



Care and Choice at the End of Life

Volunteer Action Network Toolkit:

INTRODUCTION TO COMPASSION & CHOICES AND VOLUNTEERING

Welcome

Volunteers are at the heart of Compassion & Choices' advocacy, education and outreach efforts. We're delighted to welcome you to the Volunteer Action Network! Our success hinges on the generous participation of people like you — volunteers from across the country who contribute their time and talents to help people nationwide access the full range of end-of-life options. Thank you for choosing to volunteer with Compassion & Choices!

Our toolkits will help you match your interests and skills to the most impactful actions you can take as a Compassion & Choices volunteer. Particular attention has been given to resources that promote effective advocacy, engagement and policy change.

Due to the COVID-19 pandemic, we are encouraging volunteers to maintain social distance and to follow their state health authority and CDC recommendations.

Part 1 Our Mission and Vision

Our mission is to improve care, expand options and empower everyone to chart their end-of-life journey.

Compassion & Choices envisions 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.

We're so grateful that you're willing to help us work toward our mission and vision!

2028 Strategic Objectives

1. Half of the U.S. population lives where Medical Aid in Dying is authorized.
2. More patients can access the care they want - nothing more - nothing less.

3. To increase the diversity of the movement in the areas of race, religion, party affiliation and age.

Compassion & Choices Values

We are **Compassionate** in our conviction that dying patients should be free of unwanted treatment, suffering or outside interference.

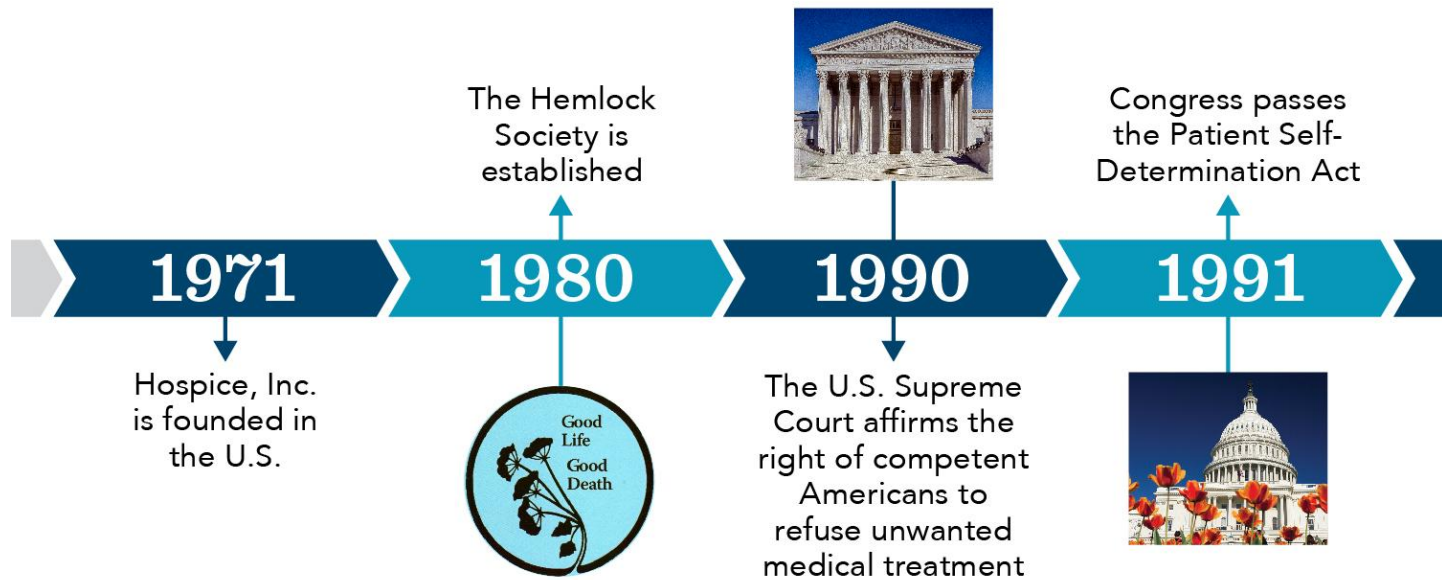
We are **Courageous** in our willingness to confront the toughest end-of-life health challenges, disrupt the broken status quo, and protect an individual's right to self-determination.

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

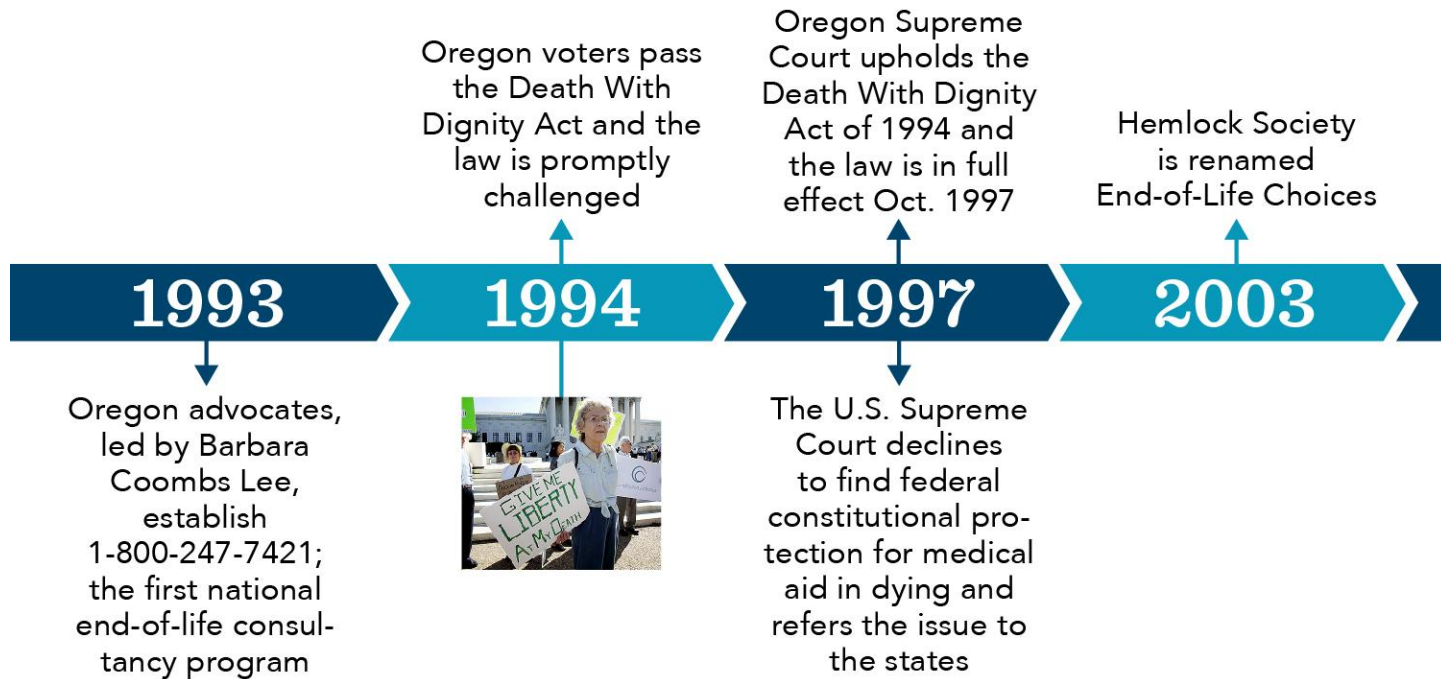
We are **Respectful** of the autonomy of individuals to decide what end-of-life options are best for them and their family.

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

History of the End-of-Life Movement



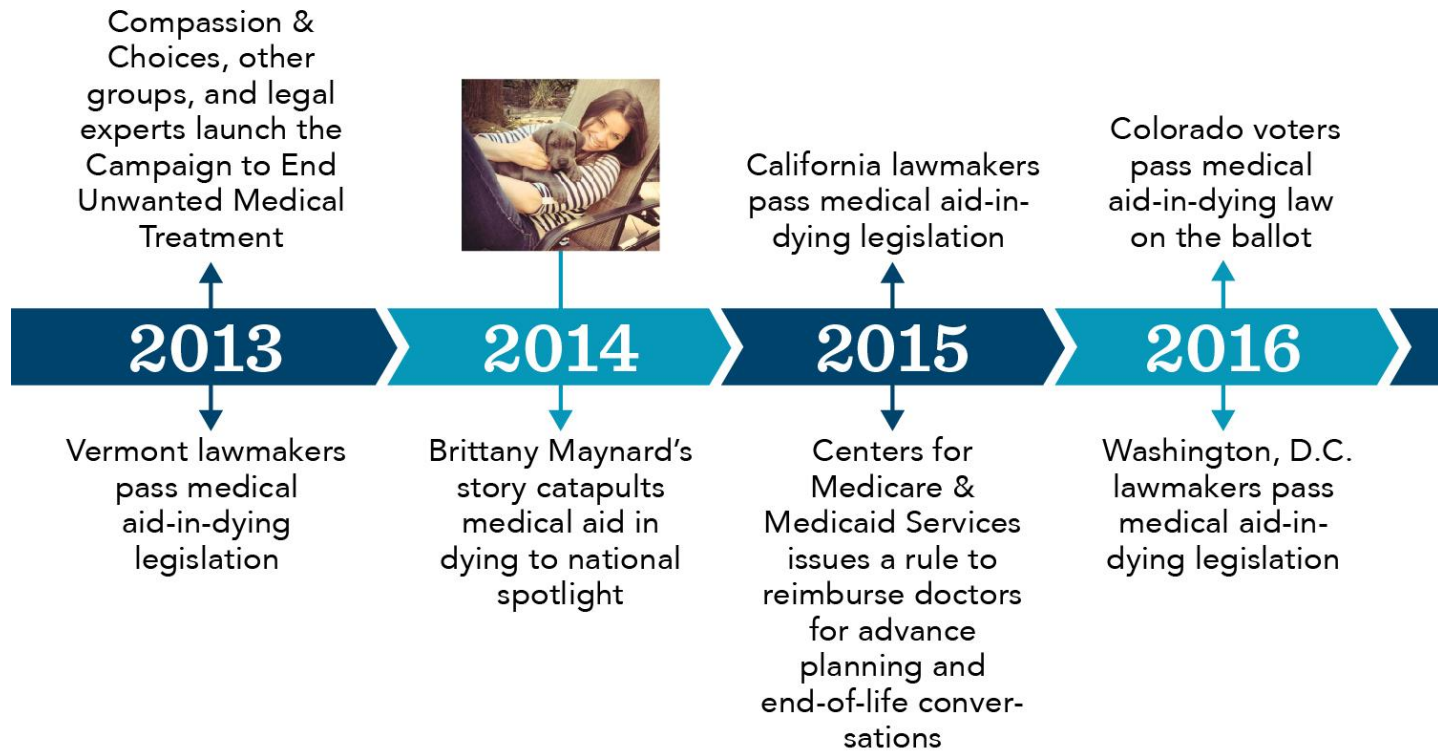
10 Years of Progress



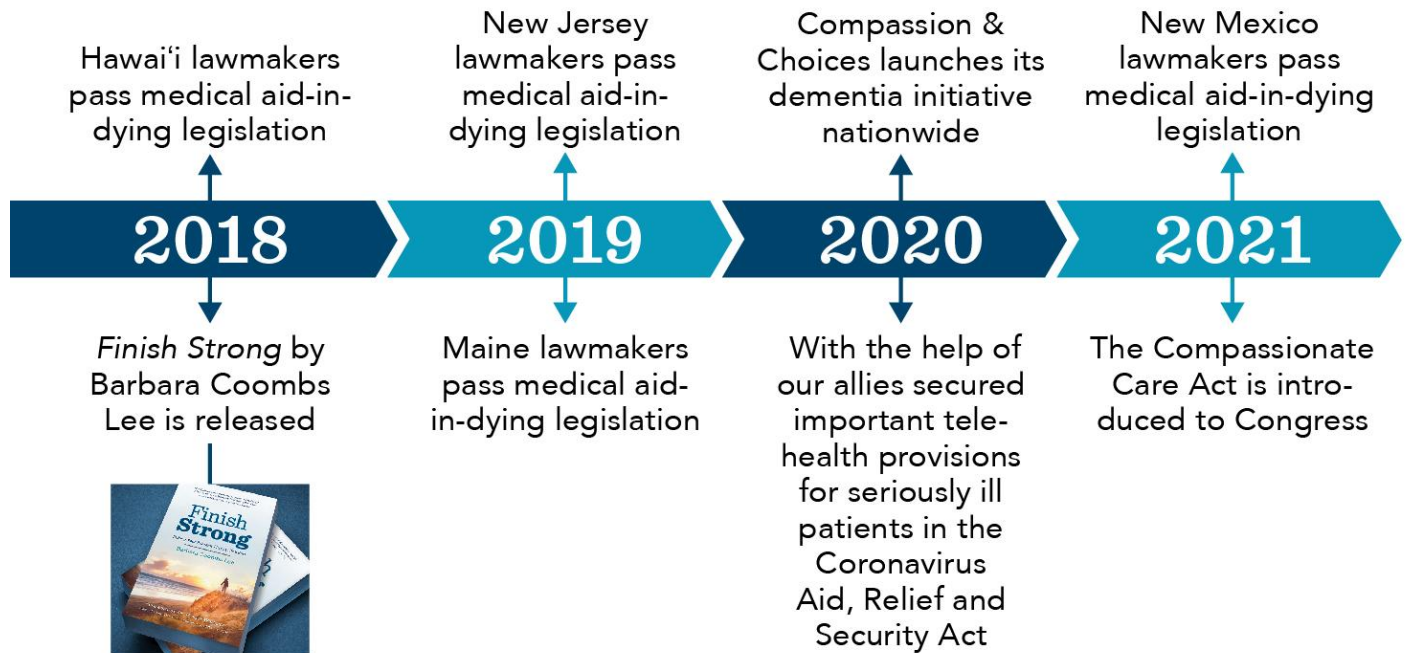
A National Conversation



The Brittany Effect



Unstoppable Momentum



Part 2

Compassion & Choices Programs

End-of-Life Consultation

Community Engagement

Political Advocacy

Implementation and Access in Authorized states

Legal Advocacy, Rights and Resources

Federal Policy

Storytelling, National Volunteer Program and Executive Volunteer Program

Dementia Initiative

Tools to Finish Strong

- **End-of-Life Consultation.** Our end-of-life consultation team provides confidential, nonjudgmental, professional support and information on the full range of options around end-of-life planning. When you call the 1 800 247 7421 Compassion & Choices number, follow the prompts to the End-of-Life Consultation staff, and we will return the call within one to two business days. While you will be talking with professional consultants, we are not set up as a crisis hotline nor do we provide medical or legal advice.
- **National Community Engagement Programs.** Compassion & Choices Community Engagement Program works across the nation to build and deepen relationships and engage audiences with constituents in these communities:
 - Latino
 - African American
 - Faith Leaders
 - Doctors for Dignity
 - Disability
 - LGBTQ
 - Asian American, Native Hawaiian, Pacific Islander
- **Political Advocacy.** Our Advocacy and Outreach Staff works with hundreds of volunteers across the country to pass, improve and protect medical aid in dying legislation. In many states our advocacy work is building capacity, engaging in public education and grassroots awareness about all end-of-life options including advance care planning, completing advance directives and dementia.

- **Implementation and Access Campaign.** By the time medical aid in dying is authorized in a state, the important work to implement the law has already begun. Compassion & Choices staff works to educate residents of their option for medical aid in dying as a standard of care option available in that state. We want to enable people to access all their legal options through their own doctors and in their preferred medical setting. We want to ensure that medical aid in dying will be a secure feature on the healthcare landscape, able to withstand the legal and legislative attacks that happen routinely in authorized states.
- **Legal Advocacy, Rights and Resources.** Compassion and Choices is dedicated to ensuring that everyone receives the best care possible and are in charge of their care options as they near the end of their lives. We have been at the forefront of end-of-life care legal issues. Our legal team litigates for plaintiffs right to end of life options, and participates in numerous cases, advocating for all people to have the right to make such decisions.
- **Federal Policy.** Compassion & Choices monitors and assists in authorizing legislation and monitoring regulations and amendments in Washington D.C. We collaborate with other groups and allies for good federal policy, and against bad policy. For example, our team worked to get several pertinent rules included in the 2020 CARES Act, regarding telehealth and the delivery of end-of-life care. In collaboration with Sen. Richard Blumenthal (CT), we are introducing the Compassionate Care Act in 2021.
- **Storytelling, National Volunteer Program and Executive Volunteer Program.**
 - The power of personal stories to inspire and drive change is undeniable. Facts and figures don't compel someone to action. We're driven by emotion. Storytelling is hard-wired into us. We'll forget statistics. But we'll never forget how someone made us feel. That's what makes storytelling one of the most powerful tools for advocacy. Lobbyists can give elected officials the polling data--but Storytellers have the power to make it feel real. Our storytelling program gives Advocates from across the country the opportunity to share their story and allow us to amplify and elevate their personal experience to help our efforts.
 - The National Volunteer Program supports hundreds of volunteer advocates who work in their community to educate, advocate and empower others. Across the country, volunteers are writing letters to newspapers and legislators, calling governors and lawmakers, testifying at public hearings, lobbying, sharing information with their networks, hosting watch parties and book clubs and more.
 - Executive Volunteer Program: Executive Volunteers employ their professional skills, networks and experience to magnify our impact and amplify our bandwidth and organizational capacity in a specific skill-set/project-based

partnership.

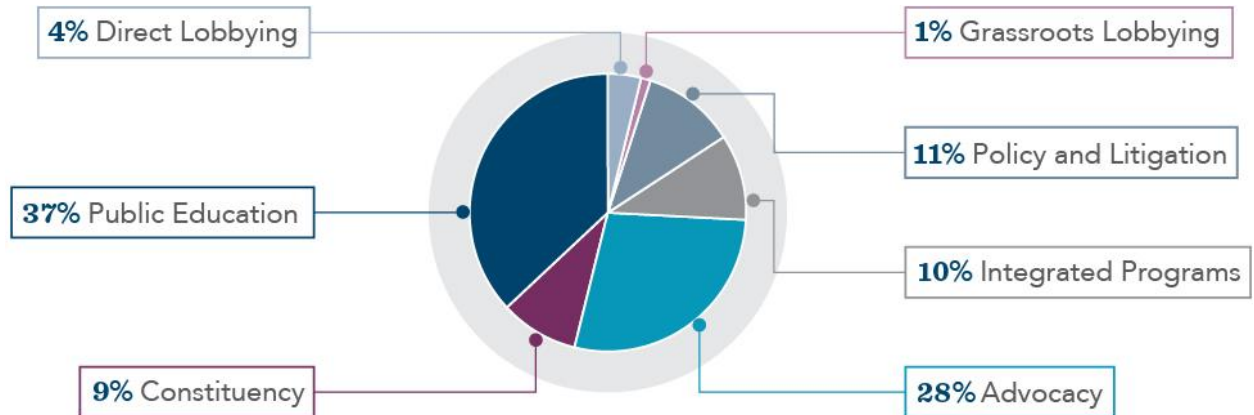
- **Dementia Initiative.** This program helps patients stay in control of their lives and care in the early stages of a dementia diagnosis. Patients can provide a set of clear-cut care instructions to their loved ones, outlining their intentions through a personalized care plan called a Dementia Healthcare Directive, which adds to a standard Advance Directive. This gives loved ones a way to confidently implement critical, informed decisions on the patients behalf.
- **Tools to Finish Strong.** This program is a collection of resources that specifically address planning your end-of-life care, including two interactive web-based tools, the Dementia Decoder and the Dementia Values and Priorities Tool. Other resources include *Finish Strong*, Barbara Coombs Lee book, and our End of Life Decision Guide and Toolkit and much more at our [Plan You Care Resource Center](#).

Funding and Expenditures

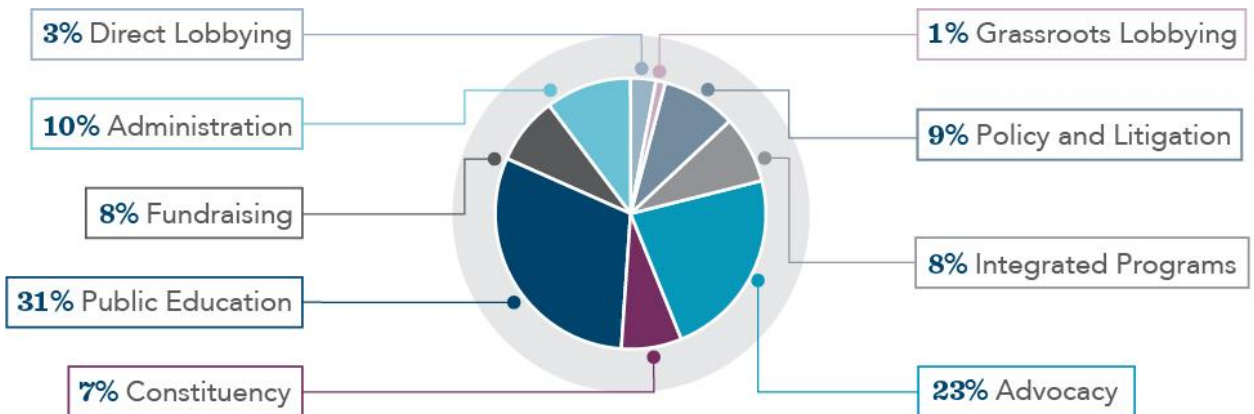
Revenue and Support

- 95% of Compassion & Choices income is from individual people who care about our work.
- We received over \$19 million in gifts from 35,709 generous donors in 50 states in FY 19/20.
- We do not receive any government funding.
- Complete information is available in the [Compassion & Choices Annual Report](#).

Program Costs 65% Public Education and Advocacy



All Costs - 54% Public Education and Advocacy



Compassion & Choices Scope of Practice

Compassion & Choices - Public Education and Advocacy

- 501(c)(3) organization
- Education and awareness
- Grassroots mobilization
- Consumer empowerment
- Gifts to Compassion & Choices generally are deductible as charitable contributions
- Limited lobbying expenses
- Cannot support or endorse candidates

Compassion & Choices Action Network (CCAN) - Political Change

- 501(c)(4)
- Ballot initiatives
- Legislative campaigns
- Electoral activity
- Gifts to Compassion & Choices Action Network are NOT deductible as charitable contributions
- Unlimited lobbying expenses
- Can support or endorse candidates

Political Action Committee (PAC)

- Compassion & Choices may elect to form a Political Action Committee (PAC) for various campaigns

Part 3

Terminology and Definitions

Basics to Understand

Advance Directive: Called “advance” because it is prepared prior to a health crisis in which it would guide medical care. Two primary elements:

1. Living Will - Where you state your healthcare wishes. 2. Health Care Proxy/Health Care Power of Attorney - The person named in your advance directive who is legally responsible for decision-making and directing care if you are unable to. Both may change. Update annually on

National Healthcare Decisions Day, April 16.

Hospice/Hospice Care: An interdisciplinary team of caregivers provides comfort, support and dignity to terminally ill people, (and their family) when medical treatment is no longer expected to cure the disease or prolong life. This service often takes place in the home.

Palliative Care: A variety of therapies or modalities that are intended to relieve suffering and improve quality of life for the patient; is available to any/all patients; not exclusively for terminally ill patients. May include music, spiritual support, massage, pet therapy in addition to medicine.

Medical Terms

VSED: Voluntarily Stopping Eating and Drinking is a legal right for any individual who wishes to shorten their dying process by refusing nourishment and hydration, orally or through a tube.

Palliative Sedation: Also referred to as terminal sedation or total sedation. Refers to the continuous administration of medication to relieve severe, intractable symptoms that cannot be controlled while keeping the person conscious. This drug-induced 'coma' state is maintained until death occurs.

Terminal Prognosis/Terminally Ill: An incurable and irreversible illness for which the medical expectation is death within six months.

Legal Terms

Refusing Medical Treatment: A legal right to refuse, or discontinue medical treatment even if that treatment is necessary to sustain life. These life-sustaining interventions can include ventilators, feeding tubes, pacemakers and dialysis.

MOLST or POLST: Medical or Physician Orders for Life Sustaining Treatment.

DNR: Stands for Do Not Resuscitate.

Other Terminology

Assisted Suicide: The instance where a person aids or assists a suicidal person to commit the act that causes their death. Assisted Suicide is an inflammatory, insensitive term for those who wish to live but are terminally ill. It is incorrect medically, legally and factually.

Euthanasia: Also known as "mercy killing." In the act of euthanasia, another person — not the dying person — who chooses and acts to cause the death of another. Euthanasia, is against the law in the United States.

Medical Aid in Dying: Medical aid in dying allows a terminally ill adult 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.

Part 4

Volunteering With Compassion & Choices

Why Volunteer?

- Leave a legacy by being part of this movement and adding to the momentum
- Help change policy and society
- Engage in democracy and the political process.
- Learn about yourself, people and politics.
- Make new friends, diversify and expand your social network.
- Educate and empower others in your community, and help them access the full range of options so their end-of-life care reflects their values, priorities and beliefs.
- Because Volunteers Make. Change. Happen!

Specific strategies and goals in every state vary and are directed by the Compassion & Choices field staff, local action team leaders, legislators and other partners leading the effort in that state. If you don't know your field staff point of contact, contact National Volunteer Program Manager AJ Hetzler at volunteer@compassionandchoices.org to find the appropriate staff contacts.

Volunteer Activities: In Person or Online

In Your Community

- Supply materials to local public places such as a community center, senior center, and other venues.
- Table at health fairs, farmers markets or other events such as a civil rights and diversity event to distribute information on end-of-life options and to find more supporters for the movement.
- Host a fundraiser or friendraiser.
- Organize a book club discussion of *Finish Strong* by Compassion & Choices President Emerita Barbara Coombs Lee.
- Ask your local library to acquire *Finish Strong*.

- Hold a video screening watch party on end-of-life issues (we have several titles to recommend) with a question and answer session.
- Become a public speaker and organize free local events to educate your community on end-of-life options, medical aid in dying and Compassion & Choices.
- Coordinate opportunities for other Compassion & Choices volunteers to provide local presentations.
- Talk to your doctor(s) and begin or continue the dialog.
- Complete your advance directive and help someone else do the same.
- Stay informed and on message.

In the Media

- Share your story and work with Compassion & Choices to raise awareness in your state.
- Help identify diverse storytellers willing to share their stories.
- Call in to a radio show to voice your support for patient-directed end-of-life care.
- Write an op-ed or letter to the editor of a local, state or national paper or magazine.
- Educate your network by regularly sharing our news and Facebook posts.
- Be a social media voice for the movement on Facebook and Twitter.
- Record a selfie video to use on social media.
- Stay informed and on message.

Grassroots Advocacy

- Start or join an action team in your state.
- Contact your lawmakers to discuss medical aid-in-dying legislation and then stay in touch.
- Speak up at town hall meetings and at legislator meet-and-greet events.
- Attend community events and initiate discussions about medical aid in dying and end of life options.
- Testify at legislative public hearings (if applicable).
- Participate in lobby days (if applicable).
- Stay informed and on message.

On Social Media

- Find content on Facebook and like, share, comment.
- Personalize content on Facebook.
- Join Twitter and follow key legislators, tag them in your Tweets.
- Join the Instagram community.
- Create a Selfie to post to social media accounts.
- Make a Youtube video testimonial.

- Participate in lobby days (if applicable).
- Stay informed and on message.

In the Medical Community

- Coordinate events to educate healthcare professionals and systems (hospitals, medical groups, hospices, healthcare associations) at grand rounds, in-services and conferences.
- Identify the policies and procedures on medical aid in dying of healthcare systems in authorized states.
- Educate and develop relationships with your state medical association and component associations to adopt supportive or engaged neutral positions on medical aid in dying.
- Champion the issue and be the subject matter expert at your hospice, clinic, hospital or facility.
- Stay informed and on message.

Help Us Track Volunteer Efforts

Visit the Volunteer Resource Center and use our [online tool](#) to log your volunteer activity so that we can record and celebrate it! Bookmark the link to visit the tool and note your efforts every time you take action.

Representing Compassion & Choices

- We're very proud that our volunteers are respectful, professional and unflappable
- We ask that you be diplomatic—try to find common ground. Don't argue or debate - agree to disagree.
- Use your authentic voice, but stay on message.
- Wear only one hat at a time.
- Honor our volunteer confidentiality and media agreements.

Supporting Compassion & Choices

- Compassion & Choices depends on individual donations from people like you and me.
- Each dollar raised advances our effort to realize our vision and mission.
- Consider helping us today by making a contribution online or sending a check to Compassion & Choices Gift Processing Center PO Box 485 Etna, NH 03750-0485.

Volunteer Resource Center and Training

For New Volunteers

[Introduction to Compassion & Choices and Volunteering](#)

[Introduction to Medical Aid in Dying](#)

[This Is Your Show Signature Song \(2020\)](#)

[Compassion & Choices 2020 Signature Event: Tributes, Stories & Song](#)

[Compassion & Choices 2021 Signature Event: Purpose, Power and Promise](#)

Our [Volunteer Resource Center](#) is your 24/7 online portal for training resources, including toolkits that cover:

- Basic Lobbying
- Communicating With Legislators and the Media
- Petitions, Tabling and Canvassing
- Passing a Local Resolution
- Hosting a House Party
- Hosting a *Finish Strong* Book Club Discussion
- Hosting a Video Screening with Q&A
- Introduction to Medical Aid in Dying
- Be a Digital Advocate in a Virtual World

The National Volunteer Program Manager can provide any assistance you may need regarding training sessions, materials or website help while you are volunteering with Compassion & Choices. Please call AJ Hetzler at 406-552-2916, Monday-Friday from 9:00 a.m. to 5:00 p.m. (Mountain time) for volunteer support.

Policies and Agreements

Below are two agreements that should be signed online before you begin official volunteer assignments or represent Compassion & Choices. If you are unsure whether you should complete these online agreement forms, contact National Volunteer Program Manager AJ Hetzler at 406-552-2916 or email volunteer@compassionandchoices.org.

[Compassion & Choices Volunteer Media Policy](#)

[Compassion & Choices Confidentiality Agreement](#)

If you are going to request or use a list of supporters from our database, we are compelled legally to ask that you sign the [Compassion & Choices Data Use Agreement](#).

If your volunteer efforts include in-person or public activities, we urge you to sign the [Compassion & Choices COVID-19 Acknowledgement](#) form which indicates you are aware of and will follow your state, local and CDC recommended guidelines regarding COVID-19.

Thank You

Once again, we're so grateful that you've chosen Compassion & Choices as a place to invest your time, energy and talent as a volunteer! To listen to our [Signature Song, click here to watch](#) on YouTube.