



# compassion & choices

**MAGAZINE**  
WINTER 2023

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the End of Life**  
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## **FIVE QUESTIONS FOR Barbara Coombs Lee**

Working toward a peaceful end of life in her book  
*Finish Strong: Putting Your Priorities First at Life's End.*



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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](https://www.compassionandchoices.org).

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# The Power of Open-Hearted Questioning

The cover of this issue features my predecessor, our foundational movement leader, Barbara Coombs Lee. Focusing the spotlight on Barbara is a long overdue recognition of the preeminent role she has played in advancing patient-directed end-of-life care. It also coincides with the release of the second edition of her powerful book, *Finish Strong: Putting Your Priorities First at Life's End*.

The latest edition of Barbara's book includes an important new chapter, *Race and Culture Matter*, which serves as an acknowledgement that, while death is universal, our views and perspectives about how we die are not.

Given that Compassion & Choices' mission is to "empower **everyone** to chart their end-of-life journey," Barbara's updated book serves as an important reminder: If we approach our work — and those who may benefit from and support our work — with a curious mind and an open heart, the end-of-life care movement will continue to flourish and expand.

I invite you to read this issue of the Compassion & Choices magazine with a curious mind and an open heart.



*Kim Callinan*

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## In the Media

### *The Dr. Phil Show*

#### Season 21, Episode 24: The Right to Die

In October, the nationally syndicated Dr. Phil show aired an episode about medical aid in dying featuring Compassion & Choices President and CEO Kim Callinan; Compassion & Choices physician board member Dr. Chandana Banerjee; advocate for medical aid in dying Dan Diaz, husband of the late Brittany Maynard and Ciara Fuentes, whose mother, Caprice Fuentes, was diagnosed with metastatic cancer in 2020 and wishes that she had the option of medical aid in dying in her home state of Oklahoma. Caprice had emailed Dr. Phil to ask for his opinion on medical aid in dying. Speaking on Caprice's behalf, Ciara said that "she just wants to be able to have the choice."

The episode prominently featured the story of advocate Brittany Maynard, who received a terminal brain cancer diagnosis in 2014 and moved to Oregon in order to access medical aid in dying because California did not authorize that option at the time. Dan Diaz described Brittany's symptoms of "pain that not even morphine [could] alleviate," and her determination not to allow cancer to be in the driver's seat. Kim Callinan strongly rebuked an opponent. "I am around so many people who choose ... the option of medical aid in dying, and those people absolutely 100% are choosing life," she said. "They get the prescription in their hand, and it is a prescription for peace of mind."

Dan Diaz (left) with Dr. Phil.



### *The Philadelphia Inquirer*

#### Why don't more people of color receive end-of-life care?

Compassion & Choices Chief Engagement Officer Brandi Alexander authored an op-ed highlighting the racial disparities that persist in end-of-life medical care. She detailed why terminally ill people from communities of color rarely utilize hospice, palliative care and medical aid in dying in the 11 jurisdictions where it is authorized, citing barriers such as institutional racism, cultural and language differences, lack of access, and economic and insurance hurdles that prevent historically underserved communities from using all end-of-life care services. "Everyone deserves equal access to all types of end-of-life care," wrote Alexander. "It will take time, cultural and religious sensitivity, and trusted voices to empower and inform diverse communities about the quality-of-life benefits of hospice and palliative care."

### *VT Digger*

#### Terminally ill woman, Middlebury doctor sue Vermont over aid-in-dying law's residency requirement

In August, Compassion & Choices filed a federal lawsuit on behalf of Lynda Bluestein, a terminally ill Connecticut resident who wants to access Vermont's medical aid-in-dying law, and Dr. Diana Barnard, a Vermont physician who regularly sees patients from neighboring upstate New York. This is the second lawsuit to challenge a state's residency requirement. A similar lawsuit was settled in Oregon in 2022. "Some of my patients, just because they live on the other side of the [state line], don't have the same access [to medical aid in dying] that my Vermont patients do," Dr. Barnard said. "It just did not seem fair. And it felt like an important issue to address."

# Speaking to a Dying Person

**Shortly before her death, longtime supporter Marcia Streen shared her wisdom for communicating with people at the end of their lives with President and CEO Kim Callinan.**



above: Marcia Streen

next page: Kim Callinan and Marcia at Marcia's home in New Jersey.

**I**n spring 2022, powerful lifelong advocate, supporter and legacy donor Marcia Streen, close to the end of her life, shared her precious time and thoughts with Kim Callinan, president and CEO of Compassion & Choices. Marcia wasn't new to advocacy. She fought for desegregation, joined the early anti-segregation sit-ins in the 1940s and protested the Vietnam War in the 1960s. Marcia's son Richard proudly refers to her as "a woman ahead of her time."

Marcia was a social worker and mother of two grown children, with interests and hobbies that included skiing, white water paddling, hiking, sailing her own boat, being a New York Botanical Garden tour guide, and volunteering in the infusion center at her local hospital. When Marcia's lung cancer metastasized to her liver after 12 years, she was glad to have the option of medical aid in dying in her home state of New Jersey, an option that she fought hard to win.

Quality of life was important to Marcia, who said, "For several years now I've talked with my sons about my interest in using medical aid in dying, and they support me. I want to go out with a laugh if I can, not moaning and groaning or crying and being sad, with my sons beside me in the place I've called home for 57 years."

As Marcia neared the end of her life, Kim visited her at her home in New Jersey to say goodbye. During that conversation, Marcia gave Kim one final gift: a blueprint for how people should communicate with those who are dying. "I get that some of my friends are uncomfortable that I am dying," she said. "However, in a few days, weeks or months, my life will be over. Society should do a better job teaching people how to act — and not act — around a dying person."

According to Kim, "For the next hour, I had the privilege of hearing her thoughts on a curriculum for 'how to be with a dying person.' It was a true gift that I promised to pass along."

Marcia completed her incredible life journey on May 26 at age 93 after taking her aid-in-dying medication. She leaves behind a legacy of compassion and kindness.

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**Communication is so important. Do you have any suggestions or ideas for how to be with a dying person? We'd love to hear from you! Please email [kim@action.CompassionAndChoices.org](mailto:kim@action.CompassionAndChoices.org). We may share some of your thoughts in a future issue.**

### *Here is Marcia's advice for visiting a loved one at life's end:*

**Stop Trying to Solve "the Problem."** Often, the initial reaction of friends and loved ones is a well-intended attempt to "fix the problem." People say things such as *Have you tried X? We'll beat this together. What's the name of your disease, again? I'll search the internet for a miracle cure or clinical trial.* End of life isn't "solvable." Marcia knew she was dying and had accepted her fate. She simply wanted her friends to acknowledge her reality, be with her and grieve with her.

**Keep Your Own Problems in Perspective.** For Marcia, one of the hardest parts of dying was listening to friends fill the "uncomfortableness" by sharing their problems with her. While Marcia understood those problems were important to her friends, she wished they would be sensitive enough to keep the attention and focus on what she needed. Of course, all dying people may not feel the same way, especially if their dying process is prolonged.

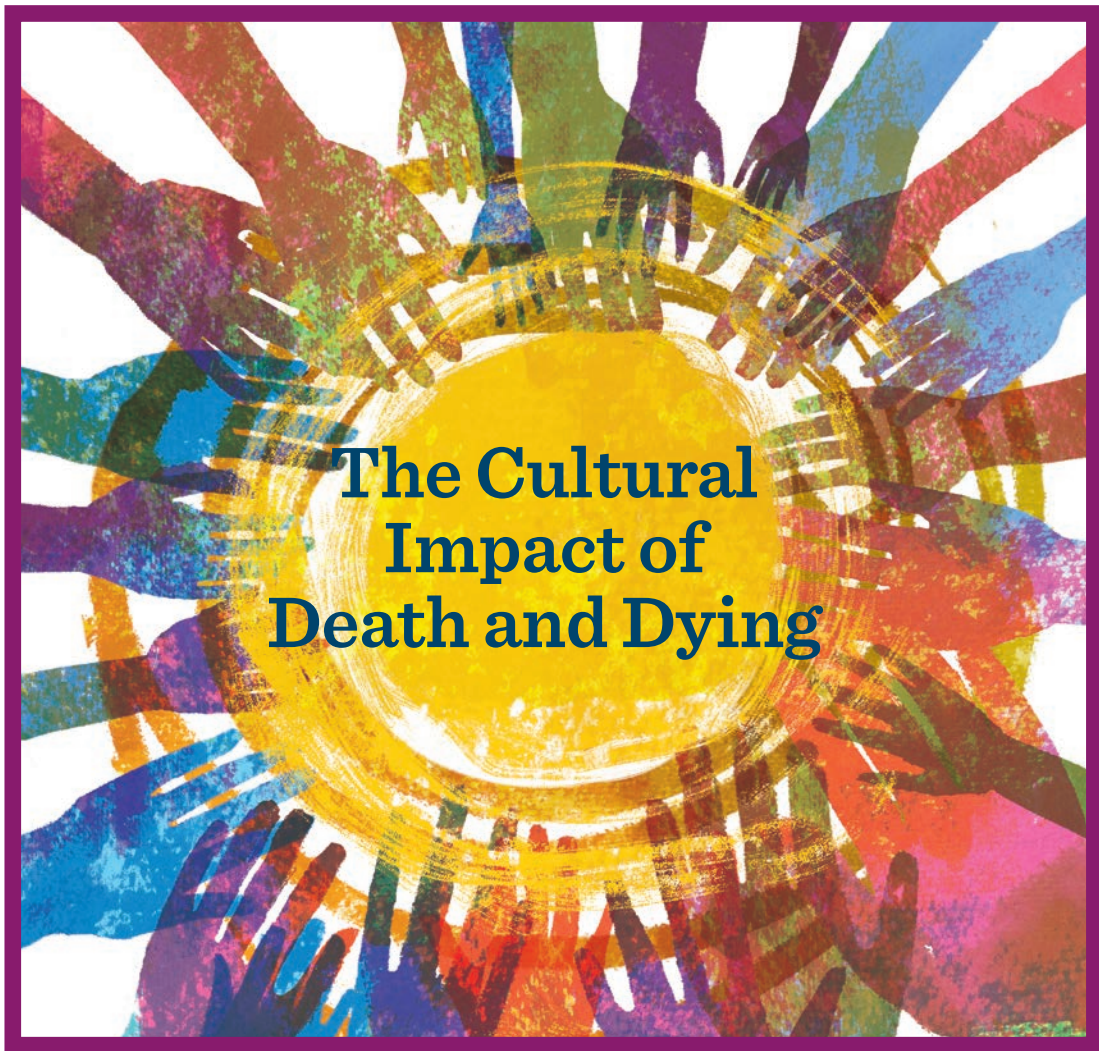
**Don't Assume.** Perhaps Marcia's biggest hope was for people to NOT assume they knew what was best for her or what she wanted. She offered several examples of Do's and Don'ts for communicating with a dying person:

- » Don't grab my hand as we are crossing the street. Ask if I need help.
- » Don't invite a friend to our lunch date. Ask me with whom I would like to spend my final time.
- » Don't guess how I feel about talking about death. Ask if I want to talk about the fact that I am dying — or if I don't.

#### **Do's**

- » Do please ask me what I want and need.
- » Do just sit and hold my hand and tell me that you love me.
- » Do just be with me in uncomfortable silence and sadness and give me the space to grieve and be complete.





## The Cultural Impact of Death and Dying

**How death and dying priorities and experiences within different cultures need to be understood and valued, in healthcare settings and at home.**

**D**eath is universal. No one gets out alive ... There's a 100% chance that you'll die ... The only certainties are death and taxes ... These cliches remind us that death happens to everyone. But what we've learned over thousands of conversations with people around the country is that the way people experience death is far from universal. Every end-of-life experience is unique to an individual, a family, a community and a culture. When we seek to understand these unique needs and attributes of the dying experience, we can better serve people from all walks of life.

Person-directed healthcare is the idea that individuals should be in the driver's seat of their healthcare decisions — that individuals should have the knowledge and resources to make the right decisions for themselves with regard to their health. This is a radical proposition for people who may trust their doctors to make decisions for them, or who want their families and loved ones involved in their care.

Compassion & Choices approaches this inclusive view of death from multiple spaces: the doctor's office, community centers, medical associations,



state houses and more. We want to give people — from doctors to nurses to patients — the tools and resources to improve end-of-life care and be effective advocates for themselves, their loved ones, their community — even people they don't know.

A compassionate death looks different for everyone. Our staff, supporters and volunteers bring their lived experiences to this work and provide insight into what end-of-life experiences look like in their communities. Our leadership councils, which continue to expand and innovate, provide insight into how we can live out a death that matches our life's values.

Stella Dawson's wife, Mary Klein, died in 2018 after advocating for Washington, D.C.'s Death with Dignity Act. Now, Stella advocates for improving end-of-life care and expanding options with the Compassion & Choices LGBTQ+ Leadership Council. She recalled a moment when a doctor asked Mary about herself, not her illness. "Mary talked about her art career, she noted how they had the same taste in wrist watches, she talked about training her dogs, she talked about our adventures together, moving across the country and around the world, supporting each other's careers ... I breathed in relief. No one before had shown they cared about her beyond the cells attacking her body."

In the doctor or medical provider's office, there are critical pieces that can help more people achieve a compassionate death. Conversations with healthcare providers are an essential part of exchanging information, but what if you don't understand what the doctor is saying? Most people can relate to the overwhelmed or confused feeling of hearing medical information they don't understand. Some communities, where there are language barriers or other barriers in communication, experience this more

acutely. That's why culturally competent communication is so important in healthcare.

Care teams, from medical providers to other healthcare workers, must embrace skills that reflect cultural competency to provide necessary services. Cultural competencies involve skills like language access and appreciation and acknowledgment of community and individual cultures. End-of-life conversations are complex and should involve an individual's loved ones and family to understand an individual's culture and history. This includes the context around the end of their life. Eunju Lee, a social worker living in New York and a Compassion & Choices Healthcare Advisory Council member, says, "Nothing is more important than for our patients to feel seen and known in their

full personhood and to offer care that honors the whole of who they are."

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**End-of-life conversations are complex and should involve an individual's loved ones and family to understand an individual's culture and history.**

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It's also important that care teams look like the patients and loved ones, whom they serve. This builds trust in a medical system that does not always foster it. Trust can come from diversity within healthcare and death care professionals.

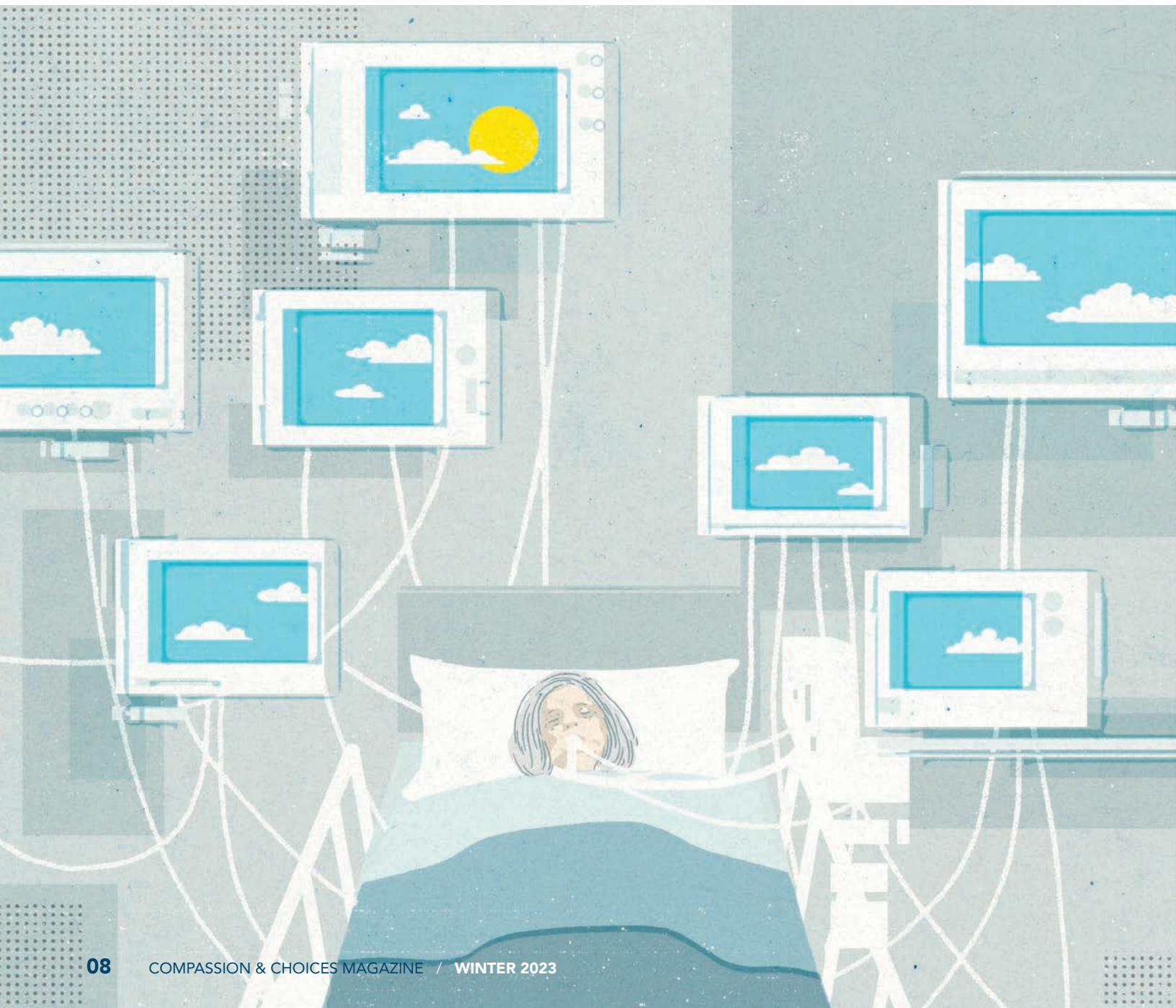
Joél Simone Maldonado, a licensed

funeral director, insurance agent and sacred grief practitioner, as well as a Compassion & Choices board member and African American Leadership Council member, says, "The feeling of peace is greatly appreciated and valued in almost every culture that I have worked with. Surprisingly, so is the feeling of release; feeling as if the person has earned their right to let go and having that feeling affirmed by not only medical personnel but also death care professionals."

The unique needs of each person and family at the end of life drive Compassion & Choices to advocate for everyone to have access to compassionate end-of-life care and the full range of end-of-life options.

# Protecting Self-Determination at Life's End

The little known but rapidly changing environment in patient autonomy is erasing freedoms in the end-of-life space.



In June 2022, the movement to protect the right to self-determination at the end of life took on extra urgency as the U.S. Supreme Court issued its ruling in *Dobbs v. Jackson Women's Health Organization*, the decision that reversed the 1973 *Roe v. Wade* precedent on abortion.

Compassion & Choices understands that there are differences of opinion about the court's ruling among supporters of the end-of-life options movement, and we remain firmly focused on advancing end-of-life rights. But, as President and CEO Kim Callinan noted in her address at this year's national online Signature Event, organizations and institutions that oppose reproductive rights for pregnant people are nearly always the same ones that oppose bodily autonomy at the end of life. And the *Dobbs* decision has only emboldened them.

### **What's at Stake**

Opponents of end-of-life rights threaten both existing end-of-life choice legislation and the prospect to pass similar laws in more states. But they also represent a threat to all aspects of healthcare at the end of our lives. These institutions and organizations won't stop at overturning medical aid-in-dying laws; they have publicly stated that they will use legislation and the courts to go after other long-established rights, like the right to utilize a healthcare



proxy, refuse a feeding tube, voluntarily stop eating and drinking, or refuse life support in the case of brain death, leaving people in a persistent vegetative state for years.

Despite the fact that a mentally competent person has the legal right to refuse any medical treatment, providers may feel free to override those wishes, and be protected by the law or the courts when they do.

### **Your Options May Already Be Limited**

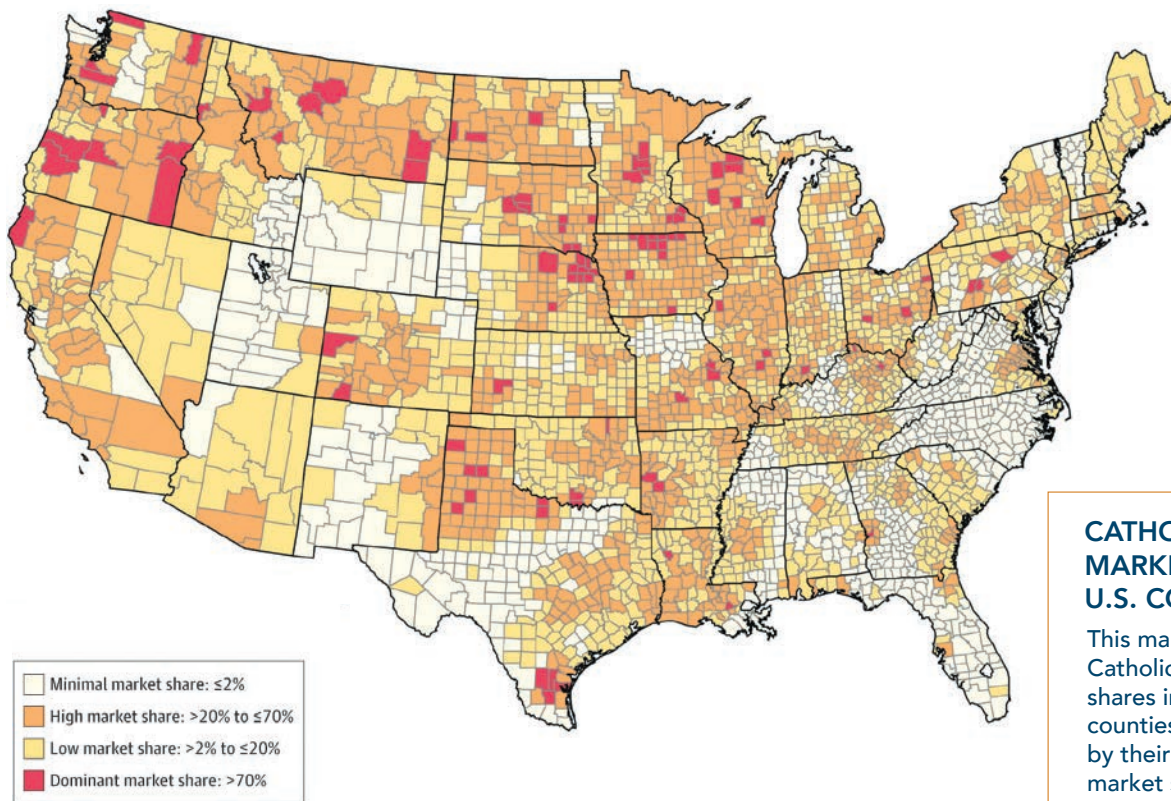
Limits on end-of-life options aren't just some future battle to be fought. In many places, those limits already exist. Healthcare facilities may now refuse to provide care or honor your wishes based on religious or ethical directives. Also known as religious exemptions, religious refusals, denials of care or "conscience protections," they allow healthcare organizations and clinicians to refuse to treat or deny patients access to lawful, medically appropriate care if it runs counter to their "moral conscience."

And it's not just at the end of life. Let's say you are due for a colonoscopy, and you have an advance directive or a DNR in place. Some providers require you to sign a document before the procedure waiving your right to have those documents honored, or they won't perform the procedure.

A 2021 study in the *Journal of the American Medical Association* found that an overwhelming 71% of Americans believe that personal decisions about their health should take priority over a healthcare facility's religious values. However, at life's end, religious institutions often dictate care decisions, regardless of the patient's preferences.

### **When Choice Is No Choice**

It may be difficult to tell if a hospital or clinic is religiously affiliated. Sometimes these facilities even "hide" their affiliation with a secular-sounding name. In certain parts of the country, the only hospitals or healthcare facilities serving the public have ethical and religious directives in place that limit or constrain patients' choice. The problem is



### CATHOLIC HOSPITAL MARKET SHARE OF U.S. COUNTIES

This map shows the overall Catholic hospital market shares in all continental U.S. counties. Counties are shown by their Catholic hospital market shares (minimal, low, high or dominant).

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multiplying as mergers, consolidations and acquisitions of healthcare facilities by religious healthcare entities increase the number of facilities that restrict end-of-life care, impacting all patients, particularly those who have been historically underserved. A 2020 Community Catalyst report noted that the number of Catholic-affiliated hospitals grew by more than 28% over the last two decades, while the number of secular hospitals dropped by nearly 14%.

### What Can Be Done to Protect Your Rights

Individual providers have the right to opt out of participating in end-of-life healthcare treatments they object to based on conscience or religious grounds. However, providers take an oath to care and treat, and people have the right to compassionate, respectful and timely end-of-life care and the freedom to make their own healthcare decisions.

That's why Compassion & Choices is advocating for legislation and rules that allow physicians to opt out without blocking care; working in courtrooms to protect the rights of patients to have access to a clinician or facility's religious or ethical directives; encouraging health systems and hospices to adopt person-directed care policies; expanding education to physicians and pharmacists; and opposing consolidations and mergers that limit options.

These positive changes will happen only when people understand and can educate each other about these religious-based limitations, and know that they have the power, as consumers and communities, to ask for the care they want and need.

To learn more about religious refusals, watch "Threats to the End-of-Life Choice and Care Movement" webinar at [CandC.link/threats](https://CandC.link/threats).

## Educating Floridians About Navigating the End of Life



Staff members Nicole Reyes-Palma and Daisy Orihuela with volunteer Barbara Toeppen-Sprigg tabling at the Ocala Pride Festival.

Staff and volunteers in Florida have made incredible strides over the last year, building a strong base of supporters and advocates who are passionate about end-of-life care and ready to inspire their friends and community to take action.

Florida currently has nine Compassion & Choices Action Teams located throughout the state. Last year marked the launch of the Florida newsletter, which has been an incredible tool for sharing resources and events throughout the year. Action Team leaders and volunteers participated in many live and virtual programs in recent months, including community presentations on Compassion & Choices' end-of-life toolkit, workshops on advance care planning, open discussion at death cafés, live events with end-of-life doulas, virtual events about care options and much more. The team has also made a connection to the organization Fearless Caregivers, providing them with advance directive resources and the Compassion & Choices' Dementia Addendum.

Last fall, the team launched an ongoing educational series called "Get Together Florida," which has been

hugely successful, featuring presentations coordinated by leaders across the state. In recognition of Hospice and Palliative Care Month in November 2022, art therapist Yelena Zatulovsky, from Accent Care Hospice, along with our C&C team, presented "Hospice 101." Team Florida continued the series in February with an introduction to voluntarily stopping eating and drinking, otherwise known as VSED. They are currently planning for the spring installments and are excited to see new faces and make connections.

"We are so thankful for the dedication and creativity of our volunteers, partners and supporters on these educational events," says Nicole Reyes-Palma, Compassion & Choices' southeast regional advocacy manager. "Our community deserves access to high-quality information and education about their end-of-life options, and Get Together Florida is a wonderful example of what happens when passionate people share purpose. We want to make sure advocacy looks like you."

What's next for Team Florida? They will continue to build and create a grassroots movement that educates Floridians about all end-of-life options available in the state, and pressures medical systems to respect and recognize patients' existing values and priorities. The team hopes to connect with new storytellers who are willing to share their experiences with end-of-life planning or dementia with their community.

The core goal is to help Floridians navigate the final chapters of their lives so that they receive "truth in treatment," and feel empowered to make decisions that align with their values and priorities.

**For more information on what's going on in Florida or to get involved, please visit the Florida state page at [CandC.org/Florida](https://CandC.org/Florida).**

## Legislative Session and State Activity Updates

Compassion & Choices continues to work tirelessly to achieve the full range of end-of-life options for everyone.

### COLORADO

Last fall, our Colorado team launched their first Train the Advocate Lunch and Learn series, which has been an incredible success. This opportunity, taking place over multiple days, gives volunteers a comfortable space to learn about Compassion & Choices' mission and work, while also gaining the practical tools needed to serve as strong advocates in their community. Looking ahead, the Colorado team is focused on one overarching goal: to ensure that more patients can access the care they want. This includes working to close the disparities in end-of-life care and planning for communities of color, and improving end-of-life care for people with dementia.

### CONNECTICUT

Compassion & Choices Action Network unveiled the "They Died Waiting" portrait project, a series of portraits of loved ones holding pictures of advocates who have died waiting for the Connecticut General Assembly to approve medical aid in dying. This powerful portrait project will hang in the Capitol building for two weeks at the start of the legislative session. A record three aid-in-dying bills were introduced in January. All were referred to the Joint Committee on Public Health. Governor Ned Lamont reaffirmed his support for medical aid-in-dying legislation.

### MARYLAND

Compassion & Choices Action Network in Maryland is optimistic about passing the state's End-of-Life Option Act in 2023. Campaign Director Donna Smith says Maryland's new governor, Wes Moore, supports the legislation. In contrast, the position of Moore's predecessor, Larry Hogan, was unknown, dampening

support among lawmakers. The bill passed in the House of Delegates in 2019, but then failed narrowly in the Senate. The 2023 campaign strategy is to seek passage in the Senate first, then in the House of Delegates. Senate President Bill Ferguson told Smith he feels hopeful about passing the bill in 2023.

### MASSACHUSETTS

Compassion & Choices Action Network Northeast Regional Advocacy Manager Melissa Stacy and Massachusetts/Northeast Campaign Organizer Sara Elkins received a warm welcome at the annual Massachusetts Council on Aging Conference in October following their presentation about end-of-life planning and the Massachusetts End of Life Options Act. Council members were very engaged and excited about the prospects. Compassion & Choices, Death with Dignity National Center and Massachusetts Death with Dignity also jointly delivered nearly 2,000 signatures from Massachusetts residents to every state legislator urging them to pass the End of Life Options Act.

### NEVADA

Our Nevada team is working in full force to pass a medical aid-in-dying authorization bill during the 2023 legislative session. Our team in the Silver State continues to build relationships with storytellers, legislators, healthcare providers, community organizations and others that support the full range of end-of-life options. In the fall, our team attended community events and conferences to engage with clinicians as well as Latino, African American, LGBTQ+ communities and other diverse communities.



These beautiful portraits on display at the Connecticut State Capitol are a powerful message from those who died waiting for medical aid in dying to pass and their surviving family members who continue to fight for change.

## NEW MEXICO

The New Mexico Access campaign continues to work closely with End of Life Options New Mexico to educate the public and healthcare providers so they can inform their patients about the full range of end-of-life options, including medical aid in dying. In the fall, our volunteers made many presentations about the Elizabeth Whitefield End-of-Life Options Act, including to a Mennonite church in Albuquerque and a Lutheran church in Santa Fe. Our advocates and supporters also attended numerous festivals and community events to ensure residents statewide understand their full range of end-of-life care options.

## NEW YORK

Compassion & Choices' New York team held a statewide winter tour to bring the fight to pass the Medical Aid in Dying Act directly to lawmakers in their home districts. The tour featured community conversations, candlelight vigils and news conferences with terminally ill advocates, loved ones of deceased advocates, healthcare professionals, faith leaders and supporters. The tour started in the North Country after Election Day and moved downstate to Western and Central New York, the Hudson Valley, New York City and Long Island, ending in the Albany region with a rally to call on lawmakers to pass the bill in 2023.

## VIRGINIA

Compassion & Choices' Virginia campaign received some excellent news for 2023. Thanks in part to the advocacy of our Doctors for Dignity Director Rebecca Thoman, MD, the Virginia Medical Society withdrew its opposition to medical aid in dying and adopted a neutral position. Advocates continue to build support for medical aid in dying through monthly outreach to Virginia lawmakers on the bill, and by attending and speaking at events across the state. On January 6, 2023, Senate Bill 930 was filed by Sen. Ghazala Hashmi. This is the second consecutive year that a Senate bill has been filed.

## WASHINGTON

Though the Washington Death with Dignity Act has been in effect since March 2009, our Washington team knows that many eligible patients face roadblocks and limited availability of providers within their community. We continue working alongside our grassroots partners at End of Life Washington (EOLW) and support legislation that will improve access by expanding the list of eligible medical providers, as well as improving the process for obtaining medication. We also support a proposed reduction in the current waiting period, allowing it to be waived in extreme circumstances. Our team is thankful for EOLW's collaboration in this work.

## **Compassion & Choices Celebrates Black History Month**

To celebrate Black History Month, Compassion & Choices was honored to partner with several inspiring Black leaders who are fostering conversations about end-of-life care in their communities. In a series of interviews, these community leaders shared some of their personal stories and perspectives on end-of-life planning.

Rev. Dr. Roslyn Satchel is a professor at Kennesaw State University in Georgia and lead researcher at the Radow Institute for Social Equity, as well as a Berkman Klein Center Fellow at Harvard Law School. For the past 25 years, she has served as an ordained minister for the African Methodist Episcopal Church. In a video with Compassion & Choices, Rev. Dr. Satchel discussed her personal experience of end-of-life planning with her father. "When my dad did pass, it made all the difference in the world that all of [his] planning was in place," said Dr. Satchel. "We didn't have to figure out anything ... And that was really a burden lifted. My mother and I were able to grieve and care for each other."

Compassion & Choices advocate Reverend Kevin E. Taylor, affectionately known as "Rev Kev," is a senior pastor and director of LGBTQ+ services at Unity Fellowship Church in Newark, New Jersey. He believes his work as a pastor includes ensuring that members of his congregation are prepared for their last rights of passage. "[These end-of-life conversations can] be shaped in such a way that people don't always have to run from it or hear it and go right to trepidation," said Rev Kev. "Compassion & Choices [can] offer some choices that can include things like ... estate planning or how to have [end-of-life] conversations with your family and when. You can't leave that stuff unanswered!"



Michael Joyner (left) interviewed Reverend Kevin E. Taylor (right) about being an advocate for end-of-life planning at a Pride celebration in Newark, New Jersey.

Last year, Compassion & Choices sponsored several events highlighting Black voices and experiences. Osha Towers, Compassion & Choices LGBTQ+ outreach manager, joined Rev Kev and other community members to celebrate Pride in Newark. "Today was about bringing together the entire community, specifically our Black and queer folks. We need space to dance a little bit, eat some good food together, listen to performances and also get resources," said Towers. "A way to honor someone is being able to live up to their wishes, leaving room for grief and joyously remembering them as they were."

**To learn more about these leaders and other voices in the Black community, visit our website at [CandC.org/take-action/community-engagement](https://CandC.org/take-action/community-engagement).**



## Looking Back and Strategizing the Year Ahead

Reflecting on the accomplishments of 2022 helps Compassion & Choices plan for ongoing successes in the year ahead. We were proud to serve 8,931 volunteers across the country as well as 450,000 dedicated supporters. Our generous 71,362 active donors supported the work of the organization. More than 50 community and organizational events reached 2,554 people through conferences and presentations. Staff and volunteers distributed over 20,000 Compassion & Choices' tools, resources and information to diverse communities. Our email subscribers topped 141,863 and our social media followers grew to 129,701. What a year!

450,000 supporters

50+ states with active volunteers, (plus D.C., Guam and Puerto Rico)

8,931 volunteers across the country

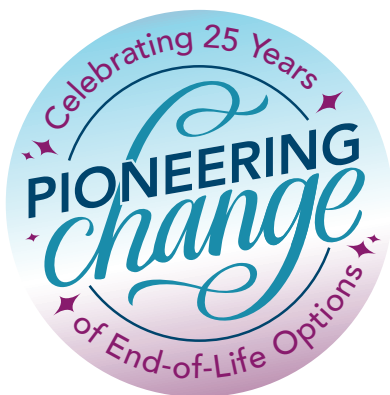
To learn more about the successes of the last year, visit [CandC.link/ar2022](https://CandC.link/ar2022).

## Signature Event Celebration



Compassion & Choices President and CEO Kim Callinan (left) hosting this year's virtual event with radio host Shawn Perry (right).

In October 2022, Compassion & Choices presented our 25th Anniversary Signature Event, *Pioneering Change: Celebrating 25 Years of End-of-Life Options*. The presentation was hosted by President and CEO Kim Callinan and emceed by Shawn Perry, host of The Senior Zone radio show. Nearly 600 viewers tuned in as we celebrated successes from the last 25 years and progress yet to come. Participants attended one of the following sessions: Change Starts with Us: Improving End-of-Life Care Together; Every Action Counts: Advocacy for Change; and Protecting & Defending Person-Directed Care.



Concurrently, Compassion & Choices celebrated the 25th anniversary of Oregon's Death with Dignity law with an in-person watch party. Guests included Barbara Coombs Lee and former Oregon Governor Barbara Roberts. The event included a reading of then-Governor Kate Brown's proclamation declaring October 27 as End-of-Life Options Day in Oregon. Thank you to all who supported the event and helped raise nearly \$300,000 to advance our mission.

Visit [CandC.org/signature-event](https://CandC.org/signature-event) to watch the virtual event and all (or part) of the breakout sessions.

## **Compassion & Choices Clinical Engagement and Education Programs**

The Compassion & Choices Clinical Engagement and Education team engages medical experts and patients through multiple channels, building coalitions of physicians, nurses, healthcare professionals, medical students and advocates who are interested in supporting our mission to improve care and expand options at the end of life. Compassion & Choices continues to produce tools and resources to support people with end-of-life planning.

Last year, Compassion & Choices launched the National Emergency and Palliative Medicine Initiative to bring together emergency medicine and palliative care teams in the emergency room. This initiative's growing network of diverse physicians, led by two of Compassion & Choices esteemed Board and Healthcare Advisory Council members, focuses on encouraging patient-directed care and starting end-of-life conversations early in a terminal diagnosis to help people avoid unwanted treatments and unnecessary trips to the emergency department at the end of life when it aligns with their values.

Recently, Compassion & Choices released three new resources that provide information about voluntarily stopping eating and drinking

(VSED), how to start end-of-life conversations with healthcare providers and tools to help plan for a dementia diagnosis.

In 2023, Compassion & Choices will produce a series of webinars about end-of-life illnesses and discuss strategies to navigate these potential diagnoses. In the webinar series called "As the End Nears," palliative care experts will explain the step-by-step progression of terminal diseases such as heart and kidney failure, ALS and metastatic cancer to provide information about what to expect in various end-of-life care scenarios.

The Compassion & Choices Doctors for Dignity program hosted four medical student interns from the National Student Medical Association to help research disparities in end-of-life care and support outreach efforts with physician advocates. The interns connected with various community groups to share information about end-of-life planning and foster conversations about end-of-life options.

**Visit [CandC.org/clinician-resources](https://CandC.org/clinician-resources) for more information.**



Compassion & Choices was a lead sponsor for the City of Hope End of Life Symposium in Las Vegas, Nevada, in February. Developed and directed by Compassion & Choices board member Chandana Banerjee, M.D., M.P.A., the 3-day symposium provided medical professionals, social workers, hospice clinicians, spiritual care representatives and many others with learning opportunities and inspiration related to end-of-life care. President and CEO Kim Callinan was a keynote speaker.

Dr. Banerjee speaking at last year's symposium.

## Policy Pushes Forward for Change

Compassion & Choices is engaging with specific regulatory processes to provide information to policy experts and lawmakers about the importance of equitable, person-directed healthcare at the end of life. This focus coincides with Compassion & Choices' legislative support, policy and legal research, resource generation and thought leadership across the country.

Aligned with our efforts to impact advance care planning nationally, Compassion & Choices observed the Health-Care Decisions Act Committee meeting in October. The Committee's leading goal is to reduce the number of Americans who lack an advance directive by removing unnecessary barriers to execution of documents. The Committee is reviewing proposed changes to the Act, which was last amended in 1993. The Uniform Health-Care Decisions Act (UHCDA) consolidates various state laws concerning advance directives for healthcare and healthcare powers of attorney. State legislatures in seven states have enacted the UHCDA. The Act defines advance directives and standards for determining an individual's capacity to make healthcare decisions.

Compassion & Choices is submitting comments about the amendments to support individual access to all end-of-life options. While the Committee's revised form is designed to be readily understandable and accessible to diverse populations, it does not go far enough to meet individual needs. We will support the proposed options for individuals to indicate goals and values, in addition to specific treatment preferences. Particularly promising for our dementia-related efforts is the commentary on the definition of "healthcare," which is to be given the broadest possible construction and includes custodial care and alternative medical treatment.



Compassion & Choices is also observing the Determination of Death Act Committee, which recently denied a proposal to significantly redefine the legal definition of death. Like the UHCDA Committee process, we will follow the Committee's review with comments supportive of a legal definition of death to ensure people are not forced to endure unwanted medical treatment at life's end.

Finally, Compassion & Choices' staff were appointed to serve on Oregon's Rules Advisory Committee to amend hospice licensing regulations. Compassion & Choices submitted comments on the need for equity-focused practices and hospice policy transparency (specifically policies that support advance care planning, voluntarily stopping eating and drinking, and medical aid in dying).

**To learn more about advance care planning, visit:**  
[CandC.org/our-issues/advance-care-planning](https://CandC.org/our-issues/advance-care-planning).

# Five Questions for Barbara Coombs Lee

Twenty-five years after passage of the Oregon Death With Dignity Act, Barbara Coombs Lee, co-author of the ballot initiative and president emerita/senior advisor of Compassion & Choices, is still working to improve the end-of-life experience for everyone.

**Q:** As is apparent in your book, *Finish Strong: Putting Your Priorities First at Life's End*, you have collected many stories through the course of your career. What do you hope people will take away from reading your book?

**A:** I hope people come away believing in their authority to manage healthcare for themselves and help their loved ones do so, throughout life. I hope they feel empowered to shape their end-of-life experience. I hope people feel confident and curious, willing to ask questions and to weigh the benefits and burdens of every test and treatment they are ever offered.

**Q:** What made you decide it was time to add a new chapter to *Finish Strong* and issue a second edition?

**A:** Disparities in end-of-life healthcare based on color and culture are unjust, and they cannot go on. The first edition did not address this problem adequately. We need to correct the fact that people of color are less likely to receive hospice and palliative care and more likely to suffer needlessly at the end of life. We are eager to welcome people from diverse communities into our movement and respond to the need, as they experience it, for education, information and concrete tools to talk about death and plan for peaceful dying. To do this, I wanted to focus an entire chapter on the problem and its history, and point to some ways forward. A second edition also created the opportunity for Kim [Callinan] to contribute a very important update on our advocacy. Finally, we had requests for an index, and now there is one!



## five questions

**Q:** What gives you optimism about the future of the movement?

**A:** I'm enormously optimistic about the future of the movement because of its wide acceptance among people in every demographic and of every political orientation. Compassion & Choices has secured and held a strong center position for medical aid in dying, grounded between the extremes of unnecessary restrictions on one end and inadequate safeguards on the other. Kim Callinan and her team are superbly capable here. I'm also optimistic because ours is a broad movement about end-of-life healthcare that reflects dignity and personal values. It's not about one particular treatment option a person might choose. Young people and people in diverse communities see the opportunity to reinforce beliefs, set priorities and remain true to self and true to culture even as life ends. Today our movement stands for integrity, community and family as much as self-determination.

**Q:** What tools do you find useful in your own end-of-life planning?

**A:** Compassion & Choices resources are the best! They present the most candid and comprehensive information available, and they keep getting better as we receive suggestions to make them even more useful and accessible. As much as I've been immersed in the subject, I still benefit from reviewing the Advance Planning Guide and Toolkit periodically. It's comforting to review the Values Worksheet and confirm that I've had the right conversations and given my family the right instructions. The same goes for the Dementia Provision. Once a year I review this document, initial and date it. That way, if my family ever has to consult it, they know my wishes are current and consistent.

But as I age, I realize that all my advance planning and preparation is really just a way to affirm a love affair with life and keep gratitude foremost in heart and mind. In the early days, our tagline was, "Assurance of a good death enhances the celebration of life." Indeed, joy is the most powerful tool, and celebration is the true goal!

**Q:** Your legacy in the end-of-life options movement is powerful. What do you hope people remember about you years down the road?

**A:** I hope people remember what we did together, a small band of activists undaunted by the powerful forces of church and state aligned against us, and all the volunteers and supporters who helped. We drew strength from each other, the rightness of our cause, and faith that the long arc of history does affirm human compassion and dignity. Perhaps that example might inspire others who work on their own just causes and face what seems like overwhelming political and judicial power. Optimism is a duty we owe our descendants, and a life of trial and perseverance is one worth dying for. As [pre-Renaissance Spanish] poet Jorge Manrique wrote, "Nuestras vidas son los ríos que van a dar en la mar, que es el morir." (Our lives are the rivers that flow into the sea, that is our dying.)



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To purchase the second edition of *Finish Strong: Putting Your Priorities First at Life's End*, please visit [CandC.org/finish-strong](https://CandC.org/finish-strong).



# 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 protect 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 entire 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 [CandC.link/free-will](https://CandC.link/free-will).



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

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### If you have any questions, contact:

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Care and Choice at the End of Life

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### START THINKING

How do you want to live through the end of your life?

### START TALKING

"I've been thinking about my future, can we talk about it together?"

### KEEP DISCUSSING

This is not one conversation, it's many conversations over a lifetime.

Start and keep planning at [CandC.org/end-of-life-planning](http://CandC.org/end-of-life-planning).

