

# compassion & choices

MAGAZINE  
SUMMER 2022

Positive Voices for  
Those Touched by  
Terminal Illness  
pg. 4

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Accessing Medical  
Aid-in-Dying Laws  
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The Gracious Role  
of Death Doulas  
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## FIVE QUESTIONS FOR Hospice Nurse Penny

Penny Hawkins-Smith, RN, has created a viral platform for normalizing conversations about death.

# A Simple Act of Care

Protect what you love by  
creating your will today.



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

## What is FreeWill?

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

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



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

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

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# No Instruction Manual for Dying

Dying is such a personal experience and, for many, one fraught with anxiety about impending pain and suffering, not to mention the pain of those we leave behind. Unfortunately, dying doesn't come with an instruction manual. Even for those of us who take time to fully prepare, there still isn't a handbook for what to expect and how to navigate decisions, care and emotions when we or a loved one is actively dying. This work can be hard and taxing, summoning tears and heartache and demanding all the courage we can muster. Yet every month, every year, I see the fruits of our efforts. These efforts grace more lives in more places in a line of progress that shows no sign of stopping.

Five years ago, I never could have imagined Oregon would remove the residency requirement to allow terminally ill Americans from other states to access Oregon's Death With Dignity Act without having to establish residency. Or that the death doula movement, which I joined in 2020 when I became a certified end-of-life doula, would emerge as a powerful support to dying patients. Or that we would win a court case in Idaho that required the state to undo the harm it had caused around an unconstitutional advance directive law.

This progress is heartwarming. Yet, our opposition is relentless. As is evidenced by their recent lawsuit (Christain Medical and Dental Associations v. Bonta) challenging the constitutionality of the recently amended California End of Life Option Act. On May 18, 2022, our litigation team sprung into action, filing a motion to intervene on behalf of Andrew Flack (featured on page 4), and three others. We stand ready for another long drawn out court battle.

Both our progress and the strength necessary to defend our gains are made possible with and because of your support.

With heartfelt gratitude for you,



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## In the Media

### *NPR*

#### [Physician-Assisted Death in Oregon Is No Longer Limited to Just State Residents](#)

In a settlement filed in U.S. District Court on March 28, the Oregon Health Authority, Oregon Medical Board and Multnomah County district attorney agreed to stop enforcing the residency requirement for medical aid in dying, allowing nonresidents to access this option in Oregon. The lawsuit that prompted this settlement is the first in the nation to challenge the residency requirement of a medical aid-in-dying law. The settlement also requires Oregon officials to initiate a legislative request to permanently remove the residency language from the law. "This requirement was both discriminatory and profoundly unfair to dying patients at the most critical time of their life," said Compassion & Choices Chief Legal Advocacy Officer Kevin Díaz. The settlement may have repercussions in eight other states and Washington, D.C., that also have medical aid-in-dying laws with residency requirements (Washington, California, Colorado, Hawai'i, Maine, New Jersey, New Mexico and Vermont).

### *The Washington Post*

#### [Opinion: Medical Aid in Dying Is for Preventing a Hideous Death, Not for Truncating an Unhappy Life](#)

This is the second of two back-to-back columns by Pulitzer Prize-winning Washington Post columnist George F. Will endorsing medical aid-in-dying laws. The column also details new policies enacted by California and New Mexico in 2021 that eliminate unnecessary hurdles for terminally ill adults to access this option. Will quotes Compassion & Choices President and CEO Kim Callinan, who explained that medical aid in dying "creates a shift within our end-of-life care system from a paternalistic model to one that is resoundingly patient-driven."

### *Univision*

#### [Aquí y Ahora \(Here and Now\)](#)

Univision television network's primetime news show *Aquí y Ahora* aired an episode discussing medical aid-in-dying laws in the United States. Compassion & Choices Latino Leadership Council members Nilsa Centeno and Isa Méndez were interviewed about their support for legalizing this end-of-life care option. Centeno recounted the agony of her son, Miguel, who died from brain cancer and could not access medical aid in dying. "All he did was complain about how much it hurt ... to be honest, that wasn't living." Méndez, who is currently facing her own terminal diagnosis, followed up to say, "Being bedridden, tied to five machines, the only thing left is suffering, and that's not quality of life."

### *The Not Old - Better Show*

#### [How Dementia Is Impacting Black America](#)

As part of their Black History month series, *The Not Old - Better Show* podcast invited Compassion & Choices National Director of Community Engagement Brandi Alexander to discuss inequities in dementia care in Black communities and share tools that everyone can use to prepare for a potential dementia diagnosis. Alexander said that African American communities "tend to have statistically higher rates [of dementia]" due to social determinants of health that are affected by historical and systemic racism, and she encouraged everyone to empower themselves with information about end-of-life options and "pick up tools on how to communicate with their families and their medical teams so that they have more understanding about what it is that they're facing and the options available to them."

# Living Out His Own Choices

**Californian Andrew Flack is a teacher, hockey player and advocate living with stage IV cancer — and he is speaking out.**

“I want to be alive.” Andrew’s simple sentence really does say it all. The 34-year-old with kind eyes, a generous laugh and a ceaseless smile is passionate about teaching, watching hockey and rollerblading around Oceanside in the beautiful California weather. He wants to spend more time at the beach, play video games, and be with friends, family and his roommate’s dog, Jaxson.

In early 2017, when Andrew finished his master’s degree at San Diego State University while working full-time as a special education teacher, he began feeling fatigued. He assumed his symptoms would abate as his schedule settled down. They didn’t.

His lack of energy progressed, and he was losing weight and nauseated or vomiting daily. Andrew had survived stage IV kidney cancer as a child. After years of treatments and surgeries, he was cancer-free. But in October 2017, a colonoscopy revealed stage III adenocarcinoma of the colon/rectum. He was 29 years old.

Andrew’s intensive treatment regimen included radiation, chemotherapy, surgery and finally eight cycles of intravenous chemo. “I want to be glowing green as I walk out of here,” he told his doctor. He completed treatments in July 2018. Doctors were fairly confident that he was out of the woods, but three months later, a minor cancer-related operation revealed that the cancer had returned. Andrew endured more radiation, more chemo, more surgery.

Andrew Flack at his home in Oceanside, California.

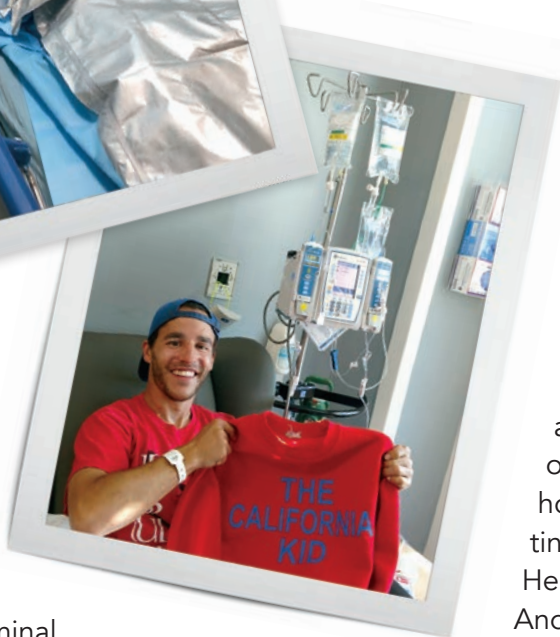




from left to right:

Andrew getting a pre-op hug from his mom.

Andrew holds a gift from his grandfather following a chemotherapy infusion July 2018.



In February 2019, Andrew underwent another major surgery and learned the cancer had spread significantly throughout his pelvic region. "We won't be able to cure this cancer," the doctor said. Andrew and his family knew then that he was terminal.

Throughout the next couple of years, Andrew continued treatments and tried to enjoy every day. He traveled by train from Seattle to Los Angeles with his mom. He spent entire days fishing with his family on Lake Geneva in Wisconsin. He saw a ballgame at Wrigley Field. He prepared to return to teaching and "crushed many pizzas" with family and old friends.

His old hockey league teammates supported him with a fundraiser that got Andrew back on the ice for the first time in two years. His gratitude for these relationships and this time is palpable.

In December 2020, Andrew returned to the hospital with a severe kidney infection. His oncologist explained that such hospital stints would likely continue as the disease progressed. He took the time to discuss with Andrew the risks and complications that lay ahead. He and another

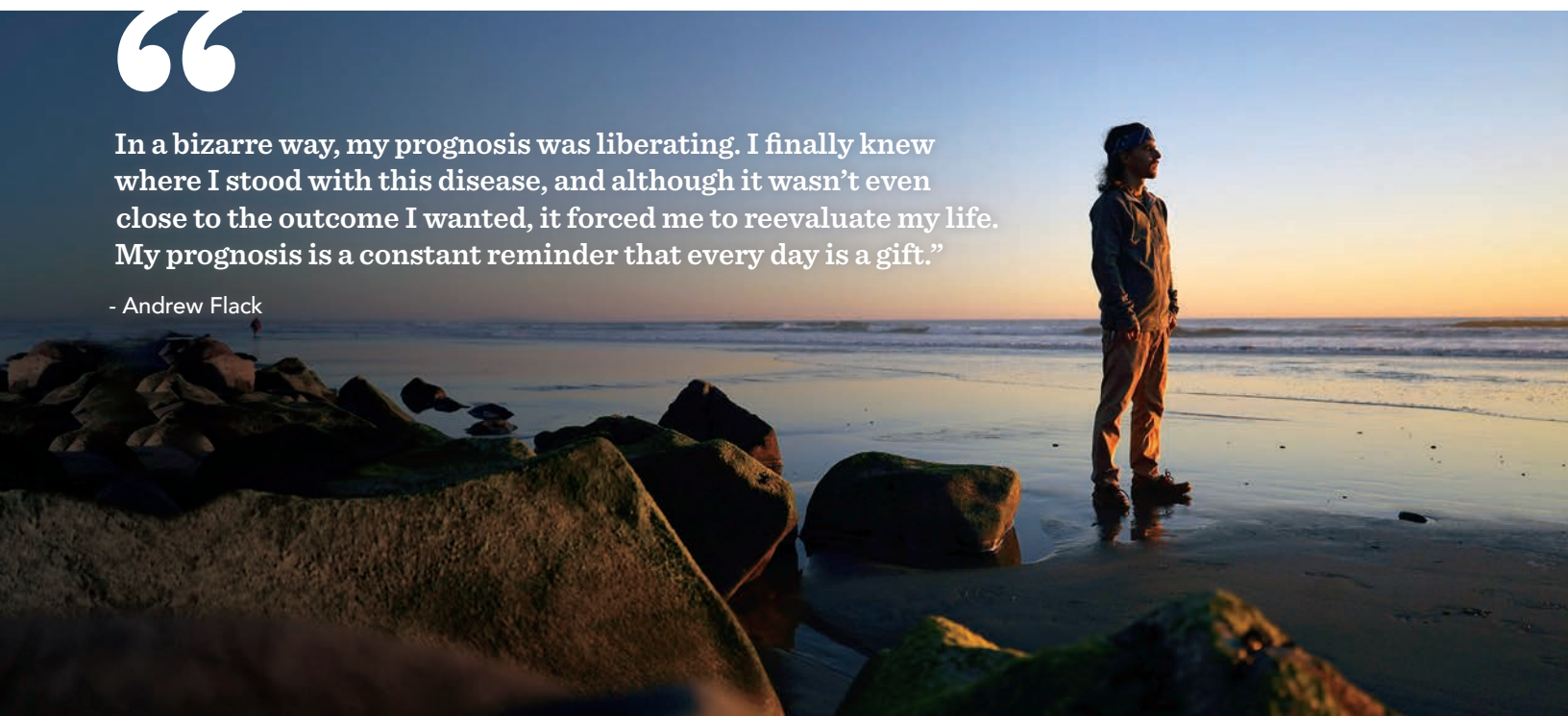
physician agreed that Andrew likely had six months or less left to live.

Andrew shared that one of his fears was that even as he was reaching the point where he was ready to die, his body would hold on and cause a lot of suffering and discomfort. Andrew's oncologist told him about

“

**In a bizarre way, my prognosis was liberating. I finally knew where I stood with this disease, and although it wasn't even close to the outcome I wanted, it forced me to reevaluate my life. My prognosis is a constant reminder that every day is a gift.”**

- Andrew Flack





California's End of Life Option Act, which authorizes mentally capable, terminally ill adults with less than six months to live to request a prescription for a peaceful death.

Andrew had never heard of medical aid in dying, and he felt scared, because learning about it meant facing the reality of his terminal illness. But he also felt a sense of relief knowing that he had this option.

### ... he also felt a sense of relief knowing that he had this option.

Andrew began the process of acquiring a prescription and speaking to his parents and three sisters about his decision. Thankfully, they

were as supportive of him as they had always been. "Having this option, I have the ability to transition from this life surrounded by the people I love the most. That's something I think about. I'll be able to be with these people and feel comfortable and secure and loved," Andrew said.

As Andrew learned more about California's medical aid-in-dying law, he discovered that finding information about it isn't easy — so he and his friend Hasban Shaikh started a podcast to provide a positive voice for others experiencing a terminal illness themselves or with a loved one.

"I like the idea of spending my final moments under the stars," Andrew said. "Luckily, from where I live



Andrew with his roommate's dog, Jaxson.

now, I've got a great view of the stars, and I can hear the ocean. I also figure I have to have a dog with me, so Jaxson, my roommate's dog, has agreed to support me at that time. I'd like to have him at my side and be surrounded by loved ones. That sounds fine to me."

Even at this stage, Andrew is considering how to get back into the classroom to finish out the school year with his students and how he can support his family while they support him. As he considers his future, Andrew seems at peace with his choices and grateful for this life he is living, moment by moment.

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To hear Kim Callinan, Dan Diaz, California State Senator Susan Talamantes Eggman and other powerful voices on Andrew Flack's Death with Dignity Podcast, visit [DeathWithDignityPodcast.com](https://DeathWithDignityPodcast.com).



# What Does Meaningful Access Mean?

**Once we pass a medical aid-in-dying law, our work continues to make sure it's within reach for the people who need it.**

**F**or nearly 30 years, a growing number of states have been authorizing — that is, making explicitly legal — medical aid in dying. But some patients still have difficulty actually using the option. Factors such as prohibitive rules, insufficient information and lack of participating qualified healthcare providers present new challenges once the excitement of a legislative victory has settled.



California reduced its End of Life Option Act's mandatory waiting period from 15 days to 48 hours. From the law's passage in 2016 until then, fully one-third of California residents seeking a prescription died before completing the process. "By the time the doctors told my husband, Chris Davis, that he would die from bladder cancer, he had less than a week to live," said Amanda Villegas, a powerful advocate in our successful campaign to improve California's law. "So

"Of all the barriers to access, the waiting period is really the biggest," said Compassion & Choices National Director of Care Advocacy Samantha Trad about the typical 15-day waiting period for a prescription, a requirement under the original aid-in-dying law in Oregon and most others since. With many terminal people too far along in their illness to survive the duration of the mandatory waiting period, much of our focus has been to address this problematic hold-up by changing guidelines for new laws and introducing "improvement" bills to modify existing ones. The results to date are encouraging.

Oregon amended its pioneering law in 2019 to allow doctors to waive at least one of the required waiting periods when a patient's death is imminent. In 2021,

shortening the 15-day waiting period for medical aid in dying to 48 hours could have made the difference between him dying peacefully and dying in agony."

Vermont enacted a new law that will address barriers to accessing the state's aid-in-dying law, including eliminating the 48 hour delay between the terminally ill person's last oral request and when the physician can write the prescription, protecting healthcare workers who act in good faith, and establishing that patients can use telemedicine when requesting the medication.

New Mexico's law, passed in 2021, was the first with a single 48-hour waiting period between when

the provider writes the prescription and when the patient fills it, and even that can be waived if the person is likely to die before then. Additional provisions of New Mexico's law seek to resolve what have historically been other accessibility barriers. These changes, among others, include requiring a single written request; allowing advanced practice registered nurses and physician assistants to serve as either the prescribing or consulting clinician (as long as the other clinician is a physician) to alleviate issues of doctor scarcity; and requiring healthcare providers who are unable or unwilling to carry out an individual's request to inform the individual of their objection and refer them to either a supportive provider or an individual or entity that is able to assist the individual in seeking medical aid in dying. Several of these changes have caught on in other states where legislation to authorize or amend medical aid in dying has been introduced.

"Of course every state is different," explained Trad, "but a lot of our work is still talking about the end of life in general, both with medical providers as well as the public, beyond letting them know about the law. Outreach to underserved and underrepresented communities is critical, because it is often much more difficult to access the law in these communities." Education, in terms of making sure not only that all people in authorized states know they have the option but that physicians understand how it works and that their patients want it, is also crucial to increasing access.

Beyond our efforts to remove barriers and raise awareness, personal advocacy still reigns. "The number one thing we want everybody to know is to have the conversation with your doctor." Trad said. "This is still the best way to help with access: talking about it, asking questions, interviewing hospices, making sure they know how important it is to you that you can actually access this option."

## Beyond our efforts to remove barriers and raise awareness, personal advocacy still reigns.



### HELP US HELP OTHERS!

Policies at individual facilities vary widely regardless of legal guidelines. Ask questions and share your experiences so we can advise people about places to seek out or avoid.

"We've heard awful stories," said Compassion & Choices National Director of Care Advocacy Samantha Trad, "such as hospices that won't reduce their waiting period because they get paid per day."

Report any friendly or not-so-friendly practices to [mwhitaker@CompassionAndChoices.org](mailto:mwhitaker@CompassionAndChoices.org).



# Death Companions

**The long tradition of death doulas moves into the forefront.**

**I**n March of 2021, Riley Keough announced she had become a death doula. The actor (and granddaughter of Elvis Presley) began her training after the sudden loss of her brother, Benjamin. For many in the United States, this was the first time they were exposed to the concept of death doulas.

Typing “what is a death doula?” into Google produces more than 1.6 million results ready for viewing in under a second. Alternatively, “end-of-life doula,” “end-of-life guide,” “death midwife” and many other variations of the term produce hundreds of thousands of results.

These titles all represent similar care: the holistic, nonmedical support of a dying person and their family. Often a community role, this work is rooted in education and empowerment. A complement to medicine and spiritual or faith leaders, death doulas serve as part of a comprehensive and knowledgeable support team. Some volunteer their services, while others have turned this into a full-time career.

Work they do for clients may include sitting bedside in the final hours of life, providing spiritual and emotional support to loved ones, designing legacy projects, and providing family members with logistical or paperwork assistance. All doulas, however,

will tell you that planning and open dialogue are the most important parts of their work.

Going with Grace is an end-of-life education organization created by death doula and attorney Alua Arthur. Program Director Tracey Walker says that end-of-life planning conversations with loved ones give everyone space to process their emotions early and often. It also ensures that no one has to make a last-minute decision in an emergency.

“There can be so much guilt associated with the death of a loved one, when decisions need to be made and we are not sure of what would have been wanted. It is heartbreaking to see time taken up with fighting, anger, guilt or ignorance, knowing it could have been avoided,” Tracey says.

Rhyena Halpern is a board-certified health coach and end-of-life doula who provides what she calls “third-act coaching” to clients entering retirement and “last-act doula” support for folks reaching their final years. Her philosophy of care was shaped by her breadth of education, along with the experience she had supporting her mother through the end of life.

**“Grief is not mandatory. Grief is love.”**

“The real gift was after she died, because when I lost other loved ones, I was in real grief and sorrow. I had this experience of incredible love after my mom died. And that was when I realized if you are really ready for death, you give your people an amazing gift by lifting their pain and letting them feel tremendous love. I miss my mom, but I have only felt a deep and sweet love since she transitioned. Grief is not mandatory. Grief is love,” Rhyena said.

Just a few generations ago, American communities were far better prepared to support themselves when death approached. Family members sat vigil with their loved ones while neighbors took care of



top: Tracey Walker, program director for Going with Grace.



center: Alua Arthur, attorney and founder of Going with Grace.



left: Rhyena Halpern, board-certified health coach.

left: Diane Button of Bay Area End-of-Life Doula Alliance with client Marilyn Brandwein.



right: Francesca Arnoldy, author of *Cultivating the Doula Heart*.



grandchildren, and faith leaders or healers prepared the funeral. But 19th century progress in medicine, commerce and education meant lots of families were soon separated by several states instead of a few miles. And these practices, which served as a form of group grief, became harder to complete.

In the hopes of reconnecting to those traditions, many are now seeking doulas for their family members and comprehensive death education for themselves. Since the mid 2010s, the number of death education programs has skyrocketed, and the list of available practitioners can be overwhelmingly long.

Francesca Arnoldy is the program director for the End-of-Life Doula Certification program at the University of Vermont's (UVM) Larner School of Medicine. She is also the author of *Cultivating the Doula Heart: Essentials of Compassionate Care*, a resource for family members and practitioners alike. Francesca recommends families seek a practitioner by searching doula registries, such as the one found on the National End of Life Doula Alliance website.

Once you find someone local who offers virtual services, Francesca suggests making sure they offer free consultations. This gives you the chance to ask directly about their training, philosophy of support, communication styles and availability without any commitments.

"[Doulas] are committed to best care, so that means we should be taking time to find out if we are a good fit through consultations. And if it's not the right match, we need to have the humility and ability to

connect folks to others in our community," she said. UVM graduate Diane Button lives in San Francisco and works with the Bay Area End-of-Life Doula Alliance, a group of practitioners with various skill sets and areas of expertise.

"As a collective, we cover for each other when needed, we work together when sitting vigil in shifts, we draw on our strengths to best serve our clients, and we take care of each other as well," she said. "Together, we are able to cover all of our clients' needs. We also maintain a thorough directory of services and resources that we can rely on if a client has a need that we cannot meet as doulas."

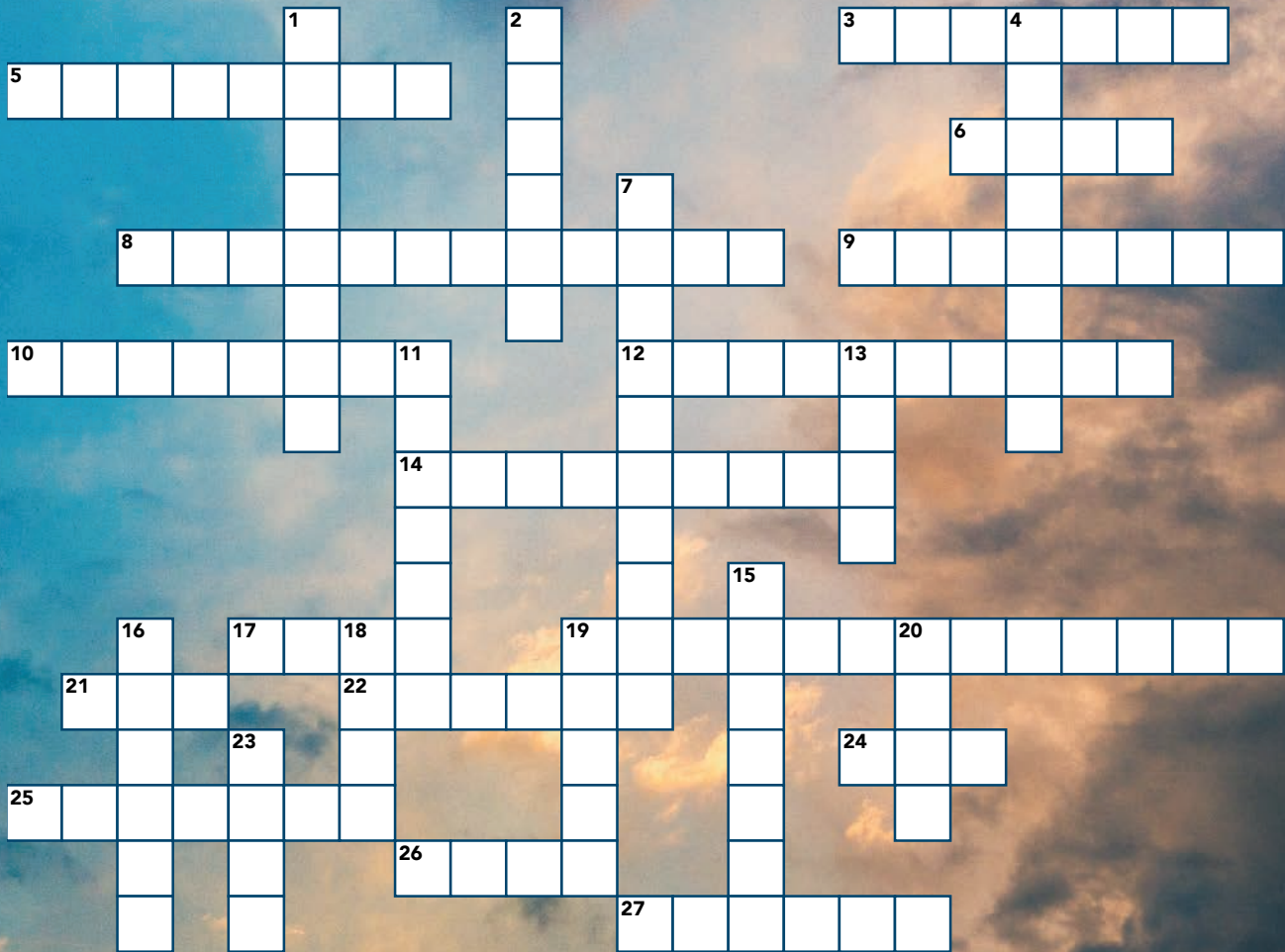
As awareness of end-of-life doulas expands and more communities experience their support, practitioners like Tracey are looking forward to what comes next.

"At Going with Grace, we would love to be out of a job someday," she said. "That would mean that death care and death doulas would be such an accepted concept, that hopefully it would return to the community care it used to be; that discussions about death and dying wouldn't be taboo, but rather something people would discuss easily."

Francesca is similarly excited for the future of her profession. "We are re-embracing what it means to be mortal and interdependent. It doesn't matter where people are coming from — I am seeing folks across the globe who are finding the courage to acknowledge their own impermanence and begin their own preparation and planning. I feel so hopeful."

## crossword puzzle

Welcome to our inaugural crossword puzzle! The clues below are all related to the theme of *Finish Strong*.



### ACROSS

3. "Be Here Now" author
5. Late end-of-life champion Maynard
6. Leave out
8. Barbara Coombs Lee book
9. Getting ready for
10. Fighting for a cause
12. Important things
14. Civil rights veteran and minister Rev. Dr.
17. Hospital's Intensive \_\_\_\_\_ Unit
19. Civil and workers' rights icon
21. \_\_\_\_\_ & Order
22. The Beaver State
24. "What's up, \_\_\_\_\_?"
25. Impart knowledge to
26. R&B icon Turner
27. Number of jurisdictions where medical aid in dying is authorized

### DOWN

1. Compassion & Choices President and CEO Kim
2. Parity
4. Disease with progressive memory loss
7. \_\_\_\_\_ & Choices
11. Give strength to
13. Journalist and end-of-life advocate Diane
15. Care for people nearing the end of life
16. Morals, for example
18. Titanic's movie survivor
19. Death and dying guide
20. C&C signature song "This is Your \_\_\_\_\_"
23. "Here Awhile" star Anna

Find the answers on page 24

## Forging the Path Ahead

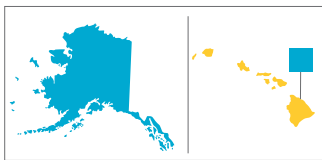
Virtual advocacy has not slowed the progress of the end-of-life options movement.

### COLORADO

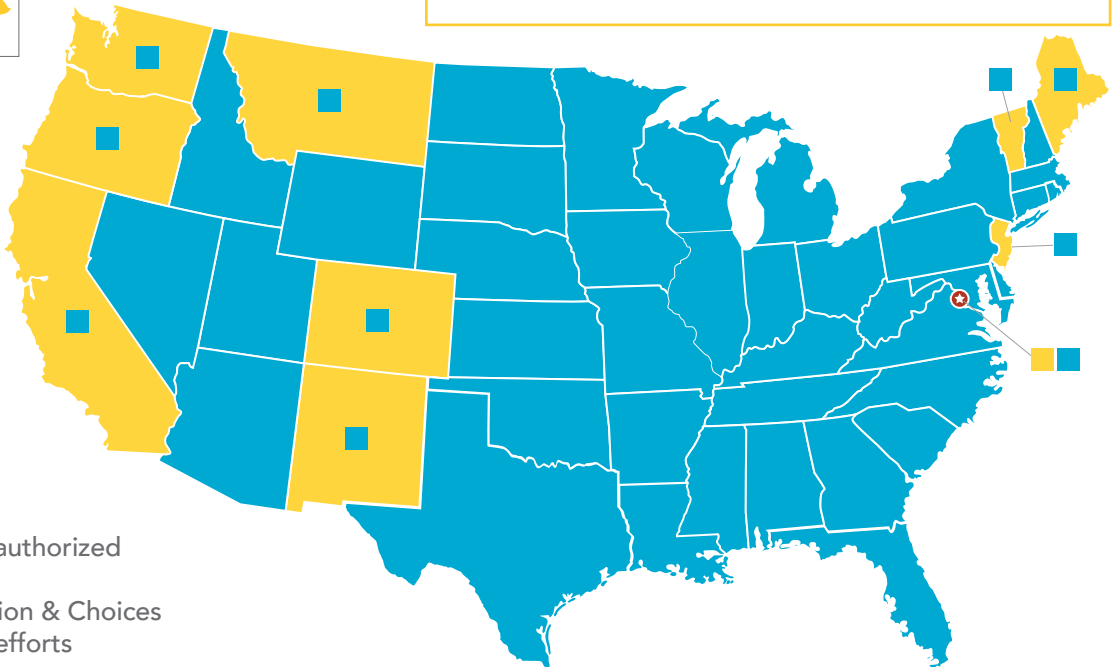
This year's report from the Colorado Department of Public Health & Environment shows that five years after implementation of the state's medical aid-in-dying law, this compassionate medical practice continues to offer peace to qualified terminally ill Coloradans. A total of 583 terminally ill residents have filled a prescription for aid-in-dying medication since the law's enactment, and nearly 9 out of 10 of those who accessed the law died at home under hospice care. Our state team continues to work with providers and healthcare systems to ensure that, regardless of ZIP code, every qualified Coloradan may access this compassionate option.

### CONNECTICUT

The first bill that Connecticut's Public Health Committee advanced in 2022 was medical aid-in-dying legislation in March, one week after an 11-hour hearing featuring over 50 volunteers for Compassion & Choices Action Network, who provided riveting testimony. Unfortunately, on April 11 the Judiciary Committee voted not to advance the bill on a 5-4 vote. "While medical aid in dying has advanced further this year than ever before, today's vote will mean immeasurable suffering for terminally ill people who shared their stories with lawmakers, and for whom another legislative session will come too late," said Compassion & Choices Connecticut Campaign Director Tim Appleton.



To learn more about what's happening in your state, visit [CandC.org/in-your-state](https://CandC.org/in-your-state).



- Medical aid in dying authorized
- States with Compassion & Choices organized volunteer efforts





left: Longtime Connecticut advocate Kim Hoffman died in January from metastatic cancer with needless suffering because she didn't have the option of medical aid in dying.



right: Massachusetts advocate Molly Walsh, whose 91-year-old physician father, Dr. Robert McConnell, died in agony from heart disease because he didn't have option of medical aid in dying.

## DELAWARE

The Delaware House Health & Human Development Committee voted in January to release the Ron Silverio/Heather Block Delaware End of Life Options Act to the House floor. During the hearing, Medical Society of Delaware President-Elect Dr. Robert Varipapa announced the society had withdrawn its opposition to the bill. Compassion & Choices Action Network volunteer Brenda Ross tearfully testified: "My husband ... died slowly and painfully from metastatic prostate cancer. ... If medical aid in dying were an option, he would have chosen it. ... We would have shared his favorite meal, listened to his favorite music ... I would have kissed him goodnight, and he would have fallen asleep."

## HAWAI'I

Despite having passed the House, Senate and six committees, a bill to ensure that all qualified residents may access the Our Care Our Choice Act did not make it to the governor's desk for his signature this year. Our advocates will continue the work to enact this important legislation next year. The bill would strengthen the existing law by adding advanced practice nurse practitioners and physician assistants to the list of providers who may fill a prescription for aid-in-dying medication. It would also allow the

prescribing provider to waive the waiting period if the patient is unlikely to survive it, preventing needless suffering by the sickest individuals.

## ILLINOIS

The Illinois team continues its medical aid-in-dying advocacy this summer, focusing on outreach to state legislators while expanding the volunteer and supporter base. In March, we hosted an event with C&C President Emerita Barbara Coombs Lee on the history of our movement and where it is headed. We had an unprecedented turnout and connected with new volunteers. In April, we partnered with Howard Brown Health for a webinar on end-of-life planning in the LGBTQ+ community. As proud members of the Illinois End-of-Life Options Coalition, alongside ACLU of Illinois and Final Options Illinois, our action teams are building a strong foundation for the future.

## MASSACHUSETTS

For the second straight year, the Joint Committee on Public Health advanced the Massachusetts End of Life Options Act on March 24. "I thank the public health committee for doing the right thing for terminally ill people in Massachusetts by advancing this bill," said Framingham resident Molly Walsh, whose 91-year-old physician father, Dr. Robert

## advocacy in action

McConnell, died in agony from heart disease. “I urge the Legislature to continue to move the bill forward quickly and pass it this session. There is no good reason that people in Massachusetts shouldn’t have the same peaceful dying option that our neighbors do in Maine and Vermont.”

### MINNESOTA

Our dedicated Minnesota team continues its year-round work to advance the Minnesota End-of-Life Options Act. Though the bills did not pass this session, the work continued with April’s *Week at the Capitol*, which brought together powerful supporters sharing their voices. In May, Twin Cities Public Television aired the documentary *When My Time Comes*, which chronicles journalist Diane Rehm’s journey to understand medical aid in dying. The statewide airing of this moving film was an incredible opportunity to bring the issue of end-of-life options to new audiences. This summer, advocates are connecting with House and Senate candidates to determine where they stand on medical aid in dying.

### NEVADA

The Compassion & Choices Nevada Action Network team is preparing for another successful campaign, anticipating lawmakers will file a medical aid-in-dying bill for the 2023 legislative session. We continue to build relationships with community and labor groups and organizations that support medical aid in dying. In addition, our team continues to hold coalition meetings to identify opportunities to add medical aid-in-dying questions to endorsement questionnaires of other groups. Our volunteers continue to plan statewide phone banking parties and community events to reach out to all communities throughout the Silver State.

### NEW MEXICO

Our New Mexico access and implementation campaign is out in full force, holding a series of clinician trainings throughout the state. Our organizer moderated a panel discussion and keynote speech to more

than 400 social workers during the National Association of Social Workers New Mexico conference in March in a session called *New Mexico’s New Law and the Role of Social Work in Practice & Advocacy*. Our volunteers also held their first in-person tabling event in nearly two years at the New Mexico Academy of Family Physicians mid-winter Conference, where we distributed information about the Elizabeth Whitefield End of Life Options Act in English and Spanish to about 400 attendees.

### VERMONT

Compassion & Choices and Patient Choices Vermont worked to pass legislation, S. 74, to improve access to medical aid in dying by: 1) allowing patients to use telemedicine to make their two oral requests, 2) providing legal immunity for pharmacists and 3) eliminating the 48-hour waiting period to get a prescription. “Those 48 hours were a nightmare. Just the sheer emotional toll it took on my mother was so painful to watch,” said Duncan Allen-Burns, whose mom, Dee Allen, used medical aid in dying to end her suffering from degenerative neurological disease. Republican Gov. Phil Scott signed S. 74 into law on April 27.

### WASHINGTON

Alongside End of Life Washington, our team worked tirelessly with storytellers and volunteers to advance ESHB 1141, a bipartisan bill improving the state’s Death with Dignity Act. It passed the House chamber in January on a vote of 58-37. It then moved to the Senate Health and Long Term Care Committee in February, where it stopped. Washingtonians who live in medically underserved areas, and those whose illnesses progress too quickly to survive the law’s 15-day waiting period, are most impacted by the failure to move this legislation. The team will continue the fight to expand and improve options across the Evergreen State.

# Historic Settlement Enables Nonresidents to Access Medical Aid in Dying in Oregon

In late March, Compassion & Choices reached historic settlement on behalf of an Oregon physician in a first-of-its kind federal lawsuit asserting the residency requirement of the nation's very first medical aid-in-dying law violates the U.S. Constitution's guarantee of equal treatment.

The lawsuit was the first in the nation to challenge the residency requirement of a medical aid-in-dying law. The settlement may have repercussions in eight other states and Washington, D.C., where medical aid-in-dying laws also have residency requirements: Washington, California, Colorado, Hawai'i, Maine, New Jersey, New Mexico and Vermont.

More than 300 websites picked up the story, including ABC News, the Associated Press, CNN.com, Los Angeles Times, National Public Radio, NBC News, The New York Times, The Washington Post, and U.S. News & World Report.

The settlement requires Oregon officials to: 1) issue directives halting enforcement of the unconstitutional residency provision of Oregon's 1994 Death with Dignity Act and 2) initiate a legislative request to permanently remove the residency language from the law.

The physician plaintiff, Dr. Nicholas Gideonse, works at Oregon Health & Science 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. It is typical for Dr. Gideonse to have an active panel of more than 100 patients receiving end-of-life care, including palliative care, when appropriate.



Dr. Nicholas Gideonse.

"I really feel very, very good about this resolution," Dr. Gideonse told The New York Times, saying he was "pleasantly surprised that it occurred so quickly" after the lawsuit was filed five months earlier.

"The residency restriction is a barrier to accessing medical aid in dying for nearly all dying people who live in a jurisdiction where aid in dying is not yet authorized," noted Compassion & Choices Chief Advocacy Officer Kevin Díaz. "A significant number of terminally ill people residing in states where medical aid in dying is authorized have also been adversely impacted by these restrictions, as many receive their regular medical care across state lines. As a result of this settlement, nonresidents may now obtain medical aid in dying in Oregon. However, due to the newness of this change, as well as a variety of other legal considerations, Compassion & Choices recommends proceeding with care."

For more information, visit [CandC.org/legal-advocacy/residency-restrictions](https://CandC.org/legal-advocacy/residency-restrictions).

# Pregnancy Exclusions in the United States

In January 2022, the Compassion & Choices litigation team reached a settlement in *Almerico et al v. Denney et al*. This case concerns the pregnancy exclusion in Idaho’s advance directive law, which made an individual’s advance directive inapplicable if they were pregnant. The settlement preserves the landmark decision from April 2021 that found Idaho’s interpretation of state law unconstitutional.

Pregnancy exclusions are provisions in living-will or advance-directive laws that invalidate an individual’s advance directive if they are pregnant. Advance directives are written documents that detail the end-of-life treatment you would or would not want if you are terminally ill or suffering a life-threatening medical event, and are unable to make or communicate medical treatment decisions yourself.

The ability to refuse life-sustaining treatment is constitutionally protected and does not hinge on one’s pregnancy status. Everyone, regardless of their pregnancy status, should be able to direct the care they would or would not want at the end of life.

More than 30 states have advance directive laws containing a pregnancy exclusion. Nine states invalidate a pregnant individual’s advance directive, regardless of whether or not the fetus can survive. While many advance directive laws contain pregnancy exclusions, some states are actively trying to remove the provision from their law books. In 2021, Colorado passed SB 193, which removed the pregnancy exclusion from its advance directive law.

As outlined under the Idaho settlement, the state of Idaho revised its advance directive template to reflect that individuals can choose whether or not

pregnancy should have an impact on their advance directive. They sent notice of the change to over 40,000 people with a registered directive, as well as notice of the change to hospitals and medical and legal regulatory bodies.

Compassion & Choices’ legal team is dedicated to removing pregnancy exclusions, or any other unnecessary restrictions inhibiting advance care planning, from advance directive laws.

**To learn more about our ongoing legal work, please visit [CandC.org/legal-advocacy](https://CandC.org/legal-advocacy).**



Hannah Sharp of Boise, Idaho, pictured here with her family, was a plaintiff in *Almerico et al v. Denney et al*. She was pregnant when the lawsuit was filed in 2018.

# Compassion & Choices Supports End-of-Life Programs

In 2019, Compassion & Choices launched the Healthcare Advisory Council, a group of medical providers who support the full range of end-of-life options and advocate for improved end-of-life care in their communities and nationally. The group unites doctors nationwide who share an interest in Compassion & Choices' mission. A goal of the Healthcare Advisory Council is to uplift the important work being done on end-of-life care. That's why Compassion & Choices is supporting projects that align with the mission of the council.

The first project is a research study among individuals who have been approved for medical aid in dying and/or their caregivers. The study asks how medical aid in dying has impacted individu-

als' quality of life, coping, hopes, as well as any barriers they may have experienced. This study will gather valuable information about the experiences of individuals and caregivers who seek to utilize medical aid in dying.

These findings will be used to develop educational and support initiatives for terminally ill individuals, their families, medical providers and medical aid-in-dying support/advocacy agencies. The research team includes palliative care social workers, thanatologists (clinicians with expertise in death and dying) and grief counselors.

Another project is being conducted by the Humane Prison Hospice Project, which seeks to transform the way people in prison die in the United States. The organization

works in prisons to train individuals in hospice care, as well as on the policy level to enact change in the system. A policy agenda to address hospice in prisons is an important step in realizing equitable end-of-life care and options for everyone.

Compassion & Choices is supporting a project that is geared toward indigenous communities in the United States. A video series will feature Native American elders and their families discussing their end-of-life wishes and customs. These videos will help medical providers and other stakeholders understand the unique needs and challenges of these communities. It will also illuminate their values as they navigate living and dying.



## **Compassion & Choices African American Thought Leaders' Multimedia Impact**

The outreach and subsequent impact of Compassion & Choices' Community Engagement work is continually elevated by the dedication and efforts of African American thought leaders. This year alone, council and staff members have made their mark in webinars, podcasts, and many national and local media placements (see Words & Pictures on pg. 3).

In February, Compassion & Choices Community Engagement team collaborated with the African American Leadership and Healthcare Advisory Councils on a Black History Month discussion: "Empowering the Black Community and the Impact of Dementia." Presenters addressed the unique needs and challenges facing Black communities in dementia care and planning. Speakers included nurse Missy Moore; Sonja Richmond, MD; and Jeff Gardere, PhD. Their experience working with individuals and families, and familiarity with Compassion & Choices' free dementia tools helped over 110 attendees better understand the importance of end-of-life planning.

Honoring Black History Month, council member Avery Leora Ross led a powerful discussion for staff on the importance of discussions and planning for life's inevitable transitions embracing death positivity, in addition to penning an op-ed.

Joél Simone Maldonado, Compassion & Choices 2021 Signature Event emcee and council member, was featured in a beautiful piece called *Black Grief Practitioners Are Protecting Black Life In Death*, which was shared on Refinery29's annual Black History Month series, ROOTS. Their goal for 2022 is to explore "Black excellence while celebrating where our past, present and future meet."



top: Dr. Richmond, Missy Moore, RN, and Dr. Gardere conducted an online presentation on dementia. below: Avery Leora Ross (right); Joél Simone Maldonado (left).

**Check our events page for upcoming virtual happenings around end-of-life care, options and inequities at [CandC.org/events](https://CandC.org/events).**

## Our Community-Driven End-of-Life Options Movement

Compassion & Choices leadership councils continue to be at the forefront of end-of-life advocacy in their communities. The Latino Leadership Council meets regularly to discuss issues facing the Latino community, how to best serve their needs and how Compassion & Choices can assist in those efforts. Latino Leadership Council member Rev. Ignacio Castuera was featured on Univision, the largest Spanish-language network in the United States. Acclaimed journalist Jorge Ramos interviewed him on *Al Punto* about medical aid in dying and the religious perspective.

The Asian American, Native Hawaiian and Pacific Islander (AANHPI) Leadership Council provided

guidance in translating end-of-life educational materials into multiple languages to make them culturally competent.

Compassion & Choices is proud to announce the formation of the LGBTQ+ Leadership Council, composed of advocates and storytellers throughout the country who support the full range of end-of-life options. The council is committed to addressing the issues facing LGBTQ+ people at the end of life. This Pride season, the council will participate in virtual events, disseminating LGBTQ+ -specific end-of-life materials and growing their numbers.

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## Faith-Based Advocacy Continues to Make a Difference

Compassion & Choices created the Rev. Dr. Paul Smith Award in honor of the former board member and civil rights leader who has dedicated more than 20 years as an end-of-life care advocate. This year's award was presented to Rev. Madison T. Shockley for his commitment to improving end-of-life care and options in his community and beyond. Rev. Shockley is the pastor at Pilgrim United Church of Christ in Carlsbad, California, and a valued Compassion & Choices board member.

Rev. Shockley's support was integral to the passage of California's End of Life Option Act. He

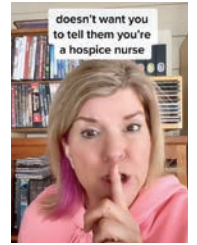
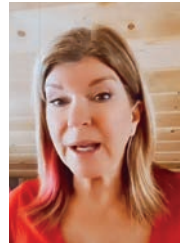
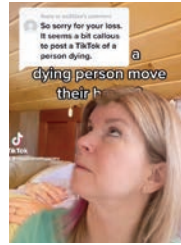
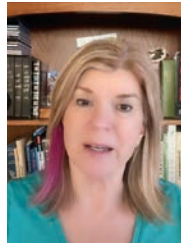
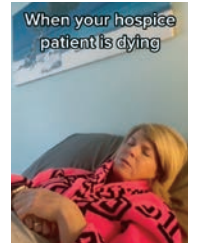
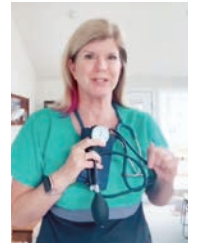
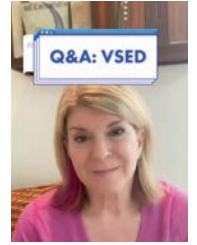
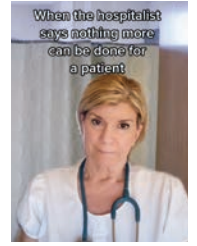
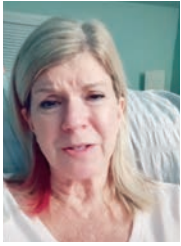
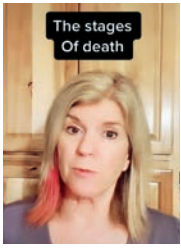
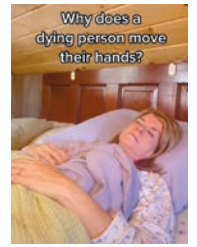
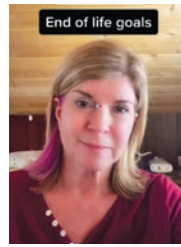
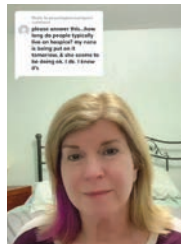
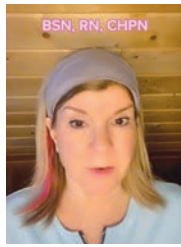
has also participated in rallies and lobbying efforts in numerous states over the years, as well as in countless events and educational opportunities encouraging all communities to make end-of-life planning a priority.

In May, Compassion & Choices officially launched Catholics for Compassion with a powerful virtual event. Members of the group were featured in videos voicing their support for end-of-life care and options, including medical aid in dying. From a theologian to a funeral director to medical providers, the experiences of Catholics for Compassion



Compassion & Choices Board member  
Rev. Madison T. Shockley.

members is varied. Their strength is in realizing the unique challenges and opportunities in their faith community.





# Five Questions for Hospice Nurse Penny

Penny Hawkins-Smith, a hospice nurse, has attracted over 400,000 followers on TikTok by sharing insights from her work. We spoke with her about using social media to help normalize death.

**Q:** What led you to a career in hospice?

**A:** I had been a stay-at-home mom, but my ex-husband and I decided to get divorced, so I needed a career. Nursing seemed like it would be a good fit for me, as I knew I wanted to do service work. I kind of had a rocky road as a young adult — got in a lot of trouble — so I felt like I really wanted to do something that was going to give back. Also, the year before, my step-mother-in-law got cancer and ended up in a hospice care center. I was so impressed with the level of compassion that the nurses have for their patients that I was just really drawn to that.

**Q:** For the uninitiated, how do you describe your work?

**A:** Hospice focuses on quality of life over quantity of life. Basically, for a person to be eligible for hospice, they must have a life expectancy of six months or less with a terminal diagnosis. So people who come on to hospice are accepting, or hopefully we'll get them to the point where they're accepting, that there is no further treatment for them. It either isn't working, or they're choosing to stop it. And our goal is to assist them with their end-of-life goals to try to improve the quality of their life as much as we possibly can for whatever amount of time they have left.

## five questions

**Q:** Have you always been comfortable with death and the dying process?

**A:** Actually, no. Growing up, I really wasn't exposed to death very much. I have a very small family: My mom was from Canada, my dad was from Texas, and I grew up in Washington state with them. So I didn't have a tight relationship with my grandparents and didn't have a lot of experience with death. When I was in my thirties, I developed severe death anxiety. I was very anxious all the time about death, worrying about what happens after we die. I was not comfortable with death. But somehow going through the experience with my ex-stepmother-in-law, it just kind of drew me toward wanting to do that type of work. Working in hospice has alleviated that death anxiety for me.

**Q:** You're enormously popular on TikTok, an app most well known for prank videos, dance routines and other light fare. How did you get started on that platform?

**A:** Well, like many people, I discovered it during the lockdown. I actually saw a news story about Dr. Nicole Baldwin, a pediatrician who was making TikToks that were pro-vaccination, and she was getting a lot of death threats for that. So I looked her up on TikTok and got sucked in by all of the dancing videos — shuffle dancing kept coming up on my feed. And I was like, that really looks fun. So I started off just trying to shuffle dance. Then I did a couple of the little "trend" things. I really don't know what possessed

me to tell a hospice story, but that's what I did. I told a hospice story, and it went viral, and I realized oh, there are people who are interested in hearing about this. That's how it kind of took off.

I love the platform because I'm able to reach a really wide variety of people with different learning styles and at different ages because there are so many ways that I can teach. Humor is one. A lot of people like to watch my TikToks that are funny. It lightens it up for them.

**Q:** Based on firsthand experience in your work and the comments and questions you get on social media, is there one takeaway you feel everyone should understand about the end of life?

**A:** Other than the fact that we're all going to die, I think it's important for people to understand that in order to have a peaceful death, you really need to have a conversation around that. Don't be afraid to talk about it, because it really does take the fear out of it. And if you're not afraid of death while you are living, you won't be afraid of death while you're dying. Death is normal!

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**Find Nurse Penny on TikTok and Instagram at [hospicenursepenny](https://www.instagram.com/hospicenursepenny).**

**Visit our [Plan Your Care Resource Center](https://www.compassionandchoices.org/end-of-life-planning) for guidance on discussing and preparing for life's end at [CompassionAndChoices.org/end-of-life-planning](https://www.compassionandchoices.org/end-of-life-planning).**

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### Crossword Puzzle Answers (from page 13)

**ACROSS** 3. RAM DASS 5. BRITTANY 6. OMIT 8. FINISH STRONG 9. PLANNING 10. ADVOCATE 12. PRIORITIES 14. PAUL SMITH 17. CARE 19. DOLORES HUERTA 21. LAW 22. OREGON 24. DOC 25. EDUCATE 26. TINA 27. ELEVEN

**DOWN** 1. CALLINAN 2. EQUITY 4. DEMENTIA 7. COMPASSION 11. EMPOWER 13. REHM 15. HOSPICE 16. VALUES 18. ROSE 19. DOULA 20. SHOW 23. CAMP



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- Rusty and Sara Foszcz, Illinois

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**SCAN:** Open camera on phone and scan QR code



This year, it's even more important to make your voice heard.



HERE ARE **5 WAYS** TO  
GET INVOLVED NOW!

- 1 FIND** upcoming activities and events in your state at [CandC.org/events](https://CandC.org/events)
- 2 TAKE ACTION** by learning how you can support medical aid in dying at [CandC.org/take-action](https://CandC.org/take-action)
- 3 VOLUNTEER** any way you can; find options at [CandC.org/volunteer](https://CandC.org/volunteer)
- 4 SHARE** your personal experiences about medical aid in dying to demonstrate why this option is so crucial at [CandC.org/stories](https://CandC.org/stories)
- 5 SIGN UP** to receive real-time updates on our advocacy campaigns, including our monthly e-newsletter, at [CandC.org/join](https://CandC.org/join)