

compassion & choices

MAGAZINE
FALL 2017

In the Courts and on
the Ground: Advocates
Fight for Options

.....

California: One
Year Later

.....

Changing Our Healthcare
System From the
Inside Out

Jorge Ramos

How a Giant of Latino Media Propelled
the End-of-Life Options Movement

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

– Kathy Cerminara, Florida



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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.



United We Withstand

By now we understand challenge follows victory. The bigger the victory, the bigger the resulting challenge. We pass a law, then must ensure people can access it. We may succeed in inspiring and equipping people to define their healthcare priorities, but

we still need to persuade doctors to heed those wishes. And at every turn we confront single-minded opposition, eager to dismantle our progress. These are big tasks — far bigger than any organization could take on alone. Success depends on an ever-widening swath of supporters and volunteers. This is our strength.

In this issue of Compassion & Choices Magazine, you'll read about some of these indispensable allies. Devoted doctors prod medical societies to reverse old and dismissive attitudes toward end-of-life autonomy. Influential figures like Jorge Ramos help us reach through barriers of language and culture. Thousands more help in myriad ways.

How great it feels to see this movement grow and expand, affecting all, reaching across boundaries of heritage, geography, politics and age. Thank you for joining us. There's plenty to keep everyone busy.

Barbara Coombs Lee, PA, FNP, JD
President

compassion
& choices

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Associated Press

Judge Allows Lawsuit on Life-Ending Drugs for Terminally Ill

bit.ly/AP17Fall

In June 2017, a year after California's medical aid-in-dying law took effect, a Riverside, California, judge ruled that a lawsuit disputing the legality of the End of Life Option Act can move forward. Kevin Díaz, Compassion & Choices' national director of legal advocacy, feels confident the law will prevail and told reporters that it is unfortunate the plaintiffs are "trying to impose their beliefs on people who are suffering unbearably at the end of life."

Univision

The Legacy of Miguel Carrasquillo, a Young Man Who Fought Until Death for His Right to "Die With Dignity"

bit.ly/univision17fall

As 35-year-old Miguel Carrasquillo took his last breath in 2016, he urged fellow Latinos to embrace the option of medical aid in dying to prevent the unbearable suffering he experienced because it was not available to him in his native Puerto Rico, nor in his former home states of Illinois and New York. Emmy Award-winning Univision anchor Jorge Ramos spoke to Nilsa Centeno, Miguel's mother, and Patricia A. González-Portillo, Compassion & Choices' national Latino communications and constituency director, one year later.

Dallas Morning News

Doctors Ignored Dying Mom's DNR Order, Family Says in Suit Against Methodist Health

bit.ly/dms17fall

Sally Jordan was kept alive by machines for 10 days despite a clear do not resuscitate, or DNR, order in

her living will. Now, with the help of Compassion & Choices' legal team, her children, James Jordan and Amanda Norris, are suing the hospital that ignored her wishes. "Our mother's dying wish was to make sure that no other family would have to experience what we had to experience," Jordan told the Dallas Morning News, one of the largest media outlets in Texas.

American Medical Women's Association Blog

Judge Gorsuch Is Wrong for Supreme Court on Medical Aid-in-Dying Issue

bit.ly/amwa17fall

Dr. Omega Silva, former president of the American Medical Women's Association, wrote this thought-provoking piece on why she opposed the nomination of Supreme Court Justice Neil Gorsuch. Gorsuch famously wrote a book opposing medical aid in dying, compelling Compassion & Choices and our supporters to fight against his nomination. As Dr. Silva wrote, "This stance should trouble anyone who values freedom and privacy to make their own decisions about end-of-life care."

Yahoo! News

Will Congress Let Mary Klein Decide How to Die?

bit.ly/yahoo17fall

Yahoo! News chronicled the process of authorizing medical aid in dying in Washington, D.C., and interviewed Mary Klein, one of the most visible advocates for end-of-life options in the city. Klein was diagnosed with ovarian cancer in 2014 and has attended hearings, met with council members and sat for countless interviews. But Klein's battle isn't over. Congressional opponents continue to threaten the law, first by attempting to override it and now by attempting to repeal it.



The *Power* of an Anchorman Known as Jorge

Educating the Latino community about end-of-life options is key to advancing the movement.

By Patricia A. González-Portillo

In 2016, as my friend Miguel Carrasquillo lived his last days, I reached out to Univision anchor and Emmy Award-winning journalist Jorge Ramos. Miguel, a 35-year-old former chef who had lived in New York and Chicago, was dying of brain cancer. Miguel had recently recorded bilingual interviews to urge fellow Latinos to support medical aid in dying to end the kind of unbearable suffering he was enduring because the option was not available to him.

Jorge's crew arranged a satellite interview from Puerto Rico — an interview that would be Miguel's last and a platform to reach millions of Latinos before his death on June 5, 2016. Jorge remembers his time with Miguel in great detail. "This has been one of the toughest interviews I have had to do," Jorge tweeted afterward.

Miguel proudly referred to himself as the "Latino Brittany Maynard" because he was inspired by the 29-year-old Californian who also had terminal brain cancer and who had moved to Oregon to access its Death With Dignity law in 2014. Latino support for medical aid in dying has dramatically increased in the United States since Miguel spoke out for this end-of-life option. Bills to authorize medical aid in dying have been introduced in more states with large Latino populations, including Colorado, where voters passed a law in 2016. In addition, more Latino lawmakers nationwide are sponsoring bills. But getting here has not been easy.

Winning in California

In 2014, Compassion & Choices launched a Latino media campaign in California, where Spanish-speaking residents represent 38 percent of the state's population. Their support is critical to passing any legislation. Our goal was to educate and mobilize Latino voters to garner their support for passing California's End of Life Option Act.

We tailored our bilingual communications to create personal stories that would connect with Latino voters and inoculate them against the Catholic Church's fear-based misinformation campaign. We successfully pitched stories featuring our Latino advocates, resulting in multiple interviews with national Spanish-language media giants Univision, Telemundo and La Opinión. We also recruited labor leader and civil-rights icon Dolores Huerta and actor, director and activist Edward James Olmos.

And we got Jorge Ramos on board.

Jorge, the voice of nearly 12 million Latinos, wrote special segments that exclusively focused on medical aid in dying. He publicly endorsed the California End of Life Option Act in an interview with Dan Diaz, Brittany Maynard's husband, before the bill was signed into law in October 2015. Jorge reiterated his support for laws authorizing medical aid in dying by writing an editorial in support of Brittany's decision to die peacefully.

By the end of the California campaign, Compassion & Choices had reached millions of people via Latino media outlets that had once been reluctant to cover our issue because their audience is predominantly Catholic. And more importantly, our outreach spurred a national conversation on end-of-life options among Latinos. But we needed more.

"One of the Toughest Interviews"

Jorge Ramos has been a widely respected journalist for over three decades. Millions of people tune in to his daily newscast and weekly political show, "Al Punto" ("To the Point"). In recent years, Jorge's audience has exceeded those of each of the four

main English-language networks. In 2015, the 59-year-old Mexican journalist, known as the "Walter Cronkite of Latin America" or the "voice of the voiceless" for immigrants like him, was on the cover of Time magazine as one of its "100 Most Influential People."

Jorge's voice cracked when he said goodbye to Miguel, who died 10 days later.

In March 2016, I traveled to Puerto Rico to meet Miguel Carrasquillo. Weeks later, Compassion & Choices launched a national bilingual campaign to introduce the world to Miguel. Miguel's story was featured in *People en Español*, and overnight he became a household name for journalists who referred to him simply as "Miguel." Then in May, I arranged what would become Miguel's last interview on Jorge's show — one that Miguel thought of



Jorge Ramos, one of the most recognizable faces in the Latino community, has anchored "Noticiero Univision" for more than three decades. He has won eight Emmy Awards and has written more than 10 books.

After his interview with Miguel Carrasquillo, Ramos tweeted that it was "one of the toughest interviews I have had to do."

canceling that morning because he could barely open his eyes. But Miguel proceeded, at times mumbling his responses. Jorge's voice cracked when he said goodbye to Miguel, who died 10 days later. "Miguel Carrasquillo, 35, didn't die as he wanted," read Jorge's editorial, which ran throughout the world in English and Spanish. "He died in pain after enduring months of agony."

Latino Support for Medical Aid in Dying

When Colorado voters passed the End-of-Life Options Act in November 2016, a majority of Latinos supported the legislation, according to exit polling conducted for the Associated Press. As Miguel's story continued to resonate among this population, we kicked off a bilingual campaign in Colorado to educate terminally ill Coloradans, families and medical providers about the benefits and requirements of the state's new medical aid-in-dying law. Weeks later, we launched a Latino campaign with Miguel's mom, Nilsa, in New York during a Dia de los Muertos event to honor departed New Yorkers.

In December 2016, we learned that 69 percent of Latinos support medical aid in dying, according to an online survey conducted by LifeWay Research. In March 2017, People en Español published a two-page spread in advance of the anniversary of Miguel's death highlighting the new statistic. The story also noted the support for medical aid in dying by popular Mexican actor Mauricio Ochmann, who recorded public service announcements for Compassion & Choices.

Miguel's Legacy

On June 5, 2017, Compassion & Choices released bilingual videos to commemorate the one-year anniversary of Miguel's death. Nilsa and I traveled to Miami for interviews with Latino media outlets, including CNN en Español and the Telemundo network. Our final stop: the Univision studios for an interview with Jorge.



To learn more about Miguel and his legacy, please visit CompassionAndChoices.org/miguel.

Patricia A. González-Portillo, Compassion & Choices' national Latino communications and constituency director, captures a selfie with Miguel Carrasquillo.

Jorge spoke about Miguel's legacy and the six states with large Latino populations that have either passed or introduced laws to authorize medical aid in dying since Miguel's death (Arizona, Colorado, Nevada, New Jersey, New Mexico and New York). Latino lawmakers are sponsors of legislation in four of those states.

After the interview, Jorge embraced Nilsa and thanked her for continuing Miguel's mission. "Miguel made a difference," Jorge said, as Nilsa fought back tears. "This is his legacy. Thank you for allowing me to tell his story." ■

Patricia A. González-Portillo is the national Latino communications and constituency director for Compassion & Choices. She is a former journalist for *La Opinión*, the largest Spanish-language newspaper in the United States; the *[Riverside, California] Press-Enterprise* and the *Brownsville [Texas] Herald*.

California End of Life Option Act: Celebrating One Year Since the Law Took Effect

Personal stories and statistics show the law is working well. But the effort continues.

One year after the California End of Life Option Act — catalyzed by terminally ill medical aid-in-dying advocate Brittany Maynard — took effect, data compiled by Compassion & Choices show the law is working very well, just as state residents and lawmakers intended. Data released by the California Department of Public Health on the first six months of the law's implementation supports this conclusion (bit.ly/CalifAnnivData).

"We won't have the full picture until the state releases its data about how many people have utilized the law during the last year, not just the first six months. But we have enough evidence to show it is working remarkably well in a state with 10 times Oregon's population," said Compassion & Choices' Multistate Implementation Manager Matt Whitaker. "The personal stories of the people who have utilized the law show it has provided comfort and relief from intolerable suffering, just as the state Legislature intended it to do."

Retired Manhattan Beach psychologist John Minor, Ph.D., is a good example. He used medical aid in dying on September 15, 2016, to peacefully end his suffering from interstitial pneumonitis, a terminal lung disease, at age 80.

"Though he didn't wish to die, he no longer had to fear the worst in the manner of his dying," said his daughter, Valerie Minor-Johnson. "Our father's gratitude toward Compassion & Choices and the legislators who stood behind them swelled with enormity. We had the rare and powerful opportunity to let each other know how much love we had for each other, say our goodbyes and be there for our dad's final moments. We have not one regret."

Despite the law's success, opponents are trying to overturn it in court. See page 11 to learn more.

Compassion & Choices continues to provide education to the public and healthcare professionals

through its bilingual access campaign, to ensure that every eligible terminally ill person who wishes to access the law can. In states where medical aid in dying is authorized, Compassion & Choices works to integrate it into the medical standard of care through our access campaigns, which ask health systems, hospices, clinics, health insurance companies and other healthcare providers to adopt policies that support patient choice. And we have had an impressive impact: In California alone, we worked with nearly 500 healthcare facilities and more than 100 hospices to help ensure that terminally ill patients under their care can access the option afforded under the End of Life Option Act.



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Healthcare Facilities Supportive of Patient Choice

(e.g., Kaiser Permanente, UCSF, Stanford, Tenet, Sutter, UCLA)



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Hospice Locations Supportive of Patient Choice

(e.g., Vitas, Seasons, Gentiva)

ADVOCACY IN ACTION

Supporters Continue to Power Progress in 2017

The first half of 2017 concluded with a burst of action: Medical aid-in-dying bills popped up in 26 states across the country.

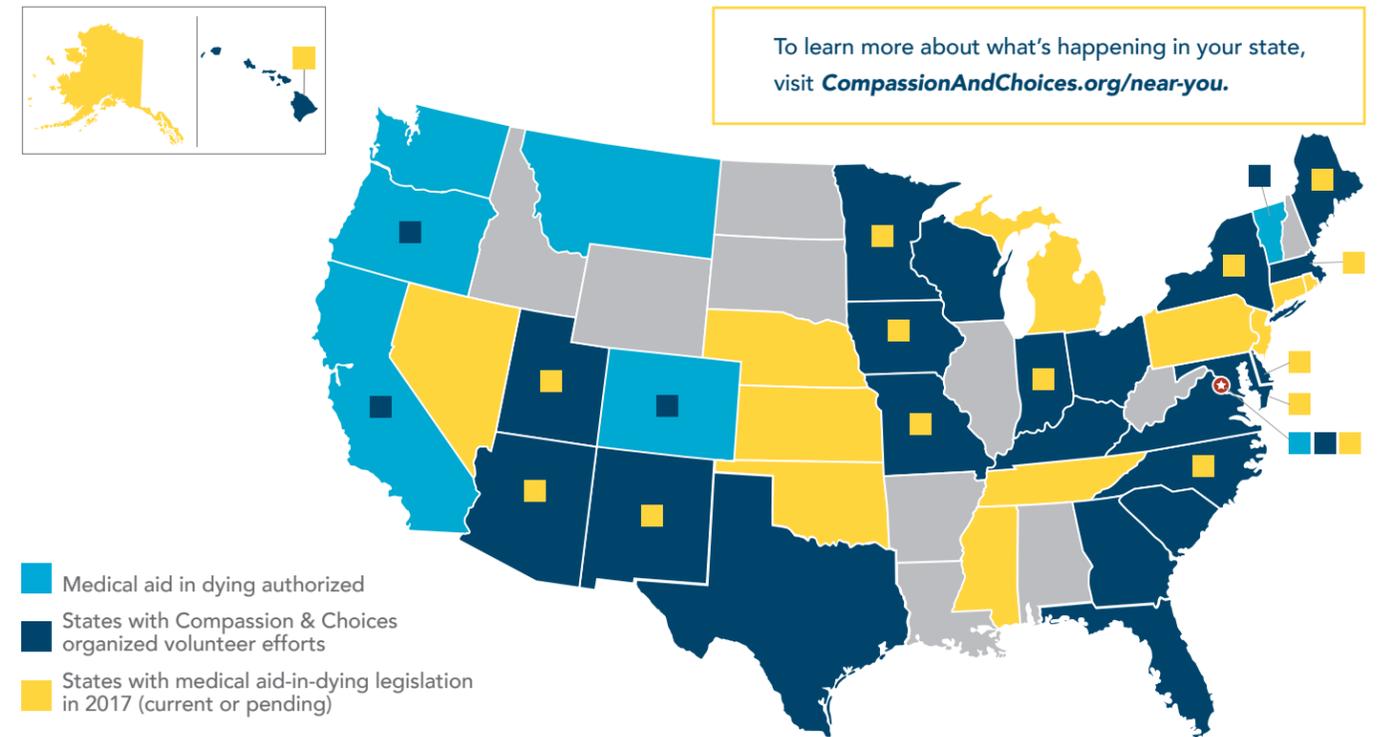
Victories in Colorado and the District of Columbia at the close of 2016 marked a historic moment for the end-of-life options movement. Medical aid in dying is now authorized in seven U.S. jurisdictions. For the first time, two laws were passed in the same year.

But we also face the biggest threats in the history of the movement. Even though a 2015 Lake Research poll showed two-thirds of Washington, D.C., residents supported the D.C. Death with Dignity Act, President Trump's proposed budget specifically states that no funds be appropriated to carry out or implement the law. Furthermore, on July 13, 2017, the U.S. House of Representatives Committee on Appropriations approved an amendment by U.S. Cong. Andy Harris (R-Md.) to repeal the D.C. Death with Dignity Act. Congress had a chance to repeal the law in February 2017 during a 30-day legislative review period, but that effort failed. Harris is now misusing the appropriations process to block funding to implement the law and even seeking to repeal it, violating the autonomy of Washington, D.C., residents. If this federal power grab succeeds, it would set a dangerous precedent that could embolden congressional opponents to ban medical aid in dying nationwide. Such a ban

would invalidate laws in six states, representing 18 percent of the nation's population, where medical aid in dying has been practiced safely for more than 40 years combined: Oregon, Washington, Montana, Vermont, California and Colorado.

Compassion & Choices served as the only representative of the end-of-life options movement at a news conference on July 10, hosted by U.S. Cong. Eleanor Holmes Norton (D-D.C.) and D.C. Mayor Muriel Bowser, designed to outline the risks to local D.C. laws during the fiscal year 2018 appropriations process.

Compassion & Choices will continue to prioritize the protection of medical aid-in-dying laws. Thanks to our dedicated supporters, advocates and policymakers, we are successfully defending against the threats while continuing to propel the movement forward. In 2017, advocates sprang into action to attend hearings, submit testimony and share their personal stories. The issue remained front and center in the media; we advanced legislation further than ever before in several states; and we laid the groundwork for continued progress in 2018 and beyond.



Our efforts helped move legislation in 26 states this session. Here are updates on just a few of them.

ALASKA

The medical aid-in-dying bill HB 54 was introduced by Rep. Harriet Drummond (D-Anchorage), and a hearing was held in the House Health and Social Services Committee on April 6, bringing the topic to the forefront of legislators' and voters' minds. Compassion & Choices testified about the merits of the bill and described how end-of-life care improves when a medical aid-in-dying law has been authorized.

DELAWARE

Championed by Rep. Paul Baumbach (D-Newark), the Delaware End of Life Options Act (HB 160) passed out of the House Health and Human Development Committee by an 8 to 6 vote on June 7.

Although it was not voted on by the full House of Representatives before the close of Delaware's 2017 legislative session, the bill moved out of committee, marking the furthest a law of its kind has ever advanced in the state. Thanks to the hard work of

How to Mobilize in Support of End-of-Life Options

We need your voices to be heard. Here's what you can do to help propel the movement forward and protect the progress we've already made together.

- » **TAKE ACTION** by sending a letter or email to your member of Congress telling them to oppose any amendment to repeal Washington, D.C.'s Death with Dignity Act: CompassionAndChoices.org/protect-dc.
- » **VOLUNTEER** through our Volunteer Resource Center at: CompassionAndChoices.org/volunteer.
- » **DONATE** to help us protect decades of hard-won progress toward self-determination for the terminally ill in our country at: CompassionAndChoices.org/donate.

advocacy in action

Compassion & Choices supporters and volunteers and the bill's sponsor, Rep. Baumbach, it will retain its place on the legislative calendar for the upcoming session in January 2018.

MAINE

The Maine Senate advanced LD 347, a medical aid-in-dying law, by a vote of 16 to 15. In 2015, end-of-life options legislation lost by a single vote in the Senate. This year, it won by a single vote. Such legislation had never received an affirmative vote in the Senate before this year.

NEVADA

In May, the Nevada Senate approved medical aid-in-dying legislation (SB 261) introduced by Sen. David Parks (D-Las Vegas) by an 11 to 10 vote. The Nevada Assembly Committee on Health and Human Services chose not to advance the bill on June 6, the last day of the legislative calendar. This is the furthest a law of this kind has ever advanced in Nevada.

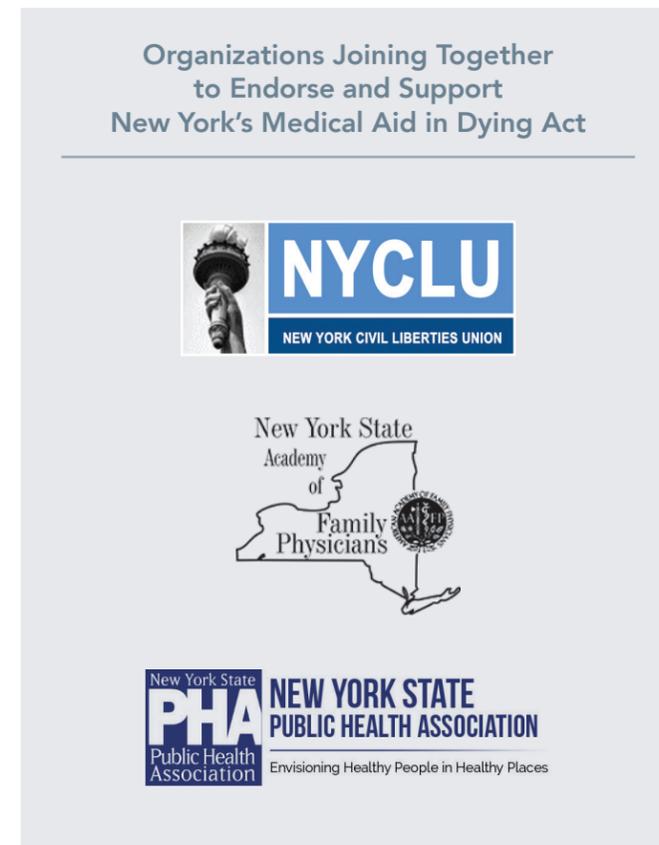
NEW JERSEY

The Aid in Dying for the Terminally Ill Act was approved by the New Jersey State Assembly in October 2016 on a bipartisan vote of 41 to 28, thanks to advocates who submitted hundreds of letters to make their voices heard. A Senate vote is pending. With the support of our incredible volunteer force, we are determined to harness this momentum in 2018 to pass a law in the Garden State.

NEW YORK

Much was accomplished by Compassion & Choices supporters and volunteers to advance the Medical Aid in Dying Act in New York during the first half of 2017. A few of the many achievements include nearly doubling the number of bill sponsors from 15 at the start of the year to 29 as of June 2017; garnering support from New York Civil Liberties Union; receiving the endorsement of the New York State Public Health Association; securing a Medical Society of the State of New York vote to survey physicians this fall about their attitudes toward aid in dying; and receiving an endorsement from the New York State Academy of Family Physicians. The New York team continues to travel the state to build the grassroots support needed to move the Legislature to act in 2018.

Organizations Joining Together to Endorse and Support New York's Medical Aid in Dying Act



The image displays three logos stacked vertically. At the top is the NYCLU logo, featuring a torch and the text 'NYCLU NEW YORK CIVIL LIBERTIES UNION'. Below it is the logo for the New York State Academy of Family Physicians, which includes a map of New York and the text 'New York State Academy of Family Physicians'. At the bottom is the logo for the New York State Public Health Association, with the text 'New York State PHA PUBLIC HEALTH ASSOCIATION Envisioning Healthy People in Healthy Places'.

NATIONAL PROGRAMS UPDATE

Defending and Protecting End-of-Life Options in the Courts

Compassion & Choices' legal cases defend and expand access to medical aid-in-dying laws.

Our litigation program is actively pursuing or monitoring cases in more than 10 states. Those currently at hand include:

Ahn v. Hestrin, California

On June 16, a superior court ruled that a lawsuit to overturn the California End of Life Option Act will proceed to trial to determine the case's merits.

Last year, the court accepted a friend-of-the-court brief filed on behalf of Compassion & Choices urging it to deny the plaintiffs' motion for a preliminary injunction. Thankfully, the court rejected the motion, as well as a prior motion for a temporary restraining order, so the law remains in effect for now.

"Overturning the End of Life Option Act would have devastating consequences for terminally ill Californians and their families," said Kevin Díaz, national director of legal advocacy for Compassion & Choices.

Kligler v. Healey, Massachusetts

On June 5, a Massachusetts judge rejected a motion to dismiss a lawsuit filed by Compassion & Choices asserting the state constitution protects, and existing state law does not bar, mentally capable, terminally ill adults from getting a prescription for aid-in-dying medication.

"My wife, Cathy, and I are elated with this initial ruling," said lead plaintiff Dr. Roger Kligler, who suffers from stage 4 metastatic prostate cancer.

"We are pleased with the court's decision because it will allow our clients to challenge the constitutionality of the law without having to take actions that could risk prosecution by an aggressive district attorney," said John Kappos, a partner at the O'Melveny law firm,

"Patients' senseless suffering without this option is equally real."

which together with the Morgan Lewis law firm and Compassion & Choices represents the plaintiffs in the case. "We need the court to clarify the law because the prosecution threat is real to physicians who provide medical aid in dying to terminally ill patients ... and patients' senseless suffering without this option is equally real."

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

Dr. Roger Kligler speaks with the press after a Massachusetts judge affirmed his right to advance the case to decide whether terminally ill patients have a constitutional right to the option of medical aid in dying.



Modern Medicine Comes Around

Medical societies and doctors increasingly support medical aid in dying.

Changing established institutions can be a slow and difficult undertaking, but it's necessary for real progress. The American healthcare system is one of these institutions, and Compassion & Choices has been working with physicians strategically for years to move it toward a more person-centered model — a hallmark of which is medical aid in dying. So, after much perseverance, we're thrilled to be seeing substantial shifts in the official positions of medical societies, powerful authorities on healthcare standards and practice, across the nation.

Nine medical societies have dropped their long-held opposition to medical aid in dying and adopted neutral or supportive stances — eight of them since June 2015. To date, this includes:

- » Oregon Medical Association (1994)
- » California Medical Association (2015)
- » New York State Academy of Family Physicians (2016)
- » Colorado Medical Society (2016)
- » Maryland State Medical Society (2016)
- » Medical Society of the District of Columbia (2016)
- » Nevada State Medical Association (2017)
- » Maine Medical Association (2017)
- » Minnesota Medical Association (2017)

The New York Academy of Family Physicians, in fact, moved from a neutral to a supportive position on medical aid in dying this past summer, noting that a "position of neutrality can have negative consequences for patients and can be viewed as patient abandonment."

“

Supporting the authorization of medical aid in dying is commensurate with the family physician's desire to empower our patients not only in their pursuit of wellness, their management of chronic disease, but also the alleviation of suffering when faced with a terminal illness.

— Dr. Sarah Nosal

President of the New York State Academy of Family Physicians

”

Such turnarounds make room for the ever-growing number of doctors who support medical aid in dying — by a margin of two to one, according to December 2016 Medscape polling data. Medical society approval or neutrality also reduces barriers to access for patients. Even more importantly, this increasing acceptance represents a sea change in the political dynamics around our issues and will help improve the overall delivery of care.

Doctors for Dignity, an initiative of Compassion & Choices, is a nationwide network of physicians who support patient autonomy at the end of life. **To join Doctors for Dignity or to learn more, visit CompassionAndChoices.org/D4D.**



With the pressures of fitting everything into a 15-minute appointment, a new online tool from Compassion & Choices helps you prepare to navigate conversations with your doctor. The Diagnosis Decoder arms you with better questions so you can receive clear information from your doctor and make fully informed treatment decisions.

Visit DiagnosisDecoder.org to generate questions designed to help you get the complete information you deserve. Because no one knows more about what you want than you do.



DiagnosisDecoder.org

TRUTH in treatment™ Truth in Treatment™ is an initiative of Compassion & Choices



A Compassionate Legacy

“We revised our estate plans to include Compassion & Choices because we know they will continue to improve lives long after we are gone.”

– Mary Klein



Make a gift in your will. Email plannedgiving@CompassionAndChoices.org, call **800.247.7421 ext. 2152** or text **720.245.5576** to learn how.

Mary Klein (left) is a retired photographer and journalist who lives in Washington, D.C., with her spouse, Stella Dawson (right). Mary and Stella campaigned tirelessly to pass the D.C. Death with Dignity Act and continue to support efforts to protect the law, which is at risk.