

compassion & choices

MAGAZINE
FALL 2014

Brittany
Maynard's
**BRAVE
CAMPAIGN**

.....

HOW-TO TIPS
for Caretakers

.....

PLUS
2014
Annual
Report

Five Questions for
**Patrick
Stewart**



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

– Ilse Gay, *New Mexico*

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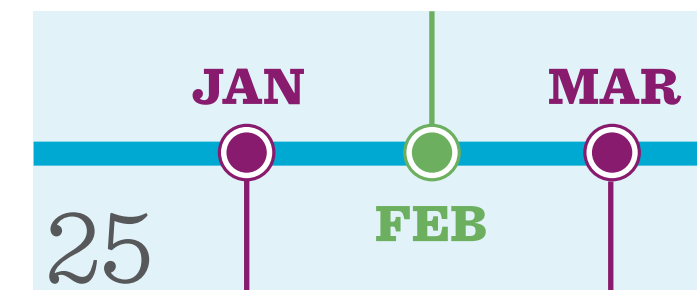
25 2014 Annual Report

We look back on a year of remarkable progress and growth.



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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.



In Your Words

"Much unhappiness has come into the world because of bewilderment and things left unsaid," wrote Dostoevsky. Indeed. When it comes to end-of-life experiences, we know what grief the unsaid can cause. At Compassion &

Choices we do our part to prevent grief arising from the unknown and unsaid. We reach out to more people than ever – to those of all ages, beliefs and backgrounds – urging them to discuss their values, priorities and what care they would want in their last days.

Starting these conversations is not really so difficult, and their empowering impact ripples through families and communities. Vicky York (p. 6) learned the ins and outs of Oregon's Death With Dignity Act when an elderly friend told her he wanted to exercise its option for a peaceful death. That knowledge eventually eased Vicky's own access to aid in dying. She hopes telling her story will make the process easier for others to navigate. Our good friend Dr. David Muller (p. 9) explains how the power and responsibility rests with each of us. Giving voice to our expectations and demands, we can change the medical industry. This issue also includes our 2014 Annual Report (p. 25), an inspiring summary of C&C's challenges, impact and victories over the past year.

Let's all keep talking about these crucial issues of dignity and control in the process of dying. Time and again, I've seen heartfelt conversation ease the terrible darkness that grows in silence. Bring up your end-of-life values with family, friends, doctors and neighbors in the coming months. I predict one year from now we'll look back to see many positive echoes of our brave words.

Barbara Coombs Lee
PA, FNP, JD, President

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"In every state across the country ... I would very much like to see ... an allowance for aid in dying."

That's what NPR host Diane Rehm told NBCNews.com after she hosted a show discussing how her husband, John, voluntarily stopping eating and drinking (VSED) to end his suffering from Parkinson's disease.

Diane and NBCNews.com also interviewed Compassion & Choices President Barbara Coombs Lee, who noted that if John had lived in Oregon he would have qualified for aid in dying. "He should have had a full range of choices," she said.

The Observer

"My husband's death was beautiful," Compassion & Choices volunteer Pam Wald told *The [London] Observer* about her husband, Ben's, peaceful passage using Oregon's death-with-dignity law. "My god, this is what dying should be for all of us."

The British Parliament is considering an aid-in-dying bill based on Oregon's model.

"The [Oregon] law," *The Observer* concluded "enjoys broad public support and has attracted little or no controversy despite vocal initial opposition from the Catholic Church and other religious groups."

VIDEOS Watch & Share!



C&C Celebrates ADA Anniversary
View at: www.bit.ly/24ada



Anita Freeman Speaks Out
View at: CompassionAndChoices.org/Anita



The Brittany Maynard Fund
View at: TheBrittanyFund.org



"Why, when 70 percent of us say we want to die at home, are we so often dying in the hospital? In America, we avoid these conversations," responded Compassion & Choices' National and Federal Programs Director Daniel Wilson on PBS' baby-boomer website, NextAvenue.org.

The story cited C&C's poll findings showing unwanted medical treatment is widespread. The author's solution? "Visit the Compassion & Choices website for resources on communicating your wishes, advance planning, writing advance directives and getting end-of-life consultations."

Kiplinger

"People aren't comfortable asserting their authority unless you've talked to them and told them exactly what you want from them," explained President Barbara Coombs Lee in a *Kiplinger Retirement Report* story entitled, "Alzheimer's Patients Can Craft Care Plans."

The author noted: "Compassion & Choices offers a 'dementia provision' that can be added to a standard advance directive to make it clear that the patient wishes the living will to take effect when dementia reaches a certain point ... The document is available at CompassionAndChoices.org."

keeping count

Patient's Orders

Healthcare providers regularly ignore end-of-life preferences or give people insufficient information to make medical decisions. Among Americans age 50 and older:



61%

support reimbursing doctors for end-of-life consultations.



65%

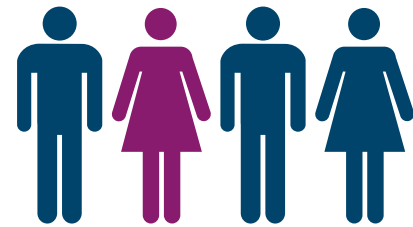
support withholding payment to healthcare providers who fail to honor their end-of-life medical wishes.

66%

say they would



“take political action to protect patients’ rights to their own choice in end-of-life care.”



1 in 4

have experienced unwanted medical treatment.

Source: 2014 Purple Insights poll of Americans over age 50.

words to live (and die) by

PALLIATIVE CARE:

Treatment focused on relieving pain and other discomfort, not to reverse or control the disease. The goal is to improve quality of life for both the patient and the family.

ADVANCED ILLNESS:

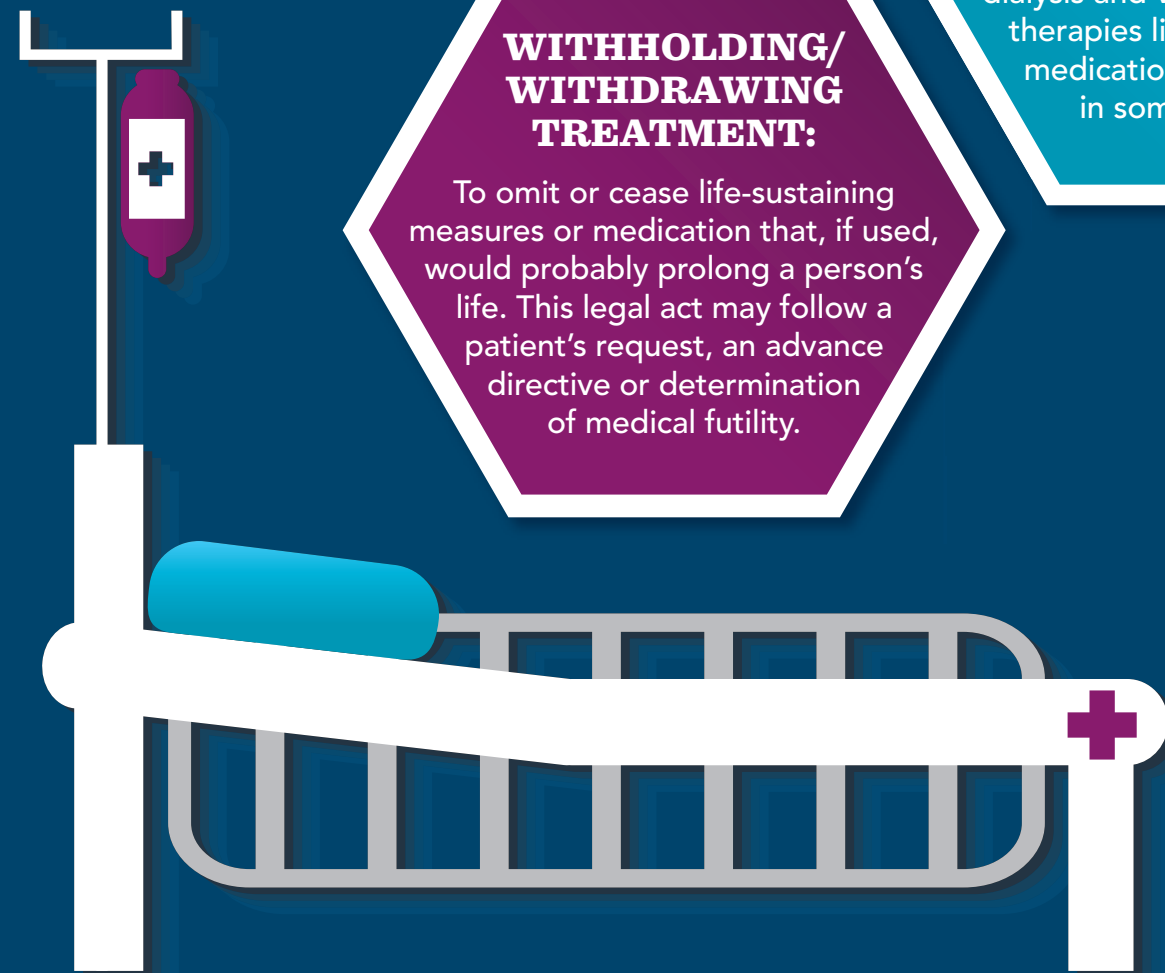
One or more ailments so severe that overall health deteriorates; decline is irreversible even with medical treatments.

LIFE-SUSTAINING MEASURES:

Any treatment that, if discontinued, would result in death. This includes technological interventions such as dialysis and ventilators, and also therapies like insulin, steroid medication and antibiotics in some situations.

WITHHOLDING/ WITHDRAWING TREATMENT:

To omit or cease life-sustaining measures or medication that, if used, would probably prolong a person’s life. This legal act may follow a patient’s request, an advance directive or determination of medical futility.





Vicky York with her son, Rick

Comes a Time

Compassion & Choices' End-of-Life Consultation (EOLC) service offers information about various options to achieve a peaceful death. We promise confidentiality. In June, EOLC client Vicky York of Portland, Ore., released us from that pledge so we would share her story publicly. She wanted others to know how to plan for the best death possible.

A 66-year-old nurse and doula diagnosed with a rare and aggressive ovarian cancer, Vicky planned to use Oregon's death with dignity law shortly after arranging with our communications team to tell her story. She knew the ins and outs of the law, having helped her good friend Cal – a "second dad" who was dying of esophageal cancer – navigate its requirements in February.

VICKY: Once Cal decided to use the law instead of undergoing chemo, the hospice social worker said, "Go straight to the Compassion & Choices people." They answered all our questions and told us what we needed to do. It was a long, exhausting process for someone as sick as he was, though. So when it became my turn, I got right on it. Cal was my role

model. I wouldn't have known anything about this otherwise, and he was an example of how to approach this choice with bravery.

Like Cal, Vicky rejected chemotherapy to treat her cancer; her medical training helped her compare its burdens with its small chance of success. She chose holistic therapies to minimize her symptoms.

VICKY: I didn't want my time filled with a body racked by chemo and all the damage that does. I wanted to go out feeling like myself for as long as I could. I've seen people with the big ugly port in their chest and neuropathy and chemo brain, and losing all of their white blood cells and their bones. It's awful. I want control of my life. I also don't want my children to



*Comes a time
when you're driftin'
Comes a time
when you're driftin'
Comes a light
feelin's liftin'
Lift that baby
right up off the ground.
Oh, this old world
keeps spinning round
It's a wonder tall trees
ain't layin' down
There comes a time,
You and I
we were captured
We took our souls
and we flew away.
We were right
we were giving
That's how we kept
what we gave away.
Oh, this old world
keeps spinning round
It's a wonder tall trees
ain't layin' down
There comes a time,
Comes a time*

"My ending, because of the law, will be gentle and not the train wreck that so many families have to deal with."

remember me as a chemo patient. I want them to remember good times, "Mom just got tired at the end, but she still looked great, and we could still have fun with her." That was important.

So because of that, because I made that choice, my son was able to fly my grandchildren out, and we had a very special six weeks. It felt like Mother's Day every day. It's just what I wanted, to have happy memories.

Vicky's son, Rick, who lives in Germany, flew to Portland again to help her complete some last practical details and be with her when she died.

VICKY: I did as much as I could before he got here – wrapping up my bank account and the cremation and all these things. But there was still a lot more to do after he arrived, and if I had chemo brain and was incontinent, it would have been a horrible experience. So far everything is just going perfectly. Hospice is great, but they give me the heavy-duty stuff, like morphine, and I don't want to go down that path either, because that's going to affect my mental state.

Even now, at the very end, we're able to have joy and humor, and go places and eat out, and we're having a blast. We are really having a lot fun. This is the way I want to go, just like this.

Having gone through the process twice, Vicky learned that even in a state like Oregon, where aid in dying is an open, available practice, it can be complicated.

VICKY: The biggest barrier is no one wants to say the word "die." I always had to be delicate. It doesn't seem scary to me, but most people are so afraid of death that it's hard to talk to anyone about it. I could not have done this without Compassion & Choices and your abundance of resources regarding Oregon's death-with-dignity law. I would say to anyone who's thinking about this: Start way in advance finding out what you need to know. My ending, because of the law, will be gentle and not the train wreck that so many families have to deal with. For me this was definitely the best choice.

I was telling Rick just this morning that maybe life here on earth is the small thing. Taking that one small step into death is taking me back into the big thing. I'm kind of excited to see. I don't have any idea what's there, but I'm ready.

I think I'll have my son turn on my favorite Neil Young tape – "Comes a Time," an album I always played when going on a long road trip – and I'll probably cry my guts out for a minute, then we'll laugh about something.

On July 2, six days after Vicky told us her story, Rick wrote: "My resplendent mother made her choice and acted on it today. She chose a good death in her home around 2:00 this afternoon, with me by her side and holding her hand." ■

Compassion & Choices' EOLC service stands ready to help, free of charge, at 800.247.7421.

Learn more about Oregon's new campaign to increase awareness of and access to the death-with-dignity law by contacting Oregon Outreach Coordinator Matt Whitaker, mwhitaker@compassionandchoices.org.

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



Dr. David Muller

Dr. David Muller is dean of medical education at the Mount Sinai School of Medicine and co-founder of the Mount Sinai Visiting Doctors Program, the country's largest physician home-visiting service. A former member of Compassion & Choices' board of directors serving for three years, he shares his ideas on how to improve the end-of-life experience in America.

"The thing I'd say is most critical is education. First, on every level in the medical profession – from medical students to residents to people who are in practice – doctors need education about palliative care, end-of-life care, symptom management, and how to have difficult discussions with patients and their families. Medical students are the ones who are the most open-minded, most progressive and most willing to change. That's who we should be reaching because in ten years or less, they'll be out there providing most of the care people in this country receive.

The other part of education is on the patient and caregiver end. There are so many resources widely available now, including Compassion & Choices' website, that I think it's incumbent on people to know they need to educate themselves. They can't rely on the healthcare system or individual physicians, just for the very fact that most doctors are too far behind the curve in terms of how to manage care at the end of life.

I feel like it cuts both ways: We would make enormous strides if there were more time and energy devoted to physician education at every step of the way,

and at the same time I think that process will be accelerated by patients or their caregivers who are coming to the office wanting more knowledge, more information, asking pointed questions and motivating their doctors to gain that information themselves. That would advance the field substantially and get patients more of the kind of care they want and need.

I feel like that's happening a lot more, partly because there's so much more accessible information. And I'm willing to bet that it's happening more in places where Compassion & Choices has had a big influence, like Oregon and Washington, where there have been very prominent public discussions about things like end-of-life care and aid in dying. I think that makes it much more evident to society that these are the kinds of questions they should be asking, these are the kinds of books they should be reading, these are the kinds of topics they should be bringing up to their doctors.

If people really want this kind of care, they're going to have to demand it. Otherwise they're leaving it to chance. And the greater the patient demand, the more the industry will respond."

"Even now, at the very end, we're able to have joy and humor, and go places and eat out ... This is the way I want to go, just like this."



My father's death truly fit the hospice experience one would expect: a loving, compassionate approach to end-of-life care and a way to live the final days in the comfort of home. Looking back, I realize now that my training as a physician is part of why the event was manageable for our family. But most caretakers are not physicians. This article explains what hospice expects from the caretakers and what the caretakers can expect from at-home hospice care.



Dr. Carolyn McClanahan



Nuts + Bolts of End-of-Life Care

by Dr. Carolyn McClanahan

FEED YOUR DYING FAMILY MEMBER

This is the time to let your loved one have whatever food she wants when she wants it. Many dying patients lose their appetite, so do not force them to eat anything. Specific tips include:

- 1.) Offer small frequent snacks that are easy to chew and swallow. Milkshakes, Jello, soups and popsicles work well.
- 2.) Sit the patient up while she is eating and drinking to decrease the chance your loved one will aspirate food or liquid into her lungs. However, aspiration is uncomfortable for only a short time when it happens. If the episode is severe, pneumonia can ensue. Although there is very little "good side" to the dying process, it is said "pneumonia is the old man's friend" because left untreated, pneumonia causes death quickly and somewhat painlessly.



Taking care of a loved one at the end of life is exhausting, scary and challenging. But if done correctly, it's a rewarding experience. By understanding the "logistics of death," you can ease the discomfort of a loved one who has meant so much in your life.

ADMINISTER MEDICATION

- » Work closely with hospice to understand how and when you can adjust medications to provide the best pain relief for your loved one. The medication instructions are not necessarily what is right for the patient.
- » Do not worry about addiction. The body develops a tolerance to pain medication. As illness progresses, it's normal to need higher doses of pain medication.

Family members of dying patients will need to do the following:

BE THERE FOR YOUR LOVED ONE

At some point, illness will cause your loved one to need around-the-clock care. To prevent fatigue and burnout, plan for reinforcements.

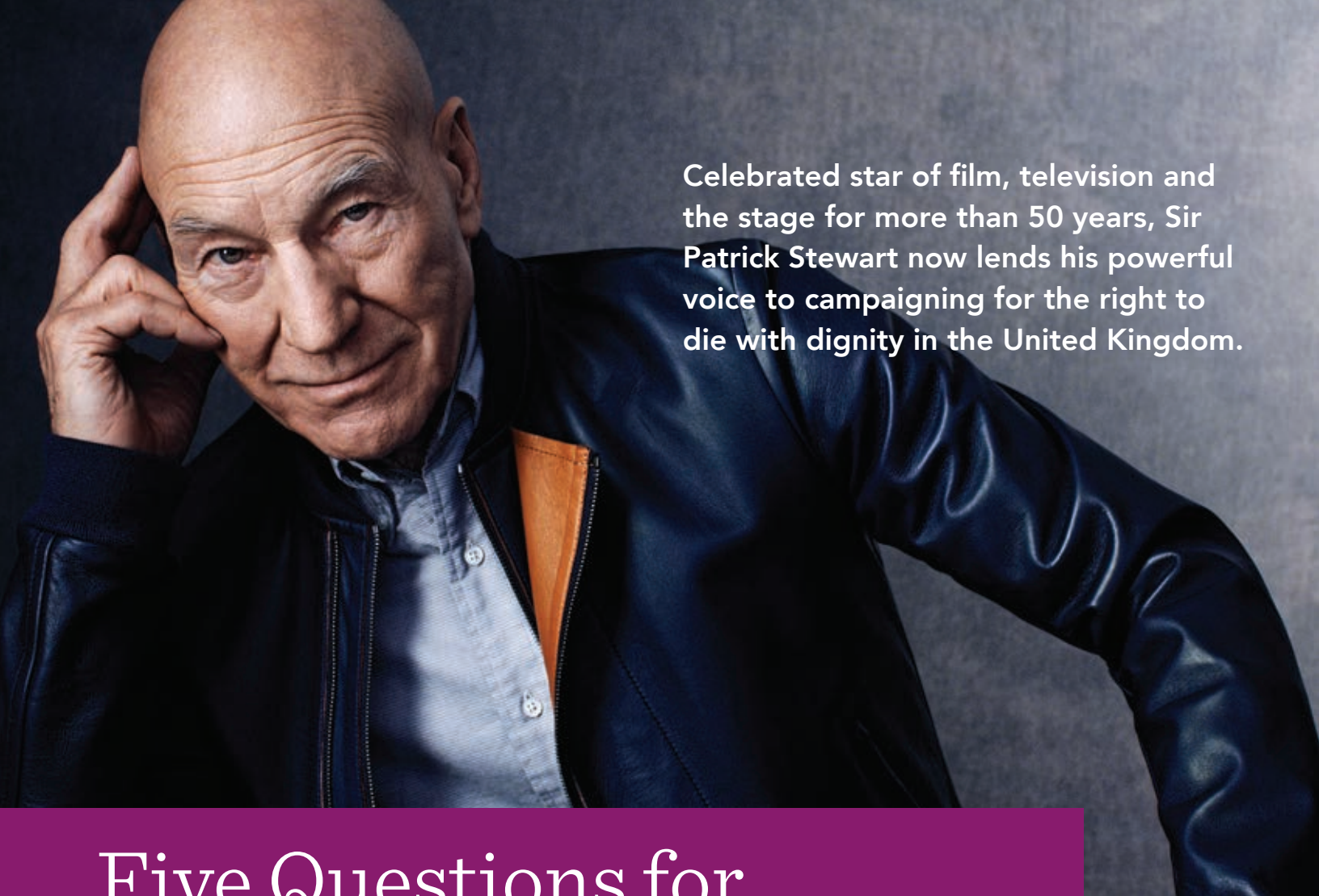
- 1.) Assign one person to do all the organization and communication.
- 2.) Mass email lists or sites such as Caring Bridge are useful. Make certain the potential caretakers understand the patient's medical status and provide them with specific details of the necessary care.
- 3.) The family needs healthy meals. Use a website such as "Take Them a Meal" to schedule food delivery from friends.

HELP WITH TOILETING & BATHING

These tasks are hard for people who are shy about their body. What is the best way to deal with them?

- 1.) Ask hospice to regularly schedule an assistant to give baths or showers.
- 2.) Illness can advance very quickly. Prepare early by obtaining a shower chair and a bedside commode.
- 3.) Transferring patients can be tricky and cause injury, so learn how to do it properly. If your loved one is heavy, ask for equipment to assist you.
- 4.) Use adult diapers early. If possible, avoid catheters since they can be uncomfortable. However, if a patient is urinating frequently, a catheter may provide more comfort.

Have more questions? When to leave the hospital? When to reach out to hospice? Where to get caregiver support?
Call our End-of-Life Consultation service for confidential, expert information at 800.247.7421.



Celebrated star of film, television and the stage for more than 50 years, Sir Patrick Stewart now lends his powerful voice to campaigning for the right to die with dignity in the United Kingdom.

Five Questions for Patrick Stewart

Q: Despite a prolific and diverse acting career, countless people – in the United States at least – will always think of you as Captain Jean-Luc Picard. Were you surprised by the durability of that role?

A: It is not just Jean-Luc Picard that has durability. All the leading characters in *Star Trek: The Next Generation* fall into that category. They were such distinctive and charismatic creations, and so vividly acted. I think that the captain stands out because of his leadership qualities, his compassion, his warmth and his courage. I hear often from all kinds of people that he was an inspiration, and that is very gratifying.



Patrick Stewart (as Captain Jean-Luc Picard) with cast of *Star Trek: The Next Generation*

Q: You've been a member of the Royal Shakespeare Company since 1966. Does classical theatre share any common ground with science-fiction blockbusters?

A: I think that classically trained actors are so often seen as suitable for blockbuster type movies – *X-Men*, *Lord of the Rings*, *Star Trek*, etc. – because they are familiar with “heightened” language and scenarios that are often above and beyond the normal. A physical presence, perhaps, and comfort with scale.

Q: Is the transition from, say, Prospero to Professor Charles Xavier difficult?

A: Every role is a separate and specific challenge. Sometimes there is an interesting carryover from one role to the next. Jean-Luc Picard and Charles Xavier were leaders of men, and so is Macbeth.

Q: As an esteemed celebrity, your activism on issues such as aid in dying, domestic violence, global human rights and support for veterans has significant impact. What motivated you to get involved?

A: Every organization I support is because of a personal connection or deep belief: Refuge and Combat Stress because of the experiences of my parents; Dignity in Dying because of the ghastly experience of a friend and his partner – and because I too am aging; Amnesty International because of my passion for worldwide human rights; and Huddersfield University because of a belief in the essential need of educational opportunities for everyone, and also because the university reconnects me with where I grew up.

Q: You're now a public spokesman for legalizing death with dignity in Britain. How, in simple terms, do you make the case for that?

A: The myriad things that medicine can do to keep somebody alive don't automatically follow as the best option. There's got to be an alternative when someone is suffering and ready to go. I have a strong feeling that should the time come for me, having had no role in my birth I would like there to be a choice I might make about how I die.



National Programs Update

Paging Doctors for Dignity

In September, Compassion & Choices launched Doctors for Dignity, an initiative to expand the increasingly critical role physicians play in our movement.

Members of Doctors for Dignity believe terminally ill patients should have choices at the end of life, including the right to choose aid in dying. They also know there is strength in numbers, and that policy-makers and medical associations listen when physicians speak.

The initiative gives doctors a platform to apply their special expertise in advocacy discussions and demand more inclusive end-of-life care and options, including aid in dying.

"Doctors' voices and credibility are critical to authorize aid in dying for terminally ill people," said Mary Steiner, project manager. "We're encouraging physicians to stand up for patients, and educate peers and policymakers on the need for death with dignity – whether by writing letters to the editor, speaking at conferences or delivering testimony."



Through Doctors for Dignity, C&C will provide information on end-of-life planning and aid in dying, and give physicians the tools they need to be more forthright and collaborative partners with their patients. Compassion & Choices aims to recruit 1,000 doctor-leaders.

If you or someone you know would like to participate, contact Mary Steiner at 808.225.4653 or msteiner@CompassionAndChoices.org, or visit CompassionAndChoices.org/what-you-can-do/get-involved/are-you-a-doctor/.



Congressman Earl Blumenauer

End-of-Life Care as a Political Issue

Two-thirds of older Americans (66%) say they would "take political action to protect patients' rights to their own choice in end-of-life care," according to a recent poll sponsored by Compassion & Choices.

This finding may bode well for bipartisan bills pending in Congress to strengthen protections for end-of-life autonomy. This legislation includes the "Personalize Your Care Act of 2013" (H.R. 1773) authored by Congressman Earl Blumenauer (OR).

The bill would provide Medicare and Medicaid coverage for voluntary consultations between patients and their doctors about advance care planning.

New IOM Report Echoes C&C's Mission



The Institute of Medicine (IOM), the nation's highest authority on health and medical matters, gave a mighty endorsement of the issues Compassion & Choices has been working to transform for decades. C&C representatives testified at multiple field hearings during the panel's research phase.

Its new report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, was released in September and examined the "mismatch between the services patients and families need and the services they can obtain." Its conclusion? End-of-life care in America is deficient at every level and requires sweeping changes.

The IOM panel included doctors, nurses, insurers, religious leaders, lawyers and other experts, and urged incentives for healthcare providers to discuss advance care planning, and to eliminate the "perverse financial incentives" for overtreating very sick people who want only pain care. "The current system is geared towards doing more, more, more, and that system by definition is not necessarily consistent with what patients want, and is also more costly," said David M. Walker, a former United States comptroller general, who chaired the panel.

"Patients don't die in the manner they prefer. The time is now for our nation to develop a modernized end-of-life care system."

– Dr. Victor J. Dzau, IOM president

Death With Dignity at 29?

Brittany Maynard, a 29-year-old from California, spent her final days outdoors – and launching a campaign for death with dignity.

Diagnosed with terminal brain cancer, Brittany took charge of her healthcare. She explored death with dignity, an option authorized in five states – but not in California. Given family support and financial resources, and because she was proactive, Brittany was able to move to Oregon. She wanted to control her dying process if it became unbearable.

She moved to Portland with her mother and husband, Dan. But she left behind her medical team, friends, pets, support system and home. She had to re-establish her life, including getting new physicians.

"Brittany Maynard is a heroine," said Barbara Coombs Lee, president of C&C. "It is abominable that our policymakers and healthcare system, through their inaction, leave terminally ill people so few options. We will shout Brittany's story from the mountaintops toward our shared goal of guaranteeing end-of-liberty for all."

Join the millions who have learned Brittany's story ...

Watch & Share
her powerful video at:
TheBrittanyFund.org



National Programs Update

Dynamic Volunteers Join C&C Leadership

Compassion & Choices (C&C) added energy and talent with three members joining its board of directors and the election of a new chair.

Longtime member Nancy Hoyt now leads Compassion & Choices' board. Hoyt, a counseling psychologist and educator who lives in Chicago and California, and her husband, Bob Hoyt, have been involved with Compassion & Choices for more than a decade.

“I relish this opportunity to use my strategic planning skills to build on Compassion & Choices’ great work to advance end-of-life choice”

– Nancy Hoyt, C&C Board Chair

The new members are:

David N. Cook, a veteran attorney from Washington, D.C.

Rev. Dr. Ignacio Castuera, a Mexican-American civil- and human-rights leader based in Claremont, Calif.

Samantha Sandler, a civic leader and conservationist who lives in New York City and Nantucket

Each new member will broaden C&C's outreach to important constituencies. Rev. Castuera, director of the Latin America Project of the Center for Process Studies at the Claremont School of Theology, will lend his voice as an experienced faith leader advocating for social justice. He welcomes the collaboration with C&C President Barbara Coombs Lee: “I know we will make a great team because I can help this great organization with outreach to the Hispanic, religious, civil- and human-rights communities.”

C&C Gains Acclaimed Legal Pro



In July Compassion & Choices appointed accomplished attorney Kevin Díaz as the new director of legal affairs. A highly regarded litigator and program manager, he comes to the organization from his previous role as legal director of

the American Civil Liberties Union (ACLU) of Oregon. Díaz was selected after a nationwide search.

Born in Perú and raised in Oregon, Díaz has spent his entire career in public interest law. “During the

past 20 years I've worked with immigrants, domestic violence survivors, students and many others in cases that have sought to protect the liberty and enhance the dignity of individuals who, for one reason or another, have been treated unfairly,” says Díaz. “I see my work at Compassion & Choices as a continuation of this work.”

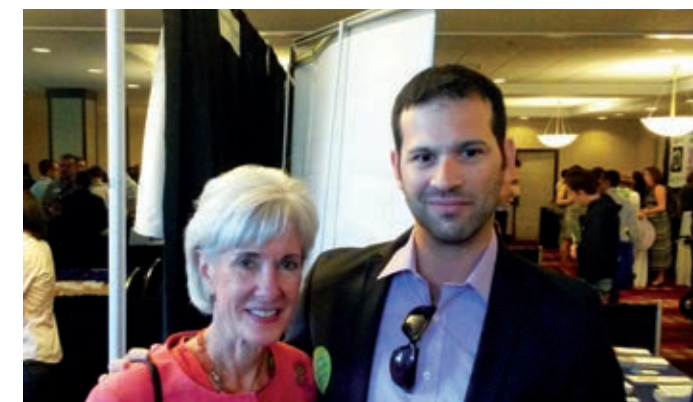
As C&C's director of legal affairs, he will head our dynamic legal affairs department, continuing C&C's groundbreaking legal advocacy to ensure that people receive care consistent with their wishes and priorities at the end-of-life. A few months into his new position, Díaz has already launched a number of key projects: “I am excited to have the opportunity to work on fundamental rights that affect us all.”

Constituency Outreach: Building Bridges, Forging Partnerships

Forming alliances across related fields is vital to building a movement. C&C representatives traveled near and far during the last few months meeting current and potential allies. “Compassion & Choices is on the cutting edge of end-of-life care and advocacy,” said Daniel Wilson, national & federal programs director. “So it's important that we be visible with these groups.”

In July, Wilson and Policy Manager Aimee Welch Champion joined the National Association of Social Workers annual conference in Washington, D.C. “Social workers are the ones who help families get back on stable ground after a crisis,” he said. “We want to make sure they have the most up-to-date information about our resources.”

Wilson and Regional Campaign & Outreach Manager Brandi Alexander traveled to Mississippi in August for the Congressional Black Caucus Political Education and Leadership Institute Policy Conference. Also in August, National Field & Political Director Jessica Grennan and Vermont State Director Linda Waite-Simpson (a member of the Vermont House) met in Minneapolis for the National Conference of State Legislatures Legislative Summit.

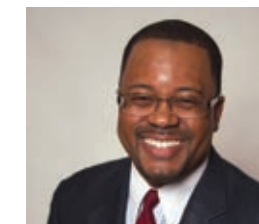


C&C's Mark Dann with former U.S. Secretary of Health & Human Services Kathleen Sebelius at the GLMA (formerly Gay & Lesbian Medical Association) conference in Baltimore

“We have an exceptionally well-connected staff who are always looking for opportunities to reach new people, strengthen alliances and promote our mission.”

In September, Wilson and Legal Affairs Director Kevin Díaz attended the Hispanic National Bar Association Convention in Washington, D.C. (Díaz is a former member of the HNBA board and past president of the Oregon Hispanic Bar Association). And Wilson and Chief Program Officer Mickey MacIntyre represented C&C at the Southeast Association of Area Agencies on Aging Annual Training Conference in Florida.

“We have an exceptionally well-connected staff who are always looking for opportunities to reach new people, strengthen alliances and promote our mission,” said MacIntyre. “Networking at conferences is a great way to find common ground and further our mission.”



top to bottom:
Daniel Wilson
Jessica Grennan
Brandi Alexander
Mickey MacIntyre



Serving up **STRAIGHT TALK** during the holidays

Football. Recipes. Black Friday and holiday sales ... Traditional topics for holiday get-togethers. But don't miss the opportunity for an important topic: end-of-life wishes.

When siblings and multiple generations come together, conditions are ideal to talk turkey about that crucial issue. Whether you want your adult children to hear your wishes or you are a baby boomer preparing to help care for your senior parents, it is valuable to begin or continue the discussion of end-of-life preferences. It is also useful for as many family members as possible to hear and understand what others want. An informed family can support the healthcare proxy and confirm they are indeed following a person's stated wishes.

There is no one way to have these discussions. Use whatever style suits your family. And while the paperwork is important, the essential thing is to get the conversation going!

4 Key Questions

Your conversation should cover these important points:

1. How do you feel about extraordinary life-sustaining treatments if you cannot speak for yourself and:
 - » You have a terminal or very advanced illness?
 - » You are permanently unconscious?
 - » You have severe dementia, as in Alzheimer's disease?
2. Do you always want all the information available? About your condition? About treatment options and their odds of success? And what success means for quality of life?
3. What will be important to you when you are dying? No pain? Hold on as long as possible? Family members present? What are your priorities?
4. Would you want to be in a nursing facility if your condition warranted?

Are You Good to Go?

We have the tools you need to guide the conversation and document the results. They're all in our **Good-to-Go Toolkit**, and they're all free.

- » A Values Worksheet to structure your decision-making.
- » Advance directive forms for every state, available online.
- » An optional dementia provision – which only Compassion & Choices offers.
- » Rider for assisted-living facility contracts. Use this to ensure your new home intends to respect your choices.

Visit CompassionAndChoices.org/advance-directive, or call **800.247.7421** to get info by mail or speak with a consultant from our **End-of-Life Consultation service**.

Conversation Starters

Here are some ways to get the conversation going. These "appetizers" will lead the way to a satisfying dialogue.

"I want to be certain you, my family, know what I would want if I ever get seriously ill and can't speak for myself. What do you think I would want? What would you say to the doctors for me? What would you want me to say for you?"

"My doctor/attorney/pastor suggested I go over my advance directive with you."

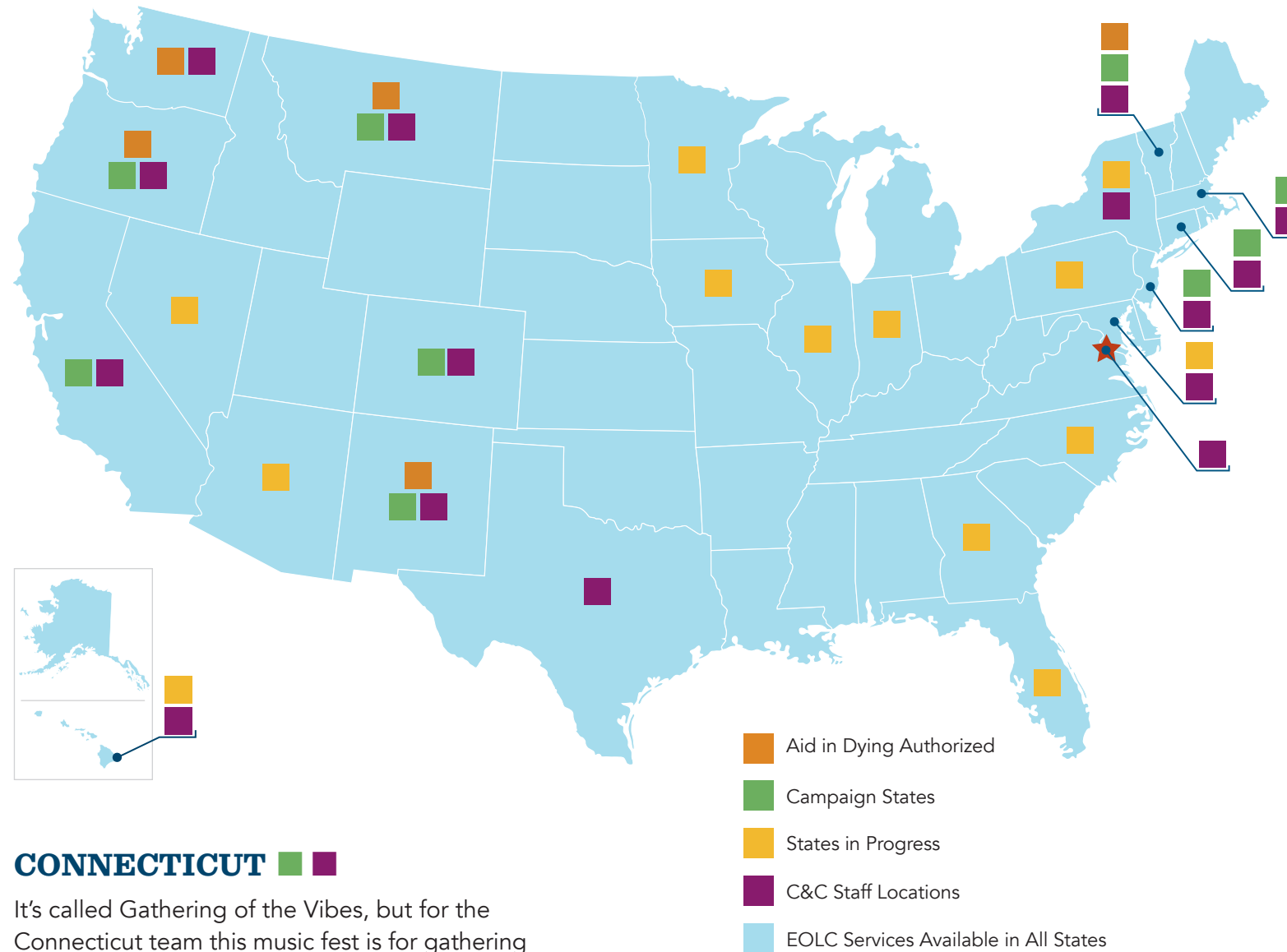
"If one of us ever had to make decisions about your treatment because you couldn't, it would be much easier if we knew what your priorities are for the end of life."

Advocacy in Action

From Rotary clubs to health fairs and farmers markets, Compassion & Choices is making friends and recruiting new activists across the country.

COLORADO ■ ■

The Colorado campaign team is laying the groundwork to support State Representative Lois Court should she introduce a death-with-dignity bill in 2015. Court has said she is inspired by an open letter her constituent Charles Selsberg published February in *The Denver Post*, just before he died from ALS. Heartbreakingly, he is not the only Denver resident who pleaded with lawmakers for compassion before succumbing to ALS. Gene Zumberge, like Selsberg, was diagnosed with ALS late in life and began to deteriorate quickly. Also like Selsberg, he chose to voluntarily stop eating and drinking (known as VSED) to control his death and shorten his suffering. Before he died in July, Zumberge wrote a letter that C&C delivered to every member of the Colorado legislature expressing that while it was too late for a law to help him, lawmakers must act to spare other Coloradans' the same fate. At an informational meeting, Rep. Court and a potential co-sponsor, Rep. Joann Ginal, explained to about 150 activists how a bill becomes law in the Rocky Mountain State, and discussed options for advancing a death-with-dignity bill.



CONNECTICUT ■ ■

It's called Gathering of the Vibes, but for the Connecticut team this music fest is for gathering signatures! More than 300 people – nurses, teachers, mothers, lawyers, sons – signed petitions expressing support for death with dignity during the annual four-day gathering. In other favorable political news, the legislator who worked tirelessly to pass Connecticut's death-with-dignity law handily won her August Senate primary. Now, if the November election goes as expected, current Rep. Betsy Ritter will be a powerful ally for C&C in the Connecticut Senate. Team Connecticut should find even more allies next year, thanks to C&C's "Ask The Question" campaign empowering voters to ask candidates where they stand on death with dignity.

At Gathering of the Vibes with C&C's Marisa Lindsey and supporters



At a Massachusetts health fair, C&C's Andrew Bishop meets supporters

MARYLAND ■ ■

Local groups in Maryland supported C&C's national outreach by staffing tables at the Gay & Lesbian Medical Association conference in Baltimore and at a meeting of the National Association of Social Workers in Washington, D.C. They have also exhibited at senior health fairs throughout the state and continue their local organizing.

MASSACHUSETTS ■ ■

You've heard the phrase, "Meet people where they're at"? Many people C&C wants to meet are at health fairs, and the Massachusetts team goes to at least one every month, all across the state. Between 50 and 100 seniors sign up or take literature at each health fair, so C&C is meeting hundreds of people proactively thinking about end-of-life care and connecting with them about advance planning. Also in the works is a "Six Words" project featuring portraits of Commonwealth residents, each expressing their support for death with dignity in six words or less. Powerful stuff! It will be something to share with new legislative allies who responded to a recent C&C questionnaire.

Massachusetts Six Word Project



advocacy in action

MINNESOTA ■

Minneapolis hosted the annual meeting of the National Conference of State Legislators, and the local C&C group provided invaluable support to C&C's Vermont Director, Linda Waite-Simpson, in staffing the C&C information table during the four-day event. According to Waite-Simpson, who also participated in the meetings in her capacity as a Vermont legislator, death with dignity is gaining real traction as a legislative priority across the country. She learned from lawmakers in two states that both are very likely to see aid-in-dying bills introduced for the first time in 2015. (The lawmakers prefer their states are not named just yet.) C&C already has a strong team in one of those states, and is planning direct talks with lawmakers in the other. Many legislators with whom Waite-Simpson spoke shared their own personal stories about why they believe death with dignity is a right everyone deserves.

MONTANA ■ ■ ■

The C&C Montana team is preparing for another legislative session that will likely see both "good" and "bad" bills introduced at the Capitol. A good bill would encode what the state Supreme Court's 2009 *Baxter* decision found: that Montanans have the right to aid in dying. A bad bill would send a doctor to prison for helping a patient exercise that right. (In 2013, C&C's strategic campaigning defeated the bill to roll back *Baxter*, the so-called "Physician Imprisonment Act.") To prepare for a two-front battle, C&C Montana is spending the fall growing its grassroots and recruiting individual Montanans with personal stories to share with legislators and the media.



A new supporter signs up at a Montana farmers market

NEW JERSEY ■ ■ ■

It's a numbers game in the Garden State. From counting votes in the legislature to tracking phone calls made and signatures collected, the C&C team spent the summer and fall laser-focused on getting an aid-in-dying bill passed in the Assembly. For example: Three is how many news stories there were about a university poll showing increased support for death with dignity in New Jersey. Two is how many Rotary Club presentations the team held in one key district. Two hundred is how many people participated in a telephone town hall with the bill's sponsor. And zero is the number of vacations the New Jersey team took this summer. With a vote possible any time after Labor Day, slowing down was not an option. An additional success? The New Jersey Libertarian Party is now firmly behind the state's death-with-dignity campaign.

NEW MEXICO ■ ■ ■

Aid in dying is legally protected in Bernalillo county through a court ruling sought by C&C and New Mexico ACLU. While that case proceeds, the C&C team is aggressively pursuing a "Start the Conversation" campaign to make sure New Mexicans know about all their end-of-life options. C&C action teams across the state are encouraging people to talk to their loved ones and doctors about their end-of-life care. C&C is also providing education for doctors to help them talk to their patients about end-of-life options including aid in dying. With newspaper ads, film screenings and public talks, C&C is educating New Mexicans about their "fundamental right," as the judge described it, to choose aid in dying.


OREGON ■ ■ ■


C&C's campaign to increase meaningful access to end-of-life choice in Oregon is really getting off the ground. An additional organizer joined the staff, and key initiatives are underway including activation of five outreach teams across the state and a speakers' bureau. Also, a C&C Continuing Medical Education program is in the works, and C&C also presented to members of Oregon's Long-Term Care Office on how to protect end-of-life choice for people in long-term care facilities.


PENNSYLVANIA ■

Forty people showed up when the Philadelphia C&C group hosted a meeting featuring State Senator Daylin Leach, Dr. Fred Goldstein, Dr. Howard Hurtig and Barbara Mancini. Mancini is the Philadelphia nurse unjustly charged in 2013 with "assisted suicide" in her father's death, a charge dismissed a year later. Now a dynamic advocate (and natural communicator) for death with dignity, Barbara Mancini intends to meet with lawmakers in her home state and throughout the country.

Keep up with all the latest updates:

 Like us on Facebook

 Follow us on Twitter (@compandchoices)

 Sign up for our monthly e-newsletter at info@CompassionAndChoices.org

VERMONT ■ ■ ■

Our state field teams work long and hard to get death-with-dignity laws passed, but that's hardly the end of their work. The next phase is making people familiar and comfortable with the law and how to access it. The "How to Talk to Your Doctor About Act 39" campaign relies on volunteers to reach out to doctors, hospices and hospitals, and find residential facilities where C&C can offer public education.

C&C's Brandi Alexander (left) with State Senator Daylin Leach, Dr. Fred Goldstein, Dr. Howard Hurtig and Barbara Mancini in Philadelphia



state spotlight

California

Death-With-Dignity Campaign Takes Off in Golden State

Compassion & Choices has built an A+ California team with an ambitious goal: to make death with dignity an open, accessible and legitimate medical practice in the Golden State.

Toni Broaddus leads the campaign. A respected Stanford-educated attorney and social-justice advocate, Toni has furthered ballot measures, state and federal legislation, and impact litigation. Charmaine Manansala brings national experience as our California campaign political director.

The first phase of our campaign is urging people to take action in their communities. Advocates are speaking out and collecting signatures at area house parties, farmers markets and other public gatherings.

Deploying a county-by-county strategy, the field team is recruiting and training activists across the state. Currently we have organizers in Los Angeles, Santa Barbara and San Mateo Counties. They have gathered thousands of petitions in support of death with dignity,

Nearly two-thirds (64%) of Californians support the right of mentally competent, terminally ill patients to choose a peaceful approach to death



hosted tabling and educational events, and built relationships with allied organizations. They've also begun meeting with local officials and prosecutors.

We are also discussing end-of-life choices with influential and philanthropic members throughout the state. Many express relief to know we are working to bring Californians the same peace of mind in their last days as their Oregon neighbors have enjoyed for 17 years.

Patricia A. González-Portillo, a veteran journalist and former editor of *La Opinión*, the largest Spanish-language newspaper in the United States, leads communications for the campaign. Her team is working with supporters to ensure their stories and voices resonate in mainstream, social and multicultural media throughout California.

Great things are happening in the Golden State; visit CompassionAndChoices.org/California to get involved!

Sixty-two years after her grandmother died in agony from cancer, Californian Anita Freeman helplessly watched her sister suffer for five long weeks from unbearable pain, also from cancer, before dying in July. Anita hopes sharing these tragedies will motivate others to help Compassion & Choices bring death with dignity to her state.

Hear more from Anita through a video and personal journal at: CompassionAndChoices.org/Anita

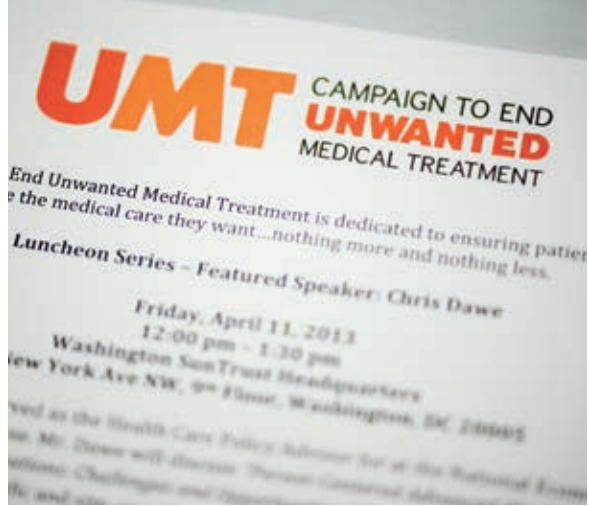
If you have an end-of-life experience to share, contact California Outreach Director Christal Smith at csmith@compassionandchoices.org. Your stories are key to illustrating why California needs the death-with-dignity option.



Annual Report 2013-14

A Year of Remarkable Progress

Thanks to your generous support, Compassion & Choices celebrated incredible achievements during the past year. Together we are building a diverse and vibrant social movement to make end-of-life choice an option for terminally ill, mentally competent adults throughout the nation. Here are some highlights you helped make possible.



After 17 years of carefully stewarding the Oregon Death With Dignity Act, Compassion & Choices Oregon launched the Oregon Access Campaign to expand awareness of end-of-life options in the nation's first death-with-dignity state.

Compassion & Choices formed a powerful coalition of 20 allied organizations to launch the Campaign to End Unwanted Medical Treatment, formalizing years of C&C consumer advocacy. Tools include EndUMT.org, where supporters can learn more and take action, and policy papers and briefings with prominent experts that routinely draw up to 70 organizational attendees.



A Pennsylvania judge dismissed all charges against Barbara Mancini, who was arrested for "assisted suicide" in the death of her 93-year-old father one year earlier. C&C advised Mancini's legal team, organized community protests, and generated nearly 500 national and local news stories, columns and editorials about the case. C&C supporters contributed more than \$25,000 to the Compassion & Choices Action Network Legal Defense Fund to defray Mancini's six-figure legal bills. "Today I am a free woman – thanks in no small part to Compassion & Choices," said Mancini.

C&C Massachusetts delivered more than 7,000 petitions to state legislators demanding passage of aid-in-dying legislation. The lobby day generated press coverage and amplified activists' voices. Despite broad statewide support, the bill stalled when lawmakers recommended further study.

For the first time, *The New York Times* used the term "aid in dying" to describe our movement. "Aid-in-Dying Movement Takes Hold in Some States" declared the front-page story. It marked a huge victory for Compassion & Choices, which works closely with reporters to ensure accurate language.

DEC 2013

In response to opposition provocation, Vermont's attorney general issued a statement to pharmacists assuring them they are authorized to fill prescriptions for aid-in-dying medication. The state is implementing its historic law, the first in the nation to pass through a legislative body.

JAN 2014

New Mexico became the fifth jurisdiction to recognize aid in dying as a legitimate medical practice, coming in a lawsuit filed jointly by C&C and the ACLU of New Mexico. In her landmark ruling, Judge Nan G. Nash wrote, "This court cannot envision a right more fundamental, more private or more integral to the liberty, safety and happiness of a New Mexican than the right of a competent, terminally ill patient to choose aid in dying."



FEB 2014

C&C launched the Volunteer Engagement Program to expand opportunities for supporters to advocate locally for end-of-life choice. C&C recruited nearly 700 active volunteers.

MAR 2014

More than 200 people packed a hearing room in Connecticut to speak out for aid-in-dying legislation. C&C mounted an aggressive legislative strategy to capitalize on majority support in the state; tactics included the End-of-Life Choice: Six Words project, a photo exhibit of supporters displayed in the capitol building. C&C's team generated ample positive press coverage and editorials, with *The Hartford Courant* noting C&C's "sophisticated digital strategy."



MY Healthcare.

National Healthcare Decisions Day is April 16th

MY Decisions.

MY Day.

In recognition of National Healthcare Decisions Day, C&C advocates and volunteers promoted end-of-life planning at events from coast to coast. C&C distributed a toolkit with talking points and sample media materials to raise awareness and encourage discussion.

Death with dignity became part of the debate in Maryland's gubernatorial campaign when Democratic candidate Heather Mizeur voiced her support and Lt. Gov. Anthony Brown, who won the primary, reiterated his support.



At a Los Angeles event, C&C officially launched its massive statewide effort to establish death with dignity in California within five years. The California campaign has more than ten campaigners on the ground and a long-range grassroots strategy that emphasizes building strong volunteer networks, forging alliances with stakeholders and reaching out to community leaders.



The Health and Senior Services Committee of the New Jersey Assembly voted 8 to 4 in favor of the Aid in Dying for the Terminally Ill Act. C&C polling shows 63 percent of New Jersey voters support the bill. Debate resumed in the fall.



On social media, we quadrupled our number of Facebook fans and increased our reach by 190%.

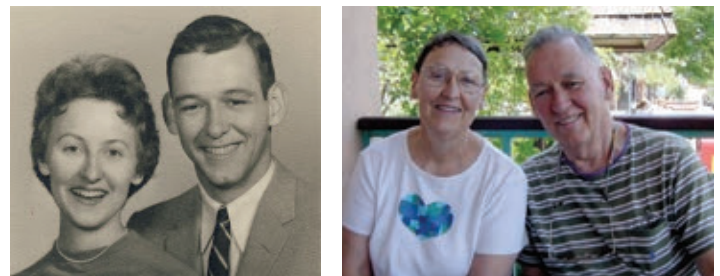
APR 2014

CharityWatch named Compassion & Choices one of the top U.S.-based charities. Among charities that provide services for the terminally and chronically ill, only C&C achieved "Top Rated" status.



MAY 2014

Longtime C&C supporter Dr. Rebecca Moss published an essay about her husband's struggle with dementia, emphasizing the importance of adding a dementia provision to one's advance directive. Moss' op-ed, which was picked up in more than 30 newspapers, generated record-breaking new requests to C&C's End-of-Life Consultation phone line, including 62 in one day.

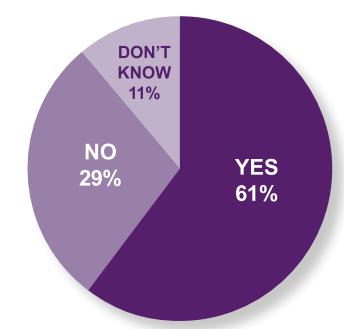


JUN 2014

Vermont celebrated the one-year anniversary of passage of the Patient Choice and Control at End-of-Life Act. C&C worked closely with allies at Patient Choices Vermont to create an infrastructure for healthcare providers to offer counseling to ensure successful implementation of the new law.

JUL 2014

C&C released a national poll showing that 25 million people a year experience unwanted medical treatment. Six out of 10 people surveyed support reimbursing doctors for end-of-life consultations.



AUG 2014

C&C launched Doctors for Dignity to give doctors a platform to engage in advocacy and work toward more inclusive end-of-life care and choice.



SEP 2014

Combined Statements of Financial Position

June 30, 2014

ASSETS

Current Assets:

Cash and cash equivalents:	
Operating	1,228,316
Investments	575,437
Unconditional promises to give, net of allowance	2,567,927
Investments	13,503,884
Prepaid expenses	82,868
Beneficial interest in charitable remainder trusts	193,189
Total current assets	18,151,621

Property, Equipment and Improvements, at Cost:

Furniture, fixtures and equipment	534,414
Leasehold improvements	55,602
	590,016
Less accumulated depreciation and amortization	328,235
Total property, equipment and improvements	261,781

Other Assets:

Unconditional promises to give, net of current portion	5,080,000
Intangible assets	3,014
Deposits	35,789
Total other assets	5,118,803
TOTAL ASSETS	23,532,205

LIABILITIES AND NET ASSETS

Current Liabilities:

Current portion of obligations under capital leases	12,763
Accounts payable	424,514
Accrued payroll and vacation	430,185
Accrued expenses	1,500
Total current liabilities	868,962

Long-term Liabilities:

Capital lease obligations, net of current portion	14,717
Gift annuity payments due	446,236
Total long-term liabilities	460,953
Total liabilities	1,329,915

Net Assets:

Unrestricted:	
Operating	21,842,989
Net investments in property, equipment and improvements	234,301
Total unrestricted net assets	22,077,290
Temporarily restricted	125,000
Total net assets	22,202,290
TOTAL LIABILITIES AND NET ASSETS	23,532,205

Combined Statements of Activities & Changes in Net Assets

For the Year Ended June 30, 2014

TOTAL UNRESTRICTED

Revenue and Other Support:

Contributions	16,774,745
Membership fees	146,702
Foundation revenue	199,235
Restricted gifts	125,000
Investment income, net of expenses	322,498
Realized and unrealized gain on investments	1,205,545
Gain on disposal of equipment	278
Other Income	522,443
Total revenue and other support	19,296,446

Expenses:

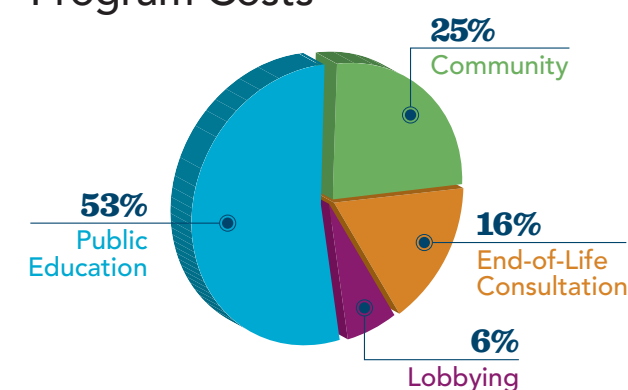
Programs	9,344,938
General and administrative	1,161,513
Fundraising	934,206
Total expenses	11,440,657
Increase in net assets	7,855,789

Net Assets:

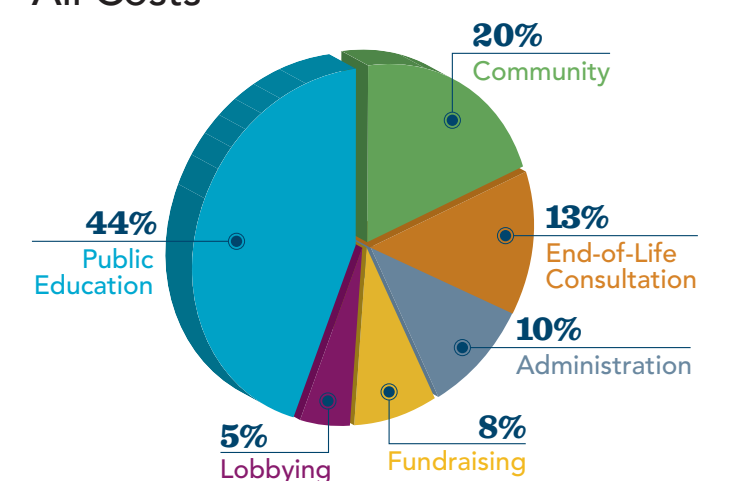
Total net assets, beginning	14,346,501
Net assets, ending	22,202,290

Costs for the Year Ending June 30, 2014:

Program Costs



All Costs



Thank You to All Our Donors

As always, Compassion & Choices is profoundly grateful to the many thousands of donors who give so generously to the mission we serve. From gifts of five dollars to grants in the millions, each is vital to our success – and existence. Though we've only listed donors here of \$1,000 or more, Compassion & Choices appreciates everyone who is committed to our mission. You are our foundation!

Totals are for gifts made in FY 2014 (July 1, 2013 – June 30, 2014)

Circle of Choice (\$50,000+)

Anonymous (4)
Apple Pickers Foundation
Mr. and Mrs. William Biggs
Ms. Norma M. James
Lynn Loacker and Jack Loacker
Open Society Institute
Mr. Charles A. Ranney
Mr. and Mrs. John Retynski
Rodgers Family Foundation
Mrs. Margaret L. Stevens

Circle of Comfort (\$25,000+)

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Ms. Beth Tietze Lowd
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Circle of Care (\$5,000+)

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Mrs. Diane Dow Wilsey
Mr. Paul R. Q. Wolfson
Wyss Foundation
Zalec Familian & Lillian Levinson Foundation
Ms. Merla Zellerbach and Mr. Lee Munson

Circle of Love

(\$2,500+)

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 Berkshire Taconic Community Foundation
 Mr. John Bernstein
 Mrs. Penny Richardson Borda
 Mr. James Fishback Boreham
 Dr. Ernestine Schlant Bradley
 Mrs. Ruth Hale Buchanan
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 Mrs. Sarah Gamble Epstein
 Mr. and Mrs. David N. Cook
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 Ms. Linda Joyce Greenhouse
 Mr. John H. Gribbin
 Mr. and Mrs. William Guensche
 Ms. Kathleen Gueymard
 Mr. Philip D. Harvey and
 Ms. Harriet Lesser
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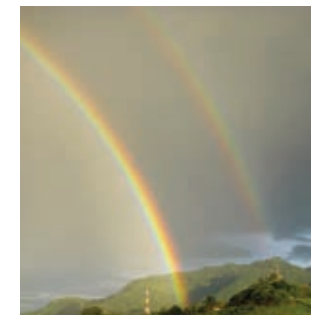
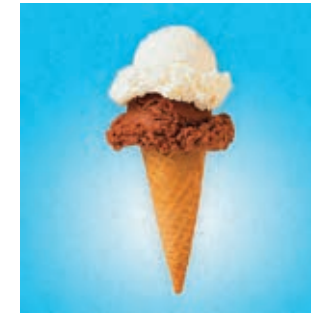
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