

Compassion & Choices



MAGAZINE
Spring 2014

**Patients
Should Decide**

**Mancini
Charges Dismissed**

5 Questions for Author

Katy Butler

Be a **CHAMPION** for Choice

"Knowing that I am automatically, once a month, financially supporting Compassion & Choices as it assists families such as mine gives me great satisfaction."

— Kathy Cerminara, Fort Lauderdale, FL

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Join our Champions Circle with the envelope in this issue or visit the link below.

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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.

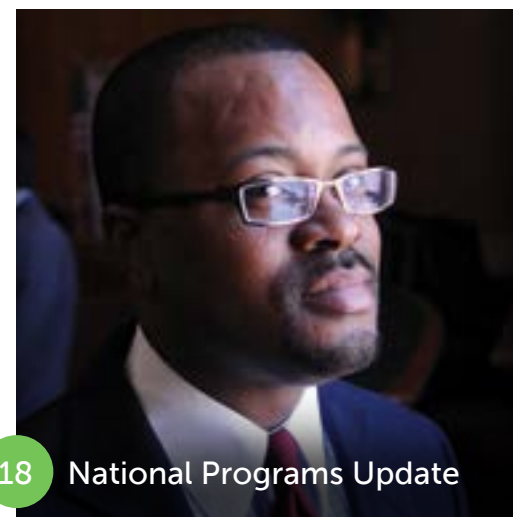
Learn more at CompassionAndChoices.org.



8 Mancini Charges Dismissed



17 State Spotlight: Massachusetts



18 National Programs Update

INSIDE VIEW It Takes All Kinds

Barbara Coombs Lee
PA, FNP, President



Those who follow our issues have been delighted to see a diverse and energetic movement emerging before them. Compassion & Choices' transformation from a single organization to leader of a powerful movement is happening so fast it's hard to keep up with all the exciting developments and changes every month.

Issue advocacy becomes a "movement" when it gets big, strong and visibly diverse. That's happening to us right now. You'll see growth, strength and diversity everywhere on the pages of this magazine. Especially diversity.

Opponents like to say end-of-life dignity and choice matter only to the white, healthy, educated and unchurched. They've always been wrong about that. Born during the AIDS epidemic, Compassion & Choices' work on aid in dying always included large contingents of LGBT individuals, educated or not. Progressive religious congregations have always been behind us. People with disabilities have always known death with dignity furthers the principle of autonomy they hold dear. People of color have always wanted their healthcare wishes known and honored.

But something is changing — diversity among death with dignity supporters is becoming visible. People like Dustin Hankinson are countering the disability hardliners who lobby against death-with-dignity laws (p. 10). A powerful new poll shows Dustin stands well in the majority (p. 17). Community support is strong and broad among people of color in New Jersey and elsewhere. A man of color just won a Connecticut Senate seat in a landslide, talking about death with dignity.

You'll see all sorts of people in the pages of this magazine. People in every socioeconomic category, of every religion and color, in every corner of our land want to live their values and beliefs. And when their time comes to die, they want the freedom to die by their values as well. This is the work of our growing, diverse, vibrant and powerful movement for end-of-life choices.

Compassion & Choices MAGAZINE

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Cover photo courtesy of Katy Butler

Barbara Coombs Lee photo by
Boone Rodriguez



Words & Pictures

The New York Times

"The Grey Lady" published a front-page story about Compassion & Choices' leadership in the aid-in-dying movement and its free End-of-Life Consultation service.



C&C President Barbara Coombs Lee noted the quiet, constant demand all over the country for the right to die on one's own terms.

"People should get the best care, but also have a choice to accelerate the time of death if the very best care cannot make their remaining days acceptable," Coombs Lee said.

▶ <http://bit.ly/AID-Momentum>

The Boston Globe

Compassion & Choices' Massachusetts campaign got noticed in a Feb. 26 *Boston Globe* headline: "Group supporting 'aid in dying' launches advocacy push."



The paper noted Compassion & Choices activated "a wave of telephone calls" from death-with-dignity legislation supporters to state legislators, lobbying them to advance this year's bill.

▶ <http://bit.ly/MassAID>

CBS

Philadelphia's CBS TV station covered a news conference organized by Compassion & Choices at Barbara Mancini's home 24 hours after a judge dismissed the assisted-suicide case against her.



"As happy as I am with this outcome ... [Dad's] end-of-life wishes were violated, so that will always disturb me," said Mancini.

C&C Director of Communications & Marketing Gwen Fitzgerald said Pennsylvania Attorney General Kathleen Kane "should back off and back out of families' medical decisions."

▶ <http://bit.ly/BMancini>

NPR

Nevada's NPR station interviewed Compassion & Choices Chief Program Officer Mickey MacIntyre about the landmark win in a case brought by C&C and the ACLU of New Mexico.



MacIntyre and State Senator David Parks also answered questions about Parks' plans to introduce a death-with-dignity bill next year.

▶ <http://bit.ly/NevadaAID>

Director of Communications & Marketing Gwen Fitzgerald in Pennsylvania



Whose Choice Is It, Anyway?

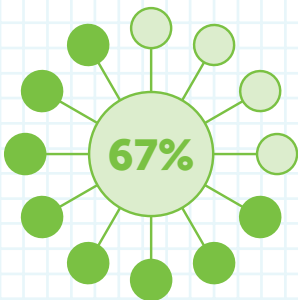
People With Disabilities Support Aid in Dying

Disability-rights groups persistently oppose death-with-dignity laws. Yet recent surveys in two states considering such legislation, Connecticut and Massachusetts, indicate strong support for this option among those living with a disability. This support tracks consistently with overall public support.

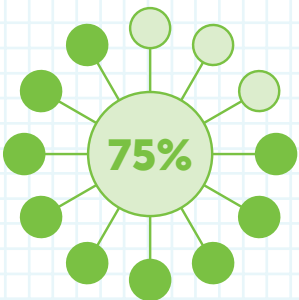
Percentage of people living with a disability who:

Support allowing mentally competent, terminally ill adults to bring about their own death

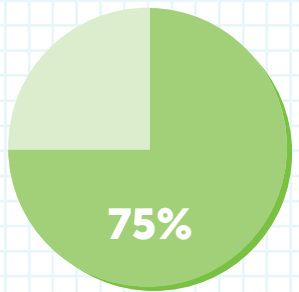
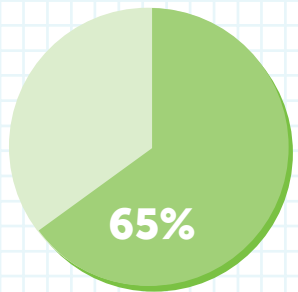
Connecticut



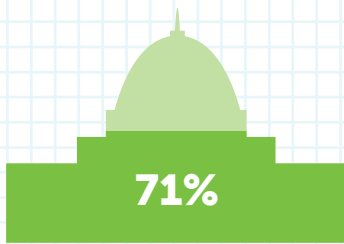
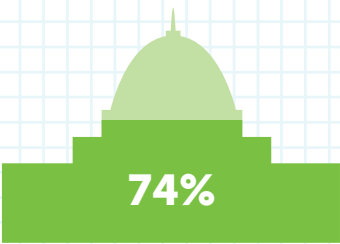
Massachusetts



Support allowing mentally competent, terminally ill adults to end their life by self-administering prescription medication



Believe government shouldn't meddle in the private, personal decisions terminally ill adults make about whether or not to end their own lives



Words to Live (and Die) By

Acute condition:

Acute conditions come on suddenly, last a short time, and can be mild, severe or even fatal. They sometimes have intense symptoms. Examples include colds, influenza and strep throat.

Progressive disease:

Also referred to as degenerative disorders, progressive diseases gradually worsen, resulting in a general decline in health and function. Some can be halted and reversed for a time, while others have no effective treatment. Depending on many factors, they may move quickly or slowly. Examples include Alzheimer's disease, cataracts, emphysema and osteoarthritis.

Chronic illness:

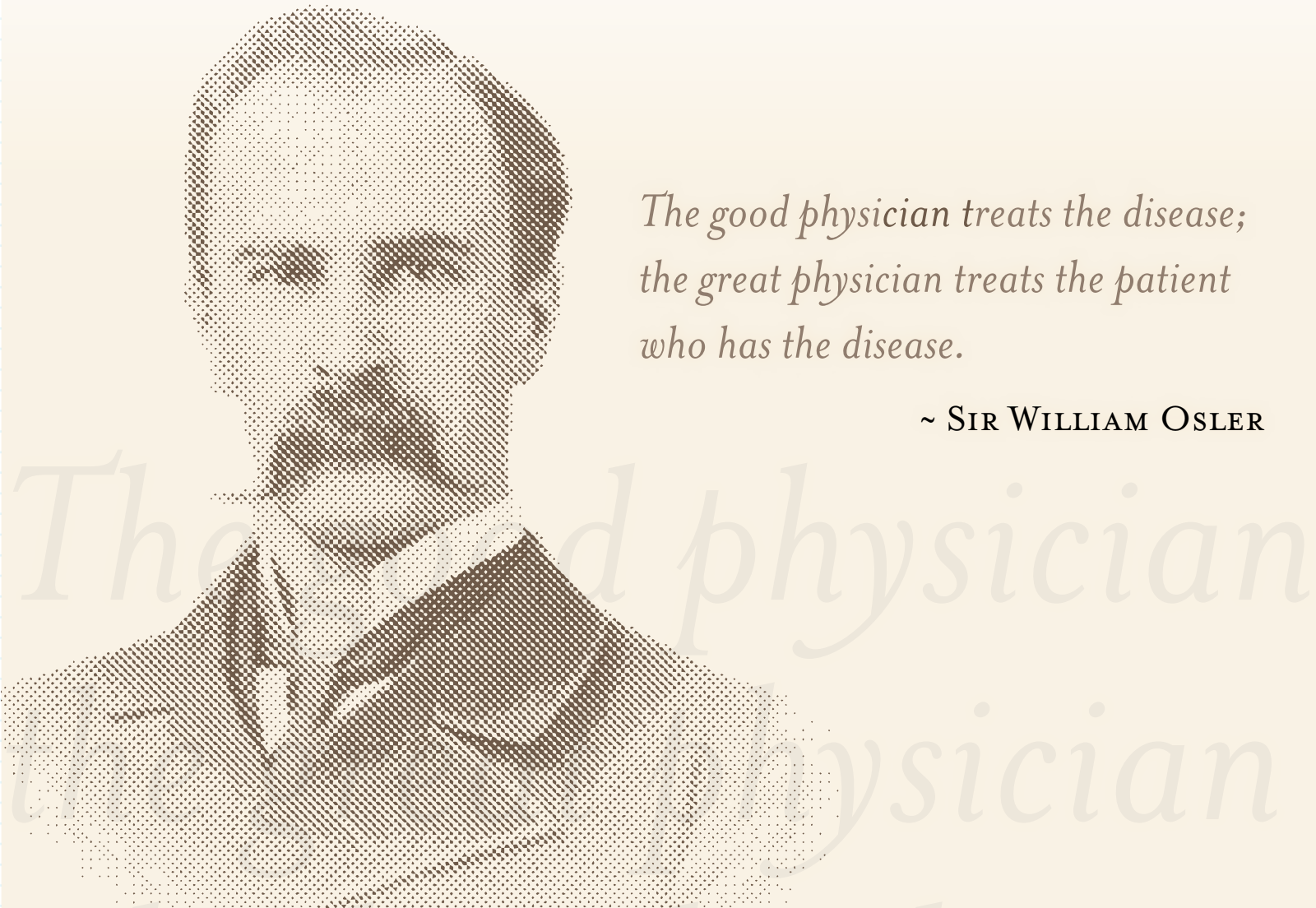
The number-one healthcare problem in the United States, chronic illnesses last for long periods of time, sometimes permanently, and are rarely curable. They range in severity. Examples include asthma, kidney disease and diabetes.

Terminal illness:

A disease that cannot be cured, nor its progression halted, and is expected to cause death within a short period of time. Patients are usually considered terminally ill when their estimated life expectancy is six months or less. Examples include advanced cancer and heart disease.

*The good physician treats the disease;
the great physician treats the patient
who has the disease.*

~ SIR WILLIAM OSLER





Year of Legal Torment Ends

Charges Dismissed for Assisting Dad's "Suicide"

C&C's Gwen Fitzgerald and Sean Crowley with Barbara and Joe Mancini (center)

Compassion & Choices' Grassroots, Legal and Publicity Actions Highlighted Wisdom of Dismissing the Case

Pennsylvania Attorney General Kathleen Kane announced Feb. 24 that she would not appeal the dismissal of the assisted-suicide prosecution of Philadelphia nurse Barbara Mancini for the death of her terminally ill 93-year-old father. The decision mercifully ends more than one year of torment for an innocent family.

Mancini faced up to 10 years in prison if she were convicted of a felony for handing her father, Joe Yourshaw, a partially filled bottle of his prescription

morphine, at his request. A hospice nurse visited the Yourshaw home after he drank the morphine and found him lethargic. She called her supervisor, who called 911, even though Barbara had her father's healthcare proxy to enforce his do-not-resuscitate order. The police arrived and arrested Barbara. Then EMS arrived and took Joe to the hospital, where he was revived. He contracted pneumonia and suffered terribly before he died four days later.

"Attorney General Kane's decision to accept this dismissal should serve as an important lesson to prosecutors nationwide: Government officials should not interfere in families' private medical decisions," Compassion & Choices President Barbara Coombs Lee told the Associated Press.



Barbara Mancini receiving a check from Compassion & Choices Action Network to assist with legal fees



Compassion & Choices provided pro bono legal consultation and publicized the case nationally. We helped formulate the strategy to pursue a dismissal of the charges prior to a full trial – an unusual move in a criminal case. C&C brought deep knowledge of end-of-life case law and submitted an Amicus brief citing our 1997 Supreme Court cases, *Washington v. Glucksberg* and *Vacco v. Quill*. Mancini's excellent defense counsel, deploying these and other strategies, effectively persuaded the court to drop the charges.

Simultaneously, C&C unleashed a publicity push, sparking a national discussion on end-of-life decisions – with public opinion strongly on Mancini's side. Since August 2013 Compassion & Choices staff generated more than 30 national and local opinion pieces criticizing the prosecution. News sites and radio stations across the country covered the story.

The day after the dismissal, Compassion & Choices presented the Mancini family a check for

\$20,000 raised through the Compassion & Choices Action Network Legal Defense Fund to offset the family's legal expenses, in excess of \$100,000. Barbara Mancini has been on unpaid administrative leave from her nursing job as a result of the case. Meanwhile her husband, Joe Mancini, has had to work extra shifts as a paramedic to make up for the lost family income.

"I am grateful to all who rallied to support me throughout this ordeal: my loyal family, Compassion & Choices, the many opinion writers who publicly opposed my prosecution and all the people who sent letters of encouragement."

Compassion & Choices launched a local Philadelphia group, which met with Joe Mancini last September to provide emotional support for the family.

Evidence in the case was weak from the start. In the dismissal order, Judge Jacqueline Russell said: "The Commonwealth's case appears to have been based on little independent investigation, significant hearsay, including

double hearsay received from third persons — speculation, guess and defendant's alleged incriminating statements." Coincidentally, Judge Russell granted the motion to dismiss the case exactly one year after Joe Yourshaw's death on Feb. 11, 2013.

"I am grateful to all who rallied to support me throughout this ordeal: my loyal family,

Compassion & Choices, the many opinion writers who publicly opposed my prosecution and all the people who sent letters of encouragement," Mancini told *The Philadelphia Inquirer*. "This support was a silver lining in the dark cloud that enveloped our lives, and it sustained us."

Patients Should Decide

by Dustin Hankinson

Dustin Hankinson captured the attention of Montana and the nation when he asserted, “I am a Montanan living with a disability, and I support the right of terminally ill Montanans to make their own end-of-life decisions.” This willingness to speak openly was crucial to protecting death with dignity from legislative attack in 2011 and 2013.

Hankinson has worked for the rights of persons with disabilities for more than a decade. Also active in democratic, progressive and discrimination issues, he remains heavily involved with Compassion & Choices and keeping death with dignity legal in his beloved home state.



Supporter Dustin Hankinson

Self-determination is one characteristic that defines human dignity. When a person reaches adulthood, it is expected that they make decisions to live the life they aspire to. Society is based on people taking responsibility for their decisions and lives.

If individuals have the right to decide how to live, they also should have the absolute right to decide the manner of their death when faced with an imminent terminal illness. It is a patient’s life, body and mind; therefore, that patient should be the decision-maker in dying.

As a 39-year-old disabled man with a terminal diagnosis of Duchenne Muscular Dystrophy, I value the expertise of medical professionals. However, I alone reserve my right as the patient to decide which treatments I receive, and I believe that my decisions outweigh those of anyone else regarding my medical care. In a free society, personal choice regarding medical treatment should be a fundamental human right!

For any who would disagree with a fundamental right to choose, I ask a simple question: After a lifetime of

taking responsibility for myself and making my own decisions, when death approaches, haven’t I earned the right to decide how I leave the world? If not, what have I earned? A situation where people who hardly know me will decide the experience of my death? How can someone else’s perspective of my life outweigh my right to decide how it ends?

Simply put, terminally ill patients should be allowed to choose their own treatment including the sovereign right to death with dignity.

“It is a patient’s life, body and mind; therefore, that patient should be the decision-maker in dying.”



Advocacy in Action

Citizens are demanding control over their end-of-life experience – and lawmakers are responding.

California

C&C continues to expand its outreach and mobilize supporters toward the goal of establishing death with dignity in five years. We opened a Los Angeles office in February to serve as a base for our Southern California team: Southern California State Director Christal Smith, Greater Los Angeles Development Manager Andrea Wilson and soon a state campaign director. Soon we will bring on a state campaign director. The enthusiasm is clearly catching: The state's showcase end-of-life choice event, the Annual Empowerment Luncheon in San Francisco, was shaping up at press time to be the best ever with more than 250 tickets sold before invitations were mailed. Supporters look forward to hearing from Mistress of Ceremonies Jeanne Phillips (Dear Abby), with U.S. Senator Dianne Feinstein serving as Honorary Chair.



Board member Robert Brody speaks in San Francisco

The Northern California staff and Leadership Council continued their tradition of hosting an annual meeting with a record crowd this year. Seizing every opportunity to enlist new activists, leaders plan talks to local groups and booths at many local senior fairs throughout the state. To find upcoming events near you, visit the new California web page.

► <http://bit.ly/cc-california>



Sara Myers at the Connecticut hearing

Connecticut

It will be another year until Connecticut lawmakers take up death-with-dignity legislation. The issue was all over talk radio, TV and front pages for several weeks across the Nutmeg state, which is why opponents quickly hired a slew of lobbyists to stop death with dignity's momentum.

Those moneyed interests won – for now. But Compassion & Choices Connecticut's efforts set the table for 2015. On March 17, more than 150 determined advocates flooded the Joint Public Health Committee Hearing in support of the aid-in-dying bill. Among them were Barbara Mancini, the Pennsylvania nurse who'd just been cleared of charges in her dad's death, and Sara Myers, a tireless advocate because – and in spite – of her ALS.

The marathon 12-hour hearing followed the debut of our high-profile portrait project, visible at CompassionAndChoices.org. The 32 three-foot high portraits of supporters were introduced at a Capitol Building press conference along with a new poll showing 2-to-1 support for death with dignity in

Connecticut. An aggressive online, newspaper and radio advertising campaign came next. Even when nervous opponents got the portraits abruptly (though temporarily) removed, momentum was unstoppable.

The Hartford Courant editorialized in favor of the legislation. Representative Gary Holder-Winfield won a special Senate election on a platform that included end-of-life choice. In the end, lawmakers had to give the bill a hearing, but they refused to vote. For now.



New Mexico

End-of-life-choice champions nationwide are still floating on air from the January court ruling finding aid in dying is a fundamental right under the New Mexico constitution. The victory earned more than 650 news stories nationally and internationally. But it's too early to put our feet up. The New Mexico attorney general has filed an appeal of the ruling.

Nowhere does Compassion & Choices' 30-plus years of experience become more crucial than in making death with dignity a reality following court or legislative authorization. If the court does not "stay" (delay) the ruling, implementation will be our priority in New Mexico. In February C&C President Barbara Coombs Lee met with more than a dozen members of the Physician Advisory Council on Aid in Dying (PACAD) to devise next steps and bring guidelines for aid in dying to New Mexico physicians. Dr. Kate Morris, lead plaintiff in the case, convened a grand rounds seminar on aid in dying February 25 at CHRISTUS St. Vincent Regional Medical Center in Albuquerque.

Nearly 70 physicians and medical staff attended. Consumer education efforts resumed, with volunteer action teams and ads encouraging people to "start the conversation" on end-of-life plans with family and physicians.

Montana

The legislature did not convene this year, but C&C Montana remains on its game, with ongoing outreach to the public and medical professionals. On February 15 Dr. Eric Kress spoke with nursing students about what to expect if they serve on a care team that provides hospice or aid in dying. C&C sponsored Mountains of Courage, the annual conference of the Gallatin Valley Circle of Compassion, an all-volunteer committee of doctors, nurses and social workers who specialize in palliative, end-of-life, geriatric and hospice care. We made many valuable connections there at our booth and with a representative speaking in the advance directive/medical planning discussion. The outreach continued at an event sponsored by the ACLU, a valued partner with C&C in several campaign states.

Vermont

In the Green Mountain State, Linda Waite-Simpson leads C&C's efforts to implement the death-with-dignity law following its historic passage in May 2013. Outreach to medical professionals is the number-one priority. C&C contacted 900 physicians across the state, offering assistance from doctors experienced in aid-in-dying practice in other states. We also offered resources for local citizens and medical professionals. Waite-Simpson educated consumers and recruited volunteers at the Vermont 50+ and Baby Boomers Expo in January.

Oregon

At the epicenter of the death-with-dignity movement, public outreach remains the name of the game in Oregon. Compassion & Choices Oregon's robust and growing volunteer corps has been active across the state providing accurate information and presentations to medical providers and the public wanting to know more about end-of-life choices. Oregon's

medical directors are also active providing education at medical and nursing schools, and supporting Compassion & Choices' efforts in other states by speaking in Vermont, testifying in New Mexico and sending advocacy letters to Connecticut legislators considering an aid-in-dying bill.

New Jersey

New Jersey Assemblyman John Burzichelli reintroduced a death-with-dignity bill. The C&C New Jersey team, having just added two new field organizers, is helping to recruit legislative co-sponsors. They have also distributed to each member of the legislature the names and hometowns of more than 7,800 New Jersey residents who have gone on record in support of the legislation.

New Jersey bill sponsor, Assemblyman John Burzichelli



Compassion & Choices Connecticut pulled out all the stops to drive action on the death-with-dignity bill this year. Our on-the-ground organizers mobilized citizens to call, visit and contact their legislators. And we conducted an aggressive communications strategy with online, radio and newspaper ads that ran in lawmakers' hometown newspapers.

The Hartford Courant acknowledge our strategy in its March 17 edition: "Through radio interviews, online ads and a sophisticated digital strategy, Compassion & Choices has sought to frame the debate as a fundamental human rights issue, part of the long sweep of history that began with women's suffrage, flowered during the Civil Rights movement and continues today with the drive for gay marriage."



Local Groups

Compassion & Choices gains ground in more states each year. This momentum is fueling advances for end-of-life choice nationwide. Find a local group or event near you at www.compassionandchoices.org/what-you-can-do

Colorado

Outreach to women topped the agenda: Lynn Weitzel addressed a women’s group in Evergreen, and board member Dr. Charlie Hamlin spoke to the University Women’s Group in Aurora. On March 2 *The Denver Post* ran a powerful op-ed by a man suffering from ALS who implores state legislators to “show mercy on the terminally ill” by considering a death-with-dignity bill.

Florida

Florida volunteers are taking on the difficult – and necessary – work of building a base of supporters, the foundation of every good campaign. The larger the base, the more activists and volunteers available to mount a successful effort. To stay motivated, the Clearwater group drew a giant green alligator that hangs on the wall. They color in one of his scales for every new supporter confirmed. Whatever it takes!

Illinois

C&C’s Illinois group leaders Jana Edge in Bloomington and Bess Schenkier in Chicago have been tirelessly speaking out and organizing volunteers to share information about end-of-life choices. Both groups organize activities to engage residents,

including roundtables on unwanted medical treatment, film screenings, petition gathering and discussion panels.

Iowa

Compassion & Choices Iowa is holding its annual public meeting on May 17 in Des Moines. The featured presenter will be Vermont Legislator and C&C State Director Linda Waite-Simpson, who will discuss how Vermont became the first state to pass an aid-in-dying law through the legislative process.

Maryland

Compassion & Choices’ national staff meets monthly with motivated area advocates and local group members to begin mapping out a legislative strategy for advancing death with dignity in the future. Currently, the action team is equipping a core group of volunteers with tools to discuss end-of-life choices with new audiences. In March, the group participated in the widely attended NBC Health Fairs in Baltimore and Washington, D.C.

Minnesota

Things are moving in the Midwest: Compassion & Choices Minnesota brought on 121 new supporters and successfully introduced an aid-in-dying resolution at the

Minneapolis Democratic Farmer Labor Party district caucus.

Pennsylvania

The big news is the exoneration of Barbara Mancini, a nurse who was arrested under the state’s assisted-suicide statute for allegedly participating in her father’s death. Barbara and her husband, Joe Mancini, have been grateful for the support from C&C’s Philadelphia group, whose members gathered petitions calling for the charges to be dropped and encouraged C&C to establish a legal defense fund. Group leader Stu Chalfin has invited State Senator Daylin Leach to appear at an upcoming monthly meeting to discuss the senator’s work on end-of-life issues and visit with local advocates.



Barbara Mancini with C&C’s Mickey MacIntyre



Field Organizer Andrew Bishop and Campaign Manager Marie Manis at Lobby Day



STATE SPOTLIGHT: Massachusetts

Support and Activism for Aid in Dying Swells in Bay State.

Popular support doesn’t always translate into political will – at least immediately. In March, lawmakers on the Joint Committee on Public Health essentially punted on aid-in-dying legislation. The Committee opted to further study the measure, which means aid-in-dying legislation won’t be considered until the 2015 session. The C&C Massachusetts team isn’t missing a beat, however. Advocates will spend the coming months building more public support for death with dignity in the Bay State.

In the lead-up to legislative action, the C&C Massachusetts team focused on the statehouse, educating lawmakers about the crucial need for aid in dying. C&C followed up a standing-room-only December public hearing with an aggressive

campaign for the legislation, starting with a citizen lobbying day February 26. Advocates delivered more than 7,000 petitions from state residents who want aid-in-dying legislation and brought another 40 constituents to lobby their elected representatives in person. Extensive news coverage amplified the advocates’ voices: Boston’s NPR station, *The Boston Globe* and several other state papers, and two local TV stations covered the event. And C&C deployed a savvy campaign of online, radio and newspapers ads backing the bill.

Death with dignity there is inevitable. An opinion poll commissioned by Compassion & Choices shows support for death with dignity is stronger than ever. Seventy-one percent of voters support aid-in-dying legislation, an increase of 10 points over a similar poll in 2012. That year a ballot initiative on aid

in dying was narrowly defeated. Opponents outspent supporters five-to-one, mostly on ads designed to scare people. But the new poll suggests that debate educated Massachusetts voters, finding 79 percent of them now oppose government meddling in the “private, personal decisions of terminally ill patients.” This is a whopping 19-point increase since 2012.



Advocates deliver 7,000 signed petitions to the Capitol

National PROGRAMS UPDATE

Compassion & Choices works in policy forums, among opinion leaders and in broad coalitions to grow the demand for end-of-life choice.

Experienced political pro Daniel Wilson joined Compassion & Choices as our first national & federal programs director. He is charged with expanding our successful policy initiatives and increasing C&C's collaboration with other leading advocacy organizations.

Immediately prior to C&C, Wilson was the director of policy and program development at the National Caucus and Center on Black Aged, Inc. He is an experienced nonprofit executive with a record of building relationships with policymakers on Capitol Hill and within the administration. Wilson has developed and implemented programs to assist low-income seniors through partnerships with major corporations, foundations and government agencies.

Wilson will take over as C&C's liaison to the Campaign to End Unwanted Medical Treatment, a growing coalition to help free consumers from the burden of medical treatments they don't want.

"I am so excited to be a part of a great movement, where we are educating individuals and their families to be advocates for their own healthcare," Wilson said. "When you know better, you live better."

National & Federal Programs
Director Daniel Wilson

Photo by Astrid Riecken

Campaign to End Unwanted Medical Treatment Gains Influential Supporters

It's the right issue at the right time – as prestigious organizations join the Campaign to End Unwanted Medical Treatment. New collaborators include the National Council on Aging, National Committee to Preserve Social Security and Medicare, Women's Institute for a Secure Retirement, and Catholics in Alliance for the Common Good. This expands the campaign to 19 like-minded organizations and thought leaders who honor the dignity, values and healthcare choices of every person at each stage of illness.

The campaign draws prominent experts to bring the issue to the forefront. In March, Bruce C. Vladeck, a widely recognized expert in healthcare policy and finance, Medicare, Medicaid, and long-term care spoke to the coalition. He described "Dignity-Driven Decision Making," a collaborative process in which patients, their families and clinicians work together to define care goals and determine how best to achieve them.

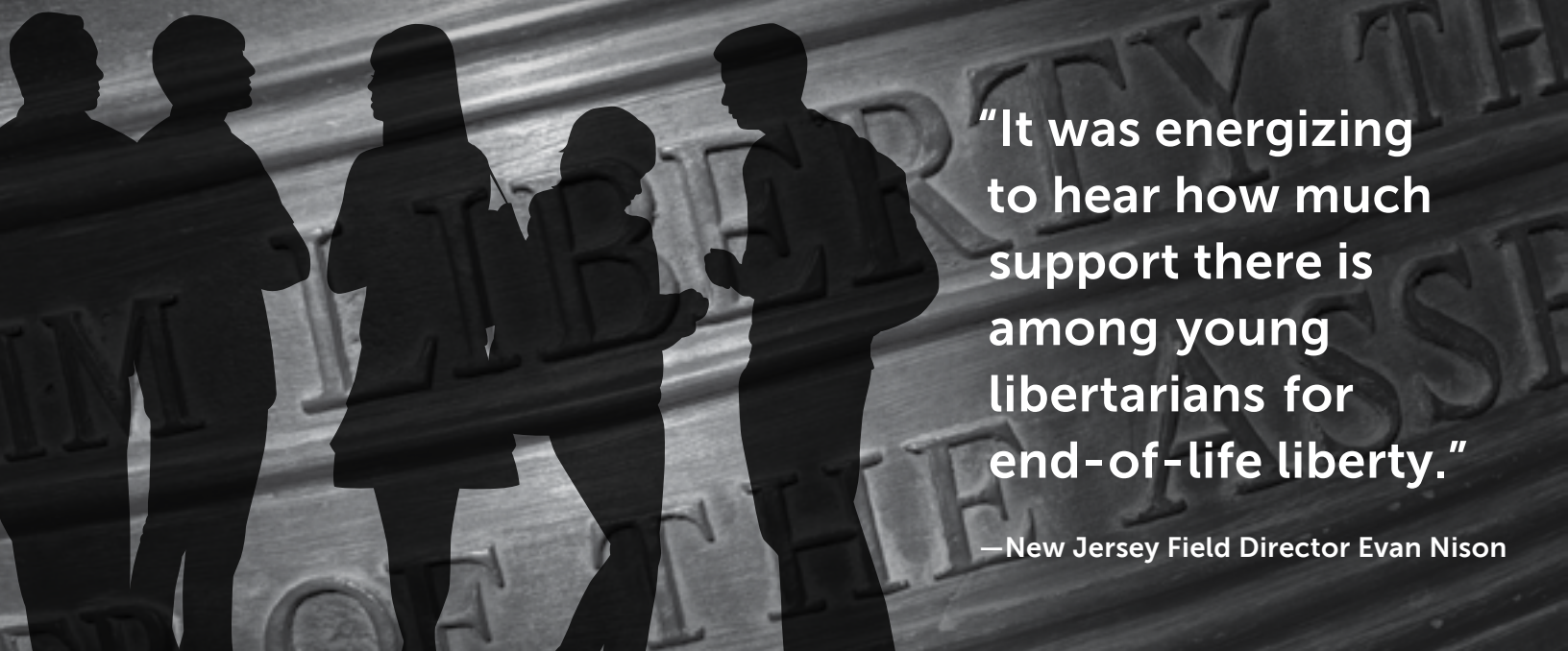
In February the National Academy for Social Insurance released its second policy brief for the campaign. The brief showcases Respecting Choices, a comprehensive program that aims to engage patients and families in informed conversations about end-of-life decision-making. "In the Respecting Choices model, advance care planning is an ongoing process of communication, integrated into the person-centered care routine and appropriately staged to the individual's state of health," wrote the brief's authors.

UMT
CAMPAIGN TO END
UNWANTED
MEDICAL TREATMENT



(L to R) Ashley Carson Cottingham, Bruce C. Vladeck and Mickey MacIntyre at the March luncheon

To learn more visit
www.endumt.org



"It was energizing to hear how much support there is among young libertarians for end-of-life liberty."

—New Jersey Field Director Evan Nison

Common Ground With New Allies

Compassion & Choices Reaches Out to Libertarian Youth

Bonding over distaste for government interference in personal decisions, Evan Nison recruited new supporters at the 2014 International Students for Liberty Conference in Washington, D.C., in February. Drawing more than 1,400 attendees, the conference is the largest gathering of young adult libertarians.

Nison, Compassion & Choices' New Jersey field director, networked at C&C's exhibit booth for the weekend event, where he talked with more than 100

attendees. He was encouraged by the students' enthusiastic embrace of end-of-life choice.

"It was energizing to hear how much support there is among young libertarians for end-of-life liberty," said Nison. "The libertarian viewpoint is significant in the national end-of-life choice discussion, and their movement could become a key ally. I'm excited to work with libertarian leaders to expand on this mutual goal."



Groundbreaking Impact Litigation

Compassion & Choices uses innovative litigation and legal advocacy to advance patients' rights and hold providers accountable when they fail to provide good end-of-life care. In the docket now is *Hallada v. Lakeland*, a case in which C&C is co-counsel and seeks damages from a hospital and nursing home whose staff members failed to transfer and honor the patient's do-not-resuscitate order.

C&C Sponsors Premier Aging Conference

For the second year, Compassion & Choices sponsored Aging in America, the American Society on Aging's conference for 3,000 of the nation's most active experts and advocates in the field.

C&C leadership attended the San Diego conference, allowing them to network in our newest campaign state. Hundreds of people discussed end-of-life issues at C&C's booth in the massive exhibit hall, with many enlisting in various state and national campaigns.

Former Director of Policy and Advocacy Ashley Carson Cottingham presented on a panel about the Campaign to End Unwanted Medical Treatment and also joined a panel of experts for a National Forum on Elder Justice.

Carson Cottingham described certain instances of unwanted medical treatment as a form of elder abuse, as older adults frequently cannot speak for themselves and receive invasive, futile medical treatment or have their end-of-life wishes ignored. She urged that the issue move up the national health-policy agenda. "As a nation we must dedicate the same type of attention and resources toward this national tragedy as we do toward eradicating child abuse and domestic violence," Carson Cottingham said. "Older Americans deserve to live their golden years free of abuse, and according to their rights and end-of-life wishes."



California State Directors Paula Taubman (L) and Christal Smith at the C&C booth

Compassion & Choices' work can't happen without you.

- ★ Join or start a local group in your state.
- ★ Help fund our programs and services.
- ★ Become a Compassion & Choices member.
- ★ Contribute your time, energy, passion and skills.
- ★ Spread awareness and help achieve our goals.

To learn what's going on near you – or to start a group in your area – visit your state's page at CompassionAndChoices.org



End-of-Life Consultation: Behind the 800 Number

Just what happens when you call 800.247.7421 seeking our free End-of-Life Consultation (EOLC) service?

This is not an emergency hotline, so first you'll reach a recorded message. Leave your information – most importantly, your phone number – and a consultant will call back, usually in one business day. That consultant can then help with a variety of concerns: end-of-life planning tips, hospice details, death-with-dignity guidance, simply an information packet or, perhaps, all of that over the course of time.

"It's rarely just one phone call. It's an ongoing, deliberate conversation about end-of-life topics," says EOLC Center Manager Jena Johnson. The conversations can continue anywhere from six weeks to several years. "Fairly frequently people call who aren't terminally ill, but they're chronically ill. Or their disease is advanced, but they're not on hospice yet. And it can transition. People may say, 'I've never heard of you – can you send information?'" in 2010.

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Expect:

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In 2012, they think something's going on, and they want to be prepared with questions for their doctor. Then the next year they call and say, 'I did have something. It's progressed.' So it can move from the most light, generic thing clear down to aid in dying with the same person."

Access our free consultation service at **800.247.7421**

Do Not Expect:

Judgment
A "magic pill"

Compassion & Choices Needs You for Our New Volunteer Engagement Program

Compassion & Choices volunteers across the nation fuel the end-of-life choice movement. The new Volunteer Engagement Program unites this rapidly growing community and streamlines the process of organizing the hundreds of active supporters eager to push C&C's work forward.

The first step for new volunteers is attending a C&C Connections webinar: an overview of Compassion & Choices, the movement and ways to get involved. Volunteers can then advance to Connections Plus for expanded opportunities. Beyond that, advocates have the option to further specialize by continuing through either the advocacy or end-of-life consultation path. More than 50 new volunteers have already participated, and a February 8 *New York Times* article featuring President Barbara Coombs Lee resulted in 45 inquiries virtually overnight.

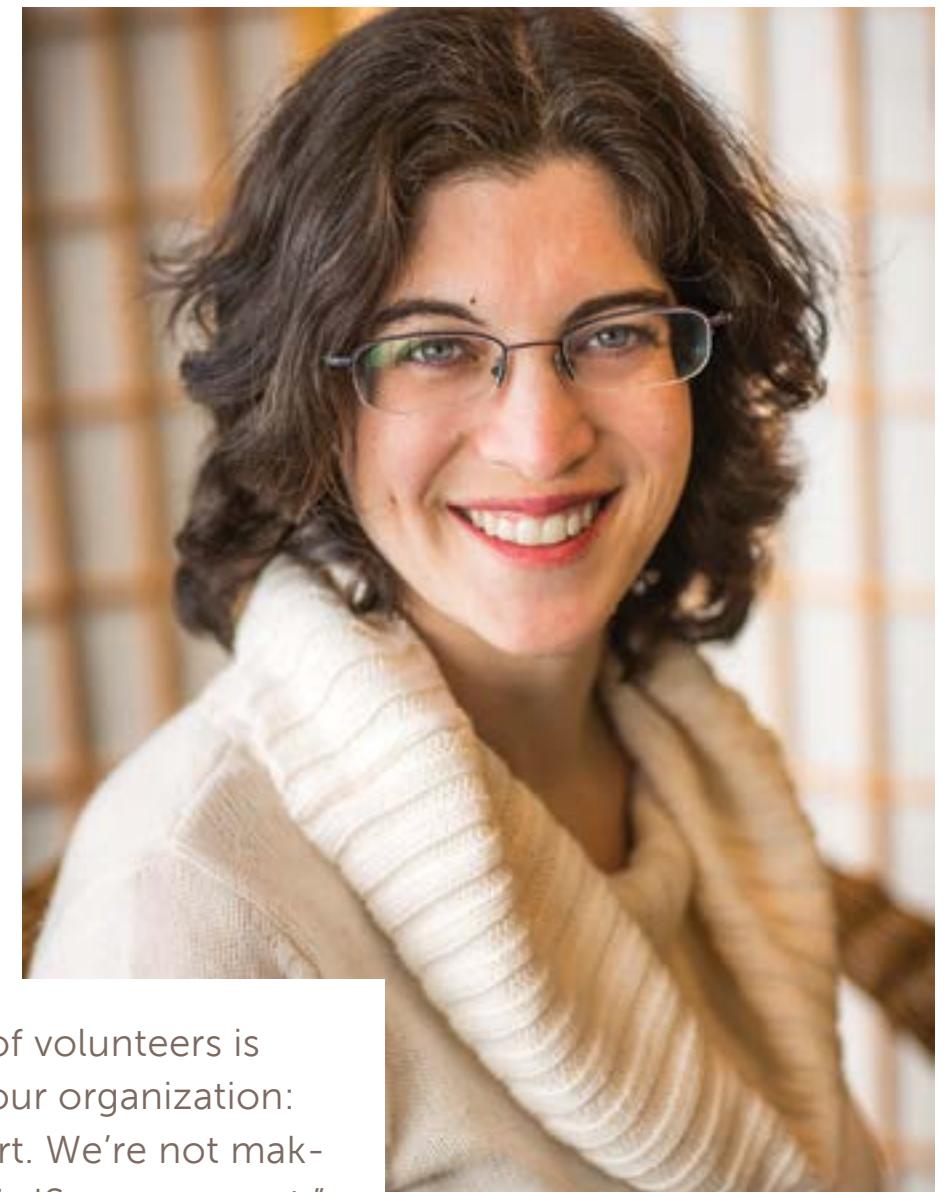
"Until now, there hasn't been a cohesive national learning process available for all volunteers, wherever they are. It's much more comprehensive than anything we've done before and much more accessible – all you need are a phone and a computer," explains National Volunteer Coordinator Marina Shuman. "The kind of people we attract as volunteers are really extraordinary. These are people who have a high level of professional skill, are very involved in their community and very passionate about the movement. As an organization we respect that."

“One of the major values of volunteers is what they symbolize for our organization: community-based support. We're not making up this movement; this IS a movement.”

Volunteers Needed!

Whether attending hearings, distributing petitions or helping expand access to end-of-life options, we can always use more help. To get involved:

Call **800.247.7421** and choose option 3



Marina Shuman, Photo by Owen Carey

FIVE QUESTIONS FOR Katy Butler

Q You make a great analogy in *Knocking on Heaven's Door*: "The default pathway to a disempowered death is a wide freeway with smooth, well-lit on-ramps and misleading signage about the final destination," while the path to a natural death is overgrown and difficult to find. What is your recommendation for changing that?

On a national level, triple the spending on palliative care and hospice so that everyone can get help with medical decision-making early on. Ask congress-people to support the "Better Care, Lower Cost Act," sponsored by Senator Ron Wyden, to improve care for people with chronic illness. Support Congressman Earl Blumenauer's effort to pay doctors better for holding honest, time-consuming, difficult conversations. And advocate to reduce payments to doctors who perform futile "Hail Mary" surgeries, tests and treatments. We have an epidemic of unnecessary suffering at the end of life!

On the personal level, start talking more honestly and realistically about the limits of medicine – in your families, and with your doctors – years before the final crisis. Less can be more. If you don't practice honesty early, you may find yourself bewildered at the door of the Intensive Care Unit (ICU), unaware that death is on its way, and fighting with your siblings about what's best for a failing mother or father.

And more doctors need to develop the moral courage to say, early on, "You are approaching the end of your life." When we are given that tough gift, our goals and expectations of medical treatment often change.

Q Had you given much thought to end-of-life issues before your parents began having health problems?

As a reporter at *The San Francisco Chronicle* in the 1980s, I spent nearly six weeks watching decision-making in an ICU. I will never forget a retired longshoreman with incurable emphysema who had a vision one night that his dead wife and many dead friends had visited him. He was ready to die. He had trouble breathing the next day, and unfortunately his niece called 911 and he ended up in the ICU. His death became a prolonged torture for everyone involved – his relatives and medical residents alike.

So I was aware we had a problem – of denial and overreliance on technology – as a society.

But before my father got sick, I thought there was "living" and "dying" and not much space in between. I didn't realize that thanks to the 911 system and a panoply of technological advances such as dialysis and defibrillators, it's very hard to die a natural death now.

Award-winning journalist Katy Butler's first book, *Knocking on Heaven's Door: The Path to a Better Way of Death*, chronicles her father's prolonged, arduous journey through the maze of modern medicine. Named "One of the ten best memoirs of 2013" by *Publisher's Weekly*, it will be released in paperback on June 10.

Q From across the country you helped your mother care for your father, becoming part of what you cleverly termed the “roll-aboard generation, the legions of long-distance daughters and the smaller contingent of sons who hoard their frequent-flier miles and often, but never often enough, roll their suitcases on and off planes.” Do you have any advice for the growing number of adult caregivers in America?

Yes! First, be forgiving of yourself. It’s a spiritual ordeal and an impossible job. Second, think in terms of two-way compassion: for your ailing relative, and for yourself. There were times when I said no to my parents, even though they were in dire straits, because I was exhausted and had other financial and personal responsibilities. Third, get help! I wish I’d pressured my brothers to do more, and delegated

other responsibilities – such as managing their investments – to professionals who were more qualified than I. The last two chapters of my book contain detailed suggestions and resources. Many of them are also listed on the open Facebook group “Slow Medicine.” And finally, help create a grassroots movement for better government support for caregivers. The Family Caregivers Alliance is a wonderful resource.

Q In that roll-aboard role, you also dealt closely with doctors and other medical professionals. Might you also have suggestions for them?

Well, they’re in a terrible bind. Most have no training in holding “the end is near” conversations. Second, they’re not paid enough to talk to us and be with us rather than do things to us. But given those constraints, I invite them to blunder ahead anyway and

hold that conversation, even if they do a less than perfect job, even if it doesn’t pay. If you really can’t bear to be honest, refer the patient to a good family medicine doctor, social worker, chaplain or palliative care program – they know how to do this.

Q Certainly your experiences affected your views on the dying process, but what about death itself?

Personally, I’m a Buddhist, but I’m also a modern American. I love my life and I don’t want to die yet. I don’t believe that my human personality or my memories or ego will survive in any form after my body dies and my brain cells blink off. There’s a reason we say to each other, “I’m sorry for your loss.” I do, however, believe that I will melt into the great unknowable beyond from whence I came, and that once I let go into that experience, I will not suffer and

I may even experience a momentary freedom from all fear, a moment of bliss.

That’s my hope at least. I’m mindful of the phrases beloved by the hospice movement, and I hope I’m ready: *Thank you, I love you, please forgive me, I forgive you, and goodbye.*

Read Katy’s full interview at <http://bit.ly/KatyButler5>.

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– Marcia Strean, Teaneck, NJ



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Maria Otero, New Mexico supporter