

compassion & choices

MAGAZINE
SUMMER 2023

National
Emergency
& Palliative
Medicine
Initiative
pg. 4

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The Death
Positivity
Movement
pg. 7

A CONVERSATION WITH
Alua Arthur

Death educator from National Geographic's "Limitless"





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 **compassion
& choices**
Care and Choice at the End of Life



04

FEATURES

04 Palliative & Emergency Medicine: A Powerful Partnership for Patients

Emergency departments in the U.S. are the primary hospital entry point for end-of-life care.

07 Death Positivity and the Stories That Sustain a Movement

Storytelling propels the movement for end-of-life care and options to new heights and informs the way everyday Americans discuss death.

18 Going With Grace's Alua Arthur

For nearly a decade, Alua Arthur has created safe places for people to talk about death.



13



17



07

DEPARTMENTS

02 Top of Mind

03 Words & Pictures

10 Advocacy in Action

13 State Spotlight: Montana

14 National Programs Update

Compassion & Choices improves care, expands options and empowers everyone to chart their own end-of-life journey. Learn more at CompassionAndChoices.org.

An Exciting Time in the Movement

Featured on the cover of this issue is Alua Arthur (see pg. 18), an end-of-life doula and death educator who supports people in coming up with their own authentic answers to the question: “What must I do to be at peace with myself, so that I may live presently and die gracefully?” When they come to their own authentic answers, Alua helps her clients make a plan that is in keeping with those values. In addition to practicing and teaching, Alua trains others to build the same skills and access the same tools she uses as a death doula.

This “pay it forward” approach to self-empowerment is precisely the direction Compassion & Choices is heading. By the time you read this, we will have released our new FY2024-FY2028 Strategic Plan, which we will feature in our fall edition.

What you’ll read here is a glimpse of what lies ahead: expanding our self-propagating networks of population-based communities; raising awareness and sharing culturally attuned care-planning tools; and engaging everyone from all backgrounds to become empowered healthcare advocates at the end of life.

I am especially excited about our work to transform the end-of-life care experience for terminally ill people who enter the ER through our National Emergency and Palliative Medicine Initiative (NEPMI) (see pg. 4). This program is as exciting as the current moment in the evolution of the movement and our organization: We’ve built the recognition, respect and reach to facilitate large-scale, game-changing collaborations to shift the paradigm of end-of-life care for all.

With excitement for what lies ahead,



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In the Media

The Mercury News [San Jose]

[How Congress Can Improve Seriously Ill Americans' Quality of Life](#)

Compassion & Choices President and CEO Kim Callinan partnered with Yanira Cruz, president and CEO of the National Hispanic Council on Aging, to pen an op-ed urging Congress to make end-of-life care available to a wider range of Americans. Citing figures from a National Library of Medicine literature review that demonstrate a widespread misunderstanding of end-of-life care options among the general public, they called on Congress to pass the bipartisan Palliative Care and Hospice Education and Training Act. The bill would improve palliative care training for health professionals and provide for a national education and awareness campaign to inform patients, families and health professionals about the benefits of palliative care.

Death & Grief Talk With the Grave Woman[®]

[How Black & Indigenous Communities Use Euphemisms, Parables and Proverbs as Tools for Preplanning](#)

In this podcast episode, Compassion & Choices staff members Zeena Regis and Elisha Hall, Ph.D. joined Compassion & Choices board member Joél Simone Maldonado to discuss the practice of storytelling in end-of-life care in Black and Indigenous communities. "Advance care planning tends to be couched in legalistic and financial and material terms, when I think many in our community also think of it in terms of spiritual and communal and storytelling terms," said Regis. Dr. Hall explained the legacy of African proverbs that emphasize the importance of story sharing among community members to help us learn from the end-of-life experiences of our elders and ancestors to inform our own end-of-life plans.

Univision Network

[Nevada End-of-Life Options Act Introduced](#)

Univision, the largest Spanish-language network in the United States, spoke to Patricia A. González-Portillo, Compassion & Choices Action Network's senior national Latino media director, to talk about the importance of passing Nevada's End of Life Options Act. "[Terminally ill Nevadans] do not want to have to suffer unnecessarily," said González-Portillo (translated). "We should not wait until we reach a [terminal condition] to have an end-of-life plan." González-Portillo also spoke about the importance of having end-of-life conversations with loved ones and referred viewers to Compassion & Choices' Spanish-language online resources to help people navigate their end-of-life care options.

The New York Times

[Vermont Removes Residency Requirement for Medically Assisted Deaths](#)

In May, The New York Times reported that Vermont became the first state in the country to allow terminally ill non-residents to access its medical aid-in-dying law. The change was spurred by the Compassion & Choices settlement of a federal lawsuit with Vermont officials, challenging the constitutionality of the state's residency requirement. We filed suit on behalf of Lynda Bluestein, a terminally ill Connecticut resident, and Vermont physician Dr. Diana Barnard. "Support for this is widespread and bipartisan," said Compassion & Choices president and CEO Kim Callinan. "People universally want to be able to make decisions about how they die." The change takes effect immediately, allowing Bluestein to access the law if and when she wants. "I was always hoping that the legislature would change the law and make it open to everyone," Bluestein said, "It's a tremendous relief."

Palliative & Emergency Medicine: A Powerful Partnership for Patients

Palliative care in emergency departments is bringing a critical shift in the end-of-life experience.



Every year there are over 137 million visits to hospital emergency departments (EDs) in the United States. Adults 65 and older use the ED more than any other age group, and half of older adults will visit the ED in the last month of their lives.

Emergency departments in the U.S. are the primary hospital entry point for end-of-life care. One in 10 people die in the emergency room. Emergency medicine clinicians are very good at what they do: they resuscitate, stabilize and save lives. For many patients, this model of care is exactly what they want and need. However, for individuals who are terminally ill, such aggressive and invasive interventions are often futile. They can be traumatic and may go against the patient's wishes.

... a revolution has been occurring, one hospital at a time ...

But thanks to a creative group of clinicians and other thought leaders, a revolution has been occurring, one hospital at a time. Practitioners, facilities and healthcare systems have been offering palliative care consults right in the ED.

Palliative care is specialized medical care for people living with a serious illness. With a focus on providing relief from the symptoms and stress associated with the illness and a goal to improve quality of life for both the patient and the family. Palliative treatments can be offered with any illness and at any stage of life, even while working to cure that illness, or can be part of comfort care for those who are facing a terminal diagnosis.

By working together, emergency and palliative medicine practitioners can provide patients with the opportunity to talk openly about their health goals. As a result, clinicians in the ED can offer the appropriate treatments and forgo those treatments the patient doesn't want, as well as connect the patient to the appropriate planning and supportive services upon discharge, where available.

Compassion & Choices is supporting this practice with a brand-new National Emergency & Palliative Medicine Initiative (NEPMI). The program brings together physicians, nurses, social workers, chaplains, end-of-life doulas and caregivers from all over the country to share best practices and data. The goal of this collaboration is a profound shift from

unwanted, expensive "one-size-fits-all" care in the ED to patient-directed care as people approach the end of life.

"If the ED is to continue to be the primary portal of hospital entry for patients requiring emergent care for acute and chronic terminal illnesses, then ... it should also be equally prepared to provide the earliest access to palliative care and advance care planning resources for patients and families who may want and benefit from these services," said Dr. Sathesh Gunaga, vice chair of emergency medicine at Henry Ford Wyandotte Hospital in Michigan and a member of the Compassion & Choices board of directors.

Because the ED uniquely impacts individuals of all racial, ethnic, socio-economic and religious backgrounds like no other clinical venue in medicine, the NEPMI initiative will seek to address long-standing inequities in end-of-life care, like the lower-than-average adoption of hospice services by diverse communities.

Clinical nurse coordinator Beka Malloy and clinical social worker Alejandra Muro co-developed a palliative-emergency medicine initiative in 2021 at Providence Little Company of Mary Medical Center in Torrance, California. Compassion & Choices invited them to participate in NEPMI and

share their experiences. “We were both delighted and excited to be a part of the NEPMI initiative as it was an opportunity for us to take the successful model that we created within our health system and see it potentially be replicated across the country,” said Malloy.

“One of the most rewarding parts of this initiative is the coming together of diverse perspectives and thoughts to create a space in which emergency medicine and palliative care services come together from all angles,” added Muro. “Not just the medicine, but the emotional and spiritual care.”



DID YOU KNOW that emergency departments (ED) are the primary portal of hospital entry for end-of-life care?



50% of older adults will visit the ED in the last month of their lives.



10 million adults aged 75 and older visit the ED yearly.



Adults 65 and older have the highest ED utilization of any age group.

Death Positivity and the Stories that Sustain a Movement

Storytelling propels the movement for end-of-life care and options to new heights and informs the way everyday Americans discuss death.

From Compassion & Choices' beginnings as leaders in passing medical aid in dying, to a new generation of advocates pushing to address inequities in end-of-life care, the movement has always brought death out of the shadows and into mainstream conversations. Over the past few years, this movement has only intensified as communities and advocates continue to illuminate the unvarnished realities of death and dying. This move towards death positivity is gaining traction in mainstream media and social media alike — and in the lives of many people in the United States.

Death positivity refers to the idea of being honest about the ways death affects all of us, especially people who are terminally ill. Attend any Compassion & Choices event — from lobby days at state capitols to educational events around end-of-life planning — and you'll hear death positivity at work. It happens when a new face voices their fears around death for the first time, or when a longtime supporter living with cancer testifies on behalf of a medical aid-in-dying law in their state.

Death positivity doesn't necessarily mean being positive, upbeat or unrealistic about the realities of death and dying — in fact, it's a radical endeavor into truth-telling about the experience. As our storytellers demonstrate, we can look at death holistically and without pretense.



This idea that death is a taboo topic is rampant in our society, but our storytellers often show that talking about death is part of life ...



ANDREW FLACK

“Cancer isn’t something anybody chooses, but I can choose how I move forward.”

But That’s So Morbid

Many of us at Compassion & Choices have been asked, “Isn’t it morbid to talk about death all the time?” This idea that death is a taboo topic is rampant in our society, but our storytellers often show that talking about death is part of life and can produce fruitful and valuable conversations with friends, families and even strangers. Andrew Flack, a teacher, hockey fan and end-of-life options advocate, died in 2022. He spent his last months talking to others about death and dying through his Death With Dignity podcast, which is both serious and joyful, and reflects a growing sense of contentment.

In recent months, Dr. Mitsuo Tomita has participated in efforts to create a webinar series about dying with heart disease, kidney disease, cancer, ALS and dementia. Dr. Tomita is a dedicated member of the Compassion & Choices Healthcare Advisory Council and Asian American, Native Hawaiian, Pacific Islander

(AANHPI) Leadership Council. In conversation with leading experts in each field, Dr. Tomita represents not only a clinical perspective, but his own perspective as a Compassion & Choices volunteer. The goal of this webinar series, entitled “As the End Nears,” is to provide practical information about the dying process so that individuals and families can be prepared for whatever comes their way.

Embracing Inspiration

In a place where these end-of-life conversations don’t always occur, death positivity involves a lot of creativity and storytelling. People share poetry, art, music and more in their quest to engage with the topic of death and dying. One group, Threshold Choir, sings soothing songs at the bedside of dying people. Another initiative, Death Cafes, encourages community members to share their feelings around death in a group setting.



RITA FLOREA

“ Having the [aid-in-dying] medication in hand means that now I have control and there’s no more anxiety about how I will die.”

When Rita Florea found out about a lung cancer diagnosis in 2022, she sent her loved ones a haiku: “Our time on this earth / A mere drop in the bucket / Yet each drop precious.” This message would inform her decision to celebrate her life while she was still here — and eventually, her decision to take aid-in-dying medication in early 2023. Rita spent her last months sharing her story and advocating for improving access to medical aid-in-dying laws.

Taking the Lead

For many storytellers, advocates, and supporters in the end-of-life options movement, planning and preparing for the end-of-life experience they want is tantamount to achieving peace and acceptance in the face of the unknown. Whether you are planning your funeral or before-death celebration, estate planning, or who you will appoint as a healthcare proxy in the event of an emergency, these are things that feel within our control.



ISA MENDEZ

“ Living with metastatic cancer is not the end, but a rediscovery of life. To conquer it is to rise — mentally, emotionally, spiritually.”

Isa Mendez, a Compassion & Choices storyteller, was diagnosed with cancer in 2017. She decided to use the lessons she’s learned to help others in their end-of-life journey by becoming a death doula. In her practice, much of her early work with clients is meeting them where they are, building trust and helping them feel comfortable engaging in a conversation about death. It is death positivity in action.

These leaders and advocates in the end-of-life options movement show that death is a part of life and something we shouldn’t shy away from discussing.

To read their stories and access these resources, visit CandC.link/death-positivity.

Progress Throughout the Country

A reflection of a hard-fought legislative session.

CONNECTICUT

During January, the Connecticut Compassion & Choices Action Network campaign launched a powerful portrait display at the state capitol, "They Died Waiting," detailing the stories of 17 Connecticut residents who could have benefited from medical aid in dying. Following a 10-hour hearing featuring 122 people in February, the Public Health Committee voted in March to favorably report out of their committee the Senate's Act Concerning Aid in Dying for Terminally Ill Patients (SB1076). In March, the Connecticut campaign produced its first-ever 30-second TV ad, narrated by Glastonbury resident Joy Cipollo, featuring her late wife, Kim Hoffman, who died in agony from metastatic cancer.

FLORIDA

The Florida team had an active couple of months working to expand our grassroots efforts. Our incredible volunteers have been holding events throughout the state, including hosting Kim Callinan in Naples

for a candid conversation on *Finish Strong: Facing Illness with Confidence and Control*; in Clearwater, our action team leader hosted a viewing of the movie *Wooden Nickels* with President Emerita/Senior Advisor Barbara Coombs Lee. The teams and volunteers participated in 10 events throughout the spring.

HAWAII

This year's legislative session included a bill (recommended by the Hawai'i Department of Health) to improve the Hawai'i Our Care, Our Choice Act, which advocates are thrilled to see come to fruition. HB 650 authorizes advanced practice registered nurses (APRNs) to prescribe medications and adds additional mental health providers to the list of approved counsel, ensuring improved access across communities. It also reduces Hawaii's mandatory minimum waiting period between two oral requests from 20 days to five, and establishes an expedited pathway for qualified terminally ill patients who are not expected to survive the mandatory waiting period. A complete wrap-up of the legislative session can be found at CandC.org/Hawaii.

MARYLAND

The Maryland Compassion & Choices Action Network campaign started strong in January when Governor Wes Moore endorsed medical aid in dying during a summit on key issues in 2023. In February, the campaign released a new poll it sponsored showing a record 71% of Maryland voters support medical aid in dying. Advocates testified at two committee hearings on Maryland's End-of-Life Option Act in March. Unfortunately, the bill stalled after Senate President Bill Ferguson, a former bill cosponsor, told



Maryland Gov. Wes Moore (right) speaking with Bryan Sears (left), government affairs reporter for the Maryland Daily Record, at a summit event where Moore endorsed medical aid in dying.

The Washington Post that he’s “trying to get a feel for what [lawmakers] are willing to take on and how many big issues [lawmakers] can take up.”

MASSACHUSETTS

The Massachusetts Compassion & Choices Action Network team sponsored a new poll to persuade state lawmakers that the voters’ narrow rejection of a 2012 ballot initiative to authorize medical aid in dying is irrelevant today. The poll showed strong support for medical aid in dying. Support increases from 73% to 79% after voters hear the facts about the Massachusetts End of Life Options Act (S 1331/ H 2246). Roughly 80% of voters say these facts make them more supportive. The survey also provided messaging guidance to persuade lawmakers and voters to support the bill.

NEW MEXICO

New Mexico is now the fourth jurisdiction to allow Medicaid funds for aid-in-dying medication, along with Oregon, California and Hawai’i. We are committed to addressing inequities at the end of life and we applaud officials in New Mexico to ensure that all eligible terminally ill people can access medical aid in dying. Volunteers with our local partner, End of Life Options New Mexico, have also focused their efforts on underserved populations, traditional Hispanic communities and large Spanish-speaking populations. Volunteers distributed brochures and fact sheets in English and Spanish to ensure residents understand their full range of end-of-life options.

NEVADA

Las Vegas Senator Edgar Flores introduced the Nevada End of Life Options Act (SB 239) in March. The compassionate legislation has 19 sponsors. Two Las Vegas moms living with incurable cancer, Lynda Brooks-Bracey and Hanna Olivas, joined Dan Diaz, husband of the late medical aid-in-dying advocate Brittany Maynard, in providing powerful testimony via Zoom before the Senate Health and Human



top to bottom: Nevada storytellers (pictured from left to right) Díaz, Olivas and Brooks-Bracey. Those three testifying via Zoom in Las Vegas for the Senate Health and Human Services Committee.

Services Committee in Las Vegas. Compassion & Choices National Director of Care Advocacy Samantha Trad and Regional Advocacy Manager Sara Manns also testified before the committee in Carson City. On April 19, 2023, the Senate passed the bill. Check CandC.org/Nevada for the most up-to-date information on the bill.

NEW YORK

Our New York Compassion & Choices team delivered more than 77 additional co-sponsors since Assemblymember Amy Paulin and Senator Brad Hoylman-Sigal reintroduced the New York Medical Aid in Dying Act (A995/S2445) in January. Working with the bill sponsors, our team led efforts with allied organizations to move the bill in committee. We held six lobby days at the state capitol. A Mother’s Day event on May 10 featured mothers of adult children and adult children of mothers who have died with needless suffering since the first bill was introduced in 2016.

advocacy in action

OREGON

Our Oregon team prepared to formally lift the residency requirement from Oregon's Death With Dignity Act with HB2279. The bill was introduced in response to the 2022 settlement of *Gideonse v. Brown, et al.*, a federal case brought by the Compassion & Choices legal team on behalf of Oregon physician Dr. Nicholas Gideonse. Dr. Gideonse has many patients in Washington state whom he was unable to support if they sought medical aid in dying. State support of the legislation was a component of the settlement, which removed the residency requirement permanently. For a full update on HB 2279, visit CandC.org/Oregon.

VERMONT

In March, Compassion & Choices reached a historic settlement with Vermont officials in its second federal lawsuit asserting that the residency requirement in a medical aid-in-dying law violates the U.S. Constitution's guarantee of equal treatment. The settlement stipulates that the patient plaintiff, Lynda Bluestein, doesn't need to comply with the residency mandate if she uses the Vermont law, and that Vermont Health Department officials support legislation to remove this requirement. The Vermont House and Senate passed legislation (H.190) to remove the residency mandate in February. Republican Gov. Phil Scott signed the bill into law on May 2.

VIRGINIA

Virginia supporters of medical aid-in-dying legislation (SB 930) held a news conference in January to advocate for a Senate committee to approve the bill. "I should not have to leave Virginia [to use Washington, D.C.'s medical aid-in-dying law] to achieve bodily autonomy and do not see how anyone who has watched a loved one suffer through a lingering death could vote against this legislation," said Barbara

Green, a Falls Church resident with metastatic pancreatic cancer. While Barbara's heartbreaking story generated several news stories, the committee rejected the bill. Our strong coalition of volunteers are committed to continuing their advocacy.

WASHINGTON

Alongside our partners at End Of Life Washington, team Washington spent early 2023 championing SB 5179. After three years of powerful advocacy, the bill passed and was signed by Governor Jay Inslee on April 6. This bill included modest revisions to Washington's Death With Dignity Act, removing roadblocks that prevented many terminally ill individuals from accessing medical aid in dying, especially those who live in medically underserved communities. Improvements include reducing the 15-day waiting period between oral requests to seven days; allowing medications to be mailed; and authorizing advanced practice registered nurses (APRNs) and physician assistants (PAs) to prescribe the medication.



On April 6, 2023, Washington Gov. Jay Inslee signed SB 5179, to improve the state's Death With Dignity Act. Compassion & Choices staff Callie Riley and Charmaine Manansala and state lobbyist Amber Ulvenes were present for the signing, along with C&C partners and legislative champions.

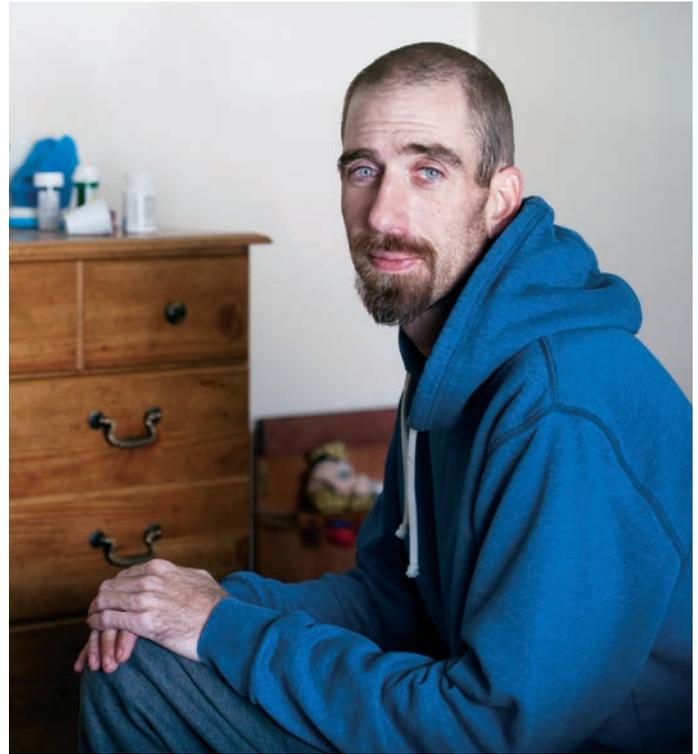
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Defeating Cruel Legislation in Montana

Passionate advocates and volunteers across Montana have much to be proud of this summer, after working together to protect Montana residents and physicians from Senate Bill 210. Nicknamed the Physician Imprisonment Act, this legislation would have subjected physicians to homicide charges for honoring their terminally ill patients' wishes by writing a prescription for medical aid in dying — a right solidified for Montanans in 2009.

Medical aid in dying became accessible to Montana residents thanks to Bob Baxter, a terminally ill U.S. Marine veteran at the center of *Baxter v. Montana*, a Montana Supreme Court case litigated in part by Compassion & Choices. The court ruled in favor of Bob, finding that “[The] Rights of the Terminally Ill Act clearly provides that terminally ill patients are entitled to autonomous end-of-life decisions.” In a profoundly devastating twist, Bob died the very day of the ruling without hearing the result. In 2017, his 36-year-old grandson, TJ Mutchler, utilized medical aid in dying after suffering greatly from stage 4 pancreatic cancer.

Since the decision in *Baxter v. Montana*, Compassion & Choices has faced biannual attempts to overturn the case or introduce bad legislation, so our staff and advocates were ready to fight the bill the second it landed. Despite the political landscape appearing to be stacked against us, our staff and advocates remained dedicated to amplifying the voices of Montanans who did not want to see this right stripped from them after more than a decade. Powerful volunteers in all corners shared their thoughts with their lawmakers, while advocates like Leslie Mutchler (Bob's daughter, and TJ's mother) showed up to hearings, wrote letters to the editor, shared news stories with friends and spoke anywhere they could. The bill progressed through multiple hearings, but advocates refused to stand down.



TJ Mutchler, grandson of Bob Baxter, was photographed in his Billings home, where he was able to end his life peacefully and on his own terms.

To show lawmakers how broad statewide support for this option is, Compassion & Choices commissioned a poll. The results were astounding: with 88% of Montanans opposed to the bill. After the release of our poll in the days leading up to the final vote, the movement to defeat this bill received an influx of media support, and aggressive lobbying by Montana residents. This inspired three lawmakers to change their mind and vote “no” on SB 210 — securing this right to access.

The team is thankful to the bevy of strong advocates who have worked alongside Compassion & Choices, some for decades, to protect medical aid in dying in Montana.

Partnering With the Institute for Mexicans Abroad

Compassion & Choices is fostering connections to improve access to end-of-life resources for Latino communities. In partnership with the Institute for Mexicans Abroad (IMA), Compassion & Choices is piloting programs to promote Spanish-language end-of-life consultation services and resources through health centers across the United States.

The IMA manages a program called Ventanilla de Salud (VDS), which operates through 50 Mexican consulates and local health organizations in the U.S. VDS aims to improve access to health services for Mexican families by providing Spanish-language information, education, counseling and referrals through local health agencies. In 2022, Compassion & Choices began a partnership with the IMA by co-sponsoring three regional meetings of VDS directors from community-based organizations. Through these conferences, the Compassion & Choices team met with 46 organization leaders to provide information about end-of-life options and bilingual resources for end-of-life planning, such as the End-of-Life Decisions Guide and Toolkit.

Starting in July 2023, Compassion & Choices will pilot a program to provide additional end-of-life resources to 10 VDS locations, including educational webinars and train-the-trainer programs designed to build capacity for community health workers, or *Promotores de Salud*, to promote end-of-life information for the Latino community.

“By partnering with VDS and providing end-of-life information and training to community health workers, our team is able to lend our resources and tools to existing organizations that have the capacity to make the biggest impact on Latino communities,” said Maria Otero, Compassion & Choices Latino engagement director.

This partnership has already amplified the outreach efforts of Compassion & Choices’ Latino Engagement team. Last year, Compassion & Choices provided sponsorships to several state organizations in the VDS program, including Research, Education and Access for Community Health (REACH), a nonprofit organization that improves community health services in Nevada, and the New Mexico Community Health Worker Association (NMCHWA). These partnerships enabled Compassion & Choices to attend over 70 community engagement events and provide over 13,000 people with bilingual resources about end-of-life options and planning.

“These programs are open to anyone, regardless of their nationality,” said Otero. “This is an excellent opportunity to promote more equitable end-of-life planning in our communities.”

Visit CandC.org/end-of-life-planning/informacion to download our Spanish-language resources, including *Mis Decisiones al Final de la Vida* (My End-of-Life Decisions Guide).



The Respect for Marriage Act and Healthcare Decision-Making

This Pride month, Compassion & Choices is celebrating LGBTQ+ communities and the 2022 passage of the Respect for Marriage Act. Healthcare access was a central issue in the fight for marriage equality. Before *Obergefell v. Hodges* in 2015, LGBTQ+ people were legally denied the right to visit their partners in healthcare settings, and not allowed to make healthcare decisions. Many employers did not extend health insurance coverage to same-sex partners, causing massive financial difficulties.

Now, with the passage of the Respect for Marriage Act, LGBTQ+ couples have further federal protection against these forms of discrimination. But this doesn't mean the fight is over. Healthcare institutions still may use religious or conscience-based objections to deny or limit our end-of-life healthcare decisions

such as the withdrawal of treatments or medical aid in dying. These issues are relevant to everyone, including every member of the LGBTQ+ community.

An additional challenge emerges for trans, nonbinary and queer people whose immediate families may reject their identities but are still given decision-making power in the event of an emergency or death. That's why planning for an emergency medical situation is so important in the LGBTQ+ community. Everyone should complete an advance directive, which includes a living will ("what I want") and a power of attorney ("who will speak for me").

To learn more about the LGBTQ+ community and end-of-life care and planning, visit CandC.org/pride.

The Importance of Establishing Values and Priorities

The Compassion & Choices Dementia Initiative has provided tools and resources to innumerable individuals with concerns about a dementia diagnosis. Dr. Susan Wilhoit, a national medical director at Compassion & Choices, who practices palliative and primary care medicine, incorporates these tools and resources into her work.

Working within her healthcare organization, Dr. Wilhoit took the time to have conversations with colleagues and leadership to show and share the positive outcomes she had when patients and families shared their values and priorities. Eventually these tools became a part of the process within the organization.



Dr. Susan Wilhoit

"The tools serve as a bridge between the clinical diagnosis and what patients are hearing from their physicians, bringing the patient's voice front and center so that all of the physicians who are caring for that patient know how to honor the patient's wishes."

"I am someone who loves a plan. I like to know that I can be prepared. I can only imagine how someone would feel when they're facing a complex diagnosis and how maybe they may want to know what to expect. I find it so important to advocate for the voices of our patients with dementia now, so that we can best care for them later, knowing that there are certain things we can expect," said Dr. Wilhoit.

First Amendment Rights of California Death Doulas Protected

Earlier this year, Compassion & Choices celebrated a judgment protecting the First Amendment rights of end-of-life doulas in California. These providers, known as death doulas, provide advocacy, information and support to dying individuals and their loved ones.

In 2021, the Compassion & Choices legal team filed an amicus brief (often called “friend of the court” brief) in support of the death doulas who were plaintiffs in the case *Full Circle of Living & Dying v. Sanchez*. The amicus brief highlighted the important role death doulas play in improving equity and individual-directed care at the end of life.

Full Circle of Living & Dying is a California-based nonprofit organization that provides practical, emotional and spiritual support for individuals and their families facing the end of life. They also offer education on end-of-life options; information and support in organizing end-of-life plans; and assistance in home funerals. Full Circle has a disclaimer on its website that they are not funeral directors, do not offer funeral home services and do not operate out of a funeral home.

The Institute of Justice filed this case in 2019 on behalf of Full Circle after the California Cemetery and Funeral Bureau attempted to regulate them as if they were funeral directors, including requiring them to purchase a funeral home space to work from. This move threatened the work of practicing doulas across the state, many of whom are offering their knowledge for free or at reduced cost.

In early 2023, a federal district court judge ruled that various regulations imposed on the death doulas, such as the requirement to own a licensed funeral home, were unconstitutional. Compassion & Choices’ brief was highlighted in the decision.

“While the case is not over, the court’s decision is a step in the right direction for terminally-ill people and their loved ones in California,” says Jess Pezley, senior staff attorney at Compassion & Choices. “Compassion & Choices will continue to advocate to ensure death doulas can offer holistic care and empower individuals with the information they need to make end-of-life decisions that are best for them.”



Compassion & Choices is committed to enforcing and expanding rights for everyone at the end of life. We work to ensure end-of-life care aligns with every person’s values, wishes and beliefs. At the forefront of end-of-life care legal issues, we work through the courts to authorize, expand and defend access to medical aid in dying; remove unnecessary restrictions in advance care planning documents; and prioritize and advance patient-directed care.

For more the most up-to-date information about Compassion & Choices legal advocacy work and cases, visit CandC.org/legal-advocacy.

Award Recipient Rabbi Ariel Stone Makes a Difference in the Jewish Community



This year, Compassion & Choices awarded Rabbi Ariel Stone with the Rev. Dr. Paul Smith award. The annual award celebrates faith leaders dedicated to our movement and is in honor of Rev. Dr. Paul Smith, a civil rights leader and end-of-life options advocate. Faith leaders of every denomination have a unique challenge and opportunity to discuss end-of-life issues with their constituents and communities. They have always played a critical role in end-of-life advocacy, as evidenced by Rev. Dr. Paul Smith's role in early efforts to pass medical aid-in-dying legislation.

Rabbi Stone has been an unwavering advocate for improving end-of-life care and options for over 25 years. She wrote a definitive text, *The Alef-Bet of Death Dying as a Jew: A Guide for the Dying out of Jewish Traditional Sources*, a spiritual guide on death and dying as seen through the prism of Jewish learning and culture.

Stone said in a recent interview: "As much as it is a blessing to be alive, it is a blessing to be able to let go of life in a way that feels right to the individual. It's the biggest challenge any of us is ever going to face. If we are privileged enough to die peacefully in a bed surrounded by loved ones, that is a tremendous blessing. And perhaps for the sake of all those who do not enjoy that blessing, perhaps in that way we might feel the responsibility — that if we are so lucky — that we do the best we can with that blessing."

Rabbi Stone has been the spiritual leader of Congregation Shir Tikvah in Portland, Oregon, since its founding in 2002. A caring and vibrant leader, she is an exceptionally knowledgeable teacher of Torah and a recognized scholar of Jewish mysticism. She is the first female rabbi to head a congregation in the state of Oregon.

Rabbi Stone is also chair of Hesed Shel Emet, the Oregon Jewish Indigent Burial Society; Rabbinic mentor for TischPDX; and convener of Portland Interfaith Clergy Resistance. She serves as adjunct faculty with the Judaic Studies department at Portland State University.



Going With Grace's Alua Arthur

An innovator in the field of end-of-life care, death doula Alua Arthur shares her story and tells us what it is like working with a Marvel superhero.

For nearly a decade, Alua Arthur has created safe places for people to talk about death. Some of these people are facing a terminal diagnosis; others are following a curiosity or calling; and at least one is a superhero. The thing they have in common is that they are all going to die.

Alua is an end-of-life doula and death educator who has been featured in *The New York Times*, *Marie Claire*, *Vogue* and *CNN*. She appears in *Last Flight Home*, a film about a California man's journey accessing medical aid in dying. In November 2022, she guided superstar Chris Hemsworth through challenging feelings around aging and death in National Geographic's show *Limitless*.

"I don't care how rich you are, I don't care how good looking you are. I don't care that you play a god, you are still human — and at some point every single human is going to have this experience.

And he was down." Alua said of working with Hemsworth, who plays Thor in the Marvel cinematic universe.

The term "end-of-life doula" (also known as a death doula) refers to someone who provides holistic, nonmedical support to a dying person and their family. A complement to medicine and spiritual or faith leaders, death doulas serve as part of a comprehensive and knowledgeable support team. Over the last decade, the popularity of this work and the people doing it has skyrocketed.

Alua launched her end-of-life doula company *Going with Grace* in 2015, with the mission of supporting people as they answer the question, "What must I do to be at peace with myself, so that I may live presently and die gracefully?" In the years since, Alua has become a trusted voice in the field that she, like many other doulas, found by surprise.



Alua with actor Chris Hemsworth during filming of National Geographic's show *Limitless*.

In 2012, Alua took time away from her decade-long career as a lawyer to focus on her mental health. While traveling in Cuba, she met a woman with terminal cancer. The two struck up a conversation Alua notes was pivotal. They talked about the



left: Alua Arthur gathers with her sister, Bozoma Saint John, around her brother-in-law Peter Saint John while supporting him during his final days of life.

below: Death Doula Alua Arthur demonstrates washing a body after death.



woman's experience with illness, how people treated her, the support she hoped for and the legacy she wanted to leave. Struck by our society's fear of discussing death, Alua left the conversation determined to support people at the end of their lives.

In a heartbreaking turn, within a year of her trip to Cuba, Alua learned her brother-in-law had been diagnosed with terminal cancer. She relocated to support him, along with her sister and niece. After his passing, she pursued death midwifery training. Alua had seen the importance of practical and logistical support alongside spiritual and emotional care. Thanks to her skills and legal background, this became her specialty.

Alua began developing her own training program in order to offer more of the planning resources she knew were needed. Her end-of-life doula coursework includes lessons around family dynamics, sentimental items, palliative and hospice care, advance care planning, legacy projects and self-care. She asks students to explore their fears, their wishes at the end, and the life they want to live while they're here. She is one of the few end-of-life doula educators who includes a comprehensive overview of medical aid in dying as an end-of-life option for terminally ill adults.

"I think medical aid in dying is important because a lot of our work [as end-of-life doulas] is about agency.

What is the most ideal death for yourself under the circumstances? It's not for me to judge. Again, we're talking about agency, which I hold as close as I hold advocacy. The two go together," Alua said.

Going with Grace has now graduated more than 1,000 end-of-life doulas, and Alua hinted that a revamped version of the course is coming soon, along with a book. Naturally, she has seen massive growth in her work and the field at large; in who does it, in who asks about it, and where it pops up. When asked to describe some of the exciting changes, her signature smile lights up.

"The most exciting of those changes, honestly, is seeing the shift in the demographic of who's doing the work. I'm finding that a lot of folks that are coming to the courses now are of color, they are queer, and they're trying to take the work back into their communities. That's by far the most exciting change."



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If you have any questions, contact:

Sam Young, ESQ-LSW, Senior Director of Legacy and Planned Giving
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Care and Choice at the End of Life

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Join Us ...

for our first annual Compassion Weekend, an interfaith celebration of community, creativity and advance care planning. Together we will share resources to support each other in preparing for the realities of death while affirming faith, love and legacy.

WHEN: July 28-30, 2023

WHERE: Your local faith community

HOW: Sign up or find more information at CandC.link/compassionweekend