

## Medical Aid in Dying:

## A Policy to Improve Care and Expand Options at Life's End

2023 Edition



#### January 2023

Nearly 30 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, 6,378 terminally ill people have used this compassionate option. There hasn't been a single documented incident of coercion or abuse. More and more people are understanding why it is crucial that everyone across the country has access to this end-of-life option.

During these past three 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 appropriate care and comfort, and the limits of modern medicine to relieve suffering at life's end. It has reinforced the need for lawmakers to pass medical aid-in-dying legislation so terminally ill individuals 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 six years (2015-2021).

We now have 25 years of data since Oregon implemented its law in 1997 and years of experience from 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 almost nothing to implement.

On behalf of our hundreds of thousands of supporters I urge you to let the evidence, data and strong public support for this end-of-life care option guide you. People nationwide are calling for medical aid in dying to be authorized this year.

Terminally ill people need the relief that this law affords them right now. Not a single additional person will die if medical aid in dying is authorized, but fewer will suffer.

Sincerely,

Kim Callinan

President and CEO

Compassion & Choices

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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.

Medical aid in dying is the preferred term for the end-of-life care option by which a mentally capable, terminally ill adult with six months or less to live requests a prescription from their healthcare provider for medication that they can choose to self-ingest if their suffering becomes unbearable. Authorizing medical aid in dying provides terminally ill individuals with an additional end-of-life care option that aligns with their values and priorities.

We recognize that medical aid in dying can seem like a complex issue, but with 25 years of experience since the law was first enacted in Oregon and years of experience from the other authorized jurisdictions, this compassionate option has 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-supported 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 sound legislation.

We thank you for recognizing that this popular nonpartisan 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 healthcare 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 law 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.
- > 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 injection or infusion via a vein or any other parenteral route 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 healthcare 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 healthcare provider must inform the terminally ill adult requesting medical aid in dying that they can change their mind at any time. This patient's 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.

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<sup>&</sup>lt;sup>1</sup> Clinical Criteria for Physician Aid in Dying. Journal of Palliative Medicine; D. Orentlicher, T.M. Pope, B.A. Rich, (2015). Available from: <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4779271/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4779271/</a>

### 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. Jurisdictions' regulatory and procedural requirements are slightly different, but each requires that:

- > The terminally ill adult must make at least one request to their attending healthcare provider.
- > The written request must be witnessed by at least one person, who cannot be a relative or someone who stands to benefit from the person's estate upon their death.

Further, at least one healthcare 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 healthcare provider writing a prescription. If an attending healthcare 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 capable of making a rational and informed healthcare decision.

### **Voluntary Participation**

Each law also ensures 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. In other words, if a provider is unable or unwilling to honor a patient's request, they can opt-out and do not have to support the patient in this option.

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 alternate provider if their regular provider(s) opt out or cannot support them in the care option. Generally, if the individual requests that their provider transfer their medical records to an alternate provider, their provider is legally required to do so within a reasonable amount of time.

The laws ensure that there is no risk for healthcare providers who choose to participate (or not to participate) under the law. The laws provide explicit authorization for qualified healthcare providers to participate in the practice of medical aid in dying. The laws protect both those qualified healthcare providers 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 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 jurisdictions 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 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>2,3</sup> Additionally, a 2022 sample of Colorado physicians showed that many physicians are both willing and prepared to discuss medical aid in dying with patients and to provide referrals.<sup>4</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>5</sup>

### Relatively Few Will Use Medical Aid in Dying, But Many Benefit From These Laws

The use of medical aid in dying, by eligible terminally ill people, 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 the jurisdictions that have already authorized medical aid in dying, for example, people report significant relief from worry about future physical and emotional pain just from knowing the

<sup>&</sup>lt;sup>2</sup> A History of the Law of Assisted Dying in the United States. SMU Law Review, A. Meisel, (2019). Available from: <a href="https://scholar.smu.edu/cgi/viewcontent.cgi?article=4837&context=smulr">https://scholar.smu.edu/cgi/viewcontent.cgi?article=4837&context=smulr</a>

<sup>&</sup>lt;sup>3</sup> Rutgers Study Examines Who Uses Medical Aid in Dying. Rutgers University, Smith, A. (2022) Available from: <a href="https://www.rutgers.edu/news/medical-aid-dying-maid-mostly-used-well-educated-white-patients-cancer">https://www.rutgers.edu/news/medical-aid-dying-maid-mostly-used-well-educated-white-patients-cancer</a>

<sup>&</sup>lt;sup>4</sup> Physicians' Attitudes and Experiences with Medical Aid in Dying in Colorado: a "Hidden Population" Survey.Campbell EG, Kini V, Ressalam J, Mosley BS, Bolcic-Jankovic D, Lum HD, Kessler ER, DeCamp M. (2022) Available from: <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8751472/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8751472/</a>

<sup>&</sup>lt;sup>5</sup> Physician-Assisted Suicide: Considering the Evidence, Existential Distress, and an Emerging Role for Psychiatry. Journal of the American Academy of Psychiatry and the Law. Gopal, AA. 2015. Vol 43(2): 183-190. Available from <a href="http://iaapl.org/content/43/2/183">http://iaapl.org/content/43/2/183</a>.

option is there should they need it, regardless of whether or not they choose to pursue it. 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 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. 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>8</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. "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, in fact, reported an increase in referrals following passage of the Oregon Death With Dignity Act.<sup>10</sup> Over 20 years later, more than 90% of those who used medical aid in dying were receiving hospice services at the time of their death.<sup>11</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:

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<sup>&</sup>lt;sup>6</sup> Lessons from Oregon in Embracing Complexity in End-of-Life Care. New England Journal of Medicine, S.W. Tolle, MD, J.M. Teno, MD, (2017). Available from: <a href="https://www.nejm.org/doi/10.1056/NEJMsb1612511">https://www.nejm.org/doi/10.1056/NEJMsb1612511</a>

<sup>&</sup>lt;sup>7</sup> Oregon's Assisted Suicide Vote: The Silver Lining. Annals of Internal Medicine, M.A. Lee, S.W. Tolle, (1996). Available from:

https://www.acpjournals.org/doi/10.7326/0003-4819-124-2-199601150-00014?url\_ver=Z39.88-2003&rfr\_id=ori:rid:cr\_ossref.org&rfr\_dat=cr\_pub%20%200pubmed

<sup>&</sup>lt;sup>8</sup> Oregon Physicians' Attitudes About and Experiences With End-of-Life Care Since Passage of the Oregon Death with Dignity Act. JAMA. L. Ganzini, H.D. Nelson, M.A. Lee, D.F. Kraemer, T.A. Schmidt, M.A. Delorit, (2001). Available from: <a href="https://pubmed.ncbi.nlm.nih.gov/11343484/">https://pubmed.ncbi.nlm.nih.gov/11343484/</a>

<sup>&</sup>lt;sup>9</sup> Geographic Variation of Hospice Use Patterns at the End of Life. Journal of Palliative Medicine, S.Y. Wang, M.D., Aldridge, C.P. Gross, et al. (2015). Available from: <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4696438/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4696438/</a>

Oregon Death with Dignity Act. Annual Report, (2021). Available from: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYA CT/Documents/year24.pdf



# The [California] End of Life Options Act really has created a new standard for how we ought to be helping people at the end of life."<sup>12</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 reiterated during the California Select Committee's second hearing on February 25, 2020.<sup>13</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 and palliative medicine, many patients experience pain at the end of life. One study found that the prevalence of pain increases significantly at the end of life, jumping from 26% in the last 24 months of life to 46% in the last four months of life.<sup>14</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, 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>15</sup>

For some people the side effects of pain medication (sedation, nausea, obstructed bowels) are just as bad as the pain from the disease. Numerous agonies simply cannot be controlled or relieved unless a person is willing to be sedated to complete and deep unconsciousness. Even

<sup>&</sup>lt;sup>12</sup> There's an Unforeseen Benefit to California's Physician-Assisted Death Law. Los Angeles Times, (2017). Available from: <a href="https://www.latimes.com/health/la-me-end-of-life-care-20170821-htmlstory.html">https://www.latimes.com/health/la-me-end-of-life-care-20170821-htmlstory.html</a>

<sup>&</sup>lt;sup>13</sup> California Assembly Select Committee on End of Life Health Care, Wednesday, January 24, 2018 and Tuesday, February 25th, 2020. Available from:

https://www.assembly.ca.gov/media/select-committee-end-life-health-care-20180124/video and https://www.assembly.ca.gov/media/assembly-select-committee-end-life-health-care-20200225/video

<sup>&</sup>lt;sup>14</sup> The Epidemiology of Pain During the Last 2 Years of Life. The Annals of Internal Medicine, A.K. Smith, I.S. Cenzer, S.J. Knight, K.A. Puntillo, E. Widera, B.A. Williams, W.J. Boscardin, K.E. Covinsky, (2010.) Available from: <a href="http://annals.org/aim/article/746344/epidemiology-pain-during-last-2-years-life">http://annals.org/aim/article/746344/epidemiology-pain-during-last-2-years-life</a>

<sup>&</sup>lt;sup>15</sup> Impact of breakthrough pain on community-dwelling cancer patients: results from the National Breakthrough Pain Study. Katz, N.P, Gajria, K.L, Shillington, A.C., et. al. (2016). Postgraduate Medicine, 129(1), 32-39. Available from: <a href="https://pubmed.ncbi.nlm.nih.gov/27846789/">https://pubmed.ncbi.nlm.nih.gov/27846789/</a>

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 people is that they 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 in addition to 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>16</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 constitutes 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>17</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 healthcare provider and loved ones, as it should be for such a deeply personal healthcare decision.

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<sup>&</sup>lt;sup>16</sup> Al Rabadi L, LeBlanc M, Bucy T, et al. *Trends in medical aid in dying in Oregon and Washington*. JAMA Network Open. 2019;2:1-7. Available from: <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6692681/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6692681/</a>

<sup>17</sup> Oregon Death with Dignity Act. Annual Report, (2021). Available from: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf



The last time I saw my partner, Jack, I could tell he was in so much pain despite the excellent hospice care he was receiving. I remember crying and Jack crying a little too. Jack was dying, imminently. There was no stopping that. But those final moments between us didn't have to be wracked with pain. Jack could have avoided days of suffering if medical aid in dying were an option available to him. Instead, Jack suffered during his last days on earth. For what? I know that if I were in Jack's shoes, with a terminal illness like cirrhosis of the liver, I would want the same option for myself. As someone living with a disability, I believe I should get to make my own decisions about what kind of medical care I receive when I reach the end of my life. No one else should get to make that decision."

- Verna O'Brien, Illinois advocate for medical aid in dying

# People Choose Medical Aid in Dying as well as Hospice and Palliative Care

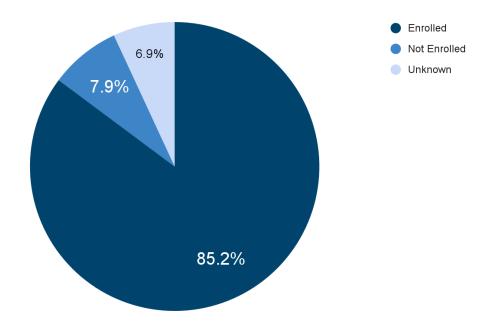
The majority of individuals who request and obtain aid-in-dying medication are enrolled in hospice services at the time of their death.<sup>18</sup>

Good hospice services and palliative care do not eliminate the need for medical aid in dying as an end-of-life care option. They are not mutually exclusive. 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 they 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.

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<sup>&</sup>lt;sup>18</sup> Medical Aid-in-Dying Data Across Authorized States, 2023. Compassion & Choices. Available from: https://compassionandchoices.org/docs/default-source/default-document-library/medical\_aid\_in\_dying\_utilization\_report\_12-13-2022.pdf?sfvrsn=697faeca\_2

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



\*This graph reflects data from all jurisdictions that report on hospice use. Currently, public health departments in nine authorized jurisdictions have issued reports regarding the use of medical aid-in-dying laws: Oregon, <sup>19</sup> Washington<sup>20</sup>, Vermont<sup>21</sup>, California<sup>22</sup>, Hawai'i<sup>23</sup>, the District of Columbia<sup>24</sup>, Maine<sup>25</sup> and New Jersey<sup>26</sup>. More detailed reports can be provided upon request. Vermont, Washington, D.C., New Jersey, and Maine do not provide this data on hospice utilization in their reports on medical aid in dying. The data excludes Colorado<sup>27</sup>, as they report those who are not

<sup>&</sup>lt;sup>19</sup> Oregon Death with Dignity Act. Annual Report, (2021). Available from: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf

Washington Death with Dignity Act Annual Report (2020). Available from: <a href="https://doh.wa.gov/sites/default/files/2022-02/422-109-DeathWithDignityAct2020.pdf?uid=63463231758e3">https://doh.wa.gov/sites/default/files/2022-02/422-109-DeathWithDignityAct2020.pdf?uid=63463231758e3</a>

<sup>&</sup>lt;sup>21</sup> Vermont Patient Choice at the End of Life Data Report (2020). Available from:

https://legislature.vermont.gov/assets/Legislative-Reports/2020-Patient-Choice-Legislative-Report-2.0.pdf

<sup>22</sup> California End of Life Option Act Annual Report (2021). Available from:

https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/CDPH End of Life%20 Option Act Report 2021\_FINAL.pdf

Hawai'i Our Care, Our Choice Act Annual Report (2020). Available from: <a href="https://health.hawaii.gov/opppd/files/2020/01/OPPPD-Our-Care-Our-Choice-Act-Annual-Report-2019-1.pdf">https://health.hawaii.gov/opppd/files/2020/01/OPPPD-Our-Care-Our-Choice-Act-Annual-Report-2019-1.pdf</a>

<sup>&</sup>lt;sup>24</sup> District of Columbia Death with Dignity Act Annual Report. (2019). Available from: https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page content/attachments/DWD%20Report%202018%20Fin al%20%20%208-2-2019.pdf

<sup>&</sup>lt;sup>25</sup> Maine Death with Dignity Act Annual Report (2021). Available from: https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/inline-files/Patient-Directed%20Care%20%28Death%20with %20Dignity%29%20Annual%20Report%20--%204-2021.pdf

<sup>&</sup>lt;sup>26</sup> New Jersey Medical Aid in Dying for the Terminally III Act 2021 Data Summary Report (2021). Available from: https://nj.gov/health/advancedirective/documents/maid/2021.pdf

<sup>&</sup>lt;sup>27</sup> Colorado End of Life Options Act Annual Report (2020). Available from: https://cdphe.colorado.gov/center-for-health-and-environmental-data/registries-and-vital-statistics/medical-aid-in-dying https://drive.google.com/file/d/1FmoyCcL2gHopDO9rCJ2lGFEMUye8FQei/view

under hospice care and those whose hospice use is unknown as one aggregated category. Montana authorized medical aid in dying through a court case, and a data report is not required by law.

### Patients Involve Their Loved Ones in the Decision

The 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>28</sup>

### The Oregon Model Has Too Many Regulatory Requirements

The current Oregon model, which laid the foundation for all of the other authorized jurisdictions, requires a lengthy multistep 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 prognosis, 85% overestimated the length of time somebody would live.<sup>29</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

<sup>29</sup> Palliative Care Clinician Overestimation of Survival in Advanced Cancer: Disparities and Association with End-of-Life Care. Gramling, Robert, Gajary-Coots, Elizabeth, Cimino, Jenica, et. al. Journal of Pain and Symptom Management, 2019: 58(4), e19-e20. Available from: <a href="https://www.sciencedirect.com/science/article/abs/pii/S0885392418310571">https://www.sciencedirect.com/science/article/abs/pii/S0885392418310571</a>.

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<sup>&</sup>lt;sup>28</sup> Oregon Death with Dignity Act. Annual Report, (2021). Available from: <a href="https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf">https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf</a>

"participation" under the act, as is argued in a New Jersey lawsuit.<sup>30</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 people through the process.<sup>31</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 confirmed, "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." 32
- > 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>33</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 within their own health system ... ." "The process takes time, and 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.

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

<sup>&</sup>lt;sup>30</sup> Fourth Amended Complaint at 4, *Petro v. Grewal* (Super. Ct. N.J. 2020) (No. Mer-C-53-19). Available from: <a href="https://compassionandchoices.org/docs/default-source/new-jersey/fourth-amended-verified-complaint-for-injunctive-and-declaratory-relief.pdf">https://compassionandchoices.org/docs/default-source/new-jersey/fourth-amended-verified-complaint-for-injunctive-and-declaratory-relief.pdf</a>

<sup>&</sup>lt;sup>31</sup> Characterizing Kaiser Permanente Southern California's Experience With the California End of Life Option Act in the First Year of Implementation. JAMA Internal Medicine, H.Q. Nguyen, E.J. Gelman, T.A. Bush, J.S. Lee, M.H. Kanter (2018). Available from: <a href="https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2665731">https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2665731</a>

<sup>&</sup>lt;sup>32</sup> Letter from Disability Rights Oregon. Executive Director, Bob Joondeph, (2019). Available from: https://compassionandchoices.org/letter-from-disability-rights-oregon-dro/

<sup>&</sup>lt;sup>33</sup> Physician-Assisted Death: Scanning the Landscape:Proceedings of a Workshop. National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Health Sciences Policy, R.A. English, C.T. Liverman, C.M. Cilio, J. Alper, Rapporteurs (2018). Available from: <a href="https://www.nap.edu/catalog/25131/physician-assisted-death-scanning-the-landscape-proceedings-of-a-workshop">https://www.nap.edu/catalog/25131/physician-assisted-death-scanning-the-landscape-proceedings-of-a-workshop</a>

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.

- "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 ..." 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.
- "Terminally ill individuals and their informal caregivers who have attempted to access DWD (death with dignity) do report barriers to participation. The most common barrier is the lack of participation of clinicians and institutions, including hospitals, hospices and clinics. Other common barriers included the cost of DWD medications, the waiting period(s) and the logistics of identifying willing physicians."<sup>34</sup> Report to the Washington State Legislature, Barriers to Death with Dignity in Washington State.

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

> Regulations. In Washington, D.C., the Department of Health developed administrative regulations that proved to be burdensome for providers willing to participate in this medical practice and terminally ill people seeking this compassionate end-of-life care

 $\frac{https://compassion and choices. site finity. cloud/docs/default-source/washington/barriers-to-death-with-dignity-legislative-report-2022.pdf$ 

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<sup>&</sup>lt;sup>34</sup> Report to the Washington State Legislature: Barriers to Death with Dignity in Washington State (2022). Available from:

- option. As a result, it took the first person months to access medical aid in dying.<sup>35, 36</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.
- Vermont's medical aid-in-dying law by passing legislation in 2022. The law now allows patients to use telehealth to request access to medical aid in dying, clearly states that all medical professionals are protected when acting in good faith under the law and removes the 48-hour wait between when the patient makes their final request to when the physician can write the prescription. These three important changes will allow eligible terminally ill adults to more easily access the law. The bill received bipartisan support, including being signed into law by Governor Scott.
- > Waiting Period. Based on 25 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>37</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 annual reports in the years after the amendment show that 20% (2020) and 21% (2021) of patients required a physician exemption in order to make it through the process.<sup>3839</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>40</sup>

<sup>&</sup>lt;sup>35</sup> DC Patients Unable to Use Aid-in-Dying Law as Paperwork Jams. WUSA9 (2018). Available from: https://www.wusa9.com/article/news/local/dc-patients-unable-to-use-aid-in-dying-law-as-paperwork-jams/65-536026 208

<sup>&</sup>lt;sup>36</sup> She Fought Cancer and Congress for D.C.'s Right-to-Die Law. Would She be Able to Use it? Washington Post (2018). Available from:

 $<sup>\</sup>frac{https://www.washingtonpost.com/local/dc-politics/she-fought-cancer-and-congress-for-dcs-right-to-die-law-would-she-be-able-to-use-it/2018/12/25/bd77476a-cbe0-11e8-a360-85875bac0b1f_story.html?utm_term=.9f9e6a75a020$ 

<sup>&</sup>lt;sup>37</sup> Senate Bill 579, 80th Oregon Legislative Assembly—2019 Regular Session. Available from: https://olis.oregonlegislature.gov/liz/2019R1/Downloads/MeasureDocument/SB579

Oregon Death with Dignity Act, Annual Report (2020) Available from: <a href="https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year23.pdf">https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year23.pdf</a>

<sup>&</sup>lt;sup>39</sup> Oregon Death with Dignity Act. Annual Report, (2021). Available from: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYA CT/Documents/year24.pdf

<sup>&</sup>lt;sup>40</sup> California SB 380 End of Life Option Act. Enacted October 2021. Available from <a href="https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill\_id=202120220SB380">https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill\_id=202120220SB380</a>

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. Additionally, New Mexico does not require confirmation of eligibility for medical aid in dying by a consulting provider if the person is enrolled in a medicare-certified hospice program.
- > Mental Health Capacity. Most of the jurisdictions 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.

For the last three years, Hawaii's Department of Health's annual report to the Legislature has repeatedly found that some of the well-intentioned regulatory requirements outlined in the Our Care, Our Choice Act create unintended barriers for terminally ill patients. The latest report from 2021 detailed that the 49 patients who died under the law endured an average waiting period of 41 days. <sup>41</sup>

As part of all three 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>39</sup>

Some of the jurisdictions 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.

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<sup>&</sup>lt;sup>41</sup> Hawaiʻi Our Care, Our Choice Act Annual Report (2021). Available from: https://health.hawaii.gov/opppd/files/2022/07/corrected-MAID-2021-Annual-Report.pdf

# **Section IV: Medical Aid-in-Dying Utilization Report**

Currently, public health departments in nine authorized jurisdictions have issued reports regarding the use of medical aid-in-dying laws: Oregon<sup>42</sup>, Washington<sup>43</sup>, Vermont<sup>44</sup>, California<sup>45</sup>, Colorado<sup>46</sup>, Hawaiʻi<sup>47</sup>, the District of Columbia<sup>48</sup>, Maine<sup>49</sup> and New Jersey<sup>50</sup>. Compassion & Choices has compiled annual report data from the authorized jurisdictions that collect data<sup>51</sup>. Key highlights include:

- > For the past 25 years, starting with Oregon and across all jurisdictions, just 6,378 people have ingested a prescription to end their suffering. This represents far less than 1% of the people who die in each jurisdiction.
- > Over one-third (37%) of people who went through the entire process and obtained the prescription never took 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 used medical aid in dying more than 87% 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. There is currently no data on utilization of medical aid in dying by nonbinary people

<sup>&</sup>lt;sup>42</sup> Oregon Death with Dignity Act. Annual Report, (2021). Available from: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYA CT/Documents/year24.pdf

<sup>43</sup> Washington Death with Dignity Act Annual Report (2020). Available from: https://doh.wa.gov/sites/default/files/2022-02/422-109-DeathWithDignityAct2020.pdf?uid=63463231758e3

<sup>&</sup>lt;sup>44</sup> Vermont Patient Choice at the End of Life Data Report (2020). Available from:

 $<sup>\</sup>underline{\underline{\text{https://legislature.vermont.gov/assets/Legislative-Reports/2020-Patient-Choice-Legislative-Report-2.0.pdf}}$ 

<sup>&</sup>lt;sup>45</sup> California End of Life Option Act Annual Report (2021). Available from:

https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/CDPH End of Life%20 Option Act Report 2021 FINAL.pdf

<sup>46</sup> Colorado End of Life Options Act Annual Report (2020). Available from:

https://cdphe.colorado.gov/center-for-health-and-environmental-data/registries-and-vital-statistics/medical-aid-in-dyinghttps://drive.google.com/file/d/1FmoyCcL2gHopDO9rCJ2lGFEMUye8FQei/view

<sup>&</sup>lt;sup>47</sup> Hawaiʻi Our Care, Our Choice Act Annual Report (2020). Available from:

https://health.hawaii.gov/opppd/files/2020/01/OPPPD-Our-Care-Our-Choice-Act-Annual-Report -2019-1.pdf

<sup>&</sup>lt;sup>48</sup> District of Columbia Death with Dignity Act Annual Report. (2019). Available from: https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page\_content/attachments/DWD%20Report%202018%20Fin\_al%20%20%208-2-2019.pdf

<sup>&</sup>lt;sup>49</sup> Maine Death with Dignity Act Annual Report (2021). Available from: https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/inline-files/Patient-Directed%20Care%20%28Death%20with %20Dignity%29%20Annual%20Report%20--%204-2021.pdf

<sup>&</sup>lt;sup>50</sup> New Jersey Medical Aid in Dying for the Terminally III Act 2020 Data Summary Report (2021). Available from: https://nj.gov/health/advancedirective/documents/maid/2021.pdf

<sup>&</sup>lt;sup>51</sup> Medical Aid-in-Dying Data Across Authorized States, 2023. Compassion & Choices. Available from: https://compassionandchoices.org/docs/default-source/default-document-library/medical\_aid\_in\_dying\_utilization\_re\_port\_12-13-2022.pdf.

- > 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.
- > Just over 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<sup>52</sup>.

All Authorized Jurisdictions (1998 – 2021)	Cumulative	
Summary Data		
People who received prescriptions (prescriptions written or filled)		10,025
People who died after ingesting		6,378
Characteristics		
Sex		
Female	3,657	48.1%
Male	3,933	51.8%
Unknown	9	0.1%
Total	7,599	100%
Race		
Asian	206	2.7%
Black	39	0.5%
Hawaiian/Pacific Islander	8	0.1%
Hispanic and/or Non-White (WA) <sup>53</sup>	32	0.4%
Indigenous American/Alaskan Native	3	0.0%
Latino/a/x (Hispanic)	141	1.9%
Multi-Race (Two or more races)	23	0.3%
Other / Unknown	91	1.2%

<sup>&</sup>lt;sup>52</sup> Views and Experiences with End-of-Life Medical Care in the U.S. (2017). Hamel, Wu, and Brodie. Kaiser Family Foundation. Available from:

https://www.kff.org/report-section/views-and-experiences-with-end-of-life-medical-care-in-the-us-findings

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.

White	6,905	92.8%
Total	7,412	100.0%
Age Breakdown (Oregon, Washington, Colorado, D.C. and Hawai'i)		
18 – 54	402	7.8%
55 – 64	904	17.5%
65 – 74	1,624	31.5%
75 – 84	1,342	26%
85+	884	17.1%
Total	5,156	100.0%
Age Breakdown (California)		
Under 60	234	10.6%
60 – 69	473	21.4%
70 – 79	680	30.8%
80 – 89	529	24%
90+	292	13.2%
Total	2,208	100.0%
Age Breakdown (Maine)		
Under 65	10	14.7%
Over 65	58	85.3%
Total	68	100.0%
Education		
High School Diploma or GED or Less	1,845	24.8%
Some College	1,808	24.3%
Associate's Degree, Bachelor's Degree, Master's Degree, Doctorate or Professional Degree	3,687	49.6%
Unknown	90	1.2%
Total	7,430	100.0%

Hospice Care		
Enrolled	5,512	87.1%
Not Enrolled	545	8.6%
Unknown	161	2.5%
Not Under Hospice Care OR Unknown (Colorado)	108	1.7%
Total	6,326	100.0%
Insurance		
Private	1,422	22.5%
Medicare, Medicaid or Other Governmental	2,198	34.8%
Medicare With Another Type of Insurance (Unspecified)	1,058	16.8%
Combination of Private and Medicare / Medicaid	269	4.3%
Insured (Unspecified)	246	3.9%
None, Other, Unknown	1,115	17.7%
Total	6,308	100.0%
Underlying Illness		
Malignant Neoplasms (Cancer)	5,371	70.6%
Neurological Disease	893	11.7%
Respiratory Disease (e.g., COPD)	456	6%
Heart / Circulatory Disease / Cardiovascular	484	6.4%
Other Illnesses	402	5.3%
Total	7,606	100.0%
Place of Death / Location Where Medication Ingested / Location of	Patient	
Home / Private Home / Residence	5,337	90.4%
Assisted-Living Residence / Nursing Home / Long-Term Care / Foster-Care Facility	397	6.7%
In-Patient Hospice Residence	46	0.8%
Hospital / Other / Unknown	125	2.1%

Total	5,905	100%
Physician or Trained Healthcare Provider Present at Ingestion		
Prescribing Physician	412	8.2%
Attending Physician	418	8.3%
Other Physician	58	1.2%
Other Provider / Healthcare Provider	1,476	29.4%
Volunteer	148	2.9%
No Provider	629	12.5%
Unknown	1,884	37.5%
Total	5,025	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 25 years of data since Oregon implemented its law in 1997 and years of experience from 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 practice by which a terminally ill, mentally capable person with a prognosis of six months or less chooses to request, obtain and take 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. 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." With medical aid in dying, the person is terminally ill — imminent death is a reality that additional therapies won't change. People request medical aid in dying to maintain some control over and comfort in their final days, to ease their pain and suffering, and to help them experience a peaceful death. In contrast, suicide is preventable, provided that an individual can access appropriate suicide prevention resources. 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.

<sup>&</sup>lt;sup>54</sup> Statement of the American Association of Suicidology: "Suicide" is not the same as "physician aid in dying." American Association of Suicidology. October 30, 2017. Available from <a href="https://suicidology.org/wp-content/uploads/2019/07/AAS-PAD-Statement-Approved-10.30.17-ed-10-30-17.pdf">https://suicidology.org/wp-content/uploads/2019/07/AAS-PAD-Statement-Approved-10.30.17-ed-10-30-17.pdf</a>.

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 jurisdictions 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."55 Furthermore, the American Association of Suicidology asserts that the term "physician-assisted suicide" should not be used. 56



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 jurisdiction 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

<sup>56</sup> "Suicide" is Not the Same as "Physician Aid in Dying." American Association of Suicidology (2017). Available from: https://suicidology.org/wp-content/uploads/2019/07/AAS-PAD-Statement-Approved-10.30.17-ed-10-30-17.pdf

<sup>&</sup>lt;sup>55</sup> American College of Legal Medicine, Policy on Aid in Dying. (2008). Available from: https://compassionandchoices.org/docs/default-source/policy/american-college-of-legal-medicine-position-statemen

England Journal of Medicine.<sup>57</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>58</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 jurisdiction, 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 only choose 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 or 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>59</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 authorized jurisdictions explicitly state that the obligations created by wills, contracts, insurance and annuity policies cannot be affected by a terminally ill person's decision to request or use medical aid in dying. In other words, people are 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

https://jimdo-storage.global.ssl.fastly.net/file/a8cc42d8-c90f-49c1-b357-1932af60b8c5/EoLLessonsOregon.TolleSWTenoJM-NEJM-03-2017.pdf

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<sup>&</sup>lt;sup>57</sup> Lessons from Oregon in Embracing Complexity in End-of-Life Care. New England Journal of Medicine, S.W. Tolle, MD, J.M. Teno, MD, (2017). Available from:

<sup>&</sup>lt;sup>58</sup> There's an Unforeseen Benefit to California's Physician-Assisted Death Law. Los Angeles Times, (2017). Available from: <a href="https://www.latimes.com/health/la-me-end-of-life-care-20170821-htmlstory.html">https://www.latimes.com/health/la-me-end-of-life-care-20170821-htmlstory.html</a>

<sup>&</sup>lt;sup>59</sup> Emanuel EZ, Battin MP. 1998. What Are the Potential Cost Savings from Legalizing Physician-Assisted Suicide? NEJM 339:167-172. Available from: <a href="https://www.nejm.org/doi/10.1056/NEJM199807163390306">https://www.nejm.org/doi/10.1056/NEJM199807163390306</a>

influence a request for physician assisted death."<sup>60</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

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 person 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 dying 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>61</sup> 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.<sup>62</sup>

### Patients Have Various Options for Taking the Medication

The type and dosage of aid-in-dying medication the qualified prescriber or healthcare provider 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 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 cost and availability

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<sup>&</sup>lt;sup>60</sup> Poverty: Not a Justification for Banning Physician-Assisted Death. Hastings Center Report, L.M. Freeman, S.L. Rose, S.J. Youngner (2018). Available from: <a href="https://doi.org/10.1002/hast.937">https://doi.org/10.1002/hast.937</a>

<sup>&</sup>lt;sup>61</sup> Compromised Autonomy: When Families Pressure Patients to Change Their Wishes. Journal of Hospice and Palliative Nursing, L. Blackler, LCSW-R, MBE, (2016). Available from: <a href="https://alliedhealth.ceconnection.com/files/CompromisedAutonomyWhenFamiliesPressurePatientstoChangeTheirWishes-1490189149086.pdf">https://alliedhealth.ceconnection.com/files/CompromisedAutonomyWhenFamiliesPressurePatientstoChangeTheirWishes-1490189149086.pdf</a>

<sup>&</sup>lt;sup>62</sup> Zhang AY, Siminoff LA. The role of the family in treatment decision making by patients with cancer. Oncol Nurs Forum. 2003;30(6):1022-1028. Available from: <a href="https://www.ons.org/pubs/article/226186/download">https://www.ons.org/pubs/article/226186/download</a>

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 person.

Once the prescription has been filled, the terminally ill person can choose to take the medication. They usually fall asleep within 10 minutes. Respiration slows over the course of an hour or two, then stops, and the person dies peacefully in their sleep. Injection or infusion via a vein or any other parenteral route 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

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 25 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

To date, there has never been a single substantiated incident of abuse, diversion or misuse of aid-in-dying medications.

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 <u>established by the Drug</u> <u>Enforcement Agency</u> and as required under state statute. Information on how to dispose of medication can be found on the DEA website or on <u>The National Association of Boards of Pharmacy website</u>.

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. 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 Certificate 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)<sup>63</sup>. 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 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.

<sup>&</sup>lt;sup>63</sup> Physicians Handbook on Medical Certification of Death. Centers for Disease Control and Prevention. (2003). Available from: <a href="https://www.cdc.gov/nchs/data/misc/hb">https://www.cdc.gov/nchs/data/misc/hb</a> cod.pdf

## **Section VI: The Growing Movement**

In recent years, public support and 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 dropping their opposition, adopting supportive policies and passing laws to authorize the practice. During the 2022 legislative session, 13 legislatures introduced 22 medical aid in dying bills. There were 329 bipartisan individual elected officials who sponsored or co-sponsored the bills. These bills were proposed in every region of the country. Six states and Washington, D.C., 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 2021 nationwide poll by Susquehanna Polling and Research reported that 68% of voters support medical aid in dying as an end-of-life care option. Additionally, when respondents are asked if they want the option of medical aid in dying personally for themselves, 67% said yes. <sup>64</sup> Gallup's 2020 Values and Beliefs poll shows that a majority of respondents have consistently favored [medical aid in dying] since Gallup first asked about it in 1996. <sup>65</sup>

### Majority Support Among Diverse Groups

Broad support spans nearly every demographic, from age to ethnic group and from religious to political affiliation.<sup>66 67</sup>

Six national Latino/a/x organizations have adopted supportive policies on medical aid in dying:

> Dolores Huerta Foundation<sup>68, 69</sup>

<sup>&</sup>lt;sup>64</sup> Nationwide Poll Shows Strong Support for Advance Care-Dementia Planning, Medical Aid in Dying, Susquehanna Polling and Research, Omnibus Survey (2021). Available from: <a href="https://compassionandchoices.org/docs/default-source/default-document-library/usa-omnibus-cross-tabulation-report-final-november-2021-2.pdf?sfvrsn=74705b4b\_1">https://compassionandchoices.org/docs/default-source/default-document-library/usa-omnibus-cross-tabulation-report-final-november-2021-2.pdf?sfvrsn=74705b4b\_1</a>

<sup>&</sup>lt;sup>65</sup> Prevalence of Living Wills in U.S. Up Slightly. Jones, Jeffrey (2020) Gallup. Available from: https://news.gallup.com/poll/312209/prevalence-living-wills-slightly.aspx

<sup>&</sup>lt;sup>67</sup> American Views on Assisted Suicide. LifeWay Research (2016). Available from:

http://lifewayresearch.com/wp-content/uploads/2016/12/Sept-2016-American-Views-Assisted-Suicide.pdf <sup>68</sup> Civil Rights Icon Dolores Huerta Partners with End-of-Life Care Advocacy Group to Launch Multi-State Bilingual Education Campaign. Available from:

 $<sup>\</sup>frac{https://compassion and choices.org/news/civil-rights-icon-dolores-huerta-partners-with-end-of-life-care-advocacy-group-to-launch-multi-state-bilingual-education-campaign-2/$ 

<sup>&</sup>lt;sup>69</sup> Let's Stand for Aid-in-Dying Law. Albuquerque Journal, D. Huerta, Guest Column Op-Ed, (2019). Available from: <a href="https://www.abgjournal.com/1270710/lets-stand-for-aidindying-law.html">https://www.abgjournal.com/1270710/lets-stand-for-aidindying-law.html</a>

- > Hispanic Health Network<sup>70</sup>
- > Latino Commission on AIDS<sup>71</sup>
- > Latinos for Healthcare Equity<sup>72</sup>
- > National Hispanic Council on Aging<sup>73</sup>
- > Nuestra Salud<sup>74</sup>

These endorsements have all come in the past four years and represent a growing recognition that Latino/a/x (Hispanic) 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. 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.

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<sup>&</sup>lt;sup>70</sup> Catholic and Latino Perspectives on End-of-Life Suffering; Hispanic Health Network, El Dario, G. Chacón, Guest Column Op-Ed (2018). Available from:

https://eldiariony.com/2018/02/11/perspectiva-catolica-y-latina-sobre-el-sufrimiento-de-fin-de-vida/

<sup>&</sup>lt;sup>71</sup> Latinos Support Medical Aid in Dying; Latino Commission on AIDS. El Dario, Dr. J. Torres, Guest Column Op-Ed, El Dario, (2019). Available from: <a href="https://eldiariony.com/2019/01/29/los-latinos-apoyan-la-ayuda-medica-para-morir/">https://eldiariony.com/2019/01/29/los-latinos-apoyan-la-ayuda-medica-para-morir/</a>
<sup>72</sup> Id.

<sup>&</sup>lt;sup>73</sup> All Americans should have access to all end-of-life care options. National Hispanic Council on Aging, Yanira Cruz, Guest Column Op-Ed, The Hill, October 28, 2017. Available from:

https://thehill.com/opinion/healthcare/357575-all-americans-should-have-access-to-all-end-of-life-care-options <sup>74</sup> My father-in-law wanted end-of-life care options. We all should have them. Maria Otero, Co-Founder, Nuestra

Salud, Guest Column Op-Ed, Albuquerque Journal, May 13, 2018. Available from:

<a href="https://www.abgjournal.com/1171348/mv-fatherinlaw-wanted-endoflife-care-options-we-all-should-have-them.html">https://www.abgjournal.com/1171348/mv-fatherinlaw-wanted-endoflife-care-options-we-all-should-have-them.html</a>

<sup>75</sup> D.C. Becomes Seventh Jurisdiction to Allow Terminally III to End Their Lives. The Washington Post, A.C. Davis and F. Nirappil (2016). Available from:

https://www.washingtonpost.com/local/dc-politics/dc-becomes-seventh-jurisdiction-to-allow-terminally-ill-to-end-their-lives/2016/11/15/da497266-ab5b-11e6-977a-1030f822fc35\_story.html 
?utm\_term=.1500305615e9

The Statement of Support Regarding End-of-Life Options, Representative Elijah Cummings, (2019). Available from: <a href="https://compassionandchoices.org/news/congressman-elijah-cummings-endorses-maryland-end-of-life-option-act&sa="bksource=docs&ust=1668784416551563&usg=AOvVaw3VIP22uoUqYTTfMfm8vrdK">https://compassionandchoices.org/news/congressman-elijah-cummings-endorses-maryland-end-of-life-option-act&sa=bksource=docs&ust=1668784416551563&usg=AOvVaw3VIP22uoUqYTTfMfm8vrdK</a>

<sup>77</sup> Former Maryland Lt. Governor Anthony Brown Endorses State's End-of-Life Option Act. (2019). Available from:

 $<sup>\</sup>underline{https://compassion and choices.org/news/former-maryland-lt-gov-anthony-brown-endorses-states-end-of-life-option-act}$ 

<sup>&</sup>lt;sup>78</sup> Black Life Journeys Matter. Chavis, Ben. Feb 13, 2020. Available from: https://compassionandchoices.org/news/black-life-journeys-matter

<sup>&</sup>lt;sup>79</sup> Dr. Jeff Gardere and Jennifer Milch: "Stop Needless Suffering. Pass the Medical Aid in Dying Act." (2021). Available from:

https://www.youtube.com/watch?v=SJBV 6n5WLQ&ab channel=CompassionChoices

"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. 80 "[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. 81 A 2021 Gynecologic Oncology survey showed 69% of respondents believed that medical aid in dying should be legalized, and in a 2020 Oncology Ethics report, 55% of oncologists surveyed said that medical aid in dying should be legalized. 82 A 2022 study of Colorado physicians noted "those who have participated in [medical aid in dying] largely report the experience to be emotionally fulfilling and professionally rewarding," despite barriers to offering the end-of-life care option.83 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."84

https://compassionandchoices.org/resource/polling-medical-aid-dying

<sup>80</sup> Statement of Support Regarding End-of-Life Options, Representative Elijah Cummings, (2019). Available from: https://compassionandchoices.org/news/congressman-elijah-cummings-endorses-maryland-end-of-life-option-act

<sup>&</sup>lt;sup>81</sup> Medscape Ethics Report 2020: Life, Death, and Pain, (2020). Available from: https://compassionandchoices.org/docs/default-source/fact-sheets/medscape-ethics-report-2020-life-death-and-pain.

<sup>&</sup>lt;sup>82</sup> Polling on Medical Aid in Dying (2022). Available from:

<sup>&</sup>lt;sup>83</sup> Campbell EG, Kini V, Ressalam J, Mosley BS, Bolcic-Jankovic D, Lum HD, Kessler ER, DeCamp M. *<u>Physicians'</u>* Attitudes and Experiences with Medical Aid in Dying in Colorado: a "Hidden Population" Survey. J Gen Intern Med. 2022 Oct;37(13):3310-3317. doi: 10.1007/s11606-021-07300-8. Epub 2022 Jan 11. PMID: 35018562; PMCID: PMC8751472.

<sup>&</sup>lt;sup>84</sup> Medscape Ethics Report 2020: Life, Death, and Pain, (2020). Available from: https://compassionandchoices.org/docs/default-source/fact-sheets/medscape-ethics-report-2020-life-death-and-pain. pdf

Additionally, a 2022 survey of nurses demonstrated that most nurses would care for a patient contemplating medical aid in dying (86%) and that 57% would support the concept of medical aid in dying professionally as a nurse.<sup>85</sup>

Over the past six years, dozens of 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 option among qualified clinicians and the public.

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

- > American College of Legal Medicine<sup>86</sup>
- American Medical Student Association<sup>87</sup>
- > American Medical Women's Association<sup>88</sup>
- American Public Health Association<sup>89</sup>
- > GLMA: Healthcare Professionals Advancing LGBT Equality<sup>90</sup>
- National Student Nurses' Association<sup>91</sup>

Because provider participation is critical to access medical aid in dying, lawmakers look to healthcare associations for input. Neutral positions, including engaged neutrality, recognize differences of opinion among providers and establish that those who participate in medical aid in dying are adhering to their professional ethical obligations, as are those who decline to participate. Six national healthcare organizations have adopted neutral positions:

- > American Academy of Family Physicians<sup>92</sup>
- > American Academy of Neurology<sup>93</sup>

https://compassionandchoices.org/resource/polling-medical-aid-dying

<sup>85</sup> Polling on Medical Aid in Dying (2022). Available from:

<sup>&</sup>lt;sup>86</sup> American College of Legal Medicine, Position on Medical Aid in Dying, (2008). Available from: https://compassionandchoices.org/docs/default-source/policy/american-college-of-legal-medicine-position-statemen

American Medical Student Association, Excerpted from: Preambles, Purposes, Principles: Principles Regarding Physician Aid in Dying. (2008). Available from: <a href="http://www.amsa.org/wp-content/uploads/2015/03/PPP-2015.pdf">http://www.amsa.org/wp-content/uploads/2015/03/PPP-2015.pdf</a>

<sup>&</sup>lt;sup>88</sup> American Medical Women's Association, Excerpted from: Position Paper on Aid in Dying (2013/2018). Available from <a href="https://www.amwa-doc.org/wp-content/uploads/2018/09/Medical-Aid-in-Dying-Position-Paper.pdf">https://www.amwa-doc.org/wp-content/uploads/2018/09/Medical-Aid-in-Dying-Position-Paper.pdf</a>

<sup>&</sup>lt;sup>89</sup> American Public Health Association, Excerpted from: Patient's Rights to Self-Determination at the End. Policy # 20086. (2008). Available from:

 $<sup>\</sup>frac{\text{https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life}{\text{policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life}}{\text{policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life}}{\text{policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life}}{\text{policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life}}{\text{policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life}}{\text{policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life}}{\text{policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life}}{\text{policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life}}{\text{policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life}}{\text{policy-database/2014/07/29/13/28/patients-righ$ 

<sup>&</sup>lt;sup>90</sup> GLMA Letter of Support on AB X2-15, (2015). Available from:

https://compassionandchoices.org/docs/default-source/california/20151002-glma-letter-in-support-of-ca-eoloa.pdf.

<sup>&</sup>lt;sup>91</sup> National Student Nurses' Association, NSNA Resolutions (2018). Available from: https://www.dropbox.com/s/8xwq5f827leqriq/NSNA%20Resolutions%202018.pdf?dl=0

<sup>&</sup>lt;sup>92</sup> American Academy of Family Physicians COD Addresses Medical Aid in Dying, Institutional Racism. (2018). Available from: https://www.aafp.org/news/2018-congress-fmx/20181010cod-hops.html

<sup>&</sup>lt;sup>93</sup> American Academy of Neurology position statement on Lawful Physician-Hastened Death. (2018). Available from: http://n.neurology.org/content/90/9/420

- > American Academy of Hospice and Palliative Medicine<sup>94</sup>
- > American Nurses Association<sup>95</sup>
- > American Pharmacists Association<sup>96</sup>
- American Society for Health System Pharmacists<sup>97</sup>
- National Association of Social Workers<sup>98</sup>

Medical associations in many of the authorized jurisdictions currently have neutral positions on medical aid in dying, including Oregon<sup>99</sup>, California<sup>100</sup>, Colorado<sup>101</sup>, Vermont<sup>102</sup>, Hawaiʻi<sup>103</sup>, Maine <sup>104</sup>, New Mexico<sup>105</sup> and the District of Columbia<sup>106</sup>. Seven other state medical societies and a component society in non-authorized jurisdictions (New York, Connecticut, Maryland,

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<sup>&</sup>lt;sup>94</sup> American Academy of Hospice & Palliative Medicine. Excerpted from: Statement on Physician-Assisted Death (2007). Available from: <a href="http://aahpm.org/positions/pad">http://aahpm.org/positions/pad</a>

<sup>&</sup>lt;sup>95</sup> American Nurses Association, The Nurse's Role When a Patient Requests Medical Aid in Dying (2019). Revised Position Statement. Available from:

https://www.nursingworld.org/~49e869/globalassets/practiceandpolicy/nursing-excellence/ana-position-statements/social-causes-and-health-care/the-nurses-role-when-a-patient-requests-medical-aid-in-dying-web-format.pdf

<sup>&</sup>lt;sup>96</sup> American Pharmacists Association, Actions of the 2015 APhA House of Delegates, Available from: https://docksci.com/report-of-the-2015-apha-house-of-delegates\_5a35bf67d64ab2ddfc6de3a7.html

<sup>&</sup>lt;sup>97</sup> American Society of Health-System Pharmacists, Board Report on the Joint Council Task Force on Pharmacist Participation in Medical Aid in Dying, (2016). Available from:

https://www.ashp.org/-/media/assets/house-delegates/docs/hod-board-report-on-task-force.ashx

<sup>&</sup>lt;sup>98</sup> National Association of Social Workers, NASW Standards for Palliative and End of Life Care, Available from: https://www.socialworkers.org/LinkClick.aspx?fileticket=xBMd58VwEhk%3D&portalid=0.

<sup>&</sup>lt;sup>99</sup> Oregon Medical Association, Excerpted from: October 27 Board of Trustees Report. Available from: <a href="http://bit.ly/2CYT6Dx">http://bit.ly/2CYT6Dx</a>

<sup>&</sup>lt;sup>100</sup> California Medical Association Position on Medical Aid in Dying. Available from:

https://www.cmadocs.org/newsroom/news/view/ArticleId/27210/California-Medical-Association-removes-opposition-to-physician-aid-in-dying-bill

<sup>&</sup>lt;sup>101</sup> Colorado Medical Society, Position on Medical Aid in Dying. Available from:

https://www.cms.org/articles/prop-106-may-june

<sup>&</sup>lt;sup>102</sup> Vermont Medical Society, Position on Medical Aid in Dying, (2017). Available from:

http://www.vtmd.org/sites/default/files/2017End-of-Life-Care.pdf

<sup>&</sup>lt;sup>103</sup> Hawai'i Society of Clinical Oncology, Hawaii Our Care, Our Choice Act Resources (2018). Available from:

https://www.accc-cancer.org/state-societies/Hawaii/resources/medical-aid-in-dying

104 Maine Medical Association (MMA) Position on Medical Aid in Dying, (2017). Available from:

http://newsmanager.com/mainemed/issues/2017-05-01/index.html

New Mexico Medical Society Position on Medical Aid in Dying (2019). Available from: <a href="https://d2zhgehghgjuwb.cloudfront.net/accounts/14766/original/2019">https://d2zhgehghgjuwb.cloudfront.net/accounts/14766/original/2019</a> 1 5 Council Minutes - PENDING APPROVA L.pdf?1547577653

<sup>&</sup>lt;sup>106</sup> Another State Medical Society Stops Fighting Assisted Death (2017). Lowes, Robert. Medscape. Available from:

https://www.medscape.com/viewarticle/889450?reg=1&icd=login\_success\_gg\_match\_norm

Massachusetts, Minnesota, Delaware and Virginia) have also recently dropped their opposition. 107, 108, 109, 110, 111, 112, 113

Additionally, the American Medical Association (AMA) and the National Hospice and Palliative Care Organization (NHPCO) have amended their policies to state that it is ethical for a provider to provide medical aid in dying to qualified patients seeking it.<sup>114</sup> The NHPCO even went so far as to replace the outdated and pejorative expression "assisted suicide" with the correct terminology "medical aid in dying."<sup>115</sup> While the AMA and NHPCO do not yet have a fully supportive policy, these changes are a significant step forward and demonstrate that acceptance within the medical field is gaining momentum.

There is growing recognition within the medical profession and healthcare organizations 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 healthcare 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 medical and other organizations that have endorsed medical aid in dying noted above, the Coalition for Liberty and Justice, the Older Women's League<sup>116</sup> and SAGE<sup>117</sup>, a national organization that provides services and advocacy for LGBT elders, have all endorsed medical aid in dying on a national level.

<sup>&</sup>lt;sup>107</sup> New York State Assembly of Family Physicians Position on Medical Aid in Dying, (2017). Available from: http://www.nysafp.org/NYSAFP/media/PDFs/Policy-Positions-Manual-TOC-links-2017.pdf

Connecticut State Medical Society Position on Medical Aid in Dying. (2019). Available from: <a href="https://www.cga.ct.gov/2019/PHdata/Tmy/2019HB-05898-R000318-Connecticut%20State%20Medical%20Society-T">https://www.cga.ct.gov/2019/PHdata/Tmy/2019HB-05898-R000318-Connecticut%20State%20Medical%20Society-T</a> MY.PDF

<sup>&</sup>lt;sup>109</sup> MEDCHI, The Maryland State Medical Society House of Delegates Position on Medical Aid in Dying. (2016)
Available from <a href="http://www.medchi.org/Portals/18/files/Events/Resolution%2016-16.pdf?ver=2016-08-26-140448-047">http://www.medchi.org/Portals/18/files/Events/Resolution%2016-16.pdf?ver=2016-08-26-140448-047</a>

<sup>110</sup> Massachusetts Medical Society Position on Medical Aid in Dying (2017). Available from: <a href="https://www.massmed.org/About/2017-Annual-Report/">https://www.massmed.org/About/2017-Annual-Report/</a>

Minnesota Medical Association Position on Medical Aid in Dying (2017) Available from: <a href="http://www.mnmed.org/news-and-publications/News/MMA-Revises-Its-Policy-on-Physician-Aid-In-Dying">http://www.mnmed.org/news-and-publications/News/MMA-Revises-Its-Policy-on-Physician-Aid-In-Dying</a>

MSD Support of Engaged Neutrality for Medical Aid in Dying (2022). Available from: <a href="https://files.constantcontact.com/01c210be101/c65122d3-bb72-4b9c-a2f6-8563b3304710.pdf?rdr=true">https://files.constantcontact.com/01c210be101/c65122d3-bb72-4b9c-a2f6-8563b3304710.pdf?rdr=true</a>

<sup>113 2022-2023</sup> Policy Compendium, (2022). The Medical Society of Virginia. Available from: https://www.msv.org/wp-content/uploads/2022/11/2022-2023-Policy-Compendium.pdf

<sup>114</sup> Report 2 of the Council on Ethical and Judicial Affairs (2-A-19), Physician Assisted Suicide (Resolution 15-A-16 and Resolution 14-A-17) (2019). American Medical Association. Available from: https://www.ama-assn.org/system/files/2019-05/a19-ceja2.pdf

<sup>&</sup>lt;sup>115</sup> Statement on Medical Aid in Dying (2021). National Hospice and Palliative Care Organization. Available from:

https://compassionandchoices.org/docs/default-source/default-document-library/medical aid dying position statement nhpco.pdf

Nation's Largest LGBT Elders Group Endorses Medical Aid-in-Dying Laws (2019). Available from: <a href="https://compassionandchoices.org/news/nations-largest-lgbt-elders-group-endorses-medical-aid-in-dying-laws?ga=2.55396968.238481543.1668781176-1514433183.1665591539">https://compassionandchoices.org/news/nations-largest-lgbt-elders-group-endorses-medical-aid-in-dying-laws?ga=2.55396968.238481543.1668781176-1514433183.1665591539</a>
 Id.

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

- > Bar Associations California 118, Connecticut 119
- > American Civil Liberties Union Connecticut<sup>120</sup>, New Jersey<sup>121</sup>, New York<sup>122</sup>
- American Federation of State, County and Municipal Employees California 123
- The Arc New York<sup>124</sup>
- Disability Rights New Mexico<sup>125</sup>, Utah<sup>126</sup>
- Equality Federation California<sup>127</sup>
- Gay and Lesbian Activist Alliance D.C.<sup>128</sup>
- League of Women Voters Maryland<sup>129</sup>, New York<sup>130</sup>, Utah<sup>131</sup>

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<sup>&</sup>lt;sup>118</sup> The Conference of California Bar Associations, Testimony in Support of ABX2-15 (2015). Available from: https://compassionandchoices.org/docs/default-source/california/l-doyle-support-for-abx2-15.pdf

119 The Connecticut Bar Association, Testimony in Support of HB7015," (2015). Available from:

https://www.cga.ct.gov/2015/juddata/tmy/2015HB-07015-R000318-Collins,%20Barbara-TMY.PDF 120 ACLU of Connecticut, Statement of Support for Medical Aid in Dying. (2018). Available from:

https://www.acluct.org/sites/default/files/field documents/acluct 2021 testimony supporting hb 6425 aid in dying

<sup>&</sup>lt;u>pdf</u>

121 Civil Liberties Reporter: Summer 2019 (2019). ACLU of New Jersey. Available from: https://www.aclu-nj.org/en/publications/civil-liberties-reporter-summer-2019

<sup>&</sup>lt;sup>122</sup> ACLU of New York, Statement of Support for Medical Aid in Dying (2020). Available from: https://www.nyclu.org/sites/default/files/field\_documents/202001\_nyclu\_2020\_report.pdf

<sup>&</sup>lt;sup>123</sup> American Federation of State, County, and Municipal Employees, Statement of Support for Medical Aid in Dying (2015). Available from: https://www.compassionandchoices.org/docs/default-source/legal/afscme-support-sb-128.pdf <sup>124</sup> The ARC of New York, Statement of Support for Medical Aid in Dying (2017). Available from:

https://www.thearcny.org/advocacy/position-statements/aid-dying

<sup>&</sup>lt;sup>125</sup> Disability Rights New Mexico, Oral Testimony for Medical Aid in Dying/End of Life Options Act HB 47, House Judiciary Committee Hearing (2019). Available from: https://bit.ly/3w99Ov9

126 Disability Rights Utah, Statement of Support for Medical Aid in Dying (2016). Available from:

www.compassionandchoices.org/docs/default-source/legal/the-legislative-coalition-for-people-with-disabilities.pdf <sup>127</sup> Equality Federation California, Statement of Support for Medical Aid in Dying (2015). Available from:

www.compassionandchoices.org/docs/default-source/legal/equalitycaabx215.pdf

128 Gay and Lesbian Activists Alliance, Statement of Support for Medical Aid in Dying (2015). Available from: http://glaa.org/archive/2015/glaaondeathwithdignityact0710.pdf

League of Women Voters Maryland, Statement of Support for Medical Aid in Dying (2019). Available from: https://www.lwvmd.org/dwd

<sup>130</sup> League of Women Voters New York, Statement of Support for Medical Aid in Dying (2018). Available from: https://www.lwvnyonline.org/programs-studies/death-with-dignity/2018/LWVNYS-Adopted-Postion-Death-With-Digni tv 040518.pdf

<sup>131</sup> League of Women Voters Utah, Statement of Support for Medical Aid in Dying (2016). Available from: https://my.lwv.org/sites/default/files/leagues/wysiwyq/%5Bcurrent-user%3Aog-user-node%3A1%3Atitle%5D/lwvutah position aid-in-dying.pdf

- National Association of Social Workers California<sup>132</sup>, Massachusetts<sup>133</sup>, New Jersey<sup>134</sup> New Mexico<sup>135</sup>
- > SAGE<sup>136</sup>
- Sam DeWitt Proctor Conference, Inc. 137
- > United Church of Christ Central Atlantic Conference (D.C., Delaware, New Jersey, Maryland)<sup>138</sup>
- United Methodist Church California-Pacific<sup>139</sup>
- Unitarian Universalist Association<sup>140</sup>
- Unitarian Universalist Church Maryland<sup>141</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 reelection — incumbent bill sponsors had a 96% reelection rate in the primary and a 95% reelection rate in the general election <sup>142</sup>.

<sup>&</sup>lt;sup>132</sup> National Association of Social Workers, California, Statement of Support for Medical Aid in Dying (2019). Available

http://www.leginfo.ca.gov/pub/15-16/bill/asm/ab 0001-0050/abx2 15 cfa 20150901 115418 asm comm.html.

National Association of Social Workers, Massachusetts, Statement of Support for Medical Aid in Dying (2015). Available from: https://www.naswma.org/news/364836/End-of-Life-Options-Act.html

<sup>&</sup>lt;sup>134</sup> National Association of Social Workers, New Jersey Statement of Support for Medical Aid in Dying (2018). Available from: <a href="https://naswnj.socialworkers.org/LinkClick.aspx?fileticket=BY5sdXt5QYM%3D&portalid=12">https://naswnj.socialworkers.org/LinkClick.aspx?fileticket=BY5sdXt5QYM%3D&portalid=12</a>

<sup>&</sup>lt;sup>135</sup> National Association of Social Workers, New Mexico, Statement of Support for Medical Aid in Dying (2018). Available from:

https://endoflifeoptionsnm.org/wp-content/uploads/2018/12/NM-End-of-Life-Options-CoalitionLetterofSupport-Natl-Assoc-of-Social-Wkrs-2018.pdf

136 SAGE Endorsement of Medical Aid in Dying Laws. Available from:

https://www.sageusa.org/news-posts/nations-largest-lgbt-elders-group-endorses-medical-aid-in-dving-laws/

<sup>137</sup> Samuel DeWitt Conference, Inc. Statement of Support for Medical Aid in Dying. Available from:

https://compassionandchoices.org/docs/default-source/legal/covenant-on-end-of-life.pdf

<sup>&</sup>lt;sup>138</sup> United Church of Christ, Statement of Support for Medical Aid in Dying. Central Atlantic Conference. (2019). Available from:

https://www.ucc.org/what-we-do/justice-local-church-ministries/justice/health-and-wholeness-advocacy-ministries/hea lth-care-justice/faithfully facing dying/

On the Even of All Saints' Day (2015). California-Pacific Conference of the United Methodist Church. Available from: https://www.calpacumc.org/bishop-carcano/on-the-eve-of-all-saints-day/

<sup>&</sup>lt;sup>140</sup> University Universalist Association, The Right to Die with Dignity 1988 General Resolution (1988). Available from: https://www.uua.org/action/statements/right-die-dignity

<sup>&</sup>lt;sup>141</sup> Unitarian Universalist Church, Maryland, Statement of Support for Medical Aid in Dying (2019). Available from: https://www.uulmmd.org/death-with-dignity

<sup>142 2019 - 2020</sup> Elections & Medical Aid in Dying: An Issue Worth Supporting, Compassion & Choices, Available from: https://compassionandchoices.org/docs/default-source/fact-sheets/2019-2020-election-report-final-12-20-20.pdf?sfvr sn=c0396c0e 5.

## **Section VII: About Compassion** & Choices

Compassion & Choices is the oldest and largest national organization committed to improving care and expanding options for 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 options nationwide. Our funding comes almost exclusively from the generosity of individuals and family foundations. Last fiscal year, more than 38,000 individual donors contributed to our work, with more than 23,000 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 people experiencing unnecessary suffering at life's end, demanding care and seeking policies that better reflect their values and priorities.

<sup>&</sup>lt;sup>143</sup> Compassion & Choices and Compassion & Choices Action Network Combined Financial Statements, Years Ended June 30, 2022 and 2021 with Independent Auditor's Report. Available from: <a href="https://compassionandchoices.org/docs/default-source/financial-documents/financial-statements/fy22-combined-financial-statements-10-25-22.pdf?sfvrsn=4e5e0079\_3">https://compassionandchoices.org/docs/default-source/financial-documents/financial-statements/fy22-combined-financial-statements-10-25-22.pdf?sfvrsn=4e5e0079\_3</a>

### **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 this compassionate practice without putting their providers and family members at risk of prosecution.

We now have 25 years of experience since the law was first enacted in Oregon and over a decade of combined evidence from the 10 other authorized jurisdictions demonstrating that medical aid-in-dying laws protect patients and provide 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 brings peace of mind to terminally ill people at or near the end of their lives. Furthermore, the cost of inaction is high.

#### Terminally ill people:

- > May not try that one last miracle treatment out of fear it will be too painful.
- > May choose violent means to end their suffering rather than this compassionate option.
- > Are deprived of the peace of mind that comes with knowing they can end their suffering if it becomes too great.
- > Could 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 providers and patients.
- > Better palliative care training.
- > Better hospice usage.

Your jurisdiction can realize these benefits for terminally ill people 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.



Care and Choice at the End of Life

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