

compassion & choices

MAGAZINE

SPRING 2017

ADVOCACY IN ACTION:
**Join the Fight
to Protect End-
of-Life Choice**

**Victory Is
Just the Start:
What's Next
in Colorado?**

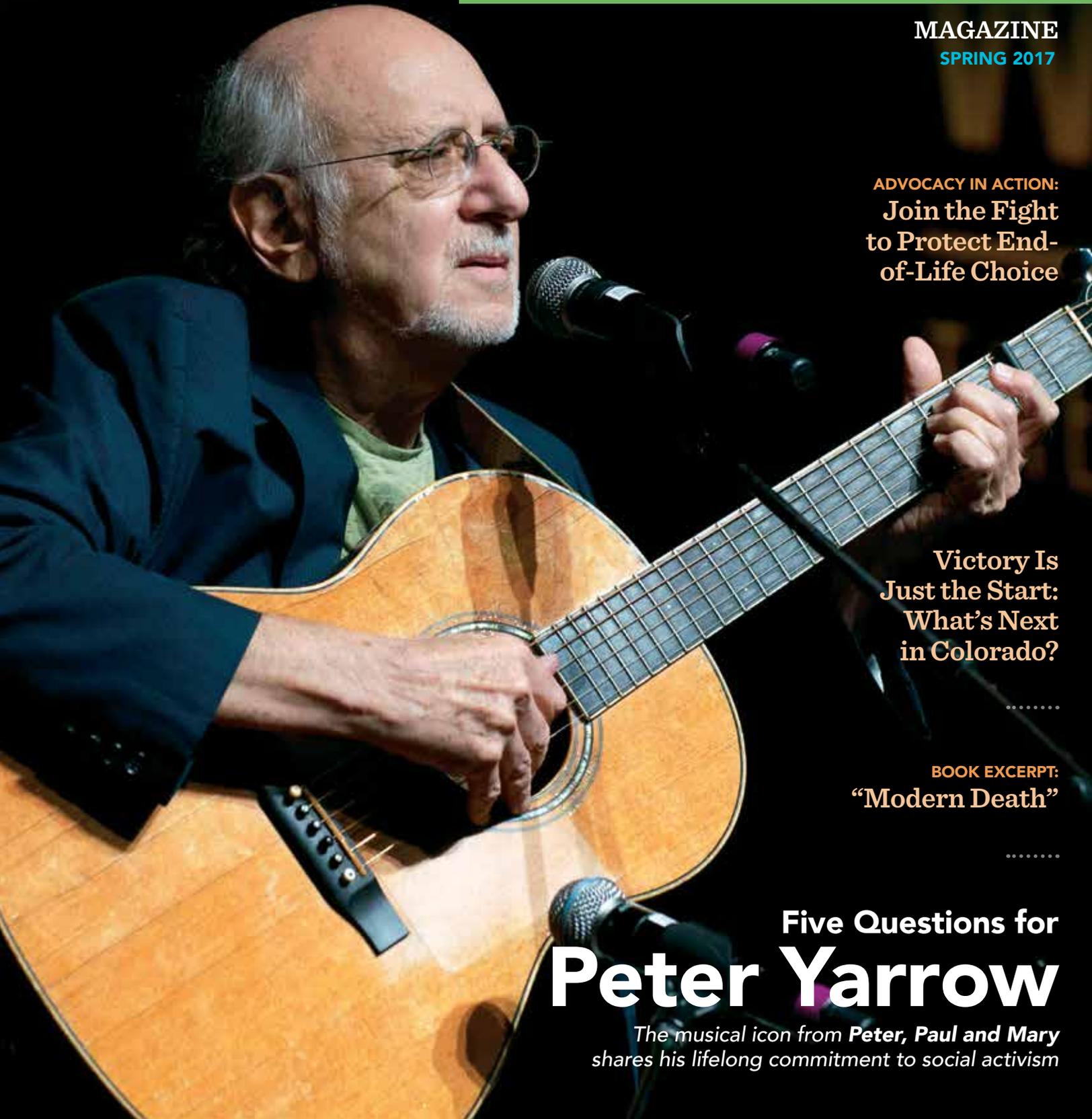
.....

BOOK EXCERPT:
"Modern Death"

.....

Five Questions for **Peter Yarrow**

*The musical icon from **Peter, Paul and Mary**
shares his lifelong commitment to social activism*



“These decisions
are medical,
not political.”

– Dr. Colette Kirchhoff
Bozeman, Montana



A Legacy of Change — Add Your Voice

The Legacy Circle honors those who remember Compassion & Choices in their estate plans. These gifts include making 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 PlannedGiving.CompassionAndChoices.org.



contents | Spring 2017
Vol. 16 / No. 1

FEATURES

04 Book Excerpt From “Modern Death: How Medicine Changed the End of Life”

Read an excerpt from Dr. Haider Warraich’s new book on the evolving nature of death and dying.

09 Victory Is Just the Start

Colorado voters pass aid-in-dying law, but the work has just begun.

20 Living and Dying on My Terms

A woman confronted with death chooses life.



DEPARTMENTS

02 Inside View

03 Words & Pictures

08 Keeping Count

12 Advocacy in Action

17 National Programs Update

22 Five Questions for Peter Yarrow



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.



Compassion in Common

Without question, we find ourselves in a new era. The last election's exposure of national discontent and disconnect caught many of us by surprise. Whatever side of the aisle you stand on politically, the expanse between has never felt so wide.

End-of-life matters, however, remain universal. And for the most part, our values around them are universal, too. Virtually everyone wants comfort and recognition of their precious, unique life. This issue of Compassion & Choices Magazine shares glimpses of that unity. You'll read about legislative wins in Colorado and Washington, D.C., where citizens and lawmakers of disparate ideologies met in common middle ground around the necessity and rightness of medical aid in dying. And you'll note the enthusiasm people from all facets of American society have for improving healthcare overall, especially as it pertains to those vulnerable final days.

Certainly we still must be constantly vigilant to fend off opponents of personal liberty. But our movement truly is a rare bridge between political persuasions in a polarized world. More than ever, we need to remember, and hold up, the things that connect rather than divide us all.

Barbara Coombs Lee, PA, FNP, JD
President

compassion & choices

MAGAZINE

Managing Editor
Kim Taccini

Art Director
Bhavna Kumar

Staff Writers
Sonja Aliesch
Sean Crowley
Alyson Lynch
Tina Posterli
Annie Singer

Contributors
Kim Callinan
Barbara Coombs Lee

Production Manager
Alyssa Cowan

Advertising, Rights & Permission

CompassionAndChoices.org
Magazine@CompassionAndChoices.org
National office: 1001 Connecticut Avenue, NW,
Suite 522, Washington, D.C. 20036

Postmaster

Send address changes to: Compassion & Choices
PO Box 101810, Denver, CO 80250

Bulk postage paid at Denver, CO
and additional mailing offices.

In the normal course of business, Compassion & Choices regularly exchanges mailing lists with other like-minded organizations. If you would like to have your name removed from these exchanges, please notify us in writing, including your name and address. We will honor your wish upon receipt of your request.

Photo/Illustration Credits

cover: LBJ Presidential Library / Alamy Stock Photo
inside front cover: Ashley Stevick
p. 1, 4: Ian McDermott
p. 1, 9, 10: courtesy of Compassion & Choices Action Network (CCAN)
p. 2, back cover: Owen Carey
p. 3, 14: Lynn Donaldson
p. 5: Shawn Rocco, Duke Health
p. 10: courtesy of Matt Larson
p. 16: courtesy of Miguel Carrasquillo
p. 21: courtesy of Martha Mabey
p. 22: Everett Collection Inc. / Alamy Stock Photo
p. 23: Sarah Coale
p. 24: courtesy of Peter Yarrow
inside back cover: Steven St. John Photography

The New York Times:

Physician Aid in Dying Gains Acceptance in the U.S.

bit.ly/nyt17spring

The New York Times "The New Old Age" column reported on the recent progress of the medical aid-in-dying movement, including passage of new laws in two jurisdictions with varied demographics: Colorado and Washington, D.C.

"I hear people talk all the time about this being a rich white person's issue," said Compassion & Choices' D.C. Legislative Manager Donna Smith, who is African-American. "Now, we have proof on the ground that that is not true."

Boston Magazine:

The Death I Want

bit.ly/bosmag17spring

Massachusetts physician Roger Kligler wrote this very personal op-ed about why he partnered with Compassion & Choices to file suit against the Massachusetts attorney general, asserting that state law allows physicians to offer terminally ill adults the option of medical aid in dying. Dr. Kligler, who has lived with prostate cancer for 15 years, wants the option for himself: "I should have the freedom to say how much suffering is too much during my final days."

People en Español:

Miguel Carrasquillo: Su Lucha por una Muerte Digna (His Struggle for a Dignified Death)

bit.ly/peopleesp17spring

In March, People en Español published a beautiful two-page spread about Compassion & Choices volunteer advocate Miguel Carrasquillo, highlighting the fact that 69 percent of Latinos now support

medical aid in dying since Miguel's agonizing death last year, as well as detailing our Latino-focused efforts in New York and across the nation. The story also notes the support for medical aid in dying by Mexican actor Mauricio Ochmann, who recorded public service announcements for Compassion & Choices.

People:

Inside a Terminally Ill Man's Decision to Die and His Emotional 'Going Away' Parties With Friends and Family

bit.ly/people17spring

People interviewed Leslie Mutchler after her terminally ill son, TJ Mutchler, died utilizing medical aid in dying. She urged Montana lawmakers to reject a bill that would imprison doctors who provide this end-of-life option and overturn the state Supreme Court decision that authorized medical aid in dying in Montana. TJ's grandfather, Bob Baxter, was the lead plaintiff in that case (*Baxter v. Montana*). "It boggles the mind," said Leslie of the Montana bill. Six days after this article was published, the bill was defeated.



In December 2016, TJ Mutchler invited Compassion & Choices to his home in Billings, Mont., to share his story for this video, which was also featured in the People article. View online at bit.ly/TJsStory.



Adapted from "Modern Death: How Medicine Changed the End of Life" by Haider Warraich, M.D. Copyright © 2017 by the author and reprinted with permission of St. Martin's Press, LLC.

BOOK EXCERPT:

MODERN DEATH

How Medicine Changed the End of Life

by Haider Warraich, M.D.



Several hours into our meeting, Rafael started to read the piece aloud.

I was handed a Xeroxed copy of a single-page essay from the Journal of the American Medical Association, published in 1988. A poet and physician, Rafael Campo, had invited myself and several other medical residents to his home for a writing workshop. We were interested in writing powerful, moving essays, and Rafael picked out what he thought was a particularly strong piece. The essay was titled "It's Over, Debbie," and it seemed to us that the most

intriguingly unusual thing about it was that the author's name had been "withheld by request." But that was before we read the piece itself.

The essay started like many other personal anecdotes penned by physicians and routinely published in medical journals: a sleep-deprived resident was paged in the middle of the night. The author, a gynecologist in training, was informed on a call night that a patient was having difficulty "getting rest." As he proceeded to check what was going on, contrary to his expectation of finding an elderly female, he found

a twenty-year-old girl named Debbie. Experiencing “unrelenting vomiting” and “labored breathing,” the young patient had terminal ovarian cancer. A dark-haired nurse was standing next to her, holding her hand and comforting her till the doctor on call arrived. “Hmmm, I thought,” wrote the author, “very sad.”

He then went on to describe scenes that anyone on a cancer ward has seen innumerable times. “The room seemed filled with the patient’s desperate effort to survive ... it was a gallows scene, a cruel mockery of her youth and unfulfilled potential.” However, it was what happened next in the essay that sent the first shiver down my spine, all the way to my toes.

I would learn later that I was far from the only one shaken to my being.

“Her only words to me were ‘Let’s get this over with.’” The author returned to the nursing station with thoughts circling his head. “I could not give her health, but I could give her rest,” he wrote. He then drew up twenty milligrams of morphine in a syringe, walked back to her room, and injected the morphine into her vein. “With clocklike certainty, within four minutes, the breathing rate slowed even more, then became irregular, then ceased,” wrote the author. The article was not a long read, only a word over five hundred. It

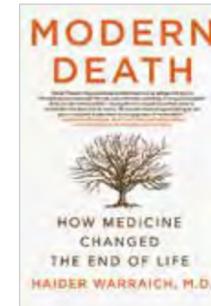
must have been difficult for Rafael to read the piece, but nothing would have been harder to write or say than the three very last words: “It’s over, Debbie.”

Few things have left me feeling as soulless as those last three words. I would learn later that I was far from the only one shaken to my being. The essay generated

a firestorm at JAMA (Journal of the American Medical Association). They received more letters in response to this one piece than to any other article published in the journal’s more-than-a-century-long history. Overwhelmingly, physicians opposed the piece and what it purportedly represented far and wide. A comment published in the JAMA in the aftermath of “It’s Over, Debbie” was perhaps the most scathing:

By publishing this report, he [the JAMA editor] knowingly publicizes a felony and shields the felon. He deliberately publicizes the grossest medical malfeasance and shields the malefactor from professional scrutiny and judgment, presumably allowing him to continue his practices without possibility of rebuke and remonstrance, not even from the physician whose private patient he privately dispatched Decent folk do not deliberately stir discussion of outrageous practices, like slavery, incest, or killing those in our care.... The very soul of medicine is on trial.

The firestorm didn’t remain buried in the back pages of the JAMA. Ed Koch, the irascible mayor of New York, was incensed, calling the article “a confession.” He went on to demand that Attorney General Edwin Meese III force the journal into releasing information pertaining to the submission. “This is not a case of an informant. This is a case of a confessed murderer.” The Illinois State attorney general Richard Daley took action and issued a subpoena to the American Medical Association, which is based in Chicago and oversees the journal, requesting that all documents related to the article, including the name of the author, be released. A Cook County grand jury ordered that all records be turned over to the state for further prosecution.



Euthanasia and medical aid in dying are sometimes used interchangeably, but there is a crucial difference: While euthanasia involves the physician himself committing the act that leads to the premature demise of the patient, in medical aid in dying the doctor provides the patients the means, usually a lethal prescription of sedatives, to commit the act of their own volition. Of the two, euthanasia has a far longer history and tradition than medical aid in dying, which is a more recent development and emphasizes patient autonomy.

Conspiracy theories swirled, with many not even believing the account to be true. Forensics experts doubted that twenty milligrams of morphine could in fact end someone’s life — least of all within the reported four minutes. Clinicians found the scenario implausible. Some doubted that any physician would make such a decision about a patient they didn’t know too well. Pressure was piled on George Lundberg, who was the editor of the journal at the time, and who had gone ahead with publishing the piece even after some of his editorial staff objected to it. Some even suggested that Lundberg’s wife, an English professor, had penned the piece.

After the firestorm that “It’s Over, Debbie” ignited, pressure kept piling on the American Medical Association from all directions to out the author and rescind the article. Yet the piece also generated a second wave, one that came from perhaps the most important stakeholders in this debate: patients and the public. A young woman whose mother had lost her mother to lung cancer wrote, “I feel very strongly that if such a patient wants to end her life by being injected with morphine or any other drug that will end her pain, then she should have the right. No one should have the right to make them suffer.” Others said that they “applaud that physician as one caring more about a patient’s pain than about cruel, outdated professional

ethics and laws.” Alex Hardy, a patient who had been diagnosed with terminal metastasized cancer, wrote the most moving account:

I have traveled down a road filled with evasion, equivocation and moral hypocrisy. Most physicians don’t want to face the fact that one of their patients is going to die. Very few will even discuss death. It is often claimed by physicians that they can’t “play God” and remove life support. Aren’t they “playing God” when the life support is ordered?... My only concern is that some misguided physician will try to keep me alive against my wishes. Being alive is not merely existing on a machine or with massive drug doses. A person must have the ability to think, function, and participate (even in a small way) in the everyday flow of human events.

Alex Hardy died less than a month after writing this commentary. What the author of “It’s Over, Debbie” described has been called many things, ranging from physician-assisted suicide, euthanasia, and mercy killing to flat-out cold-blooded murder. In many ways it crystallized what is one of the most passionately debated issues in modern culture. ■

Got Questions? Get Answers.

High-quality conversations between doctors and patients are difficult. Patients are often reluctant to be assertive, ask questions, request clarification and make their preferences known. And physicians typically wait for patients to signal interest in end-of-life discussions. But improving patient-physician communication for patients with advanced cancer can be as simple as asking the right questions.

When oncologists receive individualized communication training and patients receive question-prompt lists and communication coaching, patient-centered communication can improve.

Patients and physicians will see:



44%

increase in the use of engaging conversation, such as asking questions.

71%

increase in the expression of emotion.

38%

increase in conversations about prognoses and treatment choices.

Source: JAMA Oncology



To create a personalized question-prompt list to take with you to your next doctor's appointment, check out the newest personal advocacy tool from Compassion & Choices at DiagnosisDecoder.org. The Diagnosis Decoder arms you with better questions so you can receive clearer information and make fully informed treatment decisions.

Victory Is Just the Start...

PASSING AND IMPLEMENTING A LAW
TO EXPAND END-OF-LIFE OPTIONS
IN COLORADO

By Alyson Lynch



In December 2016, the End of Life Options Act went into effect after Colorado voters passed it by a 2-to-1 margin — the largest medical aid-in-dying ballot victory to date. But that history-making win is just one step in expanding and protecting the end-of-life choice movement.

On November 8, 2016, the Colorado End of Life Options Act, or Proposition 106, passed by a 30-point margin, with 65 percent of voters endorsing medical aid in dying in their state. Coloradans won a long, hard battle for expanded end-of-life options. After multiple failed attempts in the Legislature, Compassion & Choices and the Compassion & Choices Action Network inspired a citizen-led ballot initiative and provided financial and technical support to the Yes on Colorado End-of-Life Options campaign.

The campaign took off in the major swing state with a diverse electorate from across the political spectrum, proving that even in a turbulent election cycle, end-of-life options are a nonpartisan issue. As Matt Larson, a Colorado native who became an advocate after being diagnosed with

brain cancer at 35, put it, “This is not a left or right issue. This is not a political issue. This is an issue of compassion. More than two-thirds of people that understand the process and eligibility requirements support this. Try to get two-thirds of anybody to agree on anything these days.” Voters across a broad demographic range wanted this law, according to exit polling by The Associated Press and TV networks in Colorado. Men and women, Hispanics and whites, and people with and without college degrees said they backed the proposal.

The resounding support in Colorado was evident from the beginning of the campaign. In August, volunteers and advocates delivered more than 160,000 petitions to the secretary of state’s office, and the measure

This is not a left or right issue. This is not a political issue. This is an issue of compassion.

– Matt Larson

was certified for the November ballot a few weeks later. A dozen newspapers endorsed the measure, including the Boulder Daily Camera and the Grand Junction Daily Sentinel, and people across Colorado debated the issue in their papers’ opinion columns. Dan Diaz, Brittany Maynard’s husband, and former Oregon Governor Barbara Roberts appeared in television advertisements along with 36-year-old Larson. Even more young people showed their support through vocal endorsements from groups like New Era Colorado and ProgressNow. Also, the Colorado Medical Society dropped its decades-long opposition to medical aid in dying.

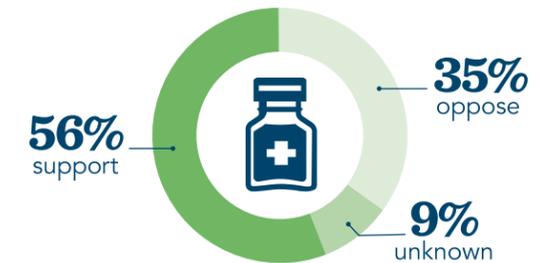
The win in Colorado expands on the momentum created by dedicated supporters and volunteers from across the country who have committed years to the movement for end-of-life options. Unfortunately, that hard work could be for naught if the law isn’t implemented effectively. That’s why Compassion & Choices is still in Colorado working on an access campaign.

The organization’s work in Oregon, Washington, Vermont and California has shown time and again that some hospital systems and health providers will resist honoring medical aid-in-dying laws without pressure from the very citizens that voted the option into existence. According to Matt Whitaker, Compassion & Choices’ multi-state implementation manager, when hospitals refuse to allow their physicians to participate in medical aid in dying, they cut off access for large swaths of people, creating a major health-equity issue. Now that Proposition 106 is law, Compassion & Choices’ goal is to ensure all Coloradans can access it.

In Colorado, as in other states with medical aid-in-dying laws, one-third of hospitals have refused to allow their physicians to prescribe aid-in-dying medication. When hospitals opt not to participate in the practice, they make it extremely difficult for people who rely solely on that facility for their care to access the law, an acute issue in rural areas and regions dominated by one large health system. Terminally ill people with only months to live could be forced to travel a hundred miles to a participating hospital, or may not be able to access the law at all. This isn’t due to a lack of support from the citizens of Colorado, as voting numbers prove. It’s hospital executives and bureaucrats making decisions for entire regions of a state. That’s why Compassion & Choices encourages people to demand access through letter-writing campaigns and educational events in their communities on a grassroots level.

When citizens make their voices heard, hospital systems listen. In California, Huntington Hospital announced it would forbid its 800 affiliated physicians from participating in the state’s law. In response, Compassion &

A Survey of Colorado Medical Society Members About Medical Aid in Dying



Source: Colorado Medical Society Member Survey, on Issues Surrounding Physician-Assisted Death, February 2016

Choices volunteers and staff organized local residents who were outraged by the decision. The result? Huntington Hospital reversed its position, even announcing it in an open letter they published in the Los Angeles Times. This is just one example of how residents in states where medical aid in dying is authorized can change healthcare system policy.

The Compassion & Choices Access Campaign also provides resources to help patients and doctors comply with the guidelines of their state’s law. The organization’s staff reaches out to physicians and healthcare providers, offering education and staffwide informational sessions regarding the requirements for medical aid in dying. Just as the ballot initiative was unique to Colorado, the Access Campaign is tailored to the specific needs of regions and communities within the state.

The more Americans who have access to the end-of-life option of medical aid in dying, the more the practice becomes open, accessible and trusted. Every time another state authorizes medical aid in dying, it builds momentum for more states to do the same. With support from nearly 7 out of 10 voters nationally, it is clear that public opinion continues to move in favor of this option. And with 21 states considering aid-in-dying bills this year, more lawmakers understand that this is an option their constituents want. ■



previous page:
160,000 boxed
petitions ready for
delivery to Colorado’s
secretary of state.

this page left:
Matt Larson with
wife, Kelly, and their
dog, Otis.

this page right:
Matt right before
a craniotomy,
June 2015.

ADVOCACY IN ACTION

Advancing the End-of-Life Choice Movement One State at a Time

Riding the momentum we set in motion last year, we kicked off 2017 with fast and furious legislative sessions across the country — laying the groundwork for future victories despite a shifting political climate.



Advocates for the D.C. Death with Dignity Act met with council members to urge support for the legislation.



In New Mexico, supporters participated in a Lobby Day to receive training and meet with legislators.

DISTRICT OF COLUMBIA

In November, the Council of the District of Columbia passed the D.C. Death with Dignity Act by a veto-proof 11-to-2 margin. But Congress tried to overturn the law before it even took effect, passing a joint disapproval resolution under the D.C. Home Rule Act. Opponents failed to get the support necessary in Congress to stop the bill from becoming law, which went into effect in February. This makes D.C. the seventh jurisdiction to authorize the practice.

HAWAII

Compassion & Choices Hawaii hit the ground running with a dual-pronged legislative and legal strategy to make medical aid in dying a reality in 2017. Alston Hunt Floyd & Ing and Compassion & Choices filed a lawsuit on behalf of a Hawaii resident with terminal cancer, John Radcliffe, and a physician asserting the Hawaii constitution and existing state law allow the practice of medical aid in dying. The Hawaii Senate's Commerce, Consumer Protection and Health Committee also voted unanimously to pass the Hawaii Death with Dignity Act (SB 1129) out of committee following a public hearing on the bill. In a full floor vote, the Hawaii Senate voted 22 to 3 to approve the bill and refer it to the House of Representatives for further consideration. The Hawaii Medical Association recently reversed its long-standing opposition to medical aid in dying and adopted a neutral stance. On March 23, the House Health Committee deferred SB 1129 until the January 2018 legislative session.



Religious leaders from several faith traditions participated in the first-ever New York faith gathering to urge passage of the Medical Aid in Dying Act.

MASSACHUSETTS

The Massachusetts End of Life Options Act was filed by Rep. Lou Kafka, and for the first time a Senate version of the bill was also filed by Sen. Barbara L'Italien, a strong disability-rights advocate. The Compassion & Choices Massachusetts team is achieving amazing progress for aid-in-dying legislation. Their efforts so far have resulted in 46 co-sponsors signing on to the End of Life Options Act, including 13 new co-sponsors since the 2015–16 legislative session.

NEW MEXICO

A state Supreme Court ruling in June of 2016 permanently overturned a district court decision that had authorized medical aid in dying in the state's most populous county from January 2014 to August 2015. Now the Supreme Court has ruled that terminally ill New Mexicans do not have a constitutional right to a physician's assistance in dying, calling for "robust debate" in the Legislature instead. Compassion & Choices, the ACLU of New Mexico and a coalition of stakeholders have worked with Reps. Deborah Armstrong and Bill McCamley and Sen. Liz Stefanics to follow through on that recommendation. The End-of-Life Options Act, HB 171 and SB 252, ensures that New Mexicans are able to make their own medical decisions, along with their loved ones and their medical team, at the end of life. HB 171 passed through the House Health & Human Services Committee, but stalled in the Judiciary Committee and was not heard before the session ended. After

passing through the Senate Public Affairs Committee and the Senate Judiciary Committee, SB 252 was defeated on the Senate floor by a vote of 22 to 20. Courageous people living with terminal illnesses attended hearings and told their personal stories, and hundreds more visited their legislators and made their voices heard — and we are confident the will of the people will soon prevail.

NEW YORK

The Compassion & Choices New York team worked closely with bill authors to reintroduce the Medical Aid in Dying Act and is building support among a growing group of diverse statewide organizations, healthcare professionals and faith leaders. On Valentine's Day, Compassion & Choices New York held its first-ever faith gathering at the New York State Capitol in Albany. "Love, Compassion and Faith" was the theme of the event, where 16 diverse religious leaders and a dozen advocates from the capital region called on New York lawmakers to pass the legislation. Rev. Dr. Johnnie Green Jr., Father Luis Barrios, Rev. Dr. Richard S. Gilbert, Rev. Valerie Ross, and Rabbi Dr. David Gordis delivered powerful speeches, and New York State Assemblywoman Amy Paulin inspired the crowd with her commitment to championing the bill. The team continues to build statewide support for the measure and is strategizing to move the bill through the requisite Assembly committees before it can be brought to the floor for a vote.

A Perfect Storm of Peril

Despite strong and growing public demand for fuller end-of-life options nationwide, devastating opposition attacks could set the movement back decades.

We have arrived at a remarkable moment, a time when 1 in 6 Americans have access to medical aid in dying. But amid all this progress, we are also facing the biggest threats in the history of the movement. A potential nationwide congressional ban threatens to obliterate the meaningful progress we've made and set our movement back to the last century.

While Congress failed to pass a joint disapproval resolution to overturn the D.C. Death with Dignity Act, some members have pledged to block funding to implement the law during the appropriations process this spring. House Oversight and Government Reform Committee Chairman Jason Chaffetz who moved the resolution through his committee, said Congress should intervene, no matter what form that action takes.

The spotlight on the D.C. legislation has catapulted the issue of medical aid in dying onto the federal agenda at a time when Congress has the power to enact a ban on aid in dying nationwide — even criminalizing the practice in states that have long authorized it.

Such legislation would also set up a decisive confrontation at the U.S. Supreme Court, to which an opponent of medical aid in dying, Neil Gorsuch, awaits confirmation (at press). Judge Gorsuch even wrote a book, "The Future of Assisted Suicide and Euthanasia" (2006), arguing for just such a ban.

The movement is facing new threats at the state level as well. In Montana, TJ Mutchler, the grandson of history-making plaintiff Bob Baxter (*Baxter v. Montana*), utilized medical aid in dying in February to end his long battle with terminal pancreatic cancer. The day after he died, a bill was introduced in the Montana Legislature that would send TJ's doctor to jail for helping him die peacefully. Before his passing, TJ recorded a video urging legislators to vote "no" on any bill that could take this option away from those who have a terminal illness and seek relief from intolerable suffering. Compassion & Choices defeated this as well as another Senate bill, and we are ardently working to thwart similarly backward-looking bills being introduced in other states.



top: TJ Mutchler, 36, was photographed in his Billings home, where he was able to end his life peacefully and on his own terms.



left: TJ's daily routine included using a feeding tube to administer medication for his unrelenting pain and discomfort.

HOW TO HELP STOP THESE DEVASTATING OPPOSITION ATTACKS

We need your voices to be heard through phone calls, letters to the editor, emails, social media and beyond. **Here's what you can do today.**



ADVOCATE AND VOICE YOUR SUPPORT:

- » TAKE ACTION by sending a letter to your local lawmaker to support medical aid in dying at: CompassionAndChoices.org/near-you.
- » VOLUNTEER through our Volunteer Resource Center at: CompassionAndChoices.org/volunteer.
- » CONNECT with other supporters in your state at: CompassionAndChoices.org/near-you.



SHARE YOUR STORY:

More than ever, we need people to recount their personal experiences with medical aid in dying to demonstrate the human impact and show why this option is so crucial. Visit CompassionAndChoices.org/stories.



DONATE:

Your generous support enables us to protect decades of hard-won progress toward self-determination for the terminally ill in our country. Visit CompassionAndChoices.org/donate.



CONNECT WITH US:

- » LIKE us on Facebook: [@CompassionAndChoices](https://www.facebook.com/CompassionAndChoices)
- » FOLLOW us on Twitter: [@CompAndChoices](https://twitter.com/CompAndChoices)
- » SIGN UP for our monthly e-newsletter at info@CompassionAndChoices.org.

Amplifying Our Voice

In 2016, Miguel Carrasquillo died in Puerto Rico from an aggressive brain tumor. His voice lives on through Compassion & Choices' educational outreach to Hispanics, Latinos, medical professionals and healthcare organizations.

Medical aid in dying has been catching the attention of Latinos nationwide because of the advocacy of Miguel Carrasquillo, a native Puerto Rican who recorded a powerful video before passing away at the young age of 35. Ever since, Compassion & Choices has been hard at work delivering his message.

Just two weeks after CNN en Español aired a compelling story that credited Compassion & Choices for advancing the medical aid-in-dying movement in the United States, LifeWay Research published a survey showing that 69 percent of Hispanics nationwide support medical aid in dying.

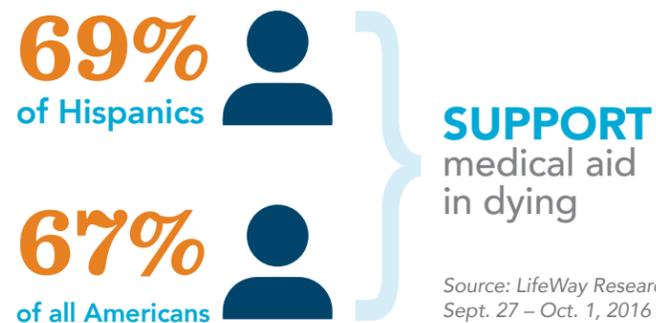
Compassion & Choices launched a statewide bilingual campaign in Colorado this past December to educate terminally ill Coloradans, families and medical providers about the benefits and requirements of the state's new medical aid-in-dying law. This access campaign mirrors the one we are running in California.

Everyone, including non-English speakers, should have access to information about medical aid in dying and the laws in their state.



In the face of terminal illness, Miguel Carrasquillo spent his final days fighting for the rights of other dying individuals. Listen to Miguel's call for expanding end-of-life options at bit.ly/candcmiguel.

Hispanic People Find Medical Aid in Dying "Morally Acceptable"



NATIONAL PROGRAMS UPDATE

Fighting for Patient Choice in the Courts

Compassion & Choices' innovative legal advocacy program continues to bring desperately needed attention to end-of-life issues.

Currently, we have two lawsuits working their way through state courts to clarify that medical aid in dying is not a prosecutable offense.

Kligler v. Healey:

In Massachusetts, the government has filed a motion claiming a court shouldn't answer the question of whether to charge a physician with a crime until after an incident occurs. In March, the court heard arguments on the motion and has taken it under advisement.

Radcliffe v. Hawaii:

The state has asked the court to dismiss the case. A hearing will be held in May.

Additional cases at hand include:

Ahn v. Hestrin:

Opponents continue trying to derail California's End of Life Option Act, but thus far have been unsuccessful. Compassion & Choices will be present during the next hearing in June, carefully monitoring developments in the Riverside Superior Court.

Oregon Prescription Drug Monitoring Program v. DEA:

Compassion & Choices and the American Civil Liberties Union are jointly representing plaintiffs to protect private prescription records from warrantless searches by the U.S. Drug Enforcement Administration (DEA). The 9th Circuit withdrew the case from consideration pending a U.S. Supreme Court decision in another case involving a technical issue related to parties who intervene in litigation. We are evaluating whether to participate as amici.



Dr. Roger Kligler is one of two physician plaintiffs in *Kligler v. Healey*. Dr. Kligler has stage 4 metastatic prostate cancer.

Vermont Alliance for Ethical Healthcare, Inc., et al v. William Hoser, et al:

Compassion & Choices, along with Patient Choices Vermont and two patients, was recently granted intervenor status in a case challenging Vermont's "right to know" law. Opponents brought suit in federal court against the state to challenge the requirement that physicians provide terminally ill patients with complete information about their end-of-life healthcare options. We look forward to participating in the case to protect this critical right. We are currently waiting for a decision from the court on motions brought by the parties.

To learn more about Compassion & Choices in the courts, visit CompassionAndChoices.org/legal-resources.

Doctors for Dignity Are Change-Makers

The Compassion & Choices Doctors for Dignity program represents hundreds of physicians who raise their voices and educate the public and medical community in support of aid in dying. Doctors for Dignity is helping medical societies and colleagues recognize that the patient's values and priorities around death are paramount, even if they differ from their healthcare providers'. The progress has been incredible. For decades, medical societies across the country have opposed medical aid in dying. Within the past two years, medical societies in California, Colorado, Maryland and Washington, D.C., as well as the New York Academy of Family Physicians, have

withdrawn long-standing opposition, adopting neutral positions. Furthermore, authors of an Annals of Internal Medicine article called on physician organizations to adopt a position of engaged neutrality, noting that professional organizations must offer "support and guidance [to physicians] on how to provide the best possible care to dying patients" who request medical aid in dying.¹ This attitudinal shift paves the way for aid in dying to be authorized in more states and represents an understanding in the medical community that patients' values and priorities around death are key to patient-centered care.

To learn more about or join Doctors for Dignity, visit CompassionAndChoices.org/doctors-for-dignity.

¹ bit.ly/AnnalsIntMedNov16

Where to Find Compassion & Choices



Compassion & Choices is committed to educating the public and healthcare professionals on end-of-life issues. To achieve this, we work with strategic partners to disseminate accurate information. An ongoing collaboration with the American Society on Aging helps reach both healthcare consumers and professionals. Here's how you can access these resources:

- » WEBINAR: "What Advances in Medical Aid in Dying Can Tell Us About Integrating the Patient's Voice Into End-of-Life Care" (bit.ly/ASAwebinar17Jan)
- » BLOGS: "End-of-Life Care: Are We Ready for Real Reform?" (bit.ly/ASAblog16Jan) and "A Key Aging Issue Shows Gains in Recent Elections" (bit.ly/ASAblog16Dec)
- » CONFERENCE PRESENTATION: "Patient-Centered Care: Translating Patients' Wishes Into Federal and State Policy" (bit.ly/ASAconf16Mar)

Additional resources from this collaboration will be available in early summer. At that time, you can find those materials at CompassionAndChoices.org/public-speeches-and-presentations.

Compassion & Choices Helps You Call the Shots

Americans have lost control of their healthcare destiny. Our healthcare system prescribes treatment with a "one-size-fits-all" approach that robs people of the quality of life they want and deserve, and ignores their values. Without clear information about all the options and their outcomes, millions of Americans submit to end-of-life care that inflicts needless suffering. **Truth in Treatment™**, Compassion & Choices' newest initiative, will give people with life-threatening illnesses the support, opportunity and courage to live life to the fullest even as their illnesses advance.

It is an audacious opportunity to:

- » Empower and educate people so they can make fully informed healthcare choices and live their remaining time on their own terms — transforming our health system for all who follow.
- » Help people obtain care that is consistent with their values and priorities, rather than losing control of their healthcare when they are diagnosed with a serious illness.
- » Improve the lives of people with varying types of serious illnesses, from dementia to cancer to Parkinson's disease.
- » Advance the end-of-life choice movement in states that are not yet primed for legislative action.

Truth in Treatment offers tools to help people work with their doctors to make treatment decisions and remain in control of their healthcare when they are at their most vulnerable.



Create a Trust Card at TrustCard.org to help your doctor know what's special about you.

Here's what you can do:

- » Visit TruthInTreatment.org to learn more and support the movement to demand change in our healthcare system.
- » Read Martha Mabey's story about taking control of her healthcare on the next page of this magazine. Then, share your story of living life to the fullest in the face of a life-threatening illness at TruthInTreatment.org/share-your-story.
- » Create a Trust Card, our first personal advocacy tool, at TrustCard.org. Share it with your doctor at your next appointment to help build a trusting relationship by clearly conveying your values in a respectful and friendly manner.
- » Create a personalized list of questions to take with you to your next doctor's appointment at DiagnosisDecoder.org. The Diagnosis Decoder arms you with better questions so you can receive clearer information and make fully informed treatment decisions.



An initiative to give people with life-threatening illnesses the support to live their fullest lives.

TruthInTreatment.org



TrustCard.org



DiagnosisDecoder.org

Martha Mabey is an energetic woman with a passion for writing and spending time with her family and friends. When confronted with a life-threatening condition, she had only a brief moment to choose how she wanted to spend her remaining days. In making her decision, she challenged a healthcare system that too often overlooks the priorities and values of patients.

Living AND Dying ON My Terms

How I Took Control of My Healthcare in the Face of a Life-or-Death Decision

By Martha Mabey, Ph.D.

Three years ago I was lying in a hospital bed, having survived a claustrophobic MRI, two CT scans, virtual massaging of my carotid arteries and the extraction of what felt like a gallon of blood.

Into the room walked a tall, good-looking man I'd never seen before. Towering over me, he announced his name and said he was a cardiac surgeon. I had a split aorta with an aneurysm ready to burst. I would die, he said, unless I immediately followed him to surgery so he could operate on me and save my life.

He indicated his nurse in the doorway, gowned up for surgery, and said I was to go with her, that he had booked the operating room.

There are worse things than dying.

There was no offer to call my family or my personal physician. No questions about who I was, let alone whether I had concerns about this abruptly announced life-or-death situation.

For a moment I was in shock. I was no longer a person with needs, loves, quirks and a unique history. I had

become only a split aorta that this masterful technician would take in his hands and, like God, repair.

Somewhere deep inside me, these words emerged: "Well, I'm not doing that."

Frowning, he reiterated that I would die if I didn't go.

By this time I was angry, no longer frightened by the prospect of dying. Who was he to tell me what to do with my body? I was a unique individual, not just a combination of organs that needed fixing. More importantly, I was a living soul with no fear of death.

He said his last patient with the same diagnosis died on the way to the operating room.

"I'm sorry to hear that," I said. With even more certainty I added, "There are worse things than dying."

At that moment I knew that under no circumstances did I want to face a long recovery from major surgery. I had done that before — with pain, weeks of physical therapy and days of helplessness. I did not want to risk the quality of life I so deeply enjoyed. I was 77 years old and liked my pace of life as a writer, former educator and art dealer. Why would I give that up to prolong an existence in a compromised situation for an unknown period of time?

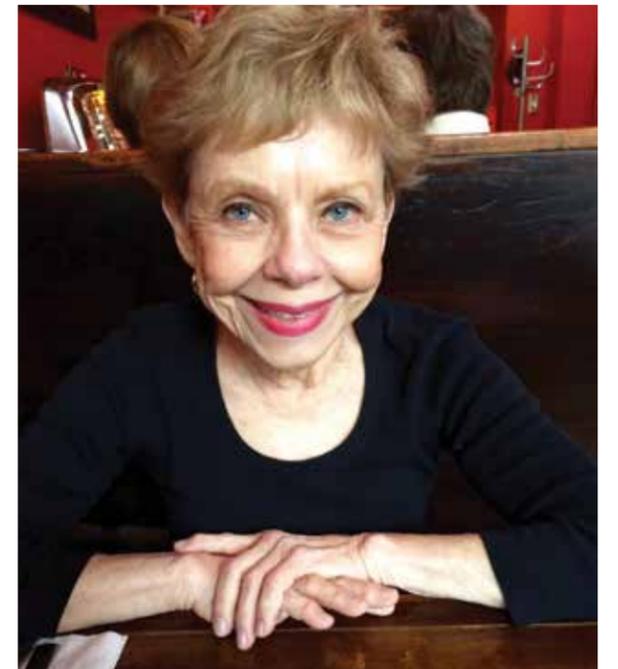
Had I been 20 or even 50 years old, my decision might have been different.

But I was certain I did not want to live just for the sake of simply living.

I paid attention to some wisdom deep inside and did not assume that an expert knew more than I did about myself after decades of joy and grief. Perhaps I'm still alive because I insisted on living on my terms — not on the surgeon's, nor on those of the medical literature that predicted my demise.

TRUTH in
treatment

Martha Mabey shared her story in support of Truth in Treatment™, Compassion & Choices' newest initiative to put patients in the driver's seat of their care. If you want to share your story, visit TruthInTreatment.org.



Martha Mabey is a former teacher, art dealer and author of five books — one of which ("Artists Die Best in Black") has been made into a movie. Her memoir, "The Last Doctor in America," concerns a physician, George Meyerhoff, who put relationships with his patients first. Her books are available through Amazon.

One-third of the iconic folk trio *Peter, Paul and Mary*, Peter Yarrow sings as a form of activism, ever striving to create a more beautiful world.

Five Questions for *Peter Yarrow*

By Sonja Aliesch

Q: After more than half a century, you're still making memorable music. When did it become a serious pursuit for you?

A: I went to the High School of Music and Art in New York — one of the so-called "Fame" schools — and believe it or not, I was an art student. It was an ideal kind of flowing, progressive environment to be part of — the most wonderful four years of my early life. Then I went to Cornell and was a fish out of water. Other than the academics, I was very unhappy there with the sexism, the racism, the status system, etc. But in my senior year I got an instructorship in English 355–356, a course in folk songs and ballads. Classes were on Tuesday, Thursday and Saturday at 10 a.m., and I was paid \$500 — which at the time was 20 percent of the cost of going to Cornell for a year. On Saturdays, instead of a lesson, there was just a sing-along in that 350-seat lecture hall, which filled up and then spilled out into the hallways. The Cornell Daily Sun called it a phenomenon.

That was a turning point for me, because I saw those Cornell kids who were so enthralled by a cultural perspective of status and wealth

and fraternities and privilege, but when they sang together in that sing-along on Saturdays, their hearts opened up. They were filled with a sense of humanity and caring. The singing brought them together. What I realized is that music of this sort, singing together like this, could be empowering and transformational.

Q: You've also been very involved in political and social causes, even appearing on stage with Martin Luther King Jr. at his March on Washington for civil rights in 1963. What are the roots of your activism?

A: My mother was a single mom with two children, a New York schoolteacher who was an immigrant from Ukraine at the age of 3 and a very, very progressive person. She belonged to Planned Parenthood when it was considered to be really radical, and was a member of the Teachers Union, which was really sticking her neck out. Losing her job was a huge fear because she was supporting us alone after a brutal divorce. It was her values and point of view that really brought me to the place I am now.

My commitment to political efforts and social movements was not a casual dalliance. My entire reason for singing became predicated on one thing: I'm there to bring people together with a certain kind of vision and a certain kind of dream, using music as a tool — and that's the most thrilling, wonderful, rewarding thing I could ever do.

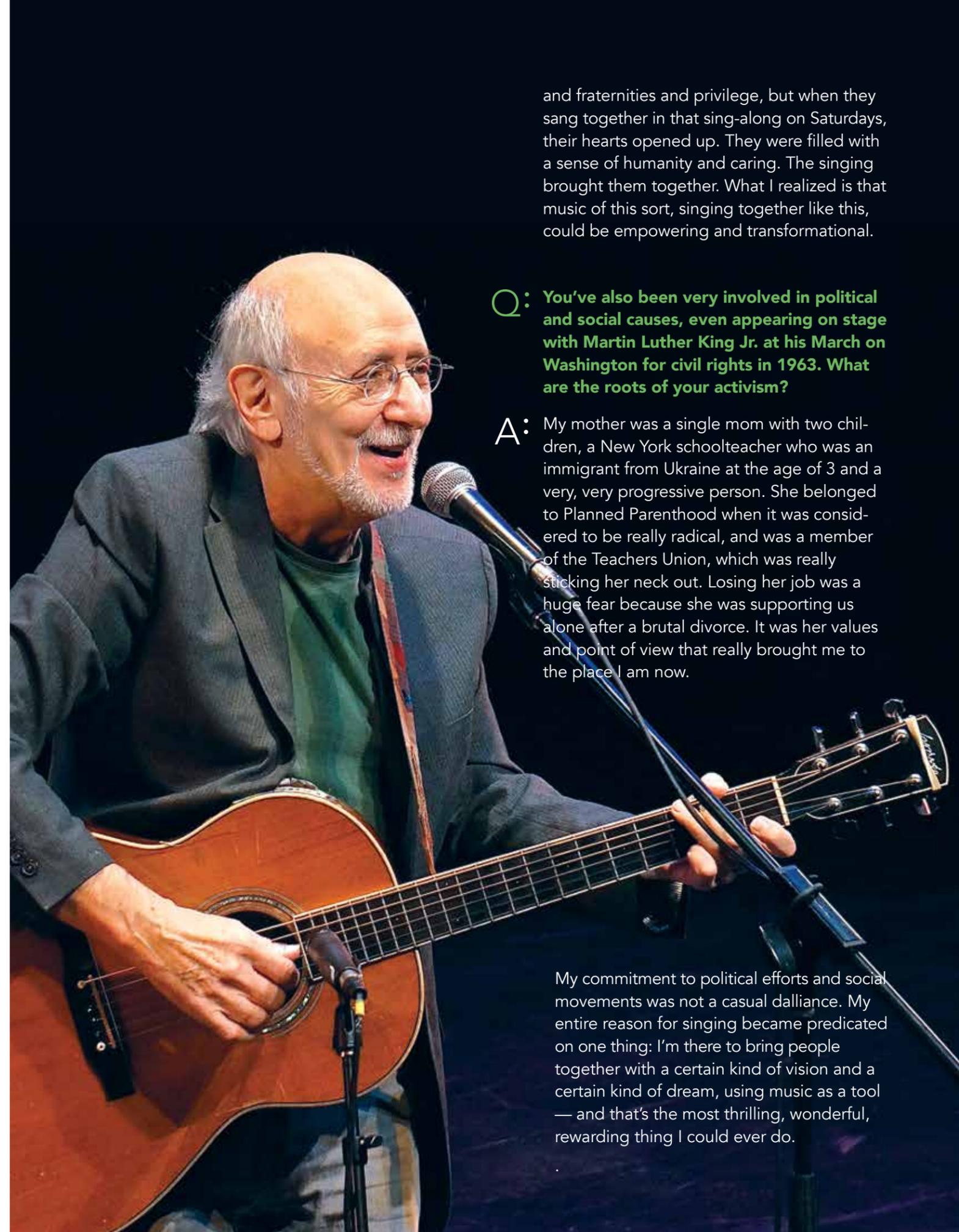


this page, top to bottom:
Noel Stookey ("Paul"), Peter Yarrow and Mary Travers, 1960s

opposite page:
Peter in solo concert, 2016

page 24, left:
Peter with Nahko Bear (right) at the ARISE Festival, 2014

page 24, right:
Youth rally in Milwaukee for Soviet Jewry, 1987





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/champions-circle

Be a **CHAMPION** for Choice

Q: Did a specific event compel you to launch your anti-bullying organization, Operation Respect?

A: It was inspired by a song, “Don’t Laugh at Me,” that my daughter introduced me to, and Operation Respect is really an attempt to create an environment similar to the one I experienced at the High School of Music and Art, where the humanity of people was so uplifted, with everybody sharing and thinking and supporting each other. And now our program is in 22,000 schools around the world.

Q: You have served on the board of the Connecticut Hospice for a number of years — since before your mother passed there. How did that come about?

A: I have a very good friend whose father was a minister there, and she asked me to do a benefit for the Connecticut Hospice. But first I wanted to visit the hospice. And when I did, it was a profound experience for me. The people who work there are like angels who float six inches off the floor.

I go to the hospice and sing for the patients, which I did every night that my mother was there before she passed. For me, these visits have the deepest spiritual value I could ever imagine. Something happens that’s so magical, that’s so unbelievable, because all ordinary

constructs are gone. People are who they are in their most basic form. They’re not wearing their jewelry. They’re not talking about how much money they made in the stock market or their new car. The only things that matter are the things that really matter. The false value stuff just falls away, and all they’re interested in is being loved and cared about and being able to love. It’s extraordinary how beautiful and spiritual people are in that state, when they’re allowed to die with dignity, allowed to be free of pain and to celebrate this time as a great moment in life — not simply the end of life, but a glorious moment.

Q: Per the lyrics of the Peter, Paul and Mary song, “And When I Die,” do you truly not fear death?

A: That song expressed something the trio all embraced, but it wasn’t so much about not being afraid of dying. It’s saying that life isn’t just there when it’s there and gone when it’s gone. We are connected to each other, part of each other. Mary Travers is dead, but she is in every song that I sing. When I open my mouth to sing, you can hear her in it. There is something beyond what we understand that makes us part of each other. And that song was an assertion that we go on living in others; our lives are continuous.



“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*



You shouldn't have to fight for the care you want, but sometimes you do.

We are here to help.

If you or a family member is having an advance directive ignored, enduring unwanted end-of-life treatments or being denied access to all options, please contact our legal advocacy team.

Use this link to tell us about your situation:
CompassionAndChoices.org/legal-intake-form.