

A black and white photograph of Leonard and Susan Nimoy. Leonard is on the left, wearing glasses and a dark turtleneck. Susan is on the right, wearing glasses, a dark turtleneck, and a dark jacket. They are both smiling.

compassion & choices

MAGAZINE
SUMMER 2016

What Dying
Doctors Want

.....

C&C Pushes Plan to
Improve End-
of-Life Care

.....

Fight for Patient
Rights Reaches the
Supreme Court

Five Questions for
Susan Nimoy

*On Life and Terminal Illness With Her
Late Husband, Actor Leonard Nimoy*

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

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

Be a **CHAMPION** for Choice

“

Death with dignity has been an essential goal of mine for over 40 years, and my financial support of Compassion & Choices will continue onward. The monthly giving program is best suited to my commitment.”

– Bruce Ramsay with his wife, Sylvia Gough
Naples, FL

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



Still Changing After All These Years

This June marks my 20th anniversary with what has evolved into today's Compassion & Choices. While so much has changed within the organization — astounding growth, a broadening mission — I find the change we've helped

foster out in the world over that time even more remarkable. C&C has made enormous progress in advancing medical aid-in-dying laws, promoting hospice and palliative care, and raising awareness about the importance of advance planning and communication in order to approach life's final months with a peaceful, secure state of mind. The national dialogue on such matters has grown exponentially from year to year. How gratifying that is!

This issue of Compassion & Choices Magazine highlights the many ways that after two decades we are more impactful and better equipped to help than ever before. With vastly expanded programming, C&C's service, education and advocacy components are far greater and more influential than the small huddle of dreamers — pioneers all — imagined back in 1996.

I thank all of you for your help to get us this far. Let's keep pushing for the merciful, meaningful changes that are such a source of pride for us all.

Barbara Coombs Lee
PA, FNP, JD, President

compassion & choices

MAGAZINE

Chief Editor
Sonja Aliesch

Art Director
Bhavna Kumar

**National Director,
Marketing & Communications**
Rabia Shirazi

Contributors
Kim Callinan
Sean Crowley
Gwen Fitzgerald
Barbara Coombs Lee
Jane Sanders
Annie Singer
Katie Wingo

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

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

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words & pictures



"I don't believe in a God that would want me to suffer and struggle to death," Elizabeth Wallner told *60 Minutes*.

A Compassion & Choices volunteer who was raised Catholic, Elizabeth supported California's medical aid-in-dying law so she could have the option to end years of suffering from cancer.

She also wants to spare her 20-year-old son, Nathaniel, the burden of seeing her suffer.

"... I can only take so much, and my family can only take so much."

bit.ly/cbs16summ



"An individual will fill out an advance directive, but unless they bring a copy with them, the provider will likely not know, or see, it exists," Compassion & Choices Chief Program Officer Kim Callinan told USA Today.

The story noted one of C&C's proposed fixes:

"Legislation introduced in the Senate [the Care Planning Act by Mark Warner, D-Va., and Johnny Isakson, R-Ga.] includes provisions that could push health facilities to ensure compatibility across different health records for advance directives."

bit.ly/usat16summ



"Compassion & Choices, a medical aid-in-dying advocacy group that pushed for the [California medical aid-in-dying] law, recently launched a bilingual campaign, a speaker's bureau and a free hotline for people who want more information," reports CNN.com. "The group also has a confidential consultation program for doctors."

"The organization is sending out volunteers to saturate the state and get the word out," said Compassion & Choices National Director of Policy and Programs Kat West.

bit.ly/cnn16summ

Pittsburgh Post-Gazette®

"Medicare beneficiaries currently are not eligible to receive concurrent palliative and curative treatments," noted Compassion & Choices Federal Affairs Director Mark Dann and C&C consultant Barbara Mancini, RN, in a Pittsburgh Post-Gazette op-ed.

"In January, Medicare expanded a pilot project in which Medicare beneficiaries can receive hospice care and concurrent curative therapies at up to 140 test sites around the country ... Compassion & Choices has consistently advocated for this type of innovative project."

bit.ly/pitt16summ

words to live (and die) by

Compassion & Choices leads the national effort to increase access to the full range of end-of-life options, and to allow everyone to direct their treatment according to their own needs and values. Several principles guide our work to transform disease treatment and end-of-life care to achieve this.

OPTIONS

People need and want a range of options at the end of life; they should be informed of and have access to those options. We empower individuals and families to make informed end-of-life plans and decisions, and we work to pass laws and policies that establish and respect expanded options.

PERSON-CENTERED CARE

Healthcare, especially end-of-life care, should be centered on and directed by the individual, in partnership with doctors and other healthcare providers, and supported by loved ones.

INFORMED DECISION-MAKING

Many say the words. We work to make it a reality. End-of-life decisions belong to individuals, who should be able to choose what is right for them and their families based on their personal preferences and beliefs — and only after receiving full information about the possible outcomes of their choices. We feel strongly that the nation's laws and medical system should establish and protect broad end-of-life options, allow for transparency and honor the decisions people make.

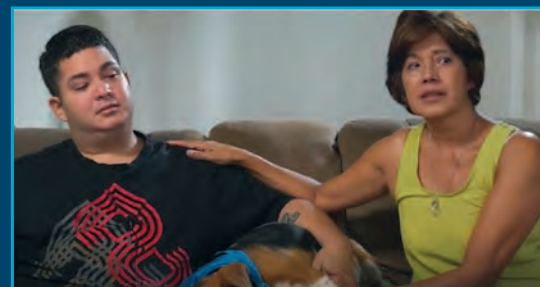
video highlights



Bilingual Video by Puerto Rico Supporter Calls for Aid-in-Dying Laws Nationwide

Terminally ill 35-year-old Miguel Carrasquillo, a native Chicagoan living in Puerto Rico with his parents, discusses why he wants better end-of-life options for himself and all Americans.

Watch it in English: <https://youtu.be/Ehxovh3qhal>
or in Spanish: <https://youtu.be/wn7pseNRkqU>



Dr. David Pratt: 10 FAQs About Medical Aid in Dying

New York palliative care physician Dr. David Pratt explains what aid in dying is and why it's an option needed for residents of his state.

Watch it here: <https://youtu.be/v8Xqk0whyqA>



keeping count

Do as I Say ...

Asking your doctor the right questions — such as whether the treatment they are prescribing is one they would choose for themselves — is an important step to avoiding unnecessary procedures in your final days.

Nearly

1 in 3 Medicare recipients had **major surgery** in the **last year of life**,

1 in 5 in the **last month** of life,

1 in 10 in the **last week** of life,

While

9 in 10 doctors say they would **reject aggressive treatment** at the end of their own lives.

Harvard School of Public Health
2011 study; Stanford University
School of Medicine 2013 study

Serendipitous events and significant encounters led Compassion & Choices President Barbara Coombs Lee to help transform end-of-life policy and practices in America. At her 20th anniversary with the organization, Barbara leads an exploding movement to change how Americans approach death. She sees the past with nostalgia and gratitude, and the future with optimism.

Heart & Soul of the Movement

by Gwen Fitzgerald

Barbara Coombs Lee witnessed many deaths — peaceful, protracted and tortured — during her 25-year career as a nurse and physician assistant. But one significant encounter with a dying patient implanted the central tenet of her future life's work. A young man dying of leukemia was nearing death and remained estranged from his parents. Barbara twice encouraged him to reconcile before he died. "Everyone has their own agenda for me," he admonished her. "But this is my death, and I'll do it my own way." That interchange solidified for her whose values and priorities must always be preeminent at life's end: the dying individual's.

Eventually the demands and repetition of clinical medicine set in, and Barbara earned a law degree. Her first job in the legal field was staff member to a committee of the Oregon Legislature. In 1991 Sen. Frank Roberts introduced a medical aid-in-dying bill to authorize qualified terminally ill adults to obtain medication to die peacefully. The legislation seemed uniquely poised to advance: a highly respected sponsor

who himself was terminally ill and married to the sitting governor. Nevertheless, lawmakers did not give the bill even a serious hearing. The cursory legislative process made clear whose values and priorities lawmakers respected. "The political environment and healthcare policy were not oriented to individual needs; they were oriented to HMOs, healthcare institutions, provider organizations and big insurance companies," Barbara says. "Then, as now, the needs of people are given short shrift."

But serendipity alighted. Among the naysayers, one voice resonated — and, again, changed the course of Barbara's career. A minister testified that his entire denomination supported aid in dying because it reflected the inherent worth and dignity of every individual, a central tenet of the faith. Soon after, Barbara found her church home with a Unitarian Universalist (UU) congregation in Portland, Ore.

The following year she joined the UU group writing the aid-in-dying ballot initiative language, and became one of three co-petitioners and its primary spokesperson. Surprising even its authors, the initiative squeaked by to passage in 1994. The law then withstood repeated legal challenges, and voters reaffirmed it by a large margin three years later.

Eighteen years after it took effect, the Oregon Death With Dignity Act is the model for bills in dozens of legislatures and several countries. Extensive data about the law provides indisputable evidence of its safety and benefits. Today, support for such laws is greater than 70 percent nationally.

"Without a passionate engagement with life, I could not do this work. And doing this work enables me to passionately engage with life," Barbara states to describe how she sustains herself in a job inundated with death.

She balances the demands of her career with healthy, mindful living: a vegetarian and Pilates devotee who gardens, spends time with children and grandchildren, and chooses enriching travel, including to Egypt this spring.

Two Decades of Increasing End-of-Life Autonomy

Working in the courts, legislatures and communities, Compassion & Choices, our affiliates, our people and our predecessor organizations have led the significant advances in the movement to expand options and improve care for the end of life. These include:

Advance Care Planning and End-of-Life Support

- » Developed the first national end-of-life consultancy program (1993).
- » Pioneered the use of and transformed advance directives from strictly legal documents to a values-based approach for communicating end-of-life priorities.
- » Helped secure the new Centers for Medicare and Medicaid Services rule to reimburse doctors for advance healthcare planning discussions (2015).

Palliative Care and Pain Management

- » Established palliative sedation as a constitutionally protected medical practice in the U.S. Supreme Court decision *Vacco v. Quill* (1997).
- » Established critical principles for pain management in *Bergman v. Eden Medical Center* (2001).
- » Made education in pain and palliative care a condition of licensure with passage of California bill.

Medical Aid in Dying

- » Compassion & Choices President Barbara Coombs Lee coauthored Oregon's pioneering Death With Dignity Act (DWDA), the model for aid-in-dying legislation nationwide and beyond (1994).
- » Protected Oregon's DWDA against 12 years of continuous attack from every branch of government, state and federal: the U.S. Department of Justice, two court battles at the U.S. Supreme Court, a repeal effort by the Oregon Legislature and a referendum to the voters of Oregon.
- » Advanced *Glucksberg v. Washington* (1997) to the U.S. Supreme Court. The landmark ruling encouraged individual states to engage in a debate about medical aid in dying.
- » Secured authorization and implemented medical aid in dying in five states: Oregon, Washington, Montana, Vermont and California.



Barbara's graduation from Cornell University School of Nursing (left); with her mother, who died in Barbara's home under hospice care in 1998 (middle); and today (right)

But it takes a special mindset to lead this work for decades — and to provide the emotional lift to staff, supporters and advocates who ride the highs and lows of a social change movement.

Barbara inspires her team with beautiful, motivational statements at key moments: holidays, victories and, of course, deaths. She composed this poignant message for C&C staff in June 2015, after the End of Life Option Act passed the California Senate:

"... You could not commit your hearts and souls to this work if you were not also willing to get your hearts broken, if you were not willing to put your love for justice and mercy on the line, knowing sometimes the world is unjust and merciless ... I'm so proud of how we celebrate together, congratulate each other and revel in our victories as a family. And I am also proud of how we can support and comfort each other if need be." She grounds herself in the joy and wonder of life. "You have to carry both rapture and grief. You make

"Without a passionate engagement with life, I could not do this work."

a life big enough to hold it all," she says. "I believe the best way to cope with life's transience is by extracting all the sweetness from every day.

"Some of the worst deaths I've witnessed have been people resisting to the end, and suffering terribly. I've wondered whether extreme resistance comes from never really living, not loving or laughing enough."



Barbara officially started with the organization as interim president of Compassion in Dying, one of C&C's predecessor organizations, in 1996. The annual budget was \$173,000. She traveled from her home in Portland, Ore., to work in the organization's Seattle office several days per week. To economize, she slept on the floor in her sleeping bag. Today, Compassion & Choices has a \$17 million annual

budget, offices in five states, more than 85 employees and an impressive list of accomplishments. (See *Two Decades of End-of-Life Autonomy* on page 7)

Like her own career, Barbara sees the future of the organization evolving with opportunities that arise with growing needs of aging and dying Americans, and her contributions are only one part of that. "I strive to apply the talents I have the best way I can every day," Barbara says. "I am grateful to see results. And I am gratified to see this growing organization and movement. It's been my privilege to accompany Compassion & Choices on this journey."

To congratulate Barbara on her 20-year anniversary or read more about her impact, visit CompassionAndChoices.org/Barbara20.



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

Rx for
PEACE
at Life's End



Dr. Charles Hamlin

Retired surgeon and Compassion & Choices board member Dr. Charles Hamlin understands not only our complex medical system but also how much effort it can take to die peacefully. The knowledge gained witnessing his father's gentle death and his mother's difficult, prolonged passing inspired him to promote the importance of preparation to ensure peace at the end of life.

"We have little or nothing to say about how we start our lives, but we most certainly ought to work to successfully navigate how it might end. The landscape of the last chapter should be a spiritual journey, but it often becomes a technological flail. Our hopes and our fears are so often obscured by an understandable anxiety about the unknown that broaching this topic with family, doctors and pastors is avoided and decisions delayed.

Yes, medicine's miracles are wonderful, but death's democracy embraces us all. So the notion of achieving a good death, a destination we all intuitively seek, remains ill-defined and essentially out of reach. We as individuals and we as a society can do better.

I admire very much what Compassion & Choices stands for. The complex puzzle of the end of life is one we all want to solve. My wish is that we all work on assembling this puzzle, and ultimately achieve autonomy with end-of-life decisions. To use the words of Elizabeth Kubler-Ross: 'Watching a peaceful death is like seeing a beautiful shooting star.' Reach for it."

Advocacy in Action

Endorsers, messengers, allies: These are some words that describe the essential role that other groups and individuals play in Compassion & Choices' work. Consumer brands use spokespeople, presidential candidates have surrogates, and businesses form associations — it's how you strengthen your voice and expand your reach when you're working toward any kind of change.

Take, for example, C&C's federal agenda for achieving person-centered, family-oriented end-of-life care. There, our efforts are strengthened by like-minded policy and advocacy organizations. One is the Leadership Council of Aging Organizations (LCAO), of which C&C is among its 72 nonprofit organizations who share the goal of providing a voice for seniors and their families in the ongoing national debate on aging policy. C&C's voice is amplified by our partnership with these allied groups.

C&C is also a proud member of the Leadership Conference on Civil and Human Rights, whose 200 members seek to protect and empower all people, which is exactly C&C's goal in the context of end-of-life healthcare. Participating in this coalition has connected us with representatives of disability rights groups and faith groups whose partnership can help us build greater understanding with new audiences.

The Campaign to End Unwanted Medical Treatment is a very special national coalition comprised mainly

of organizations representing consumers, and C&C's work has benefited tremendously from being a founding member of this 19-member coalition. Many of the groups represent aging Americans. One important recent achievement was getting Medicare to reimburse doctors for talking about advance planning with their patients.

In our state campaigns to advance aid-in-dying laws, allies and endorsers are indispensable, especially when they come from the healthcare field. Our Doctors for Dignity program is one way C&C enables physicians to tell legislators, journalists and their fellow doctors why they believe aid in dying is a good medical option for some terminally ill people.

In New York we recently launched an effort inviting our supporters to ask their doctors to join the campaign to help pass medical aid-in-dying laws. We also have a growing number of physicians adding their names to a sign-on letter for legislators in Albany.

In Massachusetts, three physicians who have been advocating for the state's Compassionate Care for the Terminally Ill Act published a letter to the editor in Vital Signs, the monthly publication of the Massachusetts Medical Society. In it they wrote, "Doctors and medical societies should debate and reconsider their positions on aid in dying." They also asked whether the Massachusetts Medical Society's opposition to aid in dying truly represented the views of its membership. Then, in the next issue, another Massachusetts doctor published a letter saying he sees opposition to aid in dying waning, especially among older doctors. He concluded by echoing the call for the Massachusetts Medical Society to reconsider its position.

State medical societies are chapters of the American Medical Association, which officially opposes aid in dying. (This, despite the fact that the majority of American physicians, the American Medical Women's Association and the American Medical Student Association all support aid in dying.) There are local chapters of these societies, and they, too, can change their positions. In Colorado, for example, both the Boulder and Denver medical societies have endorsed similar legislation for medical aid in dying; this could eventually encourage the state chapter to reverse its opposition.

Medical societies function as the voice of physicians in every state, and their opposition makes passing an aid-in-dying law difficult. When they take a neutral or positive position, however, it changes the dialogue. That is what happened in California last year: When the California Medical Society withdrew its opposition to the End of Life Option Act, serious consideration began, and the bill was on the governor's desk in a matter of months.



C&C's Doctors for Dignity campaign manager Dr. Rebecca Thoman (right) at the American Medical Women's Association meeting in Miami with its executive director Eliza Chin (middle) and C&C supporter Dr. Barbara Toeppen-Sprigg (left)

Now in California, C&C is partnering with other groups of medical professionals to make sure the law is properly implemented and widely available to eligible terminally ill Californians. Notably, when C&C held a press conference announcing the launch of our California Access Campaign, it was hosted by the California Primary Care Association (CPCA). The CPCA is among a group of community health centers, hospitals, medical and hospice facilities, and nonprofit organizations. Now they are helping to ensure that Californians know medical aid in dying is an available and trustworthy end-of-life choice.

**Ask Your
DOCTOR**

We are taking the Ask-Your-Doctor campaign nationwide! Visit our website to learn how to ask your doctor to support aid in dying:
CompassionAndChoices.org/ask-your-doctor



advocacy in action



Dr. Robert Olvera of Orange County, California, has been an outspoken advocate for the End of Life Option Act as a doctor and as a father whose daughter died a terrible death from leukemia

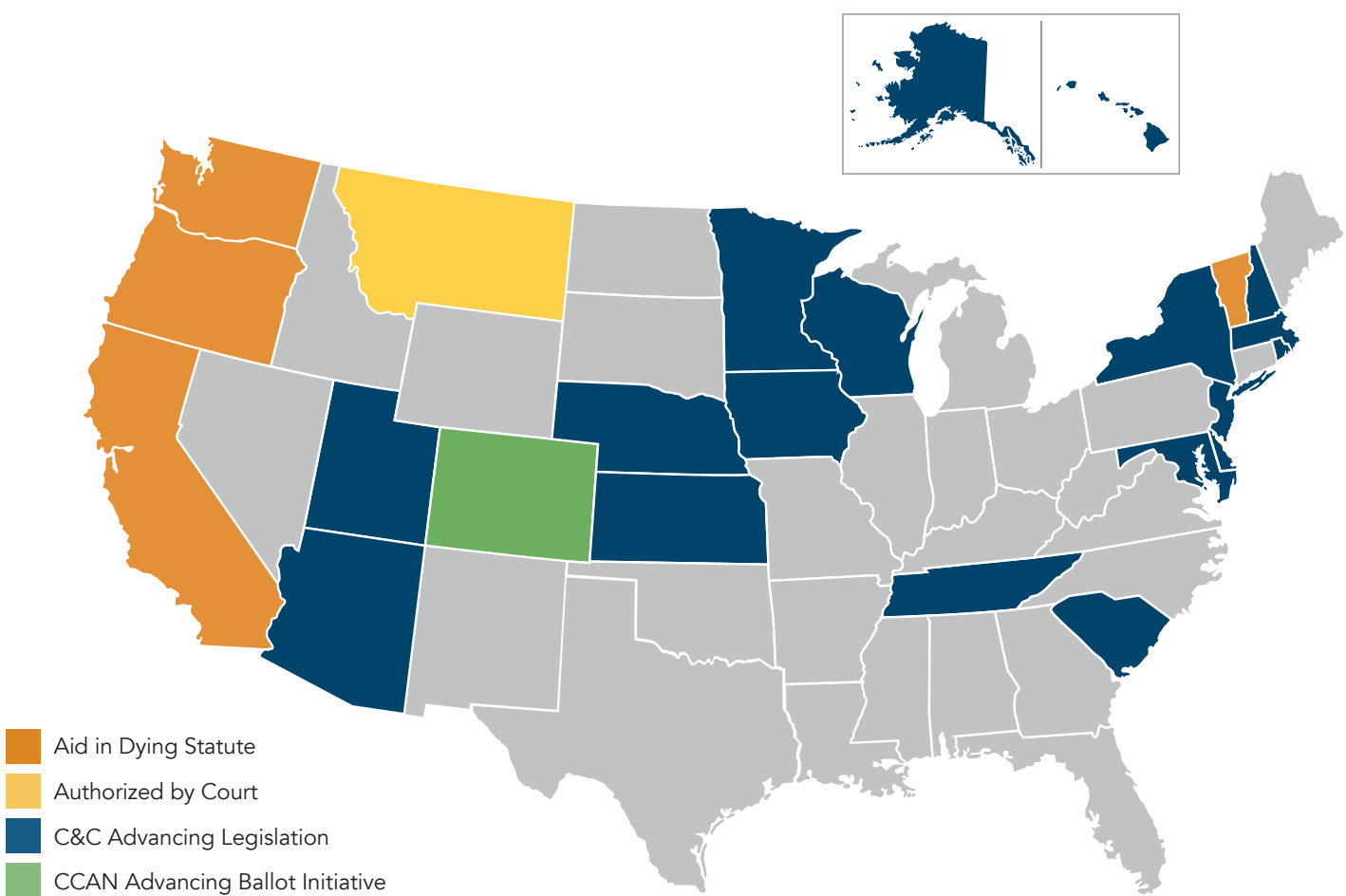


Barbara Mancini, a nurse whose father's DNR was not honored, now speaks to audiences nationwide about the importance of end-of-life autonomy

High-profile individuals are also particularly effective messengers and validators. Jeanne Phillips, popularly known as "Dear Abby," is one of C&C's most passionate supporters. She has spoken at conferences and other events, and was an outspoken advocate in her home state of California for the End of Life Option Act. She has said that because of deaths in her own family, and hearing so many painful stories from readers of her column, she has concluded that people who are facing a terminal illness should be able to make their own end-of-life choices that make sense for them and their families.

Archbishop Emeritus Desmond Tutu said he came to support aid in dying after watching his good friend, Nelson Mandela, endure multiple painful hospitalizations before dying at age 95. Tutu put it simply: "People should die a decent death."

More recently, award-winning radio talk show host Diane Rehm took a public position in support of medical aid in dying after watching her husband's drawn-out, painful death. His end-of-life suffering from Parkinson's disease was so severe, he opted to refuse all fluids and nutrition to bring about his own death. Rehm writes in her new book about the weeks leading up to his decision: "I could do nothing but listen as he railed against a medical and judicial system that prohibited a doctor from helping him die, even knowing that what awaited him was prolonged misery, further decline, and, to his mind, loss of dignity." Because she shared her late husband's frustration with a system that will not permit a dying person to pass mercifully, Rehm became a very outspoken and persuasive messenger for medical aid in dying.



Of course, fame is not a prerequisite for being an effective spokesperson on end-of-life issues. Barbara Mancini, a nurse who lives in Philadelphia with her family, is a great example. Her arrest and prosecution on the charge of aiding the attempted suicide of her dying 93-year-old father, and the subsequent dismissal of her case, has led her to become a fierce advocate for end-of-life autonomy.

Mancini is one of thousands of Americans who think we should all have more power over how we live our final days, months and years who partner with C&C to help get that message out. If you share that view and want to become a messenger too, let us know!

SHARE Your Story

IF YOU HAVE A STORY that makes you believe strongly that we should be able to choose our own care at the end of life, tell us about it here: CompassionAndChoices.org/stories

Georgia

Talk about a multi-pronged attack: The Georgia chapter of Compassion & Choices has developed initiatives to advance the full breadth of C&C's mission simultaneously.

Validated by personal experience, Chapter President Perry Mitchell is passionate about urging people to complete an advance directive and pay special attention to designating their healthcare advocate. Mitchell learned the importance of this when his 99-year-old mother, Sara, had a medical emergency.

“Having an advance directive is one of the most loving things you can do for your family.”

Mitchell believed he was Sara's appointed advocate, but it was Sara's husband. Initially Mitchell and his stepfather disagreed on a physician-recommended major operation. After Sara said, “Let me go,” her husband agreed to cancel the surgery — but only two hours before it was scheduled to occur.

Chapter board members have reached nearly 1,000 Georgians with their advance-planning presentation. “Having an advance directive is one of the most loving things you can do for your family,” Mitchell declares.

Additionally, the chapter convenes three public meetings per year, hosting expert speakers on end-of-life topics. Dr. John Laszlo, oncologist and former vice president for research of the American Cancer Society, spoke in May about his book “Understanding Cancer,” including how to talk with your doctor about a diagnosis and understand what your physician says.

The chapter also is building its strength for future success by assembling a coalition of organizations that support end-of-life policies. Board members are calling representatives of more than 35 local organizations to “see how we can work together.”

Finally, the chapter is laying the groundwork for aid-in-dying legislation based on Oregon's Death With Dignity Act. Mitchell identified areas of support in the state, and in 2015 he and another board member visited dozens of lawmakers to gauge their views. They continue to seek meetings with legislators, educate them on the bill and recruit supportive community members for future legislative activity.

To get involved with the Georgia chapter, please visit CompassionAndChoices.org/georgia and provide your email and ZIP code.

National Programs Update

Introducing the Compassion & Choices National Speakers Bureau



Dolores Huerta

Compassion & Choices introduces our new National Speakers Bureau that provides expert speakers to audiences across the country. Demand for speakers is at an all-time high with California's law coming on line and new federal policies surrounding end-of-life care being introduced. “It is our stories, more than any data or statistics, that resonate with people. Stories illustrate why end-of-life care issues are so deeply important,” explains Nancy Hoyt, Compassion & Choices board chair and member of the speakers bureau.

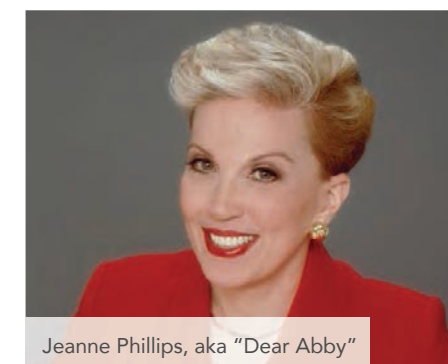
The Compassion & Choices National Speakers Bureau responds to the growing demand for greater education surrounding all things end of life by offering speakers including civil rights icon Dolores Huerta; esteemed advice columnist “Dear Abby”; husband of Brittany Maynard, Dan Diaz; and Compassion & Choices National Medical Director Dr. David Grube, to name a few.

Topics include end-of-life healthcare and medical aid in dying, federal policy landscape surrounding end-of-life care and choice, hospice and palliative care, and navigating end-of-life care.

To learn more about the Compassion & Choices National Speakers Bureau or to request a speaker for your event, visit CompassionAndChoices.org/speakers.



Dr. David Grube



Jeanne Phillips, aka “Dear Abby”

“The National Speakers Bureau is a necessary step in our efforts to meet the rising demand for expert speakers on a broad range of end-of-life topics nationwide.”

- Kat West, national director of policy and programs for Compassion & Choices

Federal Policy Progress



Americans will benefit from new federal policies taking effect this year to improve end-of-life care.

A new Medicare federal regulation addressing issues long championed by Compassion & Choices will pay doctors for talking with patients about their goals and values for end-of-life treatment.

And Medicare is expanding a pilot project, called the Medicare Choices Model, in which beneficiaries can receive hospice care **and** concurrent curative therapies at 140+ test sites nationwide.

These policy reforms demonstrate our nation now is more willing to honestly talk about and address important end-of-life issues.

Compassion & Choices has also endorsed two bipartisan bills in Congress to better Americans’ end-of-life experience:

Enhancing Clinician-Patient Communication and Advance Care Planning:

» Care Planning Act – S.1549
This bill creates a Medicare benefit for patient-centered care planning for people with serious illness. It will reimburse a team of healthcare professionals for advance care planning. The plan would reflect the informed choices made by patients in consultation with their healthcare team, faith leaders, family members and friends. The bill provides resources for the public and professional education materials about care planning. It provides clear rules on developing systems for advance directives to be included in electronic medical records.

Strengthening the Delivery of Person-Centered Family-Oriented Care:

» Hospice CARE Act – H.R.2208
This bill ensures medical professionals will be more involved in the certification of ongoing eligibility for hospice care and that people are receiving care that is in line with their goals and values. It allows medical professionals to conduct face-to-face encounters with patients to determine continued eligibility for hospice care before the first 60 day recertification period and each subsequent recertification.

Stay tuned! We are in the process of analyzing other federal bills to be introduced later this year to determine whether we will endorse them.

Patient Rights at the Supreme Court

In late March, Compassion & Choices joined hundreds of demonstrators in front of the U.S. Supreme Court to stand up for patients’ rights as the court heard arguments in a case, *Zubik v. Burwell*, that could impact end-of-life care for millions of Americans.

In February, C&C National Director of Legal Advocacy Kevin Díaz and Jon B. Eisenberg, counsel of record for Horvitz & Levy LLP, filed a “friend-of-court” brief in *Zubik*. Plaintiffs in the case include Catholic-affiliated organizations who argue that certain provisions in the Affordable Care Act violate religious freedom.

“A similar argument could be made by a healthcare provider who morally objects to a medically sound healthcare decision by a patient or surrogate, or to a provision in an advance directive such as a do-not-resuscitate order or a prohibition against the use of a ventilator or feeding tube,” said the brief.

Last year, 25 million Americans visited the emergency rooms of or were admitted to 639 Catholic hospitals. More than one-third of these facilities are the only hospital in their area.

The court has not yet reached a decision. But in an unusual move, it ordered further briefs from both sides.

Jon Eisenberg (left) and Kevin Díaz (right) at the steps of the U.S. Supreme Court



Dr. David Schrier

Doctors for Dignity Believe in Individual Choice

Dr. David M. Schrier is a medical oncologist and hospice director in Denver, Colorado, and deals with dying patients on a regular basis. He joined Compassion & Choices’ Doctors for Dignity initiative and efforts to expand end-of-life options in his state, he says, because “I firmly believe that there should be an option for a conscious, compassionate choice to end your life with peace and dignity.”

While Colorado has not yet authorized medical aid in dying, it remains a key campaign state for C&C. In February, Dr. Schrier testified at a hearing before the State House. When asked about the experience, he

continued on pg 18

Californians Have a New Option

Last October, California Governor Jerry Brown signed the End of Life Option Act into law. On June 9, the law took effect, expanding the healthcare choices of more than 38 million people. Compassion & Choices has been working hard at implementing the law and has already had some major successes in doing so.

Large healthcare organizations like Kaiser Permanente, Sutter Health and the University of California Health System have turned to Compassion & Choices to learn about what they can do to best accommodate the law. Kaiser Health consulted with us on developing a patient navigation program and has partnered with several of our advocates who are accessing the law themselves to track their progress to see how they can improve the process over the next year to make it as trouble-free as possible.

Our esteemed medical directors have provided education to several healthcare associations including the California Academy of Family Physicians, the California Medical Association, and the California Hospice and Palliative Care Association about the new law.

We're also committed to public outreach with our "Talk to Your Doctor" initiative. Twenty-four action teams have successfully converted to access campaign teams that are doing presentations across the state to empower people to begin having conversations with their physicians and healthcare team to make clear that expanded end-of-life options matter to them.

To learn more about accessing medical aid in dying in California, visit EndofLifeOption.org.

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noted how surprised he was to hear arguments minimizing other people's suffering. "You can't reach out to another person and understand their suffering until you're having your own pain and suffering. Everyone's pain and suffering is unique to them, and they're entitled to make their own decisions."

Another argument against aid in dying that comes up regularly is the notion that these laws go against the Hippocratic Oath every doctor takes. Dr. Schrier disagrees, saying that his interpretation of "do no harm" is "do not prolong suffering." He went further, saying, "I believe some of the treatments we do actually inflict suffering."

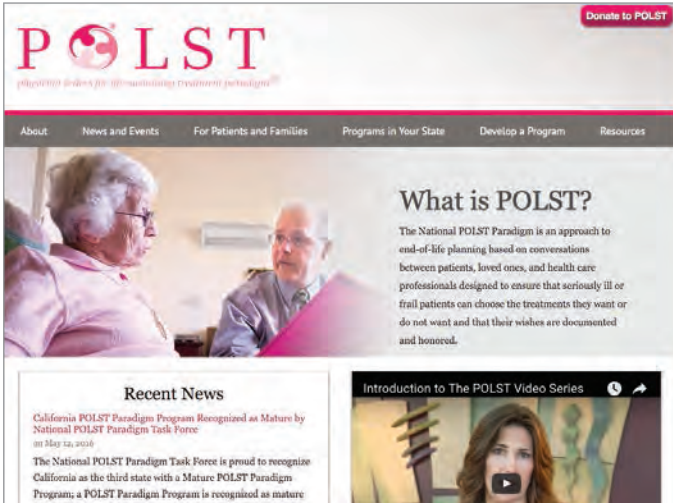


Encuentre Los Recursos en Espanol

Find some of our most useful materials translated into Spanish at CompassionAndChoices.org/informacion

What's a POLST?

A POLST, or a physician's orders for life-sustaining treatment, is a lesser-known and understood planning tool offered in many states. Compassion & Choices' end-of-life consultants are tasked with informing people at all stages of life, in different regions of the country, about their end-of-life options. End-of-Life Consultant Wendy Haile offers some great insight into this tool as states continue to develop protocols of their own.



www.polst.org



CompassionAndChoices.org/information

Here's what you should know:

- » A POLST is different from an advance directive. State-specific advance directives can (and should) be filled out by adults at any stage of life.
- » Having a POLST (or MOLST, MOST, etc.) in place is not for everyone. A POLST should be filled out only for an individual with a life-limiting illness whose physician believes they may not live beyond a year.
- » A POLST allows individuals to document the treatments they would or would not want.
- » A POLST can hold more weight than other advance-planning documents since it is signed by a physician following a conversation between the individual and their doctor.
- » The original POLST form resides with the patient or care facility. A copy can be kept with the healthcare team.

You might consider talking to your physician about the form. Because POLST is an end-of-life planning tool your doctor may be surprised to hear you bring it up if you're not seriously ill. But you're well within your rights to find out more about POLST.

POLST forms are not yet available in every state. You can see what is available in your state by visiting www.polst.org.

Find Compassion & Choices' end-of-life materials and learn more about our consultation program at CompassionAndChoices.org/information

To Face Death With Integrity

The following is excerpted from the epilogue Dr. Lucy Kalanithi wrote for the best-selling memoir her husband, Dr. Paul Kalanithi, began after receiving a terminal cancer diagnosis at age 36. A promising neurosurgeon, Paul died last year survived by his daughter, Cady, and Lucy, who had his book published posthumously.



Dr. Lucy Kalanithi and Dr. Paul Kalanithi with their daughter



Paul confronted death — examined it, wrestled with it, accepted it — as a physician and a patient. He wanted to help people understand death and face their mortality. Dying in one's fourth decade is unusual now, but dying is not. "The thing about lung cancer is that it's not exotic," Paul wrote in an email to his best friend, Robin. "It's

just tragic enough and just imaginable enough. [The reader] can get into these shoes, walk a bit, and say, 'So that's what it looks like from here ... sooner or later I'll be back here in my own shoes.' That's what I'm aiming for, I think. Not the sensationalism of dying, and not exhortations to gather rosebuds, but: Here's what lies up ahead on the road." Of course, he did more than just describe the terrain. He traversed it bravely. Paul's decision not to avert his eyes from death epitomizes a fortitude we don't celebrate enough in our death-avoidant culture. His strength was defined by ambition and effort, but also by softness, the opposite of bitterness. He spent much of his life wrestling with the question of how to live a meaningful life, and his book explores that essential territory. "Always the seer is a sayer," Emerson wrote. "Somehow his dream is told; somehow he publishes it with solemn joy." Writing this book was a chance for this courageous seer to be a sayer, to teach us to face death with integrity.

*Even while terminally ill,
Paul was fully alive.*

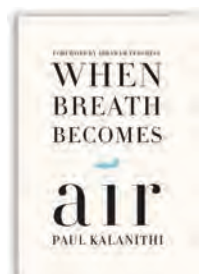
Relying on his own strength and the support of his family and community, Paul faced each stage of his illness with grace — not with bravado or a misguided faith that he would "overcome" or "beat" cancer but with an authenticity that allowed him to grieve the loss of the future he had planned and forge a

new one. He cried on the day he was diagnosed. He cried while looking at a drawing we kept on the bathroom mirror that said, "I want to spend all the

rest of my days here with you." He cried on his last day in the operating room. He let himself be open and vulnerable, let himself be comforted. Even while terminally ill, Paul was fully alive; despite physical collapse, he remained vigorous, open, full of hope not for an unlikely cure but for days that were full of purpose and meaning.

Adapted from the book, "When Breath Becomes Air" by Paul Kalanithi.

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Five Questions for Susan Nimoy

Change-maker Susan Nimoy shares how the end-of-life experience of her late husband, Leonard Nimoy — best-known for his legendary role as Spock in the *Star Trek* franchise — inspired her to help get people talking about how they'd like to spend their final days.

Q: What was it like sharing life with a cultural icon? Was the Mr. Spock character a complete departure from the real Mr. Nimoy?

A: Leonard was a very humble man. His tastes were simple; he didn't need a lot of attention. So the fact that he was a cultural icon didn't play itself out in our private life. But of course when we did go out in public, he would always be outed.

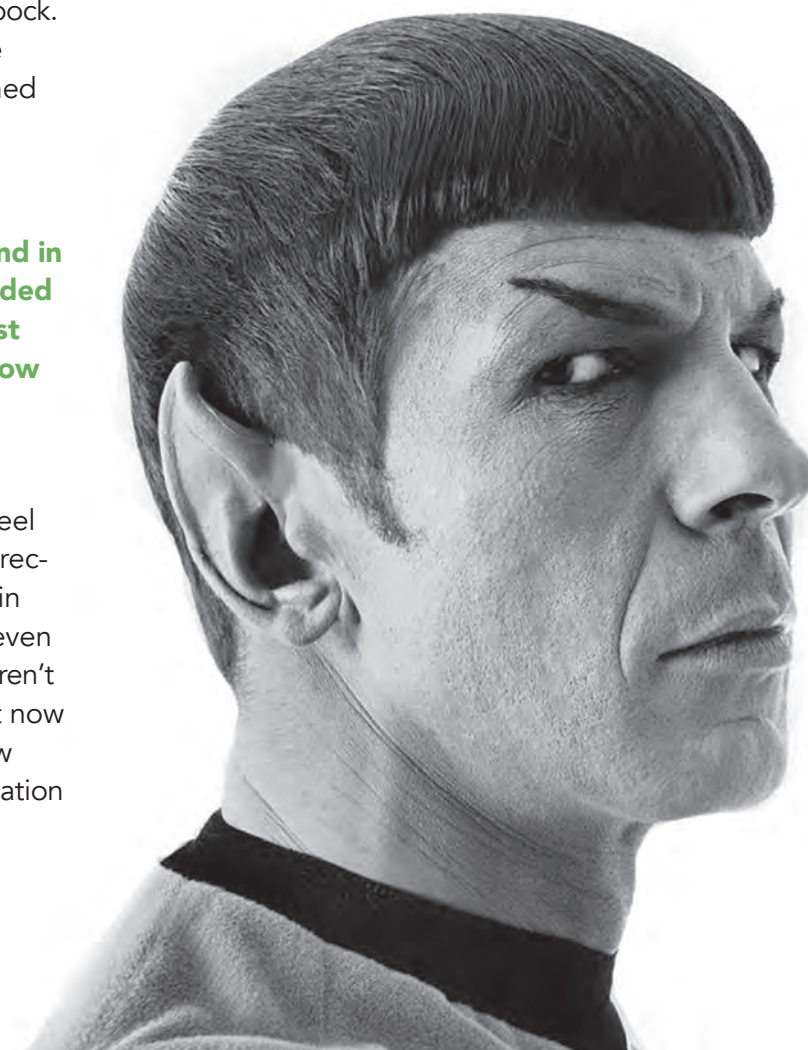
He loved to have fun and was much more relaxed than the Spock everyone identifies with. But on the other hand he was also very rational, and he processed information well. He was a thoughtful person, and he was extremely smart. So there was a lot about Spock that Leonard drew on from his own being and infused into the character. But much of Leonard never found its way to Spock. I don't know how often over the years we ever saw Spock laugh, but Leonard laughed all the time.

Q: You also have your own long background in film, as an actor and director, and founded a steering committee in 1979 to protest gender discrimination in Hollywood. How do you feel about the progress in that industry since then?

A: There has been minimal progress, and I feel badly about it. There are more women directors working today, but percentage-wise in comparison to the men working, it's not even 10 percent. And that's not because there aren't good women directors out there. At least now there's a lot more conversation about how women are marginalized, but that conversation has yet to turn into huge change.

Q: Both you and Leonard have also been generous, impactful proponents of the arts. Why do you think championing that kind of work is important?

A: I believe that art is transformative, that at its core it talks about the human condition, and it teaches us about ourselves. Our home is filled with it, and we've been fortunate enough to be able to give back by creating residencies for artists all across the country and institutions that have had residency programs. We've been able to build theaters where there were not theaters, and hopefully these gifts will encourage generations one imagination at a time to pick things to do with their lives they may never have thought of otherwise.





Q: Now you're also a strong supporter of end-of-life issues. What brought you to this movement?

A: Leonard had breathing difficulties always: asthma, then he developed emphysema, which then was diagnosed as chronic obstructive pulmonary disease (COPD), and the writing was on the wall. He would never be better; he would only get worse. He had a wonderful doctor at UCLA who was doing everything in his power to give Leonard quality of life, but there was never any discussion about his last days. The conversation that I believe needed to take place was you've got probably three months to live; how do you want to live them? I didn't know to have that conversation, and I feel it's essential. It will profoundly affect the choices people make, the doctors they seek out, the oncologists and cardiologists they work with so that they can have a conversation with these physicians that is honest and forthcoming.

Q: Recently you established the Leonard Nimoy Physicians' Education Fund. What are your hopes for that project?

A: I think physicians, nurses and patients need to learn how to look at the final chapter of life. People want to live, surely, but they would like to be able to weigh in on the quality of their last days. This program will include a hotline to speak to another human being, get information, ask questions and receive advice on how to talk to your family and doctors.

Leonard and I talked about dying at great length. He said, "Don't let me die in the hospital." I said, "You won't. You will die at home, on hospice, surrounded by your family." And that's exactly what we did — but I had to fight for it. He died with a smile on his face. His nurse said in all of her practice, she has never seen that. He was so ready. He was 83. He had lived a wonderful life and done everything he wanted to do; he was happy.

But every story is different, and everybody has to find their way. Without the information, though, you don't know what's available to you. Information is power.

P. 23:
Nimoy was known for his portrayal of Mr. Spock, the half-human, half-Vulcan character he played on the TV series *Star Trek*

ABOVE:
Leonard and Susan Nimoy in their Manhattan apartment, 2002

**“These decisions
are medical,
not political.”**

– Dr. Colette Kirchhoff
Bozeman, MT



A Legacy of Change — Add Your Voice

The Legacy Circle honors those who remember Compassion & Choices in their estate plans. These gifts include a bequest through a will or living trust, or naming Compassion & Choices as a beneficiary of an IRA or life insurance policy.

We envision a world in which everyone has a full range of end-of-life options available to them. Please add your voice to this legacy of change.

For more information about the Legacy Circle, please contact us at 800.247.7421 or send us an email at plannedgiving@compassionandchoices.org — or visit us online at CompassionAndChoices.org/donate.

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Care and Choice at the End of Life

Autonomy for All: C&C Applauds 26 Years of the Americans With Disabilities Act

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Gary C. Norman, Esq. LLM
with his guide dog, Pilot
Supporter and disability-rights activist, Maryland

