative care and hospice care

The concern about lack of access to quality care and palliative care is absolutely legitimate, particularly for poor people, people of color, people with disabilities, and those who live in rural areas. However, there is no evidence that patients who use MAID have been deprived quality end-of-life care. So, there is no good reason to prevent patients from dying by MAID just because there are other patients, not these, who do not have access to quality care. And, as mentioned above, most patients are enrolled in hospice when they die by MAID, receiving the gold standard of end-of-life care. We must continue to strive for better end-of-life care and to ensure access to quality palliative care and hospice for all, but at the same time we must not deprive those who are suffering at the end of life the option of medical aid in dying.

Most people who end their lives by MAID do not do so primarily because of uncontrollable pain or other symptoms

This is true but the argument is not valid. People suffer in different ways at the end of their lives. All who are dying and have decision-making capacity should be able

to decide if and when their suffering has become intolerable, whether because of pain, other uncontrollable symptoms, other reasons that cause suffering, or a combination of some or all of the above. What matters is that the patient has decided that life can no longer be continued because of suffering, however that suffering is determined by the patient. Mentally competent patients are currently permitted to reject any life-sustaining treatments or to stop them at any time, with the understanding that death will ensue. Decisions are routinely made to withdraw a feeding tube, stop dialysis, or turn off a pacemaker. And, they are made regardless of the nature or extent of physical or other suffering. That being the case, denying terminally ill patients the right to access MAID cannot be justified simply because in some cases the suffering is not due to intolerable physical symptoms.

Prognostications by physicians are not always accurate, so patients might end their lives prematurely by MAID

While doctors far more often predict that patients will live longer than they actually do, even more importantly, patients who choose the option of MAID almost always wait until they are in fact quite close to death. So, the issue of inaccurate prognostication is not relevant in the context of MAID. Consider too that the process usually takes some seven weeks from the time the first request is made until the drugs are taken, if ever (about one third of patients never take them). Clearly, patients should be able to make end-of-life decisions and MAID in particular, based on the prognostications of two doctors, just as they can make decisions to hasten their deaths by stopping or never starting life-sustaining treatments, even if the prognostication is inaccurate.

Patients might be coerced into dying by MAID

This would be an understandable concern if there was not over 50 years of combined experience with legal MAID, without any substantiated court or administrative findings of coercion or any other abuses. Even if coercion is theoretically possible, and will probably happen occasionally, that is not a sufficient reason to withhold access to MAID. Patients might also potentially be coerced to stop or never start life-sustaining treatments, yet we allow patients to make decisions in this regard and there is actually more opportunity, generally, for coercion in those cases than with MAID due to the strict safeguards concerning MAID and the requirement of self-administration.

Vulnerable populations are at risk and may be abused or coerced

The concern was quite understandable before there was evidence. But, there has in fact been no disproportionate impact in the use of MAID on vulnerable populations such as the poor, people of color, people with disabilities, or the elderly (see “Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact

on patients in “vulnerable groups,” *Journal of Medical Ethics* 2007; 33:591–597). There are no contrary studies to our knowledge, no findings at all. With regard to those with disabilities, consider a February 2016 letter from the executive director of Disabilities Rights Oregon, where he categorically states that “DRO has not received a complaint of exploitation or coercion of an individual with disabilities in the use of Oregon’s Death with Dignity Act.” We must certainly be vigilant about any people in vulnerable populations being abused or coerced. But to date, there is no evidence that this has been or is likely to be a problem.

There will be a slippery slope to allow patients who are not terminally ill to access Medical Aid in Dying or to allow euthanasia

This is pure speculation. There is simply no evidence in the U.S. to support this assertion, after over 20 years of states authorizing MAID in the U.S. It is highly unlikely, certainly for the foreseeable future, that MAID laws will be expanded to cover those who are not terminally ill. This is so despite the fact that although some patients who are not dying may be suffering as much if not more, due to the nature of their disease, than those who will soon die. Nor is it likely that laws will be expanded to allow doctors to euthanize patients, with one possible exception. In order for there to be any expansion of MAID either laws would have to be enacted or courts would have to render decisions in cases seeking to establish expanded eligibility for MAID. There are not currently any bills, out of dozens pending on MAID, to our knowledge, that would allow patients who are not terminally ill to access MAID. And, all higher court decisions have ruled against those who have sought to establish MAID only for the terminally ill, as either a federal or state constitutional right. It is possible that a pending court case recently filed in California could result in a decision that would allow doctors to help terminally ill patients with neurologic diseases who cannot now access medical aid in dying because they cannot physically administer the medications to do so. The unassisted self-administration requirement creates a barrier to health services available to people without those disabilities. This barrier runs contrary to disability rights laws.

The right to die by MAID, in accordance with one’s values, may become, instead, a duty to die

This is an absurd argument. At least since 1990, patients have had the right to die by stopping or never starting treatment. Any adult patient with decision-making capacity can reject life-sustaining treatment although death will result, whether by refusing to accept treatment when first offered or by having the treatment discontinued. This right even extends to those who are not terminally ill. However, very few patients reject life-sustaining treatment, unless they are close to death. Nor is there any evidence that those who have LST withdrawn feel that they have a “duty to die.” So, understandably, in the context of LST the argument has not been made that those patients will feel a “duty to die.”

Life is precious. And so, despite having the right to die, the vast majority of patients choose to live, at least until suffering becomes or is becoming unbearable, usually when death draws near. There is simply no evidence, over almost three decades, that patients are in any way feeling a duty to die.

People who ultimately choose MAID would prefer to live but are now dying. They only want to control the manner and timing of their deaths, just as do patients who hasten their deaths by withholding or withdrawing life-sustaining treatments or who die by voluntarily stopping eating and drinking.

There is now cumulative evidence over 50 years on the experience of MAID. Patients who choose this option are clearly not rushing to end their lives because of a perceived duty to do so. To the contrary, the facts conclusively show that very few people die by MAID, only about three of every 1,000. And, even among those patients who obtain the medication, about a third never take it, further evidence that patients are not feeling an obligation to end their lives. And, the MAID process usually takes about seven weeks from the time that a prescription is first requested, indicating that patients are acting in a thoughtful manner, almost always with the support of their families.

The fear mongering about a potential “duty to die” has no basis. And, one wonders if some opponents may think that there is a duty to live, even when suffering is intolerable at the end of life.

Doctors should not be involved in intentionally causing the death of their patients

We actually do not know what the intent is of any doctor who prescribes the medications for a patient who chooses MAID. The doctor may not want the patient to die but is acting to support and respect the wishes of the patient when prescribing the drugs. Similarly, we do not know what the intent of a doctor is when a ventilator is

withdrawn. The doctor may actually want the patient to die or not. We do know that in both situations the patient will die regardless of the doctor’s intent. But the intent of the doctor is not really the point. The intent of the patient is what clearly matters.

MAID is fundamentally incompatible with the doctor’s role as healer

When a patient is terminally ill, healing the illness itself is no longer possible. The relief of suffering and not abandoning the patient at a time of great need, might be considered another form of healing, compatible with a doctor’s role. And it is, of course, or should be extremely important to the doctor that the patient has the best possible quality of life, usually with the provision of palliative or hospice care, as the patient is in the last chapter of life. When suffering becomes intolerable, the relief of that suffering may include a hastened death if that is what the patient decides. Doctors must have the ability to act in accordance with the wishes of their patients, whether it is to withdraw life-sustaining treatment(s) or to prescribe life-ending medications to eligible patients. If doctors feel that they cannot do so because of their own ethical or religious values, none of the laws authorizing medical aid in dying, including the Medical Aid in Dying Act, require doctors to directly participate in the process.

Conclusion

With more than five decades of data, it is clear that there are no longer any compelling arguments in opposition to MAID. There are no justifiable reasons why this medical option should not be available to adult, mentally capable, terminally ill patients, especially when the evidence is clear that medical aid in dying laws have worked as intended.



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