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compassion & choices

Care and Choice at the End of Life

Volunteer Action Network Program Toolkit:

INTRODUCTION TO MEDICAL AID IN DYING

Approved for Public Distribution

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Medical Aid in Dying

Medical aid in dying allows terminally ill adults to request and receive a prescription for medication that they may choose to take to bring about a peaceful death. To qualify, one must be mentally capable, able to self-ingest the medication and have a prognosis of six months or less to live.

Ten jurisdictions currently authorize medical aid in dying: California, Colorado, Montana, Oregon, Vermont, Washington state, Hawai'i, New Jersey, Maine and Washington, D.C.

Although each jurisdiction's medical aid-in-dying legislation varies slightly, well-established eligibility standards and over a dozen guidelines are applied in each case. For example, two doctors 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 and go on to die from their underlying illness, 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 2016 online survey conducted by Medscape of 7,500 U.S. doctors representing 25 medical specialties indicates doctors in the United States support — by a 28% margin (57% vs. 29%) — the decision of a patient with an "incurable and terminal" disease to end their own life. By the same margin, doctors say they would also want this option for themselves. More and more medical associations and professional organizations are adopting policies that support patient-directed care. Today, nearly six out of 10 (58%) of the physicians surveyed support medical aid in dying under the kinds of circumstances that legislation being considered in more than half the states would allow.

In October 2018, The American Academy of Family Physicians (AAFP) adopted a new 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 American Association of Hospice and Palliative Medicine, 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, over 20 national and state medical and professional associations have endorsed or dropped their opposition to medical aid in dying in response to growing support for this palliative care option among 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?

According to an Institute of Medicine report, palliative care provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious or advanced illness and their families. Simply living in a state where medical aid in dying is authorized can have a palliative effect when a terminal diagnosis has been given. However, the two are not mutually exclusive. Any patient with a grave illness expecting to recover can receive palliative care. Any patient on hospice who is not expected to recover can also receive palliative care. Palliative care can be provided to reduce suffering and improve quality of life for any patient. 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 refer to medical aid in dying as suicide or assisted suicide. The medical aid-in-dying laws in all authorized jurisdictions are very clear: "Actions taken in accordance with [the Act] shall not, for any purpose, constitute suicide, assisted suicide, mercy killing, euthanasia or homicide, under the law." This is because a person who is choosing medical aid in dying already has a terminal prognosis of six months or less to live. They are not deciding to die; the disease is taking their life. They are simply choosing not to prolong a difficult and painful dying process. In states where assisting a suicide is a felony, it remains so, including states where medical aid in dying is authorized. Saying "assisted suicide" in reference to a dying person's decision, inacurrately uses the language of a criminal act to describe a legitimate medical practice.

Medical aid in dying is utilized by terminally ill people who would prefer to live and are capable of making informed decisions. Their goal in seeking medical aid in dying is to plan 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 in the United States:

- **1994: Oregon** Voters passed legislation called the Oregon Death with Dignity Act, and the law was promptly challenged; In 1997 the Oregon state Supreme Court upholds the Death with Dignity Act of 1994.
- **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** 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.
- **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.

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 History of the Movement fact sheet for a comprehensive history of this nationwide movement.

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 2018, 249 people received prescriptions under the DWDA. As of January 22, 2019, 168 people died in 2018 from ingesting the prescribed medications, including 11 who had received the prescriptions in previous years. Characteristics of Death With Dignity Act patients were similar to those in previous years: most patients were aged 65 years or older (79.2%), almost all were on hospice care (92.6%), and most had cancer (62.5%). During 2018, two physicians were referred to the Oregon Medical Board for failure to comply with DWDA requirements."

Read the report: Oregon Department of Health Statistics

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 from all the authorized jurisdictions?

Review the Medical Aid in Dying: A Policy to Improve Care and Expand Options at Life's End. This 42-page comprehensive report in the "Resources" section of this toolkit contains an aggregate body of knowledge, science and data, including physician and public polling results on medical aid in dying.

What does public polling on medical aid in dying show?

Consistently large majorities in the United States across generations, genders, educational groups and even political affiliations and faith groups favor legislation to authorize medical aid in dying. These were measured by independent polling outlets such as Gallup (74% support in May 2020), LifeWay Research (67% support in September/October 2016) and Harris (74% support in November 2014).

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 Dying.

Do faith leaders support medical aid in dying?

Independent polling data by LifeWay Research (Sept. 2016) shows that medical aid in dying is supported by people from a wide variety of 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."

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

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." 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), 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. Today the most commonly prescribed is a compounded mixture of morphine sulfate, diazepam, propranolol and digoxin, called DDMP or DDMPII.

In practice, the doctor and patient will determine whether the medication should be given as capsules that the patient breaks apart, as a powder, or as a pre-prepared solution. If dispensed in capsule or powder form, the medication is mixed together with four ounces of liquid and ingested by the terminally ill individual. If dispensed as a liquid, usually two small vials must be mixed together and then ingested.

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. They must be able to ingest the medication themselves without help from doctors or caregivers. Upon taking the medication, the individual usually falls asleep within 20 minutes. In general, respiration slows over the course of an hour or two, then stops, and the individual dies peacefully in their sleep. 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 and Maine) 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 self-ingest the medication.

Components of state laws that may vary per state 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 physicians, 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 Bob Baxter is the only case of a state authorizing medical aid in dying via court ruling.

Each state's regulatory and procedural requirements differ slightly according to state law, but the standard of care in authorized jurisdictions include four keystone provisions. The person must:

- ☐ Be an adult, 18 years or older.
- ☐ 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 include:

- ☐ The person is fully informed of all their options.
- ☐ The person must request the prescription from their physician, 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 physician 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 of a good end-of-life options law also include:

- ☐ 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.
- ☐ Physician and 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 volunteer@compassionandchoices.org 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 Compassion and Choices 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