



# Medical Aid in Dying

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## 26.1 Introduction: Why Medical Aid in Dying?

Modern scientific capability has profoundly altered the course of human life. People live longer and better than at any other time in history. But scientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by health care professionals. And we in the medical world have proved alarmingly unprepared for it.”—ATUL GAWANDE MD

As the nation’s 75 million baby boomers enter into a new phase of their life, care for their aging parents, and contemplate their own mortality, many have come to realize that our end-of-life care system is hamstrung by outmoded views of dying. It is a system that reflexively values quantity of life over quality. Sometimes the

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treatment causes more suffering than the disease or condition from which an individual is dying. Such treatments also have the potential to significantly decrease your quality of life, and even reduce the length of time that you live.

So, the conflict is often not about living or dying; rather, it's often between how one dies and how much suffering is endured. For those who reach the point of exhausting all available treatments, the question is quite simply how they will live their remaining days. While palliative and hospice care have evolved and advanced significantly in the United States, they often cannot control all pain and suffering for patients at life's end. In fact, the decline can be quite debilitating, as evidenced by many suffering with end-stage cancer.

Chris Davis was just 29 years old when he faced the late stages of bladder cancer—which was ravaging his body. Despite hospice and palliative care, Chris suffered tremendously at life's end. His swollen skin was bursting from the pressure of edema. His pain was excruciating. He died exactly how he had feared: With tubes draining various bodily fluids that protruded from his stomach, kidneys, and chest. For Chris, a peaceful death was preferable to prolonged suffering. He wanted the option of medical aid in dying; however, it was not available to him.

#### **Medical aid in dying**

refers to a practice in which a mentally capable, terminally ill adult may request a prescription from their medical provider for a medication that they can self-ingest to die peacefully if their suffering becomes unbearable.

The majority of people who use medical aid in dying are also receiving hospice and palliative care. Terminally ill people who request medical aid in dying do not request it because hospice or palliative care has failed to provide the best symptom control available. Rather, people want the option for multiple reasons all at once: pain and other symptoms such as breathlessness and nausea, loss of autonomy, impaired quality of life, and loss of dignity [1]. It is not any one reason, but rather it is the totality of what happens to one's body at the very end of life.

That said, pain control is an issue for some. The evidence from scientific studies confirms that despite the wide availability of hospice, palliative care, and pain management, up to 51% of patients experience pain at the end of life [2]. The prevalence of pain has been noted to increase significantly in the last four months of life, reaching as high as 60% in the last month of life [3]. Additionally, breakthrough pain—severe pain that erupts despite receiving a long-acting painkiller—remains a harrowing experience for some patients. It has been estimated that between 65 and 85% of patients with cancer—by far the most common disease among people who request medical aid in dying—experience significant pain [4].

For others, the side effects of pain medication (sedation, nausea, obstructed bowels) are just as difficult to endure as the pain resulting from the disease. In

some cases, these adverse effects can be controlled or relieved only through continuous deep sedation. Even then, patients may moan and grimace, suggesting significant pain may still be present. Conversely, many patients value their consciousness so highly that they bear extraordinary pain in exchange for a state of alertness during their final days.

Still others want the option of medical aid in dying because they want to try that one last, long-shot treatment with the peace of mind of knowing that if it results in unbearable pain, they have an option to peacefully end their suffering. While as a country we should improve hospice and palliative care, it is not an either or: some patients will still want the option of medical aid in dying.

### **Personal Story—Kim Callinan**

In 1970, when my mother delivered me, she had no say in her childbirth experience: she was strapped down to her bed, medication was automatically administered, and my father was relegated to the waiting room. Fast forward 30 years to when I delivered my son. I had an 8-page birth plan. I chose limited interventions. My medical team used my birth plan to guide care decisions. And my husband was right by my side every step of the way.

Over that 30-year period, an enlightened generation of women became adamant about shaping a much different experience—one of options, with partners heavily involved—and a collaborative relationship with doctors around every aspect of pregnancy. The pressure from women and their partners was so intense that the system yielded. There was a seismic shift from a paternalistic health system that completely discounted the preferences of pregnant women and fathers to a patient-driven system that recognized a patient's values should guide medical decisions.

This is the exact shift that is taking place in end of life care, and the authorization and implementation of medical aid in dying is paving the way for this transformation.

The option of medical aid in dying puts the decision-making power where it belongs: with the dying person. And it paves the way for the same type of seismic shift that took place at the beginning of life with the childbirth movement to take place at the end of life.

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## **26.2 Where Is Medical Aid in Dying Available in the United States?**

The option of medical aid in dying was first authorized in the United States in 1994 in Oregon when the voters in the state, by a citizen initiative, approved the Death with Dignity Act [5]. Today, more than one in five people, 22%, live in

**Table 26.1** States or territories where medical aid in dying is authorized

State	Name of act	Authorization date	Method	Effective date
Oregon	Oregon death with dignity act	11/8/1994	Ballot	10/27/1997
Washington	Washington death with dignity act	11/4/2008	Ballot	3/5/2009
Montana	Baxter V. Montana	12/31/2009	Courts	12/31/2009
Vermont	Vermont patient choice and control at the end of life act	5/20/2013	Legislature	5/20/2013
California	California end of life option act	10/5/2015	Legislature	6/9/2016
Colorado	Colorado end-of-life options act	11/8/2016	Ballot	12/16/2016
Washington DC	DC death with dignity act	12/19/2016	Legislature	2/18/2017
Hawaii	Hawaii our care, our choice act	4/5/2018	Legislature	1/1/2019
New Jersey	New jersey medical aid in dying for the terminally ill act	4/12/2019	Legislature	8/1/2019
Maine	Maine death with dignity act	6/12/2019	Legislature	9/10/2019
New Mexico	New Mexico Elizabeth whitefield end-of-life options act	4/8/2021	Legislature	6/18/2021

a jurisdiction where medical aid in dying is authorized, either through statute or court decision (Table 26.1).

The majority of Americans have supported medical aid in dying since the 1970s. The option has gained growing acceptance since October 2014 when Compassion & Choices partnered with Brittany Maynard, a 29-year-old woman suffering from terminal brain cancer, and her husband, Dan Diaz, to share her story [6]. Brittany and Dan moved from California to Oregon in order to access that state's Death with Dignity law. Since Brittany shared her story in 2015, six states and Washington DC have authorized this option. Prior to that, four states authorized the medical practice in a 20-year period.

### 26.2.1 Cultural Perspectives

Dozens of public opinion surveys demonstrate that the overwhelming majority of Americans support the option of medical aid in dying. A 2020 Gallup survey found that nearly three out of four U.S. residents (74%) agree that: "When a person has a disease that cannot be cured...doctors should be allowed by law to end the

patient's life by some painless means if the patient and his or her family request it [6].” In 2016, LifeWay Research released a survey that included a more in-depth look at racial and ethnic groups and found majority support among the surveyed populations, including white Americans (71%), Hispanic Americans (69%), and more than half of black, non-Hispanic Americans (53%) [7]. Data from other racial and ethnic groups were not reported.

While there is widespread support that the option should be available, there are considerable differences among demographic groups regarding utilization of the practice. Currently, public health departments in nine authorized jurisdictions have issued reports regarding the use of medical aid-in-dying laws: Oregon, Washington, Vermont, California, Colorado, Hawai‘i, the District of Columbia, Maine, and New Jersey.

Differences in data collection and reporting complicate comparisons across states, however, we are able to make some generalizations. The data suggests that users of medical aid in dying tend to be 65 or older (72%), educated (72% have at least some college), and enrolled in hospice care (85%). The state reports also demonstrate clear patterns in utilization of medical aid in dying among different races and ethnicities. Overwhelmingly, the majority of people (94%) who request a prescription for medical aid in dying are white. Asian Americans and Hispanics/Latinx each represent approximately 2% of medical aid in dying participants. The remaining races listed on state annual reports—indigenous American/Alaska Native, Native Hawaiian/Pacific Islander, and multi-race—all comprise less than 1% of medical aid in dying participants [8].

Currently, data does not exist to confirm why racial and ethnic minorities are less likely to access medical aid in dying. However, racial and ethnic minorities are also less likely to engage in advance planning or access other end-of-life care options like hospice and palliative care [9]. The literature suggests a range of reasons for these disparities:

- Differences in spiritual or cultural beliefs [10]
- Lack of trust in the healthcare system based on disparate negative treatment [11]
- Lack of awareness about medical aid in dying as an option [12]
- Less provider and patient communication about end-of-life care including the option of medical aid in dying [13]
- Less comfort in discussing death among certain populations [14]
- Lack of ability to find providers who will support their desire [15]
- Provider racial bias [16, 17].

Additional research is needed to understand why diverse populations are not choosing to access the option of medical aid in dying. If the low utilization rates of such populations result from spiritual beliefs or personal values, this is okay. However, if underserved populations are not choosing to access the option because of lack of information, mistrust of the healthcare system, a discomfort with raising the issue with their doctor or a lack of availability of supportive healthcare providers, these disparities must be addressed.

**Personal Story-Victoria Ramirez**

I have been an oncology social worker for over six years, and a social worker for EOLOA (The End of Life Option Act, California's medical aid in dying statute) for the last four years. Another possible area to explore and its effect on representation of diverse populations may be awareness about the aid in dying law. Physicians are not required to speak with their patients about medical aid in dying as an option and may not be aware that their state or institution participates. This may leave the patient to be their own advocate and there may be a lack of information in their community. It is helpful to have a navigator for patients to assist with guidance. Some institutions have a social worker who is able to partner with a patient that has expressed interest in medical aid in dying.

Patients have also expressed worry about how their physician will react if they ask about this option and a middle person contact that can provide guidance may be helpful in removing such barriers. During my time as an EOLOA social worker, I have received few requests from Hispanic patients; this is surprising considering the high percentage of Hispanics in Southern California, where our cancer center is located. I will never forget one patient: a Spanish-speaking woman, coping with metastatic cervical cancer. As she evaluated her end-of-life options, she spent a lot of time discussing EOLOA with her family in detail; eventually, she decided to start the process for the aid-in-dying medication. Unfortunately, one day, during an inpatient stay, a physician doing rounds questioned her decision-making and commented that as a Catholic, this option is not supported by the Catholic church. This physician had never met the patient before, but because the patient was a monolingual Spanish-speaker, assumptions were made about her ethnic identity and her religious preferences. After that encounter, the patient no longer wished to proceed with EOLOA. She never mentioned the topic again, despite reassurance from others, including her family, that she may choose this option without any judgment.

Many other patients I supported through this process have been Chinese, some monolingual Mandarin or Cantonese speaking. The common difficulty this population has identified is the desire to die outside of their home, for fear of bringing bad luck or further burdening their family with the sale of the home and the belief that a death in the home will impact ability to sell.

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**26.3 The Nuts and Bolts: How It Works**

The medical aid in dying legislation in nine of the 10 authorized states is very similar. (Montana is legal as a result of a Supreme Court ruling and as such, does not have aid in dying legislation.) The states modeled their laws after the Oregon Death with Dignity Act, which is carefully crafted to protect patients. A

fundamental principle of the legislation is that it is entirely optional—for both the provider and the patient.

When a patient requests medical aid in dying, it is imperative that all members of the health care team explore the reasons for the request. It is not uncommon that fears or lack of knowledge are driving the request, and often these can be addressed and resolved. Simply having the conversation about all end-of-life options, including medical aid in dying, is palliative in and of itself. Fully one-third of patients who complete the process of medical aid in dying do not ingest their prescription [8].

The legislation includes strict eligibility criteria. A person must be:

- An adult (18 or older)
- Mentally capable / volitional
- Terminally ill (less than six months to live).

Individuals are not eligible for medical aid in dying because of age or disability.

The patient must also be able to self-administer the medication. Medical aid-in-dying laws in the United States do not allow physicians, family members, or anyone else, including the dying person, to administer medical aid-in-dying medication by intravenous (IV) injection or infusion.

The law also has additional regulatory requirements which vary by state. Generally, they include:

- Two providers, licensed in the state of residence of the patient must certify the person meets the eligibility requirements (New Mexico only requires one if the person is already enrolled in hospice care)
- Requests must be made by the patient, orally and in writing
- Two witnesses must certify the patient is not being coerced. One of these witnesses may not be related to the patient, and neither may be the patient's physician/nurse
- There is a mandatory mental health evaluation if either healthcare provider has concerns about the patient's capacity and volition to make an informed health care decision (with the exception of Hawaii where the evaluation is mandatory in all instances)
- Waiting periods (vary by state).

These regulations are in addition to the education, training, and oversight that govern the practice of medicine for any medical procedure. In addition, the attending/prescribing provider, in counseling the patient, must offer all end-of-life alternatives (continued care, reduced care, hospice, and palliative care); should recommend that the patient inform next of kin/loved ones; recommend that the patient not be in a public place such as a park when ingestion occurs; and ensure that any prescribed medication be safely and securely stored.

The current Oregon model, which laid the foundation for all of the other authorized jurisdictions, requires a lengthy, multi-step process. While on paper it appears

that a person can get through the process relatively quickly, in reality it takes a dying person several weeks to several months to get through all the steps, if they are able to complete it and obtain the prescription at all.

The evidence and data from a combined 40 years across six jurisdictions (California, Colorado, Montana, Oregon, Vermont, and Washington) [8] show that many individuals die with needless suffering while attempting to navigate an unnecessarily burdensome process. For example, a study by Kaiser Permanente Southern California [18] showed that one-third of patients who requested the option of medical aid in dying were unable to complete the process and obtain a prescription before they died. It's worth noting that Kaiser is a health system supportive of patient preferences, with dedicated patient navigators to assist individuals through the process. The percentage of patients who die suffering because they start the process in a health system that forbids their doctors from participating is considerably higher.

Oregon lawmakers acknowledged the need to remove unnecessary regulatory roadblocks in July 2019, when its Governor signed a law to revise its Death with Dignity Act to allow doctors to waive the mandatory 15-day waiting period for medical aid in dying if a doctor does not believe the terminally ill person will live through the period. The 2020 annual report issued by the Oregon Health Authority showed that within the first year of the updated provision, 20% of patients required a physician exemption in order to make it through the process [19].

Lawmakers across the country are working to improve their aid-in-dying laws or create new ones that find a more appropriate balance between necessary safeguards and excessive regulatory roadblocks. New Mexico's bill, the latest state to authorize medical aid in dying as of this writing, has advanced the most innovative solution—reducing the waiting period to 48 h with a physician waiver for patients imminently dying, allowing patients to seek just one certification from a provider if enrolled in hospice, and allowing nurse practitioners and physician assistants to serve as one of the providers.

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## **26.4 Provider Knowledge, Practices, and Behavior—The Evolution**

As noted above, the Oregon Death with Dignity Act, a citizens' initiative, was first passed by Oregon voters in 1994. Implementation of the Act, however, was delayed by several lawsuits, including a petition that was denied by the United States Supreme Court. The Ninth Circuit Court of Appeals lifted an injunction on October 27, 1997, making medical aid in dying a legal option for terminally ill patients. In November 1997, a statewide Measure authorized by the Oregon House of Representatives asked citizens to repeal the Death with Dignity Act (DWDA). Voters chose to retain the Act by a margin of nearly 20% (59.9 to 40%) [20].

The lawsuits and referendum had the effect of stifling utilization and the integration of medical aid in dying into standard medical care. Finally, in March of 1998, the first medical aid-in-dying prescription in the country was written by



Peter Reagan, M.D., a Portland family physician [21]. Utilization of the practice grew slowly. In the first year of the DWDA, 23 Oregonians received prescriptions, 15 of which ingested them (prescribed by 14 different physicians) [20]. In the subsequent years, there has been growing acceptance of medical aid in dying, as noted in annual reports of the Oregon Health Authority [20]. By 2020, a total of 142 physicians wrote 370 prescriptions for medical aid in dying [22].

There has also been a growing comfort level with the practice among U.S. physicians. A 2020 Medscape poll of 5,130 U.S. physicians from 30 specialties demonstrated a significant increase in support for medical aid in dying from 2010 [23]. Today, of physicians surveyed, endorse the idea of medical aid in dying, agreeing that “Physician assisted death should be allowed for terminally ill patients” whereas in 2010 only 46% supported the option [24].

With each new state authorizing medical aid in dying, national associations and organizations removed oppositional policies, including the American Academy of Hospice and Palliative Medicine [25], the American Academy of Family Physicians [26], and the American Nurses Association [27]. Frye and Youngner, in an article in the *Annals of Internal Medicine*, argue that “beyond their current endorsement of palliative care, professional organizations should adopt a position of engaged neutrality in which they take responsibility to help minimize or avoid the potential harms” of medical aid in dying [28].

While there has been a growing acceptance among providers, more work needs to be done to ensure patients can access medical aid in dying as a part of routine end-of-life care. Because providers can “opt out” of providing medical aid in dying services, it’s not uncommon for dying patients to have a difficult time finding one who will support them. We encourage providers who want to learn more about the practice to take the Medscape continuing medical education (CME) activity—*Medical Aid in Dying: My Clinical Guide and Practice Points* (available for one credit) [29]. Other resources include City of Hope’s *How Medical Aid in Dying Really Works in Authorized States* [30] and Compassion & Choices Doc to Doc program, [CompassionAndChoices.org/d2d](https://CompassionAndChoices.org/d2d) or Call Doc2Doc: 800.247.7421 or email Doc2Doc at [doc2doc@CompassionAndChoices.org](mailto:doc2doc@CompassionAndChoices.org).

#### **Personal Story—Dr. David Grube**

Early in my career as a rural family physician, a neighbor’s son had called me to tell me that “something is wrong with my dad.” His mother was not home. His father, I knew, had end stage renal cancer and was in hospice. I was able to go to their home immediately and found his father sitting in a chair in the back bedroom with a shotgun between his legs. He had taken his life. The shock of finding him, calling the police, finding his wife, and cleaning up the terrible physical result has had a deep and lasting negative impact upon me. I promised myself that I could never let this happen to another patient ever again.

A first patient asked me, in 1999, about utilizing Oregon's Death with Dignity Act (the medical aid in dying law in the state). He was a former smoker, a tenured university professor who presented with a cough. Imaging studies revealed metastatic lung cancer, surgery was not an option and subsequent radiation and chemotherapy were ineffective. He rapidly deteriorated, and he was clearly suffering in ways that hospice and palliative care could not assuage.

His plea to me, death with dignity, was just that; a patient-centered, non-violent and compassionate end of life option. However, although I knew that I would help my cancer patient, because this was my first experience with medical aid in dying, I needed a mentor. I contacted the medical director of my local hospice, and he sat down with me and helped me with the process. He also became the Consulting Physician. Together with the patient, we went through the necessary steps (waiting periods, written request, and, at that time, a mental health referral) and I ultimately prescribed medication to the professor. While I offered to attend his planned death, he preferred to be alone with his wife and children. His wife later reported to me that his death was peaceful and gentle, and she thanked me not only then, but for years after, for respecting my patient's wishes, and providing comfort and care to him and their family.

When I think back on these two events—the violent suicide and the peaceful passing of the professor—it is clear to me that medical aid in dying is a valid and vital option at end of life. Seeking counsel from an experienced physician, as we do in all arenas of medicine, was critical and immensely helpful.

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## 26.5 Impact of Medical Aid in Dying on End-of-Life Care

The growing support for medical aid in dying is attributable, in part, to the fact that it is a compassionate and time-tested end-of-life care option. Researchers and legal scholars have confirmed that the experience across the authorized jurisdictions “puts to rest most of the arguments that opponents of authorization have made—or at least those that can be settled by empirical data. The most relevant data—namely, those relating to the traditional and more contemporary concerns that opponents of legalization have expressed—do not support and, in fact, dispel the concerns of opponents [31].” A brief summary of the evidence finds:

- **There have been no documented or substantiated incidents of abuse or coercion** across the authorized jurisdictions since Oregon implemented the first medical aid-in-dying law on Oct. 27, 1997. In 2008, the *Journal of Medical Ethics* concluded that: “Rates of assisted dying in Oregon ... showed no evidence of heightened risk for the elderly, women, the uninsured ... people

with low educational status, the poor, the physically disabled or chronically ill ... people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations [32].” In fact, Disability Rights Oregon has never “received a complaint that a person with disabilities was coerced or being coerced to make use of the Act [33].”

- **Relatively Few Will Use Medical Aid in Dying, But Many Benefit From These Laws.** Based on data from the jurisdictions that have authorized medical aid in dying and subsequently published statistical reports, less than 1% of people who die annually in an authorized jurisdiction will decide to use the law, but large numbers will benefit from simply knowing the law exists [8]. Awareness of the law has a palliative effect, relieving worry about end-of-life suffering. About one-third of terminally ill adults who receive an aid-in-dying prescription in Oregon never even take the medication. However, they report experiencing enormous relief from the moment they obtained the prescription because it alleviated their fears of suffering [34]. Quite simply, medical aid in dying is a prescription for comfort and peace of mind.
- **The implementation of medical aid in dying improves end-of-life care generally.** As an example, a 2015 Journal of Palliative Medicine study found that in addition to having one of the highest rates of hospice use, Oregon had the lowest rate of inappropriate hospice use [35]. “Inappropriate hospice use” is defined as very short enrollment, very long enrollment or disenrollment. This same study suggested the medical aid-in-dying law may have contributed to more open conversations between doctors and patients about end-of-life care options, which led to more appropriate hospice use. Hospice programs across Oregon did, in fact, report an increase in referrals following passage of the Oregon Death With Dignity Act [36]. Over 20 years later, more than 90% of individuals who used medical aid in dying were receiving hospice services at the time of their death [37].

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## 26.6 Conclusion

It’s not uncommon for progress to reveal new challenges and that is exactly what has happened with our end-of-life care system. Incredible advances in medicine have prolonged life. At the same time, in some instances, it has also prolonged suffering and delayed death beyond the point of meaningful life. As the baby boomers see this travesty first hand, they are seeking to chart a different path forward, one that provides them with a greater ability to chart their own journey and less suffering.

We have seen this story before in the childbirth movement, and perhaps that serves as a window into where we are headed. Imagine if we could have that same type of transformation for the end of life that we had in the childbirth movement? What if a person could write their own plan, decide when and where they die, decide who they want with them when they die and what they want their last sound

to be? What if they could determine how much pain they're willing to endure, even if that means accelerating their time of death? Imagine if the default standard of care for end of life was for doctors to assume the patient's values are paramount. That future is possible. In fact, we are in the midst of this transformation.

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