

# Medical Aid in Dying: A Policy to Improve Care and Expand Options at Life's End

2022 Edition



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Dear Lawmaker,

Twenty-eight years ago, in November 1994, Oregon passed the nation's first law allowing mentally capable terminally ill adults to have the end-of-life care option of medical aid in dying to peacefully end unbearable suffering. Since that time, much has changed. Medicine has made extraordinary advances resulting in improved health and longevity, for which we are all grateful; however, the very practices and medications designed to save lives sometimes prolong suffering.

During these past two years, the COVID public health emergency brought about a deeper understanding of the fragility of our lives, the tragedy of loved ones dying alone without the care and comfort of loved ones, and the limits of modern medicine to relieve suffering at life's end. It has reinforced the need for state lawmakers to pass medical aid-in-dying legislation so terminally ill residents can choose, if they want, to die peacefully, at home, surrounded by their loved ones.

Ten states and Washington, D.C., have authorized the compassionate option of medical aid in dying. Seven of these jurisdictions authorized this end-of-life care option within the past seven years (2015-2020).

We now have close to 25 years of experience since the law was first enacted in Oregon and years of experience from the laws passed in the 10 other authorized jurisdictions. We no longer have to hypothesize about what will happen if this medical practice is authorized. The evidence is clear: medical aid in dying protects patients, affords dying people autonomy and compassion during the most difficult time, improves end-of-life care, and costs states almost nothing to implement.

On behalf of our hundreds of thousands of supporters across the country, I urge you to let the evidence, data and strong public support for this end-of-life care option guide your policymaking and authorize medical aid in dying this year.

Terminally ill residents don't have the luxury of endless deliberations; they need the relief that this law affords them right now. Not a single additional person will die if you authorize medical aid in dying, but fewer will suffer.

Sincerely,



Kim Callinan  
President and CEO

Compassion & Choices  
Compassion & Choices Action Network

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# Section I: Introduction

Compassion & Choices is the nation's oldest, largest and most active nonprofit working to improve care, expand options and empower everyone to chart their own end-of-life journey. For more than 40 years, Compassion & Choices and its sister organization, the Compassion & Choices Action Network, have worked across the nation to raise the voices of those nearing the end of life, to change attitudes, practices and policies so that everyone can access the information and full range of care options to have greater autonomy and comfort at the end of life. Compassion & Choices and our predecessor organizations have played a leadership role in most of the significant advances to expand end-of-life autonomy here in the United States. As the thought leaders in this arena, we want to ensure that you have all of the necessary information to make an informed decision and take a proactive stance about medical aid in dying.

We recognize that medical aid in dying can seem like a complex issue, but with close to 25 years of experience since the law was first enacted in Oregon and years of experience from the laws passed in the 10 other authorized jurisdictions, the laws that authorize this compassionate option have proven not only to protect patients, but to improve care across the end-of-life spectrum. This resource is intended to provide you with up-to-date, data-driven, research-based, patient-driven facts about medical aid in dying and to address the most common questions, concerns and hypothetical claims that we hear across the nation. It is offered in the spirit of partnership, and in the hope that we can build on the positive evidence and experience of the authorized jurisdictions by passing evidence-based legislation in your state.

We thank you for recognizing that this popular non-partisan issue deserves your attention and look forward to the opportunity to assist you in helping to make monumental strides in the fight for patient autonomy at the end of life.

## Section II: Legislative Overview

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 choose to ingest to die peacefully if their suffering becomes unbearable. The fundamental core safeguards embedded in medical aid-in-dying laws ensure that all terminally ill individuals pursuing the option are protected from coercion and abuse.

### Eligibility Criteria, Core Safeguards and Established Process

Each of the laws authorizing medical aid in dying in the U.S. establishes strict eligibility criteria and practice requirements to ensure the highest standard of care, as described in the clinical criteria and guidelines published in the prestigious, peer reviewed Journal of Palliative Medicine.<sup>1</sup> To be eligible for aid-in-dying medication, an individual must be:

- > An adult (aged 18 or older);
- > Terminally ill with a prognosis of six months or less to live;
- > Mentally capable of making their own healthcare decisions; and
- > Able to self-administer the medication through an affirmative, conscious, voluntary act to ingest the prescribed medication to bring about the individual's peaceful death.
  - Self-administration does not include administration by intravenous lethal injection or infusion by any person, including the doctor, family member or patient themselves.

Advanced age, disability and chronic health conditions are not qualifying factors for medical aid in dying.

In addition to the strict eligibility criteria these laws establish the following core safeguards:

- > The attending medical provider must inform the terminally ill adult requesting medical aid in dying about all other end-of-life care options. These other options include comfort care, hospice care, pain control and palliative care;
- > The attending medical provider must inform the terminally ill adult requesting medical aid in dying that they can change their mind at any time. This patient right to change their mind includes deciding not to take the medication once they have obtained it;

These core safeguards ensure that individual patient preferences, needs and values are honored, and guide all clinical decisions, including the decision to use medical aid in dying.

## Additional Legislated Requirements

The U.S. jurisdictions that have authorized medical aid in dying through legislation modeled their bills after Oregon's Death With Dignity Act. Each state's regulatory and procedural requirements are slightly different, but each requires that:

- > The terminally ill adult must make multiple requests to their attending medical provider, including at least one written request.
- > The written request must be witnessed by two people, one of whom can't be a relative or someone who stands to benefit from the person's estate upon their death.

Further, at least one medical provider must confirm the terminal diagnosis, prognosis of six months or less to live, and the person's ability to make an informed healthcare decision prior to the attending medical provider writing a prescription. If a medical provider suspects the individual has any condition that may be impairing their ability to make a rational informed healthcare decision, then the individual is required to undergo an additional mental capacity evaluation with a mental health professional (such as a psychiatrist, psychologist, licensed clinical social worker, psychiatric nurse practitioner, or licensed clinical professional counselor). The request for aid-in-dying medication does not proceed unless the mental healthcare professional affirms that the individual is free of any mental condition causing impaired judgment and is capable of making a rational and informed healthcare decision.

## Voluntary Participation

Each of the laws also ensure that individual healthcare providers' values and beliefs are respected; they specifically state participation is voluntary and that no provider is obligated to prescribe or dispense aid-in-dying medication. However, if a provider is unable or unwilling to honor a patient's request, they have a professional responsibility to address the patient's request for medical aid in dying, explore reasons motivating the request, and provide information regarding all end-of-life options. The laws balance the patients' need to receive the information they are inquiring about, while also respecting and establishing clear boundaries for providers who are unwilling or unable to serve as a provider in the medical aid in dying process.

Further, federal law protects an individual's right to transfer their medical records to an alternative provider. Generally, if the individual requests that their provider transfer their medical records to an alternative provider, their provider is legally required to do so.

The laws provide explicit authorization for qualified clinicians to participate in the practice of medical aid in dying. The laws protect both those qualified clinicians who choose to and those who choose not to participate in medical aid in dying from criminal liability, civil liability and professional discipline, as long as they comply with the requirements set forth in the law and act in good faith while meeting the standards of medical (end-of-life) care. Similar immunities and

protections are extended to other healthcare providers (such as mental health professionals as well as pharmacists) and caregivers involved in the care of the terminally ill individual.

## Criminal Conduct

While those who comply with all aspects of the law and meet the standard of care are provided immunity from certain criminal prosecution (for example, homicide, assisting suicide or elder abuse) or civil lawsuits (such as malpractice), the states retain the ability to hold those who fail to adhere to these strict requirements criminally and civilly liable.

Moreover, the existing laws establish that any attempt to pressure or coerce an individual to request or use medical aid in dying is a felony.

## Section III: A Solid Body of Evidence

The growing support for medical aid in dying is attributable, in part, to the fact that it is a proven 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.”<sup>2</sup>

The evidence is clear: medical aid-in-dying laws protect terminally ill individuals, while giving them a compassionate option to die peacefully and providing appropriate legal protection for the providers who practice this patient-driven option.

### Medical Aid in Dying Protects Patients

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. A 2015 report from the Journal of the American Academy of Psychiatry and Law noted “there appears to be no evidence to support the fear that assisted suicide [medical aid in dying] disproportionately affects vulnerable populations.” Vulnerable populations include the elderly, women, the uninsured, people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses, including depression, or racial or ethnic minorities, compared with background populations.<sup>3</sup>

Additionally, in a 2019 letter to Compassion & Choices, then executive director Bob Joondeph of Disability Rights Oregon wrote that: “Disability Rights Oregon has never to my knowledge received a complaint that a person with disabilities was coerced or being coerced to make use of the Act.”<sup>4</sup>

### 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, medical aid in dying accounts for less than 1% of annual deaths. That said, the laws benefit more than the small number of people who decide to use them. Awareness of the law has a palliative effect, relieving worry about end-of-life suffering. In Oregon, for example, people report significant relief from worry about future physical and emotional pain just from knowing the option is there should they need it, regardless of whether or not they choose to pursue it.<sup>5</sup> Quite simply, medical aid in dying is a prescription for comfort and peace of mind.

## Medical Aid in Dying Improves End-of-Life Care

Oregon has long been on the forefront of end-of-life care, leading the nation in terms of the development of patient-directed practices, adherence to advance directives and hospice utilization. In fact, Oregon boasts among the highest number of people who die in their own homes, rather than in hospitals.<sup>6</sup> The experience and data demonstrate that the implementation and availability of medical aid in dying further promote these practices and improve other aspects of end-of-life care.

- > A 2001 survey of physicians about their efforts to improve end-of-life care following authorization of the Oregon Death With Dignity Act showed 30% of responding physicians had increased the number of referrals they provided for hospice care, and 76% made efforts to improve their knowledge of pain management.<sup>7</sup>
- > A 2015 Journal of Palliative Medicine study found that Oregon was the only state both in the highest quartile of overall hospice use and the lowest quartile for potentially concerning patterns of hospice use.<sup>8</sup> “Concerning patterns of 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 the more appropriate hospice use.
- > Hospice programs across Oregon did, in fact, reported an increase in referrals following passage of the Oregon Death With Dignity Act.<sup>8</sup> 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.<sup>9</sup>

In California, the availability of medical aid in dying has had a profound effect on end of life care. According to Dr. Neil Wenger, director of the UCLA Health Ethics Center:

“The (California) End of Life Options Act has really has created a new standard for how we ought to be helping people at the end of life.”<sup>10</sup>

– Dr. Neil Wenger, director of the UCLA Health Ethics Center

On January 24, 2018, just over a year and a half after the California law went into effect, the Assembly Select Committee on End of Life Health Care (California Select Committee) held a hearing on the implementation status. The testimony from patients, doctors and health system representatives echoed Dr. Wenger’s sentiments: that although the regulatory process was more complicated and burdensome than anticipated, the law has been compassionately implemented, promoted better end-of-life care and provides peace of mind to countless Californians nearing their final days. This message was echoed during the California Select Committee’s second hearing on February 25, 2020.<sup>11</sup>

## For Some, Comfort Care and Pain Management Are Not Enough to Relieve Suffering

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.<sup>12</sup> The prevalence of pain has been noted to increase significantly in the last four months of life, reaching as high as 46% in the last month of life.<sup>13</sup>

Additionally, breakthrough pain — severe pain that erupts even when a patient is already medicated — remains a nightmare experience for many patients. In the National Breakthrough Pain Study, 80% of respondents reported breakthrough pain. Among respondents who had cancer (at all stages), 83.3% reported breakthrough pain. For those cancer patients who experienced breakthrough pain, only 24.1% reported that using some form of pain management worked every time.<sup>14</sup>

For some people the side effects of pain medication (sedation, nausea, obstructed bowels) are just as bad as the pain from the disease. Some agonies simply cannot be controlled or relieved unless a person is willing to be sedated to complete and deep unconsciousness. Even then, patients sometimes moan and grimace, suggesting pain may still be present. Many value their consciousness so highly that they bear extraordinary pain in order to be somewhat alert during their final days.

While pain is less frequently noted in the Oregon data as a reason terminally ill adults request the option of medical aid in dying, this aberration is likely because the doctor, not the patient, fills out the report.

## People Decide to Use Medical Aid in Dying to Relieve Suffering

What we hear directly from terminally ill individuals is that people decide to use the law for multiple reasons all at once: pain and other symptoms such as breathlessness and nausea, loss of autonomy, and loss of dignity. 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. For some people, the side effects of treatments such as chemotherapy or pain medication (sedation, relentless nausea, crushing fatigue, obstructed bowels, to name a few), are just as bad as the agonizing symptoms of the disease. For others, they 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 suffering, they have an option to peacefully end it.

Our experience is consistent with the years of data in Oregon and Washington, where doctors are asked to select from a pre-printed form the top reasons people decide to request aid-in-dying medication under the law. The most frequently reported end-of-life concerns for people in Oregon and Washington are loss of autonomy (87%), impaired quality of life (86%) and loss of dignity (69%).<sup>15</sup>

The collective reasons total nearly 400%, which demonstrates that doctors are not selecting just one reason, but they are selecting multiple reasons. Further evidence that it is the totality of the experience of dying — all of which constitute forms of suffering at the end of life — that motivates a dying person to use this option. Suffering by itself is not one of the available options for doctors to select. Incidentally, the Oregon annual report indicates that doctors believe that 27% of patients requested this option because of concerns about inadequate pain control, whereas concerns about finances were only noted for 4.5% of patients.<sup>9</sup>

Only the dying person can determine how much pain and suffering is too much. This law puts the decision in the hands of the dying person, in consultation with their doctor and loved ones, as it should be for such a deeply personal healthcare decision.

“ As you can imagine, after 54 years together, the thought of losing him was just awful. We had talked about how we felt about long-term suffering and promised each other that we would not let that happen. But I knew I couldn't help him to go quickly. And the doctor made it plain — though he was very kind and understanding — that there was nothing he could do ... I thought, ‘Oh dear God, I just can't bear this. I can't stand the thought of him having to go through this.’ But he was so brave. When I came in a day later, he said, ‘I did not have any food or water this morning. I have decided to begin the long glide,’ as he called it. It took 10 full days for him to die, which is why I am so in favor of the goals of Compassion & Choices.”

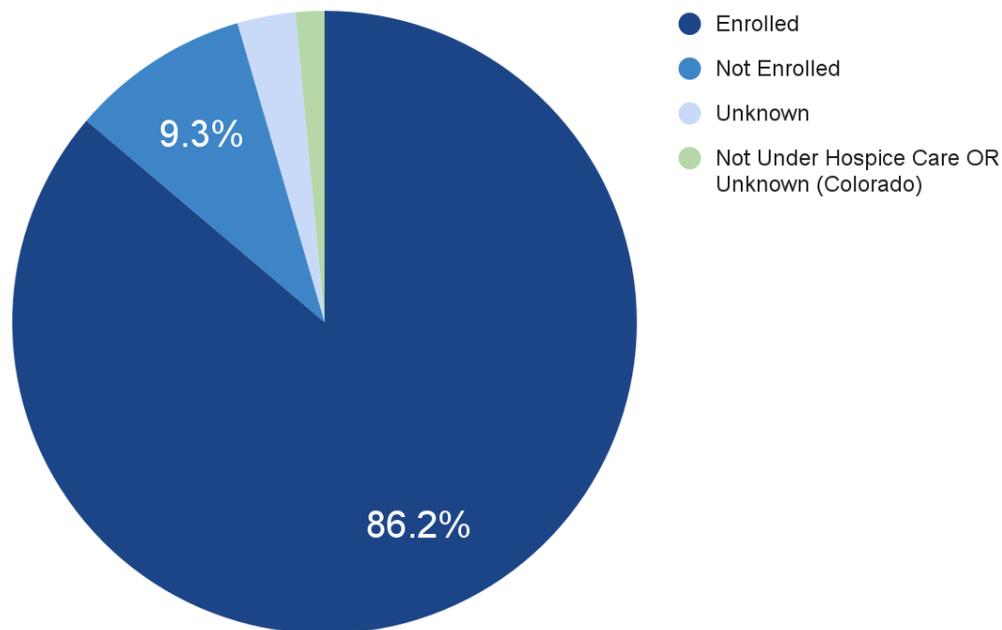
– Diane Rehm, Peabody Award-winning National Public Radio host and author

## People Choose Medical Aid in Dying as well as 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 control their symptoms. The majority of individuals who request and obtain aid-in-dying medication are enrolled in hospice services at the time of their death.<sup>16</sup>

Good hospice services and palliative care do not eliminate the need for medical aid in dying as an end-of-life care option. Terminally ill people should have a full range of end-of-life care options, whether for disease-specific treatment, palliative care, refusal of life-sustaining treatment or the right to request medication the patient can decide to take to shorten a prolonged and difficult dying process. Only the dying person can know whether their pain and suffering is too great to withstand. The option of medical aid in dying puts the decision-making power where it belongs: with the dying person.

## Hospice and Palliative Care Utilization Among Those Who Request Medical Aid in Dying\*



\*This reflects data from all jurisdictions that report on hospice utilization. Currently, public health departments in nine authorized jurisdictions have issued reports regarding the utilization of medical aid-in-dying laws: Oregon,<sup>9</sup> Washington,<sup>17</sup> Vermont,<sup>18</sup> California,<sup>19</sup> Colorado,<sup>20</sup> Hawai'i,<sup>21</sup> the District of Columbia,<sup>22</sup> Maine,<sup>23</sup> and New Jersey.<sup>24</sup> More detailed reports can be provided upon request. Vermont, Washington, D.C., New Jersey, and Maine do not provide data on hospice utilization in their reports on medical aid in dying. Further, the data includes a separate category for Colorado, as they report those who are not under hospice care and those whose hospice utilization is unknown as one, aggregated category.

## Patients Involve Their Family in the Decision

The vast majority of eligible patients involve their family in their decision-making process and most have someone (family, and sometimes a trusted healthcare provider) present at some point during their planned death, according to the Oregon data:<sup>9</sup>

- > Fully 90% of people who use medical aid in dying informed their families of the decision;
- > Additionally, the state has been collecting and publicly reporting data on the presence of healthcare providers at both the time of ingestion of the medication and the time of death since 2001. In that time, 65% of people reportedly chose to have a provider present at some point during their planned death.

## The Oregon Model Has Too Many — Not Too Few — Regulatory Requirements

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.

Unfortunately, many individuals die with needless suffering while attempting to navigate an unnecessarily burdensome process. Some of the biggest challenges include:

- > Late enrollment in hospice. Many terminally ill patients do not receive their six-month prognosis until they have far less than six months to live. One study of clinicians treating patients with advanced cancer found that only 41% of clinicians' prognosis predictions were accurate, and of the inaccurate diagnosis, 85% overestimated the length of time somebody would live.<sup>25</sup>
- > Locating supportive providers. Most of the laws in authorized jurisdictions explicitly allow healthcare systems and doctors to "opt out" of providing this care. When an institution or health system opts out, it means that their providers are not able to practice medical aid in dying, even if they want to. This restriction means any patient whose doctor works at an institution that opts out will have to reestablish care in a supportive health system and find two supportive doctors before they can begin the process of qualifying for medical aid in dying.
- > Oppositional providers. In addition, quite a bit of heartbreaking anecdotal evidence shows that sometimes patients are led to believe their doctor will "support" them when they become eligible under the law, only to find out very late in the process that supporting them means keeping them comfortable in hospice care or referring them to another doctor without sufficient time to navigate the process — not writing them the prescription. Some doctors who personally object to the practice believe they should not have to transfer a patient's medical records because they believe transferring records is "participation" under the act, as is argued in a New Jersey lawsuit.<sup>26</sup> Patients — not doctors — own their healthcare information.

The empirical and anecdotal data from Oregon and the other authorized jurisdictions suggests that this process, as currently constructed, is unnecessarily cumbersome — there are too many regulatory roadblocks for many dying patients to access the law, as indicated by the following examples:

- > A study by Kaiser Permanente Southern California 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.<sup>27</sup> The percentage of patients who die suffering because they start

the process in a health system that forbids their doctors from participating is without question considerably higher.

- > As mentioned previously, in the years since passage of the Oregon Death With Dignity Act, Disability Rights Oregon has received very few complaints from disabled Oregonians about the Act. The executive director at the time confirmed in 2019, “All of the complaints received have focused on the concern that the Act might discriminate against persons with disabilities who would seek to make use of the Act but have disabilities that would prevent self-administration ... Disability Rights Oregon has never received a complaint that a person with disabilities was coerced or being coerced to make use of the Act.”<sup>4</sup>
- > At a National Academy of Sciences two-day assisted-death conference in 2018, many of the speakers — including physicians, ethicists and scholars — concluded that the biggest problem with the law was not one of abuse or coercion, it was that the process is just too cumbersome for patients to get through.<sup>28</sup> As an example:
  - “There are certainly challenges with access where about half of the patients that we heard from were able to follow the process through within their own health system ... .” “The process takes time and that very few patients or health systems report that they are able to complete the request process in 15 days ... .” Helene Starks, associate professor of bioethics and humanities, University of Washington.
  - “All six statutes in the United States require that you be certified, all the eligibility requirements be certified, both by the attending and by a consulting physician. And that attending and consulting physician must be an MD or DO licensed in that state. But many have written that there are big and serious access problems with finding an available and willing physician. So there has been increasing literature on whether or not we should expand medical aid in dying, the clinicians to also include nurse practitioners.” Thaddeus Pope, director, Health Law Institute; and professor of law, Mitchell Hamline School of Law, Minnesota.
  - “Because there's no legal duty to participate, physicians in the state of Oregon and all the other jurisdictions, there's also — in Oregon — no legal duty to refer as well. That's become sort of an obstacle, if you will, for some patients to have access.” Courtney Campbell, Hundere professor in religion and culture, Oregon State University School of History, Philosophy and Religion.
  - “So I'll just say in urban areas, access is limited. In Portland, the three faith-based health systems ... and the VA, which comprise probably the majority of healthcare in the city, and many smaller physician groups adopted policies that forbade physicians to prescribe. Intentionally or not, this also inhibited open discussion at those places. It forced patients into the position of either abandoning their request or seeking care from one of the two health systems that hadn't forbidden prescription.” Erik Fromme, previously from Oregon, now director of Serious

Illness Care Program at Ariadne Labs at the Dana Farber Cancer Center in Massachusetts.

- “[D]ata showing lower utilization of aid in dying among low socioeconomic groups might reflect on equal access, rather than a weaker preference for aid in dying among these groups ... I can add just briefly, there's been one pharmacy in Vermont. It's been different at different times, but basically one providing all the prescriptions. And that is part of the access barriers for patients. Some of them, because people are driving long distances to get to that pharmacy, there is a mail-order option, but it seems like it's not been offered to all patients. And then sometimes there's a wait involved with waiting for the medication to come in the mail, and there have been patients that have died while they're waiting for the medication to come.” Mara Buchbinder, associate professor of social medicine, UNC Chapel Hill School of Medicine.
- “There's quite a bit of information about the lack of access in rural areas of Oregon if the patient was already enrolled in hospice and they wanted to control their death.” Linda Ganzini, professor of psychiatry and medicine, Oregon Health & Science University.

In response to the evidence compiled across the authorized jurisdictions, several states have taken action to reduce barriers, while maintaining the same strict eligibility criteria:

- > **Regulations.** In Washington, D.C., where the Department of Health added additional regulations to those required by law, creating additional roadblocks for providers willing to participate in this medical practice and terminally ill individuals seeking this compassionate end-of-life care option, it took the first person a full year to access medical aid in dying.<sup>29, 30</sup> Peace of mind was finally granted after advocates and the Legislature put pressure on the Department of Health to drop these additional unnecessary regulations. Although it is still an overly cumbersome process, a few patients have been able to access the law.
- > **Waiting Period.** Based on 24 years of practice, the Oregon Legislature passed an important amendment to the law to find a better balance between safeguards intended to protect patients and access to medical aid in dying in 2019. As long as a written request is provided and the attending qualified clinician attests that the otherwise qualified individual is likely to die while waiting, the amendment gives doctors the ability to waive (1) the 15-day waiting period between the two required oral requests; and, (2) the 48-hour waiting period if they determine and attest that the patient is likely to die while waiting.<sup>31</sup> The amendment was a direct result of evidence and data that clearly demonstrated the need for easier access for eligible terminally ill patients facing imminent death. The Oregon Health Authority 2020 annual report 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.<sup>9</sup>

California recognized that waiting periods were posing an unnecessary barrier to terminally ill patients. In 2021, the legislature amended the California End of Life Option Act to decrease the waiting period between the two oral requests from 15 days to 48 hours.<sup>32</sup>

New Mexico requires just one written request; so, there is no waiting period related to requests. However, the law requires a 48-hour waiting period between receiving and filling a prescription for medical aid in dying medication, but allows a qualified clinician to waive the waiting period if a person is going to imminently die.

- > **Qualified Prescribing or Consulting Healthcare Providers.** New Mexico also expanded its definition of qualified provider to include advanced practice registered nurses (APRNs) and physician assistants (PAs), who may act as either the prescribing or consulting healthcare provider so long as a physician acts as the other provider.
- > **Mental Health Capacity.** Most of the states require a mandatory mental health evaluation by a psychiatrist or psychologist if either provider expresses concerns about capacity. In Vermont, New Jersey and Maine clinical social workers are also able to make the assessment, and in New Mexico, master social workers, psychiatric nurse practitioners, and professional clinical mental health counselors are also able to make the assessment. In Hawaii, the mental health evaluation is mandatory for all patients.

In 2019, just one year into implementation of the Hawai'i Our Care, Our Choice Act, the Department of Health's annual report to the Legislature found that some of the well-intentioned regulatory requirements outlined in the Our Care, Our Choice Act are creating unintended barriers for terminally ill patients in Hawaii. The 2019 report detailed that the 27 patients who died under the law endured an average waiting period of 34 days; one patient waited 100 days.<sup>33, 34</sup> Similarly, the Department's 2020 annual report detailed that the 32 patients who died under the law endured an average waiting period of 30 days; one patient waited 164 days.<sup>21</sup>

As part of both annual reports, the Department made two recommendations to the Legislature: 1) adopt an Oregon-style amendment allowing doctors to waive the waiting period for patients whose death is imminent; and, 2) give advanced practice registered nurses (APRNs) the authority to serve as attending providers under the law.<sup>21</sup> In 2021, lawmakers in Hawai'i introduced a bill based on the Department of Health's 2019 recommendations, this bill carried over to the 2022 session.

Some of the states considering legislation are also considering more streamlined approaches to reduce the burden on providers and terminally ill patients like reducing or eliminating the waiting period entirely, allowing nurse practitioners and physician assistants to participate, and ensuring greater clarity and transparency from healthcare providers and facilities.

# Section IV: State Reports on Utilization

Currently, public health departments in nine authorized jurisdictions have issued reports regarding the utilization of medical aid-in-dying laws: Oregon,<sup>9</sup> Washington,<sup>17</sup> Vermont,<sup>18</sup> California,<sup>19</sup> Colorado,<sup>20</sup> Hawai'i,<sup>21</sup> the District of Columbia,<sup>22</sup> Maine,<sup>23</sup> and New Jersey<sup>24</sup> Compassion & Choices has compiled annual report data from the authorized states that collect data.<sup>16</sup> Key highlights include:

- > For the past 25 years, starting with Oregon and across all jurisdictions, just 5,171 people have ingested a prescription to end their suffering. This represents far less than 1% of the people who die in each state.
- > One-third (33%) of people who go through the process and obtain the prescription never take it; however, they derived peace of mind from simply knowing that if their suffering became too great, they would have the option.
- > The vast majority of terminally ill people who use medical aid in dying — more than 86% — received hospice services at the time of their deaths, according to annual reports for which hospice data is available.
- > There is nearly equal utilization of medical aid in dying among men and women.
- > Terminal cancer accounts for the vast majority of qualifying diagnoses with neurodegenerative diseases, such as ALS or Huntington's disease, following as the second leading diagnosis.
- > Nearly 90% of people who use medical aid in dying are able to die at home, which is where most Americans would prefer to die, according to various studies.

All Authorized Jurisdictions (1998 – 2019)	Cumulative	
<b>Summary Data</b>		
Individuals who received prescriptions (prescriptions written or filled)	8,213	
Individuals who died after ingesting	5,171	
<b>Characteristics</b>		
<b>Sex</b>		
Female	2,909	48.3%
Male	3,112	51.6%
Unknown	8	0.1%
<b>Total</b>	<b>6,029</b>	<b>100%</b>

Race		
White	5,625	94.1%
Black	16	0.3%
Asian	140	2.3%
Indigenous American/Alaskan Native	3	0.1%
Hawaiin/Pacific Islander	5	0.1%
Other / Unknown	78	1.3%
Multi-Race (Two or more races)	13	0.2%
Latinx (Hispanic)	100	1.7%
Hispanic and/or Non-White (WA) <sup>1</sup>	32	0.5%
Total	5,980	100.0%
Age Breakdown (Oregon, Washington, Colorado, D.C.)		
18 – 54	340	7.9%
55 – 64	798	18.4%
65 – 74	1,349	31.2%
75 – 84	1,108	25.6%
85+	732	16.9%
Total	4,327	100.0%
Age Breakdown (California)		
Under 60	174	10.5%
60 – 69	369	22.2%
70 – 79	500	30.1%
80 – 89	400	24.1%
90+	219	13.2%
Total	1,662	100.0%

<sup>1</sup> Between the years of 2009-2013, the state of Washington reported its data on race as either “non-Hispanic white” or “Hispanic and/or non-white.” From the years of 2013-2018, the state reported “white,” “other,” and “unknown.” As such, the Washington data on race is limited in scope.

Age Breakdown (Maine)		
Under 65	0	0%
Over 65	1	100%
Total	1	100.0%
Education		
High School Diploma or GED or Less	1,519	25.3%
Some College	1,400	23.3%
Associate's Degree, Bachelor's Degree, Master's Degree, Doctorate or Professional Degree	3,020	50.3%
Unknown	66	1.1%
Total	6,005	100.0%
Hospice Care		
Enrolled	4,578	86.2%
Not Enrolled	494	9.3%
Unknown	159	3.0%
Not under hospice care OR unknown (Colorado)	82	1.5%
Total	5,313	100.0%
Insurance		
Private	1,285	27%
Medicare, Medicaid or Other Governmental	2,040	48%
Medicare with Another Type of Insurance (Unspecified)	775	6.1%
Combination of Private and Medicare / Medicaid	261	6.0%
Insured (Unspecified)	261	4.9%
None, Other, Unknown	735	12.9%
Total	4,355	100.0%

Underlying Illness		
Malignant Neoplasms (Cancer)	4,383	71.7%
Neurological Disease	701	11.5%
Respiratory Disease (e.g., COPD)	361	5.9%
Heart / Circulatory Disease / Cardiovascular	372	6.1%
Other illnesses	297	4.9%
Total	6,114	100.0%
Place of Death / Location Where Medication Ingested / Location of Patient		
Home / Private Home / Residence	4,359	89.9%
Assisted-Living Residence / Nursing Home / Long-term Care / Foster Care Facility	338	7.0%
In-Patient Hospice Residence	36	0.7%
Hospital / Other / Unknown	117	2.4%
Total	4,850	100%
Physician or Trained Healthcare Provider Present at Ingestion		
Prescribing Physician	366	8.5%
Attending Physician	322	7.5%
Other Physician	40	0.9%
Other Provider / Healthcare Provider	1,341	31.2%
Volunteer	98	2.3%
No Provider	564	13.1%
Unknown	1,566	36.4%
Total	4,297	100.0%

# Section V: The Truth About Medical Aid in Dying

When crafting medical aid-in-dying legislation, lawmakers no longer need to worry about hypothetical scenarios or anecdotal concerns. We now have close to 25 years of experience since the law was first enacted in Oregon and years of experience from the laws passed in the 10 other authorized jurisdictions. None of the dire predictions that opponents raised have come to fruition. In fact, there has never been a single substantiated case of misuse or abuse of the laws. The evidence confirms that medical aid-in-dying laws protect patients while offering a much-needed compassionate option. The following section addresses the most common inaccurate claims about medical aid in dying and sets the record straight.

## Medical Aid in Dying Is Not Euthanasia

Medical aid in dying is fundamentally different from euthanasia. Medical aid in dying is a medical practice by which a terminally ill, mentally capable person with a prognosis of six months or less chooses to request, obtain and — if their suffering becomes unbearable — take a medication that brings about a peaceful death. In all authorized jurisdictions, only the dying person can request an aid in dying prescription under the law and if and when they decide to ingest the medication, they must self-administer it themselves. Therefore, control stays with the patient from beginning to end.

In contrast, euthanasia, sometimes called “mercy killing,” is an intentional act by which another person (not the dying person) acts to cause death. Euthanasia is illegal throughout the United States and all medical aid-in-dying laws expressly prohibit euthanasia. Because our guiding value is patient autonomy, Compassion & Choices does not support authorizing euthanasia because it would allow someone else — not the dying person — to cause the death of another.

## Medical Aid in Dying Is Different From Suicide

Factually, legally and medically speaking, it is inaccurate to equate medical aid in dying with assisted suicide. In fact, The American Association of Suicidology emphatically states “aid in dying is distinct from the behavior that has been traditionally and ordinarily described as suicide.”<sup>35</sup> With medical aid in dying, the person is already going to die—medicine or treatment can not change that reality. Additionally those who qualify for medical aid in dying may already have the option to move more quickly to their deaths by refusing unwanted medical treatment, stopping life sustaining treatment, or voluntary stopping of eating and drinking (VSED). These options are not equated with suicide because, like medical aid in dying, they are processes supported at the end-of-life by healthcare systems. The terminally ill person who decides to utilize medical aid in dying is deciding not to prolong a difficult and often painful dying process. In contrast, suicide is preventable, provided that an individual can access appropriate suicide prevention resource. Equating medical aid in dying with suicide is irresponsible and does a disservice to people who need medical aid in dying and people impacted by suicide.

Additionally, from a legal perspective, the Oregon, Washington, Vermont, California, Colorado, Hawaii, New Jersey, Maine, New Mexico, and District of Columbia laws emphasize with the same or similar language that: “Actions taken in accordance with [the Act] shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law.” Assisting a suicide remains a felony in states where medical aid in dying is authorized. Saying “assisted suicide” inaccurately characterizes a legally authorized, legitimate medical practice as criminal activity under the law.

Opponents of medical aid in dying use the term “assisted suicide” in an attempt to discredit the legitimate practice of medical aid in dying. The American College of Legal Medicine filed an amicus brief before the United States Supreme Court in 1996 rejecting the term and adopted a resolution in 2008 in which they “publicly advocated the elimination of the word ‘suicide’ from the lexicon created by a mentally competent, though terminally ill, person who wishes to be aided in dying.”<sup>36</sup> Furthermore, the American Association of Suicidology asserts that the term “physician-assisted suicide” should not be used.<sup>37</sup>

“ I’m hoping to change the narrative when it comes to medical aid in dying. I want to remove the word ‘suicide’ from the conversation. I am NOT suicidal. I want to live. (I will) go through any and all treatments in order to stay alive for as long as possible ... (but) there is nothing wrong with wanting to have as peaceful a transition as possible. The dying process doesn’t have to be painful. It doesn’t have to be filled with suffering if that’s not what the person wants. Death, if you are able to, should be something that you have some say in — whatever that is.”

– Susan Rahn, Mother, Breast Cancer Patient and Medical Aid-in-Dying Advocate

## Medical Aid-in-Dying Laws Do Not Promote Suicide

There is no evidence that medical aid in dying impacts suicide rates and it is a vast mischaracterization of suicide as a public health issue to assign the increase in death by suicide in a state to medical aid in dying, when there is no data or formal study that proves this.

While there is no substantiated correlation between medical aid in dying and suicide, data shows that medical aid-in-dying laws improve end-of-life care in general and hospice and palliative care specifically. For example, Oregon’s medical aid-in-dying law has helped spur the state to lead the nation in hospice enrollment, according to a report published in the *New England Journal of Medicine*.<sup>6</sup> Additionally, according to Dr. Neil Wenger, director of the UCLA Health Ethics Center, the California medical aid-in-dying law “really has created a new standard for how we ought to be helping people at the end of life.”<sup>10</sup>

## Insurance Companies Do Not Deny Treatment Because Medical Aid in Dying Is an Available End-of-Life Option

There is no connection between the denial of expensive or experimental treatments and the coverage of medical aid in dying as an end-of-life care option. Insurance providers cover treatments that are deemed effective and proven, and they deny coverage for those considered unnecessary, experimental or below the standard of care. Sometimes insurance companies wrongly deny coverage for life-saving treatment. This fact is a harsh reality in every state, those that authorize medical aid in dying and those that do not.

Health insurers have no incentive to encourage medical aid in dying because the vast majority of people who choose medical aid in dying are enrolled in hospice care and no longer pursuing extensive or intensive treatment. Hospice enjoys nearly universal insurance coverage, and hospices have charitable funds to cover those who cannot pay. Medicare covers hospice services — as does Medicaid — with no lag or delay in payment, as with some other services.

People are only choosing medical aid in dying to shorten the very worst, very last part of the dying process. It is shortening a person's life by weeks and days, not months. A research article from the *New England Journal of Medicine* concludes insurers have no financial incentive to pressure patients to accelerate their deaths because there are no substantial cost savings.<sup>38</sup> The article was co-authored by an opponent of medical aid in dying more than 20 years ago, when use of relatively inexpensive hospice care was less frequent.

Furthermore, with the exception of New Mexico and Vermont, each of the laws in the authorized jurisdictions explicitly state that the obligations created by wills, contracts, insurance and annuity policies cannot be affected by a terminally ill individual's decision to request or use medical aid in dying. In other words, an individual is entitled to their existing benefits regardless of whether they use medical aid in dying.

A 2018 study published in the *Hastings Center Report* noted, "Financial pressure is much more likely to influence a decision to pursue or reject aggressive life-extending care than it is to influence a request for physician assisted death."<sup>39</sup> No one wants to leave their family destitute trying to extend an inevitable and irreversible dying process, but both research and experience confirm that worry about finances is not one of the key motivating factors that lead someone to request medical aid in dying.

## Providers Do Not Have an Incentive to Coerce Patients

Healthcare providers have no incentive to pressure or coerce their patients into requesting or using medical aid in dying. Often, providers will continue to offer treatment, even when the likelihood of a change in the individual's disease is extremely unlikely. Medical providers do not make more money from prescribing medical aid in dying for their eligible patients.

## Family Members Do Not Have an Incentive to Coerce Terminally Ill Loved Ones

The terminally ill individual who qualifies for medical aid in dying only has six months or less to live. It strains credulity to believe that a greedy relative would risk criminal prosecution and felony charges (i.e., losing everything rather than inheriting anything) when the person is already expected to die soon. Further, there have been no reports of such an occurrence in the over 20 years that Oregon's law has been in effect. The reality is, if someone who stood to inherit anything of value from a terminally ill individual wanted to hasten death, there are many ways to do so that involve far fewer safeguards and less legal liability: overmedicating, undermedicating, failing to bring the terminally ill person to medical appointments, neglecting the person's needs. Access to this option does not heighten the risk of abuse; it dissuades it.

Furthermore, when faced with the prospect of losing a loved one, family members and caregivers are far more likely to cling to patients in late-stage illness and demand that all measures be taken to prolong life.<sup>40</sup> In a large U.S. comprehensive cancer hospital study analyzing decision-making in lung cancer patients and caregivers reported that 65% of caregivers experienced treatment disagreements. The same study revealed that families and caregivers were less likely to agree with patient choices regarding decisions to discontinue therapeutic treatments or do not attempt resuscitation (DNAR) status. Another study published in the *Journal of Clinical Ethics* revealed that many caregivers note that their main focus is to keep the patient alive, and that regardless of severe treatment side effects, any treatment is better than none at all.<sup>41</sup>

## Patients Have Various Options for Taking the Medication

The type and dosage of aid-in-dying medication the doctor prescribes for the terminally ill person can vary with each individual. Just like there is not just one blood pressure medicine, there is not just one medication for medical aid in dying. Historically, prescriptions for medical aid in dying involved three separate medications: two to speed absorption and prevent nausea, followed by a short-acting barbiturate. However, as science and technology continue to advance, and due to market-driven variations in the costs and availability of drugs over time, several medications and combinations of medications have been developed and are now successfully used in aid-in-dying prescriptions. Today the most commonly prescribed is a compounded mixture of digoxin, diazepam, morphine sulfate, amitriptyline and phenobarbital.

In practice, the doctor, pharmacist and patient determine whether the medication should be prescribed as a powder or as a pre-prepared solution. If dispensed in powder form, the medication is mixed together with approximately 4 ounces of liquid and ingested by the terminally ill individual.

Once the prescription has been filled, the terminally ill person can choose to take the medication. The individual usually falls asleep within 10 minutes. Respiration slows over the course of an hour or two, then stops, and the individual dies peacefully in their sleep.

Intravenous (IV) administration and parenteral injection (an injection under the skin) or infusion (insertion into the vein) of aid-in-dying medication by any person, including the doctor, family member or patient themselves, is explicitly prohibited in each of the laws.

## Accidental Overdose by a Third Party Has Never Happened and Is Highly Unlikely

There is little to no chance of an accidental overdose attributable to aid-in-dying medication — the medication requires a high dosage to work and is bitter to the point of near-intolerance (particularly without the preparatory medication). One is far more likely to overdose on common over-the-counter medications like cough syrup or the many potentially lethal medications one is often prescribed at the end of life, such as morphine. Not surprisingly, in more than 20 years of experience since the Oregon law was implemented, there has never been a reported case of an accidental overdose from ingesting aid-in-dying medication.

## Medical Aid-in-Dying Medication Is Safely Disposed of

In decades of combined experience since Oregon became the first of 11 jurisdictions to authorize medical aid in dying, there has never been a single incident of abuse, diversion or misuse of aid-in-dying medications.

Aid-in-dying medication is rarely dispensed unless concrete plans to take it are in place. In instances when aid-in-dying medication is dispensed but remains unused when the person dies, medication is to be disposed of according to guidelines [established by the Drug Enforcement Agency](#), and as required under state statute. Information on how to dispose of medication can be found on the DEA website or on the [The National Association of Boards of Pharmacy website](#).

If hospice is involved, hospice can dispose of it just as they do with all unused sedatives and pain medications, many of which are also controlled substances that are potent and hazardous drugs. If hospice is not involved, pharmacists often ask that unused opioids and sedatives be returned to them or a state-approved prescription drug take-back program for disposal.

## The Death Certificates Protocol for Medical Aid in Dying Is Consistent With Other End-of-Life Options

Death certificates for medical aid in dying are filled out to be compliant with guidelines provided by the Centers for Disease Control and Prevention (CDC). When a terminally ill person dies using medical aid in dying, the underlying terminal disease (e.g. cancer, ALS) is listed as the cause of death. It's critical that the disease that caused the death is listed and not the mechanism as the purpose of the death certificate is to track and understand trends in diseases. As an example, if a person has a stroke and is put on a ventilator that is subsequently removed, the doctor lists "stroke" as the cause of death not "disconnecting the ventilator" or "suffocation." Likewise, when palliative sedation is administered by a doctor to a person with cancer, the cause of death is listed as cancer and not a "physician-administered drug overdose."

Because public health officials use death certificates to compile data on various statistics, including leading causes of death, and report that data to the National Center for Health Statistics based upon the International Classification of Diseases (ICD), it is essential that the doctors list the underlying terminal disease. Listing medical aid in dying — or suicide — rather than the underlying terminal disease is in violation of CDC guidelines, would sabotage the purpose of death certificates and would skew data collection designed to improve healthcare. Doctors who are willing to provide medical aid in dying understand this distinction. Those people who feel that medical aid in dying conflicts with their personal values and beliefs are not required to participate in the practice.

## Section VI: The Growing Movement

In recent years, public demand for this end-of-life care option has grown. As a result, the medical community and lawmakers are recognizing the value and importance of expanding end-of-life options by authorizing medical aid in dying, dropping their opposition to it, adopting supportive policies and passing laws to authorize the practice. During the 2020 legislative session, nearly 400 individual elected officials put their names on bills as sponsors or co-sponsors in at least 16 legislatures. These bills were proposed in every region of the country. Six states and Washington, DC, have authorized medical aid in dying in the last seven years. In contrast, it took 19 years for the first four states to authorize this option. The movement's momentum is evident.

### Public Support for Medical Aid in Dying as an End-of-Life Care Option

Numerous public opinion polling from a variety of sources, both nationally and at the state level, demonstrates that the American public consistently supports medical aid in dying, with majority support among nearly every demographic group. A 2020 Gallup poll reported that 61% of voters support medical aid in dying. The authors of the survey noted, "a majority have consistently favored doctor-assisted suicide since Gallup first asked about it in 1996."<sup>42</sup>

### Majority Support Among Diverse Groups

This broad support spans nearly every demographic, from age to ethnic group, and from religious to political affiliation. In 2016, LifeWay Research, a historically conservative, christian research organization, released a survey that concluded national support for medical aid in dying stood at 67%.<sup>43</sup> The survey also demonstrated that majority support spanned a variety of demographic groups, including white Americans (71%), Hispanic Americans (69%), more than half of black, non-Hispanic Americans (53%); adults aged 18 to 24 (77%), 35 to 44 (63%) and 55 to 64 (64%); with some college education (71%), with graduate degrees (73%) and with high school diploma or less (61%). Majority support also included Christians (59%), Catholics (70%), Protestants (53%), those of other religions (70%) and those who identified as nonreligious (84%).

Six national Latinx organizations have adopted supportive policies on medical aid in dying:

- > Dolores Huerta Foundation<sup>44, 45</sup>
- > Hispanic Health Network<sup>46</sup>
- > Latino Commission on AIDS<sup>47</sup>
- > Latinos for Healthcare Equity<sup>48</sup>
- > National Hispanic Council on Aging<sup>49</sup>
- > Nuestra Salud<sup>50</sup>

These endorsements have all come in the past four years and represent a growing recognition that Latinx constituents support this option and that the laws, as written, protect vulnerable patients.

Additionally, prominent leaders in the African American community are endorsing medical aid in dying. In 2016, medical aid in dying was authorized in Washington, D.C., with the support of all but one member of the predominantly black city council and a black mayor.<sup>51</sup> Supporters include the late Maryland Congressman Elijah Cummings, the first African American to be named speaker pro tem in the Maryland House of Delegates, and Maryland Congressman Anthony G. Brown, formerly Maryland's lieutenant governor. In addition, Dr. Benjamin F. Chavis, President and CEO of the National Newspaper Publishers Association and Dr. Jeff Gardere, psychologist and ordained minister, publicly endorse and advocate for medical aid in dying.

"I have experienced the loss of far too many people ... some of whom suffered for months knowing they were about to die," wrote Rep. Cummings in a letter.<sup>52</sup> "[T]here are those among us whose conscience can never accept that any person should have the right to choose the manner and timing of their passing [but] at the end of life, an individual's right to self-determination about one of the most personal decisions that anyone could make supersedes the moral sensibilities of others."

“ Dying is part of life ... And since dying is part of life, talking about it shouldn't be taboo. People should die a decent death. For me that means having had the conversations with those I have crossed in life and being at peace. It means being able to say goodbye to loved ones — if possible, at home.”

– Archbishop Desmond Tutu

## Medical Ethical Considerations

Among U.S. physicians, support for medical aid in dying is also strong. 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. Today, 55% of physicians surveyed endorse the idea of medical aid in dying, agreeing that “Physician assisted death should be allowed for terminally ill patients.”<sup>53</sup>

Over the past six years, 30 national and state medical and professional associations have endorsed or dropped their opposition to medical aid in dying in response to growing support for this palliative care option among qualified clinicians and the public.

Six national medical organizations have taken positions supporting medical aid in dying:

- American College of Legal Medicine<sup>54</sup>

- > American Medical Student Association<sup>55</sup>
- > American Medical Women’s Association<sup>56</sup>
- > American Public Health Association<sup>57</sup>
- > GLMA: Healthcare Professionals Advancing LGBT Equality<sup>58</sup>
- > National Student Nurses’ Association<sup>50</sup>

Six national medical organizations have adopted neutral positions:

- > American Academy of Family Physicians<sup>60</sup>
- > American Academy of Neurology<sup>61</sup>
- > American Academy of Hospice and Palliative Medicine<sup>62</sup>
- > American Nurses Association<sup>63</sup>
- > American Pharmacists Association<sup>64</sup>
- > American Society for Health System Pharmacists<sup>65</sup>
- > National Association of Social Workers<sup>66</sup>

Medical associations in many of the authorized jurisdictions currently have neutral positions on medical aid in dying, including Oregon,<sup>67</sup> California,<sup>68</sup> Colorado,<sup>69</sup> Vermont,<sup>70</sup> Hawai’i,<sup>71</sup> and Maine.<sup>72</sup> Six other state medical societies and a handful of component societies from nonauthorized states have also recently dropped their opposition.<sup>73, 74, 75, 76, 77, 78, 79</sup>

There is growing recognition within the medical profession that patients want, need and deserve this compassionate option at the end of life; and this growing recognition is burgeoning into collaboration. As more jurisdictions authorize medical aid in dying, the medical community is coming together, and providers are sharing their experiences and fine-tuning their collaborative efforts to better serve dying patients.

## Support From Other Organizations

In addition to the national medical and Latino organizations that have endorsed medical aid in dying noted above, the Coalition for Liberty and Justice, the Libertarian Party, the Older Women’s League, and SAGE, a national organization that provides services and advocacy for LGBT elders, have all endorsed medical aid in dying on a national level.

Because this issue is primarily being advanced at the state level, often it is state — not national — organizations that take a position. At the state level, we enjoy support or engaged neutrality from hundreds of organizations. When organizations have a position of engaged neutrality, they have decided to not oppose medical aid in dying. Rather, their membership base has decided

to continue considering and developing their position on the matter for the time being. This support varies significantly by state and grows weekly but includes:

- > Bar Associations – California,<sup>80</sup> Connecticut<sup>81</sup>
- > American Civil Liberties Union – California,<sup>82</sup> Connecticut,<sup>83</sup> Washington, DC,<sup>84</sup> Maine,<sup>85</sup> Massachusetts,<sup>86</sup> Maryland,<sup>87</sup> New Jersey,<sup>88</sup> New York<sup>89</sup>
- > American Federation of State, County and Municipal Employees – California<sup>90</sup>
- > The Arc – New York<sup>91</sup>
- > Disability Rights Oregon,<sup>4</sup> New Mexico,<sup>92</sup> Utah<sup>93</sup>
- > Equality California<sup>94</sup>
- > Gay and Lesbian Activist Alliance – D.C.<sup>95</sup>
- > League of Women Voters – Maryland,<sup>96</sup> New York,<sup>97</sup> Utah<sup>98</sup>
- > National Association of Social Workers – California,<sup>99</sup> Connecticut,<sup>100</sup> Massachusetts,<sup>101</sup> New Jersey,<sup>102</sup> New Mexico<sup>103</sup>
- > United Church of Christ – Central Atlantic Conference (D.C., Delaware, New Jersey, Maryland)<sup>104</sup>
- > United Methodist Church – California-Pacific<sup>105</sup>
- > Unitarian Universalist Church – Maryland<sup>106</sup>

## Impact of Public Political Support

As noted above, public opinion data demonstrates wide public support for medical aid in dying, and voters are rewarding lawmakers who advance this compassionate end-of-life care option by reelecting them. In fact, the vast majority of primary bill sponsors in 2019 and 2020 who introduced medical aid in dying legislation won re-election — incumbent bill sponsors had a 95% reelection rate in the primary and a 95% reelection rate in the general election.

## Section VII: About Compassion & Choices

Compassion & Choices is the oldest and largest national organization committed to improving care and expanding options at the end of life. We have hundreds of thousands of supporters across the country. Last fiscal year, our annual budget was nearly \$20 million dollars, which was spent to improve end-of-life care and choice across the country. Our funding comes almost exclusively from the generosity of individuals and family foundations.<sup>107</sup> Last fiscal year, more than 35,000 individual donors contributed to our work, with more than 22,000 contributing less than \$100. We receive virtually no corporate support, with the exception of pro bono services provided by law firms that litigate court cases to advance our mission. We are a grassroots movement, the progress of which is the result of individuals experiencing unnecessary suffering at life's end, demanding care and seeking policies that better reflect their values and priorities.

## Section VIII: Conclusion

Decisions about death belong to the dying, and good public policy enables them to engage in open conversations with their doctors, their loved ones, and their faith or spiritual leaders about their physical and spiritual needs at the end of life. Without the explicitly authorized option of medical aid in dying, people nearing the end of life are unable to access medical aid in dying without putting their providers and family members at risk of prosecution.

With more than 20 years of experience since the first law was enacted and an additional 40+ years of combined experience from the laws passed since demonstrate that medical aid-in-dying laws protect patients, provides an option for the many constituents who believe that each person should have the ability to decide for themselves how much suffering they endure. Allowing this legislation to become law will bring peace of mind to residents at or near the end of their lives. Furthermore, the cost of inaction is high.

Terminally ill individuals:

- > May not try that one last miracle treatment out of fear the treatment will be too painful
- > May choose violent means to end their suffering, rather than this compassionate option
- > Are being deprived of the peace of mind that comes with knowing they can end their suffering if it becomes too great
- > Will experience needless agony when they die ... while families and doctors remain powerless with no legal way to respond to pleas for help.

Furthermore, society also fails to gain from the benefits that occur with medical aid in dying implementation including:

- > Better conversations between doctors and patients
- > Better palliative care training
- > Better hospice usage

Your state can realize these benefits for terminally ill individuals and their families right now by joining the growing number of jurisdictions that authorize this compassionate option.

The debate quite simply comes down to who decides and who is in a better position to ensure that compassion guides the care a patient receives at the end of life: the terminally ill patient in consultation with their doctor and loved ones, or the government?

We urge you to review the evidence, experience, data and strong public support for this end-of-life care option to guide your policymaking.

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