

Compassion & choices ACTION NETWORK

# INTRODUCTION TO MEDICAL AID IN DYING

Volunteer Action Network Toolkit

# What is Medical Aid in Dying?

<u>Medical aid in dying</u> is a healthcare practice that gives terminally ill, mentally capable adults with a prognosis of six months or less to live, the option to request a prescription for medication they can decide to self-ingest to peacefully end unbearable suffering.

Twelve jurisdictions currently authorize medical aid in dying: California, Colorado, Delaware, Hawaiʻi, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont, Washington State and Washington, D.C. Although each jurisdiction's medical aid-in-dying laws vary slightly, all include well-established eligibility standards and requirements. For example, two healthcare providers must confirm that the patient has a prognosis of six months or less to live, is able to make an informed healthcare decision, is not being coerced and is able to take the medication themselves.

Some patients who receive a prescription for medical aid in dying do not ever take the medication but research shows just having the option relieves fear and anxiety — even for those who never choose it. This toolkit strives to answer some of the most common questions and address standard misconceptions about medical aid in dying. It also details the resources available through Compassion & Choices including polling data, fact sheets and more.

## Is medical aid in dying the same as assisted suicide?

No. Factually, legally and medically speaking, it is inaccurate to equate medical aid in dying with suicide or assisted suicide. People who seek medical aid in dying are diagnosed with a life-ending illness and are making the choice to control the manner and timing of an anticipated death.

Further, assisted suicide remains a felony in states where medical aid in dying is authorized. The 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." Saying "assisted suicide" inaccurately characterizes a legitimate medical practice as criminal activity. For more, please see Medical Aid in Dying Is Not Assisted Suicide

# Does the medical community support medical aid in dying?

Data show that most physicians support medical aid in dying, with the margin in favor continuing to grow. Increasingly, medical associations and professional organizations also support the practice as evidenced with the following data:

A 2020 survey of more than 5,000 physicians conducted by <u>Medscape</u> showed that 55% believe medical aid in dying should be made legal for terminally ill patients compared to 49% in 2018.

- In October 2018, The <u>American Academy of Family Physicians</u> (AAFP) adopted a position of "engaged neutrality" on the issue of medical aid in dying. Further, in their position statement, the AAFP rejects the term "assisted suicide" in reference to medical aid in dying.
- The <u>American Association of Hospice and Palliative Medicine</u> adopted a similar position in 2016.

In June 2019 the American Nurses Association said in a six-page position statement:

"Nurses ... must be comfortable supporting patients with end-of-life conversations, assessing the context of a medical aid-in-dying request ... knowing about aid-in-dying laws and how those affect practice ... remain objective when discussing end-of-life options with patients who are exploring medical aid-in-dying [and] have an ethical duty to be knowledgeable about this evolving issue."

Since 2015, 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 end-of-life care option among physicians and the public. For a comprehensive list of organizations and societies and their official position statements, please see: <a href="Medical Professional Associations That Recognize Medical Aid in Dying">Medical Aid in Dying</a>.

#### What is the position of the American Medical Association?

On June 11, 2019, a new policy position recommended by the Council on Ethical and Judicial Affairs (<u>CEJA 2-A-19 Report</u>) was adopted by the American Medical Association (AMA). The AMA modifies its Code of Medical Ethics to affirm that physicians may practice medical aid in dying without violating their professional responsibilities.

Striking a neutral balance, the AMA highlighted two separate provisions of the Medical Code of Ethics as relevant and applicable to medical aid in dying, establishing that physicians who participate in medical aid in dying are adhering to their professional, ethical obligations *as are* physicians who decline to participate. This position allows for, respects and supports the diverse views of the AMA's membership. See more details in <a href="Where Does the American Medical">Where Does the American Medical</a> Association Stand on Medical Aid in Dying?

# **Frequently Asked Questions and Resources**

# Where is medical aid in dying authorized?

#### Medical Aid in Dying is currently authorized in 10 states and Washington, D.C.

- 1994: Oregon Death with Dignity Act. Oregon Voters pass legislation called the Oregon Death with Dignity Act (DWDA), and the law was promptly challenged; In 1997 the Oregon state Supreme Court upheld the law and the act took effect. Lawmakers pass improved legislation in 2019.
- 2008: Washington Death with Dignity Act. Washington voters pass an Oregon-style medical aid-in-dying law that takes effect in March 2009.
- 2009: Baxter Vs Montana. Montana state Supreme Court finds in favor of terminally ill Bob Baxter, authorizing medical aid in dying in Montana.
- 2013: Vermont Patient Choice and Control at the End of Life Act. Vermont lawmakers pass legislation authorizing medical aid in dying that takes effect in May 2013.
- 2015: California End-of-Life Options Act. California lawmakers pass legislation authorizing medical aid in dying that takes effect June 2016. Lawmakers pass improved legislation in 2021.
- 2016: Colorado End of Life Options Act. Colorado voters pass a medical aid-in-dying law, by a margin of 65%, that takes effect December 2016.
- 2016: District of Columbia Death with Dignity Act. Washington, D.C. lawmakers pass legislation authorizing medical aid in dying that takes effect in February 2017.
- 2018: Hawai'i Our Care, Our Choice Act. Hawai'i lawmakers pass legislation authorizing medical aid in dying that takes effect in January 2019.
- 2019: New Jersey Aid in Dying for the Terminally III Act. New Jersey lawmakers pass legislation authorizing medical aid in dying that takes effect in September 2019.
- 2019: Maine Death with Dignity Act. Maine lawmakers pass legislation authorizing medical aid in dying that takes effect in September 2019.
- 2021: New Mexico Elizabeth Whitefield End-of-Life Options Act. New Mexico lawmakers pass legislation authorizing medical aid in dying that takes effect in June 2021.
- 2025: Delaware Heather Block/Ron Silverio End-of-Life Options Act. Delaware lawmakers pass legislation authorizing medical aid in dying that takes effect immediately or January 1, 2026.

<u>Click here</u> to find the bill language and specific legal details of each state law.

# History of the End-of-Life Movement

There are many milestones in the history of the movement which has roots in the 1970s, the founding of the Hemlock Society in the 1980s, the passage of the nation's first medical aid-in-dying law in the 1990s and a merger that created Compassion & Choices in the 2000s.

#### **The Early Years**

- > 1967: A Right to Die bill is introduced in Florida
- > 1971: Hospice, Inc., the first modern hospice, is founded in the United States
- > 1980: The Hemlock Society is established
- > 1983: The Medicare Hospice Benefit is established
- > 1988: <u>The Unitarian Universalist Association</u> created a general resolution affirming the right to die with dignity and personal choice at the end of life
- > 1990: The U.S. Supreme Court affirms the right of competent Americans to refuse unwanted medical treatment
- > 1991: Congress passes the Patient Self-Determination Act

#### **10 Years of Additional Progress**

- > 1993: Oregon advocates, led by Barbara Lee Coombs, establish 1-800-247-7421, the first national end-of-life consultancy program
- > 1994: Oregon voters pass the Death with Dignity Act and the law is promptly challenged
- > 1997: Oregon Supreme Court upholds the Death with Dignity Act of 1994 and the law is in full effect October 1997
- > 1997: The U.S. Supreme Court declines to find federal constitutional protection for medical aid in dying and refers the issue to the states
- > 2003: Hemlock Society is renamed End-of-Life Choices

#### **A National Conversation**

- 2005: Compassion & Choices forms by merging End-of-Life Choices and Compassion and Dying
- > 2006: National medical organizations adopt positions supporting medical aid in dying including the American Women's Medical Association, American Public Health Association and American Medical Student Association
- > 2008: Compassion & Choices helps pass the Terminal Patients' Right to Know

- End-of-Life Options Act into law in California
- > 2008: Washington voters pass a medical aid-in-dying law
- > 2009: Montana Supreme Court decides in favor of terminally ill Bob Baxter, authorizing medical aid in dying in Montana
- > 2010: Compassion & Choices helps pass the Palliative Care Information Act in New York
- > 2013: Compassion & Choices, other groups and legal experts launch the Campaign to End Unwanted Medical Treatment
- > 2013: Vermont lawmakers pass medical aid-in-dying legislation

#### **The Brittany Effect**

- > 2014: Brittany Maynard's story catapults medical aid in dying to the national spotlight and the following year, 25 states and D.C. introduce medical-aid-in dying legislation
- > 2015: California lawmakers pass medical aid-in-dying legislation
- > 2015: Centers for Medicare and Medicaid Services issues a rule to reimburse doctors for advance planning and end-of-life conversations
- > 2016: Colorado voters pass a medical aid-in-dying law on the ballot
- > 2016: Washington D.C. lawmakers pass medical aid-in-dying legislation
- > 2017: The Arc in New York City becomes the first disability rights group to support medical aid in dying
- > 2018: Hawai'i lawmakers pass medical aid-in-dying legislation
- > 2018: "Finish Strong: Putting Your Priorities First at Life's End" by President Emerita and Senior Advisor of Compassion & Choices, Barbara Coombs Lee" is released

## **Diversifying and Expanding the Movement**

- > 2019: The Compassion & Choices African American Leadership Council is created
- > 2019: The Compassion & Choices Latino Leadership Council is created
- > 2019: Sam DeWitt Proctor End-of-Life/Medical Aid-in-Dying Declaration and Covenant
- 2019: National Organization of Black Elected Legislators (NOBEL) Women End-of-Life Resolution
- > 2019: Memorandum of Support for medical aid-in dying from SAGE, the World's largest organization committed to improving the lives of LGBTQ+ Elders
- 2019: The American Medical Association modifies its Code of Medical Ethics to affirm that physicians may practice medical aid in dying without violating their professional responsibilities
- > 2019: New Jersey lawmakers pass medical aid-in-dying legislation
- > 2019: Maine lawmakers pass medical aid-in-dying legislation

- > 2020: Compassion & Choices launches its dementia initiative nationwide
- > 2020: With the help of our allies, secured important telehealth provisions for seriously ill patients in the Coronavirus Aid, Relief and Security (CARES) Act
- > 2020: American Ethical Union resolution urging other ethical societies to support medical aid-in-dying legislation
- > 2020: The Compassion & Choices Healthcare Advisory Council is created
- > 2021: New Mexico lawmakers pass medical aid-in-dying legislation
- > 2021: The Compassion & Choices Asian American, Native Hawaiian and Pacific Islander Leadership Council (AANHPI) is created
- > 2021: NAACP Resolution solidifies the importance of end-of-life education with a formal declaration to members
- > 2021: African American Mayors Association (AAMA) Resolution committing to greater access to end-of-life care
- > 2021: The Compassion & Choices LGBTQ+ Leadership Council is created
- > 2022: The Compassion & Choices Faith Leaders Council and Catholics for Compassion are created
- > 2022: National Black Caucus of State Legislators resolution to support end-of-life planning

#### **Ongoing Efforts**

- > 2023: Nevada State Medical Society becomes the first state medical association to support medical aid in dying as an end-of-life option
- > 2023: The National Latinx Task Force passes a resolution that members inform, empower and take action on end-of-life care planning
- > 2023: Latino outreach through a partnership with Ventanilla de Salud, for advance health education initiative
- > 2024: The National Emergency and Palliative Medicine Initiative (NEPMI) Council is established
- > 2024: The Medical Society of the State of New York publicly supports the New York End-of-Life Options legislation
- > 2025: Delaware lawmakers pass medical aid-in-dying legislation
- > 2025: The Compassionate Care Act is introduced to Congress

Please reference the <u>Our Accomplishments</u> and <u>History of the End-of-Life Choice Movement</u> sections of the Compassion & Choices website for additional and more detailed up to date information.

# **Facts About Medical Aid in Dying**

# What can we learn from over 25 years of data in Oregon?

A recent executive summary of more than two decades of data from the 2024 annual report on medical aid in dying in Oregon, the first state to authorize the practice of medical aid in dying, shows:

Demographic characteristics of the Oregon Death With Dignity Act (DWDA) patients were similar to those of previous years: most patients were 65 years or older (83%) and white (94%). The most common diagnosis was cancer (57%).

Oregon Health Association made no referrals to the Oregon Medical Board for failure to comply with DWDA reporting requirements.

A total of 135 physicians wrote 607 prescriptions during 2023.

Additional details can be read at <u>Oregon Department of Health Annual Reports</u>. Please refer to each state's department of health for its specific reporting requirements.

#### Is there a compilation of data to reference?

Our publication: Medical Aid in Dying: A Policy to Improve Care and Expand Options, provides evidence-based facts about medical aid in dying and addresses the most common questions, concerns and hypothetical claims that we hear nationwide. 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 in other states.

#### What does public polling on medical aid in dying show?

Consistently, large majorities in the United States across generations, genders, educational experiences, political, racial and religious groups favor legislation to authorize medical aid in dying.

A Gallup Poll social survey in May 2020 showed 61% of participants agreed that, "When a person has a disease that cannot be cured and is living in severe pain ... doctors should ... be allowed by law to assist the patient to [access medical aid in dying.]"

A 2018 Medscape poll revealed nearly six out of 10 doctors (58%) among 5,200 physicians across 29 specialties say that "'physician-assisted dying' should be made legal for terminally ill patients." Learn more at Polling on Medical Aid in Dying.

#### How does medical aid in dying benefit society?

Society benefits when medical aid in dying laws are implemented - benefits that help everybody - regardless of whether one decides to access the law.

- Improved conversations between clinicians, providers and patients
- Better and sooner use of hospice care
- Better training in end-of-life care for physicians, nurses and other professionals.

## Do faith leaders support medical aid in dying?

Independent polling data compiled in 2016 by LifeWay Research, a Christian research group, shows that people of various faiths support medical aid in dying including Catholics (70%), Christians (59%), Protestants (53%), those of other religions (70%) and those who identify as nonreligious (84%).

"I have devoted my life to teaching people that our creator is a loving God who does not want people to suffer. That's why I am honored to help Compassion & Choices expand end-of-life care options that enable people to die peacefully at home, surrounded by their loved ones."

 Madison Shockley, member of the Compassion & Choices Board of Directors and African American Leadership Council

The Sam DeWitt Proctor Conference, a progressive faith leader group, endorsed medical aid in dying in 2019, to recommend that individuals and families educate themselves on all aspects of end-of-life planning

Additional information is also available at <u>Frequently Asked Questions</u> and <u>Faith Leaders and Communities Support Medical Aid in Dying.</u>

#### How does medical aid in dying impact people with disabilities?

The medical aid in dying and disability rights movements share important core values as Compassion & Choices: autonomy, independence and self-determination.

There is an astounding amount of often well-intentioned but extremely misleading misinformation surrounding how the sound medical practice of medical aid in dying affects people living with

disabilities. We take this seriously. Our work is about bringing people comfort during the most difficult time of their life — not causing harm, and we prioritize ensuring that any authorization of medical aid in dying protects vulnerable communities. Neither age nor disability are qualifying factors for medical aid in dying.

See also <u>Medical Aid-in-Dying and People With Disabilities</u> and <u>Misconceptions about Medical Aid-in-Dying and the Disabilities Community</u>.

## Is there diverse support for medical aid in dying?

There is consistent and growing support for medical aid in dying across numerous diverse communities. The Compassion & Choices Community Engagement program has developed leadership councils which focus on education and outreach within the LGBTQ+, African American, Asian American/Native Hawaiian/Pacific Islander and Latino communities. Additionally, we have targeted outreach to faith leaders, people with disabilities and physicians. Find out more about the diversity of the movement at Community Engagement on our website.

# Is life insurance affected by medical aid in dying?

Medical aid in dying laws prevent an individual from being denied health insurance, life insurance or annuities because they pursue medical aid in dying. There is a common misconception that utilizing medical aid in dying will have a negative impact on life insurance coverage. The fact is that there is no connection between denial of life insurance benefits and medical aid in dying. For additional information, please read <a href="Insurance Coverage and Medical Aid in Dying">Insurance Coverage and Medical Aid in Dying</a>.

## How does medical aid in dying affect a death certificate?

Medical aid in dying laws require the underlying terminal illness be listed as the cause of death on the death certificate when someone uses medical aid in dying. This practice is consistent with the way doctors routinely report death regardless of the variety of ways that people with terminal illnesses die. For example, doctors don't list "disconnecting the ventilator" or "asphyxiation" as the cause of death for a person who had a massive stroke and was ultimately removed from life support. They list "stroke" or "cerebrovascular accident." Because public health officials use death certificates to compile data on various statistics, the underlying terminal illness is the most accurate and relevant data to provide.

# What is the medication protocol?

Medical aid in dying laws do not specify the medications that should or must be used. It is up to the prescribing clinician to determine which medications will work best for the individual. The

prescription will include a combination of medications to prevent nausea and vomiting along with a compounded mixture of multiple medications that will likely arrive in powder form to be mixed with a small amount of liquid prior to ingestion.

The individual may mix medications themselves or engage the support of others to prepare the mixture. Regardless, the individual must self-administer their own medications.

Due to the multiple steps involved in the process, planning is encouraged to successfully use medical aid in dying.

For those with limited mobility, difficulty swallowing or other needs, there are other methods for taking the medication such as via a feeding tube, rectal catheter or ostomy. These alternative routes still require the individual to be able to self-administer by pushing the plunger on their own. Intravenous (IV) administration of aid-in-dying medication is not allowed or practiced in any authorized state, and injection is explicitly prohibited in each of the laws.

## How do medical aid-in-dying laws differ by jurisdiction?

All current aid-in-dying laws are modeled after Oregon's law with various nuances. Each has core protections in place to ensure the laws serve only eligible and qualified patients. For example, safeguards include that anyone seeking medical aid in dying must be terminally ill and mentally capable, must make the request on their own behalf, may withdraw their request or decide not to use the medication and must be able to self-ingest the medication.

Variances include length of waiting period or days between first and second request, whether a request must be made in writing or witnessed, reporting requirements and other definitions and references to each state's statutes. More information about the different laws can be found on each state subsection of our website's In Your State page.

Each jurisdiction's regulatory and procedural requirements differ slightly but include four key provisions. The person must:

- Be an adult, at least 18 years old
- >>> Be mentally capable of healthcare decision-making and acting voluntarily
- >> Have a terminal diagnosis with a prognosis of six months or less to live
- Self-ingest the medication

#### What's next?

Contact the Compassion & Choices staff working in your state to get involved, or email the National Volunteer Program manager at <a href="wolunteer@compassionandchoices.org">wolunteer@compassionandchoices.org</a> for more information. Visit our website to learn more about <a href="mailto:Compassion & Choices">Compassion & Choices</a> and our work.

# Resources

#### **Know the Facts**

Frequently Asked Questions About Medical Aid in Dying

Facts About Medical Aid in Dying

Insurance Coverage and Medical Aid in Dying

Medical Aid in Dying and People with Disabilities

Medical Aid in Dying and Palliative Care

Medical Aid in Dying is Not Suicide

**End-of-Life Decisions Guide and Toolkit** 

Additional End-of-Life Tools and Resources

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

Organizations Supporting End of Life Planning and Options

#### **Webinars**

How Medical Aid in Dying Really Works in Authorized States (2021)

Patient Perspectives on Medical Aid in Dying (2020)

Medical Aid in Dying and ALS (2021)

#### Storytellers share their Story

VIDEO: A Story of Medical Aid in Dying: Brittany Maynard

VIDEO: <u>Deb Robertson - Storyteller from Illinois</u> VIDEO: <u>Susy Flack - On Motherhood and Dying</u> Remember the Mission, Vision and Values of Compassion and Choices in your communications. Compassion & Choices may have talking points and messaging for some states.

#### Mission

Compassion & Choices improves care, expands options and empowers everyone to chart their end-of-life journey.

#### Vision

A society that affirms life, accepts the inevitability of death, embraces expanded options for compassionate dying and enables everyone to choose end-of-life care that reflects their values, priorities and beliefs.

#### **Values**

**Compassionate** in our commitment to dying patients having access to needed care at the end of life and being free of unwanted treatment, suffering or interference.

**Respectful** of the autonomy of individuals to decide what end-of-life options are best for them and their loved ones.

**Courageous** in our willingness to confront the toughest end-of-life health challenges, disrupt the broken status quo and protect an individual's right to self-determination.

**Credible** in all our education, advocacy and partnerships — our efforts are grounded in objective research and demonstrable facts.

**Resilient** in our capacity to respond to opportunities and threats in the movement, so that we can achieve our vision as quickly as possible.