



Care and Choice at the End of Life

INTRODUCTION TO COMPASSION & CHOICES AND VOLUNTEERING

Volunteer Action Network Toolkit

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Welcome from the CEO

Hello,

Welcome to volunteering for Compassion and Choices.

I want to express my gratitude for your willingness to serve as a volunteer! Volunteers play an invaluable and important role in helping Compassion & Choices achieve our goals. Across the country, thousands of people are making a difference in their communities and in their state for the end-of-life movement.

Thanks to you, and your volunteer efforts, we are achieving our mission: to improve care, expand options and empower everybody to chart their end-of-life journey. Now and always, I am so grateful for your support and look forward to continuing to make a difference together.

With sincere gratitude,

Kim Callinan
President and Chief Executive Officer

Welcome to the Volunteer Action Network

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 empower people nationwide to understand the full range of end-of-life options. Thank you for choosing to volunteer with Compassion & Choices.

Cheerful regards,

AJ Hetzler
National Volunteer Program Manager

1. Mission, Vision and Values

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.

2. Strategic Objectives

Compassion & Choices has identified four primary areas – inform, empower, advocate and defend – which we will focus on throughout the strategic plan for FY 2024 to FY 2028. Details about each of these aspects are below.

Improve care through systemic and policy change.

- Improve patient-directed end-of-life care through demonstration projects, continuing education units/continuing medical education (CEU/CMEs) and federal legislation, or regulatory change in advance-care planning for dementia, equity in end-of-life care and palliative care integrated into emergency medicine.

Expand end-of-life care options.

- Expand medical aid in dying so that by 2028 at least half the U.S. population lives where medical aid in dying is an open and accessible medical practice with access in each region of the country.

Defend and protect end-of-life care options.

- Defend and protect the full range of patient-directed, end-of-life care which includes blocking efforts to weaken or overturn medical aid-in-dying laws and countering healthcare restrictions based on ethical and/or religious directives that impede patient choice and reduce end-of-life care options.

Empower everyone to chart their own end-of-life journey.

- Ensure that everyone is informed, empowered and engaged so they can direct, access and receive end-of-life healthcare that is consistent with their values and priorities.

Visit CompassionAndChoices.org/about-us/cc-strategic-plan to read the full details about our strategic plan.

3. 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: [The Unitarian Universalist Association](#) 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, a Mexican public for advance health education initiative
- > 2024: The Compassionate Care Act is introduced to Congress
- > 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

Please reference the [Our Accomplishments](#) and [History of the End-of-Life Choice Movement](#) sections of the Compassion & Choices website for additional and more detailed up to date information.

4. Outreach Snapshot




By the Numbers ...

576,383 Supporters 

7,249 Volunteers Across the Country 

85,083 Active Donors 

540,942 Online Actions 

358 Bipartisan Sponsors or Cosponsors Introduced 38 Bills to Authorize or Improve Medical Aid in Dying in 21 States 

2 States Where Medical Aid in Dying Is Authorized, Removed Residency Requirements


Facebook Supporters
80,390


X (Twitter) Followers
8,706


Video Views
20.9 mil.


Instagram Followers
4,735

Top Ratings From **5** Major Charity Watchdog Groups



current as of January 2024

CompassionAndChoices.org

5. Programs

Compassion & Choices offers a host of programs, tools and resources to help people “finish strong” and plan for an end-of-life experience that matches the life they’ve enjoyed — defined by love, purpose and agency.

- > **End-of-Life Consultation.** Confidential support, free resources and comprehensive information for navigating end-of-life care and options. In addition to the resources available online at CompassionAndChoices.org/eolc, consultants are available for assistance by leaving a message at 800-247-7421 or emailing eolc@compassionandchoices.org.
- > **Advance Care Planning and Tools to Finish Strong.** This program is a collection of resources that specifically address planning end-of-life care, including two interactive web-based tools: the Dementia Decoder and Dementia Values and Priorities Tool. Other resources include “[Finish Strong, Putting Your Priorities First at Life’s End](#)” by President Emerita and Senior Advisor of Compassion & Choices, Barbara Coombs Lee. The End of Life Decision Guide and Toolkit and more which can be found at our End-of-Life Planning Resource Center and our [Tools to Finish Strong](#).
- > **National Volunteer Program.** The National Volunteer Program supports hundreds of volunteer advocates who work in their community to further our mission, vision and objectives. Across the country, volunteers are writing letters to newspapers and legislators, testifying at public hearings, lobbying and sharing information with their networks. They host watch parties, advance care planning presentations, book clubs and more. Volunteers are talking to their neighbors, loved ones and physicians about their end-of-life values and priorities. The [Volunteer Resource Center](#) also provides an array of information and resources for volunteers to take action.
- > **Executive Volunteer Program.** Executive volunteers employ their professional skills, networks and experience to magnify our impact. They help to amplify our work in skill-set/project-based partnership.

> National Volunteer Engagement Opportunities, Councils and Programs.

We work across the nation to build and deepen relationships and engage with diverse audiences. Our programs and councils work to address language and cultural barriers, expand and diversify our volunteer base and outreach and change perceptions including through the media.

- *The Latino Leadership Council* (LLC) helps Compassion & Choices in our outreach to Latino leaders and constituents, addresses language and cultural barriers to understanding, recruits Latino volunteers and storytellers, develops culturally relevant materials and educates the Latino media.
- *The African American Leadership Council* (AALC) takes an active role in our work by engaging with volunteers, leaders and organizations that speak to and for African Americans, bringing greater diversity to our volunteer base and sharing the experiences of African Americans facing end-of-life issues.
- *The Asian American, Native Hawaiian and Pacific Islander Leadership Council* (AANHPI) shares their perspectives, experiences and expertise to help us understand what end-of-life choice means to our AANHPI communities — for example, changing perceptions of hospice and palliative care — and help us strategize ways to elevate the importance of community and culture at the end of life.
- *Clinical Engagement and Education* focuses on improving end-of-life care and addressing health inequities through education and training, advocacy, promoting best practices and building collaborations with clinical providers. Clinical Engagement is a team of interdisciplinary clinicians who bring their direct patient care experience to the mission of Compassion & Choices.
- *Doctors for Dignity* is a community of physicians who support the full range of options at the end of life including medical aid in dying, advocating to reduce end-of-life disparities and bringing the voice of medicine to public policy debates.
- The *National Emergency and Palliative Medicine Initiative* (NEPMI) seeks to transform care for people with serious illness by promoting and enhancing the integration of palliative care in emergency settings.
- The *Healthcare Advisory Council* (HAC) is an interdisciplinary collective of healthcare professionals with broad experience in supporting end-of-life care across the country. HAC provides insight and practical guidance as we work towards our strategic plan and mission.

- *Faith Leaders for Compassion* recognizes that most people who adhere to a faith or religious group support expanded end-of-life options. We're creating a network of faith leaders who support our mission and vision and work in their communities to normalize conversations around end-of-life planning and options.
 - *Catholics for Compassion* is a group of faithful Catholics committed to expanding end-of-life options for individuals diagnosed with terminal illnesses.
 - *Our LGBTQ+ Leadership Council* is committed to raising awareness around the healthcare disparities and barriers that the LGBTQ+ community faces. We created the LGBTQ+ Leadership Council to build partnerships with leaders and organizations to help educate and empower LGBTQ+ residents to chart their own end-of-life care journey.
- > **Political Advocacy.** Our advocacy and outreach staff works with thousands of volunteers across the country to pass, improve and protect medical aid in dying legislation, promote patient-directed care and support all end-of-life options. In many states, our advocacy work is building capacity, engaging in public education and grassroots awareness including advance care planning and using the Dementia Tool.
- > **Access.** By the time medical aid in dying is authorized in a state, the important work to implement the law and empower the public has already begun. Compassion & Choices collaborates, supports professionals and provides education. 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 and able to withstand the legal and legislative attacks that happen routinely in authorized states.
- > **Legal Advocacy, Rights and Resources.** Compassion & Choices is dedicated to ensuring that everyone receives the best care possible and remains in charge of their care options as they near the end of their lives. We have been at the forefront of a number of end-of-life care legal issues. Our legal team litigates for plaintiffs' right to end-of-life options and participates in numerous state and federal cases, advocating for all people to have the right to make end-of-life care decisions.

- > [Federal Advocacy and Policy](#). Compassion & Choices assists in drafting and monitoring legislation and regulations in Washington D.C. We work in the halls of Congress and federal agencies, calling on policymakers to improve end-of-life care by supporting legislation and regulation that allows people to be the primary deciders in their end-of-life care. We envision a [patient-directed system](#) that honors and respects patients' values, priorities and spiritual beliefs.

- > [Storyteller Program](#). The power of personal stories to inspire and drive change is undeniable. Our Storytelling Program gives advocates from across the country the opportunity to share their stories and allows us to amplify and elevate their personal experiences to help the movement.

- > [Living \(and Dying\) with Dementia](#). Compassion & Choices works to ensure people are planning for the kind of death they want, especially if they are living with dementia. Our goal is to empower people to take action, consider what matters most and discuss those wishes. Compassion & Choices proudly offers unique tools, including the [Dementia Decoder](#) to help plan for medical appointments and the [Dementia Values and Priorities Tool](#), an interactive tool to create a dementia directive.

6. Revenue and Support

Compassion & Choices supporters can be sure we balance our resources between providing crucial services and meeting important objectives while also operating at the highest level of efficiency. You can view or download our most recent [annual report](#), or request one to be mailed to you by emailing volunteer@compassionandchoices.org.

Compassion & Choices exists to provide resources for anyone seeking to learn more about care at the end of life but we rely on grassroots support to advance our mission. Here are a few things to note about our finances:

- > Compassion & Choices receives the majority of its income from individual donors like you who support our mission, vision and objectives.
- > We do not receive any government funding.
- > Additional financial information is available at CompassionAndChoices.org/about-us/financial-information.

7. Scope of Practice

When it comes to reporting and compliance with the IRS, we are committed to ensuring that our efforts are accurately and timely reflected by our quarterly filing. This information is simply for your information and does not affect anyone's eligibility or availability to volunteer. The majority of our work is done as Compassion & Choices, a non-profit organization that works to improve the end-of-life journey for all. Often, advocacy work is done through the Compassion & Choices Action Network when we are engaged in legislative, electoral or political efforts.

Compassion & Choices - Public Education and Advocacy

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

Compassion & Choices Action Network (CCAN) - Legislative/Policy Change

- > 501(c)(4)
- > Ballot initiatives
- > Legislative campaigns
- > Electoral activity
- > Gifts to Compassion & Choices Action Network are not tax deductible
- > Unlimited lobbying expenses
- > Can support or endorse candidates with proper approval from CCAN leadership

Political Action Committee (PAC)

- > CCAN has formed Political Action Committees (PAC) to support various federal or state campaigns

8. Representation and Impact

As a volunteer, you are an extension of the organization, and your representation of our mission, vision, values and objectives matters.

Representation

- > Be diplomatic — try to find common ground
- > Don't argue — agree to disagree
- > Use your authentic voice but stay on message.
- > Honor the Compassion & Choices volunteer confidentiality and media agreements
- > Get more training on state policy, public speaking, media interviews, etc. as needed

Impact

- > Empower people to take charge of their end-of-life plan
- > Leave a legacy by being part of this movement
- > Improve end-of-life healthcare and change policy
- > Learn more about yourself and the end-of-life journey
- > Make new friends/diversify and expand your social and professional network
- > Educate and involve others in your community
- > 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 need help getting in touch with your field staff point of contact, please contact the National Volunteer Program at volunteer@compassionandchoices.org to find the appropriate staff contacts.

10. Volunteer Opportunities

In Your Community

- > Provide local organizations, community centers, medical offices and other locations with End-of-Life Decisions Guide and Toolkit and other Compassion & Choices materials.
- > Host a table at a health fair, farmers market, etc. to distribute information on advance care planning and end-of-life options, or to find more supporters.
- > Host a fundraiser or friendraiser, raising funds and getting new people to support the work of Compassion & Choices.
- > Organize a book club discussion or ask your local library, other community resource center or place of worship to acquire the book "[Finish Strong, Putting Your Priorities First at Life's End](#)" by President Emerita and Senior Advisor of Compassion & Choices, Barbara Coombs Lee.
- > Identify opportunities to host meaningful conversations about end-of-life wishes and priorities such as hosting a watch party for a film about end-of-life issues or the annual [Signature Event](#).
- > Become a public speaker and organize free local events to educate your community on end-of-life issues.
- > Coordinate opportunities for other Compassion & Choices volunteers to provide local presentations.
- > Talk to your healthcare providers.
- > Talk to your faith leader and/or spiritual counselor about your end-of-life priorities.
- > Share Compassion & Choices' advance care planning materials and the Dementia Tool at your place of worship or plan a discussion/workshop on end-of-life in your faith community.
- > Complete or update your advance directive and help someone else do the same.

Grassroots Advocacy

- > Start or join an action team in your state.
- > Contact your lawmakers to discuss end-of-life issues and legislation that affects healthcare at the end of life including medical aid-in-dying legislation.
- > Speak up at town hall meetings and legislator meet-and-greet events.
- > Engage your faith leader about a faith-based community event focused on end-of-life issues and planning.
- > Attend community events and initiate discussions about advance care planning, medical aid-in-dying and other end-of-life options.
- > Vote.

- > Testify at legislative public hearings.
- > Participate in lobby days.

In the Media and on Social Media

- > [Share your story](#) with Compassion & Choices to raise awareness.
- > Help us identify other diverse [Storytellers](#).
- > Call in to a radio show to voice your support for patient-directed end-of-life care.
- > Using our volunteer resources as a guide, write an op-ed or letter to the editor of a local, state or national paper or magazine.
- > Be a social media voice for the movement on [Facebook](#), [Instagram](#) and/or [X](#) (formerly Twitter) and [YouTube](#).
- > Send, share and/or post content from [Compassion & Choice's YouTube channel](#) to your social media pages.
- > Engage your online network by regularly sharing Compassion & Choices news and social media posts.
- > Record a selfie video to use on social media and tag us.
- > Reshare content from Compassion & Choices' main Facebook and your state specific Compassion & Choices' Facebook page.
- > Share Compassion & Choices events with your online community. If you get an email invitation to an event, copy and paste the link and share it to your social media with a short description.
- > Personalize content on [Facebook](#) about your own thoughts on end-of-life care and advocacy as well as personal experiences and stories.
- > Follow key legislators on the platform(s) where they're active. Tag them in your tweets, posts and shares.
- > Ask your online community questions about their thoughts on end-of-life care and advocacy.

In the Medical Community

- > Help identify opportunities for Compassion & Choices to participate in events, conferences and grand rounds.
- > Help us obtain information related to policies and procedures on end of life care and options such as advance care planning, voluntary stopping eating and drinking (VSED), medical aid-in-dying and hospice care.
- > Collect information about palliative care programs within your community including hospitals that have inpatient programs and those that offer services to support people at home.
- > Be an advocate and champion for end-of-life care within your community.
- > Be a member of your professional organization or society at the state and national level.

11. Volunteer Resource Center, Training and Upcoming Events

Our [Volunteer Resource Center](#) is your 24/7 online portal for volunteer forms and training resources including recorded webinars and toolkits such as:

- > Basic lobbying
- > Communicating with legislators and the media
- > Petitions, tabling and canvassing
- > Passing a local resolution
- > Hosting a house party, video screening with Q&A and/or Signature Event watch party
- > Hosting a book club discussion for "[Finish Strong: Putting Your Priorities First at Life's End](#)" by President Emerita and Senior Advisor of Compassion & Choices, Barbara Coombs Lee
- > Introduction to medical aid in dying
- > Be a digital advocate in a virtual world
- > YouTube advanced care planning videos
- > SAGE toolkit

The national volunteer program manager can provide any assistance you may need regarding training sessions, materials or website support while you are volunteering with Compassion & Choices. Please call AJ Hetzler at 406-552-2916, Monday-Friday from 9 a.m. to 5 p.m. mountain time, for volunteer support. You can also learn more by viewing our collection of Train the Advocate 101 webinar series which cover a range of topics that may be of interest to you. Here is a [link to our calendar](#) of upcoming events taking place across the country.

Help Us Track Your Volunteer Activity

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

12. 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 AJ Hetzler, National Volunteer Program Manager, 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 for outreach, we are compelled to ask that you sign the [Compassion & Choices Data Use Agreement](#). We are unable to share supporter lists without this in place.