



compassion & choices

MAGAZINE
FALL 2021

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FEATURING

Dr. Chandana Banerjee

Compassion & Choices board member's interest in clinical equity has made her a driver for change.

Legacy Challenge Match

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Care and Choice at the End of Life



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

Progress and Possibility

This month, we feature on our cover one of our newer board members, Dr. Chandana Banerjee. As director of graduate medical education as well as assistant clinical professor in supportive medicine at the City of Hope, a comprehensive cancer center, Dr. Banerjee is also the architect behind the center's transformational End of Life Symposium.

This symposium (which is now endowed so it will continue for many more years) is a monumental step in our movement — a top cancer center known for delivering miracles that save lives recognizes that in addition to developing and delivering lifesaving treatments, providers should also be trained to support patients in death, including the full range of end-of-life care options.

Dr. Banerjee is a symbol of both progress and possibility. She represents the potential for us all to have a doctor who listens to our wishes and respects our values at life's end ... the reality that the field of medicine IS responding to consumer demand and becoming more patient-directed at life's end ... and evidence that your support and partnership with us is creating transformational change in how we live the final chapter of our lives and how we die.

As Samuel H. Golter, one of the early leaders of City of Hope, said, "There is no profit in curing the body if, in the process, we destroy the soul." How meaningful it is to know that, through our collective work, more people are dying with their souls intact.



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In the Media

[MarketWatch](#)

Diagnosed with dementia? It's hard to know how fast you'll decline, so start planning for what's next

May 14, 2021

President and CEO Kim Callinan offers advice on preparing for the end of life in the event of a dementia diagnosis, encouraging those who have been diagnosed to record video statements to accompany and affirm what is in their directives. The article also mentions the Compassion & Choices Dementia Values and Priorities Tool, which helps identify your care wishes and keep you in control, and is available at CompassionAndChoices.org.

[NJ.com](#)

33 terminally ill people in N.J. ended their lives by using the Aid in Dying law last year

May 17, 2021

Data gathered from the second year of New Jersey's medical aid-in-dying law provides detailed insights as to the education, marital status, hometown and other demographics of people who accessed the law. Matt Whitaker, Compassion & Choices national director of integrated programs, also discussed efforts to diversify who uses the law, saying, "We are trying to increase access for people who are not in populated, affluent communities."

[U.S. News and World Report](#)

California Senate moves to make assisted death law permanent

May 28, 2021

New legislation seeks to amend California's End of Life Option Act, in effect since 2016, by reducing the waiting period from 15 days to 48 hours and removing the sunset provision (the law is set to expire in 2025). Samantha Trad, Compassion & Choices senior campaign director for the state, said this move was "a bold and compassionate step toward bringing peace of mind to many terminally ill Californians and their families." At the time of publication, the bill had to pass out of one final committee.

[Spectrum News](#)

"Medical Aid in Dying Act" gaining support in Legislature after years of trying

June 7, 2021

The end-of-life options movement continues to make progress in the state of New York. There are 56 sponsors of the most recent iteration of the proposed bill — more than any prior bill. Unfortunately, the New York Legislature adjourned on June 10 without advancing the Medical Aid in Dying Act; however, this just means the bill will carry over into the 2022 legislative session. Senior Campaign Director Corrine Carey said, "A good death ... is one where you can choose, where you can die according to your own faith, your own values and your own beliefs. And that's what this bill would do."



Compassion & Choices Presents ...

An original concept album of the musical *Goodbye New York*
Music by Andrew Beall, lyrics by Evan McCormack, book by David Don Miller

Compassion & Choices is supporting this album and has an executive producer role and credit! Stay tuned for more about this exciting project in our next issue.

Dementia Tools Are Making a Difference

Compassion & Choices' online tools help more people than ever.

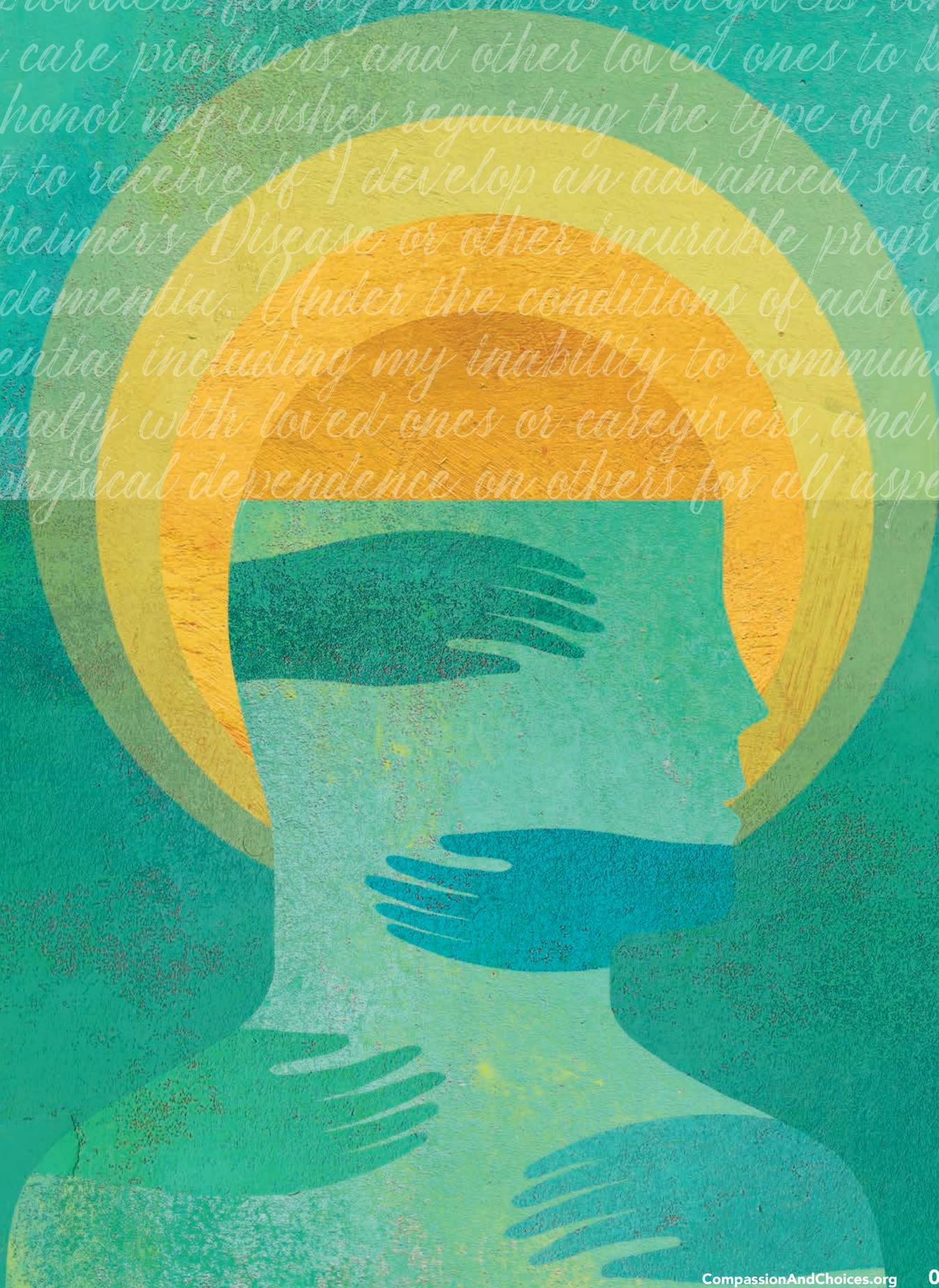
Dementia affects one in three dying older adults in the United States. Alzheimer's disease, the most common form of dementia, is the sixth leading cause of death. While this condition is rampant, few resources help families and individuals who are managing a diagnosis to understand their options.

Healthcare treatments typically include all possible lifesaving medical interventions. The majority of people with dementia continue to live for as long as eight to 10 years after their diagnosis, many of these years in the advanced stages of the disease. Without guidance, many are unable to articulate the level of treatment and intervention they would want in the event of a dementia diagnosis.

To help address this need, Compassion & Choices launched the Dementia Values and Priorities Tool and the Dementia Decoder as part of our Tools to Finish Strong initiative. The intention was to offer a set of resources to improve care and expand options at life's end by guiding users through a step-by-step process, helping them assess their own priorities, prepare for doctor visits and advocate for their chosen care decisions following a dementia diagnosis.

People with profound dementia often receive life-prolonging medical treatments — like antibiotics, pacemakers, kidney dialysis and feeding tubes — through years of mental unawareness. While this approach may align with the values and priorities of some individuals and their families, it is not for everyone. A study commissioned by Compassion & Choices found that 92% of those surveyed believe a person should have the legal right to put in writing in advance that they want their caregiver and medical team to stop medical treatments when they reach a specific stage of dementia. Eight in 10 people believe a person has the legal right to put in writing in advance that they want their caregiver and medical team to stop spoon-feeding foods and liquids when they reach a specific stage of dementia.

I am creating this document because I want my healthcare representatives/agents/proxies, medical providers, family members, caregivers, long-term care providers, and other loved ones to know and honor my wishes regarding the type of care I want to receive if I develop an advanced stage of Alzheimer's Disease or other incurable progressive dementia. Under the conditions of advanced dementia, including my inability to communicate rationally with loved ones or caregivers, and/or my physical dependence on others for all aspects of



Dan Winter's story demonstrates the importance of determining, documenting and sharing one's wishes in the event of a dementia diagnosis. Dan was resolute in his decision not to endure the same ending as his father, who suffered with dementia for 13 years, and took steps to ensure that wouldn't happen to him. Together with his husband, John Forsgren, Dan walked through the Compassion & Choices Values and Priorities Tool and selected the care options he wanted based on different stages of the disease. The result was a carefully crafted plan documenting his wishes. He then shared his intentions with loved ones. You can read more about Dan and John's journey and Dan's death through VSED (voluntarily stopping eating and drinking) in our summer 2021 issue.

Despite the best efforts of advance care planning, ensuring those preferences are followed can be a challenge. Understanding patient rights and finding a supportive team is critical to having one's wishes respected and acted upon. Sheila Callander reached out to Compassion & Choices to share the story of her mother, Margaret, who had mild dementia and deactivated her pacemaker to have a natural death in March 2017, according to her own documented wishes.

Margaret had a pacemaker for 26 years, and her heart disease was progressing into congestive heart failure. She was also diagnosed with nonterminal stage IV kidney disease. From the beginning, her family respected her wishes and supported her choice to die on her own terms. Margaret had done end-of-life planning and had an advance healthcare directive written by an attorney in 2009 that included language about not replacing her pacemaker. Before she replaced her last pacemaker in 2011, she considered "just letting the batteries run out," because she wasn't sure she wanted to live through the full lifecycle of another one. She didn't know at the time that deactivating her pacemaker was an option.

top: Dan Winter (left) and husband, John Forsgren, at their home in Portland, Oregon.
bottom: Sheila Callander (right) with her mother, Margaret.



After weeks of research, Sheila found an article presented at the 2010 Heart Rhythm Society Conference that examined the medical, ethical, legal and religious aspects of deactivating a cardiovascular implantable electronic device. In short, the article confirmed that deactivation is both ethical and legal, and is neither "assisted suicide" nor euthanasia. Still, the problem was finding someone who would perform this procedure.

Having Margaret's pacemaker deactivated was very difficult. Her medical team didn't want to be involved, and neither did the manufacturer. The family was unable to get any helpful information from the treating physicians.

One of Sheila's sisters had been contacting hospice centers, and one hospice group took an interest in Margaret's case. The staff was provided support and consultations with a physician, chaplain, nurses and social workers. The physician met with Margaret, and the full hospice staff met with the family to discuss the deactivation of her pacemaker.

The pacemaker was finally deactivated in March 2017. Margaret died 18 hours later, at the age of 90, with her five daughters at her side and the hospice physician sitting outside her door. "When Mom finally passed, I felt a mixture of sadness and relief. If I felt grief, it wasn't what I expected. I didn't feel sad, mostly grateful and also very tired. It had been a long journey and very hard on my sisters and me. Helping Mom die on her own terms, with less long-term suffering, was comforting to me. I believe everyone should have this choice," stated Sheila.

Compassion & Choices' Tools to Finish Strong help people plan for the end-of-life experience that they and their families want. The dementia tools are one very important piece of that planning. They educate and empower people to make decisions while they can still speak for themselves, before the disease takes away their voice. The need to reach wider communities has always been a goal of Compassion & Choices. To support these efforts, we have made great strides to make the tools even more accessible.

The Dementia Values and Priorities Tool is being translated into Spanish. The Dementia Decoder will be available in more than 230 languages. Both

“Helping Mom die on her own terms, with less long-term suffering, was comforting to me.”

projects are expected to be complete in September. Compassion & Choices is also reaching out to new audiences to expand the reach of the tools.

Compassion & Choices has entered into a two-year streaming agreement for a Zoom-based play about

a family's struggle to support their independent mother as she begins to show signs of cognitive decline. (See *Wooden Nickels* on page 8.) This will be a powerful vehicle to educate audiences about the benefits of advance care planning.

Peter Kaldes, president and CEO of the American Society on Aging, welcomed Compassion & Choices President and CEO Kim Callinan and Matt Whitaker, national director of integrated programs, to the *Future Proof* webcast, which aired June 21. Kim and Matt talk about the challenges facing older people with Alzheimer's disease or a related dementia, and Compassion & Choices' work to improve adoption of advance directives and documentation of desired and undesired treatments. To watch, visit <https://candc.link/asa-dementia>.

Since 2019, when we introduced this groundbreaking tool, 172,511 people have visited the Compassion & Choices website to learn more. In the last year, we have held eight webinars reaching over 1,000 people. Promoting these tools among new communities is a priority for Compassion & Choices. Through widespread advertising and continued outreach, Compassion & Choices will continue to share the tools with new audiences.

Visit Compassion & Choices' Tools to Finish Strong at CompassionAndChoices.org/finish-strong-tools.

You'll find information about the tools available to you, including the Dementia Values and Priorities Tool and the Dementia Decoder.



Wooden Nickels: Big Impact on a Small Screen

Compassion & Choices' collaboration expands death discussions through entertainment.

In the early 2000s, as a grad student studying playwriting and considering the life ahead of her, Devorah Medwin began thinking about the idea of responsibility and the roles we're given, gently or forcefully. She thought about how often we are blindsided by life's big events, like illness, aging, dying and death. Whether we become patients or caregivers, and ultimately people who grieve, we need to learn to navigate roles for which we are thoroughly unprepared.

It all started when Devorah's mother began suffering memory loss. Devorah started researching how families navigate these issues. She learned that illness, aging, death and dying most often arrive without warning, finding families poorly prepared to be patient or caregiver. Devorah's storytelling skills led her to develop the framework for a "mixed-reality" play called *Wooden Nickels*. Mixed reality allows the actors to toggle between imagination and life experience, working within the framework of a script.

Devorah was inspired by the work of Compassion & Choices early in her career, and she started asking "what if?" When a family is facing events surrounding the end of life, what if instead of trying to figure it out

by themselves, they could rely on existing tools and counsel from professionals to plan, access resources and learn how to have difficult conversations effectively?

Wooden Nickels masterfully showcases three daughters grappling with how to support their aging mother, Kiki, as she begins to show signs of cognitive decline. While they want to respect her wishes for autonomy, they fear for her safety and need to manage the logistical realities of her living situation and potential care.

When Devorah first wrote *Wooden Nickels*, the script called for a very simple set, focusing instead on the conversation. Over time, the play has been refined as Devorah's knowledge and exploration of communication has deepened, and it has been performed many times. "I knew the experience had to go beyond a performance and script," she said. "I wanted to demonstrate in real time how a family might unravel these difficult conversations and emotions. The actors, brilliant and willing to display their vulnerability, went beyond the script, bringing their own experiences and venturing into a mixed reality of improvisation, weaving their words into the play." Devorah holds a master's degree in playwriting from The Actors Studio Drama School and a certificate in

thanatology, the study of death and loss. As the director of program development at Bevival.com, a death literacy content platform, she hosts *Exit Interview*, a podcast featuring conversations with authors whose writing speaks to the end of life. Her work has been produced live; on stage, radio, television, and in virtual and mixed reality.

Years later, under a veil of COVID-19 closures, Devorah was invited to do a virtual (Zoom) performance at Pathways ARTS on Martha's Vineyard. While Devorah works hands-on with the actors and on the script, Caren Martineau, founder of Bevival.com, works to bring the play to larger audiences.

After stepping into the realm of "edu-tainment" (education through entertainment) in 2020 with the creation of *This Is Your Show*, a song written and composed exclusively for Compassion & Choices, we knew that *Wooden Nickels* offered the perfect opportunity to continue exploring new avenues to share positive messages about personal empowerment, autonomy and planning for an end-of-life experience aligned with one's personal values and priorities. *This Is Your Show* has over 110,000 views on social media, so clearly people are listening.

Compassion & Choices reached out to Devorah to work through a collaboration. After signing a two-year streaming agreement with Devorah and Caren, a plan was set to educate and entertain with this new and powerful tool called *Wooden Nickels*.

Kim Callinan, president and CEO of Compassion & Choices, noted, "We are teaching people about the importance of conversations, planning and empowerment in a way that people can relate to. Before COVID and the increased adoption of Zoom, this format might have been more challenging — but now people are used to it, and the messages come across powerfully. The inclusion of two generations is appealing to audiences of all ages."

Compassion & Choices will offer opportunities for supporters to share *Wooden Nickels* with their circles to create a deeper understanding and help them envision end-of-life planning not as a daunting task, but as a means to further their values and priorities at life's end. Stay tuned to learn more.



President Emerita/Senior Advisor Barbara Coombs Lee, playing herself, joins the family to provide consultation and a wonderful explanation of Compassion & Choices' tools and resources.

According to *Broadway World*, "Medwin adds innovation to her play with a clever segue from performance to clinical intervention. While the actors stay in character, they are joined by Barbara Coombs Lee, an expert in health policy and author of *Finish Strong: Putting Your Priorities First at Life's End*. What ensues is an informative and compelling consultation and exploration of the issues at the center of the play."

Visit CompassionAndChoices.org/finish-strong-tools to learn more about sharing your end-of-life wishes.



End-of-Life Health Equity

Compassion & Choices is working to reduce disparities in care and planning.

The end-of-life care movement has made significant progress over the past two decades, with the growing understanding of the importance of hospice care and the expansion of medical aid in dying into more states. The COVID-19 pandemic has accelerated the movement, as more of us become aware of the power of planning and documenting our end-of-life wishes — and the potential consequences of not planning.

However, data confirms that many people of color, LGBTQ+ people and people with disabilities do not have access to equitable end-of-life care. For example, millions utilize Medicare's hospice and palliative care benefits, but Black people access both at lower rates than their white counterparts. A recent study published in the *Journal of the American Medical Association (JAMA)* found that only 35% of Black study participants died using hospice services, compared with 46% of white participants. Without

adequate access to quality care and knowledge about how to pursue preferred healthcare options, historically underserved populations lack the same opportunities to chart an end-of-life journey, allowing for a peaceful death on each person's own terms.

The reasons for healthcare disparities at the end of life are complex: systemic racism and discrimination, classism, ableism, and environmental and social determinants of health are just a few.

Compassion & Choices is committed to closing disparities in end-of-life care and planning for underserved communities and advancing legislation to increase equity in end-of-life care. We continue to support a diverse, equitable and inclusive movement so that people of all demographic groups approach life's end equipped with accurate information and encouraged to claim their voice.

Our staff and volunteers do this work on a daily basis: meeting individuals and groups; speaking at churches, senior centers, medical provider conferences and so many more events. One of our primary strategies has been to ensure resources and information flow to and from community leaders and healthcare providers within specific communities. By working together with community members, we are educating, empowering and inspiring everyone — regardless of age, gender, religion, sexual orientation, disability — to take action and become drivers of their own end-of-life care plan. This work is critical, but it only addresses some of the root causes of disparities in end-of-life care.

We also recognize that broad-based change requires cooperation and resources across disciplines and among community-based, nonprofit, foundation, and local, state and federal government agencies and offices. Because so many health policy decisions occur at the federal level, as with Medicare, Compassion & Choices is actively pursuing a policy agenda in Congress that addresses health equity at the end of life.



According to a recent study, only 35% of Black participants died using hospice services, compared with 46% of white participants.

We have already begun to make progress on this front: The Compassionate Care Act, to be reintroduced this fall, will significantly expand federal resources to support advance care planning and end-of-life decision-making. If passed, the law will include a nationwide public education campaign; grants and pilot initiatives to educate providers about patient rights and the importance of developing an end-of-life care plan; and the best strategies to do so.

Similarly, the Palliative Care and Hospice Education and Training Act would promote education and research in palliative care and hospice, increase the number of palliative care professionals, and implement a public awareness campaign to educate the public on its benefits.

However, that is just the beginning. This fall, Compassion & Choices will partner with other organizations doing this important work to convene our first-ever policy summit focused on health equity at life's end. This conversation will bring together a dozen experts in related disciplines to develop a policy agenda designed to reduce disparities and create equity at life's end. By the end of the summit, we will walk away with a clear set of options and recommendations informed by research, analysis, knowledge and insight to advance federal policy.

Compassion & Choices will continue to advocate for federal legislation that puts in place policies to address disparate access to advance care planning and end-of-life care services among traditionally underserved communities.

Making Progress Together

Compassion & Choices continues providing opportunities for education and action.

CALIFORNIA

Over 100 Compassion & Choices Action Network supporters joined a Zoom call to celebrate the fifth anniversary of California's End of Life Option Act on June 9 and the May Senate passage of SB 380 to make the law permanent and improve access to it. Featured speakers included the law's co-authors, Sen. Susan Talamantes Eggman and retired Senators Bill Monning and Lois Wolk. Civil rights icon Dolores Huerta, a lifelong Catholic, delivered the closing remarks: "... It was the leadership of Bill Monning and Lois and Susan that helped me change my mind on this ... then ... I went full force to make it happen."

COLORADO

Following a terminal cancer diagnosis, Silverthorne resident Andrea "Mimi" Ankerholz was determined to have an end-of-life experience that aligned with her values and priorities. After multiple providers would not or could not facilitate Mimi's use of Colorado's medical aid-in-dying law, Compassion & Choices End-of-Life Consultation professionals provided information and a list of healthcare facilities where she could find one who would support her decision. Mimi received an outpouring of support when she shared her cancer journey via TikTok. She spoke eloquently about the role of her Catholic faith in her end-of-life journey, saying, "I finally came to the conclusion after a lot of thought and prayer ... my God would not want me in this kind of pain without having an option. And He's given me this option."

FLORIDA

Florida Sarasota Action Team leaders have been busy creating a summer schedule of Zoom webinars titled *Sarasota Advance Directives — a Three-Part*

Conversation. They plan to work with groups of individuals to ensure their advance directives are completed by the end of the monthly workshop, along with information related to Compassion & Choices dementia care tools. Sarasota residents who missed the June series will have another opportunity to participate in the conversation in September.

HAWAII

This past summer, the Hawai'i State Department of Health released its annual report on the Our Care, Our Choice Act (OCOCA). Thirty-seven prescriptions for medical aid-in-dying medication were written by 14 different doctors, almost all on the island of Oahu. The report reiterates the department's recommendation to amend the OCOCA by allowing qualified advanced practice registered nurses to participate, and by waiving the waiting period between the state's mandated first and second verbal requests if doctors determine the patient will not survive it. Hawai'i currently has the longest mandatory minimum waiting period between the two required oral requests (20 days). Compassion & Choices continues to advocate for these changes to the law in the Hawai'i Legislature.

ILLINOIS

Compassion & Choices hosted a community Q&A forum with the filmmakers of the award-winning documentary *Bob's Choice*. Over 50 people attended the virtual event based on the powerful film that followed the life of Bob Fuller, a 75-year-old Seattle LGBTQ+ activist who accessed the compassionate option of medical aid in dying in his home state of Washington. They also launched bilingual videos of Chicagoan Miguel Carrasquillo to commemorate



the fifth anniversary of his death from brain cancer and demonstrate the need to introduce and pass a medical aid-in-dying law in Illinois. The Illinois team also launched its virtual advocacy summer with a phone-banking campaign to ask supporters across the state to meet with their legislators.

MASSACHUSETTS

Compassion & Choices Action Network's campaign to pass the Massachusetts End of Life Options Act is preparing witnesses to testify at a likely fall hearing before the Joint Committee on Public Health, co-chaired by lead Senate bill sponsor Sen. Jo Comerford. To rally supporters, Westborough resident Amanda Baudanza recorded a video about her husband's death from metastatic cancer. "TJ endured weeks of unnecessary suffering and spent his final days in excruciating, unbearable pain," she said. "I made a promise that I would continue to fight for this legislation ... Please do reach out to your elected officials and press the urgency of this."

MINNESOTA

A powerful voice for patient autonomy and end-of-life options fell silent earlier this year with the loss of St. Paul resident Marianne Turnbull to ovarian cancer. Marianne testified several times before the Legislature in favor of the End-of-Life Options Act; gave radio and TV interviews; lent her image to digital ads; signed letters to the editor; and single-handedly persuaded her hometown legislator, Rep. Rena Moran, then the chair of the House Health Committee, to convene a hearing on the medical aid-in-dying bill in 2019. While Marianne died without access to the law she fought so hard for, our advocates have vowed to continue in her memory and will be back at the Capitol in 2021.

NEW MEXICO

Compassion & Choices Action Network launched a bilingual New Mexico Access Campaign to educate the public on all options for the end of life and to provide technical assistance to medical providers and

healthcare systems about the Elizabeth Whitefield End-of-Life Options Act, which went into effect on June 18. New Mexico is the 10th state and 11th jurisdiction to allow medical aid in dying as an option for terminally ill, mentally capable adults.

NEW YORK

Compassion & Choices advocate Dr. Robert Milch, an internationally recognized palliative and hospice care physician who co-founded one of the nation's first hospices in Buffalo, died of cancer in June. Just hours before his death, Dr. Milch authored an op-ed to accompany a video he recorded in 2017 urging lawmakers to pass medical aid-in-dying legislation. The Empire Report posted them one week after he died. His op-ed concluded: "Legislators, you need not endorse this end-of-life care option, but for goodness' sake, don't prohibit it. And by not acting on it, that's exactly what you're doing." His family vows to continue his advocacy.

OREGON

Compassion & Choices Action Network collaborated with other statewide organizations to push for the passage of the Equal Access to Care Act. This new law requires the state to review any proposed mergers or acquisitions involving hospitals and healthcare systems to ensure they don't jeopardize patient access to affordable and comprehensive care, including the full range of end-of-life options. Recent research shows that consolidation in healthcare leads to higher prices, does not necessarily improve quality and can lead to reductions in services. The financial pressures brought on by COVID-19 are expected to increase the rate of consolidation in healthcare nationwide.

A Legislative Session Like No Other

Delaware medical aid-in-dying bill reintroduced with record number of co-sponsors.



Tom La Follette testified twice in support of HB 140 before he died in 2020.

Compassion & Choices' 2021-2022 campaign to pass the Ron Silverio/Heather Block Delaware End of Life Options Act (HB 140) started strongly on June 30 when it was reintroduced by Rep. Paul Baumbach with nine co-sponsors — a record number since its first introduction in 2017.

The co-sponsors include four key legislative leaders whose influence could spur lawmakers to pass it when the Legislature returns in 2022: Senate Majority Leader Bryan Townsend; Sen. Sarah McBride, chair of the Senate Health & Social Services Committee; Sen. David P. Sokola, chair of the Legislative Council; and Rep. David Bentz, chair of the House Health & Human Development Committee.

The legislation would improve access to medical aid in dying by allowing both physicians and advanced practice registered nurses to prescribe life-ending medication. The bill is named in honor of two

deceased Delaware advocates, Ron Silverio and Heather Block, who both died in 2018 with needless suffering because they did not have the option of medical aid in dying.

"As Heather Block was dying in 2018 from terminal breast cancer, she courageously and relentlessly worked side by side with me to lobby Delaware lawmakers and the governor to enact the End of Life Options Act that 72% of Delaware voters now support," Compassion & Choices CEO and President Kim Callinan told Delaware's Cape Gazette.

"Ron also bravely advocated for a Delaware medical aid-in-dying law until the end of his life, including authoring an op-ed and recording a video posted by the Delaware News Journal four days before he died," said Compassion & Choices Delaware Campaign Director Tim Appleton. "Just two days later, the paper's influential columnist at the time, Matthew Albright, wrote a column endorsing the bill entitled 'The voices of the dying changed my mind.'"

Mark Hayden, Tom's husband, posted an op-ed to the Delaware State News website, along with Tom's last advocacy video. "Despite suffering from painful lesions throughout his body caused by a terminal cancer called Kaposi's sarcoma, my late husband, Tom La Follette, testified twice in recent years in support of [this] bill," wrote Mark. "Tragically, our state lawmakers did not pass medical aid-in-dying legislation before Tom died ... I urge our lawmakers to honor their constituents' wishes by passing Delaware's End of Life Options Act in 2022 so Tom's, Ron's and Heather's selfless advocacy for this gentle dying option won't have been in vain."

national programs update

Virtual Advocacy Didn't Slow Down Progress

We are less than 100 days away from the beginning of the next legislative season — when the majority of state legislatures across the country kick into high gear.

Just as the COVID pandemic changed all our lives, it changed the way our governments could operate. Suddenly, the days of bringing supporters like you face-to-face with your lawmakers were gone.

But Compassion & Choices and Compassion & Choices Action Network supporters didn't let the pandemic hold them back. We sent 20,000 messages to elected officials (a third of which were customized with personal stories and notes). Dozens of activists met with lawmakers in Zoom rooms or testified in virtual hearings.

And as sessions came to a close, our work continued. Supporters were equipped with shareable resources to ensure friends and family were supported in their most difficult decisions — from materials to help



decoding an Alzheimer's diagnosis to a guide for talking to your doctor about tough and painful subjects.

Now we're gearing up for what comes next and a return to state capitols. We're increasing our reach in crucial states, boosting our volunteer numbers and identifying our most active supporters.

To become a volunteer, sign up today at CompassionAndChoices.org/volunteer.

African American Mayors Association Resolution



On May 14, 2021, the African American Mayors Association (AAMA) adopted a resolution to educate, empower and advocate around end-of-life care for African American communities. The resolution was sponsored by Mayor Tim Ragland of Talladega, Alabama, and passed unanimously at the mayors' February 2021 meeting. The AAMA, founded in 2014, is the only organization exclusively representing African American mayors in the United States, with the goal of empowering local leaders for the benefit of their citizens.

Resolutions such as this provide a powerful endorsement of important issues and are critical to building momentum for end-of-life options nationwide.

national programs update



Dr. Micheal Fratkin speaking at our *Staying Stronger Together* Webinar Series: National Healthcare Decisions Day Town Hall.



A previous in-person End of Life Symposium at City of Hope in 2019.

Healthcare Advisory Council

Compassion & Choices Healthcare Advisory Council celebrated its one-year anniversary in June. In that year, the council has made tremendous progress. It provided feedback to recommendations for Compassion & Choices' comments on the CARES Act. Members from the council, including Dr. Michael Fratkin and board members Dr. Chandana Banerjee and Dr. Csaba Mera, spoke on multiple educational webinars, including our highly successful collaboration with City of Hope through Dr. Banerjee, which attracted thousands of new participants over a nine-part series.

President and CEO Kim Callinan and Dr. Banerjee appeared on an ASA podcast called *State of Movement With End-of-Life Care: Medical Aid in Dying* (www.asaging.org/asa-studios#leverage).

The council began a new initiative identifying key opportunities to advance research in addressing healthcare disparities at the end of life. To learn more, see page 10. They also started a new program to reach medical students, residents and fellows pursuing careers in hospice and palliative care. The council will continue to assist in identifying new partnership opportunities across the country for sharing our tools and resources.

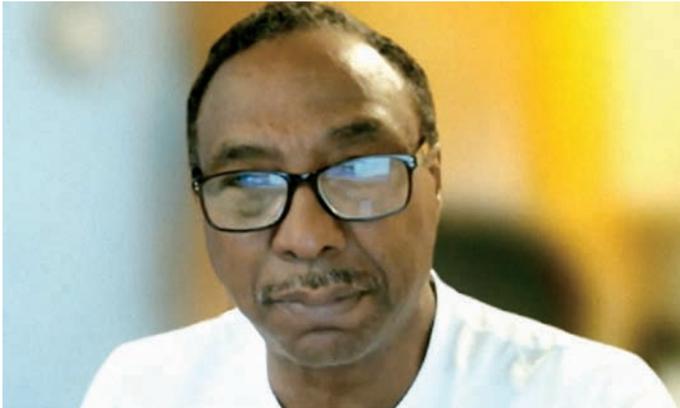
End-of-Life Symposium

After nine successful collaborative webinars totaling 12,000 registrants, Compassion & Choices continues our successful collaboration with City of Hope with the upcoming End of Life Symposium on Dec. 16 and 17 at the Waldorf Astoria Las Vegas. This symposium will have both live and virtual registration options. The in-person option will feature a three-hour interactive workshop.

This carefully curated symposium includes a variety of topics related to the end of life: pediatric and geriatric end of life, prognostication, medical aid in dying, humanities and spiritual care at the end of life, clinical and psychosocial care at the end of life, end-of-life options, communication skills, and advance care planning. The symposium is approved for AMA PRA Category 1 Credit™.

Compelling speakers from the end-of-life arena will create a powerful experience for both in-person and virtual attendees. Compassion & Choices board member Dr. Chandana Banerjee, featured on the cover of this issue, is leading the effort with the City of Hope to establish a forum for end-of-life discussions and learnings.

To learn more and register, visit
CompassionAndChoices.org/EOL-Symposium.



Rev. Madison Shockley, advocate and Compassion & Choices board member, discusses end-of-life options and his faith community.

Faith-Based Volunteer Groups

On July 8, Compassion & Choices presented a virtual Zoom gathering for its Faith Leaders for Choice volunteer group. This event provided participants the opportunity to meet one another and discuss issues centering around faith and end-of-life options. Kim Callinan, Compassion & Choices president and CEO, was the featured speaker.

The recently formed Catholics for Compassion volunteer group advises Compassion & Choices on Catholic engagement and supports the work by coordinating clear, passionate but respectful actions and messages to help equip Catholics and their families who are facing questions about suffering and the end of life. As part of their advocacy work, members of the group write letters, submit op-eds or letters to the editor, contact policymakers, and plan to visit legislative offices. The level of involvement is based on each person's interests and comfort level.

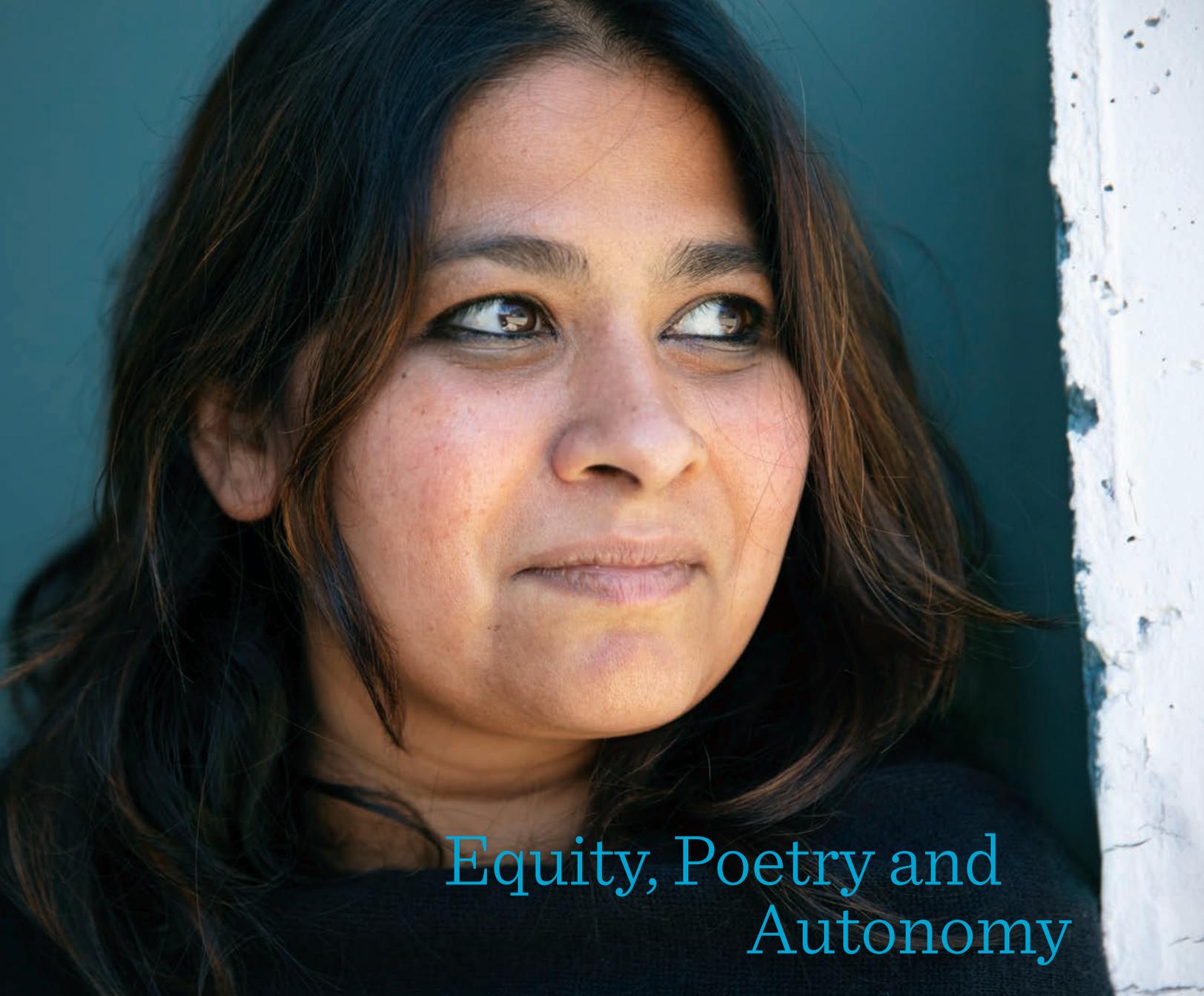
Landmark Federal Ruling

On April 6, 2021, the Federal District Court of Idaho issued a decision in *Almerico et al. v. State of Idaho et al.* In this landmark ruling, the court held that the Pregnancy Exclusion was not a required element of a valid and enforceable directive, and further ruled that the defendants' previous interpretation of the Act requiring the pregnancy exclusion violated the plaintiffs' constitutional rights.

In its decision, the court held that Idaho's law violated an individual's constitutional right to refuse unwanted medical treatment, as the U.S. Supreme Court first recognized in *Cruzan v. Director, Missouri Department of Health*, stating: "Women do not lose these rights because they are pregnant when they fall into a coma ... " The court further ruled that: "[t]he pregnancy exclusion also violates the First Amendment, which prevents the Government from compelling individuals to express certain views, just as it prohibits impermissible Government censorship of speech."

"This decision is a victory for tens of thousands of women of child-bearing age in Idaho." said plaintiff Hannah Sharp, who was pregnant when the lawsuit was filed in May 2018, but since has given birth and lives in Boise. "I am so thankful to now have the peace of mind that my directive will be valid and enforceable, despite lacking the pregnancy exclusion language.

The ruling could have repercussions for pregnancy exclusions in over 30 states, including 10 states with severe restrictions: Alabama, Indiana, Kansas, Kentucky, Michigan, Missouri, South Carolina, Texas, Utah and Wisconsin. The case has been appealed to the Ninth Circuit Court of Appeals. Compassion & Choices continues to work diligently to protect the healthcare decision-making rights of all people.



Equity, Poetry and Autonomy

Esteemed physician, thought leader, Compassion & Choices board member and gifted writer Chandana Banerjee believes everyone deserves a good death.

Born in India and raised in Connecticut, Dr. Chandana Banerjee's love of writing had her drafting poetry at age seven and graduating with honors from the University of Connecticut with a degree in literature. A concurrent interest in serving vulnerable populations drove her to pursue a master's in public administration from New York University, leading to a position in Medicaid helping children who had no insurance. "That's something I've always been drawn to," says Dr. Banerjee. "How do we bring equity and access to people who don't have it?"

Then the abrupt and unexpected death of her beloved father from emergency hernia surgery while visiting India shifted her focus entirely. She wouldn't write again for a decade.

"What blew my mind is that even with the access to high-level care and medicine he had, his post-surgical course, I believe, was not well managed. He got septic and passed away quite suddenly. It was very shocking and tormenting. It took a long time for me to come to terms with it," Dr. Banerjee recalls. "If someone truly has access and still doesn't have the appropriate options presented to them, or the appropriate prognostic information or care given to them, it's obviously a far bigger problem for people who don't even have that kind of access. How much is medicine doing a disservice to them?"

Dr. Banerjee entered medical school with a long-term focus on education and clinical equity. As a resident, she encountered many cases where patients were at the end of life or had diseases with the need for extensive advance care planning that required support and advocacy in having their preferences honored. Her experiences compelled her to pursue a fellowship in palliative and hospice medicine and to grow in the specific niche of end-of-life care as a clinician.



Dr. Chandana Banerjee speaking at City of Hope's 2019 End of Life Symposium.

“There’s no reason why, if we wish to have a good life, that we wouldn’t wish to have a good death.”

“Even with palliative medicine, there’s really a spectrum of what doctors consider the right kind of care,” she says. “You find yourself in situations where prognoses are not communicated completely to patients, so they end up having to make a lot of last-minute choices because they were never fully informed or hadn’t appropriately planned for the next step. That’s what got me even more drawn into end-of-life care specifically.

“One thing I realized very clearly, not just from my own past experiences but throughout my training and as I treated patients, was how important it was for patients with decisional capacity to really have the autonomy to choose not only how they wanted to live but also how they wanted to die. It always is about the patient. I firmly believe that. We all have roles and responsibilities in every relationship. The physician’s role and responsibility is to manage the disease and the disease process. But I don’t think anyone has the right, if a patient is dying, to force them to live under the auspices of a trial or some personal belief they may have. So that’s why I’ve always been a proponent of options for the patient, and very much about educating physicians and other clinicians, and society in general, about the way the end of life should be approached.”

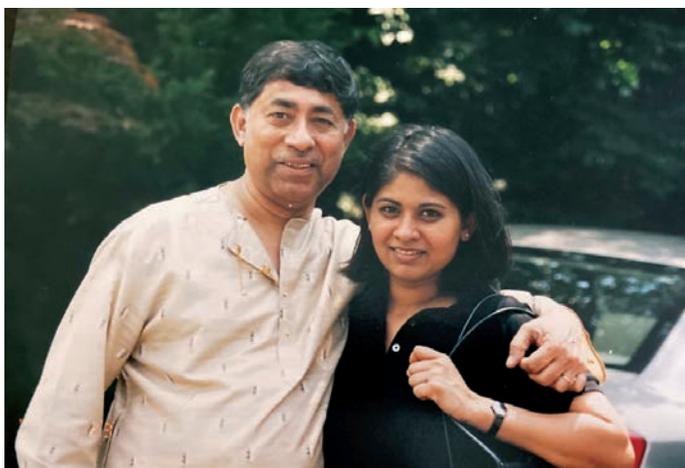
Dr. Banerjee’s motivation to inform others about the importance of options and autonomy led her to develop the End of Life Symposium through City of Hope, the renowned National Cancer Institute

designated cancer center near Los Angeles, where she is a faculty member. First held in-person in 2019, the symposium has since been endowed for multiple years through a generous donor's support and resulted in a remarkable webinar series through May 2021 to accommodate limitations of the pandemic.

"I always wanted to put together a conference that was focused specifically on the end of life — a conference that would not only attract clinicians but other people, so that as a society we start changing the way we look at the end of life," Dr. Banerjee explains. "There's no reason why, if we wish to have a good life, that we wouldn't wish to have a good death. If possible, you should be able to choose a good death! That's how I got involved with Compassion & Choices. Their mission of bringing equitable end-of-life education and options to patients is very much my philosophy. I see myself in a natural partnership that brings together the best pieces of what end-of-life care should be perceived as in society. The organization's collaboration with City of Hope on the End of Life Symposium has brought a level of excellence to the quality of and education on end-of-life care that is unique and encompassing of all end-of-life issues."

After a 10-year hiatus, Dr. Banerjee finally returned to writing. Her first book of poetry, *Ashen Leaves*, was published in 2020. "Writing is my way of coping," she says "But after my father died, I just couldn't bring myself to. I realize it was me not knowing how to express my grief, even though writing has always been that outlet for me. On the last day of my hospice and palliative medicine fellowship, in which we had to keep a journal, my final entry was the poem I wrote after a decade of not writing. I wrote *Grieving to Grieve*, which is a tribute to my father. Published in the Journal of Pain & Symptom Management, it gave me the nudge I needed to start writing again. That just got me going; I haven't stopped since. It's my way of being in touch with every situation around me. I always tell people to find the one thing that's special to them.

"As my favorite Sufi poet Rumi said, 'It's your road, and yours alone. Others may walk it with you, but no one can walk it for you.' This is a perspective that I have started sharing with everyone that I care for, including my patients. At the end of the day, culture, religion, all these things aside, it ultimately comes down to what each individual wants, and we always need to respect that."



Dr. Banerjee with her father



excerpt from *Ashen Leaves*

*Today, I will let go of him
Today, I will free myself
Today, I will grieve for us
Today, I will celebrate.*

The Purple Lady Joy of Giving Challenge

THANK YOU to Barbara Meislin for her generosity in issuing *The Purple Lady Joy of Giving Challenge* to help reauthorize and improve the California End of Life Option Act before it expires! Barbara has made an extraordinary commitment to match every gift of \$10,000 or more, dollar-for-dollar, up to \$250,000*!



Barbara, widely and affectionately known in the San Francisco Bay Area as “the Purple Lady,” strongly believes that color has a profound effect on the body, mind and heart. “For me, purple is the color of joy. It’s a way to connect deeply with other people, and it is my hope that *The Purple Lady Joy of Giving Challenge* will do just that.”

A donor to Compassion & Choices for 27 years, Barbara became a supporter after her brother’s very painful, heartbreaking death. She made a promise: “No one, if I can help in any way, will experience such suffering. That experience led me directly to Compassion & Choices.”

Barbara was a vital supporter of the historic campaign to pass the California End of Life Option Act in 2015. Due to an expiration clause in the current law, however, Californians will lose this compassionate option if the law is not renewed. Barbara is determined to ensure California’s nearly 40 million residents retain access to this important end-of-life option.

Barbara invites you to join her in supporting Compassion & Choices’ work through *The Purple Lady Joy of Giving Challenge*.

To learn more about Barbara and her challenge, visit candc.link/TPL. Gifts of all levels are appreciated and have an impact.



The Compassion & Choices family is comprised of two organizations: Compassion & Choices (the 501(c)(3) arm), whose focus is expanding access, public education and litigation; and Compassion & Choices Action Network (the 501(c)(4) arm), whose focus is legislative work at the federal and state levels. Contributions to Compassion & Choices Action Network (C4) are not tax-deductible as charitable contributions or business expenses.

* Gifts of \$10,000 or more to either Compassion & Choices or Compassion & Choices Action Network will be matched with equal gifts to Compassion & Choices Action Network, thanks to *The Purple Lady Joy of Giving Challenge*! A total of \$175,000 has already been raised, but there is still \$75,000 left in the *Challenge* to unlock as of August 2021.



Care and Choice at the End of Life

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PURPOSE POWER AND PROMISE

A Virtual Celebration to Benefit
Compassion & Choices

Wednesday, October 6, 2021

7 p.m. ET / 4 p.m. PT

Virtually, wherever you are!

This special evening will be full of inspiring stories and a strong feeling of community to benefit Compassion & Choices. National leaders will provide updates on the incredible progress we're making to transform end-of-life care. The event is free with a minimum suggested donation of \$50.

Register at:

candc.link/virtualbenefit