

compassion & choices

MAGAZINE
FALL 2020

A Message for Equitable End-of-Life Experiences

pg. 4

.....

Looking Ahead at End-of-Life Care

pg. 6

.....

Advance Care Planning Amid a COVID-19 Battle

pg. 8

.....

Coronavirus Impact on Delivering Quality Care

pg. 12

Five Questions for James Naughton

Losing his wife to cancer inspired the prolific actor to push for better options in dying.



Betsy Moss, 2019 C&C Volunteer of the Year; Rev. Frank Moss, former chair, C&C Oregon Advisory Board; Rev. Bill Sinkford, C&C Oregon Advisory Board member

“

We contribute through our IRA today and have left a bequest in our will for tomorrow. It is easy to do and a win-win! We believe in supporting Compassion & Choices' mission and ensuring everyone's right to chart their own end-of-life course, now and for future generations to come.

– Frank and Betsy Moss, Oregon, donors since 2010

”

Give Now AND Give Later

Tax savings for you and support of Compassion & Choices now and in the future.

Use an IRA now ...

If you donate directly to a charity from a qualified retirement account or IRA, of up to \$100,000 per year and are 70½ or older, you can support the programs that are important to you at Compassion & Choices and reduce your income taxes.

And a bequest later ...

When you include a bequest provision in your will, you can:

- » change your bequest designation at any time.
- » control the funding property during your lifetime.
- » avoid any potential federal estate tax for your bequest.
- » provide future support for Compassion & Choices.

For more information about gift annuities and planned giving:

Contact Sam Young, ESQ/LSW, Planned Giving Advisor, at 800.247.7421 x2152 or email plannedgiving@CompassionAndChoices.org. Visit our website at CompassionAndChoices.GiftPlans.org.



Care and Choice at the End of Life



FEATURES

04 Black Life Journeys Matter

Civil rights leader Dr. Benjamin F. Chavis Jr. discusses ensuring better outcomes for Black Americans.

06 Looking Ahead: The Future of End-of-Life Choice and Care

Compassion & Choices President and CEO Kim Callinan forecasts what's in store for the movement.

08 Finding Light in the Darkness

COVID-19 heightens the importance of advance care planning for Cecilia Vasquez-Vigil, an otherwise healthy Texas woman.



12 Caring for Terminal Patients in a Pandemic

Healthcare providers on the front lines adapt to the coronavirus pandemic.



DEPARTMENTS

02 Top of Mind

03 Words & Pictures

15 National Programs Update

16 Advocacy in Action

18 Five Questions

Compassion & Choices improves care, expands options and empowers everyone to chart their own end-of-life journey. Learn more at [CompassionAndChoices.org](https://www.compassionandchoices.org).

Reflections on a Period of Unrest

These past several months have been the most disruptive of my time, with two significant crises — one of the deadliest infectious diseases of the century and alarming racial injustices. Both crises have disproportionately impacted racially and ethnically diverse communities. Both crises lay bare the fragility of individual rights and autonomy.

This convergence of these two crises brings the issue of death and dying into sharper focus, as it knows no boundaries. The COVID-19 pandemic has shined a bright light on the limitations and outdated practices within our healthcare system — end-of-life care decisions being made by providers, patients separated from loved ones and dying in hospitals alone. At the same time, the virus is taking a disproportionate toll on diverse communities, joining the many health-care disparities that underserved communities as a whole have historically endured.

As people around the country demand justice and change, we too are demanding changes to remove the injustices within the end-of-life care movement, beginning with making sure the movement reflects the beautiful mix of cultures, traditions and faiths of our nation and giving voice and agency to those who are consistently marginalized.

We are in a period of unrest, the results of which are still left to be decided. We have the power to transform how end-of-life care is delivered so that patients have a voice and choice in the care they receive, including reducing the alarming disparities. Together, we can create a world where Americans can get the end-of-life care they want: nothing less and nothing more.



Kim Callinan

Kim Callinan
President and Chief Executive Officer

Twitter: [@KimCallinan](https://twitter.com/KimCallinan)

compassion
& choices

MAGAZINE

Managing Editor

Bonnie Lawhorn

Art Director

Bhavna Kumar

Staff Writers

Sonja Aliesch
Marci Better
Michael Cavaioia
Sean Crowley
Patrick Donges
Patricia A. González-Portillo
Alyson Lynch
Katie Wingo

Contributors

Kim Callinan
Linda Roth Platt
Tom Quash

Production Manager

Alyssa Cowan

Advertising, Rights and Permission

CompassionAndChoices.org
Magazine@CompassionAndChoices.org

101 SW Madison Street, #8009
Portland, OR 97207

Postmaster

Send address changes to: Compassion & Choices
101 SW Madison Street, #8009
Portland, OR 97207

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: Jamie McCarthy / Getty Images
inside front cover: Owen Carey
p. 1 (top), 9-10: courtesy of Cecilia Vasquez-Vigil
p. 1 (middle), 4: courtesy of Ben Chavis
p. 1 (bottom), 12: Li Zhang
p. 2: Life Unstill Photography
p. 5: Jing Jing Tsong / The i Spot
p. 6: Shannon DeCelle
p. 8: iStock.com/Yuri Arcurs
p. 16 (top): Shevry Lassiter
p. 16 (bottom): J. Emilio Flores
p. 17: Glen Kulbako Photography
p. 19: Nick Caito
p. 20: courtesy of James Naughton
inside back cover: courtesy of Gina Vadnais

In the Media

[Public News Service](#)

"HHS Asked to Rescind End-of-Life Directive Waiver"

May 1, 2020

Compassion & Choices penned a letter asking Health and Human Services Secretary Alex Azar to reverse a waiver that requires patients to be informed of their legal right to fill out an advance directive and accept or refuse treatment. Compassion & Choices President and CEO Kim Callinan said, "Reinstate the Patient Self-Determination Act requirement and instead, take some very specific actions that will result in much more widespread adoption of advance-care planning."

[Los Angeles Wave Newspapers](#)

"Compassion & Choices Prepares People for the End"

May 29, 2020

In May, Compassion & Choices National Director of Constituency Brandi Alexander told the LA Wave that people need to talk about their end-of-life wishes before times of crisis: "Occasions like Thanksgiving and family reunions are happy times; I call it 'talking turkey over turkey.'"

[Huntington Herald Dispatch](#)

"COVID-19 Could Worsen Dementia Health Crisis"

June 17, 2020

June is Alzheimer's and Brain Awareness Month, which was made even more critical given the COVID-19 pandemic and the possibility of a rise in dementia among older adults due to isolation. "Creating a dementia-specific advance care plan lifts the burden

off of loved ones to make difficult decisions when you can no longer speak for yourself," wrote Compassion & Choices President and CEO Kim Callinan in an op-ed. Remember: The actions you take now can preserve autonomy and dignity later." The Dementia Values & Priorities Tool is available at CompassionAndChoices.org.

[Hawaii Tribune Herald](#)

"You can live really well, even when you're dying"; Big Isle doctor says having an aid-in-dying option improves end-of-life care"

July 5, 2020

Dr. Charlotte Charfen, a board certified emergency medicine physician, said that having a medical aid-in-dying law in Hawai'i improves end-of-life care for everyone, not just patients who use the law. The article states, "It opens up conversations between doctors and patients — and patients and families." This benefit has been found in other states where medical aid in dying is authorized.

[NJ.com](#)

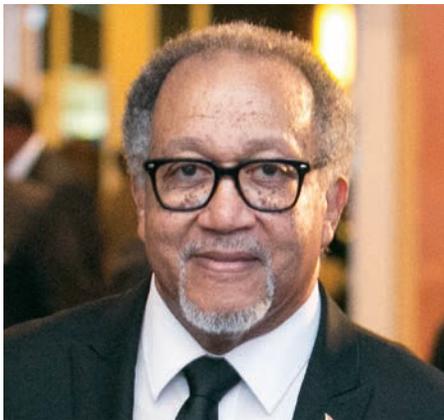
"12 terminally ill New Jerseyans ended their lives using Aid in Dying law last year, state says"

July 31, 2020

The New Jersey Department of Health released new data on the Medical Aid in Dying Act in July 2020. According to the report, 12 terminally ill people used the state's medical aid-in-dying law in 2019. Susan Boyce, a Rumson, New Jersey resident who has a progressive, terminal genetic disease, told NJ.com, "Since the law took effect, I have felt free to enjoy the rest of my life without worrying about needlessly suffering in agony when it ends."

Black Life Journeys Matter

Dr. Benjamin F. Chavis Jr., civil rights leader and president and CEO of the National Newspaper Publishers Association (NNPA), penned this op-ed in February, in recognition of Black History Month. Compassion & Choices recognizes the incredible importance of the powerful words of Dr. Chavis, as we continue working together toward equitable end-of-life experiences for everyone.



The U.S. Census is now preparing to count all who live in the United States of America. For the more than 50 million Black Americans in the U.S., the 2020 U.S. Census is vital. Our numbers do matter and must be properly and accurately counted. Our birth rates count. Our socioeconomic rates count. Our death rates count. The overall quality of life in Black America will be impacted for the next ten years as a result of the 2020 U.S. Census.

The full life journeys of all Black Americans are important. Today, we are observing and celebrating 2020 Black History Month. This is the time for understanding and learning from the past to change the present and to ensure a better future for Black America.

While there has been a lot of appropriate national attention and focus on the beginning of life's journey, there has not been enough attention on the inevitable transition and conclusions of one's life journey, particularly from the African American perspective.

This year is the 193rd year of the Black Press of America, represented today by the National Newspaper Publishers Association (NNPA) across

the nation. I am proud of the expansion and progress of the Black Press even amidst trying and challenging economic times for Black owned businesses. The NNPA corporate partners and sponsors, such as Compassion & Choices, immeasurably help to sustain the Black Press.



This is a subject that is often avoided until the finality of death confronts the loved ones of the departed. Our newspapers cover and publish the obituaries of people in the communities in which we serve as a matter of tradition and respect for the untold positive contributions of those who make their final transition at the end of their remarkable life journeys.

The NNPA member publishers and newspapers, complimented by their digital distribution of content, including a wide array of social media channels, cover the news that often-times gets left out of mainstream news media. One of the reasons why the Black Press continues to be the trusted voice of Black America is because we report on the entire journey of Black America from life to death from generation to generation.

The NNPA began a unique and important partnership with Compassion & Choices to acquire a more in-depth awareness and knowledge about how Black Americans and others are enabled to have a planned, dignified and well thought out, peaceful transition without the sudden unpreparedness that happens too often in many Black American families.

Our birth rates count. Our socioeconomic rates count. Our death rates count.

Compassion & Choices is committed to empowering people to get the care they need during a serious illness or at the end of life. One way to do that is by helping people plan well and become good advocates for themselves and their loved ones.

In other words, the entirety of one's life journey is precious and should be prepared for the end of the journey with dignity and respect. It is really about taking responsibility to ensure that your transition will be handled in a manner that you have pre-determined with the interest of all those you love and who love you.

We know that we have to show respect to each other in our families, communities, and careers. Black love is about Black self-respect. Too often Black lives are ended in some type of hardship, tragedy, brutality, prolonged sickness, or some unexpected unavoidable circumstance. But all of our final transitions should be observed with the utmost respect and dignity.

Planning for one's transition does not mean you are ready to die before your time is up or that you are attempting to hurry or rush your departure from this world. To the contrary, planning the final transition of your life is like having a sustainable life insurance policy that removes the burden of your transition from your loved ones.

Talking about and planning your transition will not kill you, but it will save your love ones the awful sorrow and agony of unpreparedness. We are grateful to Compassion & Choices for helping us to transfer our reluctance and fear of discussing the ultimate transition of our life journeys into a responsible and respectful plan of love and dignity.

Yes, Black life journeys matter at the beginning and at the end. We all have the opportunity and the responsibility to respond to this issue in a timely manner.

Pre-COVID-19 lobby day at the New York state capitol in spring of 2019.



Looking Ahead: The Future of End-of-Life Choice and Care

An interview with President and CEO Kim Callinan

How do you anticipate COVID-19 will impact end-of-life choice and care?

It will have a significant impact, though two factors really stand out. First, more people now grasp the fragility of their lives and the reality of their mortality. This new awareness escalates the importance of advance care planning across all populations, particularly underserved communities, who have been disproportionately impacted by COVID-19 and who historically are less likely to have advance directives. Second, the expanded and critical role of nurse practitioners and palliative care professionals in the pandemic will result in long-term improvements to how end-of-life care is delivered: better pain and

symptom management; improved access to all end-of-life care options, including hospice and medical aid in dying; and more people who are able to die in the comfort of their own home.

How will the increased attention around disparities with COVID-19 and the growing racial justice movement impact end-of-life choice and care?

Recent events reinforce the importance of prioritizing our efforts to create a diverse and inclusive movement and eliminate racial disparities in end-of-life planning and care. We accelerated our work in this area in 2018 when we made a concerted effort to engage more authentically with diverse communities of

color to ensure everyone has access to the full range of end-of-life options. Since that time, we have been working in partnership with our African American and Latino Leadership Councils to address disparities in advance care planning by educating people about the value of hospice and palliative care. We are committed to continuing and expanding these efforts.

How will COVID-19 impact our ability to authorize medical aid in dying in more states in 2021?

Increased competition from issues emerging as a result of COVID-19 and greater awareness of racial inequities will make it more challenging to get any law passed in the near term. However, the unfortunate reality is that large numbers of people have and continue to suffer lonely, isolated deaths. We have seen time and time again that when people experience firsthand the inhumanity of suffering at life's end, our support solidifies, intensifies and grows. This reality, along with the momentum we had coming into COVID-19 and a combined total of 50 years of experience successfully implementing medical aid in dying in 10 jurisdictions, leaves me feeling optimistic for the future. We can anticipate authorizing an average of one state per year, putting us on track to realize our strategic goal of ensuring that 50% of the population lives in a state where medical aid in dying is authorized and accessible by 2028.

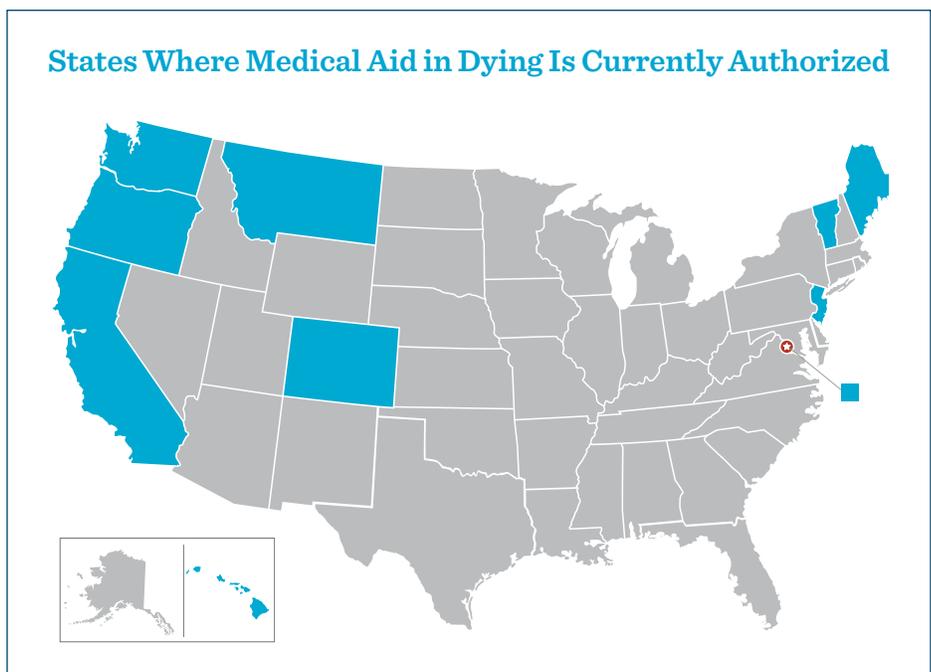
What states look the most promising for advancing medical aid in dying?

Massachusetts lawmakers, for the first time ever, advanced their medical aid-in-dying legislation during COVID-19, voting it out of the Joint Committee on Health Care Financing. We are hopeful the state will authorize medical aid in dying in the near term. In terms of the rest of the country, I

will be able to answer this question with more certainty on November 3, just after the election. I anticipate lawmakers sponsoring bills in approximately 20 states where we are organizing and working alongside coalitions to move legislation forward. The political climate and grassroots support are increasingly promising in nine of those states — Connecticut, Delaware, Illinois, Maryland, Minnesota, New Mexico, New York, Nevada and Virginia.

Last year, Oregon passed legislation to improve the existing bill. Do you anticipate other states following suit?

Absolutely. We have conclusive data that the existing law is unnecessarily burdensome, and we will work with lawmakers in some states to begin to address this reality. Fundamental improvements include 1) the elimination of or ability for doctors to waive the waiting period for patients actively dying; 2) the inclusion of nurse practitioners and/or physician assistants as allowable practitioners; 3) a requirement that providers disclose their medical aid-in-dying policies, allowing patients to make informed decisions about where to access the care they want.



Finding Light in the Darkness

A person is silhouetted against a bright, glowing opening in a dark, textured cave. The person stands with their back to the viewer, looking out into the light. The cave walls are rough and uneven, and the light from the opening creates a strong contrast with the surrounding darkness.

COVID-19 heightens the importance of advance care planning for an otherwise healthy Texas woman.

When Cecilia Vasquez-Vigil and her husband, Paul, took a road trip to Mount Rushmore and Las Vegas for a spring break vacation in March, the novel coronavirus still seemed very far away. They were supposed to travel to Europe, but with the onset of the pandemic, they canceled. At the time, South Dakota and Nevada had very limited COVID-19 cases and both seemed like safe options. Cecilia, an educator from Brownsville, Texas, was happy to get away. They left for a week of sightseeing, shows, great dining and relaxation. They ended up with more than they bargained for.

After their return home, Cecilia's symptoms started: a cough, body aches and severe fatigue. The cough was dry and the fever was as high as 105 degrees. At 8 a.m. on March 21, Paul rushed Cecilia to Memorial Hermann Katy Hospital near Houston. As a doctor administered the COVID-19 test, he said the words she feared most: "I'm pretty sure you have it. Your X-rays show pneumonia in the lobes. I'm admitting you and treating you as positive."



The fear of dying alone weighed heavily and started Cecilia thinking about her advance care planning.

What followed were 34 days of anxiety and desperation, knowing that there was no cure or vaccine for the virus that had already killed nearly 13,000 people worldwide. When Compassion & Choices spoke to Cecilia in June, more than 507,000 people around the globe had died from this horrible disease.

Cecilia is grateful that no one in her family — Paul, her stepdaughters or her son — contracted COVID-19. Still, the experience was simply terrifying. She did not think she would survive. She lay in bed in an already overwhelmed hospital for four days coughing up blood, hallucinating, with no sense of taste.

She knew that if she died, she'd likely die alone, or at best with medical staff who were supportive but not family. The fear of dying alone weighed heavily and got Cecilia thinking about her advance care planning. "One thing I wished I had done before getting sick and being hospitalized was to fill out and share my advance care directive with my family and health-care providers," she said.

Advance care planning documents spell out what care you do and don't want, and designate a proxy to make medical decisions for you in case you can't speak for yourself. In the event that your proxy can't be with you at the hospital, you can bring a copy of your advance directive with you and record a short video on your phone about your end-of-life wishes to show medical providers.

Previously, Cecilia had not really considered end-of-life planning a priority. But as a former hospice volunteer, she understood the impact of that decision once she got sick. From the hospital, she called her cousin. "Take care of Max," she said. "Take care of Mom," she said, trying to manage whatever details she could.

Next, she called her attorney.

Contracting and dealing with COVID-19 started Cecilia and her family on a journey of end-of-life discussions and planning. After working with her attorney,

Cecilia contacted a friend who works at Compassion & Choices and learned of the free bilingual resources available on our website. "I wish I had known these

resources were available to me and my family at the outset," she said. "I hope by sharing my story, others will understand and use these resources."

“Hispanics and people of color are dying at a disproportionate rate from the coronavirus compared to other Americans.”

resources were available to me and my family at the outset," she said. "I hope by sharing my story, others will understand and use these resources."

With limited beds for COVID-19 patients, the hospital discharged Cecilia after six days to make room for someone in more acute need. She spent the next 24 days recovering at home, isolated in one room. She

was unable to hug her son or husband, and was still in a lot of pain, suffering from high fevers. "I endured over a month of anxiety," she recalled.

Cecilia's gratitude — and frustration — are apparent. "I thank Jesus for helping me survive this horrible illness, and I pray to God that my Hispanic brothers and sisters and all people who are suffering will survive this pandemic. Unfortunately, Hispanics and people of color are dying at a disproportionate rate from the coronavirus compared to other Americans. We have to do better for everyone."

Cecilia finally tested negative twice, as required to break quarantine, in mid-April and received her letter from the state confirming that she had com-



previous page: Cecilia and her husband, Paul

this page: Taken on their week long road trip just before falling ill and being hospitalized with coronavirus, Cecilia with her husband, Paul, at Mount Rushmore and at the Grand Canyon, March 2020.

Compassion & Choices Advance Care Planning Tools

pleted her state-mandated isolation. Three months later, Cecilia was still suffering from the effects of the illness. She has scarring on her right lung. She is losing her hair, and her hearing is slightly impaired as a result of having had COVID-19. Her respiratory system will never be the same again.

One good thing has come out of this: Cecilia's affairs are in order. She has also inspired those around her to complete their end-of-life planning. Paul has put plans in place for himself. Cecilia's ex-husband worked with her to complete their documentation, since they co-parent a son. After some resistance, Cecilia's brother Carlos made his plans, as well. He named her executor of his will and sent an email with the subject line, "My Wishes," documenting how he wanted to be laid to rest. Even Cecilia's 90-year-old mother finally agreed to discuss her wishes for her burial.

Note: A few months after Cecilia's ordeal with COVID-19, both her brother and mother contracted the virus. Her mother was intubated for two weeks before dying alone in a hospital room in Brownsville, Texas, on July 30.

If you have not made your end-of-life plans yet, now is the time. The urgency is greater than ever, for adults at any stage of life or level of health, due to the coronavirus pandemic. Compassion & Choices offers free bilingual resources to help you define and document your wishes. What treatment options do you want if you contract the coronavirus or receive another serious diagnosis, like cancer or dementia? Would you prefer life-sustaining measures? Who will speak for you if you are unable to speak for yourself?

Visit CompassionAndChoices.org for free resources to help you with every aspect of advance care planning, including our popular COVID-19 toolkit and a webinar series to help you understand all your end-of-life care options (see page 15).

Dementia Values & Priorities Tool

This online resource helps you pre-claim your voice so a healthcare proxy can carry out your wishes should dementia take hold. It allows you to reduce the length of time you live with dementia by years if you so desire. By answering a series of questions and adding your own personalized markers, you can create a customized dementia amendment to your advance directive that you can print, download or email.

My End-of-Life Decisions: An Advance Planning Guide and Toolkit

This guide helps you work through your end-of-life priorities and empowers you to have meaningful discussions with your family and healthcare providers. The toolkit includes forms for advance-care planning that can supplement your advance directive. In addition, our website links you to state-specific advance directives. The guide is available in both English and Spanish.

Finish Strong: Putting Your Priorities First at Life's End

Available in print, e-book and audiobook, *Finish Strong* is a thorough, informative and engaging guide to achieving the positive end-of-life experience you want and deserve. Compassion & Choices President Emerita/Senior Adviser Barbara Coombs Lee, an emergency room and intensive care unit nurse and physician assistant for 25 years, shares her vast expertise and unrivaled life experience on living strong to the end.

To find these tools and additional resources to help with your end-of-life planning, visit CompassionAndChoices.org/finish-strong-tools.



Caring for Terminal Patients in a Pandemic

Fallout from the coronavirus impacts the work of healthcare professionals in communities nationwide, including palliative care providers.

Palliative care is a medical speciality dedicated to relieving pain and other distressing symptoms for people of all ages with serious, chronic and life-threatening illnesses. The goal is to improve the quality of life for both the patient and the family. This kind of care is delivered in more than 1,700 hospitals across the country, as well as in homes, residential and long-term care facilities, clinics and office practices.

For people already living with a terminal illness, an acute infection like the novel coronavirus can be catastrophic, sometimes resulting in an imminent end-of-life scenario in which palliative care becomes critical to minimize suffering. Patients with COVID-19 for whom treatment proves ineffective also benefit greatly from palliative measures.

We spoke with two providers on the frontlines of providing care to terminally ill patients and those with COVID-19: Dr. Daniel Turner-Lloveras from Harbor-UCLA Medical Center, a Los Angeles County hospital, and Dr. David Muller from The Mount Sinai Hospital in New York. Both doctors also teach at their institution's medical school. We asked them how their approach to patient care has changed due to the pandemic and what positive outcomes they hope might result from this period of intense change.

Hospitals Adapting

"It's been enormously challenging," said Dr. Muller. "The hospital is often the worst possible place for a patient with a terminal illness, even without a pandemic, because that environment doesn't allow a family to express their love in the way they would want."

Dr. Muller says that because of those limitations, Mount Sinai's palliative care program does everything possible to limit the time patients who are near the end of life spend in the hospital.

"All of us are aware that we can provide patients and their families with all the resources they need to die a dignified and peaceful death at home," he said.

According to Dr. Turner-Lloveras, some COVID-19 patients at Harbor-UCLA have not seen their families in more than a month, so the hospital offers them the ability to make FaceTime calls using hospital-provided iPads.

"Regular communication with their family members strengthens bonds," he said, "and supports the patient as they recover both physically and mentally, something especially important for our Latino patients. We hope to improve this policy that indirectly leads to family separation."

“I had a couple of patients who unfortunately passed away at home from COVID-19,” Dr. Muller added, “and in some cases the families could not be there, for risk of exposing themselves. It was heartbreaking.”

Unequal Outcomes

Both physicians said they hope the pandemic will shine a spotlight on the disparity in healthcare outcomes among white and Black, Latino and Native American communities in the United States. A recent Washington Post analysis found that majority-Black counties have three times the rate of COVID-19 infection and almost six times the rate of death as majority-white counties. The COVID Tracking Project noted that in 42 states and Washington, D.C., Hispanics and Latinos make up a greater share of confirmed cases than their share of the population. In Arizona, Native Americans account for 21% of pandemic deaths but are only 4% of the state’s population. Over 75% of Harbor-UCLA patients are people of color, as are over 80% of Mount Sinai’s.

Technology Makes a Difference

Dr. Turner-Lloveras sees the adoption of telemedicine in hospice and palliative care during the pandemic as critical both now and in the future. “We know we can provide safe, quality care virtually to patients in their own homes, where the risk of infection is much lower,” he said. “But one challenge is that commercial health plans and public health programs must provide comprehensive coverage of these services — and health professionals to deliver them.”

The UCLA-Harbor doctor believes that these reforms would allow clinicians to use digital technology, like smartphones and tablets, to deliver end-of-life care. Use of technology would also allow clinicians to



Dr. Daniel Turner-Lloveras,
Harbor-UCLA Medical Center, CA



Dr. David Muller
The Mount Sinai Hospital, NY

provide end-of-life services to more patients, while improving care and the patient experience.

The Importance of Planning

Both doctors emphasized the need for advance care planning for everyone, regardless of current health status. A recent study showed only about a third of Americans have completed an advance directive, like a living will or healthcare proxy, that explains what healthcare interventions they would want to receive if they became severely injured or terminally ill, and who will speak for them if they can no longer speak for themselves.

In the absence of such planning, Dr. Muller said, providers do their best to work with patients and families. “In our health system at Mount Sinai, we made sure that there were algorithms and information and material available so that doctors at intake, in the emergency room and in the ICU knew exactly how to frame those kinds of discussions. It took a small army of doctors, medical students and others to not only update families on the well-being of their loved one in the hospital, but to begin to have those end-of-life conversations as well.” he said.



Compassion & Choices provides free planning tools that help you fill out your advance directive, healthcare proxy and other forms depending on the state you live in. Visit [CompassionAndChoices.org](https://www.compassionandchoices.org) or call 800.247.7421 to find out more.

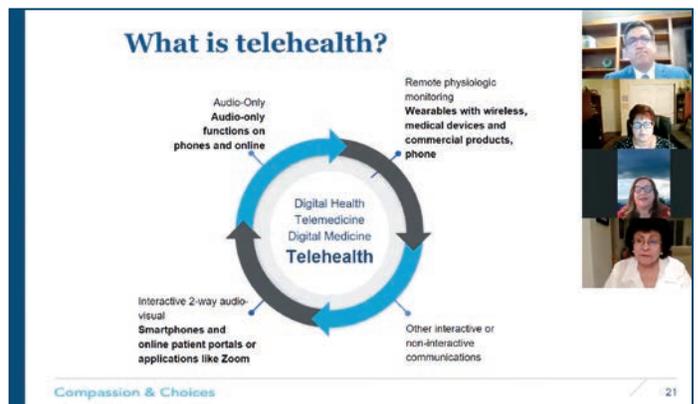
Staying Connected Despite the Crisis

In light of the pandemic, Compassion & Choices has adapted in order to stay connected with supporters and expand our work toward end-of-life autonomy and options.

Since March of this year, it has become clear that conversations around grief, loss and end-of-life issues are more important than ever. So Compassion & Choices assembled a comprehensive webinar series that tackles topics ranging from virtual advocacy to dementia preparedness. The series reached thousands of people in the span of a few months.

In addition to the webinar series, which is available free of charge at CompassionAndChoices.org, we created a COVID-19 toolkit that now includes a fact sheet on underserved communities. This was a direct response to the disproportionate effect COVID-19 is having on African American, Latino, Asian and Indian/Alaska Native populations. "COVID-19: Impact on Underserved Communities" explains the health disparities in these communities and the actions people can take, regardless of their race or ethnicity, to get the end-of-life care they want. It also includes clear, actionable items to address health inequities as a society, including addressing discrimination in medical systems and expanding telehealth services.

Compassion & Choices participated in a historic collaboration with the *Ventanillas de Salud* (Windows of Health) network to launch a bilingual educational campaign during the COVID-19 crisis to inform U.S.-based Mexican immigrants about their full range of end-of-life care options. *Ventanillas de Salud* is a national health outreach program implemented by the Mexican Consulate's secretary of foreign affairs and the secretary of health of Mexico. The initiative serves over 1 million individuals and their families located in cities with a high concentration of immigrants.



Screenshot from National Hispanic Medical Associations's COVID-19 Virtual Series Session 3.

This resulted in a series of webinars targeting *Ventanillas de Salud's* wide network.

Compassion & Choices also secured a partnership with the National Hispanic Medical Association (NHMA) to hold two webinars for their members. NHMA represents 50,000 licensed Hispanic physicians in the United States. The first webinar, in July, focused on the benefits and importance of telemedicine in end-of-life care. The second, in August, focused on Compassion & Choices' COVID-19 response and our English and Spanish toolkits. Providing these toolkits and other resources in Spanish is critical to our outreach to Latino communities in the United States.

These and other efforts are critical to reach diverse and underserved communities throughout the United States, a mission Compassion & Choices remains strongly dedicated to.

Rising to the Challenge

Compassion & Choices' mission to expand access to end-of-life care options has taken on a new sense of importance with the COVID-19 pandemic and the nationwide movement for racial justice and equity. We've responded to these challenges with new initiatives and a renewed urgency for programs that will expand our movement and lead to better outcomes for everyone.

Creating an Inclusive Movement

As the United States continues to grapple with the history of systemic racism in our country, we remain focused on how biases affect social determinants of health. We are working to ensure everyone can receive care that is consistent with their values and priorities.

In 2017, we first created Compassion & Choices' African American and Latino Leadership Councils, which are composed of community leaders from diverse professional backgrounds, including faith leaders, physicians, nurses, executives and policymakers. Their goal: educate communities and empower individuals to advocate for themselves and their loved ones. Being prepared with information can reduce disparities in end-of-life care and increase planning among these often underserved populations.

Just over two years ago, Compassion & Choices adopted a new strategic plan. A key element of the plan focuses on developing an inclusive movement in the areas

of race, religion, party affiliation and age. We started internally with our own board of directors and staff, so that our teams reflect the rich diversity of our nation and our work continues to benefit from the varied expertise and variety of perspectives of these individuals bring to our movement.

Compassion & Choices then launched a "Finish Strong" public education campaign to help diverse communities claim their voices and agency in end-of-life care. The campaign centers on sharing our many resources to help people plan for an end-of-life experience that matches their wishes and preferences.

The three primary goals of the campaign are to increase awareness among diverse populations of the importance of end-of-life care and advance care planning among people from diverse populations through tailored, culturally competent messaging, tools and resources, and channels; to encourage people from diverse populations to use Compassion & Choices tools and resources to



Members of the African American Leadership Council (top) and Latino Leadership Council (bottom)

conduct advance care planning; and to engage people within diverse populations in volunteer and outreach efforts.

This long-term effort includes expanding our communication efforts, continuing to participate in regional and national events, and working to influence health-care policy to address the existing structural impediments to equitable access to end-of-life care.

Working for You in Washington

When Congress passed the \$2.2 trillion Coronavirus Aid, Relief, and Economic Security (CARES) Act earlier this year to address the COVID pandemic, Compassion & Choices, along with other organizations, successfully advocated for several groundbreaking provisions related to telemedicine. The end result is that more people will have access to end-of-life care on their terms, including those from traditionally underserved communities in both urban and rural areas, during the public health

emergency. Now all Medicare beneficiaries are able to access healthcare from the comfort and safety of their home via telemedicine, including for hospice and palliative care, with a broader range of providers.

The law ensures patients, particularly those with a serious or terminal diagnosis, can minimize visits to emergency rooms and urgent care facilities where they could get infected with the coronavirus.

Compassion & Choices is also working to ensure that the pandemic doesn't prevent individuals

from getting the medical treatment they want if they do visit a health-care facility. This year, the U.S. Department of Health and Human Services temporarily waived a requirement for hospitals to provide information on the facility's advance directive policy. The result is that some patients may receive unwanted interventions, while others may not get the lifesaving treatments they need. Compassion & Choices is strongly advocating for the government to reverse this decision, and thousands of supporters have added their name to this effort.

Moving Our State Advocacy Efforts Forward

Compassion & Choices continues to champion legislation that expands access to end-of-life options. We're finding new ways to connect with policymakers and advocates using technology, and ensuring we continue to protect and authorize medical aid in dying in additional states.

In Massachusetts, legislation that would authorize medical aid in dying was advanced by the state's Joint Committee on Public Health. This is the first time the bill has been approved in committee

since it was originally introduced by Massachusetts Representative Louis L. Kafka in 2011.

We are also preparing for what we expect will be a very busy legislative season next year, as several states are poised to advance medical aid in dying in the very near future, including Connecticut, Delaware, Illinois, Maryland, Minnesota, New Mexico, New York, Nevada and Virginia. We are continuing our efforts to improve the law in Hawai'i. Currently, we are working closely with bill sponsors and getting our action teams ready for a busy legislative season starting in January.



Compassion & Choices Chief Advocacy Officer Charmaine Manansala testified before the Massachusetts Joint Committee on Public Health on the end-of-life options bill in 2019.

Five Questions for James Naughton

Two-time Tony Award-winning star of stage and screen James Naughton lost his adored wife, Pamela, to pancreatic cancer in 2013. He has since become a powerful advocate for medical aid in dying in their home state of Connecticut.

Q: Not only have you had a remarkably successful acting career, but your younger brother, son and daughter are also actors. Was yours a creative household growing up or did the inspiration for this legacy come from something else?

A: Actually both my parents were teachers, and I got my start in high school, where I played baseball and soccer. I did sing in the chorus, too, but it was always in a big group. My junior year, however, the choir director was producing the musical “South Pacific” and asked me to play Emile. When I told my baseball coach I wanted to play the lead in the high school musical in the spring, he actually thought it was wonderful. So together he and my choir teacher figured out a way to share me, where I left rehearsal early and then got to baseball practice late, running back and forth. And you know what? They put up with it again for my senior year, too.

In college, at Brown, it wasn’t until my junior year that I got involved in theater, and that was kind of by accident. I wandered in one night, not to audition, but the drama teacher told me to get up and sing a song. He literally said, “Where the hell have you been?” I said, “I’ve been playing soccer and

baseball.” And he said, “Ah, one of those. When soccer’s over this year, come see me.” I took his acting class and, later, his advice to audition for Yale Drama School. I got in and went with the attitude of “We’ll see how this works.” I was there two days and realized I finally had found where I belonged.

Q: It can be a tough business. Did you have any reservations about your children, Greg and Keira, following the same path?

A: Sure. My folks did too. It’s a very challenging, competitive, difficult — but ultimately, if you’re lucky enough, rewarding — way to spend your time. So I told my kids that they could do it if they wanted, but they had to get an education first. And I wouldn’t let my kids act as “little professionals.” There was a movie I was doing that had a part for a son, and my son wanted to play it. I just said no.

Q: Another enduring success was your 46-year marriage to Pamela. Was there any indication when you first met of how strong your bond would be?

A: We met when I was 17 and Pam was a year behind me. She went to the other high school in West Hartford, Connecticut. In

James Naughton delivers emotionally compelling testimony about the urgent need for end-of-life legislation before the Connecticut Joint Public Health Committee.



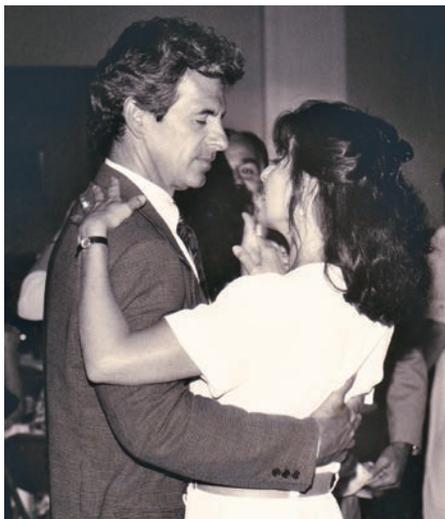
November of my freshman year, I came home for Thanksgiving. My little sister Kathy said her friend Debbie had a big sister who was thinking of going to Pembroke, which was the sister school to Brown, and wondered if I'd go over and talk to her. I had places to go, things to do, people to see, but I told Kathy to call her friend and say we'd go over and meet her sister that night. I walked into the house, and Pam was there, and we sat and talked. I remember being quite smitten with her. So I said, "The only way to really get to know a school is to spend a weekend there." She came up and

stayed with my roommate's girlfriend at Pembroke, and I showed her around. That was basically it. We were lucky that way.

Q: She fought cancer for four years, which must have been unbelievably difficult. Had you given much thought to end-of-life issues before that?

A: Well, we all know we're going to lose our loved ones, and we think of those as being our grandparents and our parents; we don't think of someone getting taken sooner than they should. But having been an actor my

five questions



James Naughton with his wife, Pamela, at a friend's wedding, 1993.

whole adult life, we deal with those kinds of questions. You're playing a part in a show where somebody dies, or in a movie where a child dies, so it's not something that I hadn't ever thought about. But I certainly never thought that I would lose my wife. And I still can't wrap my head around the fact that it has happened. It's seven years that she's been gone in April. And for four years before that, we were dealing with the disease. That's 11 years. So it's something that I don't think ever goes away — the ache, the pain. It's less acute, so you can get through the day, but it's always there.

Q: You were both born in Connecticut and, except for a few years in California, have always lived there. How does it feel to be making such a different kind of impact — legislative instead of theatrical — there now?

A: I have to say, it is satisfying to be able to do something significant that might make a difference for people. The reason this issue, the right to die with dignity, is so important was brought home personally helping my partner of 50 years cope with pancreatic

cancer. She did it heroically; she was one of these people who didn't ever complain in four years of dealing with all the ravages of that disease. The last three months or so got to be really difficult for her, and that's when we had run out of all the chemo choices. Whereas she kept looking quite beautiful, the disease was winning. It was obvious to us, but she kept going on and smiling and being a part of our lives, our children and grandchildren's lives.

Finally one morning she said to me, and I wasn't prepared for this: "I don't want to wake up anymore." It was sort of a reality check, because it made me realize how far down the road we really were and that there was nothing I wouldn't do to help her. When you've been through what we'd been through in our lives together since we were 17, there was nothing I wouldn't do. She died a day or two later. But if she hadn't, I thought, there has to be a way to help a person end their suffering when it gets to that point.

This is a humane, merciful issue, and we have to get on the right side of it. It's not for everybody, but we're not mandating that everyone choose it. For the people who do want it, though, we have to make it legal. We can't let people frame it as "medically induced suicide." It's not the medicine that's killing you; it's the disease. What the medicine does is end your suffering, not your life. People who haven't experienced this in their families are very, very lucky. But they're only one bad death away from understanding how important this legislation is.

Inspired by a Story, Motivated by Commitment



*Gina Vadnais, California,
longtime Compassion & Choices
Leadership Circle member*

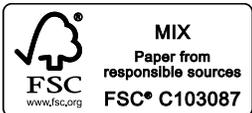
I first learned of Compassion & Choices when I began following Brittany Maynard and Dan Diaz's story after my son, a friend of Dan's, shared it with me. I immediately saw Compassion & Choices was making a difference on the issues that mattered to me with their work to expand medical aid-in-dying legislation to more states and help people plan ahead for dementia. I believe every American has the right to autonomy in life and in death, and I want to have the ability to make end-of-life decisions according to my own values and priorities.

Join me by investing in Compassion & Choices to advance this important work! Please donate at CompassionAndChoices.org/donate.



Care and Choice at the End of Life

101 SW Madison Street, #8009
Portland, OR 97207
800 247 7421
CompassionAndChoices.org



Save The Date!

Tributes, Stories and Song

A Fundraiser Benefiting
Compassion & Choices

Don't miss the premiere of Compassion & Choices original signature song!

*Tuesday, December 8, 2020
7:00 - 8:00 p.m., ET*

Please visit candc.link/dec8 and join us for this exciting virtual online event!

Sponsorships Available