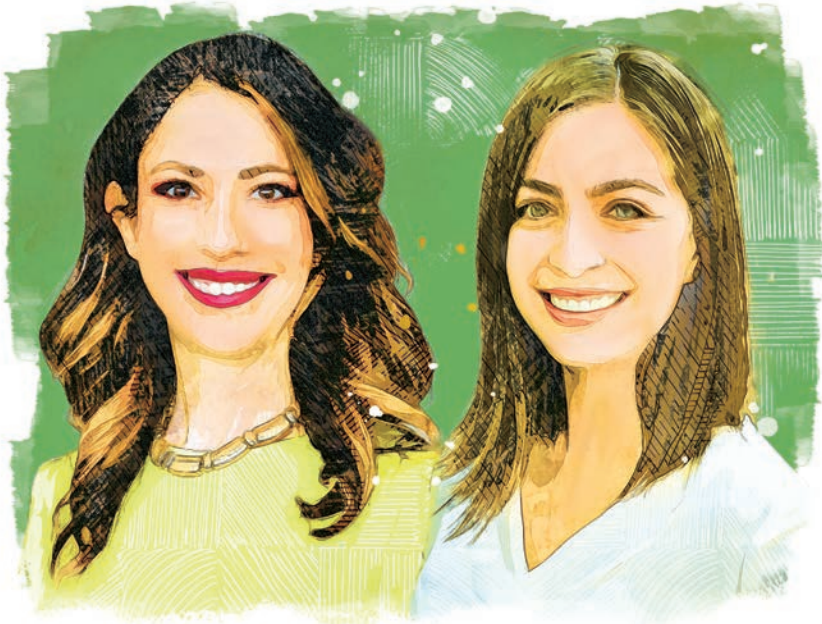




# compassion & choices

MAGAZINE  
FALL 2023



## Heroes of the Movement Guided Our Past and Fuel Our Future





# 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 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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## FEATURES

### 04 When the System Fails: Barbara Mancini's Quest for End-of-Life Autonomy

Highlighting the need for better communication and compliance in healthcare.

### 06 A Father's Love, A Family's Peace

Rev. Dr. Roslyn Satchel's father took preparing for death to heart.

### 15 Strategy Lights The Way

Heroes guiding the end-of-life care movement forward.



## DEPARTMENTS

02 Top of Mind

03 Words & Pictures

08 National Programs Update

12 Advocacy in Action

14 State Spotlight

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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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## Five-Year Journey Forward

In what felt like the blink of an eye, five years of strategic planning and execution flew by. Earlier this year, the Compassion & Choices Board of Directors began working on a new strategic plan (see page 16) to succeed the one passed in 2018. Grounded in learnings and input from hundreds of you, a bold path forward was forged: one that will move us decidedly closer to people from all walks of life having a greater voice — and choice — in how they live life's final chapter.

When we launched our last strategic plan, I was a brand new CEO. Auspiciously, my fears were quickly overpowered by your remarkable energy, intelligence, passion and resilience. So this issue of our magazine appropriately features a few heroes — out of thousands — who have made our collective progress possible.

While today I'm a more seasoned CEO, the need to be propelled forward by the collective stakeholders of this movement is no less important. As history proves when heroic acts are coupled with a wealth of smaller ones and dogged determination — meaningful progress prevails.

I hope you will join in my dogged determination and take at least one small action today. Whether you choose to volunteer, donate, make a legacy gift or spread the word, your efforts will help us realize a world whose embrace of death's inevitability leads to a far more intentional and fulfilling life — a profound outcome well-deserving of the most dogged determination one can muster.

In this issue, we reflect on being a sponsor of the 2023 Hawai'i Arts Summit, which took place before the destruction of the fires. Words cannot express my sorrow for the devastation from the fires. My heart goes out to the people of Hawai'i.

In humility, appreciation and partnership,



*Kim Callinan*

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## In the Media

### *NPR*

#### **How the Medical Aid in Dying Movement Is Gaining Momentum in the U.S.**

NPR's syndicated radio show, "On Point," detailed the progress of medical aid-in-dying laws and how the debate on the issue has evolved over time. "So back in 2015, most of the medical societies had oppositional policies around medical aid in dying," said Kim Callinan, president and CEO of Compassion & Choices. "... I think we're up around 30 or so national and state medical societies that have dropped their opposition and then also increased support among individual doctors, as well. And that comes because individuals are putting pressure on their own doctors ... And the medical societies and doctors are starting to recognize that people see this as a fundamental part of the treatment options that they want available to them at the end of life."

### *The New York Times*

#### **To Die on Her Own Terms, a Connecticut Woman Turns to Vermont**

The New York Times reported that Connecticut resident Linda Bluestein, "who was diagnosed with late-stage fallopian tube cancer, said that if chemotherapy stopped working, she intended to make use of a Vermont law that allows certain people to seek and self-administer a lethal dose of medication to hasten their death. Compassion & Choices senior staff attorney Amitai Heller told the Times, "To my knowledge, other than what is happening right now with abortion, there are no other medical procedures that are limited to people on the basis of their residency. It's just unfair, and it doesn't really make sense to restrict some sort of medical practice just based on ZIP code or residency."

### *Public News Service*

#### **OR Repeals Residency Requirement for Aid-in-Dying Law**

In June, Oregon became the second state after Vermont to remove the residency requirement from its medical aid-in-dying law. This Public News Service story reported: "The bill's passage comes after a case last year brought by Compassion & Choices in Multnomah County, that argued the residency requirement violated the equal-treatment provision of the U.S. Constitution ... The case was brought on behalf of Dr. Nicholas Gideonse, associate professor of family medicine with Oregon Health & Science University, who said the law can be hard to access. 'One of those barriers was the residency requirement which struck me personally with a couple of cases,' said Gideonse, 'patients of mine who were Washington-based ... But then once they pursued anything around Oregon's Death with Dignity Act, I was unable to continue to provide care in that area.'"

### *South Florida Sun Sentinel*

#### **Proposed Federal Prescription Rule Will Increase the Suffering of Dying Patients**

In this op-ed, Compassion & Choices president and CEO Kim Callinan and Compassion & Choices Healthcare Advisory Council member Michael Fratkin urged the Drug Enforcement Administration to modify a proposed rule to ban medical practitioners from prescribing controlled medications via telemedicine if they have not conducted an in-person medical evaluation beforehand. "If the rule moves forward as proposed, individuals at the end of life will face unnecessary pain and suffering stemming from the considerable barriers that will impede their ability to get the care they need," they wrote.

# When the System Fails: Barbara Mancini's Quest for End-of-Life Autonomy

Highlighting the need for better communication and compliance in healthcare.



Barbara Mancini is all too familiar with battling for autonomy and self-determination at the end of life. In February 2013, Barbara, an ER nurse, was helping to care for her 93-year-old father, Joe, who was terminally ill. He had significant but under-treated pain, despite being enrolled in home hospice care. Barbara handed Joe his morphine at his request, and without stating his intentions, he took far more than the prescribed dose. Barbara was unjustly arrested and charged with a felony for aiding his attempted suicide, a charge which carries a 10-year maximum sentence. Joe was taken to the hospital, which he had explicitly said he did not want, and where he suffered through painful, life-prolonging treatment against his will. He died there five days later in agony.

A year later, a judge dismissed all the charges against Barbara, but not before she racked up \$130,000 in legal fees and was placed on unpaid leave from her nursing work. Compassion & Choices covered most of her legal fees, generated 30 columns and editorials from thought leaders opposing her prosecution and provided experts for a widely-viewed episode of "60 Minutes" about her story. Barbara went on to partner with Compassion & Choices, becoming a fierce advocate for end-of-life care options and published a riveting account of her ordeal in the book *Cruel Death, Heartless Aftermath*.



After enduring all of this anguish, Barbara is the last person you'd expect to have trouble ensuring a loved one's end-of-life care is consistent with their wishes. And yet when Barbara's mom was admitted to the hospital, what should have been a coordinated effort to follow her mom's documented medical preferences instead turned into a days-long ordeal that culminated in unnecessary pain and suffering for her mother, up until her death. The events described here show how difficult it can be to navigate the healthcare system at the end of life, and why training clinicians and informing and empowering everyone to ask for the care they want remains at the forefront of the Compassion & Choices mission.

Barbara's mom, Marge, was 93 years old and receiving home-based palliative care services for a chronic heart condition. Palliative medicine is focused on comfort and symptom care, and can be delivered with or without treatments that are intended to cure a disease. Marge's goals of care were to live as comfortably and independently as possible. Her palliative care providers visited her regularly at her home in Northeast Pennsylvania. In December 2022, Marge developed an acute lung infection that caused her to have trouble breathing. Her palliative care team recommended a trip to the emergency department for some treatment, including intravenous antibiotics and other supportive measures.

Barbara was her mom's healthcare proxy, meaning she had the legal standing to make healthcare decisions for her mom if and when she was unable to do so for herself. Upon arrival, Barbara presented the care team at the hospital with her mom's POLST (Pennsylvania Orders for Life-Sustaining Treatment) form and she personally informed each care provider of her mother's goal to be as comfortable as possible. The POLST is a medical order form prepared by a patient and their primary doctor that documents the medical treatments the person wants or doesn't want near the end of their life. The document has different names in different states.

Despite breathing treatments and antibiotics, Marge's condition worsened, and she started to show signs of suffering. Unfortunately, the providers at the hospital did not provide the comfort care measures her mother had explicitly asked for in her POLST. Members of the staff disagreed with Barbara about what the clear instructions in the POLST meant.

"I found myself begging and pleading for pain relief for her while she was actively dying," Barbara recalled. "She had a massive heart attack near the end. Pain in her chest, back, entire abdomen. She screamed that she was in agony." Eventually, after a lengthy period of Barbara insisting that they treat her mom's pain crisis, the hospital staff administered an opioid. Shortly after receiving the medicine, Marge died.

"I was forced to once again relive the anguish of a parent dying in agony," said Barbara. "I knew Mom, at age 93 with serious cardiovascular disease, could have her life end at any moment. It's the way that it happened that is so difficult for me. As my husband observed, 'you did everything by the book and more, and still the system failed.'"

Barbara is determined to ensure this doesn't happen again to another patient with a POLST. Compassion & Choices is committed to working with Barbara to ensure that physicians and other providers are trained on the importance of following POLSTs and other advance healthcare directives; that hospitals and health care systems insist their clinicians honor these documents; and that state legislatures and regulators pass laws and implement rules to give POLSTs the force of law.

"My mother's story shows what all too often still happens when the modern American healthcare system is told to refrain from heroic measures at the end of a patient's life," said Barbara. "No one should have to go through what we went through."



# A Father's Love, A Family's Peace

**Rev. Dr. Roslyn Satchel's father took preparing for death to heart.**

**E**very year at Christmastime, Rev. Dr. Roslyn Satchel, a scholar and activist, had a very specific conversation with her father. Pastor Frank worried about leaving the family unprepared for his eventual death so in his late 50s, he started reviewing estate-planning documents with the family during Christmas. Dr. Roz, as she is known now, was unanimously, informally and unceremoniously selected as the family representative for these discussions.

Dr. Roz lives in Atlanta. She is the youngest of six children and witnessed the love in her parents' marriage and partnership every day. Her dad, Rev.

Dr. Frank R. Satchel, a pastor, was the center of the family. Her mom, Dorethea B. Satchel, Ph.D., and dad adored each other and loved their family. Pastor Frank, however, didn't expect to live a long life. No one in his family had lived past 60.

Over time, these conversations became an act of love. Annually, Dr. Roz was instructed on insurance policies, investments, the will and how her parents had set up a trust to benefit the family at the time of their deaths. Her father reviewed final arrangements, funeral liturgy, pre-purchased cemetery plots, advance directives, powers of attorney documents and bank





**“The legacy my parents left with me is you want to make this as easy as you can for your loved ones when you are gone.”**



accounts for him and her mom. They planned everything in advance so that the children would not have that weight on their shoulders while mourning. Over the years, Pastor Frank became increasingly emphatic about not wanting extraordinary medical intervention to sustain his life. Thankfully, he was wrong about living a short life. Pastor Frank lived to age 93.

“My father was the driver behind my motivation to learn. I still see his influence in my practices of critical media literacy, ministry/ethics and law/public policy. In fact, my social equity focus in my community organizing originated in his pastoral ministry in South Florida,” Dr. Roz said.

In 2022, Dr. Roz was introduced to the work of Compassion & Choices when she reconnected with her friend Zeena Regis, the faith outreach manager for the organization. They met years before, and their shared interests, work and careers brought them back together today to join forces in spreading the message about end-of-life planning.

“When Dad passed, my parents’ pre-planning made all of the difference in the world,” said Dr. Roz. “We didn’t have to figure out anything. We didn’t have to assume what he would want. We didn’t have to guess at who gets what. Everyone felt included. Everyone

felt loved. It was a burden lifted. My mother and I were able to grieve and go through that process without going through probate. As a lawyer, I know what probate is like for people.” Dr. Roz wants the same peace for others.

Through her work with Compassion & Choices, Dr. Roz brings her organic, academic and communal knowledge and experiences to help people around her who otherwise would not have any help through the pre-planning process. And they, in turn, can go on to help others.

“We have to take the time to honor people’s cultures and their traditions before we can teach them or impart anything. In Compassion & Choices, I see the potential for that type of intra- or inter-cultural communication dynamic that is more tailored and is more culturally competent,” Dr. Roz said.

She added, “At the end of my sermon, I always say ‘Lord, please let us be liberated so that we can liberate others. Help us to be empowered so we can empower others. Transform us so that we can help others transform themselves.’”

She smiled and finished with, “And remember, talking about death won’t kill you.”

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For some tips on holiday planning discussions, please visit [CandC.link/holiday-planning](https://CandC.link/holiday-planning).

## **Emmy-Nominated Documentary Collaboration**



The Emmy-nominated documentary *Last Flight Home* depicts 92-year-old Eli Timoner, who founded Air Florida, the fastest growing airline in the world in the 1970s. During his final days, we discover his extraordinary life filled with incredible success and devastating setbacks, such as a stroke that left him paralyzed from the waist down over four decades prior, but most importantly, an innate goodness which won him the enduring love and support of his family. At the time of the film, he is bedridden and ready to die, which he clearly articulates throughout the documentary created by his daughter Ondi, who will be featured in the winter issue of the *Compassion & Choices* magazine.

As the forefront advocacy organization for medical aid in dying, *Compassion & Choices* is collaborating with Interloper Films, the team behind Ondi's documentary, to raise awareness on end-of-life options across the country. Ondi and her family experienced challenges on the road to helping Eli die with dignity but she is also pleased that they were able to navigate the process in a loving manner and on her father's terms. We are excited to share more about Ondi, *Last Flight Home* and our collaboration, so be sure to look out for her feature story in the next issue.

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## **Compassion Weekend Impacts Communities Around the Country**

The *Compassion & Choices* first inaugural *Compassion Weekend* occurred July 28-30, 2023. Over 26 congregations in 16 states participated in this interfaith celebration of community, creativity and advance care planning. *Compassion & Choices* provided tools and resources to spiritual communities to emphasize the importance of advance care planning, including an educational program and workshop led by *Compassion & Choices* staff.

Faith communities are a major place where discussions about death and dying occur so it's a natural fit for discussions on how we can plan and prepare for our end-of-life healthcare preferences. In communities from Atlanta, Georgia to Lecompton, Kansas, *Compassion Weekend* provided community support and conversation to congregants.



Rev. Kev Taylor preaching to a congregation in Newark, NJ.

## **Doctors for Dignity Internship Celebrates Two Years**

In September 2021, the Compassion & Choices Doctors for Dignity program welcomed its first End-of-Life Disparities intern, Bryan Redmond. The goal of this role is to help medical students expand their knowledge of palliative medicine, advance care planning and the end-of-life disparities impacting patients. In the years since its launch, the program has grown into a powerful cultivator of passionate and empowered medical students, and is already making significant changes in this movement.

This spring, Bryan reached out to fellow medical students in Illinois, encouraging them to help influence the Illinois State Medical Society (ISMS) to adopt a neutral stance toward medical aid in dying. By attending the annual meeting, medical students helped move the ISMS to revoke their opposition to medical aid in dying in favor of a neutral stance, agreeing to provide continuing education and adhere to statutorily correct language.

“The most important thing is that we are connecting with medical students early in their process,” said Dr. Rebecca Thoman, Doctors for Dignity program manager, who oversees the interns. “This early education provides a new perspective on an issue that is often overlooked in medical training. Our internship is directly aiming to cultivate new physicians who are knowledgeable of and familiar with end-of-life care throughout their career.”

Advocacy remains a core component of our work at Compassion & Choices, and Dr. Thoman encourages interns to find their unique voice and perspective in medicine. Previous interns have presented at conferences, offered end-of-life planning sessions for their community and even found themselves correcting professors who were providing inaccurate information about hospice.

“During their time with us, the interns are reflecting on their families’ experiences and examining their personal feelings about death. They are finding every opportunity to share what they have learned,” Dr. Thoman added. “Exploring end-of-life care can change one’s perspective on medicine, and we need more physicians willing to do that for their patients.”



**To learn more about Doctors for Dignity and previous interns, visit [CandC.org/d4d](https://CandC.org/d4d).**



## **The LGBTQ+ Outreach Program Reaches New Heights**

Every year, Compassion & Choices celebrates Pride month in recognition and celebration of the LGBTQ+ community. The end-of-life options movement was born out of the same principles and values as the LGBTQ+ rights movement, including bodily autonomy and person-directed healthcare.

This year, Compassion & Choices released videos of advocates like Illinois resident Deb Robertson, a Compassion & Choices LGBTQ+ Leadership Council member, and Thomas Reed Jackson, a storyteller from Virginia who died last year. Sharing their stories aligns with the Compassion & Choices mission to reach diverse audiences with the message of legacy, planning and choice at the end of life.

On the ground, Compassion & Choices staff, supporters and volunteers attended dozens of Pride celebrations around the country, including New York, Montana and Florida. Compassion & Choices also



left: Deb Robertson at her home; right: LGBTQ+ engagement director Osha Towers (they/them) and longtime advocate Rebecca Doyle (she/her) tabling at the Denver Pride Festival.

participated in events hosted by SAGE, an LGBTQ+ elders group and longtime collaborator, and the Black Trans Advocacy Coalition (BTAC) Conference, a new connection made this year. These events occur throughout the year, illustrating our pride each month.

**To learn more, visit [CandC.org/pride](https://CandC.org/pride).**

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## **As the End Nears: Demystifying the Dying Process**

At Compassion & Choices, we hear from people everyday who need practical information about illnesses they or a loved one are living and dying with. As medicine continues to advance in its ability to prolong life, it becomes more important to decide for yourself when the risks of certain treatments outweigh the benefits and when treatments are going to prolong suffering and dying or fail to provide an acceptable quality of life.

In our ongoing webinar series *As the End Nears*, we follow the final stages of multiple illnesses impacting millions of Americans. The series features candid conversations with specialists and our own medical

directors about disease progression, symptoms and the physical experience of these illnesses.

Topics so far have included heart failure, cancer, dementia, kidney failure and progressive neurological disorders like ALS. Understanding what death looks like gives each of us the tools to plan and prepare for it. We aim to demystify the dying process and in turn empower you to make the best decisions for your care.

**For more information or to watch any of the previous programs, please visit [CandC.org/as-the-end-nears](https://CandC.org/as-the-end-nears).**

# **Celebrating the Asian American, Native Hawaiian and Pacific Islander Communities**

Compassion & Choices is dedicated to honoring the Asian American, Native Hawaiian and Pacific Islander (AANHPI) communities and providing resources for planning. This includes attending and sponsoring events, creating educational content and building new and dynamic partnerships.

Over the summer, Compassion & Choices attended the Asian Pacific American Institute for Congressional Studies (APAICS) Awards Gala recognizing Asian American, Native Hawaiian and Pacific Islander Heritage Month. We celebrated the contributions of the AANHPI community across the country, including our staff, supporters and AANHPI Leadership Council, a group of thought and community leaders who work with Compassion & Choices to advance the mission of improving end-of-life care.

In Hawai'i, Compassion & Choices sponsored the 2023 Hawai'i Arts Summit: Calling Out the Future! featuring more than 100 leaders of Hawaiian businesses, arts organizations and community-based organizations. The panel presentations on emerging societal issues and the arts; dynamic cultural and hula dancing; oli (Hawaiian chanting); musical

performances; and living history underscored the partnership between community and the arts.

"The 2023 Arts Summit focused on the role of artists in moving all of us toward a more inspired, inclusive and compassionate society. Art keeps traditions alive and passes culture on to the next generation," stated Brandi Alexander, chief of engagement at Compassion & Choices. "The same can be said of planning and preparing for the life we want to lead and the legacy we want to leave behind."

Compassion & Choices also released four videos about different aspects of our work with the AANHPI community. This includes a video introducing the AANHPI Leadership Council and others that outline the importance of end-of-life conversations within the AANHPI community and specifically, Hawaiian communities. The last video discusses medical aid in dying and AANHPI communities. Compassion & Choices is dedicated to providing resources to communities in Hawai'i and around the nation about the end of life.

**To view these videos, visit [CandC.link/aanhpi](https://CandC.link/aanhpi).**



left: Annual APAICS Awards Gala. right: Taiko drums musical performance at the 2023 Hawai'i Arts Summit.

## Steady Progress in the States

### DELAWARE

The Compassion & Choices Action Network 2023-24 campaign to enact medical aid-in-dying legislation in Delaware enjoys historically strong legislative support. Longtime bill champion Rep. Paul Baumbach introduced the Ron Silverio/Heather Block Delaware End of Life Options Act on May 2 with three other bill sponsors, including Senate Majority Leader Bryan Townsend and House Majority Whip Melissa Minor-Brown, and 13 bill co-sponsors. The House Health and Human Development Committee approved the bill on May 18 for House consideration. While the 2023 session ended June 30, “The bill faces positive prospects in 2024 for passage in the House and Senate,” said Tim Appleton, campaign director.

### FLORIDA

For the first time since 2020, the Florida legislature introduced bills that would authorize the option of medical aid in dying for terminally ill adults with six months or less to live, giving us hope that we may see this peaceful option in the Sunshine State sooner rather than later. Throughout the state, the movement for end-of-life options continues to gather momentum with hundreds of volunteers attending in-person events, online webinars and even talking one-on-one with a neighbor or loved one about the importance of end-of-life planning. Additionally, during the month of June, we celebrated the LGBTQ+ community and attended the first-ever Sarasota Silver Pride. During this event we were able to have one-on-one conversations with attendees about equity and end-of-life care.

### HAWAII

We took a big step forward for access to end-of-life options in the Aloha State, as the Compassion & Choices campaign to improve the state’s Our Care Our Choice Act led to the passage of a bill that took effect June 1. The new law allows qualified advanced

practice registered nurses (APRNs) to be both attending and consulting healthcare providers; allows licensed APRNs and clinical nurse specialists with psychiatric or mental health training and licensed marriage and family therapists to provide mental health counseling to qualified patients; reduces the mandatory waiting period from 20 to five days; and waives the five-day waiting period for terminally ill qualified patients who are not expected to survive that period of time.

### MASSACHUSETTS

The chances of passing the Massachusetts End of Life Options Act during the 2023-24 legislative session are stronger than ever. In June, about 90 bill advocates gathered at the State House to participate in a lobby day sponsored by the End of Life Options Coalition which included Compassion & Choices Action Network, heard speeches by five bill sponsors; and held meetings with more than 60 legislative offices. The bill has 81 sponsors out of 200 members of the legislature. The Boston Globe and Springfield Republican endorsed the bill. In contrast to her predecessor, current Gov. Maura Healey publicly supports medical aid in dying.

### NEVADA

The Compassion & Choices Action Network’s campaign in Nevada reached unprecedented heights in 2023, generating thousands of calls, emails and petitions from volunteers who successfully urged lawmakers to pass medical aid-in-dying legislation (SB 239) for the first time in both legislative chambers. Campaign highlights included a new poll showing 82% of Nevada voters support the bill and the brave advocacy of Lynda Brooks-Bracey, a terminally-ill Las Vegas mom. Gov. Joe Lombardo vetoed the bill on June 5, just two and a half weeks before Lynda’s death from pancreatic cancer.



## advocacy in action

### NEW MEXICO

In partnership with End-of-Life Options New Mexico, a team of 60 volunteers have been laser-focused on providing presentations to diverse and rural communities. Volunteers distributed hundreds of Spanish resources and tabled at Albuquerque Pride and the community health fair in Aztec to help residents of rural communities understand their end-of-life options. For National Healthcare Decisions Day in April, we ran Facebook and Instagram ads that reached over 95,000 New Mexicans and linked them to resources to help them plan ahead. We also sponsored and attended the Nursing Excellence Awards Gala and presented the Distinguished Nurse of the Year Award to Deborah Walker.

### NEW YORK

The Compassion & Choices New York campaign laid the groundwork for a big push to pass the Medical Aid in Dying Act in 2024 by increasing the number of bill cosponsors from 50 to 83 between January and the close of the 2023 legislative session in June. "We made tremendous strides this year, and we now have more than enough votes to pass the bill," said Corinne Carey, senior campaign director. "We just need to help lawmakers understand that voters will be forever grateful to [them] for passing legislation that will provide comfort and peace of mind to their dying loved ones."

### WASHINGTON, D.C.

The U.S House Appropriations Committee approved a D.C. spending bill in July with an unrelated provision that would repeal D.C.'s Death with Dignity Act and prevent the D.C. Council from re-passing it. "This outrageous rider is an invasion of dying D.C. residents' bodily autonomy and congressional overreach at its worst," said Donna Smith, the D.C. campaign director. "Congressional temporary D.C. residents have no right to use a spending bill to override the veto-proof vote of D.C. council members who passed this compassionate legislation on behalf of its residents. We will do whatever it takes to defeat it."



**I'm a New Yorker,  
and I Believe in  
Medical Aid in Dying.**



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MOVEMENT FORWARD**

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LinkedIn: [Linkedin.com/company/Compassion-&-Choices](#)

**VOLUNTEER** any way you can; find options at [CompassionAndChoices.org/volunteer](#).

**DONATE** to help us protect decades of hard-won progress toward self-determination for the terminally ill in our country at [CompassionAndChoices.org/donate](#).

Don't see your state?  
Visit [CandC.org/in-your-state](#).

## Removing a Barrier to Access: the Residency Requirement

The Compassion & Choices legal team has led the national effort to remove one of the biggest barriers to access for terminally ill adults seeking the option of medical aid in dying: the requirement that only residents of an authorized state may utilize these laws.

Vermont became the first jurisdiction to remove the residency mandate in May, just two months after Compassion & Choices settled a lawsuit with state officials asserting that the requirement violates the U.S. Constitution. Oregon's legislature voted to remove that state's residency requirement in June, following another Compassion & Choices-led lawsuit settlement.

The Vermont settlement stated that state officials would not enforce the residency requirement for the lawsuit plaintiff, Lynda Bluestein, a Bridgeport, Connecticut resident with stage 3c fallopian tube cancer, and that the state's Health Department would support a bill to repeal the residency requirement. Compassion & Choices collaborated with Patient Choices Vermont, which led the campaign to pass the revised law. To learn more about Lynda Bluestein, see page 18.

The bill signing by Vermont Gov. Phil Scott generated national news coverage. "Support for this is widespread and bipartisan," Kimberly Callinan, Compassion & Choices president and CEO, told *The New York Times*. Cassandra Johnston, 38, a resident of New York who has stage 3 breast cancer, said Vermont's law change had given her peace of mind, knowing she could go to the state to access care if needed. "This should be the standard of medical care, not the exception," Ms. Johnston told *The New York Times*.

In Oregon, Compassion & Choices brought a similar lawsuit on behalf of Dr. Nicholas Gideonse, a Portland physician who is licensed to practice medicine in Oregon but often treats patients nearby in Washington State, where he is not licensed. The settlement of that case required the Oregon Health Authority (OHA), Oregon Medical Board and the Multnomah County district attorney to issue directives halting enforcement of the unconstitutional residency requirement, and request that the legislature permanently remove the residency language from the law.

The residency repeal bill was supported by Compassion & Choices Action Network and Death



Cassandra Johnston

with Dignity National Center. The Oregon Senate passed the bill by a bipartisan vote of 17 to 8, following the House's approval of the bill by a bipartisan vote of 35 to 21. Oregon Gov. Tina Kotek signed the bill on July, 13, 2023.

"Oregon officials' agreement not to enforce the residency mandate was important, but the 35 county DAs outside of Multnomah County did not sign onto that agreement, so they were not bound by it," said Dr. Gideonse. "That's why formally removing [the residency requirement] from the law provides much more certainty to physicians in the other 35 Oregon counties and their non-resident patients that they can utilize medical aid in dying without fear of any legal risk. I thank Oregon lawmakers for removing this needless barrier so non-resident patients who receive treatment here can get the end-of-life care they deserve."



# Strategy Lights The Way

## Heroes Guiding the End-of-Life Care Movement Forward

Compassion & Choices has adopted a new five-year strategic plan, focusing our resources on the four main aspects of our mission: improve care, expand options, empower everyone to chart their own end-of-life journey and defend and protect end-of-life options. We rely on all of our supporters, volunteers, storytellers, donors and friends of the movement to help us achieve progress. The wonderful people in this article are excellent examples of heroes in the end-of-life options movement. They continue to support the Compassion & Choices mission and move our values — compassion, respect, courage, credibility and resilience — forward. These advocates and champions light the way ahead.



## Long-Term Objectives

As Compassion & Choices adopts this five-year strategic plan, we will focus our resources on the following aspects of our mission and make progress toward our 10-year, long-term objectives.



### IMPROVE CARE

Improve patient-directed end-of-life care through demonstration projects, CEU/CMEs and federal legislation, or regulatory change in three priority areas:

- » Advance-care planning for dementia
- » Equity in end-of-life care
- » Palliative care integrated into emergency medicine



### EXPAND OPTIONS

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

- » Repeal the Assisted Suicide Funding Restriction Act of 1997 to make the practice more affordable.
- » Integrate medical aid in dying into standard care through greater acceptance by medical societies, schools and residency training programs.
- » Create a path toward authorization in large, politically challenging states with increased support from Republicans and Libertarians.



### DEFEND AND PROTECT

Defend and protect the full range of patient-directed, end-of-life care:

- » Block efforts to weaken or overturn medical aid-in-dying laws or undermine a patient's rights to accurate information, timely care with access to a full range of options.
- » Counter healthcare restrictions based on ethical and/or religious directives that impede patient choice and reduce end-of-life care options such as those imposed by Catholic hospitals and hospices.



### EMPOWER EVERYONE

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

- » Train 2,500 end of life care guides to support 100,000 people to become fully empowered to demand end-of-life healthcare that is consistent with their values.
- » Foster a diverse, equitable, and inclusive movement with a focus on racial, ethnic, age, gender identity, and faith diversity and those living with disabilities.



# IMPROVE CARE

**Focusing on patient-directed end-of-life care, creating greater equity, normalizing advance-care planning for dementia, integrating palliative care into emergency medicine.**



Improving care at the end of life is paramount for everyone. All patients should have access to the full range of high-quality end-of-life care options. Supporting the integration of palliative care into emergency medicine is a key area of focus. Every year there are over 137 million visits to hospital emergency departments (EDs) in the United States. EDs in the U.S. are the primary hospital entry point for end-of-life care.

Compassion & Choices is spearheading the National Emergency & Palliative Medicine Initiative (NEPMI) to address the importance of EDs in the end-of-life experience of all people — all race, ethnic, socio-economic and religious backgrounds. Physicians, nurses, social workers, chaplains, end-of-life doulas and caregivers

from all over the country will join together in the effort to increase earlier palliative care consultations in EDs.

Clinical nurse coordinator Beka Malloy and clinical social worker Alejandra Muro co-developed a palliative-emergency medicine initiative in 2021 at Little Company of Mary Providence Hospital in Torrance, California. Before engaging with palliative-emergency medicine, the duo grappled with the questions: Why are we doing this? What's the end goal? Are we doing too much or not enough for our patients? They realized the value of goals created by earlier care discussions empowering patients and families to complete advance directives to ensure patients receive the care specific to their needs and preferences.

It became clear that they should not be waiting for a crisis in order to have these important conversations. Instead, they maximized the unique ED environment to start these discussions.

In 2022, Compassion & Choices invited Malloy and Muro to participate in NEPMI. "Recognizing

that there is a huge gap in providing quality palliative care across the spectrum, it seemed organic to join forces with like-minded people who shared our passion for improving end-of-life care for all," stated Malloy. "Even though the ED is a place where rescue interventions are offered, we can still learn about a patient's goals and preferences at the entry point of the hospital and help promote care that is aligned with their expectations," said Muro. The intention is to prepare patients and families for what is to come and ensure that if there are any limitations to their care, they are clearly discussed and documented to prepare the medical team for that patient's plan of care.

"I've come to know Compassion & Choices and what has impressed me the most is their overall vision to improve end-of-life care for all. They are a great resource, not only for patients and families dealing with serious illness, but also to the medical field as a whole," Muro said. "I am particularly excited about their commitment to health-care equity at the end of life."



## EXPAND OPTIONS

**Focusing on authorizing medical aid in dying so that by 2028, at least half the U.S. population lives where it is an open and accessible medical practice.**



Expanding options is about increasing areas where the compassionate medical practice of medical aid in dying is available and improving access to that option. The residency requirement, often written into these laws, requires a person to be a resident of the state where they go through the medical aid-in-dying process.

In August 2022, Compassion & Choices brought forward legal action to challenge Vermont's residency requirement. Compassion & Choices and our partners at Patient Choices Vermont headed a legal team that represented Lynda Bluestein, a terminally ill Connecticut woman with stage 3c fallopian tube cancer, and Dr.

Diana Barnard, a physician specializing in hospice and palliative care in Middlebury, Vermont. Together, we asserted that the residency requirement in Vermont's medical aid-in-dying law violates the U.S. Constitution's guarantee of equal treatment.

Dealing with her third cancer diagnosis in three years, Bluestein felt fortunate to be within driving distance of Vermont and to have the support and resources to accomplish her goal of a peaceful end of life on her own terms. "I was with my mother when she died and her suffering still impacts me to this day," Bluestein said. "I'm committed to having my final days be full of empowering, peaceful moments surrounded by my loved ones."

Compassion & Choices settled a similar suit in Oregon against that state's residency requirement in March of this year, making Vermont the second state to have its residency mandate challenged in court. On March 14, a settlement was reached, stipulating that Vermont officials "agree not to enforce the residency requirement" for Bluestein and that she

may access medical aid in dying in Vermont. The settlement also stipulates that "the Vermont Department of Health will support repealing the residency requirement contained in the Act if a bill to repeal the residency requirement is proposed."

On Tuesday, May 2, Vermont Gov. Phil Scott signed H. 190, immediately removing the residency requirement from the state's medical aid-in-dying law. This signing is the culmination of over a year of hard work by our partners at Patient Choices Vermont and the incredible legal team.

"It is my final act," Bluestein said. "And damn it, nobody gets to step on my lines in my final lap."





## DEFEND AND PROTECT

Focusing on defending and protecting the full range of patient-directed end-of-life care.



When litigation partner John Kappos received an email blast from the pro bono coordinator at his firm, O'Melveny, he was intrigued. He then learned of significant interest across the firm. Compassion & Choices had reached out for pro bono support on the *O'Donnell v. Harris* case.

Compassion & Choices was about to file suit on behalf of three Californians with terminal or advanced diseases and a physician asserting that California's constitution and existing state law allow the medical practice of aid in dying. It was 2015, and terminally ill, 29-year-old Californian Brittany Maynard had recently passed after leaving her home in California and relocating to

Oregon to access the Death With Dignity Act. The issue was in the news and top of mind for Kappos.

A team of lawyers who were interested in supporting the issue gathered, and Kappos stretched his bandwidth to manage the team. Kevin Díaz, chief legal advocacy officer and general counsel, was Kappos's first contact at Compassion & Choices. Together, with the help of passionate supporters, this case led to passage the California End of Life Option Act.

Kappos's devotion to this issue never wavered. To date, he and his firm have donated more than \$1 million in pro bono litigation services to Compassion & Choices. Kappos received his Ph.D. in chemistry from Harvard University and his law degree from UCLA, and thereafter specialized in patent law. He's from California, but currently resides in Dallas, Texas. With Compassion & Choices, Kappos has worked on multiple cases, including in California, Massachusetts and Texas.

Kappos's interest in end-of-life issues was inspired by his interest in science. He observed that

advances in medical technology, procedures, pharmaceuticals, and devices like coronary angioplasty, endovascular stents and statins have allowed many people to reach advanced ages. Because of these technologies, people are now living into their 80s and 90s. Kappos noted, however, that prolonging life by medical advancements does not necessarily mean a life free of suffering. Looking forward, Kappos sees his priority as legal issues surrounding residency requirements in medical aid-in-dying laws and standard of care issues raised by physicians who refuse to advise patients of all available treatment options.

"The work is gratifying and makes me, and the firm, proud of what we have accomplished," Kappos said. "The opportunity to help people who have medical conditions that are truly heartbreaking is why we are so honored to do this work and to associate with Compassion & Choices. The opportunity to change laws and expand access to end-of-life options allows us to help thousands of people. We are all going to die someday — we just hope to do so on our own terms."



# EMPOWER EVERYONE

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



Bhikkhuni Dr. Zhiyun Cai or “Ven. Dr. Yun,” holds a Ph.D., BCC-PCHAC and is a certified grief counselor and palliative care chaplain at Stanford Health Care. She has been providing palliative and spiritual services to patients with serious illnesses for over a decade. When Ven. Dr. Yun was first certified to do this work, she was the 44th certified palliative care chaplain from the Association of Professional Chaplains in the United States. Thankfully, those numbers have grown.

In her work as an ordained Buddhist nun in the Zen Buddhist tradition, Ven. Dr. Yun described the necessity of bodhisattva, dedicating

oneself to the service of people in need. She is an interfaith chaplain and provides care to people from every race, culture, faith and tradition. “We are all born and we die and we want to die with dignity, but we don’t know how,” Ven. Dr. Yun shared.

Ven. Dr. Yun had always felt the significance of treating every day as if it might be her last and the importance of eliminating worry and fear from her life. Her goal is to help others do the same. This is especially relevant at life’s end. Ven. Dr. Yun explained, “When people are diagnosed with a terminal illness, their relationships with themselves, their families, their communities and their faith change. They think ... Who am I? I am a patient. How do I support my family? How do I tell my friends? They question God. Does he hear my prayers? When a physical cure is impossible, we still work toward healing and finding peace. The process is called restoring wholeness.”

When Ven. Dr. Yun was invited to join the Compassion & Choices Healthcare Advisory Council, she

was thrilled to join a diverse team working toward a shared goal of improving the end-of-life experience for all people. She appreciates the opportunity to work across cultures and beliefs. “I have never seen a website or resources like Compassion & Choices. They are the best. I use them in my teachings. I give them out to my patients and I share those resources with colleagues.”

The best gift of this work, according to Ven. Dr. Yun, is providing services to all kinds of people — strangers at first, but then a trust develops. “I hold so many people’s hands at the end of their lives. I am honored to be this part of their life. I cry together with many people, not in sadness, but in peace and acceptance. I am lucky to meet them at the end of their life. This is a sacred and holy moment that I will always remember. Once a woman told me, ‘When I die, I will tell God about you.’”

Jane Sage Cowles, longtime donor, with her two daughters, Isabel and Sage.



“ My daughters and I are the third and fourth generations of our family to welcome conversations about end-of-life care. Compassion & Choices offers folks easy-to-use materials to facilitate family discussions around the kitchen table about this important subject. I am deeply committed to bringing medical aid in dying to my home state of Minnesota and pleased to support these efforts through my Fidelity donor-advised fund.”

- Jane Sage Cowles, Minnesota

## Planning and Giving Through the Generations

Across the Compassion & Choices community, individuals and families are coming together to support the movement while planning for their own end-of-life journeys.

### **Establish a Legacy for Future Generations:**

A planned gift through a bequest or a retirement account can provide significant tax benefits, or even lifetime guaranteed income. **Learn more** at [CompassionAndChoices.PlanMyLegacy.org](https://CompassionAndChoices.PlanMyLegacy.org).

### **Give Through a Donor-Advised Fund:**

Through your fund you can direct a one-time or recurring monthly gift. **Visit** [Freewill.com/daf/compassionandchoices](https://Freewill.com/daf/compassionandchoices).

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### **If you have any questions, contact:**

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## HEROES OF THE MOVEMENT

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Join Compassion & Choices in honoring the extraordinary people behind our greatest triumphs and the next generation of change-makers paving the way for a stronger end-of-life movement.

**THURSDAY, OCTOBER 26, 2023**

**7 P.M. ET / 4 P.M. PT**

Join virtually, wherever you are!  
VIP reception preceding event.

Learn more and register at [CandC.org/signature-event](http://CandC.org/signature-event)