

compassion & choices

MAGAZINE
FALL 2016

A Disability-Rights
and Right-to-Die
Activist's Memoir

Figuring Out
Hospice

PLUS Our 2016
Annual Report

Five Questions About

Miss Norma

*A Glimpse Into the Life of the Late Ambassador for Choosing
Quality of Life Over Quantity, Maybe Achieving Both.*





“ Control ”
provides me
peace of mind.

– Bonnie Kelley
Frenchtown, MT

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FEATURE

06 Wisdom From a Chair: Thirty Years of Quadriplegia

We share excerpts from disability-rights activist Andrew Batavia's rousing memoir on the importance of autonomy.

25 2016 Annual Report

It's been another phenomenal year of growth for C&C and the end-of-life choice movement.



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Compassion & Choices is the nation's oldest, largest and most active nonprofit working to improve care and expand options for the end of life. Learn more at CompassionAndChoices.org.



Progress, Both Deep and Wide

Wrapping up the calendar year always calls for a progress assessment at Compassion & Choices. And once again I'm struck not only by how far we've advanced, but in how many ways. Our core is still about empowering people to achieve a better end-of-life

experience. But today that work ripples out in many directions, impacting all levels of government and healthcare, and people across the nation.

In this issue of Compassion & Choices Magazine, we highlight various ways this movement for choice and empowerment enriches all our lives. You'll read about the bold individualism of Andrew Batavia and Norma Bauerschmidt, who in their own ways lived life with a truth that will inspire lasting change. And you'll also find C&C's 2016 annual report, a clear testament to the tangible results of our campaigns, programs and other initiatives.

These efforts may seem disparate on the surface, but they all move us toward the same ultimate objective: peace and satisfaction through our last moments, whatever that comes to mean for each of us.

Barbara Coombs Lee
PA, FNP, JD, President

compassion & choices

MAGAZINE

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Miguel Carrasquillo, 35, didn't die as he wanted. "He died in pain after enduring months of agony," sadly noted Emmy Award-winning Univision anchor and journalist Jorge Ramos, often called the "Latino Walter Cronkite," about the dedicated aid-in-dying advocate on the Univision website.

"I spoke with Miguel ... a couple of weeks before his death. He said that physician-assisted death is an issue that we should be able to discuss openly. 'This isn't a bad thing. Your life is your life.'"

bit.ly/ramos16fall

The Washington Post

Nobel Peace laureate Archbishop Emeritus Desmond Tutu, who has dedicated his career to advocating for human rights, offered an opinion piece about the right to aid in dying in the October 6 Washington Post stating he feels "compelled to lend my voice to this cause." The story includes a video he produced with our friends at Dignity in Dying in the United Kingdom to share his thoughts.

bit.ly/desmtutu

The Washington Post

"Some African-American residents have said the [D.C. Death with Dignity Act] reminds them of the Tuskegee experiments," reported The Washington Post.

"They are afraid ... We have to assure them they are in control of everything," Dr. Omega Silva told The Post. Dr. Silva is an African-American physician with three cancer diagnoses who supports the legislation.

The afternoon following the story publication, the D.C. Council Committee of the Whole approved the bill for full council consideration.

bit.ly/wapo16fall



"Whether Americans live in an urban or rural environment, they need much greater access to palliative care at the local level and a suite of comprehensive options at the end of life."

That's one conclusion of The Hill's "Congress Blog" coauthored by Compassion & Choices Federal Affairs Director Mark Dann. The piece also concluded we can move forward to improve end-of-life care because politicians no longer describe doctor-patient discussions about end-of-life care as "death panels."

bit.ly/thehill16fall

Help Us Make This Magazine Better!



Please take a moment to share what you like and don't like — and a bit about yourself — on our online survey. And THANK YOU for reading!

Can We Talk?

It's widely agreed that discussing end-of-life preferences with one's physician is key to getting what we want in our final days. But it's still not easy to do, for doctors or their patients.

99% of **physicians** surveyed say it is **important to have conversations** about end-of-life care **with patients**.



46% of **physicians** have had a **conversation with their own doctor** about end-of-life care ... **while only 17%** of the **overall public** have engaged in **conversations with their physicians** about end-of-life care.

Source: The John A Hartford Foundation National Poll — "Conversation Stopper: What's Preventing Physicians from Talking with Patients About End-of-Life and Advance Care Planning?" April 2016

How to Get the Right Hospice

There are many questions to ask potential hospice providers including whether in addition to care at home, which is the norm, care might be available in a facility, and whether they provide respite for family caregivers in the home setting.

For ensuring that your own end-of-life priorities will be honored and respected in hospice, here are key questions to ask:

- » What practices does this hospice employ to ensure the ongoing involvement of my loved ones, caregivers and healthcare providers?
- » What role will my own physician have once my hospice care begins, and how will they work with the hospice physician?
- » Will this hospice provide me with palliative sedation to keep me comfortable until I die if I request it?
- » If my pain or suffering cannot be controlled and I choose to voluntarily stop eating and drinking, which is my right, will this hospice support me and my family in that process?
- » If I decide to access medical aid in dying and want to obtain a prescription, will this hospice support me and my family in that process? (This question is only applicable in states where medical aid in dying has been authorized: OR, WA, CA, MT, VT as of 10/2016.)

Please visit **Compassion & Choices' End-of-Life Information Center** for resources to help make these important decisions at CompassionAndChoices.org/eolc.



BOOK EXCERPT:

Wisdom From a Chair

Thirty Years of Quadriplegia

by Andrew I. Batavia

With gratitude to Andrew "Drew" Batavia's family, Compassion & Choices is able to share excerpts of this remarkable man's memoir. Batavia spent his very full and far-too-short life advocating for civil rights, including the right to make one's own healthcare decisions at the end of life. The book, begun by Andrew and completed by his family, was published in the summer of 2016 to coincide with the 26th anniversary of the Americans With Disabilities Act.

Don Quixote is the hero of a celebrated 17th-century Spanish novel and has become a moniker for people who take it upon themselves to right the wrongs in this world. To be quixotic is to be exceedingly idealistic and unrealistic. To tilt at windmills is to be Don Quixote, battling the giants in his mind.

So it is fitting that on the cover of Andrew I. Batavia's posthumous memoir is a drawing called "Don Quixote mounted on a wheelchair and fighting the windmills of injustice." When Andrew was a senior in high school, he asked his brother, Mitchell Batavia, to draw it for him. It was Andrew's first year at school following a grueling year of rehabilitation, fighting his way back from a car accident that had left him paralyzed from the shoulders down.

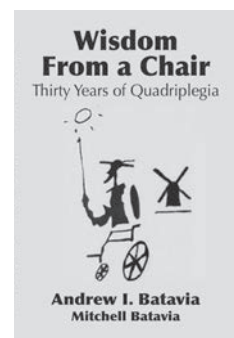
Unlike Quixote, however, the windmills at which Andrew Batavia tilted were not imaginary. They were the real injustices suffered by people like him who were living with disabilities in a world not built for them. When Andrew Batavia decided to attend the University of California, Berkeley in 1975, for example, it was in large part because there were only three campuses in the entire country that accommodated a student in a wheelchair, and Berkeley was one of them.



After receiving degrees in both law and public health, Andrew became an activist and an advocate for people living with disabilities. He grew so expert in the law and policy of disability that he was sought out by then-U.S. Attorney General Richard Thornburgh to help author the regulations — the enforcement road-map — for the Americans With Disabilities Act that deal with access to places of public accommodation.

Just as he advocated for autonomy and self-determination in daily life for those living with disabilities, Andrew Batavia was also a champion for these freedoms at the end of life. As a lawyer, he wrote amicus briefs in two landmark legal cases about the right to medical aid in dying: *Washington v. Glucksberg* in the U.S. Supreme Court and *Krischer v. McIver* in the Florida Supreme Court. He also co-founded a disability-rights organization to advocate in favor of aid in dying for people with disabilities called AUTONOMY, Inc.

Andrew Batavia was a prolific, tireless, brilliant man. Compassion & Choices is pleased to share the following excerpts of his memoir, *Wisdom from a Chair: Thirty Years of Quadriplegia*. Andrew wrote many chapters of the book, which his family later found with the request they complete it. Andrew's brother, Mitchell Batavia, did so by commenting on existing chapters and writing additional ones. It is also rounded out with observations and stories from Andrew's wife and children. The book was finally published this year by his family, 13 years after Andrew's death.



My mission in this world is to try to ensure that all people, including people with disabilities, have greater choices in and control over their lives.



(above) Andrew Batavia with his brother, Mitchell
(below) The Batavia family in the winter of 1996

From the Preface by Andrew I. Batavia:

I believe the key to happiness is to find a good mission in life, to make it your life's work, to take that work very seriously, and not to take yourself seriously at all. Most people who publish autobiographies are self-important, self-serving blowhards, who take themselves much too seriously. With some notable exceptions, this is true whether the author is a sports hero, captain of industry, or even president of the United States. Publishing one's private memoirs is, in a sense, the ultimate act of arrogance, in that it assumes that someone else would, or even should, be interested in the author's existence. So, this raises the obvious question: Why did I write and publish this particular memoir, particularly at the relatively young age of forty-five, without being famous yet, or possibly ever.

[T]here are reasons that my life may offer unique insights. First, for the last thirty years, I have not gone to a single public place or event in which I have not been part of the show. People appear infinitely interested in watching me racing down the street in my chin-controlled, motorized wheelchair. Often I would be accompanied by one or both of my beautiful children, whom my wife and I adopted from Russia; one would be standing on the back of the chair and the other sitting on my foot plates, and we would be weaving in and out among people at full speed.

Living one's life without the use of arms, legs, or hands presents some interesting challenges and appears to be inherently intriguing to many people. I suppose some are wondering what my life is like and whether they could survive under similar circumstances; I am sure that most could, in that we humans have a remarkable capacity to adapt to almost any conditions. I have never resented this voyeurism; as a person who was not disabled for the first sixteen years of my life, I am certain that I would have been similarly curious if I had not severed my spinal cord

in 1973 and if I were in the same room as someone with my current disability.

Over the years, many people have told me that I am an inspiration. Although I have always appreciated such sentiments when conveyed sincerely and without pity, for a long time I found such compliments somewhat annoying. I always find "inspirational movies" about the lives of people with disabilities a little nauseating. My mission in this world is to try to ensure that all people, including people with disabilities, have greater choices in and control over their lives. I believe that achieving this mission will make the world a slightly better place than it was before I got here. Recently, I have decided that if this orientation, or the way in which I live my life, inspires someone, that is fine.

The Right to Live and Die by Mitchell Batavia:

Drew's pioneering work in the right-to-die debate and physician-assisted dying controversy from a disability perspective was a hot-button topic and one that he saw as an extension of civil rights of persons with disabilities — the right for control over one's life, including a personal decision to end it.

His perspective on this controversy first took shape during his painful recovery following his spinal cord injury, when he was anxious about whether he would have to endure unending pain and discomfort for the rest of his life. What gave him peace of mind, however, was the notion that if life became too unbearable, he could end it along with his suffering. Apparently, he discovered others in the disability community who thought along similar lines. Drew later solidified his position on physician-assisted dying when he contracted the flu, had difficulty breathing, and was rushed to an emergency room. What if the terror he felt while gasping for breath was not a short-term event,

Drew reflected, but instead was part of an unending terminal condition? Under those circumstances, he would want the right to access a physician to help end his suffering, without government interference.

....

In the mid-1990s, he had the opportunity to advocate for mentally competent individuals who were terminally ill and sought medically assisted deaths. He did this pro bono work, which involved filing amicus briefs, while at his Florida law firm, McDermott Will & Emery. Drew authored and served as the attorney of record for a number of these briefs (where he was supportive but not directly connected to a particular case).



Drew meeting with Attorney General Dick Thornburgh at the Department of Justice

His work included the US Supreme Court cases *Washington v. Glucksberg* and *Vacco v. Quill* in 1996 and the Florida Supreme Court case *Krischer v. McIver* in 1997. These efforts were consistent with Drew's ongoing mission to safeguard the rights of people with disabilities, in this case, those who were terminally ill.

This work prompted Drew to launch AUTONOMY, Inc., a not-for-profit organization he cofounded to continue his mission of representing people with disabilities who wanted choices and control over their lives, including end-of-life decisions. He established this organization in 2002, the year prior to his death.

....

Drew assembled a board of directors, launched a website, and cultivated a strong following of more than 5,000. That year, the organization filed an amicus brief in the case of *Oregon v. Ashcroft* in support of the Death with Dignity Act, whereby terminally ill, mentally competent adults could achieve a peaceful death with the aid of physician-prescribed medication.

....

Drew's support of physician-assisted dying was likely the most contentious of his career, causing a rift in the disability community. Those against this right, such as a group called Not Dead Yet, used the slippery-slope argument that physicians who devalue persons with disabilities will opt to put them to death, given the chance. They referenced Nazi atrocities and suggested that states might find it cheaper to kill than to treat them, if the act became law. One basis for their argument is that ending someone's life is wrong. On the other hand, Drew and others in AUTONOMY argued for persons with disabilities to make their own end-of-life decisions, free from state intrusion, and based on the principles of self-determination and autonomy.

....

Drew believed the controversy of physician-assisted dying would not simply disappear. He wrote, "Our society will have to address the views of people with disabilities, who have strong opinions on both sides of this issue." ■

Learn more at www.wisdomfromachair.com.wordpress.com.

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

Rx for
PEACE
at Life's End



Dr. David Pratt

Dr. David Pratt, a New York physician who has been active in our campaign to authorize medical aid in dying in that state, was drawn to the profession through his admiration of nurses in his family and what he calls "the science, the art and the philosophy of caring for people." With a background in pulmonary medicine and more recently outpatient palliative care, Pratt has witnessed the best and worst of healthcare outcomes, and feels that appointing a strong spokesperson is one way to minimize the potential difficulties around dying.

"In spite of how wonderful our healthcare system is, many end-of-life stories are not comfortable to hear. For a number of years I was a pulmonary specialist and did intensive care, and I saw a significant proportion of care that was futile. It was to me disconcerting to see so many people thrown into the fluorescent atmosphere of ICUs with us breathing for them, knowing the low probability of them being able to recover and come off the machines.

People are suffering too long, and even in the hands of the best palliative-care specialists and hospice teams, it often goes beyond the point of seeming reasonable to families. But philosophically, families are seldom unified. It's not even unusual for married

couples to disagree on these issues. So be very careful who you select as your healthcare proxy. You want your proxy to represent *your* wishes, *your* philosophy; not their own. And it's also so important to tell your doctor who your proxy is and make sure the proxy fully understands what their role and responsibility is. Otherwise what could be a harmonious decision-making process becomes completely deranged when family members can't agree. So the default then is to just keep going, keep ventilating Mom or whomever while everyone decides what they'd like to do in terms of guiding us, and sometimes it just goes on and on and on. So get that proxy, and make sure that proxy is on your wavelength."

Advocacy in Action

Different States, Different Strategies for Authorizing Aid in Dying as a Compassionate Option

From Maryland to New Mexico, Compassion & Choices staff and volunteers are gearing up for new legislative sessions, many of which begin in January.

Compassion & Choices' (C&C's) political and policy experts travel the country, visiting with lawmakers in any state who want to advance aid-in-dying legislation, and providing technical assistance and activating C&C supporters in the area. We are anticipating bills to be considered in twenty states during the upcoming legislative session. Here is a sampling.

A top priority remains New York state, where C&C is working closely with top-notch legislative sponsors to pass the New York End of Life Options Act. The C&C NY team has been building relationships with key organizations whose support we need (nurses, groups, senior groups, etc.), but they know many legislators won't support this bill without pressure from their constituents. A big part of any C&C campaign, then, is mobilizing citizens who want access to medical aid in dying as an end-of-life option, and the campaign in New York is doing a lot of that lately. In August, C&C staff and volunteers hosted a table during each of the eleven days of the New York State Fair in Syracuse. About one million New Yorkers from all over the state come to the fair every year, so it

offered an amazing opportunity to recruit supporters for grassroots work and to share information with people who aren't sure about medical aid in dying. Six thousand new people signed up to help with efforts, and 4,200 sent postcards to their elected representatives asking them to vote "yes" on medical aid in dying in the Legislature.

After the fair, C&C NY launched its Ask-the-Candidate campaign. Like similar campaigns in Connecticut and other states, it helps the New York team gather intelligence about legislators' positions on aid in dying. Equally important, it lets incumbents and candidates alike know that their constituents care about this issue. It works like this: When candidates come knocking on doors in Binghamton, Bay Head or Brooklyn seeking votes, voters ask them where they stand on aid in dying and offer them more information. The voters also report back to C&C campaign staff, who can plan appropriate follow-up. It might be easy to feel discouraged about the political process, and it seems like our national politics get a little uglier every year. But ordinary people can make

a difference, especially at local levels, by speaking out loudly, consistently and in numbers great enough to drown out the money of organized opposition. C&C's campaigns empower Americans who want more end-of-life autonomy to get their voices heard and spur their elected representatives to action.

Next door to New York is Massachusetts, where end-of-life choice supporters are using an additional strategy to be sure state legislators hear them. C&C's Massachusetts campaign has been organizing in towns and cities to get local legislative bodies to pass resolutions supporting medical aid in dying. City councilmembers are responsive to their constituents, so if a council passes a resolution, it signals strong support in that community. For example, following a targeted campaign by two C&C supporters there, the Cambridge City Council at a September 12 hearing voted unanimously (9-0) to endorse medical aid in dying and call upon the state Legislature to pass a law authorizing it. Other cities will be targeted after the November election to make sure state legislators who represent those areas know where their constituents stand.

Speaking of local councils, Washington, D.C.'s, elected representatives sit on a body called the Council of the District of Columbia. Half state legislature, half city council, it is where most laws governing the District are made. (Living in a Federal district rather than a state, D.C.'s citizens not only lack representation in Congress, but Congress can override their laws.) Nonetheless, there is momentum behind the D.C. Death with Dignity Act. The bill was approved by the Health and Human Services Committee in October and the full Council will hold its first vote on it in November.

In New Mexico, a state Supreme Court ruling in June of 2016 permanently overturned a district court decision in a case C&C brought that had authorized medical aid in dying in the state's most populous county from January 2014 to August 2015. The Supreme Court ruling, which upheld an appellate



At its booth at the New York State Fair, C&C signed up more than 6,000 new supporters and generated 4,200 constituent postcards to lawmakers



A visitor to the New York State Fair stops to fill out a postcard to his elected representatives in Albany asking them to support aid-in-dying legislation



READ & DOWNLOAD

toolkits and handbooks that will help you become a citizen activist in your state from our Volunteer Resource Center at CompassionAndChoices.org/volunteer-resource-center.

advocacy in action

court decision, however, made it clear that this is a matter that the state Legislature can and should take up — and soon. C&C is currently working up plans to make sure lawmakers in Sante Fe pass legislation authorizing aid in dying as an end-of-life option for terminally ill New Mexicans.

Some states are amenable to legal strategies, others to local or legislative strategies. But in 26 states and the District of Columbia, taking an issue directly to the voters in a ballot initiative is also an option, and that is exactly what's happening in Colorado.

After the Colorado Legislature failed to pass a bill for a second time, Colorado proponents Julie Selsberg and Jaren Ducker filed an initiative to authorize medical aid in dying for terminally ill Coloradans.

Julie Selsberg, the lead petitioner on this measure, was motivated to file the petition to carry on her father's wishes. In 2014 her father, Charles, penned an open letter to lawmakers while he was dying from ALS, asking them to pass an aid-in dying law and spare other Coloradans the suffering he was

If 50 percent “plus one” vote yes [on Colorado End-of-Life Options] ... Colorado will become the sixth state where aid in dying is authorized.

enduring. His letter, published in the Denver Post shortly after he died, inspired lawmakers to introduce a bill. But despite two-to-one public support for the legislation, its sponsors came up short on votes two years in a row. Julie, who helped her father write the letter, shared his view and was determined to see his wish realized.

Earlier this year, Compassion & Choices and the Compassion & Choices Action Network encouraged a separate campaign organization, Yes on Colorado End-of-Life Options, to promote The Colorado End-of-Life Options Act. Volunteers with the campaign fanned out across the state to collect signatures — at farmers markets, outside libraries and on street corners — from other Coloradans who want to see medical aid in dying on the ballot. In August, Yes on Colorado End-of-Life Options submitted 156,000 signatures to the secretary of state, more than enough to officially qualify. On November 8, Coloradans

District of Columbia campaign manager Donna Smith and D.C. citizen activists talk through C&C's strategy for the Death with Dignity Act in the District Council



Dr. Omega Silva, a D.C. physician who supports aid in dying, addresses a September news conference about the D.C. Death with Dignity Act



will see The Colorado End-of-Life Options Act on their ballots. If 50 percent “plus one” vote yes (as they did in Oregon in 1994 and Washington in 2008) Colorado will become the sixth state where aid in dying is authorized.

If Colorado passes this initiative, it would be an enormous boost for the entire movement. A September poll from Colorado Mesa University showed that 70 percent of Colorado voters support the aid-in-dying initiative — and that it's the most popular measure on the ballot this year. While we are cautiously optimistic, we cannot take this initiative for granted. Our opponents are up on the air using scare tactics to raise fear and doubt among Colorado voters. Hopefully, by the time this magazine reaches mailboxes, Colorado will have become the sixth state to authorize medical aid in dying!

clockwise from top left:

Boxes containing the 150,000+ petitions signed by Colorado voters who want aid in dying on their November ballot

Campaign volunteers delivering signed petitions to Colorado secretary of state

Jaren Ducker, co-petitioner for the Colorado End-of-Life Options ballot initiative

Julie Selsberg, one of two citizen co-petitioners behind the Colorado End-of-Life Options ballot initiative

Hawai'i



C&C President Barbara Coombs Lee (right) on KHON2 (Fox)'s morning news show "Living808" with anchor Trini Kaopuiki (left)

America's 50th state is more than just a paradise with beautiful beaches and year-round sunny weather. Hawaii's welcoming "aloha spirit" and melting pot of ethnicities have made it a leader in social progress: It was the first state to legalize reproductive rights (1970), the first state to require minimum standards of healthcare by law (1974) and an early proponent of equality in marriage.

So it's not surprising that the people of Hawai'i overwhelmingly support medical aid in dying. Polls have consistently reported 75 to 85 percent of residents stand in favor of expanded options and autonomy at the end of life.

In 1998, Governor Benjamin J. Cayetano established a Blue Ribbon Panel on Living and Dying with Dignity. The panel recommended reforms for end-of-life care, including the right to aid in dying if the dying process becomes prolonged and unbearable. But an effort to codify this recommendation through legislation was defeated by the narrowest of margins in 2002.

... Hawai'i residents could finally get the range of end-of-life options they want and deserve

the range of end-of-life options they want and deserve. Compassion & Choices' (C&C) Hawai'i campaign team has been reaching out to opinion leaders and organizing grass-roots supporters. They are running advertising campaigns, hosting public forums and getting their supporters in the news to share stories. C&C's president and director of advocacy and political affairs traveled to the Aloha State in the late summer to help plan a legislative strategy for 2017 and to meet with supporters and allies.

C&C's Hawai'i team welcomes more volunteers and supporters to join the campaign to ensure Hawai'i has the full array of end-of-life choices. Email msteiner@CompassionAndChoices.org to become a volunteer or sign up on the website at CompassionAndChoices.org/hawaii.

Since then, dedicated activists have kept this vision alive, and Hawai'i residents could finally get

National Programs Update

American Medical Association to Consider a Neutral Stance on Medical Aid in Dying

Thanks in part to a coalition of physicians led by Doctors for Dignity Manager Rebecca Thoman, M.D., — and in line with the state medical societies in California, Maryland and Colorado — the American Medical Association (AMA) House of Delegates (HOD) voted to refer a resolution to study medical aid in dying as an end-of-life option to the AMA Council for Ethical and Judicial Affairs (CEJA).

The CEJA was directed to consider data collected from the states that currently authorize aid in dying and input from some of the physicians who have provided medical aid in dying to qualified patients, then report back to the HOD at the 2017 annual meeting with a recommendation regarding the AMA taking a neutral stance.

The AMA has opposed what it historically has called "physician-assisted suicide" since 1993, so even their change to using the neutral term of "aid in dying" is a positive sign. "We thank the AMA for responding to physician and public sentiment to reexamine its position on medical aid in dying," said Compassion & Choices President Barbara Coombs Lee. "... the vast majority of American doctors and their patients support medical aid in dying."

"Oregon's experience with our Death With Dignity Act shows terminally ill adults benefit from the law regardless if they decide to utilize medical aid in dying or not," said Dr. Glenn Gordon, a retired surgeon, former advisory board member of Compassion & Choices Oregon and alternate delegate for the Oregon Medical Association, which initiated the resolution.

"Oregon's experience with our Death With Dignity Act shows terminally ill adults benefit from the law regardless if they decide to utilize medical aid in dying or not."

After open hearings on the resolution, the AMA House of Delegates reference committee concluded: "... many states have proposed or adopted legislation to legalize the practice, introducing a potential conflict for our members in those states. Additional testimony recognized the need for our American Medical Association to respond to this highly relevant and expanding issue that may impact medical practice ..."



C&C's Doctors for Dignity campaign manager, Dr. Rebecca Thoman, (center) with Dr. Glenn Gordon (right) and Bob Dannenhoffer (left)

C&C Backs Bipartisan Bills to Improve End-of-Life Care

Compassion & Choices has endorsed on its website and via published op-eds the following bipartisan bills to improve end-of-life care and prevent unwanted medical treatment:

- » The Care Planning Act, which promotes increased public and provider education for advance care planning, and improves portability for advance-planning documents.
- » The Removing Barriers to Person-Centered Care Act, which would waive burdensome Medicare regulations such as allowing patients to receive Medicare coverage in a skilled nursing facility without requiring a consecutive three-day inpatient hospital stay, and allowing Medicare beneficiaries to receive home health services without requiring they be homebound.

- » The Personalize Your Care Act, which directs Medicare to establish a pilot program to provide palliative and advanced illness management services to beneficiaries whose life expectancy is 24 months or less and requires electronic health records to provide “one-click access” to advance-planning documents.
- » The Independence at Home Act, which would make permanent the Independence at Home pilot program authorized by the Affordable Care Act. It allows Medicare beneficiaries with at least two chronic conditions to obtain primary care services at home from a coordinated caregiving team.

Check out briefs on all congressional legislation endorsed by Compassion & Choices at CompassionAndChoices.org/legislative-briefs.

left: Congressman Earl Blumenauer of Oregon, longtime leader in Congress on end-of-life issues and current co-sponsor of the Personalize Your Care Act



right: Senator Mark Warner of Virginia, co-sponsor of the Care Planning Act and a Senate leader on improving end-of-life care



Access Success

In July, Adventist Health System, founded on Seventh-day Adventist heritage and values with facilities and 5,000 physicians in California, Hawaii, Oregon and Washington, lifted its 20-year ban on medical aid in dying.

“We had always encouraged Adventist Health patients to ask their doctors questions and write letters to Adventist Health. It compelled the system to seriously reconsider its policy,” said Compassion & Choices California and Oregon State Director Matt Whitaker. “Its new policy is it will neither compel a physician to participate or not participate.”

Just a few days before California’s End of Life Option Act took effect on June 9, the Los Angeles Times reported that Pasadena-based Huntington Hospital would forbid its 800 affiliated physicians to participate in the law.

In response, Compassion & Choices volunteers and staff in California organized local residents outraged by the decision. As a result, Huntington Hospital reversed its position and paid for an open letter in the Los Angeles Times (excerpted at right) to community residents to let them know it will participate in the law and allow its physicians to do so if they want.

Compassion & Choices is now launching a series of campaigns to bring about similar reversals.

An open letter to our community regarding the End of Life Option Act.

To our valued patients, friends, colleagues, partners and community members:

This morning – like every morning since the dawn of medicine – nurses, doctors, and those supporting them will pass an invisible baton at shift change to their colleagues who will continue delivering care to patients in need. As one aspect of this care, medical professionals will comfort and counsel patients confronting difficult prognoses, challenging treatments and questions about their futures. At Huntington Hospital, we think about these conversations every day, even more so in light of the passage of California Senate Bill 128, the End of Life Option Act.

••••

Earlier this year, our hospital began ongoing, thoughtful deliberations about whether and how to participate in this new law. In June, as the law came into effect, we announced that we would participate in the act while we completed our deliberations. Now, after careful evaluation of the law, its consequences, what is right for our community, and – most important – what is consistent with our vision to serve our community with kindness and dignity, our board of directors determined that Huntington Hospital will continue to participate in the End of Life Option Act. As has always been the case, physicians will individually decide whether they will participate or not.

As members of our community, it is important that you know that we heard and understood your feelings on the matter. In conversations with our physicians, palliative care experts, nurses, bioethicists, patients and community, the most critical factor in the end-of-life-discussion is individual choice.

••••



Excerpt from Huntington Hospital open letter in the Los Angeles Times on July 31

Activities for Activists

A significant portion of Compassion & Choices' progress can be credited to the dedication and talent of our nearly 5,000 volunteers around the nation. Everything from our legislative work to our End-of-Life Consultation Program gets a tremendous boost from the devoted people who give their time and energy to advance our mission.

To direct those efforts more effectively, we'll now be assembling and sending a Quarterly Action Bulletin to all volunteers, giving them specific opportunities, related resources and other ways to participate. Each bulletin will provide a variety of action steps a person may take to support Compassion & Choices' efforts nationwide. "We recognize that our volunteers across the country are willing to do so much, and we want to help focus their work and empower them to do it



Dr. Mits Tomito, San Diego C&C Action Team member, presents to a group about the California End of Life Option Act

effectively," says National Volunteer Program Manager Sarah Brownstein.

The first Quarterly Action Bulletin was sent out on October 1. **If you'd like to receive this and future editions, sign up at our online Volunteer Resource Center at CompassionAndChoices.org/volunteer.**

Compassion in the Courts

Ahn v. Hestrin: So far, attempts to derail California's End of Life Option Act have been stopped. In July, the Riverside Superior Court accepted C&Cs' amicus brief. And in an August hearing on a suit seeking to suspend the law, the judge denied a preliminary injunction to halt its implementation but allowed the case to move forward. The court noted that the plaintiffs "failed to provide any credible evidence that they — or anyone — will be harmed if the law goes into effect." The next hearing is in December, and we are prepared to continue protecting the law.

Oregon Prescription Drug Monitoring Program v. DEA: C&C and the American Civil Liberties Union (ACLU) are jointly representing plaintiffs in a landmark case seeking to protect private prescription records from warrantless searches by the U.S. Drug Enforce-

ment Administration (DEA), defending the principle that medical privacy is crucial in doctor-patient relationships. Patients should be able to speak frankly with their doctors without fear of government intrusion, and doctors should not be hesitant to prescribe sufficient medication to suffering patients. The 9th Circuit Court of Appeals will hear arguments in November.

Vermont Alliance for Ethical Healthcare, Inc. v. Hoser: Compassion & Choices is also working to oppose a suit alleging Vermont's Patient Choice and Control at End of Life Act violates the constitution by requiring physicians to give their terminally ill patients information about all of their medical options, including medical aid in dying.

"Hospice Knocks My Socks Off"

A common sentiment among Compassion & Choices' End of Life Consultation Program (EOLC) team is that the benefits of hospice cannot be overstated. Yet many people access it far later than is ideal — or not at all — because they don't fully understand how it works. EOLC Consultant Christina Kucera, who came to C&C following seven years as a hospice social worker, dispels some common misconceptions about this wonderful service:

- » **You're not giving up and won't die more quickly by going on hospice.** "Often people improve, some enough that they sign off hospice for more chemotherapy or to start a clinical trial that they were too ill to participate in before. Then down the road when they need it, they can readmit."
- » **Hospice will not come in and take over.** "Hospice is completely client-centered, the 'client' in this sense being the ill patient and

their entire support system — family, friends, caregivers — and they're in charge 100% of the time. You pick and choose what you want from the hospice team."

- » **People don't need their doctor's recommendation.** "Doctors tend to make referrals to hospice very late in the game; 50% of patients are on hospice for two weeks or less. Patients can absolutely initiate the process themselves."
- » **It's not just for people with cancer.** It used to be the vast majority had cancer; now only 36% do. People with dementia, heart disease, lung disease or just old age can absolutely benefit."

Get more great information through our EOLC Program at CompassionAndChoices.org/eolc-consultation.

Are YOU Embracing YOUR Reality?

Compassion & Choices is embarking on a new campaign and wants to hear about your experiences. Yours could be the story that inspires the next advancement in end-of-life care. We are looking for people with life-threatening illnesses who want to help break the cycle of "one-size-fits-all" healthcare.


- » Did you seek and obtain a care plan that puts you in charge?
- » Are you living despite dying and spending every minute on your terms?
- » Are you pursuing your dreams just because, not in spite, of your illness?

Please share your story and help us create a generation of people who do not suffer at the end of life.

Go online to: CompassionAndChoices.org/submit-your-story

Five Questions About

Miss Norma



Norma Bauerschmidt, better known as “Miss Norma,” made worldwide headlines when she chose to pass on cancer treatment last year for a road trip with her son and his wife in their RV: eating cake, drinking beer and enjoying life to the end. Norma died on September 30, 2016, at age 91. We spoke to her daughter-in-law, Ramie Liddle, about the inspiring escapade.

Feeling a responsibility to continue Miss Norma’s legacy, Ramie and Tim have published a book to be released May 2, 2017, sharing the back stories, hard conversations and joy of their adventure: www.drivingmissnorma.com.

Q: What was your first reaction when Norma opted to forgo treatment, and how did she make that decision?

A: To give some context, Norma had just been through the relatively sudden deaths of the two most important people remaining in her life. Her brother Ralph (91) died of stomach cancer, and one month to the day later her husband, Leo (88), died from complications related to a compression fracture in his back.

Tim and I honestly can’t remember who came up with the idea, but we invited Norma to live with us, just like many other adult children do with their elderly parents. The difference was our house had wheels — we lived on the road full time. We had no idea what it would be like but thought we would give her the option to come along if she wanted to.

Two days after Leo’s death Norma told the doctor how she was going to live the rest of her time. She watched Ralph and Leo’s last days and had no interest in heroics, treatment or additional medications. Norma was clear that the proposed medical procedures would not result in an increased quality of life for her. She imagined tremendous despair as she tried to heal from cancer treatments that would likely take her life sooner than if she ignored the diagnosis. Her decision was easily made, and we supported it from the very beginning. Our first reaction: “Let’s get packing!” We couldn’t wait to bring her along.

Q: Was her doctor supportive?

A: The doctor who presented us with the diagnosis went straight into the treatment procedures. There was nothing surprising about what he outlined: basically surgery, chemo and radiation, then a stay in a rehabilitation

facility before living the rest of her days in a nursing home with round-the-clock care. It wasn’t until Norma said, “I’m 90 years old; I’m hitting the road,” did this young doctor pause and reflect on what his elderly patient was saying. Tim explained our lifestyle and intention to take his mom on the road with us. The doctor’s shift was palpable. “Really? Right on!”

We asked if he thought us irresponsible for this approach. His reply was telling. “As doctors,” he said, “we see what cancer treatment looks like every day — ICU, nursing homes, awful side effects. Honestly, there is no guarantee she will survive the initial surgery to remove the mass. You are doing exactly what I would want to do in this situation. Have a fantastic trip!”

We wished that he had presented an option of no treatment and encouraged us to consider that as an equally viable choice from the beginning, but he didn’t. Norma, with our support, needed to be strong and imaginative enough to come up with an alternative that was not taught in medical school.

Q: Caring for a terminally ill person of advanced age can be fairly intense, even in one’s own home, near their doctor. How did you manage on the road?

A: I guess naivete helped us in the early days. We really didn’t know what we were getting ourselves into.

We wanted to foster Norma’s independence as much as possible. We gave her a voice in all our decisions and her own space in the motorhome. The wheelchair we bought her also served as a walker so she could go for walks by herself, and we encouraged her to



do what she wanted, not what she thought was the right thing to do.

Not being near her doctors was actually an asset. She could have spent her last year sitting in waiting rooms three times a week; instead she was out in national parks looking for moose or avoiding alligators. She flew in a hot-air balloon and was a VIP in a parade, not stuck in a cramped room with a strange roommate watching Wheel of Fortune at high volume. It wasn't until the last two months of her life that we were in full-on caregiving mode. Our plan all along, when she required more care than we could provide by ourselves, was to enlist a hospice team. Otherwise she was simply a wonderful travel companion, living her life until she couldn't anymore.

Q: Reflecting back, what was the best part of the experience for Norma?

A: When Norma met her hospice nurse for the first time, the nurse examined her feet. She couldn't help but notice the pink flowers painted on Norma's toenails from her most recent pedicure and was obviously impressed. Then she said, "What's up with your skin here? What is this line on your legs?" In all her

years as a nurse working with elderly patients she had never seen anything like she was seeing on Norma. Norma smiled and proudly said, "Well that's my suntan! My socks usually go right to here." She pointed to her sock line.

Norma came alive on this trip. I liken it to a flower that had not been watered in a while, and when the rain fell in the form of love and permission to live fully the flower began to open up, showing its most vibrant colors before the end of its life. She said "YES!" to living to the very end.

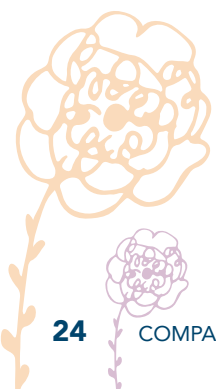
Q: How about for you?

A: All of it! Norma's spirit heartened us from early on. She showed us that you can be creative and somewhat in control of your last moments. She gave herself permission to let go and enjoy life to her very last waking moment.

Most remarkable is the millions of others she willingly carried along for the ride. Her story has gained fans from the most far-reaching and unlikely points on the globe. That was never our intent, yet we are grateful that our simple story has provided a window into the human spirit that is so very beautiful.

This year, we've gone an incredible distance to secure end-of-life options for all Americans. From the nation's capital to Hawai'i, your support drives this movement across the country —

see the road
unfold here ...



Highlights

Jul 2015 – Jun 2016



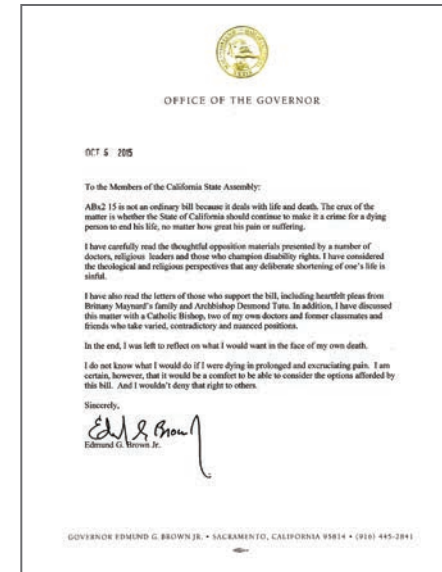
The Centers for Medicare & Medicaid Services answered one of C&C's longtime calls for change, announcing a proposal to pay doctors for having end-of-life planning conversations with their patients.

Jul 2015



C&C and its partners in the Campaign to End Unwanted Medical Treatment released a collection of five expert policy briefs stressing the importance of person-centered healthcare. The Campaign's events featured a number of distinguished guests including politicians, doctors and other influential professionals.

Sep 2015



California Governor Jerry Brown signed the End-of-Life Option Act into law, making Brittany Maynard's home state — the most populous in the nation — the fifth to authorize medical aid in dying.

Over 200 supporters packed the Massachusetts State House during a public hearing on their death-with-dignity bill while Dan Diaz gave powerful testimony to the necessity of the law.

C&C's End-of-Life Consultation Program began offering interpreters for non-English speakers who call its information line and began translating planning materials into Spanish, including our website.

Oct 2015



C&C held its first-ever event on Capitol Hill in Washington, D.C. Chief Program Officer Kim Callinan was joined by Dan Diaz, Dr. David Grube, Charmaine Manansala and Rev. Dr. Ignacio Castuera in briefing Hill staffers, policy experts and supporters about our recommendations for improving end-of-life care nationwide.

We officially kicked off our campaign to authorize aid in dying in New York state with the hire of a full-time director and release of a new poll showing 77% of New Yorkers stand in favor of aid in dying. That support extended across religion, education, political party, gender, age and geography.

Nov 2015



C&C launched a bilingual English and Spanish access campaign, making Californians aware of their full end-of-life options, including the state's newly implemented aid-in-dying law.

Dec 2015



Compassion & Choices surpassed 4,000 trained volunteers, spanning across 49 states, the District of Columbia and Puerto Rico!

Jan 2016

Brittany Maynard's video calling for expanded end-of-life options nationwide, which went viral and contributed enormously to our success in California and the push for similar laws nationwide, won the 2016 Reed Award for "Best Web Video For Public Affairs Campaign or Issue Advocacy." The Reed Awards recognize excellence in campaign management, political consulting and design.

Mar 2016

Miguel Carrasquillo, a 35-year-old diagnosed with aggressive brain cancer, became Compassion & Choices' first terminally ill Latino advocate for medical aid in dying. Referring to himself as the "Latino Brittany Maynard," Miguel recorded a bilingual video for C&C and was featured in major news outlets including the Chicago Tribune, Huffington Post and People en Español, and in a moving interview with Univision's Jorge Ramos, all before his death on June 5 in Puerto Rico.

Apr 2016

We joined hundreds of protesters in front of the U.S. Supreme Court in the case of *Zubik v. Burwell*, a challenge to the Affordable Care Act based on claims of religious freedom. We also issued an amicus brief in the case, combining direct action with legal expertise on the topic of healthcare decision making.



Compassion & Choices and the Compassion & Choices Action Network (CCAN) helped unify two pending bills into New York's Medical Aid in Dying Act, introduced on May 10 at C&C's lobby day in Albany. For the first time in the history of New York state, aid-in-dying legislation advanced through a legislative committee thanks to the tireless efforts of our team.

May 2016

In a statement, Barbara Coombs Lee and CCAN pledged to support the Yes on Colorado End-of-Life Options Act campaign. The measure will allow Coloradans to vote to authorize medical aid in dying for eligible terminally ill adults in their state.



California's End of Life Option Act went into effect on June 9 after a yearlong campaign by Compassion & Choices' team of volunteers, advocates and staff. On the same day, C&C launched a Find Care portal that provides information on participating health systems to Californians exploring their new option.

C&C and its coalition partners in the Campaign to End Unwanted Medical Treatment hosted a summit of key policy and industry leaders in Washington, D.C., to develop a clear plan of action to put people in charge of their healthcare.

Jun 2016

Democratic Rep. Rebecca Chavez-Houck introduced an aid-in-dying bill to the Utah Legislature, bringing the total number of jurisdictions to consider aid-in-dying legislation in 2016 to 19 states plus D.C.

Compassion & Choices thanks the law firms and attorneys that gave so generously of their time this past year. Collectively they contributed thousands of hours of service and were instrumental in our effort to enact the California End of Life Option Act. In particular we would like to recognize the following:

O'MELVENY & MYERS LLP

- John Kappos
- Jason A. Orr
- Britney Rogers

HORVITZ & LEVY LLP

- Jon B. Eisenberg
- David S. Ettinger
- Barry L. Levy
- Dean A. Bochner
- Scott P. Dixler

ARNOLD & PORTER LLP

- Jerome B. Falk
- Adam J. Kretz

Combined Statement of Financial Position*

June 30, 2016

Assets

Current Assets:

Cash and cash equivalents:	
Operating	1,656,078
Investments	1,007,932
Pledges receivable-current portion	2,645,150
Investments	12,879,631
Prepaid expenses	133,503
Beneficial interest in charitable remainder trusts	169,046
Other current assets	15,532
Total current assets	18,506,872

Property, Equipment and Improvements, at Cost:

Furniture, fixtures and equipment	454,920
Leasehold improvements	62,446
	517,366
Less accumulated depreciation and amortization	391,214
Total property, equipment and improvements	126,152

Other Assets:

Pledges receivable net of current portion	2,635,500
Intangible assets	14,764
Deposits	30,875
Total other assets	2,681,139
TOTAL ASSETS	21,314,163

Liabilities and Net Assets

Current Liabilities:

Accounts payable	341,733
Accrued payroll and vacation	471,800
Total current liabilities	813,533

Long-Term Liabilities:

Gift annuity payments due	477,969
Total long-term liabilities	477,969
Total liabilities	1,291,502

Net Assets:

Unrestricted:	
Operating	17,261,009
Net investments in property, equipment and improvements	126,152
Temporarily Restricted	2,635,500
Total net assets	20,022,661
TOTAL LIABILITIES AND NET ASSETS	21,314,163

Combined Statement of Activities and Changes in Net Assets*

For the Year Ended June 30, 2016

Revenue and Other Support:

Conferences and events	--
Contributions	18,808,249
Membership fees	137,311
Foundation revenue	25,000
Investment income, net of expenses	64,779
Realized and unrealized loss on investments	(39,261)
Gain on sale of asset	63,457
Other income	559,968
Total revenue and other support	19,619,503

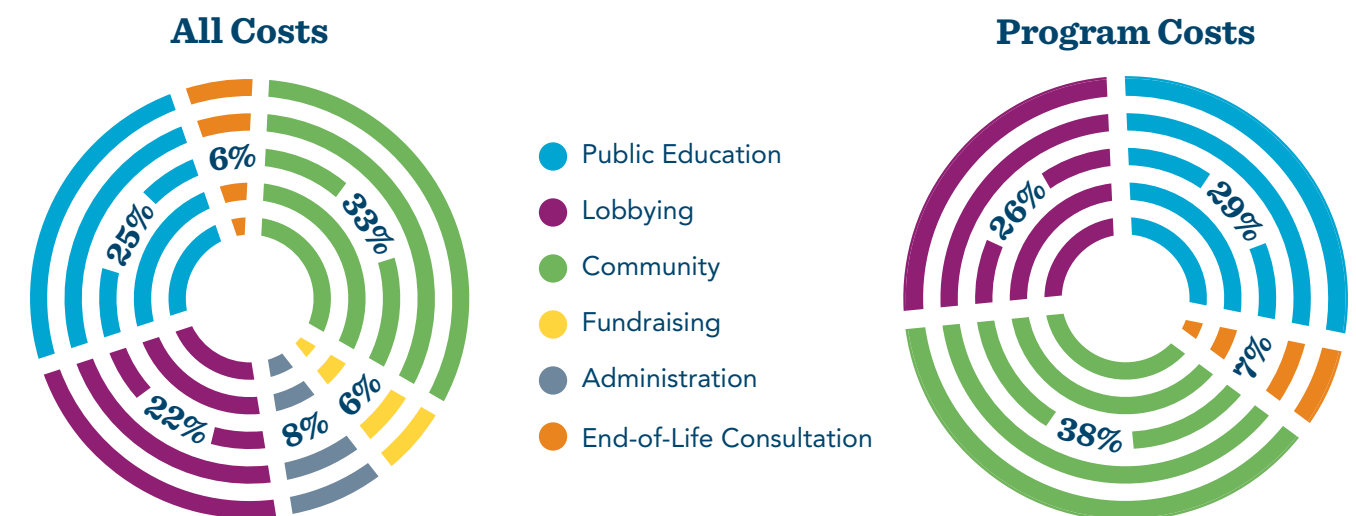
Expenses:

Programs	19,386,501
General and administrative	1,818,770
Fundraising	1,264,454
Total expenses	22,469,725
Decrease in net assets	(2,850,222)

Net Assets:

Total net assets, beginning,	22,872,883
NET ASSETS, ENDING	20,022,661

Costs for the Year Ended June 30, 2016*



* Compassion & Choices and Compassion & Choices Action Network

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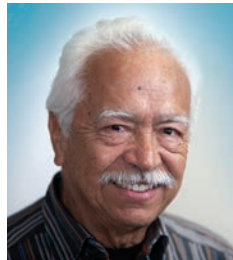
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Thank You to Our Generous Donors

Compassion & Choices and the Compassion & Choices Action Network are deeply grateful to our many donors, whose giving helps us continue to move our mission forward. In 2016, we received nearly 50,000 gifts ranging from \$1 to grants in the millions. Every dollar propels us to greater success, and the future of our movement depends on your generosity. Many donors give to us during their lifetimes; others join our Legacy Circle and include a gift to Compassion & Choices in their estate plans. While space limitations allow us to only list donors of \$1,000 or more, Compassion & Choices appreciates every single gift we receive. Through your support and commitment to our work, you provide the foundation on which we will continue to grow.

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