

Testimony regarding SB-0443
“End of Life Option Act”
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My name is Dr. Daniel Sulmasy. I am a general internist and a philosopher, the André Hellegers Professor of Biomedical Ethics and Director of Georgetown University's Kennedy Institute of Ethics. I have served on New York State Task Force on Life and the Law under Governor Pataki and on the Presidential Commission for the Study of Bioethical Issues under President Obama. I am currently a member of the Council on Ethical and Judicial Affairs of the American Medical Association. I am here today to express my strong opposition to SB-0443, the "End of Life Option Act." This law represents bad medicine, bad ethics, and bad public policy and should not be permitted to obtain the force of law.

First, a word on language. This bill legalizes a form of suicide with the assistance of a physician. Proponents call it "aid in dying," but that is merely a euphemism concocted to gain support. I aid lots of dying patients. It is my job to accompany them, care for them, treat their symptoms, and ease their dying. This bill does something different. In plain speech, it would enable patients to kill themselves by overdosing on medication prescribed by a physician. In more honest language, that means it legalizes physician assisted suicide. This dishonesty is compounded when physicians are forced to lie on death certificates, as other states have done, making them state the cause of death as the underlying illness, not an intentional overdose.

Physician assisted suicide (PAS) is bad medicine. It subverts the meaning of healing to which medicine is dedicated. No patient is healed by being made dead. PAS runs roughshod over the Hippocratic Oath which states, with good reason, "I will not give a deadly drug to any patient, even if asked, nor will I make such a suggestion." It has been recognized since ancient times that profound trust is required to enable vulnerable patients to bare their bodies and their secrets to doctors. The bare minimum of the Oath assures patients that their doctors will not disclose their secrets will not have sex with them, and will not kill them. Everyone is a potential patient, and no one should ever fear that the doctor secretly wants to do her in.

PAS is also bad medicine since it should not be necessary. We can do more than has ever been possible in the history of humankind to heal the physical suffering of patients—drugs, electrical stimulation, complementary therapies. Studies from Oregon and Europe bear this out. The chief reason patients opt for PAS and euthanasia is not pain (which can be treated) but loss of control. They say they feel like burdens. Should we say yes, you are a burden? They say they are tired of life or lonely. Is the answer enlisting doctors to help them kill themselves? DO NOT be deceived into believing the false dilemma that patients have a choice of either being strapped to machines, poked with needles, and racked with pain, or they can seek assisted suicide. Hospice and palliative care can treat physical symptoms, even, if necessary, to the point of rendering a patient unconscious through invoking the rule of double effect and the careful practice of palliative sedation. Even shortness of breath can be treated (with lower doses of morphine than it takes to treat pain). This whole movement is about something else—a very small but vocal, forceful, and powerful group of people who want to have the freedom to kill themselves rather than depend upon other people to help them. They often enroll in hospice, but refuse its routine services, demanding that they be given the drugs with which to end their lives. Most patients, however, when they learn what palliative care and hospice are about, want these services and take advantage of them.

And if the health care system is not delivering such good, state of the art hospice and palliative care to the citizens of Maryland, then fix your health care system, don't legalize medical aid in suicide.

PAS is bad ethics. Not only does it undermine the trust that ought to undergird the patient-physician relationship, it gives state sanction (and medical sanction) to the notion that being dependent upon others is so awful a state that it makes life no longer worth living. That is why the disabled are so fearful of these laws. They do not expect to have their wheelchairs lined up so that they can be forcibly injected (at least not yet). What sends shivers down their spines is that the state has said that lives like theirs are so bad that they are not worth living. They know that once it is permissible for an individual to declare his *own* life is not worth living, it is a very short step to third party determinations that the lives of *others* are not worth living—the physically disabled, the cognitively and intellectually challenged, and so many other vulnerable groups that we physicians treat. The state has an interest in cultivating a medical profession that sees the sick and disabled as worthy of service.

You see, PAS flips the default switch. At present, patients are presumed to want to live until treatments become more burdensome than beneficial, and then we stop. Once PAS is on the table, however, the question becomes, “Why haven’t you done it yet? Why are you still burdening yourself and us by continuing? Here’s your prescription, just in case you want to use it.” That poisons medical ethics.

Personal autonomy is not absolute, and there is a difference between the negative right to be free of unwanted therapy and the positive right to receive whatever treatment one wishes, including suicidal medication. As Wittgenstein once observed, if suicide is allowed, anything is allowed. If we are to have ethics and the rule of law it must be based on the idea that all lives are worthy of respect and that no one, not the state, not the doctor, not the patient, should have the power to end lives deemed unworthy of living.

PAS is also bad public policy. PAS cannot be controlled by regulations and additional amendments. Maryland should not let this genie out of the bottle. Abuse happens, and will happen. But the regulatory structures in this bill, modeled on Oregon, make it nearly impossible to detect abuse. The data collected are really bare bones. Everything depends on self reporting by physicians, who are really smart. They know how to say what will keep them out of trouble, and they don’t want a lot of bureaucratic hassle. Only state officials have access to the data, and we can’t know what we don’t observe. We do know, however, that while, on average, about 40% of terminally ill patients can be expected to be depressed, in Oregon less than 5% of PAS patients (in some years no one) is referred for psychiatric assessment. Anorexia nervosa has been deemed a terminal, qualifying condition. Diabetes has been called terminal if you decide not to take your insulin. Demented patients have used the law, even though patients are supposed to have decisional capacity. Family members have assisted patients who are too weak to self-administer, even though that constitutes euthanasia which is not permitted by the law. There are disturbing anecdotes.

Moreover, suicide of any form has a social contagion effect. We have an epidemic of suicide in this country, and data suggest that legalized PAS leads to more suicide in the general population. That’s misguided policy.

The cost-constrained environment of contemporary medical care is a really unsuitable atmosphere into which to release PAS. There are a number of anecdotes describing patients who have been offered PAS by insurers who simultaneously denied coverage for life-extending therapies. My colleagues and I have shown that there is a strong correlation between a cost-saving attitude and a pro-PAS attitude among physicians. And the Canadians have been bold enough to publish a recent cost-effectiveness analysis on how much their law will save for the health care budget.

Most importantly, assisted suicide is just the beginning. You see, once PAS is legalized, logic and law lead inexorably to euthanasia. Every proposed safeguard will be re-interpreted as a barrier. Waiting times will be shortened. Nurses will be permitted to prescribe. Residency requirements will be dropped. It will be declared discriminatory to prevent patients who are paralyzed from equal access, and that requires active euthanasia for a person can't take the pills. And what about the demented? Can't one claim that grandma would have wanted to be made dead quickly if she knew she had become demented? That will require euthanasia by third party consent. In Canada and Belgium, 5% of all deaths are by euthanasia. The indications for euthanasia in Belgium and the Netherlands include psychiatric illness since psychiatric suffering is as great as physical suffering. Canada is poised to follow them. In Belgium and the Netherlands, euthanasia is prescribed for children and for infants born with genetic disorders. Pass this bill and you'll end up in Brussels, not Portland.

Why has this not happened in yet in the US? Proponents have been very disciplined in not expanding their campaigns beyond asking for PAS until they have enough states on board. Maryland could be their tipping point. With a large mid-Atlantic state legalizing PAS, proponents will be able to claim enough momentum to carry a few more states and then the calls will start. Actually, a few such bills have already been passed in Oregon, Vermont, New Mexico, Hawaii, and California. Waiting periods are being shortened. Nurses empowered to prescribe. Residency requirements dropped. You know the real zealots don't quit. How many PAS bills have already been introduced in Maryland? They will not stop with PAS. I have attached a recent article by law professor and advocate Thaddeus Pope, who has been frank in admitting that the law you are thinking about passing is only the beginning of where advocates want to go.

So be courageous leaders for Maryland, and be careful. Bear in mind that a recent well-intentioned venture in bad medicine, bad ethics, and bad public policy led us to the present opioid epidemic. Policymakers just a few years ago were urging physicians to prescribe more pain medication and not cruelly leave patients in pain. That policy shift took on a life of its own and led to our current opioid crisis.

I care deeply about compassionate care for the dying and have worked hard over my whole career to make that care better. Physicians and legislators can work together to do improve the care of the dying through expanding access to hospice and palliative care, expanding social work and chaplaincy services, and educating physicians to do a better job in care at the end of life. That's what the vast majority of patients want and deserve. Assisted suicide plays no role in that care.

Don't pass this bill, which will do far more harm than good.

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World Medical Association. Declaration on Euthanasia and Physician-Assisted Suicide. 2019. <https://www.wma.net/policies-post/declaration-on-euthanasia-and-physician-assisted-suicide/>

The WMA reiterates its strong commitment to the principles of medical ethics and that utmost respect has to be maintained for human life. Therefore, the WMA is firmly opposed to euthanasia and physician-assisted suicide.

For the purpose of this declaration, euthanasia is defined as a physician deliberately administering a lethal substance or carrying out an intervention to cause the death of a patient with decision-making capacity at the patient's own voluntary request. Physician-assisted suicide refers to cases in which, at the voluntary request of a patient with decision-making capacity, a physician deliberately enables a patient to end his or her own life by prescribing or providing medical substances with the intent to bring about death.

No physician should be forced to participate in euthanasia or assisted suicide, nor should any physician be obliged to make referral decisions to this end.

Separately, the physician who respects the basic right of the patient to decline medical treatment does not act unethically in forgoing or withholding unwanted care, even if respecting such a wish results in the death of the patient.

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5.7 Physician-Assisted Suicide Physician-assisted suicide occurs when a physician facilitates a patient's death by providing the necessary means and/or information to enable the patient to perform the life-ending act (e.g., the physician provides sleeping pills and information about the lethal dose, while aware that the patient may commit suicide). It is understandable, though tragic, that some patients in extreme duress—such as those suffering from a terminal, painful, debilitating illness—may come to decide that death is preferable to life. However, permitting physicians to engage in assisted suicide would ultimately cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks. Instead of engaging in assisted suicide, physicians must aggressively respond to the needs of patients at

the end of life. Physicians: (a) Should not abandon a patient once it is determined that cure is impossible. (b) Must respect patient autonomy. (c) Must provide good communication and emotional support. (d) Must provide appropriate comfort care and adequate pain control.

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Top Ten New and Needed Expansions of U.S. Medical Aid in Dying Laws

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OPEN PEER COMMENTARIES



Top Ten New and Needed Expansions of U.S. Medical Aid in Dying Laws

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Pullman argues that when it comes to medical aid in dying (MAID), “Canada ... has much to learn from California” (Pullman 2023). Canada and California have similar populations: each about 40 million citizens. But, each year, while fewer than 1,000 Californians take MAID medications, more than 10,000 Canadians use MAID. This ten-fold difference is astonishing and merits attention. But how should we interpret it?

Pullman describes the Canadian numbers as “disturbingly high.” I take the opposite approach and contend the California numbers are disturbingly low. Pullman rightly notes that MAID in California is subject to “strict eligibility criteria” and that we take a “more cautious approach in the United States” (Pullman 2023). But even Pullman concedes ingenuousness in how best to strike the balance between safety and access. He does not know whether the Californian “criteria are too restrictive” or the “Canadian criteria are too liberal” (Pullman 2023).

But we already have the evidence. Significant data and testimony gathered by researchers and state legislatures show that U.S. criteria for MAID are too restrictive and impede access to individuals who want to relieve suffering at the end of life (Kusmaul et al. 2023). Similar evidence is emerging in other restrictive MAID jurisdictions like Australia and New Zealand. In this Open Peer Commentary, I describe the top ten new and needed expansions of U.S. MAID laws. These are not the only indicated reforms. We need better data to identify other barriers and disparities (Riley 2023).

PERMIT NON-PHYSICIAN PROFESSIONALS

For decades, only physicians could provide MAID in the United States. But it became increasingly obvious that this limited access (Pope 2020). Especially in rural areas, physicians weren’t always available. So, when New Mexico enacted its MAID statute in 2021, it also authorized advanced practice registered nurses and physician assistants to provide MAID. In 2023, Hawaii and Washington followed suit. Today, both current and prospective MAID states are considering legislation that would authorize not only physicians but also APRNs and PAs. Furthermore, the states are also expanding the types of clinicians authorized to conduct the mental health exams always required in Hawaii and required in other states when the attending or consulting clinician is uncertain of the patient’s capacity.

SHORTEN OR WAIVE WAITING PERIODS

Another way states are already expanding access to MAID is by reducing or waiving waiting periods. For decades, one of the standard safeguards in U.S. MAID statutes required that the patient make two separate oral requests, the second after a waiting period of at least 15 days. The rationale was to permit patients to calmly reflect and deliberate about their decision. But over two decades of experience with MAID shows that many patients cannot wait that long. Since many patients don’t seriously consider MAID until the late stages of their illness, they either die or lose decision-making capacity before the end of the 15-day period. In

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short, the waiting period frequently constitutes an undue burden.

In response, several states have either shortened or waived the waiting period. Both California and New Mexico reduced their waiting periods from 15 days to 48 h. Hawaii, Vermont, and Washington also reduced their waiting periods (Meisel, Cerminara, and Pope 2023). Today, bills in both current and prospective MAID states propose similar reductions. In addition to, or instead of, shortening the waiting period, some states exempt patients from having to satisfy the waiting period, however long it is, when the patient isn't expected to survive that period. New Mexico and Oregon, have already enacted such waiver laws. Bills in both current and prospective MAID states propose the same.

DROP RESIDENCY REQUIREMENTS

Traditionally, states limited MAID to their own residents (Pope 2020). Many patients have been able to satisfy these residency requirements by, for example, briefly renting an apartment in the MAID jurisdiction. But while surmountable, residency requirements still pose an obstacle. Consequently, physicians and patients brought federal lawsuits challenging residency requirements in Oregon and Vermont as violating the privileges and immunities clause of the U.S. Constitution. After settling the lawsuits, those states removed the residency requirement. That opened the door to patients traveling to Oregon and Vermont for MAID from other states. Now, bills in other states similarly propose authorizing MAID without a residency requirement. States appear to recognize that they can't constitutionally limit healthcare services to their own residents. A new lawsuit is proceeding in New Jersey.

ENFORCE TRANSPARENCY LAWS

All U.S. MAID laws include broad conscience clauses for both institutions and individual clinicians. Invoking these rights, many religiously affiliated institutions have opted out of participating in MAID. But to help patients make informed decisions about where to seek treatment, California and Washington require facilities to publicly post their MAID policies. That way, patients seeking MAID can make informed choices, for example to avoid enrolling in a nonparticipating hospice. Unfortunately, compliance is poor and states have not enforced the transparency requirements. Colorado now seems poised to do a better job.

PERMIT ASSISTED SELF-ADMINISTRATION

Some individuals otherwise currently eligible for MAID are unable to self-administer their medications

because of neurological conditions like ALS. A recent debate in this Journal discussed whether the Americans with Disabilities Act permits, or even requires, clinicians or others to assist these patients in self-administering MAID medications when their physical disability prevents them from completing administration by themselves (Shavelson et al. 2023). Even Pullman admits that California should permit this much (Pullman 2023).

DROP THE SIX-MONTH REQUIREMENT

All U.S. MAID jurisdictions require that the patient have a prognosis of six months or less to live. This strict temporal requirement is unusual compared to other countries, such as Canada, which require only that the patient have a "grievous and irremediable medical condition." Indeed, many seriously and irreversibly ill individuals not within six months of dying may still suffer greatly every day from their disease. A growing number of advocates (including within Pullman's target jurisdiction, California) want U.S. laws to be more like broader laws in Australia, Belgium, Canada, Luxembourg, Netherlands, Spain, and Switzerland (www.abetterexit.org).

PERMIT INTRAVENOUS ADMINISTRATION

Under U.S. MAID laws, medications can be self-administered orally, rectally, or through a feeding tube. All three methods require ingestion (through the stomach and intestines). But evidence from other countries shows that intravenous infusion is more reliable and faster than ingestion (Pope 2020). Unfortunately, IV administration is unavailable in the United States because MAID laws specifically prohibit ending a patient's life "by lethal injection." To allow safer and more effective IV administration, state legislatures should repeal that prohibition. This would not cross the line from MAID to euthanasia. While clinicians would set up the IV, the patient would take the final step of opening the valve to let the medication into their body.

REQUIRE PATIENT DECISION AIDS

All MAID laws have multiple safeguards that help assure the patient's voluntary and informed consent. But because the stakes are so high, we should use the best means available. Patient decision aids are evidence-based educational tools that dramatically improve patient understanding of their options compared to clinician discussion alone (Pope 2022). Other end-of-life decisions

are already supported by decision aids. We must develop a PDA for MAID. And we must get it certified by the Washington State Health Care Authority (Pope 2017).

PERMIT ADVANCE REQUESTS

Many older Americans fear living with late-stage dementia. But MAID isn't an option for these individuals. By the time they're terminally ill, they no longer have capacity. And when they still have capacity (for example, in early stages of Alzheimer's), they're not yet terminally ill. In response, some advocates are pushing to permit individuals to arrange MAID through an advance directive. This is already permitted in some European countries and is being actively considered in Canada. In the meantime, there has been a significant interest in VSED advance directives which direct caregivers to stop providing food and fluid by mouth (Pope 2021; Quill et al. 2021).

REPEAL ASFRA

While MAID is primarily a state matter, many terminally ill patients are on Medicare. That impedes access because the Assisted Suicide Funding Restriction Act of 1997 prohibits federal money from being spent on MAID. Consequently, patients must find another way to pay roughly \$750 for the medications. Furthermore, ASFRA deters many hospices and other providers from offering MAID because they worry about inadvertently billing Medicare for it. For these reasons, while most advocacy has been at the state level, some advocates seek to repeal ASFRA.

CONCLUSION

The Dubai World Cup is often referred to as the "world's richest horse race." In 2017, one of the favorites was Highland Reel, an Irish thoroughbred racehorse. He took an early lead and kept it for most of the race. But Highland Reel lost his lead 400 meters from the finish line. Worse, he was then passed by the entire field and relegated to a dead last finish. Analogously, the United States took an early worldwide lead with MAID when Oregon enacted its Death with Dignity Act in 1994. But like Highland Reel, the United States has lost its lead. And it is quickly falling to the back of the pack in terms of MAID safety and access.

DISCLOSURE STATEMENT

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