

# compassion & choices

MAGAZINE  
SUMMER 2019

New Online Tools  
Supporting Patients  
With Dementia

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Turning a Diagnosis  
Into an Opportunity

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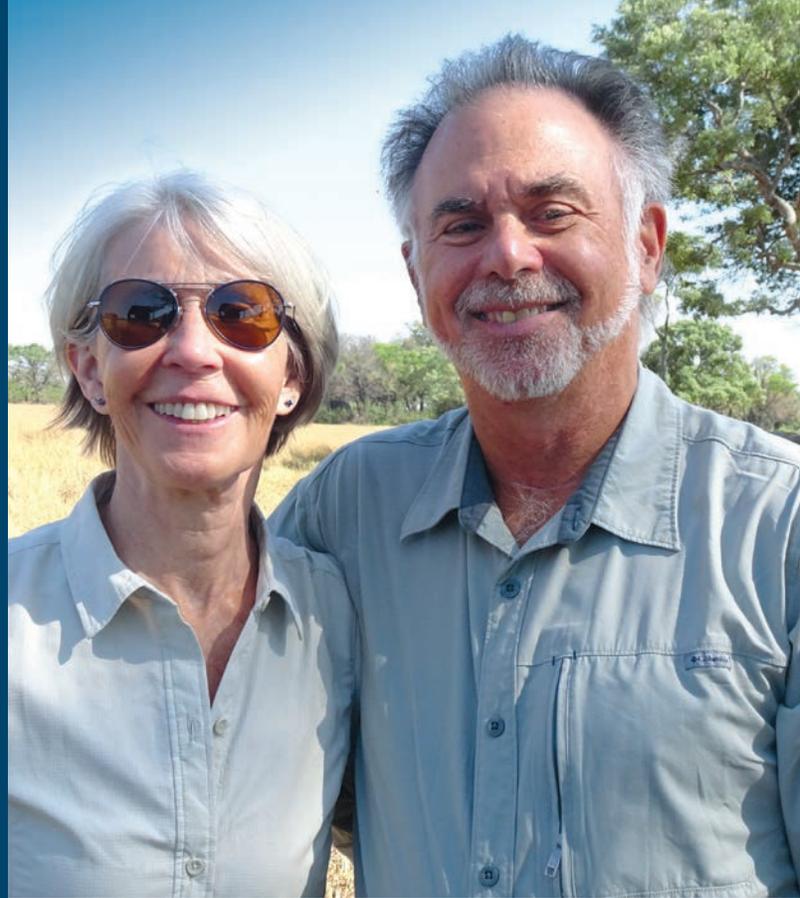
Pioneering a  
Training Program  
for Resident Doctors



Five Years Later:  
Honoring  
Brittany  
Maynard

# The Generosity of Our Donors Fuels Our Success

Compassion & Choices is grateful to the thousands of people who invest in our work every year, like longtime supporters Howard and Bev Rossman. We had the pleasure of visiting Howard on a recent trip to Chicago to discuss his deep commitment to our work.



Howard and Bev Rossman, Compassion & Choices donors.

## **What motivates your philanthropy?**

I believe that we all have the capacity and the responsibility to lend a hand to others — to give of our time, our care, our resources. For me, that means helping to bring more compassion into the world, as well as more opportunity for others to live safe, productive and fulfilling lives. I want to be associated with dedicated, inspired and well-led organizations that are engaged in those outcomes.

## **Why do you support Compassion & Choices?**

Compassion & Choices is committed to honoring and empowering every person, and they lead this movement with compassion and fierce resolve, never losing their focus on respect for the choices of each person. We need that leadership and dedication.

## **What keeps you engaged and inspired about this work?**

What brought me to this movement was what I saw when my father was dying. He was a strong man, and his main struggle as he thought about dying was having to live his final days in pain, with no control over his choices. At that time, his options were limited, but we found opportunities to exercise control. As it turned out, just knowing there were options enabled him to die peacefully, without any aid. I want to make sure others who want their final days spent in the light of loved ones and not in pain have that choice.



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

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## Eternal Gratitude

It was during the fall of 2015 that a young woman, Brittany Maynard, shared her story with millions.

With a diagnosis of terminal brain cancer, Brittany

would soon transform the national conversation on end-of-life options. I arrived at Compassion & Choices shortly after Brittany shared her story. It was evident then that Brittany would have a lasting impact on this movement; however, I don't believe any of us fully grasped just how substantial that impact would be. Five years later, and her voice still guides us.

Brittany's courage not only brought a once-fringe issue out of the shadows, it also inspired so many other heroes to come forward and share their story. The cumulative impact is extraordinary: Six states have authorized medical aid in dying; 21 national and state medical societies have dropped their opposition; and a growing number of experts and organizations, especially Latino and African American leaders, have adopted supportive policies.

This issue honors Brittany as well as her husband, Dan Diaz, who continues to partner with us passionately and effectively carrying on her legacy. It also highlights so many others who have helped through their advocacy, volunteerism, activism and financial support — and offers updates on our efforts in other areas of end-of-life importance, like managing the calamity of dementia.

Brittany would have turned 35 this November. Thank you, Brittany, and thanks to all of you who keep working alongside us to fulfill her loving legacy.

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## words & pictures

### Daily News

#### **“Just let me die in peace: A terminal cancer patient’s plea to New York state’s Legislature and governor”**

(February 18, 2019)

A famed LGBTQ filmmaker and activist with ovarian cancer, Barbara Hammer, spent the last months of her life advocating for a medical aid-in-dying law in New York. She wrote in a New York Daily News op-ed published shortly before her death in March, “I would be so grateful to be able to manage my own death by choosing the time and the person I’d like to have with me, so that I can die in comfort and with compassion. I am not talking about suicide. My love of life is as strong today as it has ever been. But I am dying. That is a fact. And it will not change.”



### New Haven Register

#### **“Weston actor joins effort for CT aid-in-dying law”**

(March 13, 2019)

In March, actor James Naughton (shown above), who appeared in *Planet of the Apes* and *Gossip Girl*, testified in support of a medical aid-in-dying law in Connecticut. Before his wife died in agony from pancreatic cancer in 2013, she told him, “I don’t want to wake up anymore.” He said to lawmakers, “We didn’t have the option at the time, and I don’t think anyone should be in the position to hear that from their loved one and not have some way to help them.”

### Newsday

#### **“Every state should pass medical aid-in-dying law”**

(May 25, 2019)

Compassion & Choices CEO Kim Callinan writes in an op-ed for [New York] Newsday, “Current medical aid in dying laws protect patients. In a combined 40 years of experience across 8 jurisdictions, there has not been a single documented incidence of abuse or coercion. In fact, in the 21 years of experience implementing the law in Oregon, fewer than 1,500 people total have decided to use the option.”

### The New York Times

#### **“Aid in dying soon will be available to more Americans. Few will choose it.”**

(July 8, 2019)

In July, The New York Times reported on the limited access to medical aid in dying for some of the 22% of U.S. residents who will have this option when Maine becomes the 10th authorized jurisdiction on Sept. 15, 2019. Samantha Trad, California state director of Compassion & Choices, said, “There are what I call deserts, where it’s difficult to find a facility that allows doctors to participate.” We work in these jurisdictions to ensure that local health systems, hospices, doctors and patients understand and can use the law.

### The Sacramento Bee

#### **“‘End my fight’: Dying Sacramento man initiates death on his terms after bucket-list tour”**

(July 26, 2019)

Kevin Roster had to move from New Jersey to California to use its medical aid-in-dying law because he wouldn’t live long enough for New Jersey’s law to take effect on Aug. 1, 2019. He died July 26, 2019. His last public words were: “I do believe that anyone and everyone else should have the right to consider all options when facing a terminal diagnosis.”

# Living and Dying With Dementia

**Two new online tools help patients and caregivers avoid prolonged suffering and support a peaceful death — even in cases of dementia.**

One in three Americans dies with dementia. This debilitating disease can mean constant confusion, impairment of everyday judgment, violent behavior that could lead to hours confined and strapped to the bed, and total loss of memory of loved ones.

Despite the fact that the majority of people indicate they do not want to live this way, the healthcare system continues to assume that the goal of care for somebody with dementia is to extend life. Many people living with dementia get life-prolonging treatments up until the very end of their life. On average, people live with dementia for eight to 10 years — far longer than one has to if you are proactive in planning.

A person with dementia should not be forced to accept human interventions that extend their life if they have documented their preference to end their suffering. Every competent adult has the right to indicate their wish to voluntarily stop eating and

drinking or refuse medical treatment. These wishes can then be carried out by their healthcare proxy to shorten the length of time they live with the most debilitating stages of dementia before death.

In September, Compassion & Choices will launch two new online tools to help patients prepare for a potential dementia diagnosis: the Dementia Decoder and the Dementia Values & Priorities Tool.

## **Dementia Decoder**

The new Dementia Decoder is designed to be completed in advance of getting dementia or in the very early stages, when a person is still able to make healthcare decisions. Through a series of questions, a person can identify and document the point at which they would want to pursue existing legal options to voluntarily stop eating and drinking and refuse medical treatments, but with comfort care to prevent pain and suffering. At the end of the tool, the user will get a customized addendum to their advance directive as well as instructions for their healthcare proxy.

## **Dementia Values & Priorities Tool**

The Dementia Values & Priorities Tool provides users with specific questions to ask healthcare providers to ensure that those living with or caring for someone with dementia will get care that is consistent with the values and priorities they specified. This guide allows users (either patients or caregivers) to select the

Since 2000, the number of deaths from Alzheimer's disease, a form of dementia, has risen by 89%.



status of the dementia diagnosis, indicate what they're hoping to learn and accomplish from a clinical appointment and customize a list of helpful questions.

Users will find helpful content covering the span of a patient's dementia experience. This includes categories such as understanding the dementia diagnosis and its various stages; avoiding unnecessary treatments, tests, pain or suffering; treatment options; and advance care planning.

The new Dementia Decoder and Dementia Values & Priorities Tool ensure treatment following a dementia diagnosis is based on the patient's documented preferences and values. These tools also provide comprehensive planning and care resources to assist dementia patients, their loved ones and caregivers along this difficult journey.

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**Please visit [CompassionAndChoices.org](https://CompassionAndChoices.org) for more information on these tools and other resources.**



Alzheimer's is the **sixth leading cause of death** in the U.S. and the **ONLY ONE** of those six that can neither be cured or arrested.



At age 80, about **75% of people living with Alzheimer's dementia** are expected to be in a nursing home **VERSUS ONLY 4% of the general population.**

# Facing the Truth

**A Minnesota philosophy professor turns a degenerative disease diagnosis into an opportunity to educate others.**



Karen Warren (left) with her daughter, Cortney.

*“Please, just tell me the truth.”*

These six words changed Karen Warren’s life forever. After 16 years of chronic health issues, the retired professor of philosophy finally received answers on a winter morning in 2016. “You have MSA, multiple systems atrophy,” her neurologist said.

Karen’s mind swirled with questions for her doctor:

*Is MSA a degenerative, neurological brain disorder?*  
**“Yes.”**

*Is MSA progressive?* **“Yes.”**

*Is MSA fatal?* **“Yes.”**

*Does MSA have a cure?* **“No.”**

*Is there any treatment?* **“No. There is only medicine to treat some symptoms and help with the pain.”**

Relief and fear settled within her. Karen faced her own mortality knowing that MSA would rob her of bodily autonomy at the end of her life. She would die without the capacity to swallow, walk, move or talk — losing the ability to say goodbye to her grandchildren, her daughter and her family. Karen called her daughter, Cortney, to deliver the news. When Cortney asked if Karen feared death, she replied: “No, I am not afraid of dying. But I am afraid of dying this way.”

Faced with a limited number of years before MSA would ravage her body and ultimately take her life, Karen channeled her nearly 40 years of experience as a philosophy professor into action — writing guest blogs for Psychology Today, where her daughter, a psychologist, also publishes, and joining Compassion & Choices to urge legislators to support end-of-life options in Minnesota. Her expertise in ethics became a lived experience.

In 2017, Karen delivered powerful testimony during a press conference in support of HF 1885, the Minnesota End-of-Life Option Act. She evoked philosopher Immanuel Kant, stating, “There are three properties that make us human, that distinguish us from other beings: rationality, dignity and autonomy.”

## federal news

### New Federal Legislation Threatens End-of-Life Autonomy

Introduced in June 2019, a Senate bill would withhold federal funding (including Medicaid and Medicare) from any healthcare entity that honors a healthcare decision that intentionally shortens or ends life, including discontinuing life support and medical aid in dying. The so-called "Patient Rights Act" also encourages pro-life zealots to report any doctor or healthcare system they suspect of not meeting broad, strict mandates for life-sustaining treatment to the Health and Human Services' Office of Civil Rights. This office must investigate all reported violations. If enacted into law, patients in every state will lose precious autonomy and dignity at life's end, because virtually no healthcare facility is able to operate without federal funding.

**Stay tuned for updates about how Compassion & Choices is working to defeat this ill-advised legislation.**

### Fighting Unwanted Treatments

In May, the Department of Health and Human Services released their final federal "conscience rule." Compassion & Choices opposes the rule — here's why.

While Compassion & Choices agrees that physicians have a right to opt out of certain medical procedures under already existing laws (every medical aid-in-dying law we've supported and helped pass includes a moral exemption clause), this new rule goes too far.

**Learn more at [CompassionandChoices.org/federal-relations](https://CompassionandChoices.org/federal-relations).**

She continued, "These three properties are precisely those that are at risk by depriving us of the option to choose medical aid in dying." In these words, Karen exposed a crucial truth: To "do no harm," it's imperative that medical professionals and loved ones honor a patient's wishes at life's end to uphold their dignity and autonomy.

Since Karen's diagnosis four years ago, every member of her MSA support group has died without access to a full range of end-of-life options. This only strengthens Karen's resolve to advocate for end-of-life choice and provide guidance to others. In a recent blog post, she encourages everyone to firmly establish their values and priorities, and take action to hold lawmakers accountable to pass medical aid-in-dying legislation:

*I am here to encourage you to confront the truth. You are going to die. So is everyone you love. So think about it now. Think about whether you want a voice and a choice. And, if you ... believe that it is a basic human right to die with one's dignity and autonomy preserved, please contact your legislators.*

Currently, Compassion & Choices supports legislation to authorize medical aid in dying in Minnesota. Introduced by Rep. Mike Freiberg on March 7, 2019, the End-of-Life Option Act (HF 2152) would give terminally ill Minnesotans like Karen the option to peacefully end their lives before their suffering becomes too great.

**Find out how you can help bring medical aid in dying to Minnesota at [CompassionAndChoices.org/minnesota](https://CompassionAndChoices.org/minnesota).**

*Karen J. Warren, Ph.D., is a retired philosophy professor. Her academic credentials include six books, 50 articles and more than 200 presentations nationally and internationally. When she was diagnosed with a rare, fatal degenerative disease, multiple system atrophy (MSA), her academic expertise became deeply personal. Now she confronts the challenges of living while dying on a daily basis. Karen's personal journey brought her to Compassion & Choices.*

# Resident Expert

**Compassion & Choices Executive Volunteer Evan Pulvers, MD, pioneered a medical aid-in-dying training program for resident physicians that continues to grow.**



Oregon native Dr. Evan Pulvers learned about medical aid in dying during childhood through the experience of a family friend. “I watched his decline through his disease,” she explains. “I saw his and his family’s relief to retain autonomy and control at the end of his life through the peace of mind the Oregon law provided.”

After attending medical school in New York City, where she co-founded a palliative care interest group, Evan entered the Contra Costa Family Medicine Residency program in California. During her first year, the state’s End of Life Option Act went into effect. Knowing the importance of this law from her prior experience, she wanted to get involved. Over the next two years, Evan worked with her residency, the palliative care department, clinical mentors, program faculty and the medical executive committee — and was informed by the ethics committee — to come up with a protocol for training licensed residents in medical aid in dying.

“When I graduated from residency training, ours was a first-in-the-nation program in managing medical aid in dying for our primary patients,” says Evan. “This is important because if we want patients to have access, we need to make sure they have clinicians who can provide this care, and that starts with allowing for this care in medical training.”

Now, as a Compassion & Choices executive volunteer, Evan has partnered with Compassion & Choices staff to make the supervised teaching structure and protocol for cases of medical aid in dying available to other training programs. She also attends conferences to continue establishing a way for physicians in training to receive support and guidance.

“It’s been rewarding to be part of a larger movement,” Evan says, “and I’m grateful for the opportunity!”

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*Compassion & Choices’ Executive Volunteer Program runs on the specialized skills so many of our supporters possess. Dozens of skill sets can benefit our work. If you have expertise or experience you’d like to share, please visit [CompassionAndChoices.org/executive-volunteer](https://CompassionAndChoices.org/executive-volunteer) and tell us more!*

# Honoring Brittany's Legacy

Five years after his wife's death, Dan Diaz carries on her advocacy to advance medical aid in dying.



Aug. 29, 2014, marked the beginning of the most impactful collaboration ever in the movement to expand and improve end-of-life care options nationwide.

That's when Compassion & Choices Director of Clinical Services Trish Bernstein (currently chief operating officer) and Director of Legal Affairs Kevin Díaz (currently chief legal advocacy officer and general counsel) met Brittany Maynard and her husband, Dan Diaz, for lunch to learn more about their story.



Initially, the story seemed too unlikely and tragic to believe: A 29-year-old woman dying of brain cancer wanted to bring attention to her forced relocation from her California home to Oregon, just so she could utilize medical aid in dying and advocate for similar laws in California and other states nationwide.

"As a former hospice professional, I could see how the steroids Brittany was taking to treat her brain cancer affected her," recalls Trish. "She told her story very clearly. That's when I realized this young couple would become the face of the movement. For Brittany

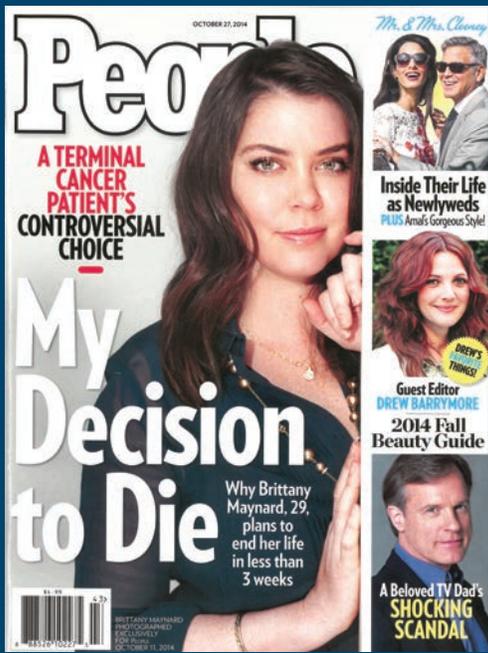
to have such courage was pretty remarkable."

"It was clearly a hard time for both of them, but Brittany was so articulate about the reasons why she wanted to spend her limited time advancing the movement," recalls Kevin. "We knew we were in the presence of what would turn out to be two of the movement's most effective advocates. She was an amazing person, wise beyond her years."

"Brittany did her research before deciding to trust Compassion & Choices to share her story," recalls Dan. "Honestly, we were very careful in determining the organization's credibility." Just one month after the official campaign launch on Oct. 6, 2014, Quartz business news confirmed their faith in Compassion & Choices' credibility and strategic campaign expertise:

"Compassion & Choices ... put into motion a brilliantly savvy national campaign [and] ... arranged for People to do a heartfelt story on Maynard's decision. They connected her with CNN Opinion to write a widely read and shared

top: Brittany Maynard with dog Charley.  
bottom: Brittany and Dan on their wedding day.



*Pursue  
What  
Matters,  
Forget  
the Rest*



clockwise from top left: Brittany Maynard appears on the cover of People, Oct. 27, 2014; Dan Diaz is interviewed by Oprah; after Brittany's passing, she and Dan appear on the cover of People, Jan. 26, 2015; Dan speaks at a legislative hearing in Washington, D.C.; Dan speaks at a California rally to support the End of Life Options Act; Dan appears with bill sponsors at a press conference at the California state capitol.

## “We knew we were in the presence of what would turn out to be two of the movement’s most effective advocates.”

op-ed ... shot, edited and released to YouTube a mesmerizing six-and-a-half minute video featuring Maynard, her husband and her mother speaking movingly about her choice. And they helped her build a website and launch a social media campaign that turned her name and the #Death-WithDignity slogan into nationally trending hashtags.”

Despite his grief over his wife’s death, Dan was determined to fulfill his promise to Brittany by continuing her advocacy to pass medical aid-in-dying bills in California and across the nation. “From January to June 2015, I was working two full-time jobs, first with my employer, Del Monte Foods, and then volunteering for Compassion & Choices late into the evenings trying to help pass the California law,” says Dan.

“I was exhausted, internalizing and magnifying every error or failure in the legislative process. Then I finally recognized, this isn’t good for me. I’m not eating right, sleeping or allowing myself the time to process the overwhelming sense of loss in my life. I knew I needed to leave my career behind and work alongside C&C as a consultant to fulfill my promise to Brittany. Afterward, my state of mind and well-being improved.”

“I have met with lawmakers in 14 state capitols. Today, I’m not as wounded when a lawmaker says ‘no’ to me. Working with Compassion & Choices to advance the national movement and authorize six jurisdictions in four and a half years is a success by any measure [California (2015), Colorado (2016), the District of Columbia (2017), Hawai’i (2018), Maine and New Jersey (2019)], and my efforts continue.

“My greatest chance to make the biggest impact is when I can get a 15-minute, one-on-one meeting with a lawmaker. They begin to understand the reality of what Brittany endured. They realize it is very likely they have constituents in Brittany’s predicament who should not have to leave home like we did. Finally, they recognize the opponents are only peddling false narratives based on fear.

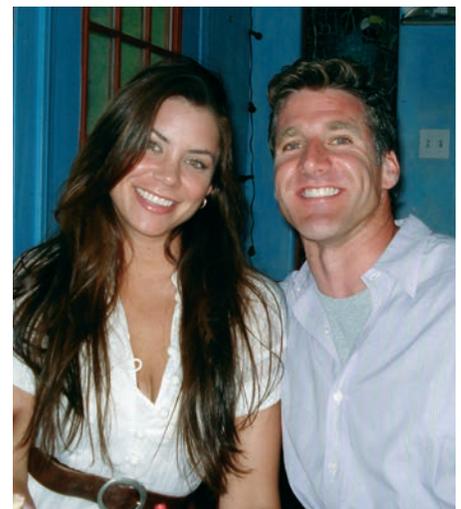
“The biggest reasons for our successful partnership with Compassion & Choices over the last five years are that people are familiar with the issue because they are familiar with Brittany’s story. Their increased awareness and the use of appropriate terminology is changing for the better. I regularly receive positive feedback from the personal and policy perspectives. Elected officials and media

personalities whom you might expect would oppose medical aid in dying because of their political persuasion frequently say things like, ‘Thank you for your continued efforts. I hope you’re doing well, Dan. God bless you.’

“Brittany would be proud of what Compassion & Choices and we have achieved so far, but with her clever grin, she’d say, ‘Nice start, Dan.’”

Compassion & Choices CEO Kim Callinan adds “Brittany Maynard and Dan Diaz have played an indispensable role in helping Compassion & Choices super-charge our movement to ensure every terminally ill person in our nation has access to medical aid in dying. We look forward to continuing to work in partnership with Dan, since he has unique insight and personal perspective on this important end-of-life care option to peacefully end intolerable suffering.”

Brittany Maynard and Dan Diaz.



## **Celebrating the LGBTQ Community**

Compassion & Choices has a long and proud history of standing with the LGBTQ community, from our early days during the AIDS epidemic to our work today supporting LGBTQ advocates and storytellers across the country. We were ecstatic and honored to receive the Distinguished Service Award from the Gay and Lesbian Activists Alliance (GLAA) in Washington, D.C., for our leadership in passing and protecting the D.C. Death with Dignity Act. This award illustrates the powerful partnership between our movements.

June was Pride month, where cities and towns celebrate the immense gains recognized by the LGBTQ community and the continued struggle for equality. Compassion & Choices staff and volunteers proudly participated in celebrations coast to coast, from large parades to small-town gatherings. We supported



New Yorkers show their support for medical aid in dying at World Pride in New York City on June 30, 2019.

these events through Pride in a Box, an educational end-of-life resource geared toward the LGBTQ community, and highlighted key advocates for helping advance our mission. Compassion & Choices mailed resources to 22 states including Colorado, Maryland, Ohio, Pennsylvania and Virginia.

## **Faith Leaders for Choice**

Compassion & Choices recognized significant gains in our outreach to the faith community. We are cultivating relationships with leaders from diverse beliefs and backgrounds, asking them to participate in our efforts to realize end-of-life options for all and educate the public on their full range of options. We reached out to hundreds of leaders, and many responded enthusiastically to participating, for example by giving educational presentations, writing letters of support and visiting legislators. This culminated in the creation of Faith Leaders for Choice, a group of 40 diverse faith leaders nationwide tasked with leading our education efforts. We hope to continue growing the council and expanding our reach in different faith communities.

## **Strengthening Partnerships**

This summer, the African American Leadership Council (AALC) held its second annual retreat in Washington, D.C. The Latino Leadership Council (LLC) also met in Los Angeles. These meetings provide members and Compassion & Choices staff with invaluable opportunities to gain insights to further advance end-of-life options, educate others and grow as movement leaders. The AALC spent its time together on Capitol Hill in D.C., educating lawmakers on end-of-life options. LLC also continued outreach to organizations like the National Hispanic Medical Association (NHMA). In June, we hosted a webinar with two LLC members and NHMA members to discuss end-of-life topics, including disparities in pain management and hospice.

## Turning the Tide With Medical Societies

The American Medical Association (AMA) adopted a new position on “physician-assisted suicide.” While the AMA maintained its opposition to medical aid in dying, they affirmed that physicians may now participate in medical aid in dying without violating their professional obligations. This is a step in the right direction and a reflection that the AMA recognizes the growing support this option has among doctors and their patients.

The American Nurses Association dropped its opposition to medical aid in dying and adopted a new policy that “nurses have an ethical duty to be knowledgeable about this evolving issue.”

State societies continue to be more amenable to updating their policy to reflect the desires of both doctors and patients. In the past five years, 21 state, national and specialty medical societies have dropped their opposition to medical aid in dying. Most recently, the Connecticut State Medical Society adopted a position of engaged neutrality. The Delaware Section of the American College of Obstetricians and Gynecologists and the Hawaii Society of Clinical Oncology adopted neutral positions.

## Introducing Powerful Stories



Hanna Olivas and husband, Jerry, comfort each other in Long Beach, CA, moments before visiting doctors at UCLA.

In April, Compassion & Choices launched a bilingual media campaign with Hanna Olivas, a 44-year-old mother of four from Las Vegas, Nevada. Hanna has been living with a rare form of incurable blood cancer, multiple myeloma, since August 2017.

Hanna courageously recorded videos in English and Spanish to urge lawmakers in Nevada and nationwide to pass laws that would allow terminally ill adults the option of medical aid in dying to peacefully end intolerable suffering. Her story was published exclusively by *People en Español*, the Spanish version of *People* magazine, which has more than seven million readers, and also ran on national TV outlets like Telemundo and Univision.

Unfortunately, Nevada’s SB 165, the Death with Dignity Act, did not advance during this year’s legislative session. Hanna and her husband shared in an interview that they may consider leaving their home in Las Vegas to move to California. They want to ensure that Hanna has the ability to access California’s End of Life Option Act, which provides the option of medical aid in dying, if her suffering becomes unbearable. Hanna has the loving support of family and friends.

## Defending and Growing

Compassion & Choices is working to expand access to medical aid in dying, while opponents seek to prohibit the practice in authorized states.

### CALIFORNIA

Compassion & Choices has issued a call to action to prevent the partnership between the University of California, San Francisco (UCSF) and Dignity Health. One of the largest healthcare systems statewide, Dignity Health has a longstanding practice of forbidding physicians and staff from helping qualified patients access medical aid in dying. As we go to press, this partnership is on hold, but we will continue to work with supporters and advocates to protect terminally ill Californians' access to medical aid in dying.

In May, Compassion & Choices President Barbara Coombs Lee spoke to nearly 350 people at four events in California about her book *Finish Strong: Putting Your Priorities First at Life's End*. Compassion & Choices board member Reverend Madison Shockley hosted one such event at Pilgrim United Church of Christ in Carlsbad.

### DELAWARE

HB 140, the Ron Silverio/Heather Block End of Life Options Act, supported by Compassion & Choices, was heard before the House Health and Human Development Committee on May 8, 2019 — the first necessary step to provide options at the end of life for Delawareans. The committee heard from many powerful advocates, including Catriona Binder-Macleod, who testified about the difficult death of her mother, and Robert Varipapa, MD, a supportive Dover neurologist and member of the Medical Society of Delaware. Supporters in Delaware are working hard contacting committee members to move the bill on behalf of Delawareans like Ron and Heather looking for more options at the end of life.

### FLORIDA

Florida continues to be one of our most active volunteer states in the country, boasting over 33,000 supporters on the ground! We are working to build our infrastructure and volunteer base in the Sunshine State by recruiting new Action Team leaders. In recent weeks, we were excited to welcome new Action Team leaders in Naples and Cocoa Beach/the Space Coast. Compassion & Choices CEO Kim Callinan visited the state in May, holding meetings in Sarasota and presenting to supporters and donors in the Palm Beach area. We are excited and encouraged by the enthusiasm in Florida, led by Michael Farmer, Compassion & Choices regional campaign, outreach and development manager.

### HAWAII

Compassion & Choices continues our campaign to educate people and health systems about end-of-life options in Hawai'i. Advocates reached a major milestone in May when the Department of Human Services Med-QUEST Division, which encompasses Hawaii's state Medicaid program, announced it will cover aid-in-dying medications under the Our Care, Our Choice Act. Eight patients received prescriptions for medical aid in dying and two used the medication to peacefully end their suffering the first five months the law was in effect, according to the Hawai'i Department of Health. David Grube, MD, Compassion & Choices medical director, has also been active across the state making Continuing Medical Education presentations to support physicians new to medical aid in dying and ensure successful implementation of the practice.

## ILLINOIS

Compassion & Choices works as a founding member of the Illinois End-of-Life Coalition, alongside the ACLU of Illinois and Final Options Illinois. Amy Sherman, Compassion & Choices new midwest regional campaigner, has been coordinating support and building a network of volunteers. Illinois has six Action Teams throughout the state and three in the works, including the new Chicago Action Team that was established this spring. Amy is building capacity by offering “train the presenter” workshops and advocacy training. Compassion & Choices board member Reverend Madison Shockley and CEO Kim Callinan visited the Prairie State to educate locals on their range of end-of-life options. Kim Callinan also participated in a fundraiser at the home of Fay Clayton and Lowell Sachinoff on June 6, with more than 80 people in attendance.

## MASSACHUSETTS

We are encouraged as legislation in Massachusetts, supported by Compassion & Choices, has already garnered co-sponsorship from more than 65 legislators, up from 46 last session. This includes nearly half of the Senate chamber (19 senators) and nine co-sponsors of the 17 member Joint Committee on Public Health. The committee held a public hearing on the bill on June 25, where they heard powerful testimony from radio personality Diane Rehm, Kim Callinan and others. A committee vote is pending.

## MONTANA

End-of-life liberty was protected once again in Montana, which remains an authorized state for terminally ill patients to seek medical aid in dying. For the fifth time in a decade, legislators tried to reverse the Montana Supreme Court’s 2009 *Baxter* decision authorizing medical aid in dying. Compassion & Choices launched an advocacy campaign with supporters, terminally ill Montanans, physicians, family members of Bob Baxter and legislative champions — ultimately defeating this year’s “Physician Imprisonment Act” (HB 284) in the Senate by a vote of 22-27. While we are celebratory in this defeat, we

must remain vigilant, as opponents will continue to work to deny options for terminally ill Montanans in advance of the next legislative session in 2021.

## NEW JERSEY

Our implementation and access campaign for the New Jersey Medical Aid in Dying for the Terminally Ill Act is in full swing! Compassion & Choices and our government relations partners in Trenton are working directly with stakeholder groups, including state agencies, to ensure a smooth rollout. The law is set to take effect on August 1, 2019.

## OREGON

Oregon was the trailblazer in our movement over 20 years ago. This year the Legislature moved along that path again by passing a bill to remove all waiting periods (not just the 15-day period between requests) for patients who are not expected to live long enough to get through them, fully at the doctor’s discretion. Compassion & Choices testified in support of this bill, which would reduce unnecessary barriers to access. Governor Kate Brown’s signed the bill into law on July 24.

Mark Connell (left), attorney for *Baxter v. Montana*, with Bob Baxter’s daughters, Roberta King (center) and Leslie Mutchler (right), at a hearing to testify against HB 284 (Physician Imprisonment Act).



## New York



Although the Hudson River between Manhattan and New Jersey is just over a mile wide, that mile is a seemingly endless chasm for terminally ill New Yorkers seeking a full range of

end-of-life options. On April 12, 2019, New Jersey became the ninth U.S. jurisdiction to authorize medical aid in dying. Qualified terminally ill New Jerseyans will have the option as early as August 2019 to get a doctor's prescription for medication they can decide to take if their suffering becomes unbearable to die peacefully in their sleep.

Compassion & Choices' New York team, led by Corinne Carey, has cultivated relationships with supporters and lawmakers throughout the state since the New York Medical Aid in Dying Act was first introduced in 2016. Compassion & Choices currently has 10 dedicated Action Teams in nine New York regions, engaging and training volunteers to coordinate outreach efforts.

This year's legislative session began with the release of a survey we conducted in partnership with Medscape/WebMD showing that 67% of New York doctors support the bill.

Our 2019 Spring Lobby Day in Albany was an enormous success. More than 130 supporters attended a morning program where they heard from bill sponsors and supportive lawmakers. Throughout the day, advocates met with 43 lawmakers who hadn't yet taken a position to support the bill, sharing stories and answering questions. We also garnered significant media attention, including coverage by New York City's NBC affiliate, the Albany Times Union, NPR and Politico.

While the New York campaign made great strides in 2019 — we persuaded 50 lawmakers to add their names as co-sponsors of the Medical Aid in Dying Act, and we won the support of both Governor Andrew Cuomo and New York City Mayor Bill de Blasio — lawmakers left Albany without taking up the Medical Aid in Dying Act. Because New York's Legislature operates on a two-year cycle, the bill will remain pending through 2020.

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## Maine



Governor Janet Mills signed the Maine Death with Dignity Act into law on June 12, 2019, making Maine the tenth jurisdiction — and the second state this year — to authorize medical aid in

dying. This victory would not have been possible without the tireless work of local advocates from Maine Death with Dignity and the Death with Dignity National Center. Our gratitude and thanks go out to these incredible activists and organizations.

The passage of the Maine bill demonstrates the incredible momentum built in the movement over the last five years. Never before in the history of this organization or the end-of-life choice movement have two states authorized medical aid in dying in the same year. With the addition of a tenth jurisdiction, we are increasing the national visibility of our cause and, in turn, closer than ever to making empowered, patient-centered care a reality in America.

The law is scheduled to go into effect on September 15, 2019. At that point, over 20% of Americans will have access to this compassionate option to end their life if their suffering becomes unbearable.

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