



# compassion & choices

**MAGAZINE**  
SUMMER 2024

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**Understanding  
and Accessing  
Hospice Care**

*Information to help you  
find support and quality  
care at the end of life*





Nancy Schwarzwald (middle) surrounded by friends.

## Financial/Estate Planning Is Essential to Your End-of-Life Plan

Nancy Schwarzwald, born in 1928, was a retired school counselor who supported the work of Compassion & Choices through a legacy gift because her belief in autonomy and personal choice was essential to her priorities. Nancy has been a donor since 2000. When Nancy passed in 2023, her generous seven-figure legacy gift included assets from a trust, IRA and life insurance. Her planned gift will tremendously impact Compassion & Choices' work to expand options and empower everyone to choose end-of-life care that reflects their values, priorities and beliefs. Like Nancy, you too can leave a legacy to Compassion & Choices with our FreeWill tool.

### What Is FreeWill?

Compassion & Choices has partnered with FreeWill, an online will-writing service, to make estate planning accessible to our community. It's never been easier to plan your legacy gift. You can create your legal will for free in just 20 minutes or less by scanning the QR code to the right or visiting [CandC.link/free-will](https://CandC.link/free-will) with no obligation.



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

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Care and Choice at the End of Life





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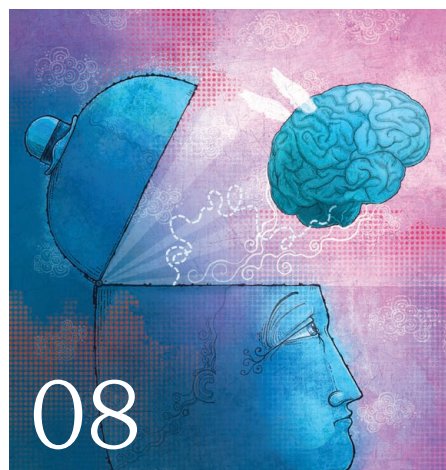
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Compassion & Choices improves care, expands options and empowers everyone to chart their own end-of-life journey. Learn more at [CompassionAndChoices.org](https://CompassionAndChoices.org).

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## The Power in Planning

Empowering people to change the way they view end-of-life planning can improve outcomes and the end-of-life experience. That conviction drives Compassion & Choices' vision to create a society that affirms life and accepts the inevitability of death, embraces expanded options for compassionate dying and empowers everyone to choose end-of-life care that reflects their values, priorities and beliefs. This issue is an interesting look at how end-of-life planning can impact different outcome scenarios at life's end.

When the family of former President Jimmy Carter and former First Lady Rosalynn Carter publicly discussed moving to hospice care, they educated innumerable people on the benefits of this option. This issue's cover article is a deep dive into preparing for and understanding hospice support.

Jon Eisenberg, Michael Schiavo's attorney, wrote the definitive book on the Terri Schiavo case and threats to bodily autonomy. He discusses end-of-life planning through his experiences within the legal system. This is a fascinating discussion.

In the article *America's Aging Population With Dementia*, we look around the world at how other countries are supporting people with dementia now and planning for the future. There is a lot of work to be done to help this growing population.

Lastly, *Journey Stories* highlights a collection of politicians and storytellers who were opposed to medical aid in dying but, through their individual journeys, became supportive.

No matter what, death impacts us all and our loved ones. We can plan and prepare to be as ready as possible for the experience when the time comes.

In service and with gratitude,



*Kim Callinan*

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## In the Media

### *Los Angeles Daily News*

**Dementia is a cruel monster that robbed my dad's mind. Families need help and information.**

The Los Angeles Daily News published an op-ed by Patricia A. González-Portillo, senior national Latino media director at Compassion & Choices, in February. She shared the personal account of her Papito's 20-plus-years struggle with "mood swings, diminished focus, attention, problem-solving skills and a limited perception of reality." Looking back, Patricia wonders why these symptoms weren't indicative of a dementia diagnosis and treatment plan. She points out that it takes 40% longer for Hispanic Americans with dementia to be diagnosed and lauds the importance of Compassion & Choices Dementia Values & Priorities Tool®.

### *The New York Times*

**I promised my sister I would write about how she chose to die**

The New York Times published a column by Steven Petrow in December recalling the final days of his sister Julie's passing from ovarian cancer. Julie utilized medical aid in dying in New Jersey, and told him, "I want you to write about this after I'm gone." Compassion & Choices CEO Kim Callinan said, "laws are meaningless if patients are not aware they exist, which is why we focus on public education during the first five to 10 years after a jurisdiction has authorized medical aid in dying."

### *Univision*

**Hispanic man with terminal cancer asks for euthanasia, resorts to California law**

In March, the Univision Network aired a story on Don José Alejandro Lemuz, the first terminally ill Latino in the United States to publicly announce his plans to use medical aid in dying. He endured numerous rounds of chemotherapy and radiation since he was diagnosed with stage 4 prostate cancer in 2018. The cancer eventually spread to his bones and in mid-March 2024, Don José enrolled in hospice. "Doctors kept pushing more chemotherapy and radiation on me," Don José told his family, "Until I said: no more." Don José died peacefully on March 31 surrounded by his family.

### *Axios*

**Carter's year in hospice sheds light on end-of-life care option**

In February, Axios featured an article about hospice care as a result of former President Jimmy Carter's stay there. Hospice care is linked to increased patient and family satisfaction, but sometimes patients don't enter hospice early enough to take advantage of it. Jessica Empeño, national director of clinical engagement at Compassion & Choices and former social worker stated, "There's so much support [in hospice], not only for the patient but for the circle of people around them."

### *Plan A Life You Love*

Compassion & Choices president and CEO Kim Callinan joins a group of talented authors in an empowering guide. In *Plan A Life You Love: A Women's Guide to Health, Wealth and Happiness Without Limitation*, authors guide you step-by-step in how to craft a life filled with happiness and fulfillment. In her chapter, "Wisdom From the Brink: Lessons to Live a More Meaningful Life," Kim shares what she has learned from years of discussions with Compassion & Choices terminally ill advocates at the end of their lives. Their valuable lessons speak to all of us.

Order your copy on Amazon today at [CandC.link/PlanALifeYouLove](https://CandC.link/PlanALifeYouLove)





# From No to Yes: Supporting End-of-Life Care Options

**Personal stories from five advocates on how they arrived at supporting the movement.**

**C**oming to terms with the realities of death and understanding the benefit of end-of-life options can be a journey. Compassion & Choices researched statements from doctors, professors and politicians and interviewed our own Storytellers to find out their personal turning point from being opposed to medical aid in dying to becoming avid supporters.

The stories of these five people illustrate two different perspectives on why each person changed their mind about medical aid in dying: watching a loved one die in agony had a profound, lasting effect and people with doubts changed their minds when they saw the emotional, physical peace and comfort medical aid in dying can bring terminally ill people and their families.



**Dr. Cynthia Chatterjee**  
*Illinois Psychiatrist*

Dr. Chatterjee's 94-year-old father and resident of Washington State decided to utilize medical aid in dying to peacefully end his suffering caused by a cardiac condition. Dr. Chatterjee shared in her written testimonial, "Although I had no objection to my father's opting for medical aid in dying, I had a lot of anxiety about the process. But once I observed his death, I was convinced that it was a compassionate act. After taking the medication, he fell asleep within three minutes, and died peacefully within 15 minutes. There was no struggling or gasping for breath, which had been his greatest fear. I came away from my father's death wishing that everyone could have the opportunity to have such a peaceful passing." (Oct. 7, 2023)



**Edgar Flores**  
*Nevada State Senator*

After learning more about the issue and hearing testimony from terminally ill Nevadans, Senator Flores became a supporter and

the lead bill sponsor. He stated, “Working with Compassion & Choices helped me understand the importance of expanding options at the end of life. The firsthand knowledge and experience of working with individuals, families and the community on these important issues empowered me to use my leadership in the Nevada Senate to help ensure people are aware about getting the care they want — or do not want — so they can chart their end-of-life journey.” (Nov. 15, 2023)



**Kenyan R. McDuffie**  
*Washington, D.C. Councilmember*

D.C. Councilmember McDuffie grappled with his own feelings about medical aid in dying prior to the passage of the Washing-

ton, D.C. Death with Dignity Act. After witnessing the death of his father earlier that year, he changed his stance. As quoted in the Washington Post, “My family had to watch him suffer, and I wouldn’t wish that on anyone else. (Nov. 1, 2016)



**Anthony Randolph**  
*New York Storyteller*

After watching his brother suffer in prolonged agony from lung cancer, Anthony became a sup-  
porter. He shared, “I understand

why people oppose medical aid in dying. But I ask you to spend 24 hours with someone who is dying and suffering. There’s no way you’re going to see

all that and not support the option of medical aid in dying. My brother suffered needlessly, and the whole family, including James’ children, watched. We suffered by watching. I still think about watching him take his last breaths. There has to be a better way. That’s why I support New York’s Medical Aid in Dying Act.” (April 2019)



**Al Taylor**  
*New York Assemblyman*

Assemblyman Taylor, a clergy leader, opposed medical aid in dying until he realized it’s about eliminating suffering. According

to the Empire Report, he said, “My dad was sick for several years and I was one of his principal caregivers. His condition — and his quality of life — deteriorated to the point that he was wrenched in agony and couldn’t get out of bed.” Taylor said his dad told him, “I can’t live like this.” Taylor is now a supporter and co-sponsor of the Medical Aid in Dying Act in New York which would legalize medical aid in dying for terminally ill people with less than six months to live. “Losing him as I did — feeling helpless in the face of his suffering and his clear desire to pass — forced me to reconsider my longstanding and adamant opposition to medical aid in dying.” (Dec. 6, 2023)

Currently, medical aid in dying is available in 10 states — California, Colorado, Hawai’i, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont and Washington State — as well as Washington, D.C. Support is needed all across the United States to create change in every state. The movement is mighty but still needs support to help inform, empower, advocate and defend everyone’s right to chart their end-of-life journey.

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Will you become a supporter? Visit [CandC.org/state-advocacy](https://CandC.org/state-advocacy) to learn how.



# Litigator Advocates for End-of-Life Autonomy

Jon Eisenberg discusses his role in the Terri Schiavo case and its impact on planning.

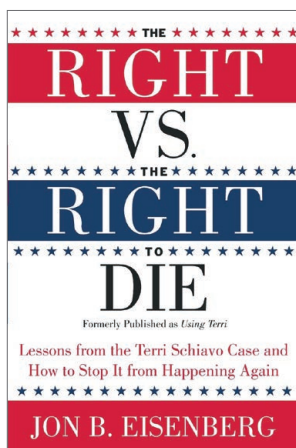


Jon Eisenberg quite literally wrote the book on the Terri Schiavo case. Michael Schiavo, a Florida man, battled all the way to the Supreme Court to have the feeding tube removed for his wife Terri. Terri Schiavo was a 41-year-old woman who suffered cardiac arrest caused by an eating disorder and existed in a permanent vegetative state for 15 years before her death on March 31, 2005. When Terri's family fought the decision to remove the feeding tube, their effort became the most publicized end-of-life case at that time.


Jon stated, "It was March 2005. I was in Washington, D.C. on other business, and while I was there, the case got thrown into a late night session in Congress to push the case into the federal courts. And I thought, Michael's attorneys are going to have an awful lot of litigation happening right now, and their main office is down the street from the hotel I'm staying at. So I called his lead lawyer, and I said, you want some help? And he said, 'Sure.'"

Jon was no stranger to end-of-life autonomy cases, having participated in such cases previously in the California and Florida state courts. In 2010, he was featured in the Los Angeles and San Francisco Daily Journal as one of "10 Lawyers Who Helped Shape a Decade."

In 1998, Jon's beloved Cousin Ros suffered a stroke and was left with global aphasia at a California hospital with no hope for improvement. Eventually Jon advocated to remove her feeding tube since she had shared with him many times that she would never want to be "kept alive at all costs." Jon shared this in his book, *Right vs. The Right To Die* (HarperSanFrancisco, 2005). Apparently, Jon was the first health-care surrogate to have ever asked that hospital to remove a feeding tube. While he had touched on these cases as a young attorney, this was Jon's first personal fight for end-of-life rights.







## **The Schiavo case shined a very public spotlight and made people realize that they can execute an advance directive and doctors are supposed to follow it.**

When the book came out, Jon was contacted by Compassion & Choices and asked to speak at meetings across the country. He also joined the local chapter's Advisory Board and eventually met Kevin Díaz, chief legal advocacy officer and general counsel at Compassion & Choices. Jon started doing pro bono work with the organization and participated in litigation regarding what's now the California End of Life Option Act.

The decade-long Schiavo case glaringly highlighted the ongoing and brutal conflict between faith and politics. Various advocacy groups opposed to end-of-life choice tried to capture Terri's story for their own mission. Revisiting the Terri Schiavo story reiterates the extreme importance of advance care planning for people of all ages.

According to Jon, public awareness of these issues nationwide has increased tremendously since the Schiavo case. Now, every state has codified the right to refuse medical treatment. The Schiavo case shined a very public spotlight and made people realize that they can execute an advance directive and doctors are supposed to follow it. "And now there's probably double the number of people executing advanced directives since the Schiavo case."

Jon discussed the overwhelming importance of documenting your wishes and choosing an appropriate medical surrogate. "I've had this unique

experience learning about bioethical implications of end-of-life decision making. My advice is to talk with your loved ones about your values and what you consider important to you, not how someone might label your condition but the effect your condition has on your ability to interact with your environment. And most importantly, choose a surrogate who knows your values and is capable of carrying out what you want. Make sure you have conversations with your surrogate to clarify your wishes."

Jon is retired now but continues his pro bono work with Compassion & Choices, advocating for expanded end-of-life options including medical aid in dying. "The battleground today is medical aid in dying, which continues to advance in state legislatures but will eventually have to survive challenges in the U.S. Supreme Court," Jon said. He's ready for the challenge.

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**Visit [CandC.org/finish-strong-tools](https://CandC.org/finish-strong-tools) to download tools to assist with your end-of-life planning.**



# America's Aging Population With Dementia

**As dementia diagnoses grow, innovation abounds around the globe and at home.**

**L**inda Rogen knew something was wrong. She was forgetting cups of coffee on colleagues' desks; she forgot her usual yoga routine too, but her doctor told her it was anxiety and depression. In March 2021, at age 69, she was diagnosed with early-stage Alzheimer's disease, a progressive brain disease. Linda is one of millions of people diagnosed with Alzheimer's every year. She is considering her options at the end of life and having necessary conversations with her loved ones about her values and priorities. With the help of a death doula, an end-of-life care and options expert, Linda filled out her advance care planning documents, including the Compassion & Choices Dementia Values & Priorities Tool®. She shared these with her family.

As reported by the Alzheimer's Association, 6.7 million Americans age 65 and older are estimated to be living with Alzheimer's disease, the most common form of dementia. Alzheimer's and other forms of dementia cause changes to memory, language, thinking and personality. Dementia also affects the ability to make decisions, making it difficult for people living with dementia to express their wants, needs and wishes.

In the United States, people with dementia, like Linda Rogen, and their caregivers are leading the way in improving dementia care. Caregivers are an important piece of dementia care, and support programs around the country provide individuals caring for people with dementia with education, counseling and respite care.

There are many innovations in dementia care around the globe. As highlighted in the New York Times on July 3, 2023, in the Netherlands, the Dutch government has financed "dementia villages" to provide safe spaces for people living with dementia. Unlike traditional memory care facilities, these villages sprawl across a secluded neighborhood that includes parks, movie theaters and restaurants.

In Japan, which has one of the oldest populations in the world, 4.6 million people are living with dementia and the number is expected to rise significantly in the near future according to the Alzheimer's Association. As reported in the Guardian (Jan. 14, 2018), the Japanese government is experimenting with different types of care and awareness campaigns. In 2015 they launched the New Orange Plan, a public health policy designed to raise awareness and



understanding of dementia. The plan is attempting to move towards an institutional, community approach. In some towns, volunteers wearing bright orange bibs distribute leaflets with dementia care information.

Initiatives like “Dementia Friends” encourage people to learn about dementia and turn that understanding into action and resources like the World Health Organization’s “Towards a dementia-inclusive society: WHO toolkit for dementia-friendly initiatives,” which seeks to reduce stigma and discrimination.

Advance planning is also critical to managing a dementia diagnosis and determining your path of care. Compassion & Choices is helping transform how people live — and how they die — with dementia in the United States. Determining and documenting values and priorities helps to ensure people get the care they want and avoid care they do not want.

In 2012, Compassion & Choices began sharing its free Dementia Values & Priorities Tool®. Since then, the landscape around dementia care has changed dramatically, moving toward more evidence-based research on advance directives and a more engaged cultural view of a dementia diagnosis. The latest tool addresses many facets of the ongoing cultural conversation around end-of-life care for dementia patients and their caregivers.

The updated Dementia Values & Priorities Tool® incorporates feedback from supporters, volunteers, community focus groups and clinical experts to address the unique needs people face as dementia progresses. The new and improved Dementia Values & Priorities Tool® is 100% confidential and doesn’t require a password or account to access. Videos embedded within the online interactive tool provide information on key terms in plain language. It also includes a custom experience with the option to skip a question as well as open space to enter additional personal details.

## Who is living with Alzheimer’s disease in the United States?



**1 in 9**  
people  
are age  
65+



**73%**  
are age  
75+

Almost  **$\frac{2}{3}$**  are women ♀

Older  
Black  
Americans are  
**2x**



Older  
Hispanic  
Americans are  
**1.5x**

as likely to have Alzheimer’s or other  
dementias as older white Americans

Alzheimer’s Assoc., Alzheimer’s Disease Facts and Figures 2023



**Access the Compassion & Choices  
Dementia Values & Priorities Tool®  
at [CandC.org/dementia-values-tool](https://CandC.org/dementia-values-tool).**

You will be asked to answer a series of questions related to the changes commonly seen in the progression of dementia. After you complete the questions, the tool will provide you with a document that can be added to your existing advance directive and shared with others. This interactive resource is invaluable to your caregivers and loved ones in supporting your care.

### **Mission-Driven Outreach to Healthcare Professionals and Beyond**

Compassion & Choices advocates and staff are participating in conferences, events and virtual webinars to share the organization's mission with healthcare professionals and the public. These events are invaluable opportunities to encourage professionals in the end-of-life care world to participate in patient-centered care and advocate for the full range of end-of-life options for their patients.

The City of Hope End-of-Life Symposium is an annual event focused on bringing together experts in end-of-life care to share their experience, skills and resources. We are proud to sponsor the event and lead two sessions: an interdisciplinary panel on

navigating a request for medical aid in dying in a healthcare setting and an interactive workshop using role-play to show the evolving care needs of a man with dementia.

Each local, state and national event that we participate in — from sponsoring, attending, presenting or tabling — raises the visibility of end-of-life options as a critical part of end of life care. We advocate for improving the end-of-life care experience of millions of people living in America in countless venues across the country by engaging with the healthcare professionals who are responsible for that care.

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### **An Ever-Growing Partnership With the American Society on Aging**

The On Aging conference, held by the American Society on Aging (ASA), is attended by thousands of people every year. This year, in San Francisco, Compassion & Choices was selected to present multiple sessions during the conference — including sessions on end-of-life doulas, dementia and a panel on end-of-life issues. ASA also awarded Brandi Alexander, Compassion & Choices chief engagement officer, with the Diversity, Equity and Inclusion Award for her steadfast commitment to the diversity and inclusion efforts in her 20 years at the organization.

Compassion & Choices is also partnering with the American Society on Aging on a four-part webinar series featuring our staff and advocates. The series will cover dementia, end-of-life options, addressing inequities in end-of-life care, goals of care conversations and emergency room visits at the end of life. We are proud to work together on Essential Conversations, a program designed to inspire conversation

about end-of-life planning and expand use of our Dementia Values & Priorities Tool®. From creating innovative collaborations, to sharing resources and information with professionals and the public, this powerful partnership keeps growing.



Brandi Alexander accepting the Diversity, Equity and Inclusion Award at this year's ASA's On Aging conference.





### **Engaging the Asian American, Native Hawaiian and Pacific Islander Community Through Advocacy and the Arts**

Compassion & Choices is engaging Asian American, Native Hawaiian and Pacific Islander (AANHPI) communities across the country and with national organizations like the Asian Pacific American Institute for Congressional Studies (APAICS). During AAPI Heritage Month in May, Compassion & Choices chief engagement officer Brandi Alexander participated in a panel discussion about Redefining and Empowering Patients and Caregivers. In Hawai'i, Compassion & Choices continues to innovate in end-of-life issues and the arts, participating in events like the Merrie Monarch Festival, a grand celebration to honor Hawaiian culture and traditions. Compassion & Choices outreach efforts continue to grow with the AANHPI community.

### **Partnering with Leading Latino Organizations to Address Health Disparities**

Compassion & Choices has partnered with the LatinX Task Force, an organization dedicated to addressing health disparities and improving access to health information in the Latinx community. In November, the task force launched a groundbreaking three-part educational series called LUCAR (Leading and Uniting Comunidades through Health and Awareness Resources), aimed at identifying and highlighting crucial health priorities, challenges and solutions within the Latinx community. Maria Otero, the Compassion & Choices director of priority populations, is a member of the LatinX Task Force advisory board and advocated strongly to incorporate end-of-life healthcare planning as a crucial sub-pillar in the LUCAR initiative.

### **The 2024 Allyne Hammer Excellence in Advocacy Award**

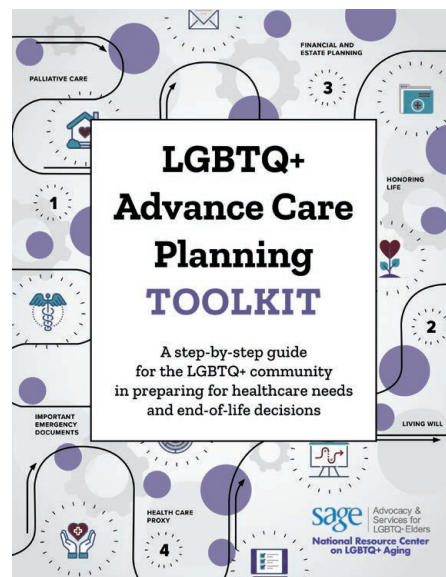
Volunteers are the foundation of the end-of-life options movement. The Allyne Hammer Award for Excellence in Advocacy was created in 2023 to acknowledge the legacy of advocate, storyteller and LGBTQ+ elder, Allyne Hammer. This year, Compassion & Choices recognized Deb Robertson for her dedication to legislative organizing in Illinois for medical aid in dying, serving on the Compassion & Choices LGBTQ+ Leadership Council and counseling other terminally ill individuals. Throughout her career, Deb has also provided drug counseling and supporting LGBTQ+ homeless youth.



Deb Robertson, recipient of this year's Allyne Hammer Award.

## **First-Ever National LGBTQ+ End-of-Life Guide**

Compassion & Choices has joined with SAGE, the world's largest and oldest organization dedicated to LGBTQ+ elders to collaborate on a national LGBTQ+ advance care planning toolkit. This comprehensive toolkit empowers LGBTQ+ people on how to navigate challenges in the legal or healthcare systems by offering a step-by-step guide to help think and talk about their end-of-life healthcare decisions. It also includes information on hospice services, funeral planning, health proxies and more. Compassion & Choices and SAGE promoted the guide on social media and hosted a webinar for National Healthcare Decisions Day in April to spread awareness and move towards a future where LGBTQ+ people fully receive the care they deserve.



The toolkit is available for free at [www.lgbtagingcenter.org](http://www.lgbtagingcenter.org).



## **A Documentary on Medical Aid-in-Dying Advocacy Changes the Tide**

"Take Me Out Feet First," a documentary series directed by Serene Meshel-Dillman, focuses on individuals facing terminal illnesses and their personal stories advocating for medical aid in dying. Meshel-Dillman was at her mother's side as she navigated the process of medical aid in dying when the idea to create the series was formed. "Witnessing firsthand how medical aid in dying offered her dignified solace from her debilitating terminal diagnosis made me realize how urgently the process must be legalized for those suffering in states without access." The docu-series is now available for streaming on Amazon Prime, offering a glimpse into the intersection of choice and compassion at life's end.

Featured end-of-life advocates include (clockwise) Isa Mendez with husband Peter; Andrea Mimi Ankerholz; film director Serene Meshel-Dillman and Ralph McFadden with partner Keo.



## **Changing the End-of-Life Care Conversation Through Stories**

Storytelling is a crucial aspect of changing the conversation about death and dying in our communities. In recent months, members of the Compassion & Choices African American Leadership Council — which was founded in 2018 to bring experts from different fields together to inform Compassion & Choices' outreach to Black communities — have shared their stories across various platforms. Dr. E. Faye Williams, CEO and president of the Dick Gregory Society, shared how important end-of-life conversations have been in her life, from her mother to comedian and civil rights leader Dick Gregory. Joël Maldonado, a Compassion & Choices board member, facilitated a Gullah Geechee Cultural Immersion Excursion in Beaufort, South Carolina to share grief and end-of-life traditions in the African American community.



Dr. E. Faye Williams speaking at the Journey Home Summit: A Comprehensive Discussion of the Power of Planning held by the Compassion & Choices African American Leadership Council.

## **Building Community and Faith-Based Conversation**

Last year, Compassion & Choices initiated conversations and presentations with congregations, large and small, about end-of-life care and options. In Cookeville, Tennessee, we brought together four congregations of different denominations to discuss this important topic. Ric Finch, member of the Unitarian Universalist Congregation of Cookeville, said, "In order to get the kind of death you want, you better get to work on planning it well in advance, otherwise it likely won't happen the way you'd like. Many events like this one need to be held across the country so that the message gets out to a wider audience."

Email [faith@CompassionAndChoices.org](mailto:faith@CompassionAndChoices.org) to host an event in your area.



## Legislative Progress Throughout the States

### CALIFORNIA

Compassion & Choices praised a court ruling in late March dismissing a federal lawsuit claiming California's revised End of Life Option Act (EOLOA) discriminates against people with disabilities. Last September, our legal team filed a motion on behalf of three California patients with disabilities and two doctors requesting to intervene in a federal lawsuit. "In throwing out the suit, the court found that the statute ensures that medical aid in dying is a voluntary and autonomous decision for terminally ill patients, so the plaintiffs wouldn't suffer any harm," said Kevin Díaz, chief legal advocacy officer for Compassion & Choices. This case is being appealed.

### DELAWARE

For the first time ever, the Delaware House of Representatives passed the Ron Silverio/Heather Block End-of-Life Options Act in a bipartisan vote in April. At the time of publishing, Team Delaware awaits a Senate hearing. "We are proud of what our team achieved in 2024, which wouldn't have been possible without the passion and dedication of lead bill sponsor, Rep. Paul Baumbach," said Heather Pope, Delaware senior organizer for Compassion & Choices Action Network. "We will leverage this momentum by continuing to engage with lawmakers about the urgent need for the option of medical aid in dying for terminally ill Delawareans."

### FLORIDA

Our Florida team continues in full force, informing residents about a comprehensive array of end-of-life care options including medical aid in dying. We kicked off spring with a visit from Kim Callinan, president and CEO of Compassion & Choices, who met with communities at local libraries and was a key speaker for the Fearless Caregiver conference. In early March, our team celebrated International Women's Day by honoring the invaluable contribu-

tions of women in our movement by amplifying their role in advocating for end-of-life choices. Our team also embraced the opportunity to participate at a *Día De Niños* (Children's Day) celebration fostering connections within Florida's vibrant Hispanic/Latinx community.

### ILLINOIS

Illinois legislators are seeing robust coverage about medical aid in dying, with over 90 news stories since the February introduction of SB 3499. We also reached the Latino community with national headlines in stories through outlets like Univision, Telemundo and La RAZA. Our storytellers spoke to the heart of this compassionate end-of-life option. Additionally, as co-leader of the Illinois End-of-Life Options Coalition in partnership with the ACLU of Illinois, we are ensuring that the diverse voices of the 7 in 10 Illinoisans who support this legislation are heard.

### MASSACHUSETTS

In February, the Joint Committee on Public Health favorably moved the medical aid-in-dying bill, the earliest our bill has ever moved. In April, for the first time ever, the Joint Committee on Health Care Financing also moved the bill favorably. Caregivers of loved ones who have died with unbearable suffering praised lawmakers for referring the End of Life Options Act to the Senate Ways and Means Committee. "My late wife, Meri Myles, who was terminally afflicted with ALS when she testified remotely to the committee, would certainly be pleased," said Mark Myles. "The prohibition on medical aid in dying is ... inhumane."

### MINNESOTA

Minnesota's End-of-Life Options Act broke new ground in 2024, advancing further in the legislative process than ever before, passing four House



## advocacy in action

committees. This historic momentum was driven by the unwavering passion of advocates, including dynamic storyteller Nancy Uden, who is terminally ill, testified in numerous hearings, met with legislators and participated in interviews. Her March Minneapolis Star Tribune profile was one of the paper's most-read stories thus far this year. Unfortunately, the Senate didn't schedule a hearing before its deadline for policy bills this year. Team Minnesota will continue urging lawmakers to authorize the option of medical aid in dying in 2025.

### NEW HAMPSHIRE

In March, the New Hampshire House passed medical aid-in-dying legislation for the first time. The bill received votes from 18% of Republican House members thanks to the partnership between the NH Alliance for End of Life Options and Compassion & Choices. "It's been a seamless partnership — NH Alliance End of Life Options leads the effort and we support their work with consulting and resources," said Melissa Stacy, northeast campaign director for Compassion & Choices. Unfortunately, in May the New Hampshire Senate referred the bill for interim study, effectively defeating the bill for the year, but the legislation still made historic progress.

### NEW JERSEY

In February, the New Jersey Supreme Court rejected an appeal of an appellate court ruling issued in 2022 affirming the dismissal of a lawsuit seeking to overturn the 2019 medical aid-in-dying law on constitutional and religious grounds. Compassion & Choices submitted an amicus brief in the case, *Glassman v. Grewal*, and argued before the court in 2022, urging the court to affirm the lower court's ruling. "I am greatly relieved on behalf of terminally ill New Jerseyans that this five-year-old case finally is over," said Jessica Pezley, a senior attorney for Compassion & Choices.

### NEW YORK

In mid-April, the Medical Society of the State of New York voted to reverse its longtime opposition to New York's Medical Aid in Dying Act and support passage of the bill. "Previously, there were a handful of lawmakers who told us they had a tough time supporting medical aid in dying while the state Medical Society was opposed, despite the support of the state Academy of Family Physicians," said Compassion & Choices NY and NJ Senior Campaign Director Corinne Carey. A January YouGov poll showed 72% of voters statewide — a 14-point jump — support the Medical Aid in Dying Act.

### OREGON

The Oregon Health Authority released its 2023 data on medical aid in dying usage in Oregon in March: 560 people received aid-in-dying prescriptions in 2023, up from 433 in 2022, an almost 30% increase. It was the first full-year report released since Oregon dropped its residency requirement in March 2022. At least 23 out-of-state residents represented 18% of the increase of 127 prescriptions. Notably, 6.5% of the total number of patients who died after ingesting aid-in-dying medication in 2023 self-identified as African American, American Indian, Asian, Pacific Islander, Hispanic, two or more races, or other, culminating to a 100% increase since 2022.

### VIRGINIA

In February, the Virginia Senate passed the End of Life Options Act for the first time. No committee or subcommittee had ever advanced the bill since its original introduction in 2019. "I'm grateful to bill author Sen. Hashmi's leadership. I plead with House members to approve this bill," said Virginia resident Barbara Green, who has metastatic pancreatic cancer. "Unfortunately, the House didn't pass the Senate-approved bill before the 60-day session ended," said Melissa Stacy, northeast campaign director for Compassion & Choices Action Network. "But we will work with House bill sponsor Delegate Hope to persuade his colleagues to pass it 2025."

Don't see your state?

Visit [CandC.org/in-your-state](https://CandC.org/in-your-state).

## Colorado Lawmakers Pass Medical Aid-in-Dying Improvement Bill, Await Governor's Review

The collaborative efforts of Compassion & Choices' Colorado team members, passionate volunteers, and compelling storytellers paid off this legislative session, when both the Colorado Senate and House of Representatives passed legislation to address inequities in accessing medical aid in dying in Colorado. At the time of publishing, Team Colorado awaits Gov. Polis' review of the bill, and hopes he will officially sign these improvements into law soon.

"We thank our dedicated bill sponsors, Sen. Joann Ginal and Rep. Kyle Brown, for this important update to Colorado's End-of-Life Options Act," said Gina Gentry, Colorado campaign manager for Compassion & Choices. "These improvements maintain the core safeguards of the ballot initiative that Colorado voters overwhelmingly passed into law in 2016, while also removing significant barriers to accessing medical aid in dying created by the overly stringent requirements of the original law."

The law would address the unnecessary barriers by: 1) shortening the mandatory waiting period between the two required oral requests from 15 to seven days; 2) allowing prescribing providers to waive the mandatory waiting period if a patient is not likely to survive the next 48 hours; and 3) allowing advanced practice registered nurses (APRNs) to become prescribing providers for medical aid in dying.

Data compiled by the program coordinator for medical aid in dying at Denver Health showed nearly 1 in 4 eligible patients going through the medical aid-in-dying process from 2018-2022 died during the mandatory 15-day waiting period.

Compassion & Choices storyteller Meghan Reese witnessed her mother Kathleen McDaniel pursue the option of medical aid in dying after her terminal



Meghan Reese with her mother Kathleen McDaniel.

cancer diagnosis, but die without it due to the 15-day waiting period and the shortage of prescribing providers. "Her last days were painful and traumatic, and I will continue advocating on behalf of other terminally ill patients to honor her life," Reese told *The Centennial Citizen* in March.

Ashley Fry, director of clinical engagement for Compassion & Choices and a Colorado Springs resident, testified in support of the bill before the House Health & Human Services Committee on behalf of the Colorado Nurses Association and expressed the importance of APRNs in rural areas of Colorado. "For my patients who live in rural communities, they often share that their primary care provider is a nurse practitioner," Fry testified in April. "Nurse practitioners have independent practice authority in Colorado, and we oversee the care for our own patients, but currently we cannot participate in this process."





# Understanding and Accessing Hospice Care

Information and checklists to help you find the right support and quality care at the end of life.

**I**n 2023, the Carter family shared that former President Jimmy Carter and former First Lady Rosalynn Carter were both, though at different times, entering hospice care in their Georgia home. After receiving treatment for cancer, the Carters shared in a February 2023 statement that President Carter, a Nobel Peace Prize recipient, “decided to spend his remaining time at home with his family and receive hospice care instead of additional medical intervention.” At this writing, he has been receiving hospice services for over a year. In November 2023, Rosalynn Carter entered hospice with a dementia diagnosis. She died a few days later.

The Carters’ willingness to share their experience with hospice introduced millions to the program. Hospice, a program providing care and services for patients and their families at the end of life, is often misunderstood and considered, if considered at all, the very last step for care in the dying process. In reality, hospice is a wonderful resource for patients and their families as they progress in the dying process. Many people who engage the service wish they had set it up earlier, as soon as they were eligible.



## What is hospice?

Hospice is a specialized type of care that focuses on compassion, quality of life and care during the final months of life. The goal is maintaining or improving the quality of life while managing symptoms for someone whose illness, disease or condition is unlikely to be cured. Each patient's individualized care plan is designed to address the physical, emotional and spiritual pain that often accompanies terminal illness. Hospice care offers support for families and caregivers during the illness and grief support after the death.

Hospice uses an interdisciplinary team-based approach to providing comfort care. The care team includes a hospice physician, hospice nurses, social worker, certified home health aides, spiritual support counselor(s), family support volunteers and grief counselors. Care is provided in the home or in residential care facilities such as assisted living, memory care or in the case of the Carters, at home.

Hospice offers supportive care to benefit the patient and caregivers as the disease progresses and ultimately helps the patient prepare for the end of life.

## Who pays for hospice?

For most people, hospice is covered by Medicare Part A, Medicaid and most private insurance plans. If the patient has Medicare and meets hospice eligibility requirements, then typically 100% of the cost of hospice care is paid for with no deductible or copayment. Medicare pays hospice providers for each day a patient is enrolled in the hospice benefit. The daily rate varies according to duration of the stay and where the care takes place (residential or in-patient).

## Why don't more people enroll in hospice?

Hospice is sometimes misunderstood as "giving up" on life. Likely, the culture of "fight language" regarding terminal illness has contributed to this myth. Phrases like she needs to "beat this disease" or he "lost his battle with cancer" create an expectation that to die is to fail and that terminal diagnoses are "winnable." Death is not the result of a lack of fighting or the desire to live.



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**“We’ve been conditioned to think one way when it comes to healthcare. And unfortunately, many patients and their families miss the opportunity to engage in the whole aspect of healthcare, the full aspect of healthcare. Hospice is an opportunity to shift the lens altogether and focus on the fact that you make the decisions that work for you. You are developing your own roadmap. It’s not a scavenger hunt. It’s really setting forth all of the aspects of your life that are important. This is advocacy at its best.”**

– Dr. Sonja Richmond, *national medical director, Compassion & Choices*

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## Statistics show that people are predominantly ENTERING HOSPICE SIGNIFICANTLY LATER than when they are eligible ...



**92.1 days** was the average length of stay for Medicare patients enrolled in hospice in 2021.



**50%** of patients receiving hospice care have a median stay of 17 days or less.

Often, when people accessed the offered hospice resources, *they were regretful* they didn't make that connection sooner.

**~ 2.8 million**

Medicare beneficiaries died in 2021

AND ONLY

**1.7 million**

chose hospice care.



National Hospice and Palliative Care Organization's Facts and Figures

### Compassion & Choices federal work

Through our federal advocacy and policy work, Compassion & Choices works to improve and expand end-of-life care through systemic and policy change. Hospice is an excellent resource, but access is limited. Compassion & Choices is exploring potential improvements to update hospice care through federal law and regulation to include two components: 1) concurrent care and 2) expanding the six-month prognosis eligibility requirement.

Many people would benefit from some period of time where they're still receiving what are considered "curative treatments" while also receiving hospice services. The patient is considered to be in a terminal phase but this phase can extend way beyond six months. One example is end-stage renal disease. Dialysis can be life-extending and is considered "aggressive" treatment. Many people would benefit from a period of time to develop relationships and build trust with an end-of-life care team before they

choose to stop dialysis to receive hospice benefits. This trust-building phase is particularly important for people who have been denied care due to discrimination and face inequities in the healthcare system. To immediately jump from receiving all aggressive or curative treatments to completely stopping may feel abrupt to people who have not had easy access to healthcare throughout their lives. It does not help create trust in the system. Concurrent care gives a period of time where some curative treatment might continue under the care of hospice.

Requiring patients to have a life expectancy of six months to be eligible for hospice doesn't allow for paths of many diseases like Alzheimers and renal disease where patients would benefit from a longer period of time. For people who have a disease with a long terminal phase, it would be more beneficial for patient care, effectiveness of care and costs to increase the length of eligibility from six months to a longer period.



## Getting Started With Hospice Care

### A hospice referral

Discuss your interest in hospice care with your healthcare team. You can also initiate hospice services without a physician referral.

### Finding and selecting a hospice

Choose a hospice that aligns with your priorities and beliefs and will honor your end-of-life care preferences. Some hospices will support you in the full range of end-of-life options while others may have limitations.

#### *Here are a few tips:*

- » Ask friends or family who have had experiences with hospices in your community for a recommendation.
- » Ask your healthcare team if they prefer a particular hospice and why.
- » Ask your insurance company. They may only pay for a particular hospice.
- » Ask hospices you are considering whether they take your insurance.

### Connecting with care

Once you've found a hospice, you may want to call and ask to speak to an intake person or a nurse. Take notes. Explain your current medical situation, tell them where you live and ask questions that are important to you like those listed here. Listen for concern, kindness and thoughtful responses.

#### *Ask questions like:*

- » How will the hospice staff work with me and my loved ones and honor my wishes?
- » How are family caregivers provided the information and training they need to care for me at home?
- » How does respite care work?
- » Are loved ones told what to expect in the dying process?
- » What happens after I die?
- » If I decide to voluntarily stop eating and drinking as I near death, will hospice support me and my family in that process?
- » How will my pain be managed? If I am in pain, will I immediately receive support to relieve it?
- » If my pain cannot be managed, will hospice provide palliative sedation to keep me unconscious and comfortable until I die?
- » If I live in an authorized state for medical aid in dying, will hospice support me and my family in that process?
- » What will happen if care cannot be managed at home?
- » What bereavement services are available for my family after I die?
- » Are all of the costs of hospice care covered by my health insurance?
- » What services will we have to pay for out of pocket? Are any services provided at no charge?



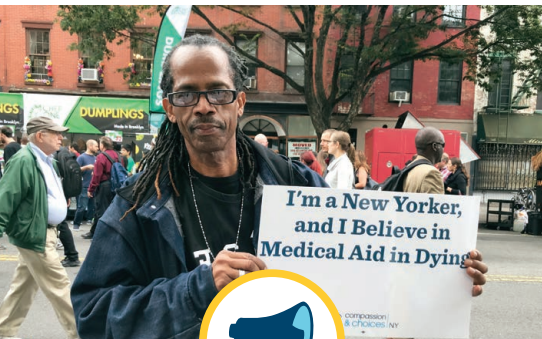
For more information, contact the National Hospice and Palliative Care Organization (NHPCO), which represents most hospice programs in the United States, at 800.658.8898 or visit [nhpco.org/find-a-care-provider](https://nhpco.org/find-a-care-provider). Remember, YOU ARE IN CHARGE.



# 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](https://CandC.org).



## Members Fighting for End-of-Life Rights Now

Together, let's fight for all people to have the power to choose the end-of-life experience that reflects their values and priorities. Your support is critical to helping us expand and defend end-of-life options for everyone.

### WE NEED YOUR MEMBERSHIP!

Membership with the Compassion & Choices Action Network is essential to the advancement of end-of-life options through its unlimited lobbying ability in critical campaigns in states moving medical aid-in-dying legislation and hold legislators accountable for their decisions. Help us fight to bring end-of-life autonomy to everyone in America with your contribution.

Visit [CandC.link/ccan](http://CandC.link/ccan) to become a member today.

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Compassion & Choices Action Network is a 501(c)4 organization. Contributions to Compassion & Choices Action Network are not deductible as charitable contributions or business expenses under IRC § 162(e). Your contribution generally supports Compassion & Choices Action Network's activities to protect and promote care and choice at end of life across the country.