

# End-of-life options and the legal pathways to physician aid in dying

Thomas Strouse, MD

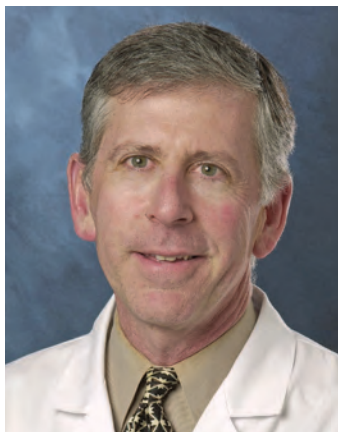
**B**y early 2017, roughly 18% of all US citizens will reside in a state with a legal pathway to physician aid in dying via lethal prescription. When the End of Life Options Act (EOLOA) went into effect in California in June 2016, it became the fourth state with laws allowing physician aid in dying (PAD). Oregon (1997), Washington (2009), and Vermont (2009) had preceded it, and Montana (2009) operates similarly as a result of a Supreme Court decision there. However, California's law also legalized PAD in a state that is much larger and more socioeconomically diverse than the other four states – with its 39 million residents, California more than triples the number of Americans who live in PAD legal states. Together, these 5 states represent 16% of the entire US population (roughly 321 million according to the 2015 Census). Most recently, in December 2016, they were joined by Colorado, adding a state population of 5.5 million.

The state laws have much in common: to “qualify” for legal access to a lethal prescription, a patient must make an in-person verbal request to his/her attending physician. The patient must also: be an adult (aged 18 years or older); be a resident of that state; have a terminal illness the course of which is expected to lead to natural death within 6 months; be making a noncoerced, voluntary request; repeat the verbal request no sooner than 15 days after the first request, followed by a witnessed, formal written request; and have the capacity to self-administer the lethal prescription in a private setting.<sup>1</sup>

In California, as in the other states, additional safeguards are built in: the terminal diagnosis and the patient's capacity to make the request must be verified by a second, independent consultant physician. If either the attending or the consultant physician finds evidence of a “mental disorder,” they are obligated under the law to refer the patient to a psychiatrist or psychologist for an evaluation. The psychological expert is charged with verifying the patient's mental capacity and ability to make a voluntary end-of-life choice, with determining whether a mental disorder is in fact present, and if it is, whether that mental disorder is impairing

the patient's judgment. A finding of impaired judgment due to mental disorder halts the legal process until the disorder is rectified by treatment, the passage of time, or other factors.

Many of the themes and concepts outlined in these laws are familiar to oncology clinicians simply because we take care of seriously ill and dying patients. Indeed, access to



the Medicare Hospice Benefit requires certification – often by an oncologist – that a patient has a terminal diagnosis with a maximum 6-month expected survival. In addition, oncologists encounter many patients who wish to talk about quality of life while they weigh various treatment options, and it is normative for patients (though often anxiety producing for clinicians) to broach topics related to end of life, symptom management, and even aid in dying. Many patients fear poor quality of life, intractable symptom burden, dependency on others, and loss of control more than they fear their cancers. Their efforts to initiate this

discussion often fit into a much larger and more durable set of personal values and ideals about suffering, dependency, futility, and personal autonomy.

## Weighing the evidence

And yet there is vigorous objection to PAD laws from many corners. Some religious organizations and faith-based health care delivery systems oppose the laws and, in opting-out of the voluntary legal pathways for participation, prohibit their employed and affiliated physicians and other professionals from doing so as well.<sup>2</sup> Some physician organizations, and individual physicians, claim that involvement in aid in dying – such as by providing a legal lethal prescription – violates the Hippocratic oath and that (in effect) there is no circumstance under which it could be ethically permissible.

There are also bioethicists, including physician ethicists, who sincerely reach similar conclusions and warn of the “slippery slope” that might lead beyond aid in dying as currently legalized in the US to assisting in the deaths of those with disabilities, those with depression or other treatable

psychiatric illness, and even to active euthanasia, including euthanasia of nonconsenting or incapable individuals.<sup>3</sup> These objectors generally remain adamant and cite what we would all agree are excesses in certain European countries, despite the absence of evidence that the European measures could be approved in the United States under current laws and practices.

The largest amount of publicly available evidence to inform this discussion in the US comes from Oregon, which has nearly 20 years of experience with the law and its reporting requirements.<sup>4</sup> Very broadly, the Oregon experience supports the view that PAD is pursued and completed by a very small percentage of the population: in 2015 (the most recent year for which data is available) 218 people possessed lethal prescriptions; 132 of them ingested the medications and died. Thus about 61% of those who received the prescription used it for its intended purpose, resulting in a Death with Dignity Act death rate of 0.39% (132 of 34,160 deaths in Oregon) in 2015. Since the law's inception in 1997, 991 patients are known to have died from lethal ingestion of 1545 prescriptions written (a 64% "use" rate).

Equally important is the evidence from Oregon describing those who seek to use the law. In 2015, as in previous years, most patients were older than the general population (78% aged 65 years or older; median age at death, 73). Of those patients, 93% were white and well educated (43% had at least a college degree), compared with the population at large. In all, 72%-78% of patients had cancer; 6%-8% had ALS (amyotrophic lateral sclerosis); and end-stage heart disease seemed to be increasing, trending up from 2% to 6% in recent years.

In addition, 90% died at home, with 92% on hospice, and more than 99% had health insurance of some kind. These figures provide strong evidence that PAD is not being inappropriately used among historically vulnerable or disempowered ethnic/racial minorities, socioeconomically or educationally disadvantaged groups, or disabled individuals. On the contrary, "uptake" or use of PAD by the disadvantaged in Oregon seems, perhaps not surprisingly, to occur at rates significantly *below* their representation in the general population of the state.

Intractable symptom burden (or fear of it) was rated as a minor contributor to the decision to pursue PAD, ranking sixth out of the 7 options and endorsed by about a quarter of patients. The three most frequently cited end-of-life concerns were: decreasing ability to participate in activities that made life enjoyable (96%), loss of autonomy (92%), and loss of dignity (75%).

### A broader range of choice

I have worked for nearly 30 years in California oncology clinical settings as a palliative care physician and psychiatrist. During that time I have been involved in the care of

two patients who committed violent suicide (self-inflicted gunshot). Both events took place before the passage of the California EOLOA, both patients were educated, professional older white men who were fiercely independent and who saw their progressive cancers as rapidly worsening their quality of life and intolerably increasing their dependency on beloved others (although their judgments about this did not take into account how the others actually felt); neither had a primary psychiatric illness, and neither had intractable symptom burden. Both men had expressed interest in and were denied access to lethal prescription. Sadly, neither had the kind of long-term, trusting relationship with a physician that appears to have provided access to non-legally sanctioned PAD for decades before the first state laws allowing it – and therefore each apparently decided to exert his autonomy in the ultimate act of self-determination. In both cases, it seemed to me that violent suicide was a *bad, last* recourse – clearly, each man regarded continued living in his intolerable state as even worse – but also the *worst possible* outcome for their surviving families, for their traumatized clinicians, and for the bystanders who witnessed these deaths and the first responders who were called to the scenes. We cannot know that the availability of lethal prescription would have pre-empted these violent suicides, but I suspect it might have given each man a much broader range of choice about how to deal with circumstances he found entirely unacceptable, and which he simply could not and would not tolerate.

### An informed, person-centered approach

It is in the context of these experiences that I have come to view "active non-participation" in legal PAD – that is, decisions by individual physicians and/or health systems not only to not provide, but also not refer patients to possibly willing providers and systems without regard for specific clinical contexts – as a toxic form of patient abandonment. I am also concerned that this rigid stance (like many rigid stances in the service of alleged moral absolutes) may lead to greater suffering and harm – such as the violent suicides I have described – than a more moderate, contextually informed, person-centered approach that does not outlaw certain clinical topics. Indeed, in my participating institution in California, it has become clear that a request for PAD leads (as a result of a carefully and comprehensively constructed "navigator" process) to a level of patient and family care that should be provided to *every* patient with terminal illness in this country. While that statement is a sad reflection on our society's general commitment to caring for the dying, it seems that the extra attention required by the process leading to a PAD, and the revelations that emerge in that process, often lead to a withdrawal of the request for a lethal prescription, and/or allows the drug to go unused if provided.

Many leading bioethical treatises, including those emerging from faith-based academic and university settings, also support the view that PAD can be and is morally justified under a certain set of circumstances. Not surprisingly, those circumstances encompass most of what is written into the state laws permitting PAD. They include, according to Beauchamp and Childress:<sup>5</sup>

- A voluntary request by a competent patient
- An ongoing physician-patient relationship
- Mutual and informed decision-making by patient and physician
- A supportive yet critical and probing environment of decision making
- A considered rejection of alternatives
- Structured consultation with other parties in medicine
- A patient's expression of a durable preference for death
- Unacceptable suffering by the patient
- Use of a means that is as painless and comfortable as possible

We tell many of our patients that cancer is now treated as a chronic illness. In the context of treating that chronic illness we have the profound opportunity – some would say the obligation – to come to know our patients as whole

individuals who often have long-held health values, ideas about what a life worth living looks like, and very personal fears and hopes. We may well come to know them more intimately while serving as their cancer clinicians than any other health professionals do – and even as do any other individuals with whom they will ever interact.

The hours in the infusion chair afford many opportunities for us to understand (and, ideally, document) a patient's advance care plans, health values, goals, views about end-of-life measures such as artificial ventilation and resuscitation. No one reasonably disputes the “rightness” of learning these things. The evidence shows us that under very rare circumstances, knowing and respecting our patients may include understanding their wishes about physician aid in dying, which requires us to build upon the profound trust that has been established by being able to hear and understand their requests. It seems to me that the end of life is the most inappropriate time for any of us to tell patients they must look elsewhere.

*The opinions expressed here are those of the author alone, and do not reflect the view of other individuals, institutions, or professional organizations with which Dr. Strouse is affiliated.*

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