

compassion & choices

MAGAZINE
WINTER 2020

Generations Align
Around Dying

.....

Preempting
Dementia Decline

.....

Beyond Black
History Month

Five Questions for Anna Camp

The beloved actress tackles
end-of-life choice in her
moving new film *Here Awhile*



Who Will Support the Next Generation of Changemakers?



YOU CAN ... Through Your Legacy Giving

Compassion & Choices Board Chair David Cook and his wife, Ann Thompson Cook, know that creating a world where everyone is empowered to chart their end-of-life journey takes more than a lifetime.

That's why David and Ann created a Legacy Gift — a future contribution through their estate plans. How? They named Compassion & Choices as a beneficiary of their individual retirement accounts (IRAs). At the end of their lives, a percentage of their IRAs will be donated to advance our work.

"We want to continue our support and help the next generation after we're gone. The beneficiary designations were so easy to do," said David.

To hear David and Ann talk about their Legacy Gift, visit CompassionAndChoices.com/Beneficiary-Designations where you'll find a brief video.

To learn more about beneficiary designations and other legacy giving options, contact our planned giving staff.

Contact 800.247.7421 x2152 or email PlannedGiving@CompassionAndChoices.org.
Visit online at CompassionAndChoices.GiftPlans.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.

Across Generations, Among Communities

Death: It's the one thing we all have in common. At some point in our lives, each of us experiences the loss of a loved one, and eventually, we will all die ourselves.

In this issue, we intentionally and randomly reach out to individuals across a span of age groups, including some less directly involved in the movement, to gauge their perspectives on the end of life. From Baby Boomers through Millennials, we heard a universal openness and awareness around the topic of death. I found this heartening and a promising indicator of our potential to continue creating a future where autonomy through death is accepted as a fundamental human right.

We see a similar awakening about the importance of end-of-life planning taking place across racial and ethnic groups. In that light and in recognition of Black History Month, we also feature our work to empower African Americans to take charge of their end-of-life care.

And finally, we highlight an approach to end-of-life planning for a condition that is gripping all generations and all races — dementia. We introduce you to a storyteller whose fears of suffering a prolonged existence with severe dementia have motivated him to use Compassion & Choices' new dementia tools — tools that we hope all our supporters, and many others, will use.

While death is the one thing we all have in common, so is life. Over the years, I have come to realize that our work together is not just about dying, it is about living. All too often, we live in fear, unwilling to embrace the inevitability of death and unwittingly robbing ourselves of the ability to fully live the time we have left. And so, with that in mind, I invite you to join me in 2020 in supporting the option to live boldly, with acceptance, courage and compassion.



Kim Callinan

Kim Callinan
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The New York Times

"The Role of Nurses When Patients Decide to End Their Lives"
(September 6, 2019)

Nurses play a vital role in end-of-life care, including when medical aid in dying is involved. This New York Times story details how nurses can be sources of comfort in the final moments of a person's life, including a nurse who was a volunteer advocate for Compassion & Choices.

People

"Mom-of-4 with Incurable Cancer, 45, Plans Her Death with Dignity: 'I Want to Die on My Own Terms'"
(October 9, 2019)

Hanna Olivas, a Las Vegas woman with an incurable rare blood cancer, shares her desire to live and die on her own terms. She is advocating for passage of a medical aid-in-dying law in her home state of Nevada, but realizes she may need to move to California to access this compassionate option. Hanna tells People, "The idea itself is terrifying, but ... I won't be in pain. I'll be in peace. That's all you can ask for."



NJ.com

"N.J. woman used new law to end her life. 'I'm ready, let's do it.'"
(October 18, 2019)

Zeporah Geller became the first publicly known patient to use New Jersey's medical aid-in-dying law since it took effect on August 1. NJ.com reported that it took two months and calls to 40 doctors for her to find two physicians to help her use the law. Matt Whitaker, director of integrated programs for Compassion & Choices, said many healthcare systems have not yet developed policies about whether they will allow their doctors to participate in the law. "There is a learning curve to get people up to speed," he said.

San Francisco Chronicle

"Brittany Maynard's profound legacy on end-of-life options"
(November 1, 2019)

The late Brittany Maynard, a 29-year-old terminally ill Californian who advocated for medical aid in dying, shared her story with the world five years ago and transformed the end-of-life options movement. Compassion & Choices CEO and President Kim Callinan and Dan Diaz, Brittany's husband, explain her outsized impact in a powerful op-ed for the San Francisco Chronicle. "She took control of how her final months played out, and in doing so, she exposed the cruel and pointless injustices in our end-of-life care system, and helped patients reclaim their voice so they can live their final chapter consistent with their values and priorities," they wrote.



Generations Share Perspectives About the End of Life

Boomers, Gen Xers and Millennials Are on the Same Page About “The Final Chapter”

Americans of all ages are concerned about death. Their own death, the death of their loved ones and the impact of their decisions on the dying experience weigh heavily on most everyone. Preparing for dying is complicated and invokes intense thoughts, fears and emotions.

Perhaps you have seen the data. Over the past several years and among multiple demographics, Americans support the concept of steering one’s own end-of-life experience, including 72% in favor, according to a 2018 Gallup poll. And while there is support among the different age groups, there are also variations and similarities between generations.

According to a 2017 U.S. Census Bureau report, with an aging population, there will be a historic increase in the number and percentage of people who die each year. Recently, as we have witnessed more momentum in passing legislation in support of medical aid in dying, how has this changed America’s comfort level with discussing death, if at all? Are Americans preparing advance directives? Are we making plans for a dementia diagnosis?

We decided to ask a few representatives from each generation to share their perspectives on the end-of-life experience, including medical aid in dying.

Generation Y, or Millennials (those born between 1980 and 1994)

A number of research studies, including the Achieve and Case Foundation's Millennial Impact Report, suggest that Millennials are largely driven by social issues, perhaps aligning their beliefs directly with our mission.

Ramona Pyos (*Washington, D.C.*) works for a government agency in the nation's capital. "I am afraid that my end-of-life experience will not be meaningful. I am afraid that it will not be planned, that it will be sudden and unexpected. It is one of my greatest fears," Pyos said. "I deal with death on a daily basis because of my profession. The thought of not being here with my family at this point of my life is hard to wrap my head around. I have discussed my end-of-life wishes with my immediate family more times than I would like to. As much as I don't like to talk about it, I have discussed them."

Shanna Anderson (*Portland, Oregon*) shared that her parents differ on their own end-of-life care. "I'm worried that if they don't put their wishes in writing, we — their kids — won't be able to make the choice they would have most wanted," Anderson said. And her own beliefs? "I would rather my family have the chance to let me go and move on to the grieving process. If it's something degenerative like Alzheimer's,

I would want to know I could make arrangements for myself while I was still mentally competent to give my family the most guidance possible," she noted.

For Brandon Johnson (*College Park, Maryland*), his main concerns for himself and his loved ones are unnecessary pain and suffering, time spent in the hospital and financial costs. "My greatest hope is that we will have available to us a way to prevent suffering, to have peace with each other and a meaningful closure at the end of life," he said. "I have not spoken about my end-of-life experience with anyone, but I am more than comfortable with the conversation. Death of a loved one is difficult to talk about in general, but I'm happier knowing the ways they prefer to end their life and make it less painful and stressful on them, whatever that may be."

Generation X (those born between 1965 and 1979)

Members of Generation X are often lauded for their entrepreneurial spirit. It was Gen Xers, after all, who founded Google, YouTube and Amazon. But does their embrace of innovation seep into their beliefs about the end-of-life experience?

Jason Gaulden (*Denver, Colorado*) is vice president of partnerships at America Succeeds and a member of Compassion & Choices' African American Leadership

Council, an advisory group of leaders who represent a host of professional and social interests, and who are dedicated to engaging the African American community with the end-of-life dialogue. "Too often, having candid conversations about death — and proactively planning for it — is still uncomfortable territory for a lot of African American families, mine included," he said. "The topic is treated with reluctance and avoidance. I guess the inevitability of death sometimes triggers feelings of powerlessness. Without clear, properly documented end-of-life plans in place, it leads to family feuds, legal challenges and costly financial consequences. I don't want that for my family and loved ones."

He added, "It's also important to normalize the conversation. These conversations help combat the stigma and overcome the taboo around the subject of death. The time to have these conversations and ensure our affairs are in order is now, not at a time of emergency or crisis."

"At age 41, I'm thinking deeply about these issues and taking action. Using an advance planning guide and toolkit (a free resource from Compassion & Choices), I am working my way through the very comprehensive checklist of critical considerations, decisions and documentation."

Jody Hoyos (*Alexandria, Virginia*) is a senior vice president at Prevent Cancer Foundation. "My greatest hope for myself and my loved ones is to feel safe, comfortable and without suffering as we enter the end of life," Hoyos said. "I am very comfortable talking about end-of-life wishes. Each of us will face an ending to this life, and if having a plan and talking about individual desires brings comfort, I'm all in. It can be incredibly stressful for people without children or with children who are not likely to play a role in end-of-life care to know who to talk to or lean on."

Hoyos continued, "My husband and I have talked about our end-of-life wishes with each other. We

have not talked to other family members about our wishes though. It really would be a good idea to all talk together, but it's the one area of life I have continued to procrastinate. We started to draft our end-of-life wishes with an advance directive, but it's been sitting in a pile for years, and I'm not even sure where it is right now. And I did not even know a dementia provision existed."

Michelle Manire Fowle (*Los Angeles, California*), a community organizer and activist, said, "I would want the end-of-life experience to be as peaceful as possible, with family around. But up to the point of actual death, I would want counseling onsite for the emotional and spiritual pain one will likely be going through as they reflect back on the meaning of their life." She acknowledged that she had an advance directive with a dementia provision, noting, "The minute my father got dementia, my husband and I did that."

Baby Boomers (those born between 1946 and 1964)

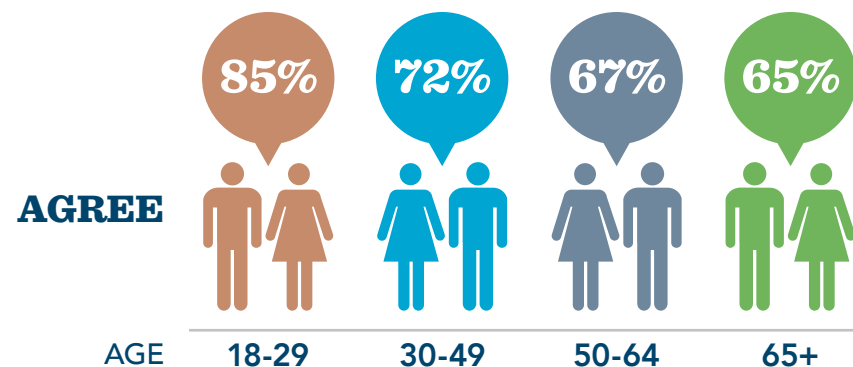
Baby Boomers make up just under 23% of the current U.S. population, and the majority are still in the workforce, according to a 2019 Pew Research Center study. But as they eye retirement, is life's final chapter also on their minds?

Mary McMahan, RN, PSN (*Parker, Colorado*) is a retired perinatal and informatics nurse specialist. "I do not want any efforts to prolong my life," she said. "Should I experience a sudden, unexpected life-threatening event, up to three or four days on life support would be acceptable, to allow time for my children to travel to be with me and say goodbye. But once all have arrived, interventions to prolong life are to be discontinued within 24 hours."

McMahan shared her personal experiences about her husband's sudden death from ALS. "We all knew he didn't want any interventions (no feeding tube or

AMERICANS SUPPORT MEDICAL AID IN DYING ACROSS DIFFERENT AGE GROUPS

"When a person has a disease that cannot be cured, do you think doctors should be allowed by law to end the patient's life by some painless means if the patient and his or her family request it?" (*Gallup Poll, May 2018*)





Leading an Inclusive Movement

tracheotomy) and that his choice was to die at home. He experienced a very peaceful and dignified end of life. Knowing that his wishes were respected helped us all accept the loss of our loved one, though we miss him greatly.”

McMahon also acknowledged her fears of a potential dementia diagnosis. “Recently, I have struggled with the concern that I might someday need dementia care, since my 96-year-old mother died six weeks prior to my husband from complications of Alzheimer’s disease, and now my 73-year-old brother is showing signs of dementia.”

Joan Eisenstodt (*Washington, D.C.*), principal of Eisenstodt Associates, lives with debilitating pain and disability. “Like I hear many people say, I too would like to die easily in my sleep. I don’t know that it is that easy — unless one has the option of choosing to die legally ... my fear is that anyone who may help me may be implicated in my death,” Eisenstodt said. “As a meeting professional for so much of my life and someone who always upgrades flights to first class (so I am ‘flying the plane’) because I’m a bit of a control person, I do want control of my end-of-life experience.

“What I find painful is that many do not want to talk about their own end-of-life wishes and cut others off

from having those conversations,” Eisenstodt added. “We are such a strange society. When my spouse and I redid our wills some years ago, before compassion in dying became the law in D.C., we discussed with each other and with our attorney. I’ve discussed with my primary care physician, and he has our directives. I am clear about what I want and do not want. The U.S. makes dying so difficult.”

Cathy Ivory, PhD, RN, BC, RNC-OB (*Nashville, Tennessee*) is with Vanderbilt University Medical Center. “As a labor and delivery nurse, I believe the end-of-life experience is just as important as the beginning-of-life experience. My greatest hope is that the end-of-life experience is treated as such,” Ivory said. “My mother died earlier this year, and my husband and I discussed that no one asked her about her end-of-life wishes, but she accomplished them anyway.”

Whether retired or just starting a professional journey, Americans of every generation recognize the importance of having an end-of-life experience that aligns with one’s wishes. Though there may be differences in our political, economic and social priorities, we will all face death. And there seems to be a shared recognition that we want that “final chapter” to be one we write ourselves. ■

Diversifying the end-of-life movement and creating a welcoming and inclusive space for people of color is an organization-wide initiative. Led by Brandi Alexander, national director of constituency, Compassion & Choices has brought the issue of all African American healthcare disparities and end-of-life conversations to many communities at churches, conferences and even Capitol Hill.

This Black History Month we honor leaders from the African American community who are committed to ensuring that all Americans are empowered to make informed end-of-life decisions. Advocates like Dr. Omega Silva of Washington, D.C., Rev. Dr. Paul Smith of Silver Spring, NY and Rev. Madison Shockley of Carlsbad, CA, have been focused for more than a decade on advancing our mission. Compassion & Choices African American Leadership

Council members are actively working to ensure that resources are being distributed widely and that people are having open and candid conversations about the end of life. In fact, the council launched a Facebook page to help get the message to an even wider audience and conducted 14 meetings with Congressional Black Caucus offices.

Compassion & Choices is also participating in Black History Month celebrations around the country, highlighting our African American supporters and staff through a blog series, and being included in USA Today’s Black History Month edition — on newsstands during the entire month of February and distributed online to more than five million subscribers.

When recognizing our work with people of color this month, we must also recognize how far we



still have to go. We invite you to join us in celebrating Black History Month, but also in extending that recognition throughout the entire year. We have a lot of work to do to ensure that equitable end-of-life care is available to all people, and we, as an organization, will work toward making that possibility a reality.



Honoring Rep. Elijah Cummings

This Black History Month, we continue to honor and celebrate the life and work of Maryland Rep. Elijah Cummings, who died last October. In 2018, Rep. Cummings publicly endorsed the Maryland End-of-Life Option Act. We are grateful to him for speaking out in his home state about medical aid in dying and join the countless others who remember Rep. Cummings’ leadership on so many important issues.

In My Own Words ...

by Dan Winter

Compassion & Choices storyteller Dan Winter serves on the boards of the American Civil Liberties Union (ACLU) and the ACLU of Oregon. Diagnosed with early-stage Alzheimer's disease two years ago, Dan wants to avoid the agonizing decline his father suffered. In the meantime, he is lending his voice to our new initiative to raise awareness about the need for more compassionate ways to die with dementia.



Dan Winter discussed his dementia diagnosis at the Compassion & Choices Oregon event celebrating the 21st anniversary of the first-in-the-nation Death With Dignity Act.

My story is not unique. Everyone knows about Alzheimer's and related dementias. It's a truly awful disease: unforgiving, relentless and ubiquitous.

Having Alzheimer's disease means that every day you are forced to accept some degree of loss. The things that make you human are under attack.

At age 70, my super-independent, always-on-the-go dad got his Alzheimer's diagnosis — and he died 13 years later.

The last day that I saw my father was several months before he died. We sat silently together; he couldn't speak nor meet my eye nor understand the simplest words. He didn't know who I was. He didn't know who anyone was. He didn't know who he was. It was advanced-stage Alzheimer's, and it was brutal.

It occurred to me on that day that Dad was devoid of his humanity, his rabid individuality, his personhood. His distinct sense of self had slipped away. To me, the only thing left that defined him as a person was his failing body. There was no empathy, no intelligence, no humor, no self-awareness, no yearning, no anxiety, no love. There was no HIM. It was lights out.

Then I got mad as hell. The tears in my eyes were not sadness; they were from anger. Had Dad been able to see himself on the day of my last visit, he would have been horrified. It was then that I vowed to myself that if I ever got a terminal diagnosis, I would work to determine the manner and timing of my own death. I began to think rationally about my own mortality, how I wanted to live and how I wanted to die.

To honor him, I told myself I wasn't going to die like he did — without agency, without choice ...

In 2011, I decided to move to Oregon. I could have moved anywhere in the country, but I chose Oregon in part because of its Death With Dignity Act. My kids thought that a bit weird, but ultimately our conversations about my move to Oregon sparked conversations about my views on the end of life.

All that talk got startlingly real when about two years ago, at age 59, I got my own dementia diagnosis. Early-stage, they call it. Likely to become full-blown Alzheimer's, they said.

Immediately, I began thinking about my end-of-life preferences. Things had to be different than my dad's experience. To honor him, I told myself I wasn't going to die like he did — without agency, without choice, without the capacity to feel love.

Now I am trying to be up front with friends and family about the intentional life I want to lead from here on. I'm also up front about the death I want and the death I don't want. I want to outsmart Alzheimer's and deny it the ability to erase my personhood during my last lap.

After my diagnosis, I addressed my biggest fear about this unpredictable and stealthy disease. As I said to my loved ones, "I'm not scared to die. But I am scared to live — to the bitter end — with this insidious disease that will steal my capacity to do the things that make me human."

I let my driver's license expire this year because I don't want my kids and my amazingly supportive husband to have to force me to do so as my disease advances, when I won't be thinking straight about the risks that

RESOURCES FROM COMPASSION & CHOICES:

Dementia Values & Priorities Tool

This tool walks those living with dementia and their caregivers through the common stages of dementia and helps them to identify when, if ever, their goal for care may change from "do everything possible" to "allow for my natural death." The tool allows users to create a Dementia Healthcare Directive to add to a standard advance directive, which empowers healthcare proxies to implement critical, informed decisions — guilt-free — on a patient's behalf.

Dementia Decoder

This tool allows those living with dementia and their caregivers to indicate the current status of their dementia diagnosis, specify what they hope to learn and accomplish from an upcoming clinical appointment, and customize that experience from a list of helpful questions. Responses can then be printed or emailed to a provider or family member to ensure that these high-stakes medical appointments allow for the important discussions that everybody in the room needs to be part of.

Find these tools and other resources at CompassionAndChoices.org/finish-strong-tools

I present to others. The new Compassion & Choices' Dementia Values & Priorities Tool already helps me face practical questions like that. With the help of these new tools, I am developing the emotional skills to address my end-of-life options. There is nothing else out there like this. To me, it's been a godsend to realize I have choices that I didn't know I had.

To hear more of Dan Winter's story, please visit CompassionAndChoices.org/stories/dan-winter.

Connection Through Constituency Efforts

Compassion & Choices' robust Constituency Outreach program has been actively engaging, empowering and educating communities of color, faith leaders, LGBTQ people and healthcare professionals.

With the understanding that the need for end-of-life education is universal, our focus has been continuing to build organizational relationships, develop resolutions and work with state leaders to help advance on-the-ground efforts.

In August, SAGE, the leading national LGBT elders organization, endorsed medical aid in dying. "Within our LGBT community, many elders are haunted by the memory of loved ones suffering from HIV/AIDS, for whom aid in dying became all the more important ... LGBT and end-of-life options movements are deeply intertwined." Compassion & Choices sponsored a SAGE event in Washington, D.C., over the summer.

On November 1, Compassion & Choices staff and African American Leadership Council member Shawn Perry represented our work at the fourth annual Caregiver Conference, which was hosted by TERRIFIC Inc. in Washington, D.C. This wonderful community-based event, held annually in the nation's capital, focuses on providing quality caregiving services to those in need. The theme, "Caregiving: a Choice, a Challenge, a Commitment, a Celebration," ties directly into our work with the African American community as we seek to educate and inspire communities across the country to embrace end-of-life discussion and planning. Shawn Perry was the master of ceremonies for the second year in a row, and Compassion & Choices was an exhibitor at the

conference, engaging more than 200 attendees about the importance of advance care planning.

Later in the month, City of Hope, a world-renowned cancer research and treatment center, held its first-ever End of Life Symposium. Over 250 doctors, nurses, health professionals, researchers and others attended this daylong symposium located just outside of Los Angeles. Attendees were energized to learn how to support and honor their patients' end-of-life priorities. The goal of the symposium was to address and manage symptoms at the end of life, define the role of hospice, outline California's End of Life Option Act, explain advance directives and identify resources to help provide support for caregivers. The exhibit hall featured 11 booths, sponsored mostly by local hospices.

The symposium featured Compassion & Choices President Emerita/Senior Adviser Barbara Coombs Lee as the keynote speaker. Compassion & Choices CEO Kim Callinan gave the closing remarks, summing up the monumental day. Dr. David Grube, Compassion & Choices medical director, and Samantha Trad, Compassion & Choices California state director, gave presentations on California's End of Life Option Act. Dan Diaz, end-of-life options advocate, presented on the end-of-life experience and legacy of his late wife, Brittany Maynard.

Compassion & Choices was also an exhibitor at the National Baptist Convention Inc. annual gathering in New Orleans. This was an opportunity to speak to attendees about the importance of advance care planning and end-of-life education. Compassion & Choices' Faith Communities for Choices — a new initiative to foster positive relationships with faith leaders — now has 42 members!

On October 9, People magazine featured a story on Hanna Olivas, Latina mother of four with incurable blood cancer who plans to move from her home state of Nevada to California to access medical aid in dying (see page 3 for more details). Hanna, a 45-year-old makeup artist from Las Vegas, was inspired by Brittany Maynard's advocacy for end-of-life options. Hanna's story was also covered by Today.com, the Tamron Hall Show, HLN, and Spanish-language giants Univision and Telemundo.

We again hosted a Day of the Dead (*Dia de los Muertos*) celebration in San Diego on November 1. Nearly 60 people gathered at the city's First Unitarian Universalist Church to remember those who died working to pass the California End of Life Option Act. The service was presided over by Elizabeth Semenova, MSW MTS, and ordained by the Universal Life Church. Speaking at the event about the importance of access to medical aid in dying were Hanna Olivas, Dan Diaz, Amanda Villegas, Dr. Lisa Heikoff and Samantha Trad. Diaz's late wife, Brittany Maynard, died exactly five years prior, on November 1, 2014. A retired Kaiser Permanente physician, Dr. Heikoff specialized in geriatrics and palliative medicine. The event featured photos of loved ones displayed on the altar, and some attendees painted their faces in the traditional *calaveras* style of white skulls with colorful features.

top: City of Hope End of Life Symposium was attended by over 250 participants. center: Dr. Chandana Banerjee spoke at the City of Hope symposium. bottom: Dr. Lisa Heikoff spoke at our Day of the Dead celebration in California.



Reaching Across the Nation

Compassion & Choices Is Forging a Path for Expanded End-of-Life Options.

Five years ago, Brittany Maynard and Dan Diaz’s decision to partner with Compassion & Choices to share Brittany’s story super-charged the end-of-life options movement. Brittany had been diagnosed with terminal brain cancer at the age of 29 and wanted to bring attention to her forced relocation from her California home to Oregon, so she could utilize medical aid in dying and advocate for similar laws in California and other states nationwide. Brittany helped create an environment conducive to authorizing medical aid in dying in **California** (2015), **Colorado** (2016), the **District of Columbia** (2017), **Hawai’i** (2018), **New Jersey** and **Maine** (2019).

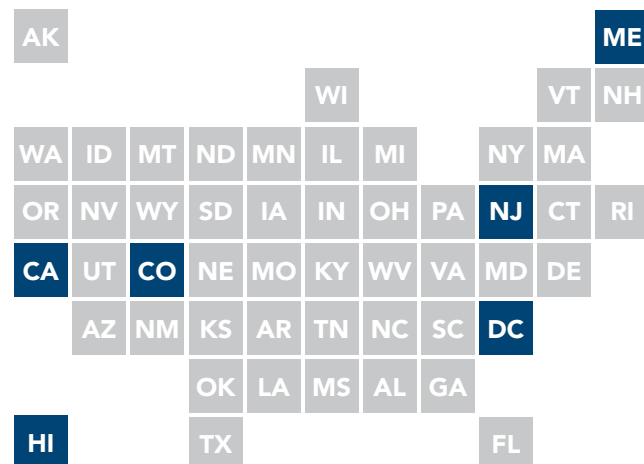
The momentum for expanding and protecting end-of-life options across the country has never been stronger, with unprecedented support building in states such as **Illinois**, **Florida** and **Minnesota**. We have ambitious goals for the upcoming 2020 state legislative session, during which we expect lawmakers in as many as 21 states to introduce bills in favor of medical aid in dying. In addition to the good work being done in these states, we expect bills to be introduced again in **Utah**, **Alaska** and **Arizona** in 2020, and are laying the groundwork for successful campaigns in **New Mexico** and **Nevada** in 2021.

Read on for some of the advocacy activities we’re expecting next year and information about our efforts to educate and empower individuals to choose their end-of-life care.



left: Brittany Maynard appears on the cover of People magazine, Oct. 27, 2014, sharing her story with the world. top: After Brittany’s passing, she and her husband, Dan, appear on the cover of People, Jan. 26, 2015.

FIVE STATES AND D.C. HAVE AUTHORIZED MEDICAL AID IN DYING IN THE LAST FIVE YEARS SINCE BRITTANY’S DEATH



Our efforts in **Massachusetts** this session will include a letter from doctors urging a committee vote on pending legislation to authorize medical aid in dying. The 17-member Joint Committee on Public Health held a public hearing on the bill in June. If you are a physician who would like to sign-on in support, visit CompassionAndChoices.org/madocs19.

In November, we got some sad news from **New Mexico**: Our friend Bill Johnson, an important voice in the campaign to authorize medical aid in dying, died on Tuesday, October 29. Bill was a U.S. Army veteran and longtime public servant, having served as secretary of the New Mexico Human Services Department and for decades as CEO of the University of New Mexico Hospital. His legacy lives on in our advocacy work.

New Mexico remains primed to consider medical aid-in-dying legislation, hopefully in the very near future. We anticipate that our previous bill sponsors will reintroduce legislation for the next 60-day legislative session, scheduled for 2021. In 2018, Governor Michelle Lujan Grisham told the Albuquerque Journal, “We should provide patients with humane end-of-life options, including medical aid in dying for terminally ill, competent adults.”



New Mexico Senator Liz Stefanics (bill cosponsor) speaking at a lobby day at the New Mexico Capitol in 2019.

We were busy building momentum in **New York** last summer and fall, with public outreach and petition drives at both large and small community events, including NYC Pride/WorldPride and the Brooklyn West Indian Day Parade, an arts festival and farmers market in western New York, and a health fair on Long Island. In addition to our persistent grassroots efforts, we’ve been working diligently to shore up legislative support by driving phone calls into targeted legislative offices and holding meetings with lawmakers in their district offices. New York’s Medical Aid in Dying Act has more than 50 cosponsors as lawmakers headed back to Albany in January for the 2020 legislative session, and Governor Andrew Cuomo has publicly urged the Legislature to pass the bill.

In neighboring **New Jersey**, we’re prepared to face any legal or legislative challenges to the medical aid-in-dying law enacted in 2019. In August, a state judge granted a temporary restraining order preventing physicians from writing prescriptions for medications in accordance with the law. The appellate court granted a request by New Jersey Attorney General Gurbir Grewal to overturn the suspension and, as a result, the law was reinstated and will remain in effect pending future court activity. We will continue to vigorously defend the legal right of New Jerseyans to use this compassionate option when lawmakers return to Trenton.

Thanks to the continued support of advocates like you, we’ve been able to add New Jersey medical facilities — at least one facility within 50 miles of every city in the state — to our Find Care Tool. The Find Care Tool helps terminally ill individuals and their families find healthcare facilities that allow physicians to prescribe medical aid in dying. You can use the tool to explore facilities in New Jersey at CompassionAndChoices.org/find-care.

advocacy in action

Members of our **New Jersey** team have led educational presentations on the New Jersey legislation at several organizations, including the state's Home Care & Hospice Association, the New Jersey Advanced Practice Nurses Association, the New Jersey Hospital Association and New Jersey Board of Pharmacy. On October 21, Compassion & Choices Director of Integrated Programs Matt Whitaker and Planned Giving Advisor Sam Young, JD, LCSW, presented to a sold-out crowd at the New Jersey Association of Social Workers' 2019 Health Care Social Workers Symposium. Their presentation focused on the role of social workers as advocates and educators on end-of-life care.

Also as part of our medical education efforts, in October the Western Clinicians Network (WCN) — a peer-led volunteer professional association of clinical leaders of community health centers in western states — sponsored a free educational webinar hosted by Compassion & Choices National Medical Director Dr. David Grube. Around 100 people signed on for the webinar, for which physicians practicing in **California, Hawai'i, Arizona** and **Nevada** were able to claim continuing medical education credit for attending.

Compassion & Choices launched a new statewide education campaign in **Florida** to ensure that health-care systems, hospices, long-term care facilities and resource providers in the state have policies in place that guarantee access to all legal end-of-life options. In addition to those trainings, Barbara Coombs Lee hosted *Finish Strong* book presentations in Sarasota and Naples to sold-out audiences in November.

On Wednesday, September 11, the **Minnesota** End-of-Life Option Act (HF 2152) received an information-only hearing in the House Health & Human Services Committee. More than 100 supporters wearing our signature yellow t-shirts came out to show their support for the bill. Barbara Coombs Lee testified, accompanied by storytellers Marianne

Turnbull, Bobbi Jacobsen, Dr. David Plimpton, Rev. Harlan Limpert and volunteers Tara Guy and Stephanie Jirik. The hearing made a big splash in the media with over a dozen stories and coverage in the Washington Post. While no vote was taken, this was a tremendous success and a milestone for the bill in Minnesota. Our hope is that the committee will hear the bill and pass it out of this committee in 2020.

Our **California** team celebrated the release of a new comprehensive study on aging and illness by the California Health Care Foundation (CHCF) on October 30. Among the findings is sustained support for the End of Life Option Act: 75% of Californians, a resounding majority, approve of the state's medical aid-in-dying law across race, ethnicity and income levels. In addition to these very encouraging results, the CHCF report supports the education and outreach our Access Campaign is built on: patient-directed care and a desire to have complete information about end-of-life options. Nearly 9 in 10 people expressed a desire for palliative or hospice care if they become seriously ill, but only 4 in 10 receive this care. Only 1 in 5 seriously ill or senior patients talked with their physician about their choices for the end of life. We continue to encourage doctors to discuss these issues with their patients.



A hearing on Minnesota's medical aid-in-dying bill was attended by over 100 Compassion & Choices supporters.

In October, nearly 250 **Illinois** residents attended forums in Normal and Chicago featuring Compassion & Choices President Emerita/Senior Adviser Barbara Coombs Lee, author of *Finish Strong: Putting YOUR Priorities First at Life's End*. The forum was hosted by the Illinois End-of-Life Options Coalition, a group comprised of ACLU of Illinois, Final Options Illinois and Compassion & Choices. Support for end-of-life options continues to grow in the state, with nine Action Teams conducting outreach to local legislators and communities, hosting events, and raising awareness about end-of-life planning and the option of medical aid in dying in the media.

Access efforts continue in **Hawai'i** as we mark one year of implementation of the Our Care, Our Choice Act. In October, we worked with the Department of Health to host a summit on the new law. Our partnership with the Department of Health in Hawai'i is integral to the success of outreach and education efforts. We are also helping physicians connect with each other through our Doc2Doc hotline, which offers support as they consult with patients about their end-of-life values.



Compassion & Choices Midwest Regional Campaign Manager Amy Sherman speaking to a group of Normal, Illinois' residents.

You can help propel the movement forward and protect the progress we've already made together.

- » **FOLLOW** Compassion & Choices on Facebook, Instagram and Twitter, and sign up for our mailing list at CompassionAndChoices.org/join for the latest legislative updates.
- » **VOLUNTEER** any way you can; find options at CompassionAndChoices.org/volunteer.
- » **DONATE** to help us protect decades of hard-won progress toward self-determination for the terminally ill in our country at CompassionAndChoices.org/donate.

With so much progress being made across the country, it can be hard to keep current! We have resources to keep you up to speed on the latest local and national news in the movement to expand and defend end-of-life options:

- » **VISIT** CompassionAndChoices.org/in-your-state for the latest information on events and activities near you.
- » **SIGN UP** for our mailing list at CompassionAndChoices.org/join to receive real-time updates on our advocacy campaigns, including our monthly e-newsletter.



Five Questions for Anna Camp

Star of such diverse works as HBO's *True Blood*, the *Pitch Perfect* movie series and NBC's new comedy *Perfect Harmony*, actress Anna Camp recently completed filming *Here Awhile* about a woman seeking medical aid in dying.

Q: You started acting in the second grade. Has the reality of a career in that industry been anything like you thought it would be back then?

A: No, it has not! It's definitely been a wild ride. Where I am today I did not see coming at all. I thought I was only going to do theater when I moved to New York after college. I was going to do Broadway and off-Broadway. Then *True Blood* came along and pulled me out of New York and brought me to Los Angeles in this kind of surprising way, and I started doing more TV work, which led to film work. It's been a lot of ups and downs. I've dealt with lots of rejection in this career, and as a kid growing up you don't think about that as much. Luckily I keep working, but it's been a rollercoaster for sure.



top: Actress Anna Camp's character confronts terminal cancer in "Here Awhile."



right: Anna in a scene with costar Kristin Taylor.

Q: You seem equally adept at comedy and drama — even singing. Do you have a favorite type of performance?

A: I don't really. I love all mediums and all tones. What I love the most is a very complex character whether I'm doing something crazy and off-the-wall like in *Unbreakable Kimmy Schmidt* or *True Blood*, or doing something very real and grounded and difficult like I did in *Here Awhile*. So good writing is key for me to really enjoy acting.

Q: Speaking of *Here Awhile*, in that film you play a woman who chooses to use Oregon's Death With Dignity Act. How familiar were you with end-of-life issues prior to that?

A: I was not that familiar. I've had people in my life who were diagnosed with cancer — no one terminal thank goodness — but I definitely did a lot of research, which was very moving. It was overwhelming at first taking on this role, but I was honored to do it.

Q: What kind of research did you find helpful?

A: I watched the documentary *How to Die in Oregon*, and that really opened up my mind and my heart. I also did some reading on what it's like to be in hospice. It taught

me so much about what people and their families are going through, and how important the right to choose is. That's something I believe on all fronts; we shouldn't be told what we can do with our own bodies.

Q: Do you think entertainment such as film, television and theater can serve as an instrument for social change?

A: Yes, 100%. As an actor of course you want to make people laugh and be entertained, but it's these types of stories you don't get to play often that are the important ones. When you get to bring a voice to someone who's fighting for their right to use the Death With Dignity Act in a state that doesn't allow it, I feel that movies and TV shows like this can get the word out. This is a topic that people shy away from — most people don't want to talk about death. But we're all ultimately going to die at some point; it's inevitable. Some of us are lucky and will die at an old age peacefully in our beds, and some are forced to suffer. No one should be forced to suffer. To have a method like this, to die at your own pace and to have control at a time in your life when you feel like everything is out of your control, there's no greater gift than that because we do only get one life. I just hope that people see this film and are moved by it.

Three Generations of Giving

When I was 6, my father, Chester Nimitz Jr., read aloud *Charlotte's Web* to my sisters and me. The book was our first encounter with mortality, and it triggered our first family discussion about the cycle of life and death.

During my teenage years, our parents talked a lot about how best to live and die. Along the way, they began to make donations to organizations that supported end-of-life liberty. Likewise, we baby boomers open our checkbooks and our personal networks to support Compassion & Choices.

Translating conviction into action has also caught on with the younger generation: In New York, my niece Beth recently opened her home for a Compassion & Choices fundraiser, and on the west coast, my son Peter serves the organization as an executive volunteer.

And so the cycle is renewed: My father's initial investment in a cause close to his heart has become a family enterprise that continues to shape our own stories.

Betsy Van Dorn

Former Compassion & Choices board member and longtime donor





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