

Volunteer Action Network Program Toolkit:

INTRODUCTION TO MEDICAL AID IN DYING

What is Medical Aid in Dying?

Medical Aid in Dying is a medical practice that provides a **terminally ill,** mentally capable adult with a prognosis of six months or less to live with the option to request a doctor's prescription for medication they can decide to self-ingest to peacefully end unbearable suffering.

Eleven jurisdictions currently authorize medical aid in dying: California, Colorado, Hawai'i, 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, well-established eligibility standards and over a dozen guidelines are applied in each case. For example, two healthcare providers must confirm that the patient has a prognosis of six months or less to live — due to terminal illness, not because of age or disability — is able to make an informed healthcare decision, is not being coerced and is able to take the medication themselves.

Many who receive a prescription for medical aid in dying do not ingest the medication, but research shows just having medical aid in dying as an 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 is also an introduction to the resources available through Compassion & Choices, including polling data, fact sheets and more.

Does the American Medical Association support medical aid in dying?

On June 11, 2019, a new policy position recommended by the Council on Ethical and Judicial Affairs (CEJA 2-A-19 Report) was adopted by the American Medical Association (AMA). For the first time, the AMA affirmed that physicians participating in medical aid in dying are acting consistently with their professional obligations.

Striking a 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. There are more details regarding the 2019 policy of the AMA in this Fact Sheet: Where Does the American Medical Association Stand on Medical Aid in Dying?

Where does the medical community stand on medical aid in dying?

A Medscape Oncology Ethics Report of 2020 showed this: When asked "should physician assisted dying be made legal for terminally ill patients?" 55% of the more than 5,000 oncologists surveyed nationwide said "yes," compared to 49% in 2018."

A 2020 survey of 5,000 physicians conducted by Medscape [
https://www.medscape.com/slideshow/2020-ethics-report-life-death-6013311#2] indicates doctors in the United States agree — by a 38% margin (55% vs. 17%) — that physician assisted dying should be made legal for terminally ill patients.

More and more medical associations and professional organizations are adopting policies that support patient-directed care.

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 AAFP joined the <u>American Association of Hospice and Palliative Medicine</u>, which 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 dropped their opposition to, or endorsed 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, their official position statement, the number of members, and date of their statement, please refer to this fact sheet: Major Medical Associations That Recognize Medical Aid in Dying.

How are palliative care and medical aid in dying related?

A New England Journal of Medicine study of hospice nurses and social workers in Oregon reported that symptoms like pain, depression, anxiety, extreme air hunger, and fear of dying were less pronounced among hospice patients who requested aid-in-dying medication, indicating a strong palliative care benefit for having an aid-in-dying prescription on hand regardless of whether it ever gets filled or ingested. Get more details in the fact sheet Medical Aid in Dying and Palliative Care

Is medical aid in dying the same as assisted suicide?

No, they are not the same. Factually, legally and medically speaking, it is inaccurate to equate medical aid in dying with assisted suicide. Those who qualify for medical aid in dying may already have the option to not prolong their deaths by refusing unwanted medical treatment, stopping life sustaining treatment, or voluntary stopping of eating and drinking (VSED). These options are not equated with suicide because, like medical aid in dying, they are processes supported at the end-of-life by healthcare systems. The terminally ill person who decides to utilize medical aid in dying is deciding not to prolong a difficult and often painful dying process.

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

Medical aid in dying is utilized by terminally ill people who seek a gentle, peaceful death and avoid unbearable suffering in the final days of the dying process. Please see the fact sheet Medical Aid-in-Dying Is Not Assisted Suicide

Frequently Asked Questions and Resources

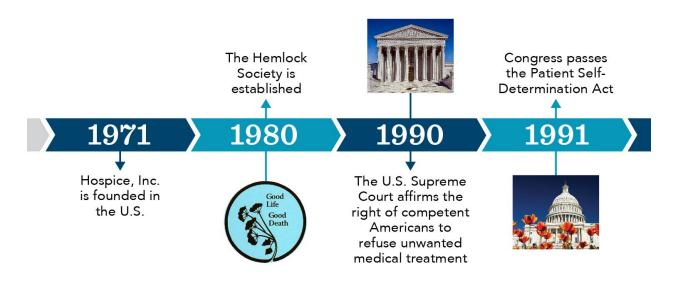
Where is medical aid in dying authorized?

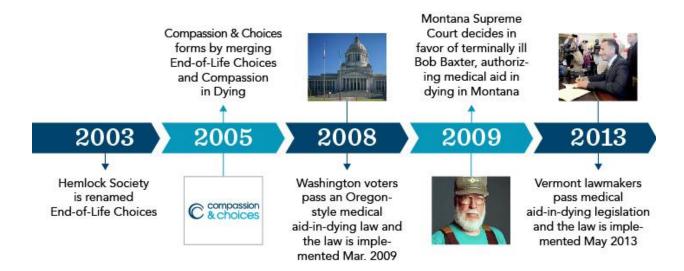
Medical Aid in Dying is authorized in ten states and Washington D.C.

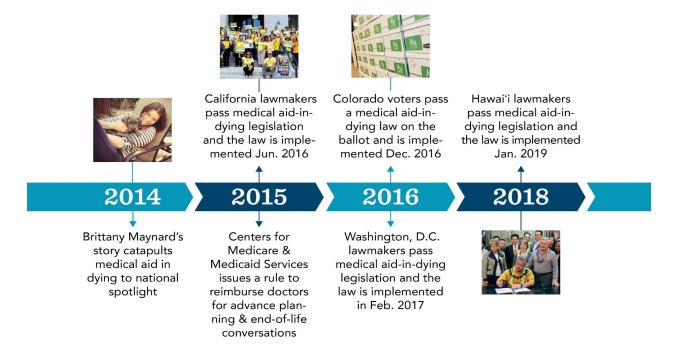
- 1994: Oregon Voters pass legislation called the Oregon Death with Dignity Act, and the law was promptly challenged; In 1997 the Oregon state Supreme Court upheld the Death with Dignity Act of 1994. Lawmakers pass amended legislation in 2019.
- 1997: Oregon Death with Dignity Act takes effect.
- **2008: Washington Voters** pass an Oregon-style medical aid-in-dying law that takes effect in March 2009.
- **2009: Montana State Supreme Court** finds in favor of terminally ill Bob Baxter, authorizing medical aid in dying in Montana.
- **2013: Vermont Lawmakers** pass legislation authorizing medical aid in dying that takes effect in May 2013.
- **2015: California Lawmakers** pass legislation authorizing medical aid in dying that takes effect June 2016. Lawmakers pass amended legislation in 2021.
- **2016: Colorado Voters** pass a medical aid-in-dying law on the ballot, by a margin of 65%, that takes effect December 2016.
- **2016: Washington, D.C. Lawmakers** pass legislation authorizing medical aid in dying that takes effect in February 2017.
- **2018: Hawai'i Lawmakers** pass legislation authorizing medical aid in dying that takes effect in January 2019.
- **2019:** New Jersey Lawmakers pass legislation authorizing medical aid in dying that takes effect in September 2019.
- **2019: Maine Lawmakers** pass legislation authorizing medical aid in dying that takes effect in September 2019.
- **2021: New Mexico Lawmakers** pass legislation authorizing medical aid in dying that takes effect in June 2021.

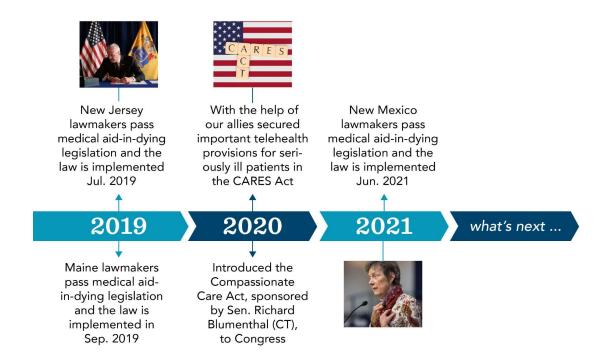
What is the history of the end-of-life options movement?

With 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, there are many milestones in the history of the movement. Visit the <u>History of the Movement fact sheet</u> for a comprehensive history of this nationwide movement. This timeline has some of the highlights:









What can we learn from over 20 years of data in Oregon?

In a recent executive summary of more than two decades of data on medical aid in dying in Oregon, collection and publication of which is required by the Oregon Health Authority as a condition of the law, it was shown:

"In 2020, 370 people were reported to have received prescriptions under the DWDA. As of January 22, 2021, 245 people had died in 2020 from ingesting the prescribed medications, including 22 who had received prescriptions in previous years. Demographic characteristics of DWDA patients were similar to those of previous years: most patients were aged 65 years or older (81%) and white (97%). While cancer still accounted for most underlying illnesses (66%), patients with heart disease (11%) outnumbered those with neurological disease (8%) for the first time in 2020. OHA made no referrals to the Oregon Medical Board for failure to comply with DWDA requirements."

Read the details: Oregon Department of Health Annual Reports

Each state where medical aid in dying is authorized has its own reporting requirements with their Department of Health. Please refer to the state government Department of Health for more information.

Is there a compilation of data to reference?

Review this report: Medical Aid in Dying: A Policy to Improve Care and Expand Options at Life's End. This resource provides you with evidence-based, patient-driven facts about medical aid in dying and addresses the most common questions, concerns and hypothetical claims that we hear across the nation. It is offered in the spirit of partnership, and in the hope that we can build on the positive evidence and experience of the authorized jurisdictions by passing evidence-based legislation in your state.

What does public polling on medical aid in dying show?

Consistently large majorities in the United States across generations, genders, educational, political, racial and 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 suicide' or 'physician-assisted dying' should be made legal for terminally ill patients." Learn more in the fact sheet Polling on Medical Aid in Dving.

Do faith leaders support medical aid in dying?

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

Archbishop Desmond Tutu expressed, "I have been fortunate to spend my life working for dignity for the living. Now I wish to apply my mind to the issue of dignity for the dying. I revere the sanctity of life — but not at any cost ... People should die a decent death. For me that means having had the conversations with those I have crossed with in life and being at peace. It means being able to say goodbye to loved ones — if possible, at home."

The Sam De Witt Proctor Conference, a progressive faith leader group endorsed medical aid in dying in 2019.

Fact sheet: Frequently Asked Questions for Faith Leaders

Fact sheet: Faith Leaders and Communities Support Medical Aid in Dying

What are the facts about medical aid in dying and people with disabilities?

Disability Rights Oregon (DRO) has received no complaints about coercion or abuse of the practice in the 20-plus years since Oregon's medical aid-in-dying law was implemented in 1997. In a letter dated February 14, 2019, Executive Director Bob Joondeph states,

"In the years since passage of the Oregon Death with Dignity Act (the Act), DRO has received very few complaints from disabled Oregonians about the Act. All of the complaints we have 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, thereby denying these persons the ability to use the Act. DRO has never to my knowledge received a complaint that a person with disabilities was coerced or being coerced to make use of the Act."

Gene Hughes, a disability rights activist from New York, sums up his support of medical aid in dying like this:

"We cannot advocate for the rights of people living with disabilities to be able to make their own choices and healthcare decisions during life, only to deny those freedoms at the end of life. I believe much of the objection to medical aid in dying is driven by fear and misunderstanding. Dying is a part of living."

Fact Sheet: Medical Aid-in-Dying and People With Disabilities

Fact Sheet: Misconceptions about Medical Aid-in-Dying and the Disabilities Community

Is insurance affected by medical aid in dying?

There is a common misconception that utilizing medical aid in dying will have a negative impact on insurance coverage. The fact is that there is no connection between denial of insurance coverage and medical aid in dying.

Fact sheet: Insurance Coverage and Medical Aid in Dying

How does medical aid in dying affect a death certificate?

The underlying terminal illness is listed as the cause of death when someone uses the option of medical aid in dying. This practice is consistent with the way doctors routinely report death on a death certificate 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, including leading causes of death, and report that data to the National Center for Health Statistics based upon the International Classification of Diseases (ICD), the underlying terminal illness is the most accurate and relevant data to provide. Learn more from the fact sheet Medical Aid-in-Dying and Death Certificates

What is the medication protocol?

Patients have various options for taking the medication. The type and dosage of aid-in-dying medication the doctor prescribes for the terminally ill person can vary. Just like there is not one blood pressure medicine, there is not just one medication for medical aid in dying. Historically, prescriptions for medical aid in dying involved three separate medications: two to speed absorption and prevent nausea, followed by a short-acting barbiturate. However, as science and technology continue to advance, and due to market-driven variations in the costs and availability of drugs over time, several medications and combinations of medications have been developed and are now successfully used in medical aid-in-dying prescriptions.

Once the prescription is filled, the terminally ill person continues to have the option to take or not take it, or to delay the date. 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. In rare cases, the medication may be given via rectal catheter or feeding tube.

How do medical aid-in-dying laws differ by state?

Medical aid-in-dying laws (Oregon, Washington, Vermont, California, Colorado, Hawai'i, the District of Columbia, New Jersey, Maine and New Mexico) are all similar to and 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, core 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.

Components of laws that may vary per jurisdiction include length of waiting period or days between first and second request, whether a request must be made in writing or witnessed, reporting requirements for Qualified clinicians, and other definitions and references to each state(s) statutes. More information about the law in each authorized state can be found on each state subsection of the In Your State page on the Compassion & Choices website.

The Montana State Supreme Court finding in favor of plaintiff Bob Baxter is the only case of a state authorizing medical aid in dying via court ruling.

Each jurisdiction's regulatory and procedural requirements differ slightly according to the laws of the jurisdiction, but the standard of care in authorized jurisdictions include four keystone 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.

Other regulatory and procedural requirements with some variation in each state may include:

- >> The person is fully informed of all their options.
- >> The person must request the prescription from their qualified clinician, verbally and in writing.
- >> Witnesses must sign the request form confirming the person is acting voluntarily.
- >> There may be a waiting period between an initial and second request.
- >> The qualified clinician must offer the person multiple opportunities to take back the request.
- >> Residency in the state where they intend to ingest the medicine.

Additional important components may also include specific details and definitions:

- Medical aid-in-dying is specifically not considered suicide or assisted suicide.
- >> The terminal disease is listed as the cause of death on the death certificate.
- Wills, contracts, insurance and annuity policies are not affected.
- People have the right to rescind their request at any time.
- >> People have the right to decide not to take the medication once they have it.
- >> Unused medical aid-in-dying medication is subject to the same safe disposal procedures as all other controlled substances, including lethal drugs.
- The person must not take the medications in public.
- >> Provider participation is entirely voluntary, not mandated.

When forming legislation for medical aid in dying, there is a balance to find the right guidelines and requirements without making the burden of access for the person and their family too great to bear; in addition, legislation should avoid creating unusual reporting restrictions on providers, facilities or the department of health. Contact the Compassion & Choices staff working in your state for further details on policy and legislative efforts.

What's next?

Contact the Compassion & Choices staff working in your state to get involved, or email the National Volunteer Program manager at <u>volunteer@compassionandchoices.org</u> for more information.

Compassion & Choices is the nation's oldest, largest and most active nonprofit working to empower everyone to chart their end-of-life journey. For more than 30 years we have worked to change attitudes, practices and policies.

Compassion & Choices' vision is a society that affirms life and accepts the inevitability of death, embraces expanded options for compassionate dying and empowers everyone to choose end-of-life care that aligns with their priorities, values and beliefs.

Visit our website to learn more about <u>Compassion and Choices</u> and our work.

Resources

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

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