## compassion & choices

Compassion & Choices President: Past, Present and Future

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Our New CEO's Vision

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The Dementia Initiative

**Five Questions for** 

Dr. Haider Warraich

Powerful words and dedication from this author, physician and new Compassion & Choices board member

MAGAZINE SPRING 2018

Warralch, M.D. E HEART CENTER\* Healing hearts

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People need the power of information and options at the end of their lives.



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 <u>CompassionAndChoices.org</u>.

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### inside view



### Embrace Change

Life is nothing if not a constant progression of changes, major and minor, voluntary and inevitable, common and extraordinary. It's time for a pretty big one at Compassion & Choices. After many years of balancing dual roles here — president and CEO — I will

now focus less on the internal day-to-day function of the organization and more on engaging outwardly through dialogue and writing.

Fortunately our ranks already included a person with the ideal mix of talent, heart and passion for managing this work. Kim Callinan, who for three years achieved tremendous success as chief program officer, has accepted the position of CEO; I'll remain as president. I am so very grateful to Kim for bringing her prodigious skills to Compassion & Choices and for her eagerness to step into this role.

You'll hear more about Kim throughout this issue and about other exciting changes: medical societies dropping long-held opposition to aid in dying, medical aid-in-dying bills introduced with an increasingly diverse base of backers, and a brilliant young Harvard-trained doctor — and our newest board member — whose bestselling book about how medicine has changed the way people die encourages a change for the better.

I hope and trust our Compassion & Choices family will walk into this new phase with open hearts and hope for an even brighter future ahead.

Barbara Coombs Lee, PA, FNP, JD

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President



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### words & pictures

### The Orange County Register

"Medical Aid in Dying Is a Christian Option to Stop End-of-Life Suffering"

bit.ly/christianoption

The Rev. Sergio Camacho of Compassion & Choices Latino Leadership Council explained why he signed a letter from 59 faith leaders to members of Congress opposing measures that would jeopardize medical aid-in-dying laws nationwide: "We all need to accept the fact that the spiritual truth for each individual will vary and that the end-of-life option care each terminally ill dying person decides is best for them needs to be honored and respected," he wrote.

### **NPR**

"Should Patients With Dementia Be Able to Decline Spoon-Feeding?"

bit.ly/dementiapatients

NPR reported that patients with dementia are kept alive with spoon-feeding, even when they have advance directives in place opposing it. Compassion & Choices Staff Attorney Jonathan Patterson told NPR, "The hard part about advance directives is even though you put your wishes there, it doesn't mean a medical professional will honor it, or that a facility will honor it."

### **Boston Globe**

"Massachusetts Medical Society Ends Opposition to Physician-Assisted Suicide, Adopts Neutral Stance"

bit.ly/mmsstance

Last December, the Boston Globe reported that the Massachusetts Medical Society voted to drop its longstanding opposition to medical aid in dying. Dr. Roger Kligler, a retired Falmouth physician and medical society member with stage IV cancer, concluded, "This is ... a game changer."

### Baltimore and D.C. AFRO-American

"Why We Must Fight the Effort to Repeal D.C.'s Death With Dignity Act"

bit.ly/mustfight

Donna Smith, Compassion & Choices D.C. Access Campaign public outreach manager, wrote that watching her close friend Pam die in overwhelming pain from breast cancer inspired her to advocate for the D.C. Death with Dignity Act. Smith concluded, "It's our responsibility to tell our Maryland senators ... to stop this congressional overreach and stand with D.C. residents."

### **Ensuring Compassion & Choices' Enduring Legacy**

In a video commemorating Barbara Coombs Lee's new focus on her community-facing role as president of the organization, and Chief Program Officer Kim Callinan's transition to CEO, both women talk about the work before them and that which lies ahead.





### Harvesting the Learnings of a Lifetime

As President Barbara Coombs Lee settles into her new role, she reflects on Compassion & Choices' past and shares some of her plans going forward.



Barbara Coombs Lee (top center) was a member of the original Oregon Right to Die campaign. The staff are shown here after their 1994 victory passing the nation's first medical aid-in-dying law.



Barbara Coombs Lee (right) gives testimony in the court case *Morris v. New Mexico* with oncologist Dr. Katherine Morris (center) and patient plaintiff Aja Riggs (left).

By Barbara Coombs Lee

What I'm probably most proud of over the last 25 years is my ability, my doggedness really, to stick to our roots. This movement is by, for and about people. Our "true north" has always been the patients whom we serve and the work we do enabling them to live their values and beliefs, and advocate for themselves in healthcare decisions.

People are the agents of change. Institutional reform — the reform of medicine — comes because people's habits, expectations, understanding and range of options change. Our focus has never wavered. It's individuals, not institutions, who will make the difference, who will spark the transformation of medical care.

In narrowing my function to president of Compassion & Choices, I'm most looking forward to expanding a conversation about the meaning of this movement, for individuals and for society as a whole. This conversation will happen with our supporters and with people of influence and authority throughout the nation.

Related to that, I hope to complete my second book this year. It's not a "tell-all" or a history, which is what publishers and agents encouraged me to write. It's a practical book to empower people to approach the end of life with a different attitude and relationship with their medical providers. I'd like readers to come away feeling they can be in charge of their life's course and maintain their unique personhood to the end, through any illness, including Alzheimer's.

It's time to harvest the learnings of a lifetime, to immerse myself more in the external community, to raise the visibility of Compassion & Choices and to deepen people's understanding of the profound importance of this movement. I hope to connect with many of you in the coming months.

# Helping People With Dementia Get the Care They Want

A donor's generosity ignites change with the potential to help millions.



By Alyson Lynch

When talking to Americans about the end of life, the ravages of dementia come up often in stories of stricken loved ones or in admissions of deep fear of the disease. According to the Alzheimer's Association, 1 in 3 seniors die with Alzheimer's or other forms of dementia. A person can live with dementia for 8 to 10 years, drawing out an already agonizing dying process.

Fewer end-of-life options are available to people with dementia as they lose cognition — medical aid-in-dying in particular. Eligibility criteria allow only mentally capable, terminally ill adults to request it. And though we strongly believe access should not be extended to people with advanced dementia, more must be done to enable them to realize a dignified death.

Compassion & Choices has long sought to reduce the terrible outcomes associated with this ailment. Our exclusive Dementia Provision, which we have offered for years, may be added to any advance directive to state a person's care priorities should they be unable to communicate them in the face of Alzheimer's or other forms of dementia. Now we are at the beginning stages of creating additional tools and resources to help people with dementia get the care they want and have a more peaceful end-of-life experience.

We are grateful to Jerri Lea Shaw, Compassion & Choices board member and longtime advocate, for her generous gift to underwrite the initial phase of work on our dementia initiative. "I made this gift because someone in my family is in the beginning stages of dementia, and so many individuals with whom I have talked are also beginning this difficult journey with family members," said Jerri. "I believe people have an undeniable right to identify and articulate their values and priorities while they are still mentally capable, and to access tools that will help them and their families negotiate with the healthcare system to abide by those preferences. I know I will want this for myself if the time comes, and I dearly want it for those I love. It is an honor to support this initiative."

## Compassion & Vision

Listing someone's past accomplishments tells you only so much about them. Certainly Kim Callinan's experience — two decades working collaboratively with others to engineer social change, such as reducing the number of uninsured Americans and improving children's health; running political campaigns at the federal, state and local levels; and leading the programs at Compassion & Choices for the past three years, during which we've realized unprecedented progress — provides an excellent foundation for the work that lies ahead in her new role as Compassion & Choices CEO.



### In Kim Callinan's Own Words:

ack in 1992, I was a staff person working on a convention at which four woman governors came to speak, and one of them was Barbara Roberts. I stood on the convention floor and was absolutely mesmerized by her. I still to this day can remember her up there. She was small, but her size did not stop her. She was powerful and inspiring. She spoke about the importance of public service and how one person can make an impact. I have carried that speech and memory with me throughout my whole career. She left such an impression on my life early on, and now to have her so deeply involved in the issue that I'm advocating for, there's something that feels special about that.

I started my career, like many young people, wanting to make a difference in the world. So I came to D.C., got my master's in public policy and simultaneously began working in electoral politics. After a decade, I worked to bring change through large social-marketing initiatives. From there I was recruited to run a large public health practice in a government consulting firm. After eight years of consistent increases in responsibility and compensation, I realized that my career success was not bringing me life satisfaction. So about three years ago, with the support of my family, I followed my heart and passion to Compassion & Choices to serve as its chief program officer. It was one of the best decisions of my life. Every day, I get to work side by side with talented, hardworking and passionate staff and supporters, while helping to realize a world that recognizes and respects the basic human right of autonomy and dignity at the end of life. It has been an absolute honor to serve as the chief program officer, and I'm both humbled and thrilled to take on my new role as CEO.

Something I've learned is that no problem is too big to solve if the right people are helping to solve it. My approach is to identify smart people who know far more than I do, and figure out how to inspire them to get involved and contribute their time, talents and



Kim (left) with former Oregon Governor Barbara Roberts at the 20th anniversary celebration of the passage of Oregon's Death With Dignity law.



When I read Kim's résumé, it seemed to me her career had been one long apprenticeship preparing her to lead the movement for end-of-life choices. She has a unique, vital combination of strong management abilities and a visionary perspective. We are very lucky to have her.

- Barbara Coombs Lee, President



resources. As we have proven in California, Colorado and Washington, D.C., when the movement comes together, we win.

Looking to the future, I think it is completely achievable that in 10 years half the country will have access to medical aid in dying. But that's just the beginning. The authorization of medical aid in dying is serving as a catalyst to transform the medical system, so that the patient is the ultimate decider in regard to their healthcare. If you think about the kind of change that has been realized in the childbirth movement, and the recognition of the patients' voice in their care, that is the kind of change that is underway in end-of-life care.



### Transforming End-of-Life Care

"Compassion & Choices is leading a revolutionary shift in end-of-life care from a paternalistic system to a patient-driven model reminiscent of the recent evolution in childbirth."

That's the conclusion of Compassion & Choices' new CEO, former chief program officer and mother of two Kim Callinan, in an op-ed entitled "People Should Have Choices as Their Life Is Ending," published December 26, 2017, in the Republican of Springfield, Mass. The following is a modified excerpt.

Before my son was born 17 years ago, I researched the type of childbirth I wanted. My husband and I discussed the options. We wrote a birth plan. We reviewed it with our medical team. And our medical team made decisions with our preferences in mind.

The result? A healthy baby boy was born with minimal interventions.

I had a very different childbirth experience with my son than my mother had birthing me 30 years earlier. She had no plan. She had no options. She had no support. She was alone. Strapped to a bed, doped up on drugs, she remembers nothing. Over that 30-year period, an enlightened generation of women

Kim Callinan as an infant with her mom, Connie Callinan, in 1970.

became adamant about shaping a much different experience of options, with partners heavily involved and a collaborative relationship with doctors around every aspect of pregnancy.

The pressure from women and their partners was so intense that the system yielded. There was a seismic shift from a paternalistic health system that completely discounted the preferences of pregnant women and fathers to a patient-driven system that recognized a patient's values should guide medical decisions.

Imagine if we could have that same type of transformation for the end of life: if a person could write

their own plan, decide when and where they die, decide who they want with them when they die — and determine how much pain they're willing to endure, even if that means accelerating their time of death.

Imagine if the default mode at the end of life was for doctors to assume the patient's values are paramount. That future is possible. In fact, I would suggest that we are in the midst of this transformation.

For decades, medical societies have strongly opposed the passage of medical aid-in-dying laws. In fact, they served as a primary obstacle to securing the authorization of this humane end-of-life care option.

In June 2015, the California Medical Association dropped its 28-year opposition to medical aid Imagine ... if a person could write their own plan, decide when and where they die, decide who they want with them when they die ...

in dying and adopted a neutral position. Since that time, eight other medical societies have followed suit: Colorado, the District of Columbia, Maine, Maryland, Minnesota, Nevada, Vermont and now Massachusetts.

Importantly, the changed positions by the medical societies in California, Colorado and the District of Columbia paved the way shortly after for the authorization of the practice in those jurisdictions.

This trend is an indication that state medical societies are catching up to the values and expectations of their patients and physicians. According to dozens of

surveys, about 7 out of 10 adults support medical aid in dying.

In the same way that childbirth plans have transformed the relationship between doctor and patient for the entire pregnancy to a patient-directed relationship, the adoption of supportive medical aid-in-dying policies changes the relationship between doctor and patient to a patient-directed relationship for all end-of-life care decisions.

This seismic shift indicates that in the not-too-distant future, and hopefully within my lifetime, the medical system will afford patients the same type of respect at the end of life that we now have at the beginning of life. This change will once again come because patients themselves are demanding it.

TTTTT
Nearly
7 in 10
Americans
say medical
aid in dying
is "morally
acceptable."

To view writings and interviews from Kim Callinan, visit <u>bit.ly/KCallinan</u>.

### The Power of Local Impact

Across the country, Compassion & Choices advocates are mobilizing in their communities to engage local governments and organizations in passing resolutions or proclamations in support of medical aid in dying for terminally ill people who want the option.

Resolutions send an important message about the urgency of end-of-life options and show state legislators that other levels of government are supporting medical aid in dying. These actions also inspire other local elected officials across states to do the same and empower legislators to back medical aid-in-dying laws by demonstrating overwhelming support of their constituents. Here are a few states currently making an impact at the local level.

### **ALASKA**

In December 2017, the Girdwood Board of Supervisors voted unanimously in support of medical aid-in-dying legislation in Alaska. Girdwood is the first jurisdiction in Alaska to endorse medical aid in dying. This resolution was transmitted to Girdwood's elected representatives in the state Legislature. Rep. Harriet Drummond (D-Anchorage) plans to reintroduce her medical aid-in-dying bill in 2018.

### **HAWAl'I**

On January 11, the Hawaii State AFL-CIO, the state's largest labor union, passed a resolution in support of Hawaii's end-of-life options campaign by a unanimous vote.

After 20 years of working in Hawai'i to pass medical aid-in-dying legislation, Gov. David Ige signed the Our Care, Our Choice Act, on April 5, 2018. This makes Hawai'i the seventh state and eighth jurisdiction to authorize medical aid in dying. We have already launched a Hawai'i Access Campaign to ensure effective implementation when the law takes effect on January 1, 2019.

### **MASSACHUSETTS**

Massachusetts closed out 2017 by passing three resolutions in support of medical aid in dying. This past November, the Northampton City Council became the third jurisdiction in the commonwealth of Massachusetts to pass a resolution urging state lawmakers to pass the End of Life Options Act (H.1194/S.1225). This was followed by Amherst and Lexington. The three resolutions — all unanimous — were transmitted to the governor, the house speaker, the senate president and state legislators representing those jurisdictions.

These build on the 2016 resolutions passed by the Cambridge City Council and Provincetown Board of Selectmen and amplify the voices of Massachusetts voters who overwhelmingly support this critical end-of-life option.

Here's what you can do to help propel the movement forward and protect the progress we've already made together.

- TAKE ACTION to encourage your local government to pass a resolution or proclamation in support of medical aid in dying at CompassionAndChoices.org/take-action
- VOLUNTEER through our Volunteer Resource Center at <u>CompassionAndChoices.org/</u> <u>volunteer</u>
- DONATE to help us protect decades of hard-won progress toward self-determination for the terminally ill in our country at CompassionAndChoices.org/donate

### state spotlights

### Colorado Anniversary

December marked one year since the Colorado End-of-Life Options Act went into effect. Shortly after Compassion & Choices worked with its partners in the state to compile a preliminary look at the law's impact, the Colorado Department of Public Health and Environment released official numbers in February. Sixty-nine prescriptions were written for medical aid in dying, putting Colorado's first year of access on par with states like California and Oregon, adjusting for population differences.

In addition, all major secular healthcare systems in the state now have supportive policies of the law. This helps to increase access for those who need it, with 81 medical facilities and 16 hospice locations on board. According to the official report, 39 individual doctors wrote prescriptions, which is also a good indicator of increasing access.

Reducing suffering is the most important goal of implementation in Colorado. "When we actually got the medication, it was like a weight had been lifted off her shoulders," said Aurora resident Herb Myers



about his wife, Kathy. "She was down to 76 pounds, and she put on four pounds, which was a big deal. She felt so much more at ease with life in general." Kathy Myers is believed to be the first Coloradan to receive a prescription for medical aid in dying. "The fact is, [her death] was very gentle," said Herb.

Compassion & Choices continues to educate medical providers, hospices and Coloradans about the law.

### Oregon: Legacy Health

Twenty years after Oregon voters approved the Death With Dignity Act, Legacy Health, one of the largest healthcare systems in the state, finally adopted a supportive policy to allow their doctors to prescribe aid-in-dying medication. Compassion & Choices worked very closely with Legacy doctors, staff and patients to help make this change possible. We're very grateful for Legacy's leadership and our team's efforts in making this compassionate end-of-life option available to patients.



### national programs update

### **Congressional Threat and Hill Briefings**

Compassion & Choices mobilizes grassroots to battle amendment.



From left to right: Mary Klein, Brandi Alexander, Sondra Battle, Eleanor Holmes Norton, Mary Cheh and Adam Eidinger speak at a Congressional Black Caucus event hosted by Norton.

Compassion & Choices spent July 2017 through January 2018 successfully defending against a harmful U.S. House of Representatives Appropriations bill amendment to overturn the D.C. Death with Dignity Act. The harmful amendment will be an issue again in the future. C&C also faced House Concurrent Resolution 80 (H.Con.Res.80) condemning medical aid-in-dying. While the resolution doesn't have the force of law, it clearly is an attempt by our opponents to build congressional support for banning medical aid in dying even in states where it is already authorized.

**July:** Compassion & Choices' Kim Callinan spoke at a news conference with U.S. Cong. Eleanor Holmes Norton (D-D.C.) and D.C. Mayor Muriel Bowser opposing the House Appropriations bill amendment.

**August:** Compassion & Choices organized a telephone town hall for 5,000 volunteers and a week of action aimed at reaching all 535 members of Congress, particularly from states where medical aid in dying is authorized. Advocates made calls, sent emails and paid in-district visits to build opposition to the bill amendment and identify members who support the practice of medical aid in dying.

**September:** Compassion & Choices' Brandi Alexander spoke at the annual Congressional Black Caucus (CBC) legislative briefing urging CBC members to oppose H.Con.Res.80 and including the bill amendment in the final appropriations bill.

**October:** The National Hispanic Council on Aging endorsed medical aid in dying and announced its opposition to both bills.

**November:** Compassion & Choices released a letter to Congress signed by 59 diverse religious leaders nationwide pressing members to support medical aid in dying and to oppose H.Con.Res.80 and the harmful amendment. Compassion & Choices also hosted briefings for 20 congressional offices, the Congressional Progressive Caucus and the Congressional Hispanic Caucus. C&C will hold a future briefing for the Congressional Asian Pacific American Caucus.

### national programs update

### **Building a Unified Voice**

Compassion & Choices works to give all Americans access to the full range of end-of-life options. In an effort to expand that work, we proudly launched our African-American and Latino Leadership Councils last November.

The successful passage of recent medical aid-in-dying laws can be largely attributed to the hard work by communities of color. We honor those communities through the formation of our African-American and Latino Leadership Councils, which bring together influential voices that will help us further advocate for expanded end-of-life options.

"We could not have passed the laws in California, Colorado and the District of Columbia without the partnership, support and voices of multicultural communities," said Compassion & Choices Chief Executive Officer Kim Callinan. "These councils will guide our efforts to provide culturally appropriate information to terminally ill people to facilitate conversations with their doctors about all their end-of-life care options. That way, they can make fully informed decisions that align with their values."

One of the main goals of the African-American and Latino Leadership Councils is to educate their respective communities on end-of-life care, to empower people to make informed healthcare decisions. "It's important to shift perspectives of hospice and encourage dialogue to occur early and often. We want to change the way the African-American community approaches the end of life," said National Constituency Director Brandi Alexander.

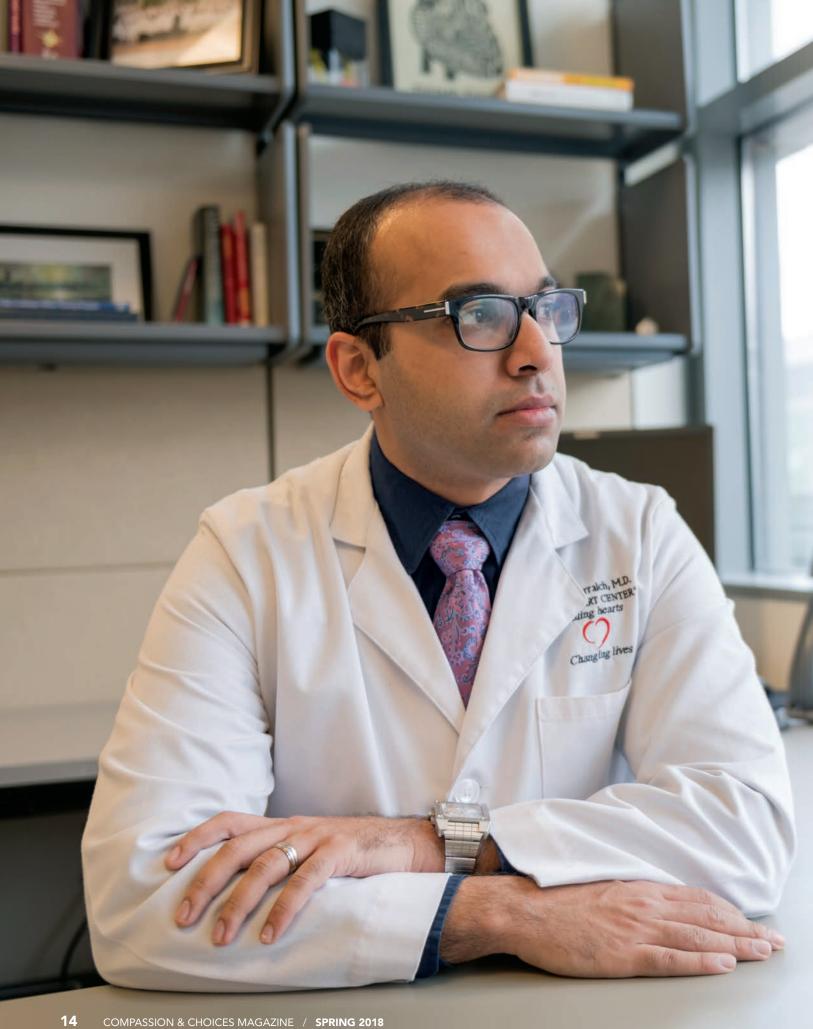
Led by Alexander and National Latino Communications and Constituency Director Patricia A. González-Portillo, the council members represent a range of backgrounds and perspectives. Both national and state polls show strong support for medical aid in dying across the ethnic, political and religious spectrum, including 69 percent of Latinos nationwide and 53 percent of African-Americans.

"Most of our Latino council members already have advocated that terminally ill Latinos from California to Puerto Rico should have access to the full range of end-of-life care options," said González-Portillo. "Their powerful stories about the need for medical aid in dying to peacefully end intolerable suffering have helped strengthen public support for this practice among both Latinos and Latino lawmakers, and they will continue to inspire others to endorse it."

Learn more about our African-American and Latino Leadership Councils, including a list of the members, by visiting <u>CompassionAndChoices.org/people-of-color-for-choices</u>.



Members of Compassion & Choices African-American Leadership Council including (from left to right) Sultan Shakir, Jason Gaulden, Channté Keith and the Rev. Madison Shockley, met with congressional staff in February.



## Five Questions for Dr. Haider Warraich

Compassion and Choices' Newest Board Member

Haider Warraich, M.D., is a cardiology fellow at Duke
University Medical Center and the bestselling author of
Modern Death: How Medicine Changed the End of Life. He
also regularly writes for the New York Times, the Guardian,
the Wall Street Journal and the Atlantic, and serves as a
member of Compassion & Choices' board of directors.



As both a highly regarded doctor and a successful author, what compelled you to pursue a career in medicine?



Before I became a physician, I always considered myself a writer, and I think one of the great things about medicine is that if you're interested in people and their stories, there's no other profession that gives you the privilege of being part of people's lives at really important moments. That has really kept me going, as well. You have these long nights, and you train forever. But whenever you start to question your decision, the patients always remind you of why you embarked on this path in the first place.

### five questions

Q:

How, if at all, have your own views on the end of life changed over time?

**A**:

One of the big things that happened while writing my book was that I read more about medical aid in dying and about patients who wanted that option, and it made me fully come out in support of aid in dying. After doing all the research, I came to the conclusion that physicians should be helping patients who have a terminal illness and want to have some form of autonomy in what the end might look like for them.

Q:

We are thrilled to have you on our board of directors. Why did you decide to join?

A:

The opportunity to be on the board is a great honor for me. No other movement is as patient-centered as the expansion of end-of-life options, and Compassion & Choices has done such a great job of championing the movement from the ground up and at national and state levels. What I've learned firsthand is that everyone on that board cares deeply about patients: about patient rights, autonomy and dignity. And it's more than a board; it's like a family. So it's really been a wonderful experience for me so far.



Do you have any thoughts on the organization's recent executive transition?

A:

Barbara is the heart and soul of this movement. But when I met Kim at a recent board meeting, I was left with no doubt that we are in the best of hands. Kim brings her own personality and leadership style to this organization, and I have only the highest degree of confidence in this transition.

Q:

Your book, *Modern Death*, illustrates how life's end has changed drastically in the last century, and not for the better. Is there a clear path to improving how people experience death?

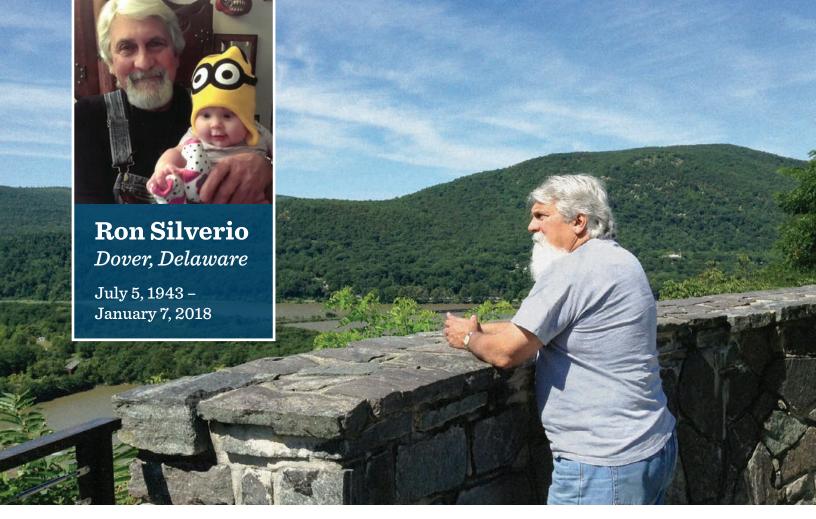
A:

In many ways, we are living that improvement as we speak. What's changing how patients experience the end of life is really giving them a better position when it comes to decision-making, giving them a stronger voice when it comes to dictating what kind of care they would like and giving them a better view of what the end of life could look like. This is why I wanted to write the book. I didn't want people to have to live through it themselves to understand what goes on.

I think already we've seen a lot of changes, such as the proliferation of advance directives and healthcare proxy documentation, the emergence of the entire field of palliative care, and the growth of the aid-in-dying movement. Just during these past few years, we've made so much progress, and I think as medicine continues to become more patient-centered, we'll continue to see an evolution.



Haider with his wife and their child holding his book Modern Death.



### **RON SILVERIO'S PLEA:**

"Medical aid-in-dying legislation would enable me to get on with living my last days instead of worrying about how I'm going to die."

Even as Ron Silverio battled terminal prostate cancer, many of his final days were spent advocating for the Delaware End of Life Options Act. Although Ron died without the access to medical aid in dying he so desired, his story will continue to influence lawmakers and the public as we continue his fight.

Do you have a compelling story about living with an advanced illness or the end-of-life care of a loved one?

Visit <u>CompassionAndChoices.org/stories</u> to learn more about Ron and submit your story today.





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### A Life Well Lived

Monique Bondeux, a remarkable person with enthusiasm for life, art and choice, was a tireless advocate for end-of-life options. For her memorial service, she wrote, "I always believed that dying was a part of living."

Her Living Trust gift to Compassion & Choices carries on her legacy of support for options at the end of life.



If you would like to create a Legacy gift for Compassion & Choices in your will, living trust or other estate plan, please contact Ken Williams, director of planned gifts, at **720.245.5576** or <a href="mailto:kwilliams@CompassionAndChoices.org">kwilliams@CompassionAndChoices.org</a>.