compassion & choices

MAGAZINE WINTER 2024

Selecting Your Medical Surrogates and Proxies pg. 4

The Journey Home Summit: Plan, Prepare and Care pg. 6

End-of-Life Care Misconceptions pg. 8

Five Questions for Filmmaker Ondi Timoner

She documented her family's loving journey as they surrounded her father during his final days in the film Last Flight Home.

FREEWILL

A Simple Act of Care

Protect what you love by creating your will today.

Estate planning is an important part of end-of-life planning and essential to protecting your family and the causes you care about. You can give yourself and your loved ones the comfort, peace and relief you deserve by taking advantage of Compassion & Choices' partnership with FreeWill.

What Is FreeWill?

Compassion & Choices has partnered with FreeWill, an online will-writing service, to ensure that our community has access to estate planning. Nearly 70% of Americans don't have an updated legal will, despite it being an essential task. Everyone needs an estate plan, regardless of your wealth or where you are in life.

If you do not have an up-to-date estate plan in place, you can create your legal will for free in 20 minutes or less by scanning the QR code to the right or visiting <u>CandC.link/free-will</u>.



Open camera and scan this code to start your free will today!

If you have any questions, contact:

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Compassion & Choices improves care, expands options and empowers everyone to chart their own end-of-life journey. Learn more at **CompassionAndChoices.org**.

The Importance of End of Life Options

As I settle into the new year, I am grateful for so many things. At the top of my list are our supporters, storytellers, volunteers, legislators, councils, board and staff members who work to move forward our strategic goals. Secondly, I am also grateful for the availability of expanded end-of-life options.

This issue highlights Ondi Timoner, a Primetime Emmy[®] Award nominee. Ondi showed us — and the world — why the availability of end-of-life options matter when her father, Eli, chose to die on his terms in her documentary *Last Flight Home*. While Ondi initially shot this footage to share with other loved ones, she realized the power of Eli's story to educate others about their own options and partnered with Compassion & Choices to advocate for change across the country.

Of course, medical aid in dying is only one end-of-life option; our commitment is to empower all individuals to choose end-of-life options that are consistent with their wishes. In this issue, readers will discover useful tools to help prepare and plan for the right care for themselves including a guide about how to select medical surrogates and proxies; common misconceptions in end-of-life care; and an overview of a very successful summit in Washington, D.C., hosted by our African American Leadership Council.

In this relatively new year, I hope you will share your wishes with those you love join us in our advocacy efforts as we work together pass laws to improve care and expand options at life's end.

In service and with gratitude,



Kim Callinam

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In the Media

The New York Times

How Aid in Dying Became Medical, Not Moral

In October, The New York Times published an article detailing the evolution of language in the debate over how to describe medical aid in dying. The article explores how language choices like "death with dignity" and "medical aid in dying" aim to distinguish the practice from suicide and address the moral concerns surrounding this issue. Compassion & Choices President Emerita Barbara Coombs Lee was interviewed, remembering a time in 2004 when Compassion & Choices described which language to use going forward. She said that the impetus "was probably another frustrated conversation about another interminable interview with a reporter who insisted on calling it suicide." A phrase like "medical aid in dying," Compassion & Choices concluded, would reassure patients that they were taking part in a medically sanctioned, highly regulated process.

Radio Bilingüe

Day of the Dead: Issues Related to the End of Life

In this interview with the nation's leading Latin public radio network and producer of Spanish-language content, Patricia A. González-Portillo, senior national Latino media director at Compassion and Choices, spoke about dying well and the importance of other issues that people face at the end of life. California is one of ten states that have passed medical aid-indying laws, an option for terminally ill adults that is supported by a large majority (68%) of California Latinos. The interview featured a conversation about the federal lawsuit by three California patients with disabilities and two physicians who are seeking to invalidate California's End of Life Option Act.

Greenfield Recorder

Aid in Dying Forces Try Again, With Healey on Their Side

In October, the Massachusetts-based newspaper reported on renewed efforts to authorize medical aid in dying in the Bay State. Reps. James O'Day and Edward Philips and Sen. Jo Comerford introduced a new medical aid-in-dying bill in the 2023-24 legislative session. "The bill, titled [the] End of Life Options [Act], is meant to emphasize that this bill offers a compassionate option to mentally capable patients with terminal conditions to choose a peaceful and humane death with dignity," said Comerford, noting that Gov. Maura Healey supports the legislation. O'Day told the Committee on Public Health, "The End of Life Options Act gives terminally ill patients a choice, their own choice, a choice on the quality of their life, a choice on the control of their lives."

The New York Times

How a Lawsuit in N.J. Could Bring Aid in Dying to Millions

As reported in September, Compassion & Choices filed a federal lawsuit challenging the residency requirement of New Jersey's medical aid-in-dying law. The lawsuit argues that New Jersey's residency requirement violates the Constitution's privileges and immunities, dormant commerce and equal protection clauses. As with our Oregon lawsuit in 2021 and Vermont lawsuit in 2022, this lawsuit seeks to enable non-residents of new Jersey to more easily access medical aid in dying. Judy Govatos, a terminally ill plaintiff who lives in Wilmington, Delaware, says that to be able to end her life when her suffering becomes unbearable "is a question of mercy and kindness."

How to Select Your Medical Surrogates and Proxies

How will you choose the person who will best carry out your wishes?



Planning for dying is a decision to make the most of every day and a strong way to honor a life well lived. And, if there comes a point where you can no longer make decisions for yourself, choosing a proxy ensures your voice is still heard.

What does it mean to be a proxy? This person, a representative named as your healthcare proxy, has the power to advocate for your medical wishes and make healthcare decisions for you if you are unable to do so. This person is named in your advance directive, a legal document.

Choosing the right proxy is important. Sometimes the person you think to choose — a partner, child, family member or trusted friend — is not necessarily the right choice, because they might not share your values, aren't vocal enough under pressure to advocate for your wishes or will be too emotionally distraught to make rational decisions during an intensely difficult time. Above all, your proxy should be someone you trust to understand your values and carry out your wishes.

From a legal perspective, in most states your proxy must be at least 18 years of age. You can name an alternative representative to step in if your primary representative is unavailable. Once you've chosen your representative, avoid potential conflict by letting others know your choice.

... your proxy should be someone you trust to understand your values and carry out your wishes.

You cannot appoint your primary care physician or any other healthcare practitioner involved in your care unless they are related to you by blood, marriage or adoption. It's also generally preferable not to appoint co-proxies.

When choosing a proxy and documenting your decision, consider if they fully understand what is required to advocate for you if needed with regard to your living will, advance directives, funeral, cremation, memorial and more. Note that a healthcare proxy has no authority over financial decisions; a power of attorney handles financial matters.

After selecting a healthcare proxy, review your end-of-life wishes with them (follow the link to our end-of-life planning guide below to help you determine these) so they are able to represent your interests if called upon.

The Compassion & Choices Storytellers program includes many stories from people advocating for a loved one at the end of their lives. The common thread to these stories is a need for communication and understanding of their loved one's wishes.

Visit *CandC.org/stories* to learn how Peter Oftedahl, Kim Holland and Tara Lee managed communicating for a loved one at the end of their lives. Click the "Tell Your Story" button if you have a story to share.



When Selecting a Representative, Ask Yourself ...

Are they assertive? You want someone who is comfortable speaking with healthcare providers and advocating for you.



Will they be able to think clearly and act rationally in a crisis?



Are they comfortable talking about death? They will need to engage with the subject.



Do they live nearby? In a crisis, having someone local can be important.



Will they respect your decisions? They need to understand where you're coming from and be willing to honor your requests.

Early conversations matter. Talk about your preferences regarding the extreme measures doctors might use to prolong your life. Is your potential representative comfortable with your choices?

Adapted from My End-of-Life Decisions: An Advance Planning Guide and Toolkit

Download our free resource, My End-of-Life Decisions: An Advance Planning Guide and Toolkit at <u>CandC.link/toolkit</u>.



The Journey Home Summit

Bringing together Black voices for change.

eath is a heavy subject, but a necessary one. This was one takeaway from many people who attended "The Journey Home: A Comprehensive Discussion on the Power of Planning," a summit held by the Compassion & Choices African American Leadership Council. This hybrid event took place in Washington, D.C. and virtually. Whether in-person or online, everyone got the opportunity to participate, ask questions and think about their relationship with end-of-life care and planning.

"During times of such turmoil, it can be challenging to remain inspired and motivated," said Brandi Alexander, chief engagement officer for Compassion & Choices. "That is what made this gathering so special. The goal was to bring together our community to celebrate the rich culture and acknowledge the realities that are beyond our control, while also taking agency by proactively planning for what we can. It was encouraging and energizing to see people come together around the shared goal of empowerment at life's end and do so with compassion, honesty, respect and laughter." The summit brought together African American thought leaders, experts and community members from across the country and all walks of life, from healthcare providers to community activists. Attendees seemed excited to share the importance of planning for yourself, loved ones, caregivers and their communities. Nearly 1,000 people registered for the event and more than 15 presenters including clinicians, caregivers, morticians, financial experts and faith leaders — shared their firsthand experience in this critical step to ensuring their loved ones' wishes were honored at the end of life.

The keynote speaker, Bishop Vashti Murphy McKenzie, argued that, "Planning precisely is an act of love and compassion to those who are left behind."

Participants discussed topics like the value of end-of-life planning; tips on financial planning; and the impact of faith, family and Black culture around death and dying. The summit provided a space to explore empowering options for end-of-life planning and care, uplift families and honor legacies.



Previous page pictured from left to right: panel discussion with Dr. Gregory A. Bolden, Beverly M. Morgan, and Dr. E. Faye Williams; Brandi Alexander with welcoming remarks. This page from left to right: panel discussion with Ottamissiah "Missy" Moore, Joél Simone Maldonado, Ashley Johnson and moderator Dr. Jeff Gardere; Dr. Nyasha Grayman-Simpson leading panel discussion.

Panel discussions included "Our Village," "A Peaceful Transition," "Protect Your Legacy and Wealth" and "Faith. Love. Compassion." During "Our Village," speakers discussed why they advocate for improving end-of-life care and planning. One of the panelists, Lillie Tyson Head, is the founding president of the Voices for Our Fathers Legacy Foundation, a nonprofit organization led by the descendants of men who were unethically and immorally treated in the United States Public Health Service Study of Untreated Syphilis in the Negro Male (USPHSSUS) at Tuskegee and Macon County, Alabama. Head said, "I thought I knew how important [end-of-life planning] was at first, but having interactions and looking more into Compassion & Choices' work and what they advocate for, I think I need to do a little bit more."

"A Peaceful Transition" brought together death workers, including doctors, nurses and death doulas. Ashley Johnson is the president of the National End-of-Life Doula Alliance and has over a decade in death care. When discussing culture and end-of-life care, she said, "As an end-of-life doula, I integrate my work with helping people become comfortable with talking about death, dying and grief."

The conversations and relationships that were fostered at "The Journey Home: A Comprehensive Discussion on the Power of Planning" stretched beyond the day of the event. Missy Moore, a nurse and speaker, said, "Understanding is a precursor to action."

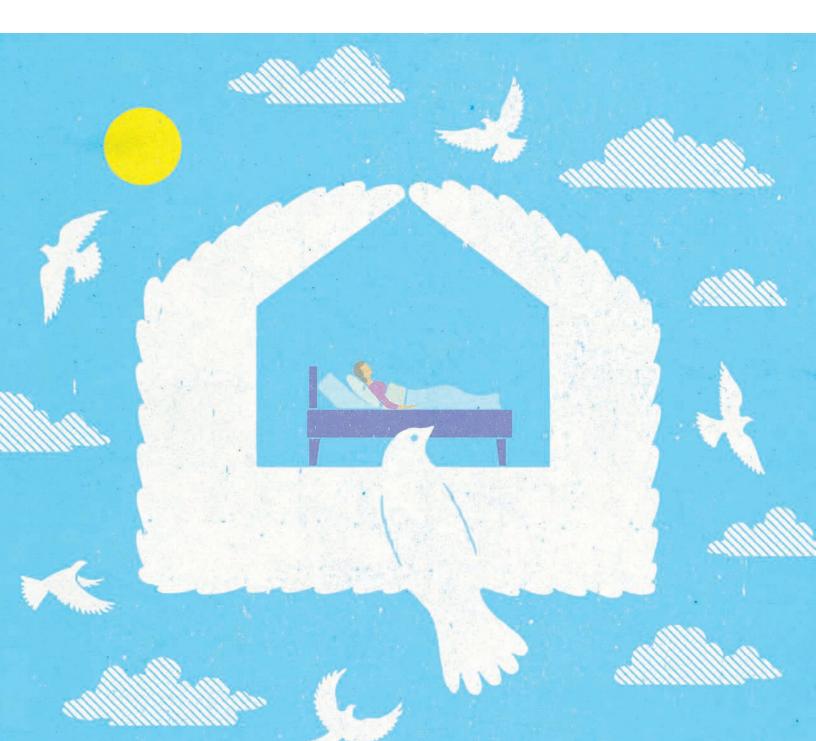
Do you want to watch "The Journey Home: A Comprehensive Discussion on the Power of Planning"? Visit <u>CandC.link/JourneyHome</u> to watch each discussion or the entire event.

Do you want to get started on end-of-life planning? Visit <u>CandC.link/toolkit</u> to utilize the End-of-Life Decisions Guide and Toolkit, our most popular resource!

Do you want to learn more about our work with the African American community? Visit <u>CandC.link/AfricanAmerican</u> to find the latest.

Common Misconceptions in End-of-Life Care

Empowering people with well-researched and accurate information so they can choose the right care for themselves.



hen former President Jimmy Carter publicly announced he was receiving hospice services, our country lit up with conversation. On social media, in the newspaper and at work, people shared their stories, concerns and fears. Misconceptions around death are not new in our society, but this news certainly brought many of them to light and launched important conversations about end-of-life care.

Compassion & Choices is dedicated to affirming life while accepting the inevitability of death. The best way to empower people to choose the care that is right for them is to inform them of those options. To help, several common misconceptions are outlined below.



HOSPICE CARE

One of the most common misconceptions about hospice is that it is only for people in their final days of life. In fact, hospice is for people with a terminal illness who according to physicians' estimates, have approximately six months or less to live if the illness runs its "usual" course. However, since that can be difficult to predict, some people in hospice live longer than that.

People may also see hospice as losing hope and giving up the will to live. In reality, hospice is care that specializes in comfort, symptom management, guidance and support. Choosing hospice means goals that are less about aggressive, life-prolonging treatments and more about quality of life.

Some may fear that they will be seen as "giving up" by choosing hospice. This damaging belief keeps many from getting beneficial care and support in order to avoid judgment from those around them. The reality is that the goal of hospice care is to give each person control over their end-of-life experience while creating a plan focused on the things most important to them at the end of life. Evidence suggests that hospice can, in some instances, lengthen the time someone lives in addition to improving their quality of life.

Although hospice specializes in the care of people at the end of life and provides numerous benefits, many people are not presented with the option of hospice — in a timely manner or at all — and are not aware it is a benefit covered by Medicare as well as Medicaid and private insurance. There can also be cultural, language and geographic barriers and inequities in accessing hospice. The result is that many people — especially from historically underserved communities — receive hospice for a very short period of time or not at all.

More information about hospice care can be found at <u>CandC.org/our-issues/hospice-care</u>.



PALLIATIVE CARE

Palliative care is often spoken about in conjunction with hospice care, but it is very different. Though both programs focus on comfort, pain relief and quality of life, palliative care is available to anyone at any age who is living with a serious illness. Palliative care includes the option to continue curative treatments while receiving palliative support, which is not the case with hospice. Additionally, the availability of palliative care outside a hospital setting is rare, due in part to inconsistent insurance coverage.

More information about palliative care can be found at <u>CandC.org/our-issues/palliative-care</u>.





Where authorized, medical aid in dying allows mentally capable, terminally ill adults with a prognosis of six months or less to live to request medications that control the manner and timing of their impending death. Medical aid-in-dying laws across the country include safeguards to ensure a person choosing this option is making the decision independently but has support from their community and healthcare team.

Preparation of the medication — such as opening capsules, mixing solutions, filling a reservoir or feeding tube — can be done by a loved one or nurse. However, one safeguard is that anyone accessing this option must be able to self-administer the medication. This means that the terminally ill person must ingest the medication through the mouth or through a feeding or rectal tube. Drinking through a straw, pushing a plunger, opening a valve or clip are considered self-administering. Loved ones or providers may hold a cup still for someone to drink from.



Information about medical aid in dying and the associated safeguards can be found at <u>CandC.org/our-issues/medical-aid-in-dying</u>.

VOLUNTARILY STOPPING EATING AND DRINKING (VSED)

VSED (sometimes referred to as terminal fasting) is when a mentally capable adult living with advanced illness wishes to control their own dying by making a conscious decision to refuse foods and fluids of any kind in order to advance the time of their death. This option is more often utilized by people with certain degenerative diseases, including Alzheimer's, ALS and MS, who are not eligible to access medical aid in dying due to the physical or cognitive impacts of their illness — or they live in states where medical aid in dying is not available.

Though a safe and legal option in all states, VSED requires planning and intensive support. Anyone pursuing it will need 24-hour care once the process has begun. The additional support of hospice is highly recommended. The first step is discussing end-of-life wishes and concerns with loved ones and healthcare professionals to prepare the necessary support.

More information about VSED can be found at <u>CandC.org/our-issues/vsed</u>.



ADDITIONAL RESOURCES

Compassion & Choices has resources regarding these options available for sharing. Our End-of-Life Consultation page includes frequently asked questions and links to planning tools. You can review these resources and learn about connecting to our consultants by visiting <u>CandC.org/eolc</u>.

Compassion & Choices Waging Legal Battles in New Jersey and California

After spearheading lawsuits in Oregon and Vermont that led to the first-of-its-kind legislative repeals of residency requirements to access their medical aid-in-dying laws in 2023, Compassion & Choices filed a similar lawsuit in New Jersey in August 2023.

The lawsuit, filed on behalf of two New Jersey doctors and two cancer patients in neighboring Delaware and Pennsylvania, asserts that New Jersey's residency mandate unconstitutionally discriminates against out-of-state patients who get medical care in New Jersey, since it prevents doctors from providing equal care to all their patients, regardless of what state they live in.

For plaintiff Judy Govatos, a Wilmington, Delaware, resident with stage 4 lymphoma who wants the option to access medical aid in dying in New Jersey since it's not authorized in Delaware, repealing New Jersey's residency requirement would lift immeasurable weight from her shoulders.

Her eight years of cancer treatments have taken an extraordinary toll on her body. Judy worries that without access to medical aid in dying, she faces an excruciating, prolonged death. "I'd like not to die in horrible pain and horrible fear, and I've experienced both," she told The New York Times in September.

Additionally, Compassion & Choices is defending California's updated End of Life Option Act against a federal lawsuit claiming it discriminates against people with disabilities. We represent our sister organization, Compassion & Choices Action Network; three California patients with disabilities; and two California doctors who filed motions in September to ask the court to intervene in the lawsuit and dismiss it.



Judy Govatos, Delaware resident involved with New Jersey lawsuit to access medical aid in dying.

"The only people who qualify for [medical aid in dying] are terminally ill with a prognosis of six months or less to live, and who have the capacity to make the decision," Compassion & Choices senior staff attorney Jess Pezley told the California News Service.

Patient intervenor Peter Sussman, a Bay Area resident living in chronic pain after a series of spinal surgeries, said, in the same story, "When my time comes and I am certified by doctors to be dying within six months, I do not want to die suffering needlessly. The government shouldn't be able to tell me the manner of my own death."

To learn more about Legal Advocacy at Compassion & Choices, visit <u>CandC.org/legal-advocacy</u>.

Dementia Tools, Resources and Partnerships

Recently, Compassion & Choices launched an updated "Living (and Dying) With Dementia" webpage featuring streamlined content, additional resources and access to a new page called Dementia Education & Videos. The online Dementia Values & Priorities Tool[®], which is being updated and enhanced, will include informational videos to explain key terms and concepts.

Through a partnership with the American Society on Aging (ASA), Jessica Empeño, MSW, national director for clinical engagement at Compassion & Choices, partnered with psychologist Dr. Jeff Gardere to host "The Truth About Dementia," a three-part series focused on the realities of end-stage dementia and the importance of advance care planning. Future work with ASA will continue to focus on dementia and advance care planning through education and outreach. Additionally, Compassion & Choices will sponsor and lead breakout sessions during the 2024 On Aging conference in San Francisco in March.



Screenshot from video with experts Dr. Sonja Richmond, registered nurse Ottamissiah Moore and psychologist Dr. Jeff Gardere discussing the importance of having an advance directive.

To find a wealth of tools, resources and videos about living and dying with dementia, including the Compassion & Choices ASA programming, visit <u>CandC.org/living-and-dying-</u> with-dementia.

An Unfolding Bi-National Partnership

In continuing partnership with Ventanilla de Salud (VDS), Compassion & Choices' sponsorships have been extended to several state-level Latino health organizations. The VDS program is a Mexican government public health education initiative designed to provide reliable information on health topics, counseling and referrals to available health services in local communities. They operate through 50 Mexican consulates and local health organizations in the U.S.

Regarding the importance of end-of-life education in the Latino community and the partnership with Compassion & Choices, Hilda Dávila, the national coordinator of VDS, said, "This is an issue that has not been addressed in our community and it is a very unique opportunity to provide education on end-of-life directives. The way Compassion and & Choices deals with this is very clear and very simple."

Over the past year, this partnership has allowed Compassion & Choices to participate in over 200 community engagement events, reaching out to more than 15,000 individuals with bilingual educational materials about end-of-life options and planning. Through these events, Compassion & Choices offered training opportunities to Community Health Workers (CHW), strengthening their skills and knowledge so they can become effective advocates and educators for end-of-life care. These trainings also allow CHWs to address the unique needs and barriers faced by the Latino community, opening up pathways for further education.

Faith, Love and Compassion in Our Communities

Compassion & Choices continues to work with faith communities around the country. In Detroit, Michigan, a pilot program with Living Our Legacies encourages church health workers to be resources for end-of-life life planning and care to their communities. Church health workers work within a church community to promote the health and wellbeing of their ministry, a natural place where discussions about death and dying take place. Zeena Regis, director of priority populations, said, "We are thrilled to be in Detroit and partnering with Living Our Legacies to bring more information about end-of-life care to churchgoers and community members in the area."

Alter Dementia, an organization based in Georgia, focuses on African American faith communities, giving them the tools to help people and families affected by dementia. They provide resources, including Compassion & Choices End-of-Life Decisions Guide and Toolkit, to create more inclusive spaces for people with dementia. Brandi Alexander, Compassion & Choices chief engagement officer, stated, "Dementia affects every community, and meeting people in the spaces they love, like their church or fellowship, helps destigmatize the disease and puts the power in the hands of community members to achieve a peaceful transition."

These programs, happening across the country and in interfaith spaces, exemplify the importance of reaching people of different faiths with a wide range of resources about end-of-life care and planning. From community health workers to ministers, faith communities have a built-in relationship and responsibility to their congregants. When faith communities are open and honest about the need for end-of-life planning and different forms of end-of-life care, they provide a vital service to the public.



Allyne Hammer Award Recipients Show Volunteer Strength and Compassion

In September 2023, Compassion & Choices awarded the inaugural Allyne Hammer Award to two remarkable individuals who have demonstrated unwavering commitment to the end-of-life options movement: Doris Fischer of Montana and Rosalind Kipping of Maryland. The Allyne Hammer Award was designed to spotlight the outstanding achievements and dedication of individuals across the country who volunteer with Compassion & Choices in their communities. The award is named after Allyne Hammer as a way to honor her enduring legacy as a volunteer leader for Compassion & Choices, including advocating for the End of Life Option Act in California, serving as a storyteller and leadership volunteer with the LGBTQ+ Leadership Council.



Doris Fischer



Rosalind Kipping

Doris Fischer has been a volunteer at Compassion & Choices for 16 years, and her steadfastness has made an impact on Montana residents seeking medical aid in dying. Her passion comes from an unshakable belief in the Compassion & Choices mission and a desire to honor the memory of her partner, who died without access to medical aid in dying. Aid in dying was authorized in Montana in 2009 via a court ruling, *Baxter v. Montana.* The ruling has been targeted by opponents ever since. Undeterred, Doris has testified at every legislative hearing and is committed to lobbying. Her efforts have positively impacted the state's policy landscape and inspired friends and family to join her advocacy. Upon being notified of winning the award, Doris said that she was "stunned and grateful. I stand with others in this fight. I have no words."

Rosalind Kipping was an advocate for end-of-life options for decades. Her journey took her from California, where she was a member of the Hemlock Society USA, to Maryland in 2007, where she found her home with Compassion & Choices. Rosalind's leadership was instrumental in the then-Washington area chapter of Compassion & Choices, where she served as vice president and president. She went on to serve as an Action Team member and outreach volunteer, where she identified, organized, tabled and presented end-of-life planning sessions and amassed hundreds of new supporters for Compassion & Choices. Shortly after getting the award, Rosalind died peacefully at home surrounded by her loved ones. They appreciated this award, given how important C&C was in her life. One day, when we see the passage of a medical aid-in-dying law is passed in Maryland, we will again celebrate Rosalind's incredible commitment to this movement.

Historic 300-Mile Walk Across Connecticut Builds Support for Medical Aid in Dying

State campaign director's 28-day trek draws major news coverage.

In late October, Tim Appleton, the Connecticut senior campaign director for Compassion & Choices Action Network, concluded an unprecedented 300-mile, 28-day walking tour through two-thirds of the state's legislative districts to build awareness about the urgent need to pass medical aid-in-dying legislation in the Nutmeg State.

Wearing a bright yellow vest that read "ASK ME ABOUT AID IN DYING", Tim paused his walks, often in cold rain, to talk to residents about the campaign to pass the bill. He stopped at diners and coffee shops, hosting discussions and events with advocates and legislative champions, all which were arranged by Heather Pope, senior northeast campaign organizer. This herculean feat has never been attempted by the Connecticut team or our organization before. It attracted major news coverage.

"However uncomfortable it is to walk 10 miles a day ... it pales in comparison to the agony and suffering of those who have literally died waiting for this legislation to pass," Tim told the CT News Junkie. "That's the message: people are literally dying in agony."

"People will vote 'no' right up until they don't," Tim said. "The only way we can get to that tipping point is to continue the advocacy on the legislation. Every year this bill is put forward is an opportunity to better educate lawmakers and the public about what this bill is and what it isn't; what it does and doesn't do. The only way to get there is to keep proposing the legislation." Sen. Saud Anwar, M.D., told the CT Examiner, "If you look at the testimonies of the various legislators, they will tell you that they were a hard no at one point to the bill, myself included. But, over time, we realized the situation and how many people were impacted." He said he plans to bring the measure up for a vote in 2024.

The walking tour's conclusion made the front page of the Saturday/Sunday edition of CT Insider as well.

"The other element of logistics that was really amazing and heartwarming was the community of people that helped get me from where I ended back to my car so I could go home (each day), or from where I ended to a place where I could spend the night, and then from where I spent the night back to the place where I ended off to start the next day," Tim said. "It built up this great community of supporters."

Tim Appleton, joined by supporter Maribeth Abrams, on the final day of his 28-day walk in support of medical aid in dying.



Moving Forward With Compassion

CALIFORNIA

In September, Compassion & Choices filed motions on behalf of three California patients with disabilities and two physicians to intervene in a federal lawsuit seeking to invalidate California's End of Life Option Act and dismiss the case. The lawsuit claims the revised End of Life Option Act discriminates against people with disabilities. "The End of Life Option Act is completely voluntary for both patients and physicians. There have been no substantiated cases of coercion in over 25 years and by law a patient cannot qualify solely because of a disability," said Kevin Díaz, chief legal advocacy officer for Compassion & Choices.

DELAWARE

"I suffer from a neurological disease called spinocerebellar ataxia type 2. Ataxia is one of the most horrible diseases that most people have never heard of," wrote Compassion & Choices Action Network advocate Dawn Lentz in a Delaware Daily State News op-ed. "Most people with my condition die of aspiration pneumonia. That's how my mother, uncle and grandmother died ... Some disability rights advocates oppose this compassionate legislation ... But I'm disabled, and I don't need anyone speaking for me ... I want that option ... It's the best way to prevent more Delawareans from experiencing needless suffering at the end of life."

FLORIDA

Our Florida Compassion & Choices team continues to expand conversations and presentations with diverse communities throughout the state. In the fall, our hardworking volunteers and advocates participated in various presentations with members of the LGBTQ+, faith and disability communities. Our team attended the Sarasota Pride Festival and the Fearless Caregiver Conference in October, which provides caregivers a place to learn about new resources and educational opportunities. We look forward to expanding our volunteer list and continuing our presentations with Floridians to raise awareness of the importance of the full range of options at the end of life.

ILLINOIS

In October, the Illinois End-of-Life Options Coalition team hosted an exhibit in the state capitol about the urgent need to pass medical aid-in-dying legislation in spring 2024. More than 15 supporters and storytellers attended the event, reaching out to legislators and staff. The exhibit featured a poll, sponsored by Compassion & Choices Action Network, showing 71% of Illinois voters want the state legislature to pass medical aid-in-dying legislation. Lawmakers also had the opportunity to learn about Illinoisans who support medical aid in dying because they are terminally ill or lost a loved one who suffered painfully before their death.

MARYLAND

In November, Compassion & Choices Action Network Maryland held special screenings in Hyattsville and Silver Spring for the Oscar-shortlisted and Emmy-nominated film, *Last Flight Home*. The documentary details a 92-year-old man's utilization of California's medical aid-in-dying law with his family's loving support. The screenings featured Q&A sessions about possible passage of the Maryland End of Life Options Act after its re-introduction in 2024 by Sen. Jeff Waldsteicher and Del. Terri Hill, a physician. They urged attendees to contact their colleagues, including legislative leaders, to tell them to make passing the bill a top priority in 2024.

Don't see your state? Visit <u>CandC.org/in-your-state</u>.

advocacy in action

MASSACHUSETTS

In October, Compassion & Choices Action Network (CCAN), our partners and advocates delivered passionate testimony — and 70+ advocates submitted written testimony — to the Massachusetts Joint Committee on Public Health in support of the End of Life Options Act. "Terminally ill people who are eligible under this act are dying. Giving them the option to choose when they've had enough, to save them from excruciating suffering in their final days, is the compassionate choice," testified Melissa Stacy, northeast campaign manager for CCAN. Gov. Maura Healey "supports legislative action to allow medical aid in dying, provided it includes sufficient safeguards for both patients and providers."

MICHIGAN

Michigan State Senators Cavanagh, Hertel, Singh, and Klinefelt introduced a "death with dignity" legislative package on Nov. 9 (SB 678-681), which was referred to the Health Policy Committee. A 2023 phone poll of Michigan voters sponsored by Compassion & Choices showed 73% overall support for medical aid in dying. Surveyed voters indicated by a 28-point margin that they are more likely to vote for state legislative candidates who support medical aid in dying. Compassion & Choices hopes to see legislation to authorize medical aid in dying advance in 2024.

MINNESOTA

The Compassion & Choices Action Network Minnesota team's optimism about running a successful grassroots campaign to pass the state's End-of-Life Options Act is at an all-time high. The 2023 House of Representatives State Fair Poll of more than 8,000 Minnesotans showed that 73% support medical aid in dying. Bill authors Sen. Kelly Morrison, M.D., and Rep. Mike Freiberg will emphasize the need tocodify bodily autonomy as an end-of-life care option, just as it has for reproductive and genderaffirming healthcare.

NEW YORK

The Compassion & Choices New York campaign team hired new team members to help move the Medical Aid in Dying Act to a floor vote in 2024. Westchester-based field organizer Tara Herman has been building support for the campaign among progressive groups in key legislative districts. Marathon Strategies, a public relations firm with a deep field of professionals who have successfully advanced some of the most challenging issues in Albany, began working with the team to help design winning messaging for 2024.

PENNSYLVANIA

Compassion & Choices sponsored a phone survey showing that 74% of Pennsylvania voters believe a mentally capable adult with a terminal illness and a prognosis of six months or less to live "should have the legal option to obtain prescription medication to pass peacefully in their sleep." This supermajority support for medical aid-in-dying legislation spans demographics, political ideology, ethnicity, and gender identity. The regions most in favor of medical aid in dying are Northwestern Pennsylvania (84%), Philadelphia/Southwestern Pennsylvania (79%), and Central Pennsylvania (73%).

WASHINGTON, D.C. (FEDERAL)

Compassion & Choices is urging the U.S. Senate to eliminate an unprecedented policy rider attached to a federal spending bill passed by the U.S. House of Representatives in November to repeal D.C.'s Death with Dignity Act and prohibit the D.C. Council from ever re-passing a medical aid-in-dying law. "... [I]n recent elections and polls, American voters have clearly demonstrated that they don't want federal or state lawmakers intruding into the personal healthcare decisions they make in consultation with their doctors and loved ones, including their end-of-life healthcare decisions," said Compassion & Choices President and CEO Kim Callinan.

Five Questions for Ondi Timoner

Internationally acclaimed filmmaker Ondi Timoner has been making documentaries for more than three decades. When she learned her father, Eli, decided to access the California End of Life Option Act and end his suffering with medical aid in dying, Timoner, with her family's blessing, tried to capture as much of her father's remaining days on film as she could.



How did you feel about your dad's decision to end his life on his own terms?

I was really taken by surprise. I had no idea that my 92-year-old Dad would ever make a decision like that because he was incredibly tenacious and loved his family. In my mind, he was always going to be there for us. In January 2021, he was hospitalized with complications due to COPD. He was told he would have to go to a facility and live away from Mom.

Upon hearing this, my Dad said, "Please help me die." I understood his decision, but it was also completely surprising because I was unaware that such a law existed in California. Thanks to this, he had the right to end his life on his terms after a 15-day waiting period. Death was something we really never talked about, as is common in our culture. The conversation began when my brother mentioned medical aid in dying in California. He contacted End of Life Choices California and they suggested a local hospice that could help us fulfill Dad's wishes. I felt relieved that he could have the peace he wanted, but of course it was terrifying knowing I was losing him in a matter of weeks.

Unquestionably, we supported Dad's choice for bodily autonomy at the end of his life. It was vital. He was a hero as a leader, father, grandfather and husband. This goodness was innate. As soon as he was granted his wish and came home to start hospice, his humor and spirits returned. I believe he had hope that his suffering would be relieved and had a sense of agency over his body for the first time in decades.

How did documenting your father's end-of-life experience impact the grief journey for you and your family?

At my core, I am a documentary filmmaker, but I was never planning to make a documentary about my father. It came to me like a light bulb turning on. If I could document Dad, maybe I could bottle him up and we'd have something left of him when he was gone. It was a gut instinct that was impossible to deny, yet felt extremely inappropriate. So I went to see a therapist, who said, "If you think you should film, you should." I called my father to ask his permission and he replied, "I instinctively know you are on the right track."

For a decade, I had been writing a scripted feature film about his life. In the film, you see papers on his bed — I was reviewing it



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with him one last time, still in total denial about the documentary. I didn't realize that we'd share our very intimate journey with the world until my sister asked me to make a short memorial video a couple weeks after he died. I sat down to edit, and that's when I realized everybody who came in that room those last few weeks changed for the better. Dad was alive in the editing system, and he was sharing wisdom the world should witness. I couldn't stop editing.

Everything that you see in that documentary was made possible by medical aid in dying. Because my father's actual passing was planned, my sister, a very busy rabbi, was able to travel to see him. His grandchildren were able to come home from college and receive his guidance, and we planned many Zoom calls with people from all aspects of his life who he had touched deeply. We all had closure and peace around his passing that so many families don't have the chance to experience.

What did you learn about end-of-life options through this experience?

The process of accessing medical aid in dying was more difficult than necessary. There was misinformation about how Dad needed to ingest the meds. Dad signed many documents agreeing to take the medicine to end his life. Overall, the process needs to be simplified so that precious time can be more peaceful.

I believe medical aid in dying has not progressed further because death and dying is not a topic many people think about until they have to — but it applies to everyone. We are all going to die and, quite possibly, lose a loved one to a terminal illness.

We have been moved by audience members who come to us and have felt powerless to help their loved ones. Conversely, every family we met that experienced the loss of a loved one with the help of medical aid in dying had closure. It is truly a compassion-

five questions

ate law which is greatly misunderstood, and that's why we have been on an impact tour in partnership with Compassion & Choices and the Completed Life Initiative, traveling the country, sharing the film and speaking to lawmakers, religious bodies, as well as future doctors, spiritual leaders and law students at Ivy League schools. We hope to help change the law for other families.



What message do you want people to walk away with after watching this film?

My sister, Rabbi Rachel Timoner, said it well in her sermon at the end of the film. "It's not too late to measure our lives by love. Why don't we start today?"

The film is as much about how to live as how to die. My father founded the fastestgrowing airline in the history of the world, but once disabled at 53 years old, he was pushed out of the company he founded and lost all of his money. He carried that shame for decades. Seeing that was awful, but thanks to the work we did together in those last weeks, and the opportunity to reflect back onto him the massive contribution of loving kindness he had given us, he was able to realize he had measured his life wrong and let it go. But we have to decide to be brave and voice what we are ashamed of, and we don't have to wait till we are one day from our deaths to do so.

How does your film help individuals or lawmakers who may be on the fence about medical aid in dying?

 We are introducing a bill called "Eli's Law" that will hopefully reform a current federal ban on medical aid-in-dying funding and the gag order that restricts VA hospitals from sharing that it is a right with veterans in states where medical aid in dying is legal. This ban has existed for 25 years and makes medical aid in dying affordable only to those who have the means to pay for it. We feel strongly that people deserve equal access and information about their end-oflife options.

The film is a very personal family story, but it gives people a chance to transpose their own families onto the screen, imagining what it would be like to make such a choice. I hope the film inspires people to start prioritizing loving relationships, because that matters more than any kind of bank account, award or material possession. It's my Dad's final gift to all of us.



Last Flight Home premiered at the 2022 Sundance Film Festival. It was nominated for a Primetime Emmy[®] Award and can be viewed through major streaming services. To learn more, visit <u>www.interloperfilms.com/lastflighthome.</u>



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 Eleanor Hall and Roger Hale, proud supporters from St. Paul, MN.

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