

# compassion & choices

MAGAZINE  
SUMMER 2021

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René Auberjonois talks  
about taking control  
over terminal cancer.**  
*Five Questions for Judith Auberjonois*



# Pride — AND — Purpose

Matthew Nelson and Kip Beardsley's wedding in Sherwood, Oregon.

We've been involved with Compassion & Choices since 1994, when Oregon passed the nation's first medical aid-in-dying law. Our experience at multiple bedsides during the height of the HIV/AIDS epidemic solidified our core belief that autonomy, agency and dignity at life's end are fundamental human rights. We are so grateful for the opportunity to advance this cause through our regular contributions, legacy giving and past service on the national board.

**Support autonomy, agency and dignity at life's end by visiting [CompassionAndChoices.org/pride-2021](https://CompassionAndChoices.org/pride-2021) or calling 800.247.7421 today!**



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

## Reshaping the Culture of Death and Dying

Medicine has given us the gift of longer and healthier lives. It has also changed how we die. Death today is rarely sudden, and for some comes later than we would like — descending upon us, sometimes slowly and with great pain and suffering.

The understanding that we will die is clear, particularly as we age or are diagnosed with a serious or terminal illness. But the nature of death, given advances in modern medicine, is what gives many of us pause — making our movement so critically important.

This month's issue is brimming with stories of the many heroes who are helping us reshape the way care is delivered at life's end and enable people to chart an end that is consistent with their own values and priorities. They are the changemakers who are reshaping the conversation about death. They are the many, many people who gave everything they had over the course of several years to bring medical aid in dying to New Mexico residents. They are gutsy and resolute people who have died trying to leave this life on their own terms and the loved ones who courageously tell their stories. And they are you — the supporters, volunteers, donors and allies who continue to push for change in end-of-life care in our country.

Few of us know when death will come; we all know that it eventually will. Preparing for death is one of the greatest gifts we can give to ourselves and those we love.



*Kim Callinan*

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& choices

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## In the Media

### Mercury News

**"Dear Abby: She's not the cancer-battling type, but he won't accept that"**  
Nov. 23, 2020

In "Dear Abby," the nationally syndicated column, the advice columnist Jeanne Phillips responded to a reader whose mother suffers from advanced lung cancer. He and his twin brother disagree as to what choices they feel are best for their mother. Phillips stated, "I firmly believe in a person's right to make their own decision when it comes to continuing or discontinuing treatment for a terminal illness." Phillips recommended two books to help guide discussions: *Finish Strong* by Compassion & Choices President Emerita Barbara Coombs Lee, and Diane Rehm's *When My Time Comes*, which is also a PBS documentary of the same name.

### Los Angeles Times en Español

**"Piden apoyar proyecto para mejorar acceso a muerte asistida en California" ("They ask to support a project to improve access to assisted death in California")**  
March 24, 2021

Civil rights icon Dolores Huerta and Hollywood actor Mauricio Ochmann, both longtime Compassion & Choices supporters, were quoted in this piece voicing their support for improvements to California's End of Life Option Act. Ochmann said, "We must uphold this compassionate law for terminally ill Californians, including Latinos and those living in underserved communities, so they do not have to suffer at the end of their lives." The current law is scheduled to expire at the end of 2025, but lawmakers have authored a bill, SB 380, to remove this sunset provision and reduce the current 15-day waiting period.

### Kaiser Health News and TIME Magazine

**"Getting a Prescription to Die Remains Tricky Even As Aid-in-Dying Bills Gain Momentum Across the U.S."**  
March 29, 2021

This nationally syndicated Kaiser Health News article published by TIME Magazine examined the obstacles people who seek medical aid in dying still face in the state of Montana. The story quoted Compassion & Choices President and CEO Kim Callinan as saying, "People who are seeking medical aid in dying want to live, but they are stricken with a life-ending illness." The latest legislative attempt to criminalize medical aid in dying in Montana stalled on a tie vote March 1, 2021.

### Agencia EFE

**"Hanna Olivas quiere una muerte digna y peleará para conseguirla" ("Hanna Olivas wants a dignified death and will fight to get it")**  
April 7, 2021

Nevada resident Hanna Olivas, who suffers from multiple myeloma, has become the face of the medical aid-in-dying initiative in the state. Nevada lawmakers are again considering the End of Life Options Act (AB 351), which would expand end-of-life healthcare options in the state.

## Reading List

### Choosing To Die: A Personal Story

by Phyllis Shacter

This is an honest, moving, detailed account of Shacter's husband, Alan's, concurrent diagnoses of cancer and Alzheimer's, his path to VSED (voluntarily stopping eating and drinking), and how their story continued after his death. Shacter covers a broad range of related topics, including spirituality, religion, alternative modalities, grief and healing.



# New Mexico Makes History Passing Innovative Bill

**After years of work, a team of advocates see passage of the Elizabeth Whitefield End-of-Life Options Act.**

Compassion & Choices, the Compassion & Choices Action Network and the New Mexico End-of-Life Options Coalition made history with passage of the Elizabeth Whitefield End-of-Life Options Act. Despite the alarming and swift onset of COVID-19, or perhaps because of it, lawmakers finally followed the desires of the majority of New Mexico residents by supporting legislation to give eligible terminally ill adults the option of medical aid in dying. Gov. Michelle Lujan Grisham signed the bill into law on April 8. New Mexicans will be able to access this compassionate option on June 18, 2021.

In 2016, after the state Supreme Court decision, a formidable and diverse group of local leaders came together to establish the New Mexico End-of-Life Options Coalition. Compassion & Choices, a national advisor and member of the coalition, has been the primary source of funding since its inception.

Together we launched a robust bilingual, multifaceted campaign including extensive media outreach to Spanish-language publications. Compassion & Choices and the Compassion & Choices Action Network funded an on-the-ground organizer, rural outreach coordinator, lobbyist and communications staff. Together with our volunteers and supporters, we organized hearings; placed paid, earned and social media; and inspired strong grassroots efforts. Volunteer advocates shared their stories and support through emails, phone calls, lobby days, social media and videos. Compassion & Choices secured the participation of New Mexico native and civil rights icon Dolores Huerta, who advocated throughout the state, recording videos in English and Spanish to urge fellow residents to support the bill.

With years of public education, grassroots organizing and lobbying behind us, we came into the 2021 legislative session in a strong position, knowing that

this very well could be the year terminally ill New Mexicans' voices were finally heard. With an all-virtual session, we leveraged the power of our diverse storytellers to put a human face on the issue, flooding news outlets with story after story of terminally ill residents who don't have the luxury of time and need the relief that this law affords them now.

Legislative sponsors and local legal experts carefully drafted a bill that proved to be a turning point in the movement, recognizing the need for a more appropriate balance between safeguards and access. We reviewed and provided input throughout the process. Lawmakers sought to eliminate excessive, unnecessary barriers. This bill includes key provisions allowing advanced practice registered nurses and physician assistants to serve as prescribing or consulting clinicians; streamlining the waiting period to 48 hours; and clarifying healthcare providers' obligations if they object to participating in medical aid in dying.

This law is a momentous achievement for New Mexicans. It also represents a new chapter for the end-of-life options movement. For the first time since the Oregon law was passed in 1994, lawmakers debated the merits of the law, questioning whether it could be improved to ensure more people could access it.

Key to success were the extraordinary bill champions, Rep. Deborah A. Armstrong and Sen. Elizabeth "Liz"

Stefanics, who gave their hearts and souls to this effort; the local leaders who served as expert witnesses and brought credibility to the efforts; and the powerful storytellers who described their personal experiences with this issue. In partnership with the New Mexico End-of-Life Options Coalition, volunteers and supporters, we secured endorsements from local organizations and resolutions within central municipalities; spoke at local events, health fairs and town halls; and put a human face on legislation for communities across the state.

The bill was endorsed by a collection of professional medical and advocacy organizations. Many of the major medical societies took positions of engaged neutrality. We also created a collaboration with Ventanillas de Salud, a national health outreach program implemented by the Mexican Consulate's Secretary of Foreign Affairs and Mexico's Secretary of Health.

This victory continues the trend of authorizing medical aid in dying in an average of one new state per year as we progress toward our strategic goal that half the U.S. population lives in an authorized state by 2028. Ten states plus Washington, D.C., now authorize medical aid in dying. Our victory was made possible through the unified effort of Compassion & Choices, the Compassion & Choices Action Network and the New Mexico End-of-Life Options Coalition. Together we made history.



left: The NM bill was named for Elizabeth Whitefield (shown with her husband, Paul Thorne) after she faced a painful death from a terminal illness. right: Maria and Jorge Otero wait as Albuquerque City Council members decide whether to vote on a resolution to support medical aid-in-dying legislation in New Mexico, 2018.



To learn more about our storytellers and the history of the Elizabeth Whitefield End-of-Life Options Act, visit [CompassionAndChoices.org/NewMexico](https://CompassionAndChoices.org/NewMexico).



Compassion & Choices lobby day at NM state capitol, 2019.

**“We should provide patients with humane end-of-life options, including medical aid in dying for terminally ill, competent adults.”**

– NM Gov. Michelle Lujan Grisham, 2019



# Laura Hall: Changemaker in Action

Alabama Rep. Laura Hall is on a mission to educate and encourage African Americans to plan for their end of life.

With a rich culture steeped in the traditions of family and faith, the end-of-life experience for Black Americans is complex and challenging. Like every other demographic most Black Americans want to die in peace at home, surrounded by loved ones. Many die in emergency rooms, undertreated for pain.

Complicating matters is the tendency to avoid discussions about end-of-life issues, much of which

stems from the fact that talking about death is not encouraged, so planning for death is not a priority. These challenges have been amplified by the alarming and disproportionate death rate of Black Americans during the COVID-19 crisis.

According to Alabama Rep. Laura Hall, it's an enduring issue that must be addressed. Many Black Americans are reticent to talk about death. The issue is compounded by the fact that often the people initiating those discussions are not from the community.

"When you have someone that does not look like you telling you you ought to be making these decisions, it just doesn't resonate," said Hall.

Rep. Hall was elected to the Alabama House of Representatives in 1993. She is the vice chair of the Madison County Legislative Delegation and ranking minority member of both the General Fund Finance and Appropriations and Internal Affairs committees. She also serves as president-elect of the National Black Caucus of State Legislators. In 2020, Rep. Hall was the first African American woman to be chosen as the chairperson to lead Alabama's delegation. She champions bills that advance the rights and wishes of Alabamians of all walks of life — such as a bill that created a system for finding missing persons with dementia and designating Dec. 1 as Rosa Parks Day.

Rep. Hall's desire to look out for others started with her childhood. Growing up in South Carolina, the oldest of five, her family didn't have much, but that didn't stop them from looking out for others and taking care of those who couldn't take care of themselves. Hall's mother was a domestic worker, and her father worked in a plant. Hall was an inquisitive child, thirsty for knowledge about anything and everything.

Rep. Hall earned a bachelor's degree in biology (chemistry minor) at Morris College, a master's degree in science education from Ohio State University, and an administration certification from Alabama Agricultural and Mechanical University. She taught for more than 40 years in the public school system before running for the Alabama House of Representatives, experience that guides her work today.

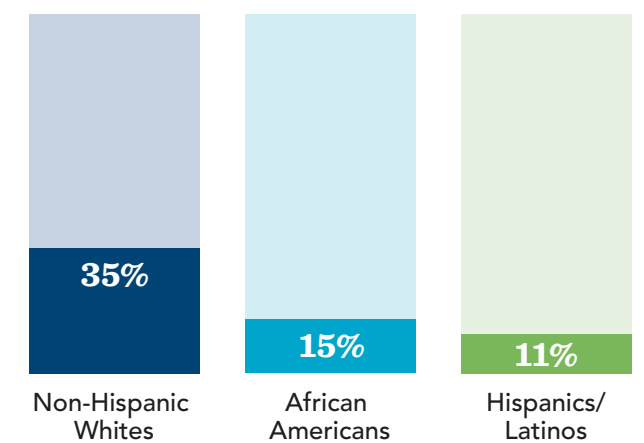
In 2014, Rep. Hall was president of National Organization of Black Elected Legislators (NOBEL) Women when she first met Brandi Alexander, national director of community engagement for Compassion & Choices, at the NOBEL Women Annual Conference. NOBEL Women is a group of Black women legislators with a shared goal of lifting the voices of African American

women through increased presence in government, nonprofit and corporate leadership. Hall recalled hearing Alexander's presentation about end-of-life planning and afterward found the consensus in the room to be, "What in the world are we talking about the end of life for?"

Data suggests that initial reaction is fairly common. Black Americans are less likely to have an advance directive, enroll in hospice care, receive palliative care or receive adequate pain management at the end of life. This underscores the need to better educate people of color about the importance of end-of-life planning and to empower them to be the director of their last months, weeks and days of life.

Despite the reaction of the room during that first presentation, Compassion & Choices has been invited back to NOBEL Women the following year and every year since. Donna Smith, diversity & inclusion advisor & state director, continues to build on the partnership with NOBEL Women, which has expanded to joint regional webinars and on-the-ground work with

## DOCUMENTED END-OF-LIFE WISHES BY RACE



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

Compassion & Choices staff in various states. “Rep. Hall has been instrumental in encouraging NOBEL Women and other organizations to embrace the need to educate our community on the need for advance planning,” said Smith.

Hall recalls that as she became more aware of end-of-life issues and the benefits of planning, she began to see the magnitude of the problem. She saw people from all walks of life who had not begun to have end-of-life discussions with their loved ones or for that matter documented what they want and don’t want at the end of life.

### **Now a leading voice on end-of-life issues in the South, Rep. Hall recognizes it will take more than education.**

That’s when she realized planning had to start at home. Beyond her own planning, Hall regularly visited extended family in South Carolina prior to the pandemic and has continued those conversations despite some lighthearted pushback. “Having an opportunity to have the experience with Compassion & Choices ... made me much more aware of how important it is for us to begin to make choices and decisions that will make life easier for our children and grandchildren.”

Compassion & Choices returns to the NOBEL Women conference every year, members of which took up the cause, bringing to light the inequities in end-of-life planning and care, and the work that can be done to address these problems. Together, Compassion & Choices and Rep. Hall championed end-of-life care and planning through a resolution for NOBEL Women titled *NOBEL Women Resolution to Educate, Empower and Advocate around End-of-Life Care 2019* (visit [www.nobel-women.org/policy](http://www.nobel-women.org/policy) and scroll to 2019 resolutions).

Now a leading voice on end-of-life issues in the South, Rep. Hall recognizes it will take more than education; it will take follow-through. “Educating people so they understand this is an important issue, one that needs to be addressed, is one thing,” she said. “Taking the steps needed to create a plan, fill out an advance directive — that’s the hard part. And that’s where we often go wrong; we educate, then we stop.”

Hall’s impact has had a profound ripple effect. Compassion & Choices sought her guidance again in working with the National Black Caucus of State Legislators (NBCSL) to create a resolution there. The influence of these resolutions continues today. They have allowed Compassion & Choices to partner with NOBEL Women and NCBSL in the states they represent. They have led to a collaboration with Minnesota Rep. Rena Moran on a webinar about end-of-life options and planning for her constituents. Earlier this year, Hall championed our issue with the African American Mayors Association, which just passed its own end-of-life resolution.

Just as there are healthcare disparities during life, those disparities carry over to the end of life. We must address these inequities. We need to change perspectives on death and make it easier to have necessary discussions with loved ones to plan in advance for the inevitable. Having those plans in place will benefit not only the terminally ill, but those close to them who won’t have to guess about their wishes. And the world will always need changemakers like Rep. Laura Hall to lead the way.

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**To access free resources and learn more about Compassion & Choices’ work to help everyone achieve end-of-life care that reflects their own personal wishes and priorities, visit [CompassionAndChoices.org/community-outreach](http://CompassionAndChoices.org/community-outreach).**



Dan Winter (left) with husband John Forsgren in their Oregon home.

## Living Out His Intentions

**Beloved storyteller Dan Winter ends his suffering through VSED.**

**A**fter learning of his Alzheimer’s diagnosis, Dan Winter was determined not to have the same ending as his father, who suffered with dementia for 13 years. Dan described his last visit with his father: “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.” Dan didn’t want that fate for himself.

Dan considered his options carefully with his husband, John Forsgren. With the help of Compassion & Choices’ Values and Priorities Tool, Dan created a plan and documented his wishes. He communicated his intentions to loved ones and became a powerful advocate for Compassion & Choices resources through his words, public appearances and a video.

Three years into his dementia diagnosis, Dan began to decline quickly. He experienced auditory hallucinations, was losing the ability to follow conversations and frequently got confused in familiar surroundings. He did not want to lose agency. In January 2021, Dan began the VSED (voluntarily stopping eating and drinking) process. VSED is an option by which a mentally capable person may choose to control their own dying by making a conscious decision to refuse foods and fluids of any kind, including artificial nutrition and hydration.

Dan and John prepared by arranging hospice care and social support for both of them. Dan wanted to die “a natural and dignified death.” He stopped eating and drinking, and passed away peacefully at home on Feb. 3, with John at his side — exactly as he intended.



**Compassion & Choices offers tools to finish strong for planning your end-of-life care at every stage, even after a dementia diagnosis. Visit [CompassionAndChoices.org/finish-strong-tools](http://CompassionAndChoices.org/finish-strong-tools).**

**Phyllis Shacter’s book, *Choosing to Die*, may also be of interest (see page 3).**

# Diane Rehm Wants to Talk About Death

The radio legend's new film and companion book showcase Americans' varying perspectives on medical aid in dying.



Renowned radio host and Compassion & Choices champion Diane Rehm has interviewed presidents, international figures, national icons and everyday folk throughout her distinguished career. But her more recent enterprise, *When My Time Comes*, a collection of interviews in both film documentary and book formats, captures a deep personal journey and is poised to galvanize a national dialogue about death.

Directed by documentary filmmaker and Compassion & Choices Virginia Action Team Leader Joe Fab, the film introduces viewers to Diane's own story of her husband John's Parkinson's disease and decision to voluntarily stop eating and drinking (VSED) in 2014 to end his debilitating suffering. What followed was Diane's direct involvement in the end-of-life care movement and, specifically, the pursuit to pass medical aid-in-dying legislation not only in her neighboring state of Maryland (she lives in Washington, D.C.), but in several other jurisdictions across the country.

The film chronicles Diane's gripping conversations with legislators, advocates, clinicians, clergy, terminally ill patients and critics of medical aid in dying. The documentary also features commentary and

top: From the documentary "When My Time Comes," Diane Rehm shares her personal wishes for the culmination of her life journey. bottom: Rehm discusses the impact of Brittany Maynard's story with Brittany's husband and Compassion & Choices advocate Dan Diaz.

public testimony from the Compassion & Choices community, including President Emerita/Senior Adviser Barbara Coombs Lee, National Medical Director David Grube, M.D., and President and CEO Kim Callinan.

"Joe [Fab] had me ask each and every person we interviewed, 'What do you think of as a good death? What would be a good death for you?'" Rehm shared. "And the surprise for me was that whether you were on one side or the other side, everybody, every single person, wanted the same thing: They wanted to die at home, peacefully, with friends and relatives by their side. I thought that was fascinating. It's certainly what I want for myself."

Fab said, "I was constantly being educated while we were making the film. I was really in a state of disbelief when we were in California and I realized how many Californians didn't even know that they had the [medical aid-in-dying] option. There are all these systems that have to be set up so you can actually implement the law, and that can take years. Many people don't realize this. And finally, once these laws are on the books, they must be defended on an ongoing basis."

To create the film, Rehm interviewed approximately 50 subjects. Twenty five of these interviews are featured in the book. Getting people to speak on what many consider a controversial issue was not as laborious as one might have imagined. Rehm explained, "We were in a church in Massachusetts, and I started my talk by asking, 'Please raise your hand if you are planning not to die.' And there was this nervous titter in the audience. Well, that titter still exists among many people, but I do think there is a great willingness among the general population to at least think about it. Among those who do not support medical aid in dying, I think their firm commitment against it remains. But what I find so satisfying is that younger medical students seem to understand it and indeed support it so well, so easily. I think times are changing — I really, really do."

Fab added, "People want to be understood and heard. I think that's a great benefit for documentarians and I think all interviewers. And on this subject, they absolutely have things to say, either pro or con. I want people to see this film, and I don't want them to ever stop talking about it."

With the April release of the documentary across PBS stations nationwide and the publication of the companion book, *When My Time Comes* introduces the topic of dying as a source for conversation, not avoidance, particularly for audiences unaccustomed to or uncomfortable with the discussion.

"My hope is that this film and this book help to generate conversation within families, among friends, between patients and doctors that the whole idea of death in and of itself gets taken off the taboo list and moved into the 'death is part of life' category," Rehm said.

Fab added, "If you will talk about it, let everybody know what you want, you can take that burden off the table and not have it come up at the end of life — the worst time to try and figure out what somebody wants, somebody who may not even be able to communicate. Then the end of life can be indeed unburdened at least and joyous very possibly."

Rehm shared, "What a joy it was for me to work on this film because it so helped me work through so many issues of my own, to really come face to face with them through the eyes of other people, listening carefully to their objections, what they wanted and their experiences," she said. "I learned so much."



To get a copy of the book, go to [www.randomhouse.com](http://www.randomhouse.com). To learn where you can view the documentary, visit [www.whenmytimecomesmovie.com](http://www.whenmytimecomesmovie.com)

## Apart but Working Together

Despite continued distance engagement, our impact remains strong nationwide.

### COLORADO

The state's annual report on Colorado's medical aid-in-dying law shows that, four years after implementation, this compassionate option continues to help qualified terminally ill Coloradans peacefully end their suffering. Our work to increase access by educating physicians and residents about the law is paying off, with the report showing a 10% increase in the number of aid-in-dying prescriptions written and a 22% increase in the number of doctors who have written prescriptions and an increase to 22% of prescriptions written in non-Front Range counties.

### CONNECTICUT

Compassion & Choices' Connecticut campaign made history in March 2021: On Feb. 26, Compassion & Choices President and CEO Kim Callinan joined 50+ volunteer advocates testifying in support of the medical aid-in-dying bill (HB 6425) during a marathon 15-hour hearing before the Public Health Committee. One week later, committee members approved the legislation for the first time in 27 years on a bipartisan 24-9 vote. We also commissioned a new poll showing 75% of Connecticut residents support the legislation. Unfortunately, on April 20 the Judiciary Committee put a hold on the bill, preventing floor votes on it this year.

### HAWAI'I

Our staff is holding a series of meetings with Native Hawaiian Kupuna (elders) to discuss advance care planning and ways to empower the Native Hawaiian community to prepare for an end-of-life healthcare experience that is in line with their values. This includes ensuring written materials are accessible in Hawaiian. We continue to look for solutions to

expand access to medical aid in dying and address the shortage of medical providers of end-of-life care options, especially on neighboring islands, including amending the Our Care Our Choice Act to include advanced practice registered nurses. We are also hosting a series of well-attended webinars for clinicians to learn more about the Hawai'i law.

### ILLINOIS

Compassion & Choices presented at a bilingual Facebook Live event for the underserved Hispanic/Latino community hosted by Howard Brown Health, a federally qualified health center and one of the largest LGBTQ organizations in the nation. The Illinois team recently hosted a series of virtual training workshops, including Train the Presenter and the Illinois Advocacy Training Workshop with the ACLU of Illinois. The Illinois team also presented Dementia in the Age of COVID-19, a training workshop hosted by the Illinois Chapter of the National Association of Social Workers, and a training on advance care planning to the Illinois Township Association of Senior Citizen Services Committees.

### MASSACHUSETTS

Compassion & Choices Action Network Massachusetts campaign is off to a strong start in 2021 after the Joint Committee on Public Health approved the End of Life Options Act in 2020 the first time since the original legislation was introduced in 2011. But COVID-19 preempted further legislative action on the bill. On Feb. 8, it was reintroduced by two new sponsors, Sen. Jo Comerford and Rep. Jim O'Day. There is currently a record 92 sponsors in the House and Senate.

### MINNESOTA

Compassion & Choices President Emerita Barbara Coombs Lee spoke about the importance of end-of-life planning and her book *Finish Strong* at the Westminster Town Hall Forum in March. For more than 40 years, the Forum has invited subject matter experts to explore the key issues of our day from an ethical perspective. You can check out Lee's excellent presentation at [westminsterforum.org](http://westminsterforum.org). Minnesota's medical aid-in-dying bill, the End-of-Life Options Act, was also introduced in March, and we thank bill sponsors Rep. Mike Freiberg and Sen. Chris Eaton for their continued leadership and advocacy.

### MONTANA

For the sixth time since the state's Supreme Court ruled that terminally ill adult Montanans could consent to medical aid in dying, the state Legislature tried to pass a law that would mean doctors could be successfully prosecuted for writing an aid-in-dying prescription. Our advocates once again led the fight against this bill and narrowly secured a win to preserve this option in Montana, though opponents vowed to bring it up again in two years. Sen. Diane Sands (District 49) said it best during the Senate's debate on the bill: "This is truly government overreach, right into your death bed ... We should preserve the right of compassionate care at the end of our lives."

### NEVADA

On April 9, Compassion & Choices President and CEO Kim Callinan and National Medical Director Dr. David Grube served as lead witnesses for the Assembly Health & Human Services Committee in a four-hour hearing. The HHS Committee moved the bill out of committee, but it was re-referred to the Ways & Means Committee, exempting it from all legislative deadlines. Once Ways & Means advances the legislation, it will go to the Assembly floor for a vote, then on to Senate HHS. The bill must pass both chambers by Sine Die on June 1.

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

- » **MOTIVATE** your local government to pass a city or county resolution in support of end-of-life options. Learn how at [CompassionAndChoices.org/take-action/in-your-state](https://CompassionAndChoices.org/take-action/in-your-state).
- » **VOLUNTEER** any way you can; find options at [CompassionAndChoices.org/volunteer](https://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](https://CompassionAndChoices.org/donate).

### NEW YORK

Compassion & Choices' 2021 New York campaign is going strong. On Jan. 25, hundreds of supporters joined a virtual rally to pass the Medical Aid in Dying Act, including bill sponsors Assemblymember Amy Paulin and Sen. Diane Savino, and Compassion & Choices President and CEO Kim Callinan. We created and aired the first in a series of three television ads in January, featuring Buffalo-area terminally ill supporter Jennifer Milich and Dr. Jeff Gardere. Advocates throughout the state shared their stories with lawmakers through emails, calls and virtual meetings.

### WASHINGTON

In the 2021 legislative session, Compassion & Choices Action Network partnered with End of Life Washington to advance a bill to improve access to the state's Death With Dignity law. The existing law works well for those who are able to access it, but there are prohibitive barriers for many Washingtonians, especially those who are very ill and live in rural areas. The proposed legislation would shorten the wait time for people who are actively dying, allow more qualified providers to prescribe aid-in-dying medication and modernize the prescription process. The bipartisan bill passed the Washington House but unfortunately was never voted on by the Senate. We are confident that with our advocates by our side we will be able to succeed in the next session.



## California Progresses Toward Making End of Life Option Act Permanent

Full Senate Set to Vote on SB 380



Amanda Villegas with her husband, Chris Davis, in his last days.

Compassion & Choices Action Network is making significant progress in our 2021 campaign to make California's End of Life Option Act permanent and improve the law. It started with a virtual Zoom news conference on Feb. 11 to announce the introduction of legislation, SB 380, authored by Sen. Susan Talamantes Eggman and Assemblymember Jim Wood, to prevent the End of Life Option Act from expiring on Dec. 31, 2025, and improve access to the law.

"We know that thousands of Californians have been able to access the law, but we also know that there are unfortunately too many unnecessary regulatory roadblocks that are preventing dying patients from being able to access the law," Compassion & Choices Action Network President and CEO Kim Callinan told the Los Angeles Times. "Instead of allowing them the peace of mind that comes when they get the

prescription, we are forcing them to continue to suffer, and they die an agonizing death instead of having the autonomy and compassion that this law affords them."

Those who have died before they could complete the 13-step process include Chris Davis, a 29-year-old Ontario, California, resident who died from bladder cancer in June 2019. "I feel like he had his suffering prolonged extensively," his wife, Amanda Villegas, told the Los Angeles Times. "I feel like with the medication, it would have cut some of the suffering, and I feel like he wouldn't have endured so much pain."

Three weeks later, the Los Angeles Times endorsed SB 380. "... the law has worked as intended, with not a single reported case of coercion or abuse," the editorial stated. "But that doesn't mean it can't work better, and the changes proposed would do so by making it easier for those who are dying to end their lives on their own terms."

After months of negotiations, Senate Health Committee Chairman Dr. Richard Pan, who opposed the End of Life Option Act in 2015, supported SB 380, leading to an 8-1 vote to approve it. The Senate Judiciary Committee approved the bill 9-1, and the Senate Appropriations Committee approved it 5-2 for a Senate floor vote. If the Senate passes SB 380, then the Assembly will consider it.

To learn more about SB 380 and how you can help, visit [CompassionAndChoices.org/California](https://CompassionAndChoices.org/California).

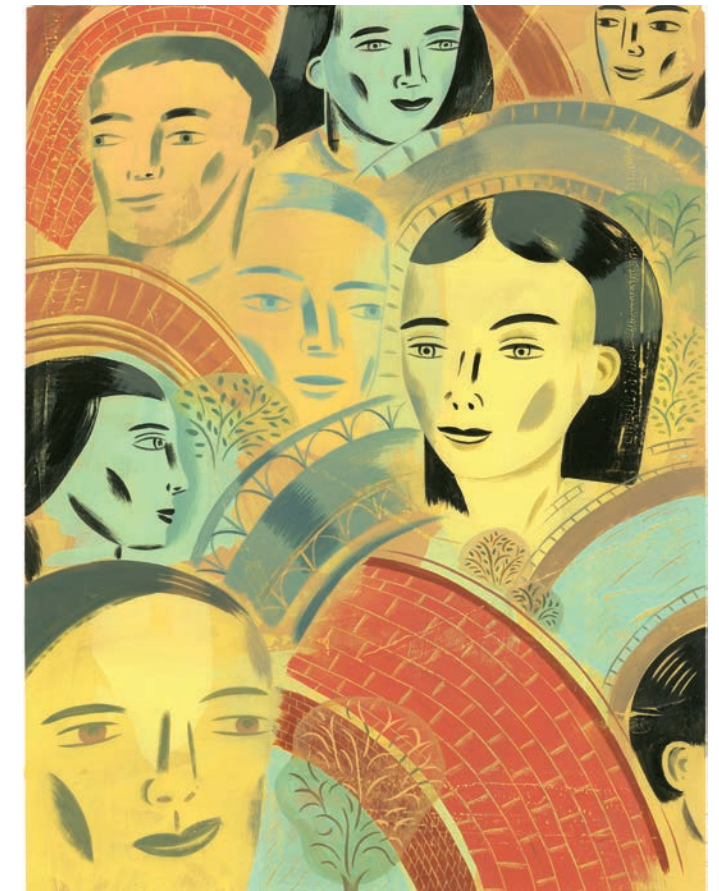
## Building Bridges to Empower Each Other

Compassion & Choices continues to partner with like-minded organizations to reach new audiences and build the movement for end-of-life options.

In early 2021, the African American Mayors Association endorsed end-of-life options and planning in a resolution passed by their members. The endorsement acknowledges that Black people are less likely to fill out an advance directive, utilize hospice or be given adequate pain medication at the end of life. It concludes, "The African American Mayors Association must be proactive in educating, empowering and advocating for our community at the end of life, and we will work with and encourage our legislators to share resources with our constituents."

This spring, our work with Research, Education and Access for Community Health (R.E.A.C.H.) allowed us to participate in community outreach activities for those underserved populations in Nevada. Nationally, we continue to collaborate with Ventanilla de Salud (Mexican Consulate) to host a series of virtual informative sessions to Mexican communities in the U.S.

Doctors for Dignity, Compassion & Choices' program that unifies doctors advocating for end-of-life options, is partnering with the Student National Medical Association (SNMA) to offer a paid internship focusing on end-of-life issues. The SNMA is an association



of minority medical students committed to diversifying the face of medicine and addressing the needs of underserved communities. Over the course of eight weeks, the student intern will learn about end-of-life options, hospice, advance care planning and the factors that lead to disparities in end-of-life care. They will then connect with local health and community organizations to provide information about end-of-life disparities and planning. The goal is to engage the next generation of African American physicians to advance our mission to reduce end-of-life care disparities.



Watch our latest community engagement videos!

Compassion & Choices created a set of videos to explain the importance of our community engagement efforts and showcase the diversity of our movement.

Watch them at [candc.link/videos](https://candc.link/videos).

## Combating Disparities Through Inclusive Leadership

In 2017, Compassion & Choices created the African American and Latino Leadership Councils consisting of community leaders, faith leaders, physicians, nurses, executives and policymakers who provide counsel, insight and leadership for our efforts.

Since then, the councils have worked to change the conversation about death in our communities and have made important progress in that endeavor. From meeting with lawmakers on Capitol Hill to engaging our supporters, our councilmembers are critical to advancing the mission of Compassion & Choices. That's why we are expanding our councils and programs to new communities, including faith leaders; the Asian American, Native Hawaiian and Pacific Islander communities; and the LGBTQ community.

The Asian American, Native Hawaiian and Pacific Islander (AANHPI) communities face disparities in end-of-life care. The AANHPI Leadership Council will bring together thought leaders and community voices to address the specific needs of this population. The LGBTQ community faces end-of-life care disparities as well, including discrimination in health-care and specific family-based needs. This council will continue Compassion & Choices' long relationship with the LGBTQ community that dates back to our beginnings and foster new relationships with like-minded organizations.

Compassion & Choices continues our outreach to faith groups through our Faith Leaders for Choice program. The goal of this effort is to build an inter-faith community of leaders who support the full range of end-of-life options. Our faith leaders write letters to the editor and op-eds, participate in our

webinars and events, provide testimony in support of medical aid-in-dying legislation, and encourage end-of-life planning across the country. We recently hosted a virtual meeting of faith leaders that fostered dialogue around how to talk about death and dying with different communities, and the importance of sharing resources and information widely.

The expansion of our leadership councils and programs to include more diverse communities is in line with our strategic priority of addressing health disparities at the end of life for underserved communities. It will take efforts on every level to combat these disparities — from the grassroots to engaging legislators and community leaders. We are confident that the addition of these councils will further our work to ensure the intersectional needs of these communities are being met.

Al Thomas is a newspaper publisher, entrepreneur and a member of the Compassion & Choices African American Leadership Council. He advocates for improving end-of-life care in the Black community.



## Engaging the Public in Our Mission

Compassion & Choices participates in conferences across the country in order to reach new audiences with our tools, resources and mission. For example, Compassion & Choices sponsored the State of Black Health Conference, attended by hundreds of people over three days. We hosted a panel discussion with staff and African American Leadership Council members titled End of Life Economic and Psychological Impact on Families. The panel acknowledged that Black families are often unprepared for the end of life for a host of reasons and discussed ways people can plan having difficult conversations now to avoid financial and family challenges later.

Every year in April, National Healthcare Decisions Day is an opportunity for Compassion & Choices to expand our reach and engage new audiences with motivation to complete end-of-life planning. This year, we hosted a webinar geared toward younger people who may not be familiar with Compassion & Choices and our mission. Civil rights icon Dolores Huerta partnered with us to record videos in English and Spanish to explain the basic steps for individuals and their families to advocate for the care they want at the end of life. The webinar reached 350 people, and the video was watched more than 30,000 times.



**1 in 3 Seniors Dies With Some Form of Dementia.**

## Continuing Dementia Planning Efforts

Compassion & Choices continues to conduct outreach around our dementia resources, the Dementia Decoder and Dementia Values and Priorities Tool. Both are meant to help people make decisions surrounding a dementia diagnosis that help them stay in control of their care and their options. Compassion & Choices is partnering with organizations to share these tools following a string of webinars in the Midwest and Southeast. We have participated in senior fairs and presentations to the public, and our volunteers continue to spread the word about these important tools.

Our ongoing outreach, coupled with concerns around the pandemic, have led over a thousand new users to access the tools in the last six months. This is a testament to the importance of our local and national efforts to bring the tools to as many people as possible.

To find these tools and additional resources to help with your end-of-life planning, visit [CompassionAndChoices.org/finish-strong-tools](https://CompassionAndChoices.org/finish-strong-tools).

# Five Questions for Judith Auberjonois

Screenwriter and producer Judith Auberjonois talks about walking alongside her husband of 56 years, celebrated actor René Auberjonois, through his lung cancer diagnosis and decision to use California's End of Life Option Act.

**Q:** You hold a degree in drama and have enjoyed a long career in theater and film. What inspired you to forge this creative path?

**A:** Romance; infatuation when you're too young to know! I grew up in New York City, and especially then, in the '50s and '60s, the arts were just so predominant. There was a natural gravitation toward them. I went to a fabulous high school called the High School of Music and Art, which was a very artistic environment to be in at a young age. Then I went to drama school for university, now called Carnegie Mellon. That's where René and I met when I was 17. We married when I was 19, in my junior year.

**Q:** Your husband, René, was a prolific actor. Were the dramatic arts set aside at the end of the workday for you both, or did they flow into other aspects of your life as well?

**A:** Yes, like my kids — they're both actors. They're actors, they married actors, go figure! Either we did something right or we did something wrong.

**Q:** Once you learned René had advanced lung cancer, how did your family react to such a brutal diagnosis?

**A:** He had the battery of treatment at City of Hope cancer center: chemo, some immunotherapy. He moved from infusions to oral chemotherapy, which gave us a really good amount of independence and freedom. So we could travel, and we did, all the way through the entire year of 2018. But the cancer was beginning to take its toll. It's hard to really fight against stage 4 metastatic cancer.

In the summer of 2019, it was detected in his brain, because lung cancer often migrates. They offered him whole-brain radiation. The side effects of that are almost certain erasure of short-term memory. So he didn't want to live like that; he didn't want a grandkid walking in the room and not knowing who that person was. So he demurred on that treatment. But they warned us that his cancer might take over the brain and lead to seizures or stroke, and sure enough in October of 2019, he did have seizures. It was a terrible experience to go through.

Judith and René Auberjonois attending a reception in Los Angeles, 2006.





René Auberjonois played Odo on TV series *Star Trek: Deep Space Nine*, 1993-1999. Judith (bottom center) with their two children (left and top center) and her husband, René (right).

## Create YOUR Legacy Today With the Legacy Challenge Match

Notify us of a new planned gift, and a generous anonymous couple will contribute \$500 in your honor today.



Leslie Jennings Rowley and her family in New Jersey

That really was the beginning of the end for him. They told us most assuredly he'd have them again. About a month later, he started really declining. In fact, the night before Thanksgiving, he was so weak he couldn't even turn over in bed. On Thanksgiving morning, I called hospice. We had already started the legal process of medical aid in dying. We just knew that really was the path that he, and we, would go down.

**Q:** As someone who has been through the process, what do you think might be helpful for others who are considering medical aid in dying to know?

**A:** When René's oncologist at City of Hope realized he was wanting to pursue that path, she said, "You may as well get started on it as soon as possible, because it is a process. It takes time; there are gaps in scheduling of appointments that are mandated ... " So he did immediately get to it. I do so appreciate that counsel about sooner rather than later.

Also, some people are very private, so I think it's a good idea to not only understand the timeline, but what the specifics are in the appointments, particularly the questions: Is this your own decision? Has anyone influenced you? Do you understand what you are wanting to do? Do you know you have to do it yourself? They are thoughtful questions, but it would be good for people to understand that will be put to them. As for René and I, we were very much of the belief that it's our own life to hold and cherish, and treat ourselves with the respect of our souls.

**Q:** René did use medical aid in dying, at home surrounded by family. Were you aware of this option prior to his illness?

**A:** No. I had some vague awareness that Oregon was the leader, and I didn't even realize California actually had it as a law on the books, too. I certainly would have voted for it! When you're confronted with this sort of thing, you think, "Well, we should go to the Netherlands or Switzerland," not even thinking that it really is possible close to home.

**“** Because Compassion & Choices was there with information about end-of-life options when my father needed it most, I want to do all that I can to support the organization through volunteering and giving. I am thrilled to be able to extend my contributions by creating a legacy gift while also having my gift matched with money that will be put to use now. It was simple; I made Compassion & Choices a designee of an IRA.

*My family and I are proud to support Compassion & Choices and grateful to be able to take advantage of the Legacy Challenge Match!”*

- Leslie Jennings Rowley, Compassion & Choices Board Member

**To unlock the \$500 Legacy Challenge Match, notify us of your new planned gift!**

Visit [CompassionAndChoices.org/legacy-challenge-match](https://CompassionAndChoices.org/legacy-challenge-match).

**For more information, contact:**

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