

A portrait of Samuel L. Jackson wearing a brown fedora, a red suit jacket, a red tie, and a light-colored checkered shirt. He is standing outdoors with a blurred green background.

compassion & choices

MAGAZINE

FALL 2022

**Samuel L. Jackson
Portrays a Harsh
Reality at the
End of Life**

pg. 4

.....

**Planning for a
Peaceful Death**

pg. 7

.....

**Enjoying Life as
Long as Possible**

pg. 9

.....

**A Stunning Victory
for the Movement**

pg. 12



A Simple Act of Care

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Sam Young, ESQ-LSW, Senior Director of Legacy and Planned Giving
phone: 800.247.7421 x2152
email: plannedgiving@CompassionAndChoices.org





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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.

Stirring Society's Conscience Through the Arts

I am thrilled to have Samuel L. Jackson on the cover of this issue of the magazine. I am even more pleased that one of America's most well-respected actors is raising public awareness about the harsh realities of dementia and the injustices in end-of-life health-care experienced by the Black community and other underserved populations in our society.

At Compassion & Choices, we are proactively addressing inequities in end-of-life planning and care, as well as working to empower more people to take charge of how they die — even in the face of a dementia diagnosis. Recent research shows that one in every two seniors will die with or from dementia. And the inequities in end-of-life care are pervasive: People from historically underserved populations receive less palliative and hospice care at life's end; are less likely to have an advance care plan; and are more likely to receive aggressive, nonbeneficial end-of-life treatments than white Americans.

Fortunately, these and other end-of-life issues are becoming increasingly visible through TV series like "The Last Days of Ptolemy Grey," full-length movies, paintings, poems, songs, photographs, plays, musicals, museum exhibits and other creative projects. As they have since the days of ancient Greece, the arts are shining a light on what is broken in society and stirring the collective conscience to do something about it.

Slowly but surely, people's minds and hearts are opening. And gradually, the dominant paradigm for care at life's end is shifting toward a model that is founded on everything we stand for: compassion and choices.



Kim Callinan

Kim Callinan

President and Chief Executive Officer

Twitter: @KimCallinan

compassion
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MAGAZINE

Managing Editor

Bonnie Lawhorn

Art Director

Bhavna Kumar

Staff Writers

Sonja Aliesch
Erika Bieranowski
Michael Cavaola
Sean Crowley
Patricia A. González-Portillo
Alyson Lynch
Chris Meacham
Keaton Whittaker
Meagan Williams

Contributors

Kim Callinan Ann Thompson
Tom Quash Mark Robinson

Production Manager

Alyssa Cowan

Reprints, Reuse and Additional Copies

CompassionAndChoices.org
Magazine@CompassionAndChoices.org

To request additional copies please email the address above.

Postmaster

Send address changes to: Compassion & Choices
101 SW Madison Street, #8009
Portland, OR 97207

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In the Media

Lavender Magazine

[Making a Hard Choice: A Lesson From "Bob's Choice"](#)

In June, Compassion & Choices' Minnesota team hosted a public screening of "Bob's Choice," a powerful documentary showcasing the final weeks of life for an LGBTQ+ activist and advocate from Washington state who elected to use medical aid in dying. In conjunction with this event, Lavender Magazine, an LGBTQ+ publication based in Minneapolis, interviewed Dr. Rebecca Thoman, who is both director of Compassion & Choices' Doctors for Dignity Program and lead for Minnesota's advocacy work. "There is far more power in personal stories than statistics," said Dr. Thoman. "And the LGBTQ+ community has always been at the forefront of sharing truth as activism."

People en Español

Dolores Huerta Talks About the Painful Family Experience That Led Her to Support End-of-Life Options for Hispanics (Translated)

People en Español, the largest Spanish-language magazine in the United States, with readership in excess of 2.5 million, published a story covering the Dolores Huerta Mission and Vision award presented to its namesake in Sacramento earlier this year. The magazine captured the personal aspect of the iconic civil rights activist's work in end-of-life advocacy as it relates to her own experience watching her mother's painful battle with terminal cancer. "When [Compassion & Choices] asked me to ally with them, I remembered my mother's suffering, and I wish that other people didn't have to follow that path, that there is another way they can end their life." Huerta said.

The Republican Herald

[1 in 2 Older Adults Now Die With a Dementia Diagnosis, Reinforcing Importance of End-of-Life Care Planning](#)

Compassion & Choices President and CEO Kim Callinan penned this op-ed to underscore the importance of advance care planning ahead of a dementia diagnosis. She urged families to use holiday gatherings as a chance to have open discussions with their loved ones about each family member's end-of-life care wishes. Callinan pointed out that the default mode in our current medical system is to "extend the patient's life, regardless of the quality of life, even for people with advanced dementia" and she encouraged everyone to create a personalized end-of-life care plan using Compassion & Choices' dementia values and priorities online tool.

Capital Tonight TV, Spectrum News 1, New York

[Advocates Push for Medical Aid in Dying Act](#)

Compassion & Choices Senior New York Campaign Director Corinne Carey and advocate Daren Eilert joined Spectrum News 1 host Susan Arbetter for an interview on her TV program, "Capital Tonight" after a candlelighting ceremony in Albany honoring advocates for end-of-life care options who died while urging lawmakers to pass medical aid-in-dying legislation. Eilert, who lost his 24-year-old daughter, Ayla Rain Eilert, earlier this year to tongue cancer, spoke lovingly of Ayla's artistic spirit, her painful battle with cancer and her advocacy for end-of-life care options. Carey followed up to implore state lawmakers to take up the mantle and pass medical aid-in-dying legislation before other New Yorkers suffer needlessly.



Samuel L. Jackson Miniseries Addresses Social Issues Plaguing Communities

"Ptolemy Grey" depicts the inequities in how people die.

"The Last Days of Ptolemy Grey" tells the story of Ptolemy Grey, played by Samuel L. Jackson, who lives alone under terrible conditions and suffering from advancing dementia. Grey's nephew Reggie Lloyd, played beautifully by Omar Benson Miller, does his best to look in on "Papa Grey" and make sure his basic needs are fulfilled. When Reggie doesn't show up one day, Ptolemy learns that his beloved nephew has been murdered. "Now what?" we ask as viewers.

"The Last Days of Ptolemy Grey" is an Apple+ streaming miniseries written and produced by Walter Mosley, based on his 2010 book. This powerful story depicts Black people's justified mistrust in

the medical system. When Ptolemy engages with a doctor he calls, "The Devil" and volunteers for a drug trial to cure dementia, facts about side effects and the impact on his own cognition are withheld until it is too late. All participants in the trial appear to be Black, while the medical staff is all white. The message is powerful.

Without giving too much away, the story becomes a wild ride as we experience Ptolemy Grey's distorted reality and then improved clarity. As the title suggests, the last days are critical to solving the mystery of Reggie's murder and creating a secure future for Ptolemy's loved ones.



Samuel L. Jackson with Dominique Fishback (previous page) and Denise Burse (right) in "The Last Days of Ptolemy Grey."

Samuel L. Jackson's never disappoints. His portrayal of a 91-year-old man confused between his memories, real or imagined, and difficult reality is a paramount performance. This story is both interesting and intense, and will inspire many conversations about social and cultural issues related to end-of-life planning, dementia care, financial planning, the role of family and so much more.

"The Last Days of Ptolemy Grey" reflects multiple facets of the work of Compassion & Choices. It is a strong education tool creating a "what if" scenario that will hopefully encourage end-of-life planning. Conversations help us along that critical path to planning, an important process that includes documenting and communicating your goals and values with healthcare providers and family. This iterative and ongoing process is key to ensuring your wishes are honored at the end of life.

The COVID-19 pandemic has illuminated the urgency and need to make decisions and plan for life's end. These realizations and decisions are especially critical in underserved communities. According to the Kaiser Family Foundation, Black, Latino and American

Indian/Alaskan Native populations have died at higher rates and experienced more acute surges from COVID-19 than white people.

Like "Ptolemy Grey," end-of-life planning, hospice and palliative care are gaining popularity as topics in movies, television, books and podcasts. These stories help people understand the impact of their decisions

regarding care and planning, and can be productive tools for preparing for the end of life.

Understanding the options for end-of-life care is an important part of planning. Unlike therapeutic care, which focuses on treating or curing the disease,

palliative care is for people with serious or advanced illnesses and is focused on providing relief from pain and other symptoms, and addressing the physical, emotional, intellectual, social and spiritual needs of a patient, with the goal of improving quality of life. Part of the medical team, palliative care physicians help patients choose care options that are consistent with their values and priorities.

While there are similarities, hospice care differs from palliative care. Hospice is a service (covered by

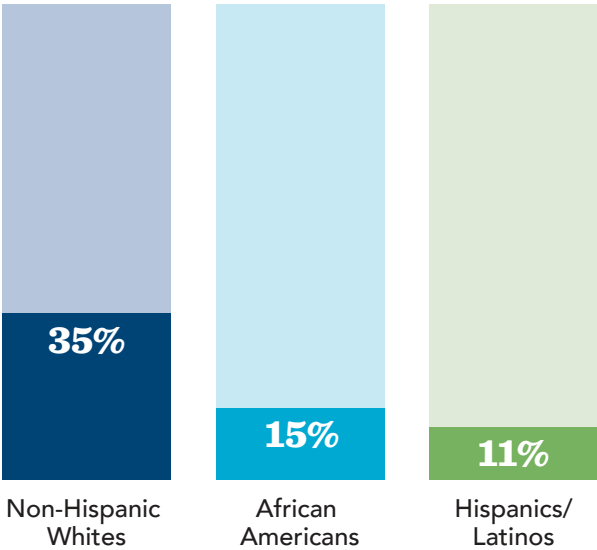
Conversations help us along that critical path to planning.

Medicare, Medicaid and most private insurance) that provides compassionate, typically in-home care for patients who are likely to die within six months. The goal of hospice is to maintain or improve quality of life for someone whose illness, disease or condition is likely terminal, and who is ready to stop curative treatments. When the time comes, hospice caregivers provide personal support to help people achieve a peaceful death.

Compassion & Choices is working to transform how people with dementia die by ensuring that they are aware, empowered and supported in getting the care they want. During a recent webinar about dementia and the Black community, Compassion & Choices Healthcare Advisory Council member Dr. Sonja Richmond said, “Truth, knowledge, all of that is power. And never stop or accept anything but the best for yourself and for your family. Advocate. Research. Expand. Explore. And also do it in love and in grace. And know that the answers are there, know that the support is there.”

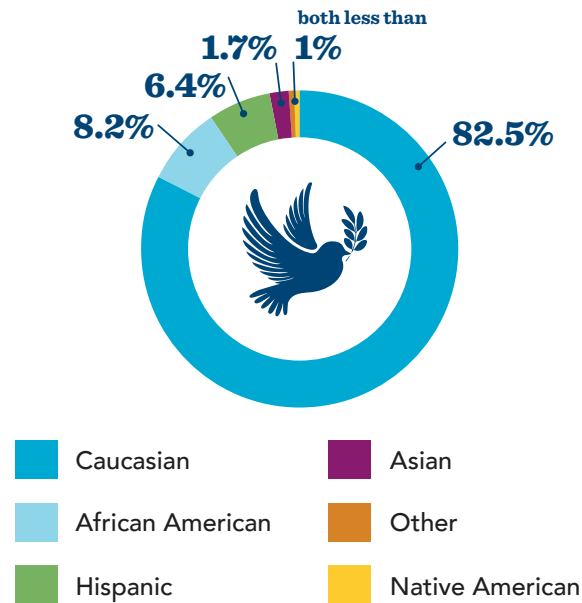
Compassion & Choices provides tools and resources to help people understand how to get started on their planning. By visiting our online Plan Your Care Resource Center, you can take the first step: CandC.org/end-of-life-planning.

DOCUMENTED END-OF-LIFE WISHES BY RACE



Kaiser Family Foundation View and Experience with End-of-Life Medical Care in the U.S., April 27, 2017.

HOSPICE PATIENTS BY RACE



National Hospice and Palliative Care Organization’s Fact and Figures: Hospice Care in America 2018 Edition.

The Loving Gift of End-of-Life Planning

Making one's wishes known and understood lights the path forward.



Cheryl Harms Hauser (center) with her children.

About half of older adults die with or from dementia.* “Over the last century, as we have discovered cures or treatments for many diseases that used to be life-threatening, life expectancy has increased, and now more people are dying with and from dementia. In short, medicine can extend how long the body lasts, but not yet the mind,” said Kim Callinan, Compassion & Choices president and CEO. Mental abilities deteriorate, even when bodies keep going. To ensure that our values and priorities are understood, respected and enacted, it is critical that we consider how we want to manage a potential dementia diagnosis and end-of-life process in advance.

Cheryl Harms Hauser was diagnosed with Alzheimer’s disease in 2019. At 75, she is focusing on the people and activities that bring her joy. Her love of family, friends, music, painting, being outdoors and traveling has contributed to a full life. Since her diagnosis, with the support of her family, Cheryl is taking a proactive role in planning for her peaceful death.

In sharing their story and journey, Cheryl and her daughter Wendy Longacre Brown hope to educate people about their options for control at the end of life and leave a legacy of empowerment for those living with a dementia diagnosis.

After witnessing Cheryl’s brother’s brutal death from dementia, Cheryl and Wendy read Phyllis Shacter’s book, *Choosing to Die*, and Cheryl knew right away, “If I do have Alzheimer’s, this is not how I would want

* JAMA Health Network, April 1, 2022



Cheryl (left) with her daughter, Wendy.

“It is very important to me to die at home with my husband and children ...”

begins her recordings and documents with a statement about why she is deciding to VSED. The family has planned how to support Cheryl through her VSED journey. Cheryl’s physician referred her to hospice. Cheryl

my suffering. I don’t want to endure the final stage of this disease. My brother had a very rough last few years of his life. He was scared. I don’t want to have to live like that.”

After her own diagnosis in June 2019, Cheryl lost the ability to spell. She could no longer read a book. She became disoriented in her own kitchen and completely lost in an airplane bathroom. “I felt inadequate, I felt stupid, I felt frustrated,” Cheryl said. “But I’m not at all scared. I’m not at all fearful of dying. But I just feel more and more that I’m done.” Cheryl decided to make a plan to voluntarily stop eating and drinking (VSED). (See page 9 for more information on VSED.)

With the support of her family and medical team, Cheryl documented her intentions. She has also taken steps to ensure that, as her cognition declines, she continues to understand her own desire to VSED. She has recorded statements about her intentions with VSED via video and then also in document form. Cheryl defined her values with statements like, “I’ll be closer to VSED when I can’t ...” At first it was, “When I can’t work the dishwasher or the microwave or can’t dress myself.” She has tweaked her list over time.

Cheryl and Wendy consulted Compassion & Choices’ Dementia Values and Priorities Tool and Dementia Decoder, which they found to be very helpful. Cheryl

shared that she feels committed and unafraid, and she thinks she will be fine. She has decided to engage 24/7 nurse care in addition to hospice to support her throughout VSED. “It is very important to me to die at home with my husband and children in the roles of my husband and children, not as my caregivers.”

Cheryl seems proud of her family and their decisions to support her journey. “Something that makes me so happy is that Wendy is a death doula, and my other daughter, Sarah, is a birth doula. So I have these two daughters bookending life,” she said. “What’s most important is that we want to educate people. It’s not just my story. I want there to be a legacy to what I’m doing.”

Planning for your own care is important. Compassion & Choices is making that easier, expanding and updating our Dementia Values and Priorities Tool. This tool will be available in a new format that includes an interactive video experience featuring clinicians from Compassion & Choices Leadership Councils. Users will be able to view video explanations of end-of-life terms, watch a video walk-through of each step of the tool and save their documents for later revision. These resources will also be integrated into our Plan Your Care Resource Center so that users can see a full visual glossary of commonly used end-of-life terminology.

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

Living a Full Life Until the Very End

Two stories of loving families supporting each other through VSED.

As Compassion & Choices works with all communities to improve care, expand options and empower people to chart their end-of-life journey, we encounter some who share their families' powerful end-of-life stories of love, wisdom and grace.

The intentional act of voluntarily stopping eating and drinking is usually referred to by its initials, VSED. Compassion & Choices supports VSED because many people struggle with the unrelieved suffering of an incurable and progressive disorder. For some people, VSED is the preferred end-of-life option, even in states where medical aid in dying is legal.

Missouri resident John Griffith, at the age of 99, stopped eating and drinking and died last March. Ninety-eight year old Opal Sloane was living in California when she stopped eating and drinking. John's son, Ben Griffith, and Opal's daughter, Marcia Sloane, shared their stories with Compassion & Choices.

Free will and the ability to choose are cornerstones of maintaining one's quality of life and dignity in the final days. Both John and Opal understood that. Their stories demonstrate two strong individuals with loving, supportive families.



Ben Griffith and his father, John, shared the Quaker practice and faith. After his wife died in 2003, John lived alone. His mind and body were sharp. He continued his daily practice of meditation and enjoyed reciting poems and psalms from memory. He was a competitive swimmer well into his 90s. For years, John researched and planned VSED to control his end-of-life experience. He showed signs of cognitive decline, and by fall 2021 he expressed his wishes for VSED to his family and friends. In February, he received a dementia diagnosis, and hospice agreed to accept him.

When the time came, Ben stayed with his father throughout the process. Ben said, "In the days since my father's death, it's become more and more clear to me how well he planned for the end of his life. He couldn't have done it better."

Marcia Sloane said her mother, Opal, approached death the same way she had lived her life: "She was breathtakingly practical."

In her late 90s, Opal communicated that day-to-day living was getting harder and harder. She had always loved gardening, eating out and using her computer, but carpal tunnel syndrome made it difficult for her

to use her hands. Her weight dropped to 85 pounds, her appetite decreased, and just visiting friends or going to the main dining room of her senior residence facility took an enormous toll on her. She had always been a very independent person and had only recently stopped driving because she struggled to get in and out of her car. Soon, she suspected, she wouldn't be able to leave her apartment.

Opal had researched VSED using resources provided by Compassion & Choices. In 2017, at the age of 98 and feeling she'd had a good and full life, she decided it was time to begin VSED. Marcia, her only child, supported her wishes and did all she could to help her mother die in the way she wanted.

Marcia and her husband, Todd, were Opal's caregivers. Opal's VSED journey took seven days. Marcia documented her mother's journal in a piece called *Journal of My Mother's Death: a VSED Chronicle*. Visit CandC.org/vsed-journal to read her story.

To learn more about John Griffith's experience with VSED, visit CandC.org/stories/ben-griffith. Read about Cheryl Hauser on page 7 for more about how to prepare for VSED in the event of a dementia diagnosis.

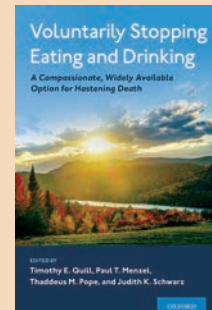
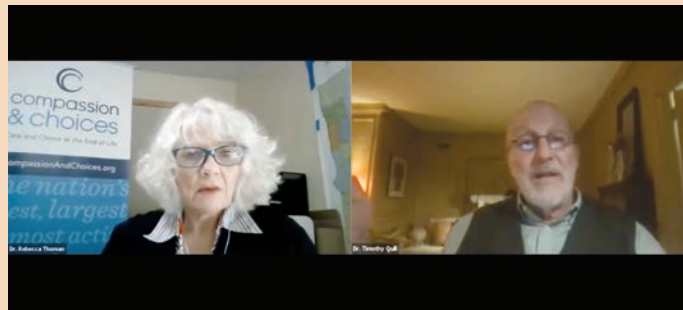
left: Ben and John Griffith; right: Opal and Marcia Sloane.



With appropriate caregiving and/or hospice support, a determined and well-informed individual can successfully pursue the end-of-life option of VSED. VSED is when a mentally capable individual with an incurable or terminal condition decides to control their own dying by making a conscious decision to refuse foods and fluids of any kind, including artificial nutrition and/or hydration, in order to advance their death.

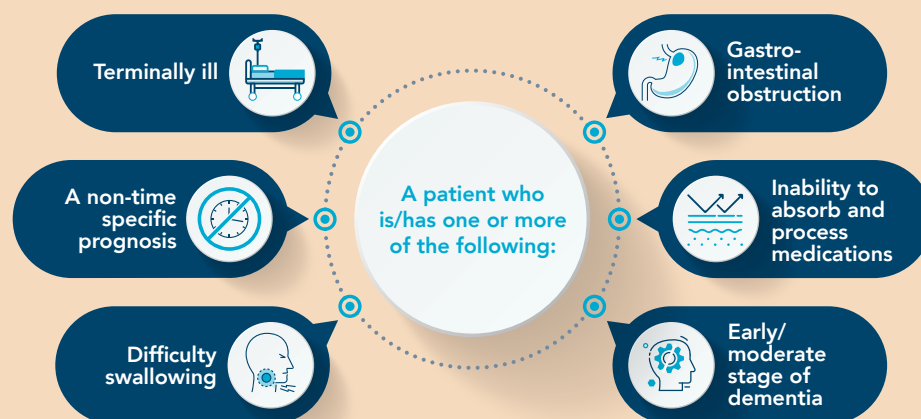
Compassion & Choices has been actively sharing the option of VSED with more communities.

Dr. Rebecca Thoman, who is both director of Compassion & Choices' Doctors for Dignity Program and lead for Minnesota's advocacy led a webinar discussion with Dr. Timothy E. Quill, "Everything You Wanted to Know About VSED But Were Afraid to Ask." Quill is co-editor of the new book, *Voluntarily Stopping Eating and Drinking: A Compassionate, Widely Available Option for Hastening Death*.



Compassion & Choices President and CEO Kim Callinan and C&C Healthcare Advisory Council member Dr. Sonja Richmond presented a poster session titled "Voluntarily Stopping Eating and Drinking (VSED): A Compassionate Pathway to Death" at the American Society on Aging's annual conference, which is attended by hundreds of geriatrics professionals across the country.

WHO CHOOSES VSED



To watch the webinar, view the full poster or see other VSED resources, please visit CandC.org/vsed.

Walking the Line

Compassion & Choices represents an Oregon doctor and achieves a victory that could reverberate nationwide.

Dr. Nicholas Gideonse practices family medicine in Portland, Oregon, a city just south of the Washington border. Though both states authorize medical aid in dying — the first two in the United States to do so — Dr. Gideonse could not help any of his nearby Washington state patients who sought this option. Oregon's Death With Dignity Act was only available to Oregon residents.

Dr. Gideonse has supported terminal patients through the aid-in-dying process since shortly after the law's implementation in 1997. Twelve years later, Washington followed Oregon's lead with its own nearly identical Death With Dignity Act in 2009. Dr. Gideonse attends to many patients who are Washington residents but was unable to provide them with medical aid in dying, unnecessarily interrupting the continuum of care and degrading the doctor-patient relationship.

"The Oregon residency requirement is both discriminatory and profoundly unfair to dying patients at the most critical time of their life. I don't have to ask dying patients for proof of residency to provide them with hospice care. There is no rational reason that I should have to ask dying patients for proof of residency to provide them with medical aid in dying,

especially since 95% of Oregon patients who use medical aid in dying are enrolled in hospice," said Dr. Gideonse.

"Compassion & Choices had heard of concerns about serving southwestern Washington patients, similar to those that Dr. Gideonse had, and decided to do something about it," said Kevin Díaz, chief legal advocacy officer for Compassion & Choices. "We started talking to physicians and other stakeholders to craft a strategy to address this outdated, fundamentally unfair and nonsensical restriction."

In October 2021, Compassion & Choices filed suit in federal district court on behalf of Dr. Gideonse challenging the residency requirement in Oregon's landmark Death With Dignity Act. Our legal team asserted the requirement violated the U.S. Constitution's Privileges and Immunities Clause, which prevents a state from restricting nonresident visitors access to medical care within its borders; and the Commerce Clause, which prohibits state laws that discriminate against interstate commerce.

Five months later, Dr. Gideonse and the State of Oregon defendants reached a settlement in the case. As a result, the Oregon Health Authority (OHA),



Dr. Nicholas Gideonse, a hospice medical director and doctor at Oregon Health & Science University.

Oregon Medical Board and the Multnomah County district attorney all agreed to suspend enforcement of the residency restriction. The OHA also pledged to initiate a legislative request to permanently remove the residency restriction from the law.

The nonenforcement of the residency requirement means that people from outside of Oregon are able to travel into the state to access its Death With Dignity Act. Considering that 40 states still do not have the option of medical aid in dying, this is a major step forward for the movement. However, while the residency requirement has been removed, patients still need to establish a therapeutic relationship with a doctor and complete other steps to access the law. So anybody from out of state who is interested in accessing the law should start early and contact Compassion & Choices' End-of-Life Consultation team for help.

What might this settlement mean for other jurisdictions where aid in dying is authorized? "We are optimistic that we will see residency requirements removed in other states as well," said Compassion & Choices Senior Staff Attorney Amitai Heller. "Our hope is that newly introduced laws will not contain the residency language. In terms of changing

existing residency requirements, we're hoping that states will proactively recognize the problem in order to avoid litigation. If the unconstitutional residency requirements do stay in place, it's likely they will face legal challenges in the future."

"I have such appreciation for Compassion & Choices as an organization for helping move this forward," Dr. Gideonse said. "I deeply hope that this encourages states where there's not yet legal access to medical aid in dying to reconsider their position, and develop a schema that works for their residents and their doctors so that people aren't forced to use the victory we have achieved."

Cooperating attorneys at Bradley Bernstein Sands LLP and Angeli Law Group LLC were invaluable co-counsel in this case.

Compassion & Choices is dedicated to ensuring that everyone receives the best healthcare possible as they near the end of their lives. Sometimes legal representation is needed to achieve that. If you or someone you know is interested in no-cost legal help from Compassion & Choices regarding end-of-life care, visit CandC.org/legal-advocacy.

Nursing Sorority Commits to Raising End-of-Life Care Awareness

In recent years, Compassion & Choices staff and supporters have secured end-of-life care resolutions with various community entities, from the medical field to city councils to education and other advocacy groups like ours. These resolutions encourage people to educate themselves on all aspects of end-of-life planning.

Compassion & Choices African American Leadership Council member Beverly Morgan helped secure an end-of-life care and planning resolution from the Lambda Psi Nu Sorority, Inc., which she founded in 2019. Lambda Psi Nu Sorority, Inc. is a professional association of licensed nurses, both practical and vocational, that focuses on cultural diversity and community service. Nurses are trusted sources at the forefront of end-of-life care and, as such, are well equipped to provide education and resources.

A member of the leadership council since its inception in 2017, Morgan believes that people need to understand their options and exercise the same type of control and thoughtful decision-making throughout their lives, including as they near the end. “Having a choice as to how you want to live at the end — aligning your end of life with the same

level of dignity and respect you once lived — is an amazing opportunity,” she said. “Put your house in order. Share quality moments with friends and family. Be the author of your untold story by living your best life.”

The Lambda Psi Nu resolution recognizes health disparities in end-of-life care for the Black community and its lower rates of conversations about end-of-life care, resolving that “it is imperative to empower our community with information to better make informed decisions when planning for the end of life and have candid conversations with friends, family, faith leaders and medical providers about end-of-life care before a time of crisis.”

The resolution concludes, “Lambda Psi Nu Sorority, Inc. must be proactive in educating, empowering and advocating for our community at the end of life. We are committed to developing an awareness campaign to share resources with our constituents.” Compassion & Choices and our leadership councils will continue to work with organizations across the country to inform, empower and advocate about the importance of end-of-life care.



left: Lambda Psi Nu sorority.

right: Beverly Morgan, nurse, entrepreneur, community activist and Compassion & Choices African American Leadership Council member.

AANHPI Leadership Council Members Share Their Stories

The Asian American, Native Hawaiian and Pacific Islander (AANHPI) Leadership Council provided their thoughts on the intersection of end-of-life care advocacy and their communities in the following quotes.



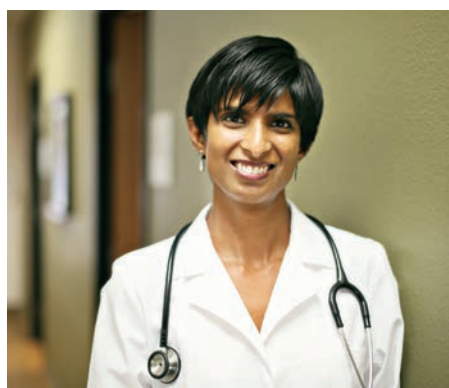
Mahina Paishon-Duarte (Hawai'i)

"The modern story of Native Hawaiians is one of resilience. When Captain James Cook mistakenly arrived in Hawai'i in 1778, he found a thriving and sophisticated society of upwards of 1 million people. He also brought with him harmful venereal diseases that devastated the native population, until only 24,000 Native Hawaiians remained in the world. I am here today as a living survivor and descendant of these 24,000, and advocate for end-of-life planning among AANHPI communities to support 'ohana (families) to prepare their beloved to rejoin their ancestors with dignity, in aloha, and to heal from historical trauma."



Dr. Mitsuo Tomita (California)

"I'm an advocate for end-of-life planning and expanded options because when someone becomes seriously ill and can't speak for themselves, it rests on loved ones to make difficult decisions. These are difficult things to talk about, to learn about and to think about. But we all eventually die, and having planned ahead can reduce some of the distress for everyone."



Dr. Sue Royappa (Texas)

"We must normalize conversations about death with our loved ones and healthcare providers. We should encourage our communities to lean on cultural strengths and practices that enable us to view a good death as part of a life well lived."

New Latino Community Videos Make Progress

The Compassion & Choices Community Engagement team has worked tirelessly to promote end-of-life education and planning in their communities. Part of this ongoing work includes a video series crafted by Compassion & Choices. The videos are in English and Spanish, and feature leadership council members, community leaders, advocates, organizational partners, staff and more. They represent individuals from many walks of life nationwide.

The videos feature personal and cultural experiences with death and dying, as well as advance care planning, dementia and medical aid in dying. They are intended to support and enhance community engagement in the Latino community and will be shared via social media ads and the Compassion & Choices website, as well as other platforms for conferences and events.

Visit www.youtube.com/CompassionChoices to view our videos on a variety of end-of-life topics.



clockwise: Participants in video series include Silverio Pérez; Nilsa Centeno; Brian Colón; Rep. Micaela Cadena and sister, Denicia; Rev. Dr. Ignacio Castuera; Monica Toquinto with her son; Norma Ang Sanchez; and Norma Vásquez de Houdek with her wife, Mary.

Celebrating LGBTQ+ History Month

Pride is traditionally celebrated every June, but many cities and towns recognize the LGBTQ+ community with parades and events throughout the summer and fall. October is nationally designated as LGBTQ+ History Month to acknowledge and honor the LGBTQ+ community's past.

Compassion & Choices continued our popular "Pride in a Box" campaign over the summer with state-based events. We also created a national communications campaign to celebrate our LGBTQ+ Leadership Council, supporters and staff. In addition, we are producing an ongoing blog series by LGBTQ+ staff about the connections between LGBTQ+ advocacy and the end-of-life options movement.

Visit CandC.org/resources/pride-in-a-box-toolkit to learn more.



Parade-goers celebrate Pride in New York.

Protecting Patients' Rights

In May 2019, the U.S. Department of Health and Human Services (HHS) released the 2019 "Protecting Statutory Conscience Rights in Health Care; Delegations of Authority" rule (2019 Conscience Rule). This new rule allowed any individual or entity involved in a patient's care to put their personal beliefs ahead of the patient's health and values. It allowed any employee to diminish the rights of patients to have autonomy in their healthcare decisions, especially at the end of life.

Following the announcement, three federal district courts vacated the rule. Although the rule was vacated, lawsuits on the rule continued. Without complete removal, the rule could still pose a threat in the future.

In January 2022, with assistance from the National Women's Law Center and the American Civil Liberties Union, Compassion & Choices penned a letter that asked Secretary Xavier Becerra for "the swift removal of the 2019 'Conscience Rule,'" leaving the 2011 rule in effect. Fifty diverse advocacy groups signed onto the letter. Among the 50 organizations that signed the letter are Catholics for Choice, Human Rights Campaign, National Women's Law Center and Planned Parenthood Federation of America. HHS formally began the rule-making process to consider removal of the rule in April 2022. The official rule will be available in the coming months.

Facing Challenges With Courage and Compassion

Our volunteers and advocates keep inspiring us to pursue the mission.

DELAWARE

Compassion & Choices Action Network sponsored a poll showing 74% of Delaware physicians support the state's End of Life Options Act, including 77% who identify as members of the Delaware Medical Society; 71% of physicians surveyed said if they became terminally ill, they would want the option of medical aid in dying. "The evidence is clear: Delaware doctors and the patients they serve are overwhelmingly united in support of medical aid in dying," said Tim Appleton, Delaware campaign director for Compassion & Choices Action Network. "It's time Delaware lawmakers honor their constituents' wishes and pass the End of Life Options Act."

FLORIDA

The Florida team is making more connections in the Sunshine State. In spring 2022, staff and volunteers had the opportunity to participate in several conferences, from Tallahassee to Miami, including the Florida Council on Aging Conference in August. We formed a new partnership with the Fearless Caregivers Conference, which provides caregivers a place to learn about new resources and educational opportunities. Florida residents and others interested in expanding end-of-life options in the state can visit the state page on our website and subscribe to a monthly newsletter email.

GEORGIA

Advocates in Georgia continue to make the case for expanded access to end-of-life options in the state. A spring visit to Clayton County's Senior Mayfest sparked a surge of activity and led to many new volunteers joining the movement, along with the opportunity to provide resources and information

to about 300 seniors in the area. A new partnership with Georgians for End of Life Options will focus on advance care directives and dementia addendums. Soon, a state-focused newsletter will be launched to share local events and community resources.

MASSACHUSETTS

Compassion & Choices Action Network sponsored two questions for a Suffolk University/Boston Globe poll that showed 77% of Massachusetts residents support medical aid-in-dying legislation, including majorities across the state's regional, political and demographic spectrum. This represents a seven-point increase from their pre-COVID 2019 poll. "I pray this poll result will spur lawmakers to pass the End of Life Options Act before it's too late for the many terminally ill people who will needlessly suffer without it," said Wenham resident JoAnn Vizziello, who has incurable blood cancer and testified in support of the bill.

MINNESOTA

The Minnesota team is focusing on community building and education. Alongside Rainbow Health and the First Unitarian Society of Minneapolis, the team hosted a Pride Month screening of the documentary "Bob's Choice" and a panel discussion that included Sen. Scott Dibble. Lavender Magazine served as media sponsor for the event, while Compassion & Choices Doctors for Dignity Program Director Dr. Rebecca Thoman talked about our work in Minnesota and the importance of planning. New storyteller Andrea Anderson also joined the movement and continues to share her father's story to inspire change and education to prevent others from needlessly suffering at the end of life.

NEVADA

The Compassion & Choices Action Network Nevada team is working hard to build another successful campaign while lawmakers prepare to file a medical aid-in-dying bill for the 2023 legislative session. Advocates continue to build relationships with legislators, healthcare providers, educators, community organizations, labor groups and others who support medical aid in dying. In addition, the team is building coalitions with Nevada's diverse faith, Latino, African American and LGBTQ+ communities to advance the movement for equitable access once the bill becomes law.

NEW JERSEY

Compassion & Choices helped secure a major victory to preserve New Jersey's medical aid-in-dying law in June, when the state's Appellate Court upheld a Superior Court's dismissal of a lawsuit seeking to overturn the law based on constitutional and religious objections. Compassion & Choices submitted an amicus brief in the case, *Glassman v. Grewal*, and made oral arguments in May to the Appellate Court urging it to affirm the Superior Court's dismissal. The law was briefly suspended for 13 days in August 2019 but reinstated when the Appellate Court ruled Superior Court Judge Paul Innes' temporary restraining order was an abuse of discretion.

NEW MEXICO

In partnership with End of Life Options New Mexico (EOLONM), the New Mexico access and implementation campaign continues in full force to ensure residents understand their full range of end-of-life care options, including medical aid in dying. To increase awareness among prescribers and navigators, Compassion & Choices sponsored the New Mexico Nursing Excellence Awards, and EOLONM provided the keynote address for the National Association of Social Workers New Mexico Chapter, with more than 650 attendees at each event. New Mexico State Rep. Debbie Armstrong, an EOLONM board member, and nurse practitioner Hunter Marshall also made a



Lindsay Wright speaking about her husband's agonizing death during the candlelight ceremony in Albany.

presentation about the Elizabeth Whitefield End-of-Life Options Act at the Nurse Practitioners Conference.

NEW YORK

Lawmakers and supporters, including the relatives of more than 20 advocates for New York's Medical Aid in Dying Act, which was originally introduced in 2016, participated in an emotional candlelighting ceremony at the state capitol in late April to honor the memory of those who died while awaiting passage of the bill. "These advocates — who have all died during the course of our six-year campaign — met with legislators, spoke at rallies and news conferences, organized family and friends, and so much more," said Corinne Carey, Compassion & Choices senior New York campaign director. "They will always hold a place in my heart and fuel my resolve to pass this bill."

WASHINGTON

In Washington state, Compassion & Choices Action Network remains an active participant in the Keep Our Care Act Coalition, in collaboration with End of Life Washington, ACLU of Washington, Pro-Choice Washington, Planned Parenthood of the Great Northwest and other organizations. The Keep Our Care Act would safeguard access to high-quality, affordable healthcare, and protect access to meaningful end-of-life care options, reproductive healthcare, and gender-affirming care in the face of mergers and acquisitions between healthcare institutions. The coalition will work to pass this critical legislation in 2023 to protect Washingtonians' healthcare.

Compassion & Choices Illinois Is Building an Equitable End-of-Life Options Movement



The Compassion & Choices Illinois team is committed to expanding access to end-of-life care and options throughout the state. A network of advocates, storytellers, medical providers and other volunteers work shoulder to shoulder with Compassion & Choices staff, meeting with lawmakers and continuing to grow the movement in the Land of Lincoln.

Nine volunteer action teams cover much of the state, sharing information and building support for end-of-life options among legislators, medical professionals and the public. Compassion & Choices is a proud co-leader of the Illinois End-of-Life Options Coalition, alongside ACLU of Illinois and Final Options Illinois.

This summer, the Twin Rivers Action Team (DeKalb/Kane Counties) just outside of Chicago hosted an event with the Geneva Public Library, featuring a screening of "Living & Dying: A Love Story." This documentary follows Charlie and Francie Emerick, a couple married for 66 years, who chose to utilize medical aid in dying together.

Other volunteers have been busy with community presentations, tabling at fairs and submitting letters to the editor. For example, the North Suburban Action Team had a full calendar of "summer coffees" with neighbors and friends to discuss planning tools, upcoming goals and how to get engaged in the movement. Midwest Advocacy Director Amy Sherman noted, "These summer coffees have been such a powerful organizing tool, and the kind of intimate connection we need as we grow our grassroots base and empower advocates to share their stories."

Also of note, the second annual Illinois Compassion in Nursing Award will honor up to three Illinois nurses and certified nursing assistants who excel in hospice and palliative care. During National Hospice Month (November) the Illinois team will choose the honorees, who will each receive a \$500 honorarium and be recognized in publications and on social media. Over 400 hospices and home hospice agencies were invited to nominate clinicians for this recognition. This award is an important way to connect with nursing and hospice organizations while honoring the incredible healthcare workers in the community.

The coming months involve more community gatherings, workshops, faith group outreach, action team meetings and legislative education.

For an up-to-date list of these activities, or to get involved, please visit the Illinois state page at CandC.org/Illinois.



“ *We gladly support Compassion & Choices through gifts directed from our donor-advised fund, an easy way to give and advance the work we care so deeply about.”*

*- Eleanor Hall and Roger Hale,
proud supporters from St. Paul, MN.*

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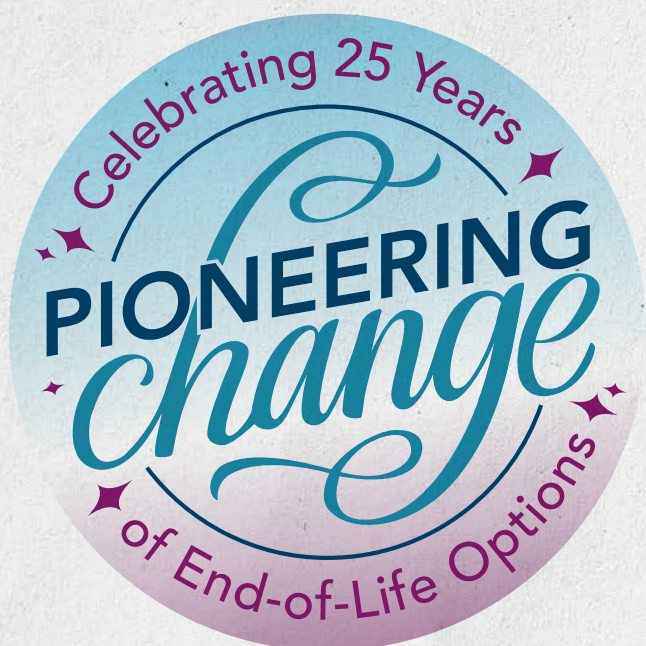
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Join us virtually on Thursday, October 27, to celebrate the strides we've made and honor those whose voices and actions are paving the way for our future success.

Register at
[**CandC.org/signature-event**](http://CandC.org/signature-event)