



compassion & choices

MAGAZINE
WINTER 2022

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**Five Questions for
Rev. Dr. Paul Smith**

The civil rights leader and end-of-life choice pioneer
wants people to face death, not fear it.

Legacy Challenge Match

Let us know of a new planned gift or provide a new notification of an existing planned gift, and a generous anonymous couple will contribute \$500 in your honor!



Dan Diaz (left) holding a photo of his late wife, Brittany Maynard, and Harlan Seymour (right) holding a photo of his late wife, Jennifer Glass.

AND THE BEST PART: Your planned gift will support Compassion & Choices' transformational work to improve care and expand options at the end of life — today and in the future.

Four popular options for creating a planned gift are:

- » **Qualified Charitable Distribution (QCD) from your IRA:** If you're 70½ or older, you can make a tax-free gift of up to \$100,000 per year (spouses individually) directly to Compassion & Choices. And if you are 72½ or older, your gift will also satisfy your annual Required Minimum Distribution (RMD).
- » **Charitable Gift Annuity (CGA):** A CGA provides a tax deduction, tax-free income and guaranteed income for life.
- » **Appreciated Securities:** You can avoid capital gains tax and receive a full fair market deduction.
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and then scan
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 **compassion
& choices**
Care and Choice at the End of Life



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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).

Expanding Our Reach — Deeper, Stronger, Smarter

“We’re going to die, so we need to get ready for that.”

- Rev. Dr. Paul Smith (featured on our cover)

Despite the constant reminders over the last two years that life truly is unpredictable, many of us are not ready. Why not? Plain and simple: Avoiding end-of-life planning allows us to deny the reality that our time on this earth is limited.

Sadly, though, the consequences of avoidance are significant:

- » Loved ones left guilt-ridden having to make unconscionable and uninformed decisions.
- » Invasive and sometimes painful treatments that result in more suffering.
- » Death in a hospital, hooked up to machines, sometimes alone.

While these realities are true for all populations, they are particularly true for families from communities that have been habitually and systemically marginalized. What gives me hope is the increasing community voices who are working with us to make sure all people — regardless of their age, race, ethnicity, sexual orientation or gender identity — have the resources and tools they need to plan for an end-of-life experience that reflects their wishes and priorities.

It’s people like Rev. Dr. Paul Smith and Elaine Saunders, and organizations like the NAACP, NOBEL Women, SAGE and so many others that you will learn more about in this issue, who are using their voices to influence change.

Collectively, we are and will continue to make a difference.



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In the Media

Discover Magazine

[Medical Aid in Dying: A Comprehensive Breakdown](#)

Discover Magazine interviewed Compassion & Choices board member Dr. Chandana Banerjee about how aid-in-dying medications work. Dr. Banerjee, an assistant clinical professor of hospice and palliative medicine at the City of Hope National Medical Center in Duarte, California, said the process is usually relatively quick because the patient is already in the process of dying. "Their bodies are naturally frail and shutting down," she said. "Compared to someone who is healthy, the effects of these medications are going to be more pronounced."

The Santa Fe New Mexican

[At the End of Life, Peace for Terminal Patients](#)

New Mexico authorized medical aid in dying in April 2021. In an editorial last year, the Santa Fe New Mexican noted that while not all new laws have an immediate impact, this compassionate law had already helped at least 30 terminally ill residents end their intolerable suffering. The editorial compared the stories of two sisters, Vicki Bergman Marks and Linda Bergman Sprague, both diagnosed with terminal cancer. While Linda was able to access the New Mexico law and died a "peaceful, gentle, soft" death, Vicki's family reported that she died "in pain and despair" without the option of medical aid in dying.

Public News Service

["Death Doulas" Fight for Right to Serve Families](#)

Last year, Compassion & Choices submitted an amicus brief in support of Full Circle of Living & Dying, a collective of death doulas in California. The group filed a lawsuit against the California Cemetery and Funeral Bureau, which is requiring them to establish themselves as a funeral home. This change would cost hundreds of thousands of dollars and negatively impact dying Californians. Jess Pezley, Compassion & Choices staff attorney, explained the difference between doula services and those of a funeral home. "[Death doulas] don't embalm. They aren't transporting the body. They aren't offering crematorium services," Pezley said. "And they're not doing anything that would put themselves or others at risk ..."

The New York Times

[For Terminal Patients, the Barrier to Aid in Dying Can Be a State Line](#)

This story details Compassion & Choices' federal lawsuit on behalf of an Oregon physician asserting that the residency requirement in Oregon's medical aid-in-dying law violates the U.S. Constitution. "This is the only medical procedure we can think of that is limited by someone's ZIP code," said Compassion & Choices Chief Legal Advocacy Officer Kevin Díaz.



Dolores Huerta Mission and Vision Award

The inaugural Dolores Huerta Mission and Vision Award was given to its namesake, Dolores Huerta, for her commitment to expand and protect options at the end of life. The award will be given each year to a leader who has dedicated their efforts to Compassion & Choices' mission of improving care, expanding options and ensuring that everyone can chart their own end-of-life journey according to their values and priorities.





The Expansive End-of-Life Options Movement

As we move into 2022 and look back over the last 50 years, the advancement of the end-of-life options movement from the fringes into the mainstream has been remarkable.

In those early years, palliative care and hospice were still new ideas, struggling to take hold within standard medical care. Thirty years ago, there were no laws supporting medical aid in dying; today, 1 in 5 Americans have this authorized option.

In the prologue of *Finish Strong: Putting Your Priorities First at Life's End*, Barbara Coombs Lee talks about how the first seeds of understanding the need to "finish strong" began to germinate for her in 1972.

As a young nurse, Barbara was providing care to Ed, a patient in end-stage heart failure. She grew close to him and his wife over their months of hospital stays. Eventually, when Ed's heart went into fatal arrhythmia, Coombs Lee did as she was trained to do: She used the defibrillation paddles to shock Ed's heart, restoring him to normal rhythm. Ed woke up angry and let Barbara know it. At that moment, she learned that heroics and technological interventions are not always in line with a person's values and priorities. For Coombs Lee, a mission was born.

After her 25-year career as a nurse and physician assistant, Barbara moved on to law and health policy, focusing her efforts on individual choice and empowerment in healthcare. Coombs Lee went on to lead Compassion in Dying and steward its merger with End of Life Choices (formerly the Hemlock Society, founded in 1980) to form Compassion & Choices. She currently holds the title of president emerita/senior advisor. In 1994, Coombs Lee co-authored and became one of three chief petitioners who successfully campaigned for Oregon's Death with Dignity Act.

The U.S. Supreme Court's landmark ruling in *Washington v. Glucksberg* (1997) encouraged individual states to engage in an "earnest and profound debate about the morality, legality, and practicality" of medical aid in dying to relieve unbearable pain and suffering at the end of life. This state-driven movement gathered momentum. Twenty-five years later,

1 in 5

AMERICANS HAVE ACCESS TO MEDICAL AID IN DYING



left: Founder of Compassion & Choices Barbara Coombs Lee.

below: President and CEO Kim Callinan.



10 states and Washington, D.C., now authorize medical aid in dying as an end-of-life option for mentally capable, terminally ill adults.

Genuine patient-directed care requires more than just the authorization of medical aid in dying. It requires that everyone has the tools and the information to lead their end-of-life journey according to their values and priorities. That includes understanding the importance of advance directives and transforming how people with dementia die.

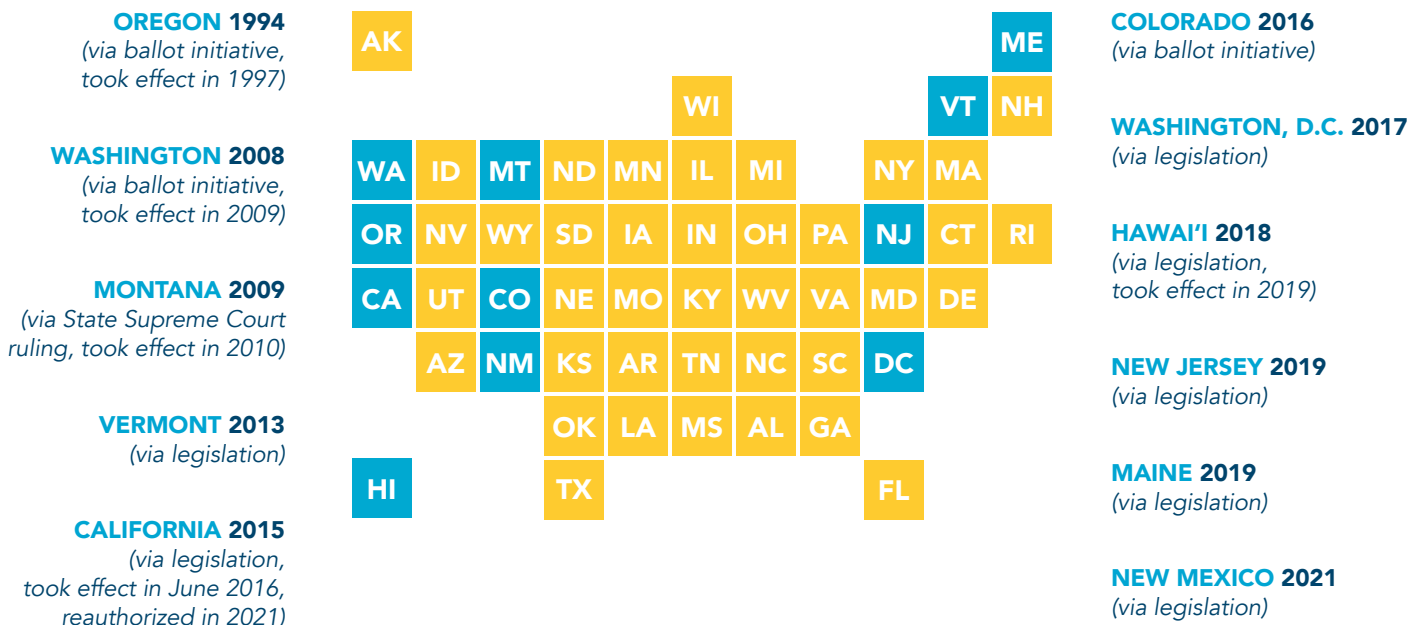
Kim Callinan, president and CEO of Compassion & Choices, states the scope of end-of-life options includes medical aid in dying, voluntarily stopping eating and drinking (VSED), hospice and palliative care, and patient-directed care, among other options. "We must create a paradigm shift in our thinking around end-of-life care. When we as a society are able to accept the inevitability of death, we will experience far less suffering and far more

compassion during our final days. We are working toward an America that respects everyone's right to make their own end-of-life care decisions, in consultation with doctors and loved ones."

To support that paradigm shift, Callinan has increased outreach and education programs across the country. She has worked with staff and volunteers to create a group of councils to inform our efforts with important communities, including the African American; Latino; Asian American, Native Hawaiian and Pacific Islander; LGBTQ+; the disability rights; and many faith groups. The Compassion & Choices Healthcare Advisory Council serves as a liaison to medical networks on matters of end-of-life care and medical aid in dying.

Exacerbated by systemic barriers, hospice utilization is lower among historically underserved communities. The benefits of hospice care create a critical path to improving end-of-life experiences for everyone.

MEDICAL AID IN DYING AUTHORIZED IN 10 STATES + WASHINGTON, D.C.



“When we as a society are able to accept the inevitability of death, we will experience far less suffering and far more compassion during our final days.”

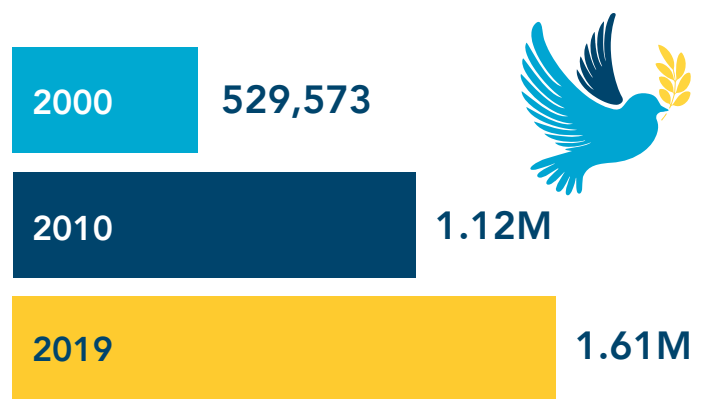
- Compassion & Choices President and CEO Kim Callinan

Hospice can include multiple disciplines of care, including nurses, physicians, social workers, chaplains, aides and volunteers trained to help patients and families manage pain, provide spiritual and emotional support, and guide them through the dying process. More recently, care has expanded to include a greater understanding of diverse cultures and traditions.

Hospice pioneer Dame Cicely Saunders first introduced the idea of specialized care for the dying to the United States in a lecture at Yale University in 1963.* According to the National Hospice and Palliative Care Organization (NHPCO), 1.61 million Medicare beneficiaries received hospice care in 2019. This represents a considerable increase over 2000 (529,573) and 2010 (1.2 million).**

In 1972, when Barbara Coombs Lee began to consider end-of-life values, the movement was in its infancy and allies were few. Fifty years later, Compassion & Choices supporters and partners include national organizations like the NAACP, National Hispanic Council on Aging, Congressional Black Caucus, SAGE, American Medical Student

MEDICARE HOSPICE USERS



source: NHPCO

Association, American Medical Women’s Association, American Public Health Association and many other hospital systems, scores of local and statewide civic and rights-based organizations, lawmakers, national influencers, celebrities, and 450,000 folks like you across the country. We will continue to grow, one heart and one mind at a time.

The most immediate way to ensure an end-of-life experience that aligns with your values and priorities is by documenting and communicating your end-of-life wishes. Compassion & Choices offers a host of free, accessible, customizable tools for your use. Visit CompassionAndChoices.org/finish-strong-tools.

* National Hospice and Palliative Care Organization, “History of Hospice.”

** Melissa D. Aldridge, Maureen Canavan, Emily Cherlin, Elizabeth H. Bradley, “Has Hospice Use Changed? 2000-2010 Utilization Patterns,” NIH National Library of Medicine, PubMed.gov.



A Different Kind of Courage

Minnesotan Danna Nelson has always lived boldly. A terminal diagnosis at age 22 was not going to change that.

In April of 2018, Danna Nelson was waiting to see her surgeon. The Minnesota native and accomplished trombonist had been living in Finland for three years. Over the previous few months, she had been struggling with ear and sinus issues that impacted her music. Doctors suggested a cold, a sinus infection or maybe polyps. Finally she was going to have answers.

Alone in a foreign country at 22 years old, Danna was told she had rhabdomyosarcoma, a muscle and soft tissue cancer rare for someone her age.

Moving to another continent at 19 is unimaginable to many, but Danna's independence and excitement were far stronger than any fears she held. Like many American teenagers, the idea of running off to Europe was exciting and romantic — something you see in movies. Her trombone instructor was originally from Finland, and Helsinki happened to have a wonderful music school. With a plan and a passport, the future for many musicians was right at her fingertips.

After Danna's diagnosis, her mother joined her in Finland while she underwent her initial treatments. First were chemotherapy and facial radiation, which resulted in more hospital visits and medications. Danna had to stop playing the instrument that was such a huge part of her life.

More treatments and surgeries followed. Danna felt herself changing. Body image issues plague our culture, and that doesn't go away just because of a diagnosis. "I remember thinking that I had to stay skinny so I would look good in my coffin," she divulged. "Which is such an awful thought, in so many ways, but I had it."

The changes started in her body, and then in her mind and spirit.

opposite page: Danna at her parents' home in Minnesota during a video photo shoot urging passage of legislation authorizing medical aid in dying.



Danna was a marathon runner and musician living in Finland when she was diagnosed with cancer.

In 2020, Danna had to make the heartbreaking decision to leave Finland. This special place had represented potential: her musical dreams, relationships and so much joy. In Minnesota, Danna began to rely more on her parents and saw fewer friends. Daily routines and events were planned around treatments.

After moving back to Minnesota, she found herself becoming a fierce advocate for medical aid-in-dying legislation.

"I'm privileged to have my parents around to help me navigate all of this," Danna acknowledges. "But, in a lot of ways, I think I am a less independent person now."

Though supported, Danna still finds herself feeling isolated. Her social life in Finland was thriving and busy. Now, it is harder to make new connections or find the energy to spend time with friends the way she used to. Cancer has begun to push its way in, often feeling like the core of her identity.

Acquaintances, neighbors, strangers — all have something to say about her diagnosis, and about death itself.

"I don't blame anyone, but it has been really hard socially to connect with people my age. They're just not thinking about the same stuff I am," she said. "The hardest

part about it is I feel like my cancer is in the way. Maybe that's why we're not clicking. It must be because of everything on

my mind, not because of them." It isn't just friendships that feel different. The word "cancer" on a dating profile creates a new dynamic in romance. Some potential partners have brushed her diagnosis under the rug; others have been fearful.

"It feels like nobody will get on board because people [my age] are looking for a stable future. People want to meet the person that they're going to be with forever," Danna said. "I am looking

for something meaningful for my forever, too."

Early in her treatments, Danna sought opportunities to connect. It all began on Instagram, where she found other young adults facing illness, new friends and people who want to discuss mortality openly.

Danna is currently writing her memoir — an exploration of her life, intertwined with her thoughts on death and dying. After moving back to Minnesota, she found herself becoming a fierce advocate for medical aid-in-dying legislation. She partnered with Compassion & Choices in 2021, sharing her story candidly and her smile brightly. Recently, she appeared in a video urging Minnesota lawmakers to make this option available for terminally ill Minnesotans, like her.

"Sharing has given me purpose," Danna beamed. "I don't feel like I can do a lot of things anymore, but I can use my voice, and I can advocate. It has been so cool."

A Career in Kindness

Compassion & Choices National Medical Director Dr. David Grube retired late last year, leaving an immeasurable legacy of helping improve the end-of-life experience.

David Grube didn't know what to think about medical aid in dying when it first passed in Oregon in 1994. "But a very dear patient of mine asked me in 1999 if I would help him," recalls Grube, who at the time had been a family physician for over two decades. "This guy was having terrible symptoms of his disease, so I talked with the medical director of a local hospice, and he mentored me through. That was the first patient I wrote a prescription for."

In the following years, Grube's connection to Compassion & Choices evolved from consulting the organization for guidance, to serving as a volunteer and finally becoming a national medical director in 2015. In that time, Grube has witnessed — and helped further — great progress in public understanding and sentiment around medical aid in dying. "I think attitudes have changed a lot," he says. "I've seen incredible growth. It used to be that all hospice organizations were opposed. Now most non-Catholic hospices in authorized states are pretty neutral and engaged, and that's a huge change we've seen just in maybe the last 10 years. But there is still a long way to go, because many people don't really understand it yet. The thing is, very few physicians do end-of-life care — not a dermatologist or ophthalmologist or gastroenterologist. Family doctors do end-of-life care — intensivists, oncologists and geriatricians. So even a lot of the medical establishment who are opposed to medical aid in dying don't know what it is."

Grube also led our Doc2Doc program, speaking to nearly a thousand doctors over the years who



needed information or just wanted to talk. He feels gratified by work that is immersed in compassion: "There just can't be enough kindness," he says. "In our world today, people need to be more kind — especially at the end of life. That's why I've enjoyed the work I've done for Compassion & Choices. The people who work in this arena really do care about that."

At Compassion & Choices, we are tremendously grateful for the gift of working with Dr. Grube. As he retires, his absence will be felt by all of us.

Kindness, and even his favored concept of empathic curiosity, will carry on in Grube's retirement. Passionate about music, he and his wife joined a threshold choir four years ago, singing at the bedsides of the dying, and he plans to devote more time to expanding threshold choirs internationally. He is also considering volunteering for Dial-A-Bus, which provides free transport for seniors and people with disabilities. "I've always liked to talk to people — that's why I went into family medicine — and I've never had a traffic ticket, so I think I'll drive a bus ... singing!"

Moving Forward Still

Despite ongoing challenging circumstances, our progress continues.

COLORADO

Compassion & Choices Campaign and Outreach Manager Sam DeWitt moderated a discussion about end-of-life options at Tattered Cover Book Store in Denver, featuring physicians and other practitioners. Participants discussed how to remove barriers to medical aid in dying for those who are eligible and the importance of end-of-life planning for all age groups. The Colorado Medical Provider Advocates group continues to grow and is now nearly 30 members strong. The interdisciplinary group works to inform Colorado providers about the latest practices and education regarding end-of-life care.

CONNECTICUT

The Connecticut Compassion & Choices Action Network team is building on its successful 2021 campaign, when the Public Health Committee approved the End of Life Options Act for the first time in a bipartisan 24-9 vote. The 2022 campaign will spotlight a terminally ill social worker in Glastonbury, Kim Hoffman, who recorded an emotional YouTube video in which she says: "There's actually 30, 30 measurable cancer lesions in my brain. There's so much cancer, it's unbelievable, and it's uncomfortable, and it's painful, and it's scary, and it's disturbing. I'm going to die ... I'd love for my end to be peaceful, pain-free."

HAWAII

The Hawai'i team has organized a well-attended series of online education programs to ensure clinicians have the latest information about the state's Our Care, Our Choice Act. Topics include standards of care for medical aid in dying, mental health assessments and training for nurse navigators to help

people access the law. With assistance from the Hawai'i Department of Health, Kaiser Health and Hawai'i Pacific Health, providers receive clinical education credits. Our advocates, donors, healthcare providers and staff are committed to ensuring every resident who is eligible may access this compassionate law.

ILLINOIS

The Illinois team is driven to educate even more state residents about end-of-life decision-making and options. Connecting with community members, healthcare providers and legislators is a continued focus for the coming year. Compassion & Choices Action Network is also planning a statewide event in March to recruit volunteers to form action teams. Advocates are organizing a virtual town hall to update residents on efforts to expand the full range of end-of-life options in the Prairie State.

MINNESOTA

Advocates and team members continue working to educate their fellow Minnesotans about end-of-life healthcare and what the Minnesota End-of-Life Options Act would bring to residents. We've welcomed storytellers like Danna Nelson, a 25-year-old Blaine resident living with stage 4 cancer, and DeeDee Welles, who watched her mother's painful death from ovarian cancer and now lives with the same diagnosis. In the past few months we've also added four new action teams around the state. Winter's Minnesota fundraiser was an incredible success, proving that residents are dedicated to seeing this act pass and ready to use their voices across the state. To learn more about Danna's journey, see page 8.



YOU CAN HELP PROPEL THE MOVEMENT FORWARD

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VOLUNTEER any way you can; find options at [CompassionAndChoices.org/volunteer](https://www.compassionandchoices.org/volunteer).

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

NEW MEXICO

The New Mexico team continues to educate health-care providers so they can inform their patients about end-of-life options and provide the care their patients want. We are planning public outreach events to ensure New Mexicans understand their rights and can choose from the full range of end-of-life care options, including medical aid in dying. The team continues to provide technical support to help healthcare systems and hospices adopt policies and procedures supportive of patient choice. In addition, our Medical Provider Advocates Team continues with ongoing presentations to professional organizations, physician groups and medical societies.

NEW YORK

The New York Compassion & Choices team kicked off its 2022 campaign with a January news conference to highlight a large-scale display leading to the Well in the Legislative Office Building to make a strong visual case for why lawmakers should pass the New York Medical Aid in Dying Act. The campaign is promoting a powerful video featuring the family of Dr. Bob Milch, co-founder of Hospice Buffalo, who died in agony from cancer last June. "No one needs to suffer that way at the end of their life," said Dr. Milch's wife, Linda. "Pass New York State's Medical Aid in Dying Act."

OREGON

Compassion & Choices filed a federal lawsuit on behalf of Dr. Nicholas Gideonse, a physician at Oregon Health & Sciences University, stating that the residency requirement in the Death with Dignity Act is unconstitutional, as it prevents Dr. Gideonse's patients who live in Washington state, less than 30 minutes away, from accessing the compassionate option of medical aid in dying (see page 15 for more information). Compassion & Choices believes that geography shouldn't be a barrier to access for terminally ill individuals who qualify for medical aid in dying, and we hope this first-in-nation lawsuit will bring some certainty and relief to both patients and providers.

WASHINGTON

Compassion & Choices Action Network has once again partnered with End of Life Washington to support HB 1141, legislation that would remove barriers for patients accessing medical aid in dying. In 2021, the bill failed to make it to the Senate floor. HB 1141 would support terminally ill Washingtonians by broadening the scope of prescribing clinicians, simplifying the pharmacy process and reducing the waiting period patients must endure. It would also allow prescribers to waive the period entirely in certain circumstances. The groups are also partnering in support of the Keep Our Care Act Coalition Campaign's legislation regarding transparency in hospital mergers to ensure these mergers do not impact patient access to care that aligns with their values and priorities.

Compassion & Choices Action Network Scores Big Win for Dying Californians

Terminally ill Californians will have much better access to the End of Life Option Act (EOLOA) in 2022, thanks to the tireless work of Compassion & Choices Action Network's (CCAN) staff, donors, volunteers and action-takers. That's because SB 380, authored by Sen. Susan Talamantes Eggman and Assemblymember Jim Wood, took effect on Jan. 1 after it was signed into law by Governor Gavin Newsom on Oct. 5, 2021, the 6th anniversary of the EOLOA passing in California. SB 380 significantly improves the EOLOA in three key ways:

- » Reduces the mandatory minimum waiting period between the two oral requests for aid-in-dying medication to 48 hours for all eligible patients.
- » Requires healthcare entities, including hospitals, hospice facilities and nursing homes, to post their medical aid-in-dying policies on their websites.
- » Clarifies that the first oral request must be documented in a patient's medical record even if the physician is unwilling or unable to support the patient in the option.

More than 6,000 Golden State residents emailed their lawmakers, testified during hearings, lobbied their elected representatives during CCAN's Senate and Assembly lobby days, and shared their stories in newspapers across the state.

Storyteller Amanda Villegas rallied friends and family, testified during committee hearings, and shared her late husband Chris' painful experience of dying without being able to access the EOLOA with the Los Angeles Times. Their story also was featured in the editorial endorsement from the Los Angeles Times and the Los Angeles Times en Español, which showcased the powerful photos Amanda took at the end of Chris' life — a key reason the editorial board of the Los Angeles Times endorsed the bill.

Dr. Catherine Sonquist Forest testified days after her husband used the EOLOA to peacefully end his suffering. She shared with lawmakers that even for physicians like her who are well acquainted with the complexities of the healthcare system, it was very difficult to access the law — making it critical to reduce unnecessary barriers to access.

Dr. Chandana Banerjee, a CCAN board member featured on the cover of our fall 2021 magazine, testified in support of the legislation and wrote an op-ed published in the Los Angeles Daily News sharing her perspective as a medical provider who supports patients in accessing medical aid in dying through the EOLOA.

It took a coordinated effort — and many of our supporters met the moment with fierce advocacy and relentless support. This success story sets an important precedent for our campaigns to improve access to medical aid-in-dying laws nationwide.



Chris Davis shown with his wife, Amanda Villegas. A more transparent hospital policy and shorter waiting periods might have allowed Chris' story to end very differently.

Challenging Barriers to Access for Medical Aid in Dying

On Oct. 28, 2021, Compassion & Choices filed a federal lawsuit on behalf of Oregon physician Nicholas Gideonse so that he will be able to support his Washington state patients in accessing medical aid in dying. Medical aid in dying is the only medical procedure with an arbitrary law that prohibits doctors from prescribing to patients based solely on their state of residence, and this barrier is having an unintended impact on patients, especially those who regularly receive medical care just across the border in an authorized state.

The lawsuit alleges that the residency requirement in the state’s law that provides terminally ill adults with the option of medical aid in dying to end unbearable suffering violates the U.S. Constitution’s guarantee of equal treatment. The suit asks the court to prohibit Oregon officials from enforcing this unconstitutional provision of the law. The lawsuit is the first of its kind, challenging the residency requirement of a medical aid-in-dying law.

“The Oregon residency requirement is both discriminatory and profoundly unfair to dying patients at the most critical time of their life,” said Dr. Gideonse, the plaintiff. “I don’t have to ask dying patients for proof of residency to provide them with hospice care. There is no rational reason that I should have to ask dying patients for proof of residency to provide them with medical aid in dying, especially since 95% of Oregon patients who use medical aid in dying are enrolled in hospice.”

Dr. Gideonse works at Oregon Health & Sciences University in Portland; Kindred Hospice in the Salem and Portland metro areas as well as the broader Willamette Valley region; and Blue Mountain Hospital in John Day, Oregon. Within the past year, Dr.



Dr. Roger Kligler, plaintiff in *Kligler, et al. v. Healey, et al.*, testifying before the Massachusetts legislature.

Gideonse, who is licensed to practice medicine in Oregon but not in Washington, has treated at least 16 patients residing in Washington, where accessing medical aid in dying is often particularly difficult.

Compassion & Choices is also representing Dr. Roger Kligler in the Massachusetts case *Kligler, et al. v. Healey, et al.*, which will be heard and decided by the Massachusetts Supreme Judicial Court. Compassion & Choices will be arguing that medical aid in dying is not a crime under Massachusetts law and that even if it were prohibited by law, prosecuting doctors for assisting patients with medical aid in dying is unconstitutional. Oral argument has been set for March 9, 2022.

To learn more about Compassion & Choices’ legal advocacy work, visit CompassionAndChoices.org/legal-advocacy.

Fostering Relationships Yields Lasting Results

Compassion & Choices continues to maintain and strengthen our connections with like-minded organizations, producing incredible outcomes.

Last October, the NAACP passed an end-of-life care resolution. The resolution affirms the NAACP's commitment to ensuring its members are informed about the full range of end-of-life options. The resolution states, "The NAACP advocates that families educate themselves on all aspects of end-of-life planning, including advance healthcare directives, healthcare proxies, organ donation, wills, trusts, powers of attorney and end-of-life options such as hospice, palliative care and achieving a physician-assisted peaceful transition."

Compassion & Choices also received the Corporate Champion Award from the National Organization of Black Elected Legislative

Women (NOBEL Women). The award was in recognition of Compassion & Choices' leadership in end-of-life planning education. Our collaboration with NOBEL Women started with presenting at their annual conference and has flourished in the past few years into a resolution adoption about end-of-life planning and dementia.

As a part of our Staying Stronger Together webinar series, Ottamisiah "Missy" Moore, a Compassion & Choices African American Leadership Council member, led a powerful webinar about the importance of hospice and palliative care called *Making Your Wishes Known: Living Your Values by Planning Ahead*. She shared her personal story involving her son Demetrice, who received hospice support before his death in 2017. This experience, and her decades as a hospice nurse, informed her presentation. Find this and other



Compassion & Choices advocate Elaine Saunders talks about end-of-life planning.

webinars at CompassionAnd-Choices.org/webinar.

Another Compassion & Choices advocate, Elaine Saunders, was featured in a series of powerful videos about end-of-life planning. Saunders, a Washington, D.C., resident, shared the importance of having meaningful conversations with your loved ones about death. The video is part of our outreach to diverse audiences and elevates the voices of community leaders.



Signature Event Success!

On Oct. 6, 2021, Compassion & Choices hosted *Purpose, Power and Promise: A Virtual Celebration to Benefit Compassion & Choices*. Emcee Joél Simone Anthony and C&C President and CEO Kim Callinan led the program, which included Jason Gauden and storytellers Amanda Villegas, Isa Mendez and many more. Our second national virtual event reached nearly 1,300 registrants from all 50 states and raised over \$300,000! **View it on YouTube:** <https://candc.link/purpose>.

End-of-Life Care Inequities Summit Informs Agenda

Compassion & Choices hosted a one-day virtual summit on Nov. 4, 2021, featuring 14 experts who responded to research about disparities in end-of-life care and planning. Research based on demographic data including race, ethnicity, immigration status, sexual orientation and gender identity reveals tremendous barriers to palliative care, hospice and end-of-life planning access. Experts

included palliative care, hospice and primary care practitioners and advocates focused on addressing healthcare disparities, ending systemic racism and discrimination, and providing end-of-life support for LGBTQ+ communities. As the experts talked about the inequities within the communities they serve, participants, including Compassion & Choices senior leadership and staff, identified

promising policy changes to address the inequities.

The Summit conversations and ongoing collaboration will help us develop a federal policy agenda designed to further address inequities in end-of-life care and planning. Key partner organizations for the summit included NOBEL Women, Latinos for Healthcare Equity, VITAS Healthcare and SAGE.

Making a Difference in the Communities We Serve

Compassion & Choices' councils continue to transform the end-of-life options movement with innovative and visionary ideas. The Asian American, Native Hawaiian and Pacific Islander (AANHPI) Leadership Council proposed a plan to translate Compassion & Choices' end-of-life resources into multiple languages spoken in AANHPI communities.

The Healthcare Advisory Council delved into transformational medical outreach and continued to provide end-of-life resources to those in the healthcare space. Multiple members participated in the City of Hope End-of-Life Symposium held in December 2021. The symposium successfully trained providers in all aspects of end-of-life care, from different care options to funerals and burial practices.

Discussing Your Options With a Dementia Diagnosis

Compassion & Choices is maintaining the momentum around our efforts to transform the way people die with dementia. Every November is Alzheimer's Awareness Month, and last year Compassion & Choices held two webinars about dementia and voluntarily stopping eating and drinking (VSED) to educate the public about their options with a dementia diagnosis.

Dr. Timothy Quill, an expert on VSED, discussed the issues that arise in the context of choosing the option for those suffering from dementia. Our staff also walked participants through the Dementia Values and Priorities Tool, which helps individuals identify the level of care they want in the face of advancing disease and provides an addendum to a healthcare directive.

Five Questions for Rev. Dr. Paul Smith

From participating in the Selma to Montgomery marches with Rev. Dr. Martin Luther King Jr., to creating multiracial churches around the nation, to being a pioneer in the end-of-life autonomy movement — Rev. Dr. Paul Smith, also a member of Compassion & Choices' African American Leadership Council, seeks to transform humanity into "a beloved community."

Q: You have been active in the civil rights movement since its earliest days. We are seeing that this nation still has a long way to go in terms of inclusivity and equality. Is it surprising to you that progress seems to be moving so slowly?

A: I'm surprised that it has taken so long to identify what the real issues are. Division in terms of race is wider than we ever expected, and that's what this is all about. White fragility and white fear are root causes of systemic racism in America, and will be until we address them. So I'm not surprised at all about any of it. I'm disappointed, but not surprised.

Q: What do you think people are not understanding that keeps them stuck in prejudice?

A: They understand, but they're afraid. I think particularly some white people are afraid that what they did to us, we're going to do to them. There's no evidence that we're seeking revenge. Charleston is a good example of that. Nine were killed, but Black people talked about forgiveness. Too many Americans don't want to face white fragility, white suppression, white superiority, white privilege, all of that. There's denial about it. So now critical race theory is an issue? To hide the whole fact of systemic racism in America is just appalling to me.



top: Rev. Dr. Paul Smith preaching at First Presbyterian Church, Brooklyn, New York.



middle: Rev. Dr. Smith speaking at a press conference in support of a medical aid-in-dying bill in Maryland.

bottom: Rev. Dr. Smith with Barbara Coombs Lee, Compassion & Choices president emerita/senior adviser.



five questions

Q: Your history with religious study and faith leadership is long as well, with a nearly 50-year pastorate. When did you know that would be your path?

A: Probably early on. As a child, I spent a lot of time on my grandmother's porch. I saw how she would relate to people and thought maybe I could do that as well. Then I ended up being able to speak from the pulpit of my home church in South Bend, Indiana, and went on from there. I decided it might be a good calling, since I was able to really talk to people and I had some understanding of scripture — so that's how I got into it.

Q: In your book *Facing Death: The Deep Calling to the Deep*, you discuss your role in helping others through the dying process, including tennis legend and fellow civil-rights activist Arthur Ashe. How did you become involved in end-of-life issues and eventually with Compassion & Choices?

A: I had people who were listening to me, particularly as a pastor, who were talking a lot about grief. So I wanted to explore that a bit deeper. The real change came when I met Barbara Coombs Lee. Once I met Barbara, I realized that not only did I have a gift, but I had information. So I was able to translate my personal experiences with the experiences of other people in my congregation. Barbara was the link to learning and having more information about what I was doing intuitively and from my pastoral studies, which was very different.

Q: Divinity, end-of-life autonomy, racial equality — do you see any connection between these facets of your life's work?

A: Oh, absolutely. I think because of the pandemic — which has wreaked havoc upon our psyches, creating unprecedented racial, social and political conflicts — people, and particularly African Americans, took to the fact of death. We talk about it in our songs and gospel music and so forth, but the pandemic makes it more of a reality. We're going to die, so we need to get ready for that. The NAACP passing their resolution is a real opening, and kudos to Compassion & Choices for making that happen, because we need to talk about death, and we need to take care of our business. African Americans have had a difficult time doing wills, establishing power of attorney, using hospice — all of that was sort of foreign, but we're much more open to it now.

All of my life I have believed in God, and I will not abandon that faith when death comes creeping in my room. I believe that wherever God is is where I want to be. So whether I'm dead or whether I'm alive, as long as I'm with God, it doesn't make any difference to me. My entire ministry has been creating the beloved communities where people may be heard, helped and healed. That is why I joined Barbara Coombs Lee and Compassion & Choices in creating beloved communities where we believe my mentor Dr. Howard Thurman's mantra, "Death is not the worst thing to happen to us." It's been quite freeing for me to talk openly about the fact of death, since death is a fact. We need to face it, not fear it.



Read more in *Building Beloved Communities: The Life and Work of Rev. Dr. Paul Smith* by Dr. Hildi Hendrickson.



Going the Distance

Marcia Vincent, donor since 1990, with daughters Bambi, Karen, Shari and Jamie.

Marcia Vincent, a retired classical guitarist, artist and mother of four daughters, has been comfortable talking about death with her family since reading various books about end-of-life care and Dr. Elisabeth Kübler-Ross' *Stages of Grief* in the 1980s. She now includes Barbara Coombs Lee's *Finish Strong: Putting Your Priorities First at Life's End* on her required reading list and wrote a review of the book for her local newspaper.

Early on, Marcia's support was driven by her belief in the ideal of end-of-life autonomy. In the years since, her connection to the mission of expanding end-of-life options has become much more personal. Both her mother and her husband, David,

died in states where medical aid in dying is not authorized. Marcia is committed to helping authorize her home state of Arizona.

"My four daughters, and now my grandchildren, have grown up having these important conversations about death and end-of-life wishes," says Marcia. "We are proud to make our annual contributions to support the critical work of Compassion & Choices. In fact, I received a gift in honor of my birthday from one of my granddaughters that brought tears of gratitude to my eyes. I want to see progress continue for my grandchildren and generations to come. Please join my family and me in supporting their work with an annual contribution."

Visit CompassionAndChoices.org/donate

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