



compassion & choices

MAGAZINE
SPRING 2016

Read From
**Diane Rehm's
New Book**

.....

C&C Brings
End-of-Life Issues to
Capitol Hill

Five Questions for

Gail Sheehy

Groundbreaking Author & Journalist



“Respect in living,
Respect in dying.”

- Sarita Bhalotra, MD, PhD
Waltham, MA

Invest in our future ...
and yours.

Support Compassion & Choices' work and receive steady payments during your retirement years with a charitable gift annuity.

Donate cash, stocks or other assets, and receive a fixed amount each year for the rest of your lifetime while helping expand end-of-life options across America.

For more information on making a charitable gift annuity or other contribution, call 800.247.7421 or visit CompassionAndChoices.org/donate.



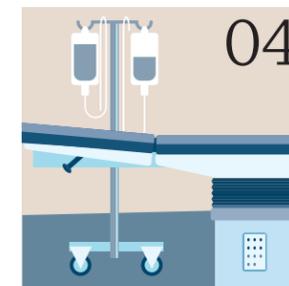
FEATURES

06 A Decision

Read from Diane Rehm's new book, "On My Own," about the death of her husband.

22 Five Questions for Gail Sheehy

The renowned writer discusses the importance of palliative care and end-of-life autonomy.



DEPARTMENTS

02 Inside View

03 Words & Pictures

04 Keeping Count

05 Words to Live (and Die) By

11 Rx for Peace at Life's End

12 Advocacy in Action

16 State Spotlight: Minnesota

17 National Programs Update

Compassion & Choices is the nation's oldest, largest and most active nonprofit organization committed to improving care and expanding choice at the end of life. We work nationwide in state legislatures, Congress, courts, medical settings & communities to:

- > empower people with information and tools
- > advance policies
- > authorize and implement medical aid in dying

Learn more at CompassionAndChoices.org.



The Right Path

People sometimes wonder how we at Compassion & Choices can immerse ourselves in the stark truth of mortality yet still feel hopeful and inspired. Well, it's because we witness life's transience that we are inclined to keep believing, hoping, loving, laughing and

doing our best every day. It's also because in acknowledging that inevitability, we can arm ourselves with the information and options to ensure our experience plays out in a manner consistent with our values and priorities for life's final chapter. And, it's gratifying to share that knowledge – that power – with you.

There is no single best path to life's end: Any fully informed, carefully considered choice is the right one. In this issue of Compassion & Choices Magazine, we point out the various options to make dying less of an out-of-control gamble. You'll read about our work in the nation's capital to ensure the system does not burden people with unwanted, ineffective and painful tests and treatments at the end of life. And you'll hear from a doctor who learned the power of acceptance from his terminally ill patients, embracing hospice as a gentle solution when options for cure are exhausted.

I send gratitude to you and our entire C&C family for accepting the whole cycle — life and death, light and dark — and so, helping bring clarity and comfort all the way through.

Barbara Coombs Lee
PA, FNP, JD, President

compassion & choices MAGAZINE

Chief Editor
Sonja Aliesch

Associate Editor
Annie Singer

Art Director
Bhavna Kumar

Contributors
Barbara Coombs Lee
Sean Crowley
Katie Wingo
Jane Sanders

Advertising, Rights & Permission
CompassionAndChoices.org
Magazine@CompassionAndChoices.org

National office:
1001 Connecticut Avenue, NW, Suite 522
Washington, D.C. 20036

Postmaster
Send address changes to:
Compassion & Choices
PO Box 101810, Denver, CO 80250

Bulk postage paid at Denver, CO,
and additional mailing offices.

In the normal course of business, Compassion & Choices regularly exchanges mailing lists with other like-minded organizations. If you would like to have your name removed from these exchanges, please notify us in writing, including your name and address. We will honor your wish upon receipt of your request.

Photo/Illustration Credits
cover, p. 22-24: courtesy of Gail Sheehy
inside front cover: Glenn Kulbuko
p. 1, 6-10: courtesy of Diane Rehm
p. 1, 14, 17: Zoeica Images
p. 2: Owen Carey
p. 11, 15: Cindy Hegger
p. 16: courtesy of Senator Chris A. Eaton
inside back cover: Steven St. John

words & pictures



Compassion & Choices President Barbara Coombs Lee spoke to USA Today about our growing influence and strength in a story titled: "Aid-in-dying advocacy group girds for battles after California victory."

The article cited C&C's successful campaign in California, recent jumps in public support, the tripling of volunteers and a six-fold increase in bill introductions.

"What keeps me going all these years is knowing the comfort and peace of mind that giving people this option for aid in dying brings to people looking at death in the face," concluded Coombs Lee.

TIME

"I've spent almost a year without my wife, Brittany Maynard," wrote C&C advocate Dan Diaz in a Time op-ed. "But in some sense, she has been entirely present. Last week, the California End of Life Options Bill passed the Senate Floor ...

"What have I learned? ...

"I've learned that we have to advocate for our loved ones ...

"I learned that one voice truly can make a difference in this world. Brittany's certainly did."

THE NATION

Compassion & Choices assisted The Nation magazine in an important investigative story about Catholic hospitals and end-of-life care. "These hospitals now make up 10 of the 25 largest healthcare networks in the United States and, in some places and for some people, they are the only realistic option," the story notes. "But Catholic hospitals don't do 'death with dignity,'" because they follow guidelines in the Ethical and Religious Directives for Catholic Health Care Services, which prohibit it. Doctors interviewed for the story expressed a broad sense of frustration at their inability to provide this compassionate option, and being "gagged" and unable to even discuss it with their terminally ill patients.



"My mom paid a painful price for not completing an advance directive," wrote C&C National Medical Director Dr. David Grube in The Hill Congress Blog. "She died ... after prolonged, unbearable and unnecessary suffering ...

"That's why it is critical for the Centers for Medicare & Medicaid Services ... to reimburse doctors for communicating with patients about whether and how they would want to be kept alive if they become too sick to speak for themselves," Dr. Grube concluded.

PBS' "Religion and Ethics Newsweekly"

An excellent segment on aid in dying aired on January 10 featuring C&C advocate Alexa Fraser, "I see nothing kind about somebody being at the end of their life, not getting the choice they want to make, and in pain and suffering."

Watch at:
www.pbs.org/wnet/religionandethics/video/#28538

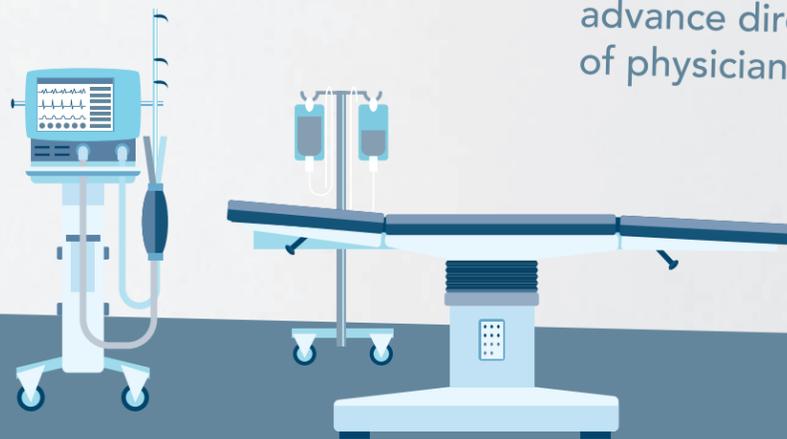


Document *and Discuss*

Outlining your end-of-life preferences in an advance directive will increase the likelihood you get the kind of treatment you want – but only if you share it. Show it to your doctor and your spouse, sibling, child or closest friend.

Less than 30% of Americans have completed an advance directive.

Even when patients have an advance directive, **only 25%** of physicians know about it.



So although **70%** of Americans say they would prefer to die at home ...

... **nearly 70%** die in a hospital or care facility.

Sources: Critical Care Journal and Centers for Disease Control

words to live (and die) by

The right words help Compassion & Choices educate people about our work, one component of which is advancing state legislation to authorize aid in dying. Some people misrepresent this end-of-life option in order to undermine support for it. Below you will find the best, most accurate way to describe this practice.

Aid in dying *IS* ...

a medical practice authorized under Oregon's Death With Dignity Act and also in Washington, Montana, Vermont and California. It is available to mentally capable adults who have a terminal disease with a prognosis of six months or less and request it. A doctor prescribes aid-in-dying medication, which the person takes when and if they choose, to bring about a peaceful death if the dying process becomes unbearable. It is an entirely patient-directed medical practice.

Aid in dying *IS NOT* ...

euthanasia. The dying person self-administers aid-in-dying medication, and in one-third of cases, they never take it at all. The patient remains in complete control of aid in dying, unlike euthanasia, in which someone else administers life-ending medication.

Aid in dying *IS* ...

one end-of-life option among others for people experiencing a prolonged, difficult dying process. Some people choose palliative care (pain management) alone for their final days or weeks. Others may choose VSED (voluntarily stopping eating and drinking), or stopping artificial ventilation or other life-sustaining therapy to advance the dying process. The more options we have, and the more information we have, the likelier it is that we can make medical decisions consistent with our own values, beliefs and priorities.

Aid in dying *IS NOT* ...

suicide. People who use it would prefer to live, but they are already dying from a terminal disease. Most people who access aid in dying are already receiving optimal end-of-life care in hospice.

The following is an excerpt from chapter one of the new book “On My Own” by iconic radio show host Diane Rehm.

A Decision

On My Own
Diane Rehm



On June 14, 2014, my husband, John Rehm — age eighty-three — began his withdrawal from life. The aides at Brighton Gardens were instructed to stop bringing medications, menus, or water. His decision to die came after a long and difficult conversation the day before with Dr. Roy Fried, his primary physician; our son, David; our daughter, Jennifer, who was on the phone from Boston; and me. John declared to Dr. Fried that because Parkinson’s disease had so affected him that he no longer had the use of his hands, arms, or legs, because he could no longer stand, walk, eat, bathe, or in any way care for himself on his own, he was now ready to die. He said that he understood the disease was progressing, taking him further and further into incapacity, with no hope of improvement. Therefore, he wanted to end his life.

Clearly, his expectation — and his misunderstanding — was that, now that he had made his decision, he could simply be “put to sleep” immediately, with medication. When Dr. Fried explained that he was unable to carry out John’s wishes, that he was prohibited from committing such an act in the state of Maryland, John became very angry. He said, “I feel betrayed.” Tears came into his eyes, tears of frustration and disappointment. Here was a man who had lived his life able, for the most part, to take charge of events, to be certain that his well-considered decisions would be carried out. And now he was making the ultimate decision, and having it thwarted.

It was then that Dr. Fried explained that the only alternative John had, if he truly wished to die, was to stop eating, drinking fluids, or taking medications. In other words, he could bring his life to an end through those means, but no one could do it for him. Dr. Fried added that he hoped John would not make the decision to end his life, but that, if he did so, as his physician he would honor it.

My husband had moved into assisted living at Brighton Gardens in Chevy Chase, Maryland, in November 2012, because he could no longer stand or walk without falling, or care for himself without assistance. We’d spent months talking about the decision we both knew was coming. We went over and over various possibilities, such as having someone move into our apartment to care for him on a twenty-four-hour basis, but we knew that wouldn’t work: there was simply not enough room for another human to be here full-time.





Most days I spent part of the afternoon with John at Brighton Gardens. Sometimes we'd sit silently, particularly in the weeks immediately after he moved in. Although he never admitted feeling resentful, it was clear he was unhappy. He had a private room, but was now in an institution, in the company of strangers, eating foods he didn't care for in a large communal dining room, and feeling an extreme loss of privacy. But slowly he regained his sense of humor, his interest in world events, and his happiness each time I walked through the door.

Over the years, John and I had talked many times about how we wanted to die. We had promised that we would do everything we could to support each other's wishes in the face of debilitating and unalterable conditions. Yet here I was, helpless to keep my promise. I could do nothing but listen as he railed against a medical and judicial system that prohibited a doctor from helping him die, even knowing that what awaited him was prolonged misery, further decline, and, to his mind, loss of dignity.

So John did what I dreaded, but knew in my heart he would do: he declared he would stop eating, drinking, or taking medications. He asked Dr. Fried how long the process of dying would last and was told it could be ten days to two weeks. John wanted to know, "Will I be in pain?" "Absolutely not," responded Dr. Fried. "I promise you, you will be kept comfortable."

A few months before this, John had come down with what's so often been called the old man's blessing. I was in South America, on a cruise with NPR listeners. It was a Saturday evening in March, and before I went to join the group for dinner, I called Brighton Gardens to check in. Our dear friends David and Mary Beth Busby were there with John, and Mary Beth answered the phone. When I asked how John was, she said, to my shock, "He's not responsive." I wasn't sure I was hearing correctly. "What do you mean, Mary Beth?" "Well, just that," she said. The two of them had been sitting there with John for an hour or so, and he was simply not moving; he was in a deep sleep, not responding to their questions, not moving when they prodded him. I asked her to feel his head. "Warm," she said. I immediately called Dr. Fried, who instructed an aide to take his temperature. It was 101.5 degrees. Dr. Fried said John was probably experiencing pneumonia. Urgently I demanded to know what he would do next. Dr. Fried



said he would order oral antibiotics for him, but warned it could be four hours before they arrived, and that John might not be able to swallow them.

At this point, I lost all composure. I screamed into the phone, "But he could be dead in four hours!" Dr. Fried then said he would go to a nearby pharmacy to obtain an injectable form of antibiotic, which he did, taking it to Brighton Gardens that night and giving John what may have been a lifesaving dose of the drug. It was 6:30 Saturday evening, and I was in Buenos Aires. I tried to get a flight out that very evening, but it was too late, so I flew to Miami the next night and then home to Washington on Monday.

By the time I arrived, John had responded well to the medication and was making a good recovery. All of our friends, as well as our son, David, who had hovered over him during the critical period of my absence, were amazed and delighted at the turnaround.

Sadly, within three weeks of my return, pneumonia again crept into John's lungs. Whether it was a remnant of the first infection or a brand-new one, he was again feverish, coughing, and exhibiting all the other symptoms he'd had earlier. He was put back on antibiotics, this time for a longer period. After the second bout of pneumonia, and lengthy and extraordinarily frank and compassionate discussions with Dr. Fried and me, John said he no longer wished to be treated with antibiotics should he experience pneumonia yet again. He was clearly in a more weakened state.

Two months later, he was placed under hospice care, which meant the doctor had concluded that he had six months or less to live. John had already made clear his wishes for "comfort care only."

And so on June 14, John began to carry out his decision to withdraw from life. Some of the aides at Brighton Gardens were clearly uncomfortable with the instructions to cease bringing all food, water, and medications, and during the first two days came to see him, asking whether he didn't want to change his mind. John said "No" pleasantly, even cheerfully, as though, somehow, he had taken back his life and could do with it as he chose. So I sat by my husband's side as he slowly died.





I rage at a system that would not allow John to be helped toward his own death. He was of rational mind, with no hope of recovery, knowing full well that the only way ahead was a slow downward slide, moving toward more incapacity and even greater indignity. Why should it be that only a few states allow aid in dying with help from a trained physician willing to offer the ultimate gift? Why should my husband have to starve himself to death? I wonder, too, why John should have had to be so alone in the dying process. I cry at the loss of what might have been this final intimacy between us, replaced by a long descent into oblivion, unaware of his family and friends beside him offering him a loving farewell and wishing him a peaceful journey. ■

From the book "On My Own" by Diane Rehm, copyright 2016 by Diane Rehm. Published by arrangement with Alfred A. Knopf, an imprint of The Knopf Doubleday Publishing Group, a division of Penguin Random House LLC.



Diane Rehm has hosted "The Diane Rehm Show" on WAMU 88.5 FM in Washington, D.C., since 1979; the show has a weekly listening audience of two and a half million. Featuring interviews with prominent political and cultural figures, it is broadcast nationally and internationally by NPR. She has received numerous honors, including a Peabody Award in 2009 and a National Humanities Medal in 2013.



The doctors in our movement are heroes. Their courage and altruism help make end-of-life options possible.



Dr. Mike Turbow testifying in favor of California's aid-in-dying law

Rx for PEACE at Life's End

Retired oncologist Dr. Mike Turbow practiced medicine for 40 years and served as a hospice medical director for 25. He now gives lectures about the end of life and teaches at Stanford medical school in addition to volunteering for Compassion & Choices.

“When I went into practice in the mid-1970s, there were very few treatments available for cancer, and nothing effective for the vast majority of patients with cancer I saw. Supportive care is what we had to offer. Hospice care was new, the first hospice being established in the United States in Connecticut in 1974. Providing that kind of care and making it possible for people to die comfortably at home seemed preferable to their dying in a hospital. I became interested in hospice and end-of-life care, and I became comfortable talking about death.

Now there are many different treatments for all types of cancer. It's much easier for a doctor — takes less time, less effort — to offer another treatment. Getting patients to accept their own death is a much greater challenge. My goal was to educate them about their disease. They needed to learn that some things can't be fixed. And at the very end of life, they needed to realize that some things shouldn't be fixed. I think what's really important is to understand all your options and to remember that you can even say no to your doctor and decline further treatment.

The American way of dealing with death is to ignore it. My premise is that you don't ignore it; you deal with it, and you will come out better through the process. Accepting our own mortality enables us to enjoy life more fully in whatever time we have left. That's a lesson I learned from my patients.

Advocacy in Action

Compassion & Choices has a broad mission to give Americans more say in their healthcare, particularly toward the end of life. As C&C grows, so do our programs — and so do our supporters' opportunities to help. Please read on to learn how you can get involved.

In the States

C&C is supporting grassroots and legislative efforts to expand end-of-life options in more than half the states this year. To accommodate the unprecedented interest in aid-in-dying legislation after our 2014 campaign with Brittany Maynard, we expanded our reach so we could be active in multiple locations at once.

Our New York team keeps gaining traction in the Empire State. They held a lobby day where aid-in-dying supporters met with their elected representatives in Albany, and the team is recruiting allied organizations to help move the New York End of Life Options Act. In New Jersey, the calendar flipped over to a new session, and C&C's campaign team didn't miss

a beat, keeping the pressure up in the state Senate and reaching out to new members of the Assembly. In Maryland we are expanding our staff and partnering with savvy grassroots volunteers — including doctors and PR pros — to keep pushing legislation forward in Annapolis. We are building on last year's momentum in Colorado and deploying well-trained activists across the state to boost support for an aid-in-dying bill.

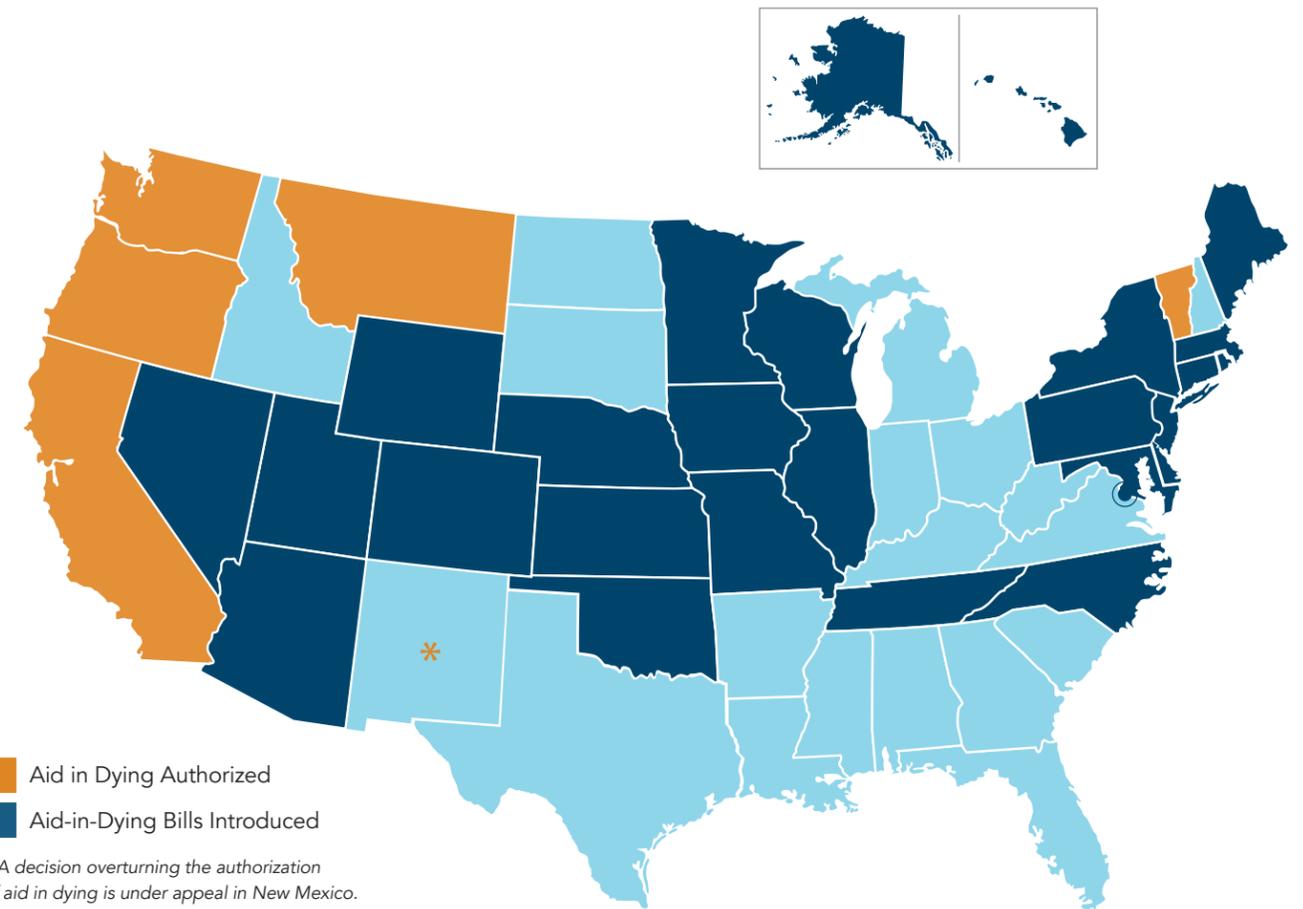
In addition to our local field staff in these and other states (including Massachusetts, Minnesota, Illinois and Hawaii), we have an impressive team of regional campaign and outreach managers who oversee several states, meeting with lawmakers and volunteers to provide strategic guidance and other resources.

To join a legislative campaign, send an email to volunteer@CompassionAndChoices.org or call 800.247.7421.

Also exciting is that we have learned our constituents can make real gains by urging local governments to declare support for death with dignity. C&C volunteers in Arizona got the cities of Tucson and Bisbee to issue resolutions expressing support for aid in dying as an end-of-life option. Local resolutions raise the visibility of needless end-of-life suffering and influence lawmakers to act. You can find a Local Resolutions Toolkit at our online Volunteer Action Center: CompassionAndChoices.org/volunteer-action-center.



News cameras and a packed room for a legislative hearing at the Massachusetts State House



HOW TO GET INVOLVED TODAY ...

Join a Legislative Campaign:

Send an email to volunteer@CompassionAndChoices.org or call 800.247.7421.

Find a Local Resolutions Toolkit:

Download at our Volunteer Action Center, CompassionAndChoices.org/volunteer-action-center.

Write a Letter to Your Local Lawmaker:

Send online at CompassionAndChoices.org/state-action-center.

Help Increase Access to Aid in Dying in Authorized States:

Contact our national volunteer manager at volunteer@CompassionAndChoices.org or call 800.247.7421.

Share Your Personal Story:

Submit at CompassionAndChoices.org/submit-your-story.

advocacy in action



Senator Mark Warner advocates for the Care Planning Act of 2015 at a Campaign to End Unwanted Medical Treatment briefing

Federal Advocacy

We are also mobilizing action teams in states across the country to advocate on behalf of our federal policy agenda. For example, when Senators Mark Warner (D-VA) and Johnny Isakson (R-GA) introduced the Care Planning Act of 2015, C&C supporters sent more than 7,000 emails to their own senators asking them to co-sponsor the bill, which would give doctors, patients and families more opportunities to discuss and document end-of-life preferences. Citizen voices from Georgia, Florida, Arizona, Wisconsin, North Carolina and elsewhere are already helping us move federal health policy closer to the person-centered model C&C envisions, where individuals' goals and priorities for care are heard and honored by their doctors.

Implementing Newly Passed Laws

It takes a campaign to get aid-in-dying legislation passed and signed into law, and it takes a campaign to turn that new law into a truly accessible end-of-life option for people throughout a state. In states like California, Vermont and Oregon, C&C leads access campaigns that rely in large part on grassroots volunteers. Strategic initiatives powered by volunteers



C&C Medical Director Dr. David Grube addresses a press conference announcing the California Access Campaign

educate and empower people to talk about their values and beliefs, and access end-of-life options. Access campaigns also help medical providers by providing technical assistance and encouraging people to talk with their doctors about options including medical aid in dying.

The importance of public education and expanded access to the full range of end-of-life options cannot be overstated. For example, before C&C's access campaign in Oregon, not enough doctors felt competent with medical aid in dying. Too many patients were waiting too long to initiate the aid-in-dying process, acting only after their pain and suffering became unbearable. Because of efforts by C&C's medical directors and volunteers, many more hospices and healthcare providers in Oregon now participate in the practice, and many more patients are educated, empowered and able to receive the care they want.

If you live in a state where medical aid in dying is authorized (WA, OR, MT, CA and VT) and you want to help make this hard-won option more widely accessible, please contact our national volunteer manager via email at volunteer@CompassionAndChoices.org or call 800.247.7421.

Experience Matters

Readers of this magazine know C&C was the state-wide force behind passage of the California End of Life Option Act, which Governor Jerry Brown signed into law late last year. Now, C&C is scaling up and adapting those winning strategies, refined by our talented California team, to other campaigns and programs. Here are three examples.

Storytelling

When the End of Life Option Act moved through California's legislature it became a testament to the power of individuals' stories. California native Brittany Maynard's experience confronting terminal brain cancer, which she explained in her own steady and strong voice, inspired two compassionate lawmakers to sponsor a death-with-dignity bill and persuaded many in her home state to support that legislation. But what she also did was show that "one voice truly can make a difference in this world," as Brittany's husband, Dan Diaz, said. Her example inspired dozens of other courageous Californians who, facilitated by C&C, shared their stories, spoke to journalists and testified before lawmakers about the need for more end-of-life options for terminally ill adults.

Stories are the way we — and that includes journalists, doctors and policymakers — interpret and understand the world around us. If you have experience with either a difficult or peaceful death, or with unwanted medical treatment or getting an advance directive honored, we want to hear from you. Please visit our Submit Your Story page at CompassionAndChoices.org/submit-your-story and fill out the form. We might follow up with you, and we promise to protect your privacy unless you authorize us to share your story and identity.

Legislator Connections

The California End of Life Option Act succeeded in large part because of the clear-eyed conviction and

political wisdom of its sponsors, Assemblymember Susan Talamantes Eggman, Senate Majority Leader Bill Monning and Senate Majority Whip Lois Wolk. These three legislative champions are partnering with C&C on conference calls with like-minded legislators across the country to share lessons learned about winning votes for aid-in-dying legislation.

Multilingual Outreach

Nearly half of all Californians speak a language other than English at home, and more than 15 percent of Californians are monolingual in Spanish. Our campaign in that state was bilingual in Spanish and English, and we are taking our translation project national. As a first step in expanding our outreach to multiple language populations, C&C has created an entire End-of-Life Planning Center with web content and downloadable documents, all available in Spanish. You can find it online at CompassionAndChoices.org/informacion.



One of the most powerful advocates for aid in dying, Christy O'Donnell, shares her story with lawmakers in Sacramento shortly before they passed the California End of Life Option Act

Minnesota



Senator Chris A. Eaton

Minnesota is poised to take up death-with-dignity legislation in 2016. Since the state's Compassionate Care Act was introduced last year, there has been one legislative hearing and four local "listening sessions" on the bill (in Brooklyn Center, Duluth, St. Paul and Mankato). The bill is a proposal to authorize the medical practice of aid in dying for terminally ill adults in the state. Each listening session featured local experts who answered questions and lawmakers who listened to public comments.

The listening sessions were organized by the bill's author, Senator Chris Eaton, a nurse with more than twenty years of experience in mental health, so she speaks from a position of authority and knowledge. And like most of C&C's legislative champions, she also has a personal story: feeling helpless as her own mother endured a painful, drawn-out death. The bill's author in the House is Representative Mike Freiberg, a public health attorney and an eloquent advocate for expanding end-of-life options.

We have many reasons to be optimistic about an aid-in-dying bill advancing in Minnesota. Key members of the health committee charged with reviewing the legislation support it. C&C also has nearly 10,000 supporters from Bemidji to Albert Lea, and is working with physicians and members of the clergy to build grassroots support among those constituencies. Also important is that advance planning is becoming the standard of care in Minnesota.

We have many reasons to be optimistic about an aid-in-dying bill advancing in Minnesota.

The Twin Cities Medical Society is coordinating a statewide Honoring Choices initiative, modeled on an innovative program in La Crosse, Wisconsin, to help ensure every person's healthcare choices are clearly defined and honored.

As Minnesotans become increasingly empowered and educated about end-of-life care and planning, it becomes likelier that they will demand more and better options, including medical aid in dying.

National Programs Update

Compassion & Choices Advances Agenda in Nation's Capitol

It was standing room only at C&C's Capitol Hill briefing this winter. Policy analysts, legislative staffers and others heard us outline our policy agenda to protect and expand end-of-life options, and ensure healthcare providers honor and enable their patients' decisions.

The briefing had two goals:

- » Inform federal lawmakers about Compassion & Choices' newly developed federal policy agenda, which includes goals such as expanding hospice and palliative care, and reducing unwanted medical treatment.
- » Provide federal policymakers an opportunity to better understand medical aid-in-dying legislation, since it recently passed in California and is currently advancing in legislatures and courts in more than half the states.

To that end, C&C invited some of its most compelling advocates for end-of-life choice to share their insights.

Brittany Maynard's husband, Dan Diaz, addressed the packed room in the Rayburn House Office Building. Diaz described how his wife died peacefully thanks to Oregon's death-with-dignity law and talked about how gratified she would be that her home state of California has now passed a similar law. Two other people key to advancing the California End of Life Option Act also spoke. Charmaine Manansala, C&C's California political director, outlined the new law's provisions. C&C board member Rev. Dr. Ignacio Castuera, who worked tirelessly alongside thousands of other volunteers to urge California lawmakers to pass the legislation, spoke from a religious and ethical perspective. The audience also heard from

Dr. David Grube, a C&C medical director, who shared his experience as an Oregon family physician and answered questions about how aid in dying works in practice.

C&C's chief program officer, Kimberly Callinan, provided an overview of the federal policy agenda and moderated the event.



C&C board member Rev. Dr. Ignacio Castuera tells a Capitol Hill audience about his commitment to expanding end-of-life options alongside Chief Program Officer Kimberly Callinan

Read C&C's Federal Policy Brief Here:

CompassionAndChoices.org/federal-policy-agenda

Watch a Video of the Briefing at:

CompassionAndChoices.org/federal-briefing-video

Doctors for Dignity Speak Out



Dr. Seth Morgan, a board-certified clinical neurologist, diagnosed his own multiple sclerosis in 2004. After 23 years in medicine, he retired in 2006 when the disease inhibited his practice. A Maryland resident, Dr. Morgan now works with Compassion & Choices through our Doctors for Dignity program. As a person living with disability, he hopes to spread awareness that aid-in-dying laws grant patients a choice based in self-determination, a key tenet of the Americans With Disabilities Act.

At the “Fall Study” session by Maryland’s death-with-dignity joint committee, Dr. Morgan testified in support of an aid-in-dying bill, addressing fears over coercion and the commonly used “slippery slope” argument.

“It’s time to give people facing the end of life a reasonable option for personal choice.”

In his testimony he emphasized the law’s many safeguards and argued that aid-in-dying laws simply provide an additional medical

option at the end of life. He concluded his testimony saying, “It’s time to give people facing the end of life a reasonable option for personal choice.”

Stay tuned for more about Dr. Morgan as he joins Compassion & Choices’ work with the disability community.



Interested in becoming a doctor for dignity? Learn more at CompassionAndChoices.org/doctors.



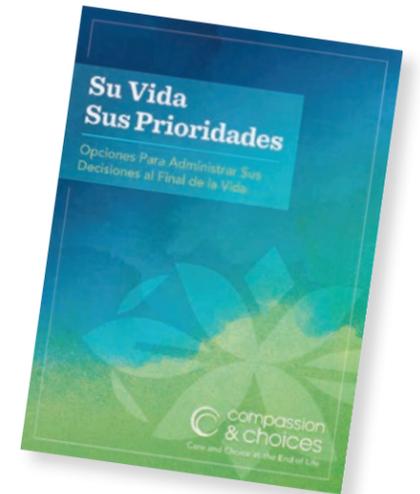
Supporting families in their advance planning is central to C&C’s mission. Take advantage of the resources we offer at CompassionAndChoices.org/information.

End-of-Life Care Materials Available in Spanish

Compassion & Choices is excited to announce our new online Spanish-language resource. All planning materials, including the “Your Life, Your Priorities” booklet and “Good-to-Go” toolkit, are now available in English and Spanish. These materials are accessible to more people than ever, equipping Spanish-speaking communities with important planning tools.

Kimie Ueoka, Compassion & Choices’ End-of-Life Care Program manager, believes this process has served as a learning experience for C&C in expanding to other language audiences. The availability of translated materials is an important step toward eliminating barriers for people who wish to access information and empowering those from diverse backgrounds.

You can access Spanish-language end-of-life care materials at CompassionAndChoices.org/informacion.



Compassion & Choices Launches Volunteer Brownbag Series

Last October, Compassion & Choices kicked off its Volunteer Brownbag Series to provide ongoing education for our national volunteer force. Led by Sarah Brownstein, National Volunteer Program manager, the series presents an opportunity for volunteers to gain a comprehensive understanding of end-of-life options and issues surrounding the movement.

To date, each hour-long teleconference has featured a presentation by C&C leadership and experts followed by a Q&A on the given topic. The series is open to volunteers and staff, and has drawn a high number of participants since its inception.

Presentations so far have focused on state campaigns and implementation of medical aid-in-dying laws. The January edition, for example, covered plans to build on our strong base of support in New York, and to engage and educate NY legislators about end-of-life options. Future topics will include religious and moral perspectives on the end of life and legal aspects of aid in dying.

Is there a topic you’d like to learn more about? Please contact Sarah at sbrownstein@CompassionAndChoices.org.

Meaningful Access to an Important Option

In some ways, the real work of helping people access more end-of-life options begins *after* we pass a death-with-dignity law. That's when implementation begins, and Compassion & Choices Access Campaigns focus on educating doctors, volunteers and residents in states where aid in dying is authorized. Training supporters in every community and creating networks of physician participants and advocates is how these laws succeed. We have three access campaigns in progress:



Oregon

The first state to pass and implement an aid-in-dying law continues to expand accessibility and recruit physicians even now, 18 years later. This year we launched a statewide speakers bureau to create a network of community educators and leverage key opportunities to partner with healthcare systems. The result: C&C's Oregon Access Campaign increased the number of prescribing physicians by 70% in less than a year. Integrating aid in dying into the medical practices of oncologists, internists and family physicians throughout the state keeps it safe from attack by opponents.



Vermont

This year the Vermont team achieved a major victory when two community clinics that did not previously provide aid in dying agreed to include all authorized end-of-life options in their practice. Six regional volunteer teams went into action to educate Vermonters about these options.



California

Before the End of Life Option Act even took effect, Compassion & Choices launched an Access Campaign in California to take on the enormous task of supporting 39 million residents in navigating a full range of end-of-life choices. The campaign continues to educate and train our 90,000 supporters, over 1,000 volunteers and 26 action teams to be champions for healthcare empowerment and to create a network of physician advocates.

Learn more about our California implementation efforts at EndofLifeOption.org.

Brief Filed With New Mexico Supreme Court



(from left to right) Adrienne Dare, Jean Berlowitz, Dr. Aroop Mangalik, Alexandra Smith, Aja Riggs, Elizabeth Armijo, Dr. Katherine Morris, Kevin Diaz, Erin Marshall, Laura Schauer Ives

The New Mexico Supreme Court soon will rule on a suit, originated by Compassion & Choices and ACLU of New Mexico, asserting the state constitution protects medical aid in dying.

Before the October hearing in the case *Morris v. New Mexico*, Compassion & Choices filed a friend-of-the-court brief, which concludes:

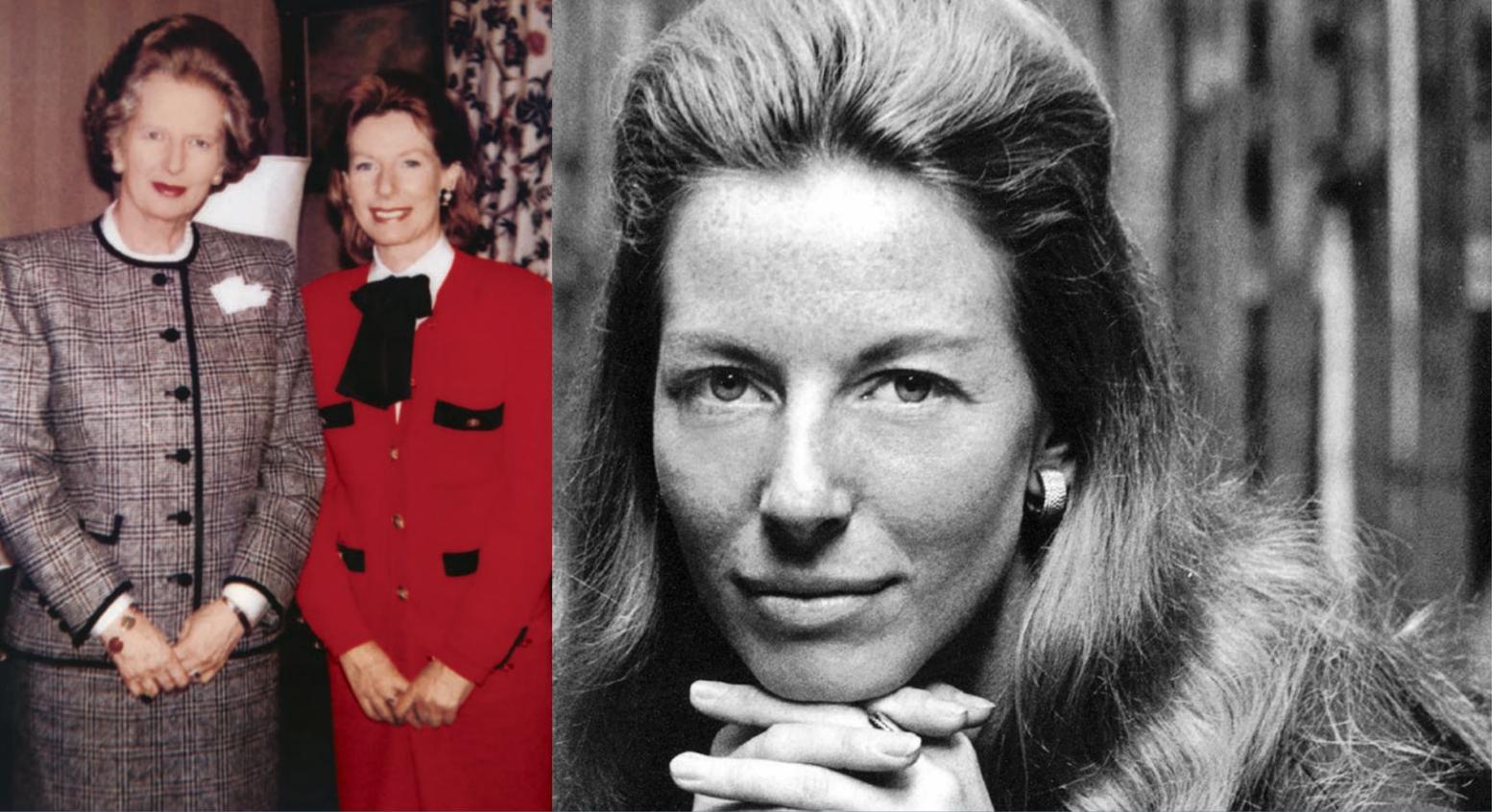
"... the Oregon experience has taught us that pursuit of physician aid in dying does not appear to have a negative effect on surviving family members and, in fact, may help some family members prepare for the terminally ill patient's death. This is in stark contrast to what family members must endure in tragic situations where terminally ill patients felt no option was available to them, and they ended their lives violently."

Award-Winning Attorney Joins C&C

Compassion & Choices welcomes new staff attorney Jonathan Patterson, recipient of the 2015 Oregon New Lawyers Division Advancing Diversity Award for his outstanding service to the Oregon legal community. The University of Oregon Law School graduate previously worked with Oregon Federal Magistrate Judge John V. Acosta and clerked for judges in the Multnomah County Circuit and Lane County Circuit Courts.



Jonathan Patterson



Five Questions for Gail Sheehy

Called "America's emotional tour guide" by The New York Times, Gail Sheehy outlined the stages of life — including caregiving — in her renowned "Passages" series. The Manhattanite now speaks out in support of Compassion & Choices' efforts to expand end-of-life options in the Empire State.

Q: You've had a remarkable career as a journalist and author. When did you know you wanted to be a writer?

A: I wanted to be a writer from the time I could type, which was age seven, when my grandmother gave me a typewriter. It felt like I was making a book because it came out on paper, you could pull it out and decorate it, and I thought that was the most exciting thing! But I didn't actually get a job in that field until I was 23, at the Rochester Democrat and Chronicle. I had one of those interviews that women did at that time: "Uh oh, how long is it going to take before you get pregnant?" I said, "I didn't know this was a maternity exam; I thought it was a job interview." It impressed the editor so much he sent me to the city editor of the paper. So that was my start.

Q: Which other fields have you worked in?

A: My first job out of college was at J.C. Penney headquarters in New York, where they had a management training program. I found out there were 50 people in the program, but not any women. I kept asking about it, so they finally sent me up to J.C. Penney himself, James Cash Penney, with his handlebar mustache and suspenders. When he said, "So I understand you want to be in management training," I somehow popped out, "I would like to, but do you pay the girls as much as the boys?" He kind of pulled himself up and said, "Well, I don't know. But we should." And they did! That was my first job, as a management trainee getting paid as much as the boys.

Q: Of the many notable figures you've profiled, including Mikhail Gorbachev and Hillary Clinton, who was most surprising to you up close?

A: I think Margaret Thatcher. I spent a long time preparing in London, interviewing like 53 people before I actually got my interview with her. What I had observed and learned was what a flirt she was. You would never think in a million years of this helmet-haired woman using her sex appeal, but she was pretty overt, and it had an effect. Actually, her flirtation with Mikhail Gorbachev led to his unyoking his Soviet satellites peacefully. That was when Reagan was able to go to Berlin and say, "Mr. Gorbachev, tear down this wall."



five questions

Q: What brought your attention to end-of-life issues?

A: When my husband, Clay, who had four different cancers and two very radical neck surgeries over the course of 17 years, had to have a feeding tube. He couldn't swallow. As his caregiver, I came to what I call the "I can't do this anymore" stage. What saved me was finding a palliative care doctor, who treated Clay at home, with a team that included a nurse practitioner, social worker and chaplain.

At one point his feeding tube came out, so I called the palliative care doctor, who came right over and reinserted it. Two days later, it came out again. This time when I called the doctor, he said, "Did you ask him if he did it?" I went from shock to this sudden insight that he probably did. I then questioned his aide, who said yes, he had taken it out. Finally I asked Clay, "Are you ready to let go?" He said yes, so I said, "Then let's do that together."

Q: Having cared for your husband through those years of illness, what advice do you have for the increasing number of adults who find themselves in a caregiver role?

A: I certainly would urge any caregiver with a long-term proposition to join a support group. I didn't, and I wish I had. The beauty of my situation was we beat cancer three times. It was the fourth cancer that finally took Clay down. But in between those times were these wonderful reprieves where we appreciated the very essence of every moment we had. They were some of the best years of our lives.

It was only when I learned about palliative care that there was some hope we could get through the slow-dying period, which lasted a year and a half of great suffering on both his part and mine. Palliative care is now available quite widely, but it's almost always offered only for a few days, in the hospital. The real place where palliative care works is at home. At home, a patient can be surrounded by family and friends, familiar with everything around them, and they can go out in the world. It makes all the difference. I hope with so many boomers facing this crisis with their parents and with their spouses now, there will be more and more support for palliative care and Compassion & Choices.

p. 22 - (clockwise from top left) Gail Sheehy with then British Prime Minister Margaret Thatcher; Sheehy's author photo for her best seller "Passages"; Sheehy with husband Clay Felker; Sheehy with a young Hillary Rodham Clinton; Sheehy with husband Clay Felker



The Champions Circle monthly giving program allows you to contribute automatically each month, helping us plan our work more effectively. Signing up is simple, and you can make changes or cancel at any time.

Join our Champions Circle with the envelope in this issue or online at CompassionAndChoices.org/donate.

Be a **CHAMPION** for Choice



“It is important to me to support organizations that champion a person's right to die in a time and place of their own choosing. Making automatic monthly donations guarantees that this is accomplished.”

– Ilse Gay, *New Mexico*



Three great reasons ... to visit CompassionAndChoices.org right now:



- 1.** We redesigned our website. It's easier to **find** information, **learn** what's happening and **take action** for change.
- 2.** We made it simpler to find our free, unique resources to help you plan for the end of life.
- 3.** We made it mobile-friendlier so you can read it on your phone or tablet.

Same name, new experience: **CompassionAndChoices.org**