

compassion & choices

MAGAZINE
WINTER 2015

**Brittany
Maynard's
Noble Legacy**

.....

**More States
Demand
Death With Dignity**

.....

**C&C Honors
Black History
Month**

Five Questions for

Diane Rehm

NPR talk show host



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Be a **CHAMPION** for Choice



“

I live life according to my own terms. The end of my life should be no different. It gives me great pleasure to know my automatically recurring quarterly gifts help make that happen for people in more and more states in the meantime.”

– Jay Dackman and his dog Buddy, Maryland



FEATURES

06 A Proud Man

Aris T. Allen Jr. tells how his father, a history-making black politician, seized control of a terminal diagnosis.

08 The Voice That Shook the Movement

Brittany Maynard's death with dignity ignites nationwide change.

11 C&C Celebrates Black History Month

Our dialogue with black leaders and citizens continues.



DEPARTMENTS

- 02 Inside View
- 03 Words & Pictures
- 04 Keeping Count
- 05 Words to Live (and Die) By
- 12 Advocacy in Action
- 17 State Spotlight: Colorado
- 18 National Programs Update
- 21 Rx for Peace at Life's End
- 22 Five Questions for Diane Rehm

Compassion & Choices is the nation's oldest and largest nonprofit organization working to improve care and expand choice at the end of life. We: **Support** patients and families **Educate** the public and professionals **Advocate** across the nation

Advancing death with dignity since 1980. Learn more at CompassionAndChoices.org.

inside view



Growing Louder

Medical aid in dying has hit mainstream media – you’ve likely noticed. Not long ago we noted in these pages how diverse our movement has grown, with broad support across ethnic, religious and political lines. Now, due largely to the astounding impact of

iconic advocate Brittany Maynard (p. 8), the 29-year-old Californian who relocated her family to access aid in dying, our backers span generations and geographies like never before. People have awakened to the reality that death defies demographics, and they’re not satisfied with the current options in most jurisdictions.

The Brittany phenomenon demonstrates how powerful one voice can be. Brittany placed our cause before the widest audience, prompting the “Aha!” moment when people realize it is unjust and cruel for government to prevent a person in Brittany’s position from limiting the amount of suffering she endures before dying. It also shows how universal is the desire for options and self-determination, bringing new supporters to Compassion & Choices by the hundreds of thousands in a matter of weeks. Lawmakers in states where we previously had no foothold are pledging to pass their own death-with-dignity laws (p. 12). And recent surveys show solid majorities of doctors and the general public believe an individual should be able to choose the course of their lives, up to its very last moments (p. 20).

Whether you are new to the end-of-life choice movement or a veteran ally, enjoy this wonderful solidarity. Add your voice to our ever-growing chorus by sharing your own story or spreading your passion to others. Finally, the world is listening.

Barbara Coombs Lee
PA, FNP, JD, President

compassion & choices MAGAZINE

Chief Editor
Sonja Aliesch

Art Director
Bhavna Kumar

Director of Communications & Marketing
Gwen Fitzgerald

Contributors
Barbara Coombs Lee
Mickey MacIntyre
Jane Sanders
Sean Crowley
Anne Singer
Jeanne Duncan
Katie Wingo

Advertising, Rights & Permission
Compassion & Choices
PO Box 101810
Denver, CO 80250
800.247.7421 (t)
303.639.1202 (t)
303.639.1224 (f)

CompassionAndChoices.org
Magazine@CompassionAndChoices.org

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words & pictures



A *People Magazine* cover story and thousands of others about Compassion & Choices’ historic partnership with Brittany Maynard appealed to editorial writers across the nation.

“There are tons of Americans who don’t have time or the ability or finances [to access death with dignity], and I don’t think that’s right or fair,” explained Brittany in her first video on www.TheBrittanyFund.org.

Apparently, 18 newspapers in 10 states agree with Brittany because they cited her case in their endorsements of aid in dying.



“I don’t know why better end-of-life care and death with dignity can’t coexist,” Barbara Mancini told *60 Minutes* correspondent Anderson Cooper during the Oct. 19 broadcast.

After a Pennsylvania judge ended the year-long prosecution of Mancini for her dad’s death, she told Cooper she travels the country advocating for comprehensive end-of-life care and choice.

“What happened to Barbara Mancini was rare, but the risk of what happened to her pervades every bedside of every dying individual,” Compassion & Choices President Barbara Coombs Lee told Cooper.

The New York Times

“I watched my 66-year-old sister die in pain ... It took five weeks, and it was excruciating for both of us.”

C&C volunteer advocate Anita Freeman of Long Beach, Calif., wrote those heartbreaking words in a *New York Times* op-ed.

“Elizabeth asked her doctor to help her go to sleep so she could die peacefully. Tragically, he said he could not honor her request because we live in California ...

“No one should suffer as my sister did.”



“Most people say, ‘I’m not afraid to die. I am afraid to suffer,’” Compassion & Choices End-of-Life Consultation (EOLC) Program Manager Jena Johnson told CNN.com in a profile story.

Her mother, raised in an era when people rarely questioned a doctor’s orders, died painfully of lung cancer in 1990 – even though, Johnson says, “She had very pronounced ideas of how she wanted to go.”

Johnson says that had she known then what she knows now, she could have discussed other options with her mother.

Compassion & Choices 2014 Year-End Video

Last year was a remarkable one for Compassion & Choices and the death-with-dignity movement, and we owe this success to people like you. Join us in celebrating a year of amazing progress and growth, and watch the video:

CompassionAndChoices.org/year-end-video-2014



90% of Americans believe having end-of-life conversations is important

Less than **30%** have had them

Let's Talk

The Institute of Medicine's panel of experts recommends that more people discuss death, and much earlier in life. But based on findings in its recent 500-page report, *Dying in America*, too many Americans are avoiding "the conversation."

Recommended age to start these conversations is **16**

Yet **most do not** until they are over **65**

Source: *Dying in America*, Institute of Medicine of the National Academies, September 2014

END-OF-LIFE CARE:

Healthcare for those of any age with a terminal condition that has become advanced, progressive and incurable; not only for patients in the final hours or days of their lives.

ADVANCED DISEASE:

A severe condition, such as cancer, for which a cure is not an option. Some people will live for many years after a diagnosis of advanced disease, while others may only live for a short time.

HOSPICE:

Care designed to support people in the final phase of a terminal illness. It focuses on quality of life rather than cure, neither hastening nor postponing death. Hospice's goal is to bring dying people comfort so that they live each day as fully as possible, providing support for emotional, social and spiritual needs as well as medical symptoms as part of treating the whole person.

ADVANCE DIRECTIVE:

A set of planning documents that includes a living will ("what I want") and a medical durable power of attorney ("who will speak for me") that outline your end-of-life preferences. Each state has its own forms and guidelines.



Find your state's advance directive form and other planning documents at www.bit.ly/CCAdvanceDirective

A PROUD MAN

by Aris T. Allen Jr.

Learn how to make your end-of-life preferences known by calling our End-of-Life Consultation service at 800.247.7421.

Allen at his father's memorial in Annapolis, Maryland



Physician, legislator and Army pilot Aris T. Allen was the first African-American chair of the Maryland Republican Party. His son recalls how his distinguished father took control of a terminal diagnosis in the winter of 1991.

It was a normal day. I had gone to work, and upon returning home, I followed my normal routine of changing my clothes, checking the telephone answering machine and opening the mail. While listening to the phone messages, there was an unusual one from a neighbor and friend that said, "I'm sorry about your dad."

I was surprised and perplexed, so I dialed my parents' home phone to get clarification from my mother. A neighbor answered their phone, which caught me by surprise; again, I was perplexed. I asked what was happening, and he put my mother on the phone.

She said, "Something has happened to your dad." I could tell in her voice that she was distraught but in control. I asked, "What do you mean?" She uttered the words, "Tee ... your dad is gone ... he's dead."

I was speechless and in disbelief. All I could say was, "I'm on my way." I jumped in the car and began the 35-mile drive to their home. I was in shock as I drove, but I knew I had to maintain my cool.

I telephoned my brother en route, and he gave me more details. Upon approaching my parents' house, I saw cars parked in front. When I entered, neighbors and friends greeted me and expressed their condolences. All I wanted to do was to see my mother. I found her sitting at the breakfast table surrounded by people, including her doctor. I hugged her and asked if she was OK.

She was maintaining her composure, but I could only anticipate what she was feeling, and I knew I had to be strong for her. Her doctor assured me that she was all right under the circumstances. I, too, had to maintain my composure as neighbors, friends and newspaper reporters came and went.

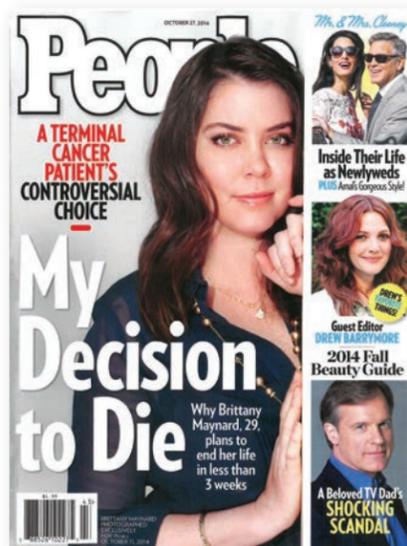
Although I knew what had happened, I wanted to know "why." I needed answers. When my brother was finally able to get me alone, he told me that Dad had prostate cancer and didn't want us to know. Although he had been in treatment, his prognosis was terminal.

Dad was a proud man. He was a very accomplished medical doctor who had served in the military and in the Maryland House of Delegates and Senate. He alone made the decision to end his life. My mother didn't even know he was contemplating it. We do recount that he always said he wanted to die with his boots on. Days later my mother said that when he learned of his deteriorating health, he was concerned about being a burden on her and the rest of the family.

I share this only to point out that the time that followed could have been chaotic, devastating, guilt-ridden and confusing. But it was less so because he had spelled out his final wishes, completing his will and expressing what he wanted to have happen upon his death. My parents had shared this with my brother and me. But in spite of the emotional reaction my mother, my brother and I experienced, we knew why this happened. We knew and understood the medical reasons. We knew the nature of my father and understood his decision. He was always in control of his life when living, and wanted to be in control when he died. I wish other options for controlling the end of his life had been available to him. That's why I'm proud to work with Compassion & Choices and share my story.

Following my dad's death, my mother, brother and I had many conversations, and we shared our feelings. The loss of a loved one can be devastating. But we were able to focus on healing and all of the wonderful memories without the sudden burdens and responsibilities associated with the death of a family member. I would recommend that everyone have "the conversation" and talk with their loved ones about what they want and don't want, as well as to complete an advance directive so their wishes are known.

The *Voice* That Shook the Movement



Brittany Maynard's story of dying on her own terms was the most important event in the end-of-life choice movement since passage of Oregon's groundbreaking Death With Dignity Act in 1994, according to Compassion & Choices President Barbara Coombs Lee, who co-authored the law. "Her phenomenal visibility helped increase already-gathering momentum," Lee said.

Maynard's story was ubiquitous from the moment it broke on People.com Oct. 6 through mid-November, well after her Nov. 1 death via aid in dying. And early in 2015, Maynard's family stepped forward, working with Compassion & Choices (C&C) to carry out her legacy. Her husband, mother and brother-in-law gave national media interviews, met with legislators in multiple states and spoke out in

Sacramento at the press conference to announce the introduction of the End-of-Life Option Act in California, Maynard's home state.

During a January media tour that C&C arranged, Maynard's husband, Dan Diaz, his brother Adrian and Coombs Lee appeared on a number of NBC programs including *The Today Show*, *The Meredith Vieira Show* and MSNBC's *The Last Word* with Lawrence O'Donnell. They used the stages to urge people nationwide to demand their lawmakers support death-with-dignity laws in all states.

It's clear Maynard's story is driving change. Since early October, there have been advances in legislation, a spike in public and physician support, and a wave of volunteerism toward making aid in dying an open, accessible and legitimate



Debbie Ziegler (Brittany's mother) spoke at a California press conference with lawmakers, family and advocates

the Movement

medical practice in more states. For the first time, most American physicians believe – by a 23-percent margin – that patients with an "incurable and terminal" disease should have the option to choose death with dignity, also known as aid in dying. That was the finding of an online survey conducted by Medscape of 17,000 U.S. doctors representing 28 medical specialties. Maynard's story drove a surge in public support as well: 74 percent of American adults believe terminally ill patients who are in great pain should have the right to choose to end their own lives, according to a December poll by HealthDay and Harris Poll.

C&C declared a national day of action for death with dignity on November 19, which would have been her 30th birthday. Staff

also held a webinar briefing for journalists, released a new call-to-action video narrated by Maynard and organized events across the country. The webinar featured Rep. Dan Zwonitzer (R-WY), who

Maynard has inspired a whole new generation of death with dignity supporters.

introduced a death-with-dignity bill in 2015, and Rep. Mark Rozzi (D-PA), who introduced a death-with-dignity bill on Oct. 15, nine days after Maynard's story broke.

Rep. Rozzi's father died of brain cancer, as Maynard did. "I had to watch my father die of cancer ... It was the most gut-wrenching experience our family and he had to endure," Rep. Rozzi told *The Huffington Post*. "He would

always tell me this is not the way he wanted to live." Compassion & Choices expects 21 states and Washington, D.C., to consider death-with-dignity bills in 2015.

Maynard has inspired a whole new generation of death-with-dignity supporters. Hundreds of first-time volunteers are engaged with C&C, and tens of thousands of advocates

signed up online. She also has lifted the voices of longtime advocates of aid in dying, some of whom were featured in the call-to-action video released Nov. 19.

After seeing her in the video, MSNBC's Lawrence O'Donnell interviewed Anita Freeman from Long Beach, Calif., about her sister's horrifically painful five-week-long death from recurrent cancer. "We have got to somehow

“She started this enormous wave of change; it would be foolish to squander that. So I just want to see it through until we get legislation in the books. Then I’ll feel at peace.”

- Dan Diaz on his wife Brittany Maynard’s legacy on The Meredith Vieira Show, January 14, 2015



from top to bottom:

Anita Freeman
Alexa Fraser
Dan Diaz

get our lawmakers ... to give us this ability to choose what happens to us when we’re terminal,” Freeman told O’Donnell.

About 25 Maryland death-with-dignity advocates rallied in the state capital of Annapolis on what would have been Brittany’s 30th birthday, generating coverage from three TV stations. Rockville-based advocate Alexa Fraser told Baltimore’s ABC affiliate that she wished her dad could have utilized aid in dying when he was battling Parkinson’s disease.

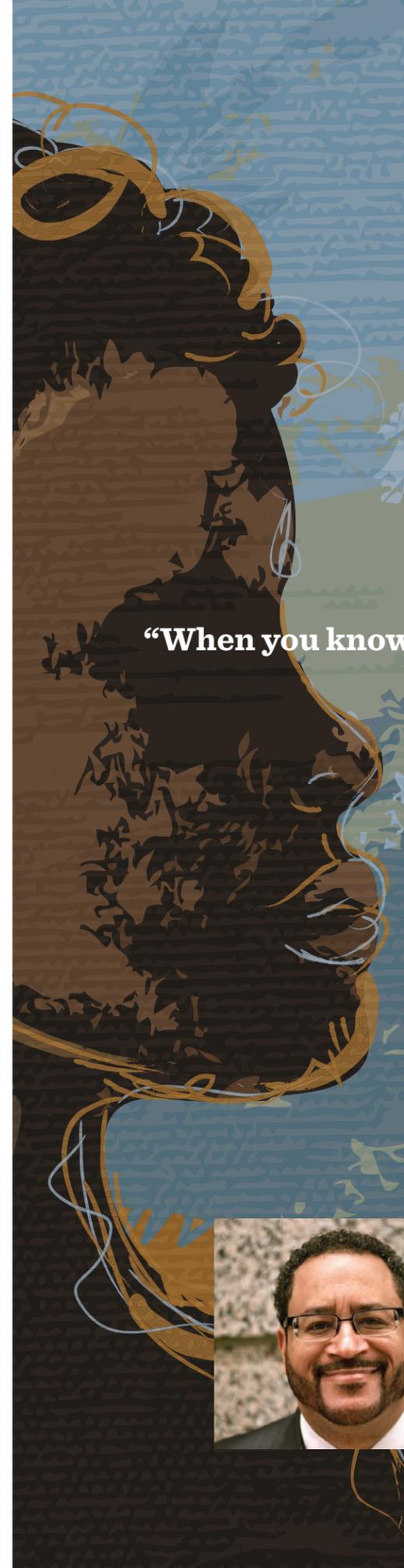
“Eventually he chose to shoot himself, and he did die in that way. And it was terribly sad. I wish I could have been with him, and I wish he could have died peacefully in his bed the way he deserved to die,” said Fraser. “This [aid in dying] is just a small movement change in the date. There’s no question that my dad was going to die.”

Across the nation, four TV stations and two print media outlets covered a Nov. 19 candlelight vigil with aid-in-dying supporters. The ceremony took place at the First Unitarian Church of Portland,

where, in 1993 and 1994, Coombs Lee coauthored the Oregon Death With Dignity Act through its many drafts. “The change is starting now. We’ve never had so many elected representatives contact us and say, ‘I want to introduce a ‘Brittany law’ in my state,’” she told the local Fox news affiliate.

New Mexico C&C Campaign Manager Erin Marshall, a member of the Well Women Project, read Maynard’s obituary in Albuquerque. Action teams across the state observed a moment of silence.

Hearing Maynard’s story on a local radio station inspired Solano, Calif., Compassion & Choices member and retired commercial fisherman John La Grange to write an op-ed for *Zocalo Public Square* about his wife’s agonizing death from cancer. “I went through a very long process with my wife’s cancer, and no one told us how bad it would truly be at the end,” La Grange told People.com. “If she had had the chance to end her life so that she wouldn’t be in so much pain at the very end, she would have taken it.” ■



“When you know better, you live better.”

- C&C National & Federal Programs Director Daniel Wilson

C&C Celebrates Black History Month

Compassion & Choices and the National Caucus and Center on Black Aged, Inc., (NCBA) hosted “The Journey Home” to celebrate Black History Month. The keynote speaker was Dr. Michael Eric Dyson, best-selling author, Georgetown University sociology professor and acclaimed public intellectual who was named by *Ebony* magazine as one of 100 most influential black Americans. Dyson also serves as a commentator on NPR and CNN, and a political analyst for MSNBC. During The Journey Home symposium, clergy, caregivers and thought leaders in the black community held a conversation on end-of-life issues. The February 24 event in Washington, D.C., follows the success of an intimate November conversation among African Americans in Chicago that featured Aris T. Allen Jr. ([see his story on p. 6](#)).

Dialogue with black leaders and citizens is ongoing. C&C will continue the conversation on a national level among influential groups such as the Congressional Black Caucus, NOBEL (National Organization of Black Elected Legislative) Women, African American sororities and fraternities, community leaders, and physicians regarding the importance of discussing end-of-life priorities. Attendees at these events receive planning resources such as Compassion & Choices’ Good-to-Go toolkit and access to the End-of-Life Consultation service that provides interested people information on approaching their aged loved ones to start a discussion.



from left to right:
Dr. Michael Eric Dyson

(L to R) Host Monica Murphy, C&C board member Nancy Hoyt, Aris T. Allen Jr., Brandi Alexander and Daniel Wilson

Advocacy in Action

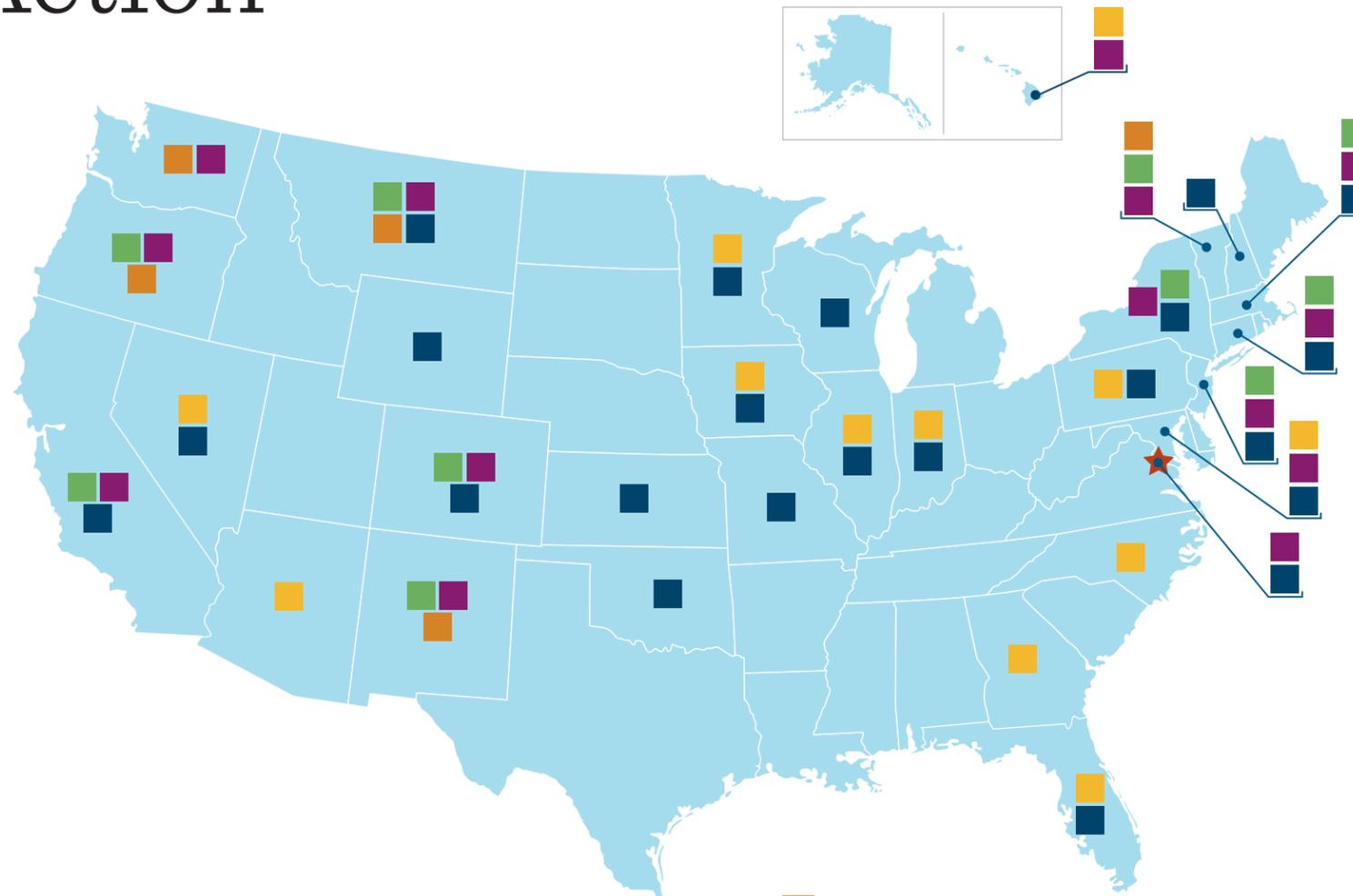
Compassion & Choices' work educating, advocating and organizing coalesced around Brittany Maynard's powerful story, and now a record number of state legislatures will consider death-with-dignity laws in 2015.

CALIFORNIA ■ ■ ■

At a press conference announcing "The End-of-Life Option Act" on January 21, one of its co-authors, Senator Lois Wolk, made it clear that end-of-life decisions "should remain with the individual as a matter of personal freedom and liberty without criminalizing those who help to honor our wishes and ease our suffering." The Compassion & Choices California team has been busily amassing public support up and down the state, and Sen. Wolk noted that support for the law "runs across all demographic categories, from every ethnic, religious and economic background." California was home to Brittany Maynard, and now to the family she leaves behind. Her mother, Debbie Ziegler, made her first public appearance at this packed event. She spoke of her



Dr. Olvera holds up a picture of his late daughter, Emily Rose, at a Sacramento press conference



- Aid in Dying Authorized
- Campaign States
- States in Progress
- C&C Staff Locations
- DWD Bill to Be Considered
- EOLC Services Available in All States

CONNECTICUT ■ ■ ■

When *How to Die in Oregon* screened in Hartford three days after Brittany Maynard's story broke, a capacity crowd filled the theater, and the state's major newspaper, *The Hartford Courant*, made it front-page news. The next day, the *Courant* published its third editorial endorsing aid-in-dying legislation, which will be taken up again in 2015 by the Connecticut General Assembly.

Moved by Brittany Maynard's story, lawmakers nationwide pledged to consider death-with-dignity bills in their states including:

- | | |
|---------------|------------------|
| California | Missouri |
| Colorado | Montana |
| Connecticut | New Hampshire |
| Florida | New Jersey |
| Illinois | New York |
| Indiana | Nevada |
| Iowa | Oklahoma |
| Kansas | Pennsylvania |
| Maryland | Washington, D.C. |
| Massachusetts | Wisconsin |
| Minnesota | Wyoming |

FLORIDA ■ ■

Palm Beach County State Representative Dave Kerner is ready to introduce a death-with-dignity bill, telling a local news station there is no better time to talk about compassion for people at the end of life than right now. He's right! Many Floridians new to the cause joined a recent conference call to get involved.

GEORGIA ■

In response to C&C's call to action, record numbers of Georgians are asking their state legislators for an aid-in-dying law. C&C Georgia is also getting support from new partners like SAGE, an LGBT seniors group.

(R to L) Senator Gary Holder-Winfield with President Barbara Coombs Lee, Bethany Bowen Brockmeyer and Patty McQueen during Q&A after the *How to Die in Oregon* screening



Stan Curtis (right), whose wife Cody is at the center of the film, talks to the audience and media at the Chicago *How to Die in Oregon* screening



advocacy in action

NEW HAMPSHIRE ■

An eloquent advocate for death with dignity is V. Gene Robinson, retired Episcopal bishop of New Hampshire. Inspired by Brittany Maynard's choice, he wrote a powerful column for *The Daily Beast*, which read in part: "[T]here is nothing innately good about allowing 'nature' to take its course in a prolonged and painful journey to an inevitable death. It doesn't make you a better person because you endured the indignity and trauma of it. You don't get extra stars for it."



Portrait from Montana's Six-Word Project

ILLINOIS ■ ■

In Chicago, 180 people turned out for a screening of *How to Die in Oregon* followed by a panel discussion that included Stan Curtis, husband of one of the film's protagonists, Cody Curtis; Prof. Holly Nelson Becker from Loyola University School of Social Work, and C&C President Barbara Coombs Lee.

IOWA ■ ■

Iowa's hard-working local groups got a welcome boost when the state's top newspaper, *The Des Moines Register*, editorialized in favor of death with dignity, motivated by Brittany Maynard's story: "In a country that prides itself on personal liberty, shouldn't our freedom extend to making decisions about the final moments of our lives?"

MARYLAND ■ ■ ■

Marylanders are talking about death with dignity. Syndicated NPR host Diane Rehm revealed her husband died an unnecessarily painful death in their home state (see cover story). Delegate Heather Mizeur elevated the issue with her campaign for governor. And on the national day of action for what would have been Brittany Maynard's 30th birthday, Annapolis saw a very successful rally where 30 volunteers braved the bitter cold weather and earned excellent media coverage. Speakers at the rally included Maryland advocates Catherine Weber, who suffers from end-stage cancer, and Alexa Fraser, whose father took his life due to debilitating Parkinson's disease. Later, an 85-year-old supporter saw her senator, Ronald Young, at a Wal-Mart, talked to him about death with dignity – and he committed to introduce a bill!

MASSACHUSETTS ■ ■ ■

With 19 lawmakers already on board, the Massachusetts team keeps expanding its base, exhibiting at the Massachusetts Conference for Women, forging relationships with end-of-life care leaders at major hospitals and building partnerships with community leaders. A Facebook campaign inviting supporters to post six-word "selfies" about end-of-life choice was a huge success.

MINNESOTA ■ ■

One stop in Barbara Mancini's national advocacy campaign was St. Paul, where she told a rapt audience about being wrongly prosecuted under Pennsylvania's assisted-suicide statute in her father's death. Legislators, faculty, law students, medical and hospice professionals, and community members attended. Their sympathetic reaction to Mancini's story was mirrored in a Minnesota newspaper editorial that said state laws are "out of step with the wishes of Americans" on death with dignity.

MONTANA ■ ■ ■ ■

It has been five years since Bob Baxter's successful lawsuit won the right to death with dignity for all Montanans. C&C celebrated by publishing a retrospective report on *Baxter v. Montana*, holding public events statewide and unveiling portraits of 42 Montanans expressing support for end-of-life options in six words. The MT team is also preparing to defend *Baxter* against new legislation that would roll it back.

NEW JERSEY ■ ■ ■ ■

Death-with-dignity legislation has moved quickly through the New Jersey State House. In November, Assemblyman John Burzichelli's aid-in-dying bill passed that chamber 41-31 on a bipartisan vote, and a Senate health committee considered it the following week and passed it for the entire Senate to take up. The Senate president is championing the bill, saying it's "the humane thing to do." Adding to the momentum, Brittany Maynard's widower, Dan Diaz, visited the state following some national media interviews next door in New York. Dan met with legislators and also sat down with a few key journalists. We expect a full Senate vote early in 2015.



TV cameras and crew cover the C&C rally in Annapolis, MD



NJ Senate President Sweeney (center) talks with C&C team outside hearing room

advocacy in action

NEW MEXICO ■■■

Drs. Peter Reagan and Kate Morris presented the Clinical Practice Guidelines for Aid in Dying to the New Mexico Medical Board this winter. The conversation that followed included discussion of the board endorsing the end-of-life medical practice. This kind of physician outreach is a priority for C&C so that more New Mexicans can access aid in dying, which is protected as a “fundamental right” thanks to a 2014 District Court ruling in *Morris v. New Mexico*, a case brought by C&C and the ACLU of New Mexico. In January, a state court heard an appeal in the case, and will issue its ruling in the coming months.

NEW YORK ■■■

The Empire State is now a C&C campaign state! There are 12 professionals on the team lobbying, organizing and publicizing to implement a multi-level strategy to make death with dignity available for New Yorkers. With committed lawmakers in Albany and a record spike in volunteers signing up to advocate, momentum is building rapidly.

OREGON ■■■

The C&C experts in Oregon had a busy fall and winter fielding requests from journalists interested in Brittany Maynard’s choice to access the state’s Death With Dignity Act. Between interviews, they continued their education campaign, hosting 30 public events in October alone.

It’s organized citizens who convince legislators to act.

Join this movement!

[CompassionAndChoices.org/
get-involved](http://CompassionAndChoices.org/get-involved)



Rep. Mark Rozzi with his late father, who he is honoring with his bill

PENNSYLVANIA ■■

Mark Rozzi, a state representative from Berks County, introduced death-with-dignity legislation nine days after hearing Brittany Maynard’s story. Mark’s father died of glioblastoma, the same brain cancer that ended Maynard’s life.

VERMONT ■■■

In the law’s first 18 months, seven dying Vermonters had aid-in-dying prescriptions written under Act 39, and increasingly, healthcare providers are supporting those who choose this option. Other positive developments include the University of Vermont Nursing School incorporating the law into its end-of-life care curriculum and the Vermont Nurses Association collaborating with C&C to develop aid-in-dying education materials for its members. C&C stands ready to defend Vermonters’ access to death with dignity under Act 39 during this year’s legislative session.

WYOMING ■

Dan Zwonitzer, who represents Cheyenne in the Wyoming legislature, introduced an aid-in-dying bill this year. He remembers his grandfather’s prolonged, painful dying process. Also, as an auctioneer, he has handled too many estate sales, which, he says, “often result from a violent suicide committed by people who are terminally ill and desperate to end their suffering.”

state spotlight

Colorado



Julie Selsberg and her father, Charles Selsberg

One year ago, a Denver man named Charles Selsberg voluntarily stopped eating and drinking (VSED), aiming to shorten the cruel dying process he was suffering from ALS. Just after his death, *The Denver Post* published his letter asking lawmakers to give Coloradans access to aid in dying. Now, Representative Lois Court has introduced **The Bill For an Act Concerning a Terminally Ill Individual’s Freedom to Make End-Of-Life Decisions**.

For much of last year, Court and co-sponsor Rep. Joann Ginal held public forums and meetings to secure buy-in from key stakeholders – for example, hosting regular sit-downs with Coloradans in the disability, hospice and medical communities, allowing them to address issues or concerns before drafting a bill.

Public sentiment is strong. Coloradans already favor a death-with-dignity option by a 2-to-1 margin.

“Nobody should have to go through that, and you just can’t make that decision for somebody else. It is a personal decision.”

Julie Selsberg, Charles’ daughter, recently started sharing her story, taking up the work her father began a year ago when he chose VSED to hasten his own death. Julie told a reporter: “That just to me says everything about why these laws are so important. Nobody should have to go through that, and you just can’t make that decision for somebody else. It is a personal decision. And he had 13 days to change his mind, and he didn’t.”

Find the latest about how you can help in Colorado at CompassionAndChoices.org/colorado.

National Programs Update

UMT Policy Briefing Dissects Physicians' Report Findings

End-of-life care in America is woefully deficient and in need of sweeping changes.

That's the gist of a report released last fall by the Institute of Medicine (IOM) – and the focus of the fifth in a series of Washington, D.C., policy luncheons sponsored by the Campaign to End Unwanted Medical Treatment, a coalition of 20 national organizations, including Compassion & Choices.

Experts on aging and consumer issues joined operatives from Congress and other federal agencies to delve deeper into the report. The luncheon featured a lively discussion on how to create healthcare policy that honors individual goals, wishes and preferences at the end of life.

Dr. Adrienne Stith Butler, IOM senior program officer and the study's director, led the conversation, aided by Naomi Karp, a policy advisor at the Consumer Financial Protection Bureau and a member of the IOM Committee on Approaching Death.

"This will be a great springboard for our policy work," said Daniel Wilson, C&C's national and federal programs director. "We'll use the findings to shape our agenda and advance it on Capitol Hill."

Learn more about the Campaign to End Unwanted Medical Treatment at EndUMT.org.



Dr. Adrienne Stith Butler (top) presents IOM findings with Naomi Karp (right)



DIY Activism

Eager to step up your support for end-of-life care and options? Look no further than Compassion & Choices' brand-new online Volunteer Action Center, where you'll find all the tools you need to get started.

"There are so many ways to participate," said Andria Hansen, C&C's national volunteer program coordinator. "The Volunteer Action Center contains toolkits for activities anyone can do, no matter where you live or how much time you can donate."

With seven detailed, downloadable toolkits and several videos – with more to come – there's something for everyone. The Barbara Mancini DVD Discussion Kit has resources to host a house party, including checklists, potential discussion questions – even a

sample flyer. The Student Activity Guide features great suggestions for college students, like on-campus tabling, conducting research or writing for the college paper.

Then there's Activism 101: the Letter Writing Toolkit. "This is a fantastic way to open the conversation in your community," says Hansen. "Writing letters to your local paper or lawmaker can be an incredibly powerful way to affect the debate."

See for yourself – visit the Volunteer Action Center at www.bit.ly/VolunteerActionCenter today to download a toolkit or sign up to volunteer.



Questions on End-of-Life Issues? Call Us.

Compassion & Choices' dedicated and hard-working end-of-life consultants saw a dramatic increase in new clients in 2014, up 88% from 2013. Last year 4,190 unique cases came to Compassion & Choices, representing people who wanted to begin learning, start the conversation or plan their end-of-life path. C&C's End-of-Life Consultation (EOLC) service connects those with questions to one of our deeply knowledgeable consultants.

In November, Jena Johnson, Compassion & Choices' EOLC manager, spoke with CNN.com about the program and the increased demand for its services. Headlined, "Her job is to help you have a good

"My job is to educate, to empower. I am glad the conversation has been elevated in the public consciousness."

– Jena Johnson, C&C EOLC manager

death," the piece noted that Johnson defines "good" death as one in which a person's wishes for the end of his or her life are respected and carried out, no matter what those wishes are.

Need answers on end-of-life planning or care? Talk with a knowledgeable, compassionate consultant free of charge at 800.247.7421.

Straight Talk, Doc 2 Doc

More people than ever are asking their doctors about end-of-life care and choice. Compassion & Choices' Doc 2 Doc program can help physicians give their patients the most up-to-date information. Doc 2 Doc is a free, confidential telephone consultation service – staffed by physicians for physicians.

“Doctors from all across the nation call Doc 2 Doc and talk with us about end-of-life care,” said David Grube, MD, one of Compassion & Choices' national medical directors. “The information we offer helps them give their patients the best care possible.”

Doctors obtain guidance from Doc 2 Doc about the full range of end-of-life options – from palliative and hospice care, to advance

healthcare planning, to helping patients achieve their wishes for a peaceful death. Many doctors inquire specifically about aid in dying, including current clinical guidelines in states where the practice is authorized, or what to say to patients who ask about withdrawal of life-sustaining treatment or VSED (voluntarily stopping eating and drinking).

It's uniquely challenging to treat patients with terminal illnesses – and vitally important to talk candidly with them about their options. Doc 2 Doc physicians stand ready to help colleagues navigate this difficult terrain.

For a confidential consultation call 800.247.7421 or email doc2doc@CompassionAndChoices.org.

Doc 2 Doc is tailored for physicians seeking guidance about end-of-life issues.

Doc 2 Doc consultation may include discussion of:

- » hospice and palliative care
- » patients' request for assistance in achieving a peaceful death
- » advance healthcare planning
- » death with dignity, or aid in dying
- » voluntarily stopping eating and drinking
- » patients' inquiries concerning withdrawal of life-sustaining treatment

Most Doctors Support Death With Dignity



A clear majority of American physicians now supports the option to choose death with dignity. According to a *Medscape* survey posed to 21,000 doctors, 54% percent believe that if a “disease is incurable and terminal” that a patient – or they themselves – should be able to access aid in dying. “It represents a remarkable shift,” said renowned bioethicist Dr. Arthur Caplan.

C&C's Doctors for Dignity initiative aims to get supportive physicians across the nation to speak out on and advise colleagues about aid in dying and other end-of-life issues. **Sign up or learn more at doctorsfordignity@CompassionAndChoices.org or 303.217.2081.**

The doctors in our movement are heroes. Their courage and altruism made – and keep – death with dignity possible. Their wisdom and experience are inspiring.

Rx for
PEACE
at Life's End



Dr. Diana Barnard

Dr. Diana Barnard, a native Vermonter, is a family practice and palliative care physician at the University of Vermont Medical Center and an assistant professor at the university's College of Medicine. A passionate advocate for patient-directed care at the end of life, she campaigned for her state's death-with-dignity law, which passed in 2013.

“**W**e plan ahead for many life events: retirement, buying a home, sending our children to college. Yet for something really important like the end of life, we just don't make the time. One of the most crucial parts of my work is reminding people that death is a normal part of life, and encouraging them to have open conversations about what is important to them and to develop a plan. Sometimes medical providers and patients become so focused on things that we can “fix” and the many options for prolonging life that it's easy to lose sight of our end-of-life priorities, to push death to the side.

Palliative care is about maximizing quality of life. We are experts in symptom management, psycho-social support, translating medical jargon and creating a plan that matches patients' treatment preferences with the reality of their medical condition. While some people mistakenly believe palliative care is only for those who are dying, the care we provide is actually much more than that; it's about living with serious illness as best as you can, for as long as you can, and also about making sure that you have a plan for dying well.

There are still far too many unfortunate instances where people are referred to palliative care specialists too late, when patients are in fact nearing the end of life. Yes, end-of-life care is one part of what we do. But there's so much more we could do to address needs much earlier on, even at the time of diagnosis of a serious illness.

With the passage of the law in Vermont, I think we're already seeing many benefits. More people are having serious, proactive conversations about the end of their life. For many of the people I care for, just knowing that they don't have to worry about those final days and weeks if their suffering becomes unbearable – having that safety mechanism in place – alleviates a huge amount of anxiety and stress. It allows people to focus on living their lives fully.

Probably the most important consequence of legislation is the reminder that the patient should remain in control. Dying is not a medical event. It is a deeply personal experience. My job as a palliative care provider is to explore, identify and then honor what is important for each unique patient. Dying isn't about me or what I think is right; it's about what's important for the individual.”

Five Questions for Diane Rehm

More than 2.6 million listeners across the country tune in each week to *The Diane Rehm Show*, one of NPR's most popular programs. Among other compelling topics, Rehm does not shy away from discussions around choice in dying on her program.



Q: You've worked in radio for more than four decades, all at the same station, WAMU. Did you imagine you'd last that long in the business?

A: I never imagined myself "in the business" in the first place! So the idea of lasting this long never occurred to me. I was at home for 14 years raising two wonderful children who have become two glorious adults, so I never thought about a career.

Then along comes 1972. People started talking about Betty Friedan's book, and I began wondering, "What in the world am I going to do with the rest of my life?" So I took a course at George Washington University called New Horizons for Women. It was so funny because in the first group discussion, people kept saying to me, "You ought to be in broadcasting." And I thought, why in the world would anyone say that to me? I can't do anything like that.

Then somebody mentioned that there was a volunteer opening at a local radio station. So I went, and there I was, in 1973, on the air the first day. I wasn't supposed to be, but the host was out sick. It was really a shock. But my family did not have a television set until I was about to graduate from high school, so radio has always been my medium. I felt totally natural.

Q: How has radio stayed relevant?

A: I think radio is a mind-to-mind experience. When you hear the voice coming out of the radio, it's going directly into your head. Whereas with television, you're distracted by the images. With radio, it's just the words, and they go directly into your thought process. I think it's the most intimate medium we have.

Q: In 1998 you were diagnosed with spasmodic dysphonia, a neurological disorder that attacks the voice. How did you overcome something that could have been disastrous to your career?

A: I don't think I've ever overcome it. At first when I started having these symptoms back in 1992, and doctor after doctor kept saying, "It's all in your head," it really drove me nuts. Finally, in 1998, I got the diagnosis at Johns Hopkins Hospital within one hour. I have to have injections into my vocal chords two or sometimes three times a year to keep this voice going.

Q: Your husband, John, died last June; he stopped eating and drinking to end his suffering from Parkinson's disease. How did you feel about that choice?

A: As you can imagine, after 54 years together, the thought of losing him was just awful. We had talked about how we both felt about long-term suffering and promised each other that we would not let that happen. But I knew I couldn't help him to go quickly. And the doctor made it plain – though he was very kind and understanding – that there was nothing he could do except to say, "The one thing you, John, can do is to stop taking in any kind of fluid, any kind of medication, any kind of food." I thought, "Oh dear God, I just can't bear this. I can't stand the thought of him having to go through this." But he was so brave.

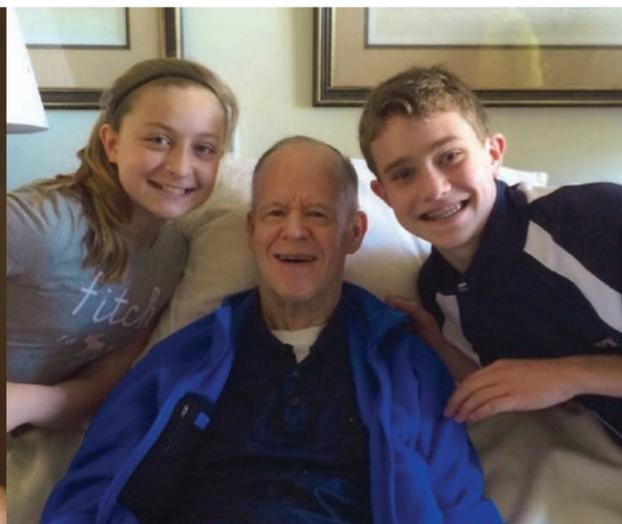
When I came in a day later, he said, "I did not have any food or water this morning. I have decided to begin the long glide," as he called it. It took 10 full days for him to die, which is why I am so in favor of the goals of Compassion & Choices.

Q: You've discussed end-of-life issues a number of times on your show, before it was as widely talked about as it is now. What first inspired you to tackle this topic?

A: My mother died of liver cancer when I was 19. At the end she suffered, and I know she didn't want any more treatments, but they kept treating her. So it probably got planted in me way back then.

I really do believe that people have a right to control their own bodies and certainly to control the end of their lives. So tackling these issues for me has been a matter of bringing the idea of death closer to life, which is where it belongs. We shouldn't be thinking of death as something totally separate from life; it's part of life. So we need to plan and think ahead to what we want.

I have the feeling that before very long this will finally make sense to people, and there's going to be a quick movement across the country. I hope so; I really do.



from left to right:
Diane with her husband, John, on their 25th wedding anniversary

John with their grandchildren



**“ Control ”
provides me
peace of mind.**

– Bonnie Kelley
Frenchtown, MT

A Gift That Brings You, and Others, Peace of Mind.

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

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PO Box 101810
Denver, Colorado 80250-1810
800 247 7421
CompassionAndChoices.org



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... *Yes, You!*

Supporter Alice Weyrauch does. She brings copies to doctors' offices and pharmacies throughout Cowlitz County, Washington, "talking up" Compassion & Choices as she goes.

So can you! Give this issue to neighbors and co-workers, or share around your community.

info@CompassionAndChoices.org

Alice Weyrauch
Castle Rock, WA

