



compassion & choices

MAGAZINE
FALL 2024

**End-of-Life
Conversations
Take the Stage**
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**Accessing
Medical
Aid in Dying**
pg. 8

Five Questions for Tembi Locke

Author, co-creator and
executive producer of the
Netflix adaptation, *From Scratch*



A Simple Act of Care

Protect what you love by
creating your will today.

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

What Is FreeWill?

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

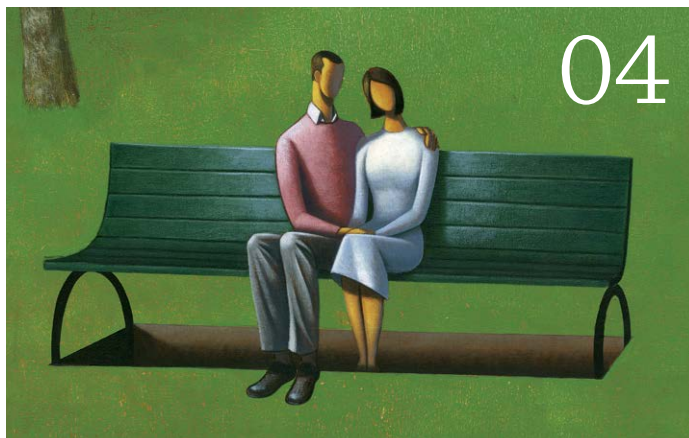
If you do not have an up-to-date estate plan in place, you can create your legal will for free in 20 minutes or less by scanning the QR code to the right or visiting CandC.link/free-will.



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code to start
your free will
today!

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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).

From Fear to Treasure: The New Narrative of End-of-Life Choices

We are delighted to feature Tembi Locke on the cover of our magazine and in the Five Questions (page 17). Her powerful memoir, *From Scratch: A Memoir of Love, Sicily, and Finding Home*, which inspired the Netflix series starring Zoe Saldana, exemplifies how issues of death and dying are gaining increased prominence in movies, TV and the media (see the article *The Progress Toward Acceptance of End-of-Life Conversations* on page 4).

This progress is both exciting and noteworthy; however, we have the potential to create a far more empowering narrative that shifts the taboo topic of death and dying to one that is embraced and treasured. Our courageous terminally ill advocates have illuminated the path forward for us all.

These advocates have taught us that by facing our own mortality, we can infuse our everyday lives with greater meaning and purpose. Their courage and wisdom remind us of the importance of living fully, appreciating each moment, and fostering deeper connections with others. Check out an excerpt from my recently published book chapter, "Wisdom From the Brink: Lessons for Living a More Meaningful Life" from the book *Plan A Life You Love* (page 7).

One day, as a society, we will transform our relationship with death into a powerful reminder of the joy of living, leading to lives filled with greater impact and fewer regrets. Together, we can achieve this transformation, one person, one conversation at a time.

In service and with gratitude,



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In the Media

El Diario NY

Enough Excuses: It's Time to Pass Medical Aid in Dying in New York

In this impassioned op-ed, Compassion & Choices' Bronx advocate Arelis Torres wrote about the importance of passing New York's Medical Aid in Dying Act. Four years ago, her wife was diagnosed with leukemia which went into remission after aggressive and painful treatments. Should the cancer return, her wife wants the option to take aid-in-dying medication to pass peacefully. "My wife and I pray to God that this damn disease never comes back. But if it ever comes back, we don't want to move to another state where medical aid in dying is authorized.... Our family and support group are here in New York. Giving a dying person the option of medical aid in dying is one of the greatest acts of love and respect."

The Legislator

Tomorrow's Conversation's Today: Why Lawmakers Must Lead in End-of-Life Healthcare

Compassion & Choices' Chief Engagement Officer Brandi Alexander and African American Engagement Director Dr. Elisha Hall co-authored a piece about health disparities that persist across the United States caused in part by end-of-life care inequities. Educational initiatives with clinicians and the Black community have broadened the conversation on this issue, but further efforts are needed. Alexander and Hall said legislators are in a unique position to act as healthcare leaders and offered a range of solutions "from legislation that addresses access and inequities to listening and being the voice of community members. We challenge lawmakers to elevate equity-centered end-of-life healthcare for the benefit of their constituents."

The New York Times

Doctor-Assisted Death Is Legal in 10 States. Could New York Be No. 11?

The New York Times published a story in June discussing the Compassion & Choices protest in the New York State Assembly chamber gallery demanding that legislators pass the Medical Aid in Dying Act. The Times reported the passage of the bill was personal for protestors, "some holding canes, others slowed by the effects of cancer treatment." The movement gained momentum in New York in part due to endorsements from influential groups like the Medical Society of the State of New York and efforts of activists but the bill still faces significant challenges in the legislature.

Forbes

Filmmaker Serene Meshel-Dillman Tackles End of Life Options in Amazon Prime Docuseries *Take Me Out Feet First*

In June, Forbes published a story discussing filmmaker Serene Meshel-Dillman's exploration of end-of-life care options by producing her number one ranked Amazon Prime docuseries, *Take Me Out Feet First*. Produced in partnership with Compassion & Choices and inspired by her personal experiences, the docuseries chronicles Meshel-Dillman's parents' use of medical aid in dying under California's End of Life Option Act as well as Compassion & Choices' advocacy for authorizing medical aid in dying in states nationwide. Through personal stories of Compassion & Choices advocates and interviews with patients, families and experts, Meshel-Dillman shows the compassionate and humane aspects of this option.



The Progress Toward Acceptance of End-of-Life Conversations

Conversations take center stage.

End-of-life options have vastly expanded since hospice was introduced in the United States in 1974 — improvements that are a direct result of efforts to bring end-of-life conversations into the mainstream. People are increasingly taking control of their care and talking openly about it. Just look at the visibility former President Jimmy Carter brought to hospice.

Compassion & Choices has led the way by empowering individuals to share their stories, translating those stories into powerful education and advocacy, and propelling those messages onto national platforms to push for substantive changes in health-care policy.

While the Compassion & Choices storytellers program has served as a vital connection between the people who make up this movement and the public, we all need to be storytellers. Informing our loved ones, communities and healthcare professionals about our end-of-life wishes is a crucial step to getting care that aligns with our values. While most people will share their wishes privately, others allow their stories to be told publicly. As these conversations make their way to larger audiences, their impact grows exponentially.

In 2011, the groundbreaking documentary *How to Die in Oregon* debuted at the Sundance Film Festival, where it won the Grand Jury Prize for

documentary. Produced and directed by Peter Richardson, the film showcased Oregon's Death With Dignity Act. It was heralded as an inside look at the medical practice that is now authorized in ten states and Washington, D.C. The film was considered highly controversial at the time, and HBO was praised for taking a risk. Some interior scenes were filmed from outside, through a draped window, to protect the privacy of those involved.

Now, 13 years later, the availability of information about end-of-life care is markedly different, with consumers driving a cultural shift toward greater openness about death and dying. Conversations about death have been normalized, as evidenced by the growing body of books, television shows, podcasts and films that handle the topic with candor and ease. This culture shift is shattering taboos about death and making discussions about end-of-life care more open and acceptable.

For example, this year two documentaries — the film *Last Flight Home* and the Amazon series *Take Me Out Feet First* — were big hits. Each was made by filmmakers who tell deeply personal stories about individuals planning the end-of-life experience they want. In the Netflix series *From Scratch*, Tembi Locke describes how she and her family dealt with her husband's cancer diagnosis and death (see page 17). The fictional film *Here Awhile* (starring Anna Camp, who was featured in our winter 2020 issue) tells the story of a terminally ill young woman who returns to her home state of Oregon to seek medical aid in dying. Contemporary films like these depict death and dying in ways that were unheard of just 13 years ago.

Writers and producers often reach out to Compassion & Choices for advice to ensure accuracy. In the case of *Last Flight Home* and *Take Me Out Feet First*, Compassion & Choices served as an advisor and also promoted the film to supporters, in the media, and in joint in-person and virtual events.



Film poster for *How to Die in Oregon*.

Compassion & Choices is front and center in the conversation on multiple platforms. C&C staff have participated in podcasts and web series, including *Fades*, *Fish Fries*, and *Funerals*, a YouTube show featuring honest conversations about death in the Black community. Compassion & Choices President and CEO Kim Callinan participated in a debate with New York Times columnist Ross Douthat and has been a guest on several podcasts, including *The Disagreement with Dr. Ira Byock* and *The Truth About Your Future* with financial expert Ric Edelman. Callinan also contributed a chapter to *Plan a Life You Love*, a new book that illustrates the lasting impact of advocates' stories on the end-of-life options movement (see page 7).

Compassion & Choices works closely with health-care providers to integrate end-of-life planning into routine medical care, ensuring that these discussions are normalized and take place before it is too late. Medical aid in dying is just one of several end-of-life options, including hospice and palliative care, better pain management, life-extending care, and voluntarily stopping eating and drinking (VSED).

History shows that our collective stories can change hearts and minds. As more individuals assert their right to make informed decisions about their own end-of-life care, we are forging a path to meaningful changes in the availability and acceptance of the full range of end-of-life care.



CONVERSATION TIPS AND RESOURCES

Initiating conversations about your end-of-life wishes with loved ones, friends and healthcare professionals can be daunting. Compassion & Choices has a host of tools to get you started. Planning and communicating allows individuals to spend their final days with friends and family while focusing on the present. Informing loved

ones of your wishes ahead of time relieves them of the burden of making decisions about your final arrangements when they are grieving your loss.

Use this checklist as your first step, and consider which of the following are appropriate for your situation:

- Discuss your wishes with family and loved ones.
- Discuss your wishes with your healthcare surrogate.
 - Make sure they are comfortable making decisions on your behalf
 - Make sure they know where important documents (see list below) can be found
 - Provide them with a copy of your advance directive
- Discuss your wishes with your provider(s) and healthcare team.
- Create and/or locate important documents.
 - Advance directive or living will
 - Durable power of attorney for healthcare
 - Durable power of attorney for finances
 - Last will and testament — Compassion & Choices has partnered with FreeWill to offer this service at no cost, available at CandC.link/free-will.
- Living trust
- Life insurance policies (with beneficiary information)
- Information about financial accounts, assets, property
- Information about final arrangements, funeral plans, pre-paid services
- Ensure important documents are up to date and reflect your current wishes. Provide a copy of your current advance directive to:
 - Healthcare provider(s)
 - Healthcare surrogate
 - Hospice team (if applicable)
- Name a guardian for children, pets.

Note: This checklist is excerpted from Compassion & Choices' My End-of-Life Decisions: An Advance Planning Guide and Toolkit. This free resource is available at CandC.org/eoldgt.

Please visit the **Compassion & Choices website** for more resources, including how to start conversations, at CompassionAndChoices.org/plan.

The following is an excerpt from *Plan A Life You Love: A Women's Guide to Health, Wealth and Happiness Without Limitation*.

Wisdom From the Brink: Lessons for Living a More Meaningful Life

Compassion & Choices
President and CEO Kim Callinan joins a group of talented authors in an empowering anthology and guide. In the book, *Plan A Life You Love: A Women's Guide to Health, Wealth and Happiness Without Limitation*, authors walk you step-by-step how to craft a life filled with happiness and fulfillment.

Last Holiday: A Storyline Resonance

Picture this: It's 2006, and *Last Holiday* graces the big screens, introducing us to Georgia Byrd, portrayed by Queen Latifah with charm and vibrancy. In this heart-warming romantic comedy, Georgia, a seemingly ordinary woman, is jolted by the news of a terminal illness. Faced with a stark timeline, she embraces her limited time, embarking on a luxurious European adventure, living courageously and freely without inhibition.

Real-Life Inspirations: Our Terminally Ill Advocates

While a fictional tale, aspects of this cinematic journey resonate deeply with me in my role at *Compassion & Choices*, America's leading nonprofit organization championing improved care and expanded options at life's end. As CEO, I've met many individuals like Georgia at the crucial crossroads of their imminent mortality. These real-life heroes, our terminally ill advocates, choose to live their lives fully in the face of devastating diagnoses, demonstrating remarkable resilience. They organize their affairs, let go of grudges, say the unsaid, and forge unforgettable memories with family and friends. While some, with the resources and energy, embark on vacations and travels like Georgia, most simply live with increased clarity and intention, being discerning with their time and ensuring that their encounters are meaningful.



Their commitment extends beyond personal spheres; they strive for meaning, spending their remaining time advocating for societal change. They collaborate with us to educate the public and lawmakers about end-of-life care and choice, using their unfortunate experiences to advocate for much-needed end-of-life policy changes. Many understand that their efforts may not benefit them directly, yet they persist, wanting to do whatever they can to leave a lasting impact on the world, and they do.

The resilience and conviction displayed by our advocates with terminal illnesses are both inspiring and profoundly impactful. With their rare clarity and conviction, some have an effect that defies the odds and transcends the impossible. Take Brittany Maynard, the courageous 29-year-old who moved from California to Oregon to access medical aid in dying. ...

To finish reading Kim's essay, order your copy of *Plan a Life You Love* on Amazon today at CandC.link/PlanALifeYouLove.



José Alejandro Lemuz's Long Journey to the End of Life

Vulnerable populations face barriers to medical aid-in-dying access.

José Alejandro Lemuz described himself as a “low-income body shop mechanic.” He made a big impact on the movement for end-of-life options by becoming the first Latino in the United States to publicly announce his plans to utilize medical aid in dying to end his suffering from a terminal illness.

Lemuz did not speak English. He lived alone, but his two teenage children and their mother were sometimes able to care for him. In a translated editorial published in the Los Angeles Daily News, he stated, “My family doesn’t even have money for my burial.”

Lemuz was diagnosed with stage 4 prostate cancer in 2018. Over the next five years, he endured numerous rounds of chemotherapy and radiation to keep the cancer under control. In the summer of 2023, the secondary effects from the treatments became too painful and debilitating. He could not eat. He could barely walk, and the cancer had spread to his bones. Lemuz’s cancer was terminal, and his pain management medications left him confined to his bed.



top and bottom: Lemuz at his California home a month before his passing; middle: Lemuz with his son the day he took his aid-in-dying medication.

Lemuz was facing death. Yet, his doctors never informed him of the option of medical aid in dying even though California's End of Life Option Act became effective June 2016, almost eight years prior to Lemuz's passing. His doctors continued to push aggressive treatments and withheld information about medical aid in dying even when he explicitly asked for it. He had accessed hospice care, but did not receive the support necessary to access aid-in-dying medication.

Obtaining a medical aid-in-dying prescription and filling it can be challenging for anyone. For vulnerable people, it can be even more difficult — particularly for those who are not offered adequate support and those who face discrimination and bias in relation to their race, ethnicity, age, financial resources or lack of insurance.

Lemuz and countless others like him have experienced healthcare disparities that leave them fighting for basic information and their medical rights ...

Lemuz sought information and heroically advocated for himself. Before his death, in an interview with Compassion & Choices, Lemuz said, "I learned about medical aid in dying from a YouTube video of a Californian who had asked their doctors for a prescription. Then I learned about Compassion & Choices through Univision." He also discovered the late Miguel Carrasquillo, a medical aid-in-dying advocate and Compassion & Choices' first Latino storyteller, who died in 2016 in his native Puerto Rico.

His challenges illustrated systematic health inequities and demonstrated the difficulties vulnerable populations face with the healthcare system. Lemuz and countless others like him have experienced healthcare disparities that leave them fighting for basic

information and their medical rights, down to the last days of their lives. Lemuz may have been eligible for medical aid in dying months before he was prescribed the medication since he met the criteria of being an adult over the age of 18, was terminally ill with a prognosis of six months or less to live, mentally capable of making his own healthcare decisions and able to self-ingest the medication.

"I am immensely grateful to each and every member of Compassion & Choices for your personal support during my last days of life," Lemuz said moments before taking the aid-in-dying medication. "Thank you for giving me the option to die peacefully, not painfully."

Susan Wilhoit, MD, a medical director for Compassion & Choices, said, "José's story is a reminder for all of us to listen to our own knowledge, trust our own bodies and be vocal about the things that matter to us."

On Easter Sunday, 60-year-old Lemuz passed away peacefully after using California's medical aid-in-dying law at his home in Wilmington, California.

We are making progress daily as Compassion & Choices and other like-minded organizations advocate for better access to end-of-life options. Compassion & Choices is dedicated to creating and promoting multilingual educational tools and planning resources to ensure that everyone is informed so they can direct, access and receive end-of-life healthcare that is consistent with their values and priorities.

Please visit the Compassion & Choices website for end-of-life resources including Spanish-language versions at CandC.org/tools.

Reflecting on the Rev. Dr. Paul Smith’s Legacy

The Rev. Dr. Paul Smith’s legacy is deeply anchored in his advocacy for end-of-life care, intertwined with his broader mission of social justice and compassion. Entering ministry in 1960, Smith was influenced by civil rights giants the Rev. Dr. Martin Luther King Jr. and Andrew Young. Smith marched alongside them in the historic Selma to Montgomery marches. As a prominent member of the Compassion & Choices African American Leadership Council, Smith has been a passionate advocate for end-of-life autonomy. He is the namesake of “Rev. Dr. Paul Smith Award,” given annually to a faith leader who is dedicated to the end-of-life options movement. His work in this area seeks to ensure that the dying process is approached with compassion, respect and understanding, aligning with his broader vision of transforming society into “a beloved community.” Smith’s advocacy for end-of-life autonomy continues to inspire, ensuring that individuals can face their final moments with dignity and peace.



Rev. Smith at a press conference in support of Maryland’s medical aid-in-dying legislation.

Smith is so committed to our mission that he has named Compassion & Choices as his legacy of choice and is asking his network to contribute to us on his behalf. To honor Smith’s legacy, you too can make a gift to Compassion & Choices in his honor. This act would significantly impact our society, echoing Rev. Smith’s lifelong dedication to greater humanity for all at life’s end. **Donate at [join.CompassionAndChoices.org/a/revdrpaulsmith](https://www.compassionandchoices.org/a/revdrpaulsmith).**



Compassion & Choices staff tabling at a Pride Festival in Washington, D.C.

A Summer of Pride Celebrations

This summer, Compassion & Choices participated in 20 vibrant and diverse events in 10 states to celebrate the LGBTQ+ community. Each event represented the unique experiences of LGBTQ+ people, from parades to festivals, and Compassion & Choices staff and volunteers were present to share our mission to achieve person-centered end-of-life healthcare. We engaged with thousands of attendees, sharing stories and spreading awareness about end-of-life options. From longtime supporters to learning about us for the first time, we fostered the spirit of our shared movements for healthcare rights and bodily autonomy.



left to right: Episode 1 of “Fades, Fish Fries and Funerals” with Stephan Swearingen; Steven Starks creator and host of *Black Barbers Doc*; and Zeena Regis and Dr. Elisha Hall of Compassion & Choices.

The Community Engagement Team Reaches New Audiences Through Podcast and Radio

This year, Compassion & Choices representatives have been featured on several podcasts and radio shows to speak about the importance of advance care planning.

Black Barbers Doc is a podcast created by Steven Starks that brings people together in a barbershop setting to swap stories and discuss all aspects of life. The first episode of the four-part series focused on advance care planning in Black communities was titled “Fades, Fish Fries and Funerals.” It featured Director of Priority Populations and Faith Engagement Zeena Regis and African American Engagement Director Dr. Elisha Hall in a conversation about the significance of equitable end-of-life care and planning in Black communities. On shaping the end-of-life conversation in the Black community, Hall said, “The reason why it is so important for us to have this conversation is because we’re getting behind because we’re *not* having this conversation.” Regis added that “when we get away from the idea of end of life, advance care planning and estate planning as this taboo subject that’s going to make us ‘catch death,’ we can actually have real conversations.”

The Latino Engagement team, in collaboration with local Ventanilla de Salud pilot programs, made outreach efforts by appearing on multiple Spanish-language radio programs and podcasts in order to more directly connect with Spanish-speaking communities about advance care. Latino Engagement Manager Leslie Martinez Ramirez has appeared on Philatinos Radio in Philadelphia, La Grande Radio in Dallas and two times on Virgen de Guadalupe Radio in San Antonio.

Director of Priority Populations Maria Otero said, “We’re grateful for this opportunity to appear on Spanish-language radio programs across the country in order to reach people in their homes and communities to inform them about the necessity of advance care planning. It’s allowed us to reach people in areas where other forms of communication may not penetrate, especially in remote or rural areas where access to healthcare information might be limited. We are looking forward to more opportunities in the future.”

Makes Strides in Integrating Palliative Medicine into Emergency Rooms

The Compassion & Choices National Emergency and Palliative Medicine Initiative (NEPMI) aims to integrate palliative care into emergency settings to improve care for those with serious illnesses. The initiative gathers clinicians nationwide to share best practices, enhance patient-centered care and address disparities in end-of-life care. By focusing on managing symptoms, establishing patient goals and reducing unnecessary interventions, NEPMI seeks to improve quality of life and patient satisfaction while reducing hospitalizations and healthcare costs. Despite guidelines recommending early palliative care, widespread adoption remains limited in the U.S.

Compassion & Choices is meeting with thought leaders, including emergency medicine clinicians, to gather information, data and research about the intersection of palliative and emergency medicine. With an online resource hub and new materials, the initiative will reach new audiences and continue to make a difference in hospital settings around the country.



50% of older adults will visit the emergency department in the *last month of their lives.*



Marshallese Outreach Efforts

This year, Compassion & Choices met with Gay Mathews, director of philanthropy for Applied Hope Foundation, and Dr. Eric Rasmussen, CEO of Infinitum Humanitarian Systems, to review outreach strategies to Marshallese populations across their Pacific diaspora. The Republic of the Marshall Islands, a sprawling chain of atolls and islands in the central Pacific Ocean, is on the frontlines of climate change as one of the world's lowest-lying nations. The team was invited to travel to Kwajalein Atoll in the summer to address relocation efforts due to rising sea levels, increased storm intensity and diminishing access to fresh water. Compassion & Choices is building the groundwork of support and connection in communities like this to ensure everyone gets the end-of-life resources and information they need and deserve.

Celebrating Five Years of the City of Hope End-of-Life Interdisciplinary Symposium

Compassion & Choices sponsored the 2024 City of Hope End-of-Life Interdisciplinary Symposium, now in its fifth year, which brought together over 150 medical providers and other leaders in the end-of-life care space. Compassion & Choices staff presented a half-day workshop about advance care planning for people living with dementia. This well-attended session included an interactive role-playing exercise which followed a patient through their journey with early stage Alzheimer’s disease through their last days. At each step, participants and audience members discussed how clinicians, patients and loved ones can work together to document the patient’s values and priorities and ensure the care they receive aligns with those wishes.

Compassion & Choices staff also hosted a panel discussion about how providers in authorized states can navigate a request from a patient for medical aid in dying — from documenting the request to exploring the safeguards built into the various state laws. Other sessions on the agenda included a discussion about the therapeutic use of ketamine

and other psychedelics during the dying process, a panel discussion on the experience of first responders with death and dying as well as several attendees who offered international perspectives on end-of-life care.

In addition to these sessions, the symposium featured workshops on grief counseling and effective communication strategies for discussing end-of-life options with patients and families. There was an emphasis on the latest research and innovative approaches in palliative care, underscoring the importance of a multidisciplinary plan in providing holistic and compassionate care.

Throughout the three-day conference, staff and supporters also met with doctors, nurses, social workers, death doulas, hospice executives, palliative care experts and others to provide them with information and resources they can use in their practice. The event concluded with a commitment to ongoing education and advocacy to improve end-of-life care across various healthcare settings.



Compassion & Choices staff attending the 2024 City of Hope Symposium in Las Vegas.

Momentum Across the States

CALIFORNIA

Our California team and volunteers hosted the first statewide conference which highlighted our impactful work regarding medical aid in dying, dementia, palliative care, reaching Spanish-speaking and faith communities and normalizing conversations about death. The team was honored to work closely with the family of José Alejandro Lemuz, a 60-year-old California man who died of prostate cancer and was the first Latino to publicly use medical aid in dying. They provided guidance and resources for Lemuz to navigate the complex health system and access the California End of Life Option Act which allowed him to die the way he wanted — peacefully, not painfully.

COLORADO

Compassion & Choices, alongside advocates and clinicians, praised Colorado Gov. Jared Polis for signing legislation in June to significantly improve access to medical aid in dying for terminally ill patients. “We thank Gov. Polis and Colorado lawmakers for reviewing the evidence, listening to their constituents and taking action to ensure that eligible Coloradans have access to medical aid in dying,” said Kim Callinan, president and CEO of Compassion & Choices. “Colorado lawmakers join California, Hawai‘i, New Mexico, Oregon, Vermont and Washington in ensuring their medical aid-in-dying law eliminates unnecessary barriers while maintaining needed safeguards.” The updated law took effect Aug. 7.

FLORIDA

Our mighty Florida team had an exciting summer season. They participated in various Pride Month festivals where they showcased Finish Strong tools with diverse life planning communities. They also held a workshop at the Florida Conference on Aging. The team continues its efforts to inform residents about the full array of end-of-life care options

including medical aid in dying. Stay up to date on our activities by joining us on Facebook and look out for our next Florida newsletter. We look forward to connecting with you and appreciate your support in empowering diverse communities throughout the Sunshine State.

ILLINOIS

The Illinois team continues in full force to advance SB 3499 to authorize medical aid in dying in the Prairie State. Supporters made 1,600 contacts with legislators and earned more than 100 news stories in English and Spanish since the bill was introduced in February. We reached thousands of readers and viewers through stories that highlight storytellers like Lombard resident Deb Robertson, a retired social worker with a rare type of terminal cancer and Naperville resident Suzy Flack, whose only son Andrew, utilized medical aid in dying in California.

MASSACHUSETTS

On July 24, Compassion & Choices Action Network hosted an End-of-Life Options Massachusetts Coalition news conference and rally at the State House. Speakers included Sen. Jo Comerford, Rep. Jim O’Day, advocates JoAnn Vizziello, David Storto and Dr. Roger Kligler. Afterward, advocates delivered storybooks to all 200 legislative offices. Simultaneously, a mobile digital billboard circulated Beacon Hill, Boston Common and Boston Public Library, highlighting the stories of advocates and urging lawmakers to pass the End-of-Life Options Act before the formal session ended on July 31. While that didn’t happen, the historic legislative progress in 2024 bodes well for 2025.

MICHIGAN

On June 15, the Compassion & Choices Michigan team hosted the quarterly Midwest “Train the Advocate” workshop to prepare Midwestern

advocacy in action

volunteers to advocate for all our work, ranging from dementia resources to medical aid in dying. Thirty-two volunteers attended the five-hour training, including 10 from Michigan. On June 18, Compassion & Choices Michigan volunteers Dorothy Engelman and Lisa Perhamus gave a presentation at the North Muskegon Library. It marked the Michigan Action Team's first event on the western edge of the state as we work to expand our geographical reach and bring our message to a wider audience.

MINNESOTA

In May, Rep. Mike Freiberg, author of the Minnesota End-of-Life Options Act, spoke at a Beth Jacob Congregation event entitled, "Medical Aid in Dying: Jewish and Bioethical Considerations," sponsored by Scientists in Synagogues. The main speaker was Rabbi Elliot Dorff, who has authored or co-authored over 30 books and published more than 200 articles on Jewish theology, law and ethics. He changed his position in 2020 from opposing to supporting medical aid in dying in certain circumstances for terminally ill individuals. Approximately 50 people attended. Three individuals said they would like to get involved in the Minnesota legislative campaign.

NEW JERSEY

The Compassion & Choices New Jersey team is working with government relations consultants to address barriers to accessing medical aid in dying. For example, communities of color — Blacks, Hispanics, Asians, Native Hawaiians/Pacific Islanders and American Indians — represent 47% of the population but only 10% of the individuals who have used the law. Steps include reducing the 15-day waiting period between two oral requests for terminally ill adults who are not expected to survive it, lifting the residency requirement and addressing healthcare inequities by ensuring dying individuals who can't afford the medication have an avenue to access it.

NEW YORK

The Compassion & Choices New York team came agonizingly close to persuading the legislature to pass the Medical Aid in Dying Act before the session ended on June 8, securing the endorsement of Speaker Carl Heastie. "Unfortunately, Sen. Majority Leader Andrea Stewart-Cousins claimed there were not enough votes in her Democratic caucus to pass the bill," said Corinne Carey, senior campaign director for Compassion & Choices in New York. "The reality is we could have passed the bill with a bipartisan vote in both chambers. Now, we just need to laser focus on persuading the senate majority leader to allow a vote in 2025."

WASHINGTON, D.C.

Compassion & Choices' federal team continues to work hard to prevent Congress from repealing D.C.'s Death with Dignity Act and prohibiting D.C. from purportedly passing such legislation in the future. The House Appropriations Committee approved a policy rider attached to last year's House Financial Services and General Government appropriations bill, which has jurisdiction over DC's budget, but failed to bring up the legislation for a vote. Today, the House has, once again, attached a similar rider (Section 819), but, as last time, failed to bring up the latest bill for a vote. In the meantime, the Senate has approved its version of the Financial Services and General Government Appropriations bill, but without this onerous policy rider. We continue to work with D.C. Delegate Eleanor Holmes-Norton to ensure Congress maintains D.C.'s Death with Dignity law.

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Visit CandC.org/volunteer.

Historic Victory: Delaware's Legislature Passed the End of Life Options Act

Ten years of tireless advocacy by the Compassion & Choices Action Network Delaware team and our terminally ill advocates appeared to have paid off when the legislature passed the Ron Silverio/Heather Block End of Life Options Act.

It was an emotional roller coaster ride and Gov. John Carney's current stance on the bill was unknown at the time of this magazine's publication. The House passed the bill in a bipartisan 21-16 vote in April. Two days before a scheduled Senate vote, the Compassion & Choices Action Network's legislative champions were confident of its passage. Then a confirmed "yes" vote switched to "present but not voting," surprising bill supporters. In response, Sen. President Bryan Townsend quickly changed his initial "yes" vote to "no," resulting in a tie 9-9 vote, but preserving his right to bring the bill back to the floor for another vote before the end of the session on June 30.

Our advocacy went into overdrive as constituents contacted the wavering senator who pledged to vote yes if the bill came up for a vote again. It did, and the Senate passed the bill 11-10 on June 25.

Gov. Carney opposed the bill in 2022, but at press time had not decided whether to sign the bill into law, veto it or allow it to become law without his signature.

"I cannot express how much I appreciate the Senate and House passing this compassionate legislation after working for six years to persuade lawmakers to support it," said terminally ill Wilmington, Delaware resident Judy Govatos. "I am pleading with Gov. Carney to sign this compassionate legislation as every other Democratic governor has done in states where medical aid-in-dying legislation has passed,



Rep Baumbach, advocates and Compassion & Choices staff celebrate the passage of HB140 from the Delaware legislature. Susan Lahaie (middle) holds a photo of her late husband, Ron Silverio, for whom the bill is named.

including several Catholic governors like him. I have had cancer twice in the last 10 years. At age 80, my time is running out, and without this law, I am facing a prolonged period of needless suffering when I die."

"Even if this is not an end-of-life care option that Gov. Carney would choose for himself, the data shows that as drafted, this bill harms nobody," said Kim Callinan, president and CEO of Compassion & Choices Action Network. "I hope he will respect the wishes of the overwhelming majority of Delaware voters and physicians who support this legislation and allow the Delaware End of Life Options Act to become law."



Five Questions for Tembi Locke

New York Times best-selling author, actor, screenwriter and TV producer Tembi Locke penned the bestselling memoir *From Scratch: A Memoir of Love, Sicily, and Finding Home*. *From Scratch* was adapted into a Netflix series and tells the story of Tembi and her husband Saro Gullo. After

a 2002 diagnosis of leiomyosarcoma, Saro died in 2012. Tembi is a nationally recognized speaker, discussing resilience, loss, creativity and the power of storytelling aiming to inspire people to embrace their inner strength, love and the power of community.

five questions

Q: How has your family's experiences altered or solidified your values for end-of-life, patient-directed care?

A: Growing up, I watched a lot of caregiving in my own family. Caregiving was something that was always present. When my husband was diagnosed, caregiving suddenly took on a new sense of awareness and then urgency in my own life.

As my husband's disease progressed and it was clear that he was near the end of life, I was a young mother. I became aware of how woefully unprepared I was to meet that moment. I was well-versed in being a cancer caregiver and what that looked like. But at the end of Saro's life, I didn't know what he needed emotionally, what he needed physically, what we needed as a family when we weren't searching for the next chemotherapy protocol and there was no more radiation.

On the other side of his passing, I thought, what if I had known so much more? What if we had been prepared along the way because the end game for all of us is we will all die. And, when you are dealing with a critical long-term illness that has no cure, which is the kind of cancer Saro had, it should have been a part of the conversation along the way to the degree that we could take it in.



Tembi with her late husband, Saro.

Q: In your book, *From Scratch: A Memoir of Love, Sicily, and Finding Home*, you share stories from Saro's days in the hospital and how you addressed the staff's implicit racism and a lack of communication. How would you advise families dealing with similar concerns?

A: I wrote about a nurse in the hospital who assumed that we were not husband and wife because we are two different races. He did not ask questions. Just came in and immediately assumed I was the paid caregiver who was there to sit and watch this gentleman. I was not. I was Saro's wife of 20 years and the mother of his daughter.

There was a kind of invisibility that I had to address and get in front of. I write about that to remind anyone who's working with the public at the most vulnerable and critical stages of their life to be mindful. It is incumbent upon people in those spaces to actually be more aware of their implicit bias or assumptions.

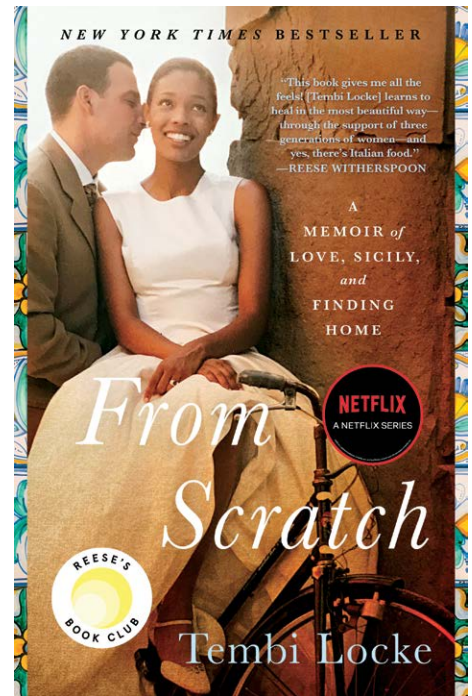
I had to say, "Hello. Let me introduce myself. My name is Tembi. This is Saro. I'm his wife. The picture by his bedside is our daughter. Thank you for being here today. Can we talk through what's going to happen?" Everyone is human in this equation.

five questions

Q: “End-of-life planning, Sicilian style,” is a quote from your book referring to your mother-in-law communicating her intentions for her final days and how she would want to be cared for during a potential hospital stay. Can you talk about how empowering doing your own end-of-life planning and sharing it with others was for you?

A: I had the blessing of a grandmother who was very thoughtful about how she wanted things at the end. She prepaid the plot, had the headstone carved. The only thing we had to do was add the date of her death. I also had the blessing of my mother-in-law with whom I developed a very close relationship after my husband passed when I would visit her each summer in Sicily. She had a different approach. She talked about death openly and frequently. Culturally, death, in Sicily, is talked about very openly, particularly with her generation. They were always kind of planning for death. It was just a part of the conversation.

In my own planning, we had a trust. We had sorted through certain logistical and financial aspects of planning when my husband was alive. After he passed, I had a different perspective on what planning looked like. I needed to think about emotional well-being as well as financial stability. With my young daughter, I thought about wanting to put the least amount of stress on a child who’s potentially having to care for and grieve her mother’s illness and death. Make a difficult situation easier, if I can. Now, I revisit my plan every five years or so. The planning is intentional and reflects what matters to me. Starting the conversation is what I learned in Sicily. End-of-life planning is something you’re doing all the time.



Q: You often talk about access to palliative care and hospice in your work. Can you please explain why it is so important to all of us?

A: I come to this conversation as simply a wife and a mother who was walking her husband up to the end of life. I needed help. There were resources all around me but nobody pointed me in the right direction. When we got to the end of Saro’s life, we didn’t know how much time he had. At this stage you’re in and out of the hospital a lot. In the last two months of his life, he was in the ER every five days as triage for these big situations.

What I eventually learned was that was the perfect scenario for something called palliative care. Our doctors could have said, “Hi, there’s something called palliative care. You aren’t being treated with chemotherapy anymore but you need comfort care.” In

five questions

general, they should sit with you earlier and say, "What does the family need? How can we assist and help medically so that you aren't coming to the ER every five days?"

So we got palliative care and hospice very late, a week before Saro passed. The question should have been asked sooner, "What would you like to do with your time left?" Saro would have loved for someone to have asked him that question. He would've been able to say, "I want to go home. I want my daughter to be able to be with me. I would love to pass at home." My daughter and I could have had more time to integrate what was happening. (See page 12 to learn more about Compassion & Choices' work in Emergency Departments.)

Tembi with Saro.



Q: On your podcast, *Lifted*, you host discussions about pursuing the courage to heal while inspiring collective change and sacred joy. How do you think Saro would have felt about inspiring such a positive legacy?

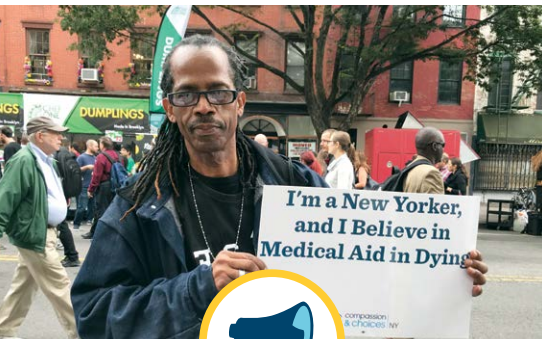
A: Thank you for mentioning *Lifted*. It's a passion project of mine. As a caregiver, I was the benefactor of so much generosity and so many people who sought to lift me, lift us, lift our family above what was happening. I hope, with these conversations, to give a little of that back in the world by talking to other women, particularly those who have met a moment of change, been inspired by something. I hope we all get to grow and become more capacious as a result of these conversations.

I think Saro really, quite frankly, would just laugh at this whole thing. I don't mean that in a dismissive way. I think he never saw himself as particularly unique or special or deserving of any kind of spotlight in any way. I think some part of him, I would hope, would be touched that I endeavored to write our story down. All the parts of our story ... the joy of it, the sort of swell and sweeping nature of how we met in Florence and fell in love and his artistry and his poetry and the ways in which he was just a sexy and 3D human. All of that. We co-created this moment and I couldn't have done it without him. I couldn't have written the book without calling upon his love and energy. It felt like an impossible task to try to write it all down. It felt like an impossible task to try to make a TV show about it. So, I would hope that he would feel well ... good. It's good. We're helping people. That's good. I think he would be like, "Oh, that's kind of cool."

How Can I Help?

We Are GLAD You Asked!

At Compassion & Choices, we're committed to empowering individuals to make informed decisions about their own end-of-life wishes and to changing laws and systems to provide better care for all of us. But we can't do it alone. Here's how you can help:



CHAMPION

Be a beacon of change in your community by spreading awareness:

- » Share information on social media or with your networks
- » Serve as an ambassador; talk to your family, friends and networks
- » Share your story
- » Volunteer your time and talents
- » Contact your elected officials
- » Talk to your doctors and other healthcare professionals
- » Host an event to engage your networks

INVITE

Encourage advocacy and support by inviting your community to ours:

- » Donors
- » Media contacts
- » Celebrities
- » Organizational and community partners
- » Professionals (clinicians, faith leaders, financial planners, bankers, lawyers, etc.)
- » Storytellers

INVEST

Fuel our efforts to provide education, advocacy and support to individuals facing end-of-life decisions:

- » Contribute today by check, credit card, cryptocurrency, stock or mutual funds, donor-advised funds and more
- » Include Compassion & Choices in your estate plan with planned giving taxwise strategies, such as a bequest in your will or trust, an IRA, charitable gift annuities and gifts of life insurance or real estate
- » Offer your firm's services pro bono

Your support is invaluable to improve care, expand options and empower everyone to chart their end-of-life journey. **Together, we can make a difference.**

Learn more at CandC.org.



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We call our recurring monthly givers champions because the consistency of their gifts is the drumbeat that continues to propel our work forward each day, week, month and year. The Champions Circle allows you to plan a monthly donation which helps us react quickly to urgent needs. Signing up is simple, too.

By joining our Champions Circle, your monthly donation:

- » Fuels our legislative campaigns.
- » Funds legal battles for your rights.
- » Provides updates with essential resources on our website.
- » Trains healthcare providers all across the country.
- » Keeps the End-of-Life Consultation line staffed.
- » Empowers everyone to chart their end-of-life journey.

Join today at CandC.org/monthly-giving and drive the change we need!