

THE

Death with
Dignity
NATIONAL CENTER

Dignity Report

A publication of the Death with Dignity National Center

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Victory in Washington, D.C.
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Cover photo: MarshaRose Joyner (see p. 8)

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You can support our work in many ways:

- an outright gift;
- a gift honoring a loved one;
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- including us in your estate planning.

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*From the Desk of
Dr. Peg Sandeen,
Executive Director*



The word “progress” has become a true earworm for me lately. Last year, two states, California and Colorado, enacted statutes modeled on the Oregon Death with Dignity Act. Just this February, a similar law went into effect in our nation’s capital (see p. 4). And twenty-five states have taken up similar legislation in the 2017 session. The momentum for end-of-life policy reform continues unabated.

I cannot be more pleased about our successes and more honored to be working with talented, hard-working people all over the country. In addition to the best staff I could ask for at our headquarters in Portland, Oregon, and the best board of directors, with Mark Glaze in D.C., Geoff Sugerman in Salem, Oregon, Brittany Ross in Honolulu, advocates including Valerie Lovelace in Maine, Scott Foster and MarshaRose Joyner in Hawai’i (see p. 8), Cindy Merrill in Texas, and many other individuals and organizations, we have formed a collaborative structure working in concert, nationally and on the ground. If it takes a village to raise a child, it takes a nationwide network to ensure she can make her own

end-of-life decisions and choose from a full range of options.

There is, of course, a lot of work to be done. It is amazing to see advocacy groups and organizations rising up in many states across the U.S. and connecting with them to support their nascent campaigns. We are formalizing these collaborations with our new state leadership incubator program, Dignity50, which supports legislators and independent groups from North Carolina to Ohio to South Dakota to Hawai’i in their efforts to pass Death with Dignity legislation.

On a final note, *The Dignity Report* is but an occasional compendium of news. Please visit our website www.DeathwithDignity.org for the latest updates and resources as well as to sign up for our emails, take action in your state, or donate. Get involved, we cannot win in all 50 states without you.

Thank you for all you do,

A handwritten signature in black ink, appearing to be 'Peg Sandeen', written in a cursive style.

Victory in Washington, D.C.: How the Nation's Capital Was Won

On February 21, 2017, the District of Columbia became the 6th jurisdiction in the United States to enact an Oregon-style assisted dying statute.

In D.C. from Day 1

The day came exactly two years and three days after we first started working with the law's sponsor, Councilmember Mary Cheh, to make this end-of-life option available to Washington, D.C. residents.

On January 14, 2015, when the Councilmember introduced the Death with Dignity Act of 2015, her office requested assistance from us with shepherding the bill through the Council of the District of Columbia. From that point on, we have been by Councilmember Cheh and her colleagues' sides to get the bill passed.

We commissioned a research poll, which showed that 67% of D.C. residents support the law. We sponsored Facebook ads and a Change.org petition to engage D.C. residents on the issue. We accompanied the Councilmember to an interview with *Washington Post's* editorial board for the

paper's strong endorsement of the legislation. We visited with several Councilmembers and gave testimony at a public hearing on the Oregon and Washington experiences as well as clear evidence to counter opponent's fear-based arguments.

As the Council continued considering the measure in 2016, we redoubled our efforts. We engaged supporters in the D.C. area to encourage the Council to support the measure and to call Mayor Muriel Bowser urging her to approve the bill. We spoke with the *Washington Post* again, for their second endorsement last September. We worked directly with Councilmembers, whether through private communications or conference calls, to give them the evidence they needed to make an informed decision and debunk the opposition's lies.

The process culminated quickly last November and December. The Council voted (twice) to pass the law on a decisive 11 to 2 vote. Like the Council before her, Mayor Bowser refused to give in to misinformation from the opponents of Death with Dignity, listened to

the will of the people, and signed the bill without delay.

Against Congressional Interference

Under the lawmaking rules in the District, the Act had to undergo a 30-day review by the United States Congress. Several members of Congress attempted to block the law with a resolution of disapproval. Based on personal or religious disagreements with the law, the same members of Congress who talk nonstop about small government and states' rights sought to use their federal power to override the will of the Washington, D.C. residents, whom they don't represent.

In collaboration with Councilmember Cheh, D.C. Congresswoman Eleanor Holmes-Norton, and our Oregon Congressional delegation, we worked behind the scenes to defend the new D.C. law. The House of Representatives Committee on

Oversight and Government Reform voted to override D.C.'s new law on a nearly straight party-line vote. But the review period expired a few days later without either chamber's vote. Days after that, qualified terminally ill D.C. residents won the end-of-life option to end their lives in a legal, peaceful manner.

Our Advocacy, Our Leadership

As the first national right-to-die organization on the ground in D.C., we were proud and honored to see two years of campaigning and advocacy work bear fruit.

Our work is not always on the front page or the evening news. It is the style of advocacy that seeks not to draw attention to our organization, but rather focuses on the movement and the behind-the-scenes political work necessary to move controversial legislation through the political process. That's what

(continued on next page)



1997 OREGON

2008 WASHINGTON

2013 VERMONT

2016 CALIFORNIA, COLORADO

2017 DISTRICT OF COLUMBIA

true leadership on this issue entails. And that's what the Death with Dignity National Center has done for decades, ever since we campaigned for the groundbreaking Oregon law.

Thank You

In our moment of accomplishment, we were also grateful to you. We would never have made it to the finish line in the District without your activism and your support. Your emails and calls to legislators, your generous contributions to our effort, your words of support were proof that we have the power to make change if we show up.

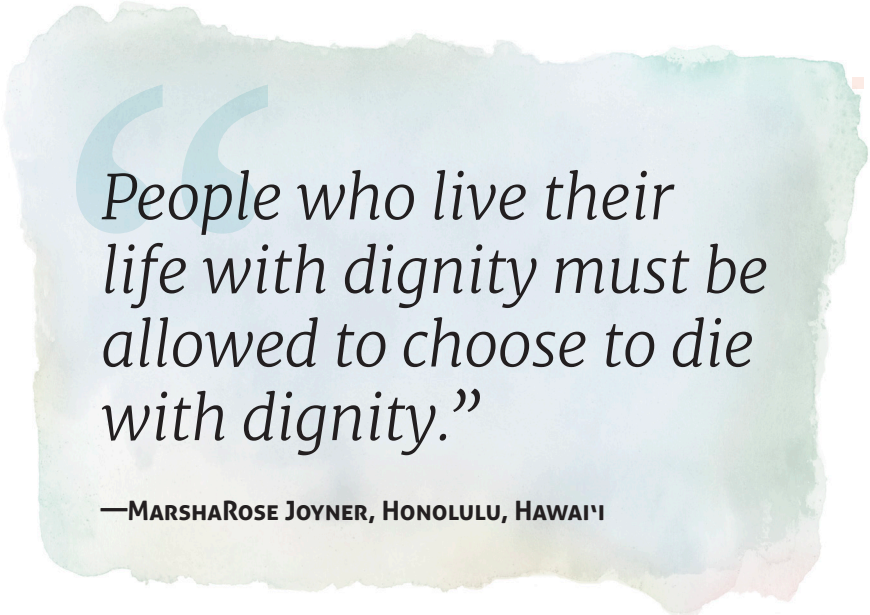
The Battle Ahead

Despite the win, we did not run a full victory lap. The members of

Congress who failed to block the D.C. law through the disapproval process pledged to take the fight to the next round. Using Congress' power over the Washington, D.C.'s budget, they will attempt to use the appropriations process to gut the funding for the Death with Dignity Act needed to set up the reporting process.

We have successfully defended the Oregon and Washington laws, and we will resist any efforts to roll back the D.C. Death with Dignity Act of 2015. Not just for the District, but to preserve the gains we've made since 1994 and keep up the momentum that propels us.

Learn more at our website www.DeathwithDignity.org. ■



“People who live their life with dignity must be allowed to choose to die with dignity.”

—MARSHAROSE JOYNER, HONOLULU, HAWAII

Oregon Leads the Nation in End-of-Life Care

A new study published in the *New England Journal of Medicine* by Drs. Susan Tolle and Joan Teno has found that Oregon may be the best U.S. state in which to die.

Dying at Home

“Persons dying in Oregon are less likely to be hospitalized and more likely to use hospice services at home than are patients...in the rest of the United States,” the authors write. In 2013, nearly two-thirds of Oregonians who died did so at home; the same year, 97 percent of people who used the Death with Dignity Act died at home. In contrast, even though 85 percent of Americans want to die at home, fewer than 40 percent get to do so.

Similarly, patients in Oregon are 61 percent more likely to be enrolled in hospice than other Americans

How to Die Well in Oregon

Oregon was the second state in the nation to legalize advance directives and the first to both use POLST (Physician Orders for Life-Sustaining Treatment) and enact an assisted dying statute. All of these policies are supported with complementary policies.

It is, however, not the mere presence of these tools that has improved the experience of dying in Oregon. Linking patients’ goals for end-of-life care to actionable care plans supported by both local healthcare systems and state regulations is key.

Education through the media and physicians raises Oregonians’ awareness about their end-of-life options. State regulation around POLST ensures forms are completed correctly, distributed among healthcare professionals at all levels, and honored. Change in culture supports healthcare professionals in collaborating with colleagues and conducting honest conversations with patients. Home hospice allows patients to die not at a hospital but in their own bed.

Death with Dignity Act: An Option

No matter what opponents of Death with Dignity falsely claim, the Death with Dignity Act has not only resulted in no negative outcomes, it has been an integral part of a complex system of end-of-life care helping to honor the wishes of Oregonians dying from terminal illness. ■

Local Advocate Spotlight: MarshaRose Joyner, Hawai'i



As of this writing, SB 1129, the Hawai'i Medical Aid in Dying Act, has been approved in the State Senate by 22-3, the first full legislative chamber this year to approve a Death with Dignity bill (unfortunately, the bill is bottled up in a House Committee and will not advance this session).

We have arrived at this point in large part thanks to our friend MarshaRose Joyner.

Activist Since Teen Age

Raised in Baltimore (her family had lived in Maryland since 1773), where she was one of first young women of color to graduate from her high Catholic school, and where she learned the ropes of democratic

activism, Marsha, 78, moved to Hawai'i in the 1970's with her husband who was stationed there. She has become a bedrock of the Honolulu community.

A Honolulu Pillar

A sampling of her current activities shows Marsha has not missed a beat since the days of 1950's sit-ins and continues to be a fervent activist. She is the Director of the Chamber of Commerce for Persons with Disabilities, Friends of the Gandhi Statue in Waikiki, Friends of Chinatown, and the Hawaii Peace Center. Her activism has earned her accolades and prizes, including the Nagasaki Peace Prize and awards from the ACLU, American Red Cross, Girl Scouts of America, City of Honolulu and many others.

A self-described "political junkie, wife, mother, grandmother, great-grandmother and cancer survivor," she is also a writer, minister, radio and TV producer. One of her colleagues once described her as "energetic, imaginative, and creative" as well as "a combination of activism, visionary, entrepreneur, and 'tree-hugger'."

Marsha sees her role in life as a

grain of sand. "To make a truly beautiful pearl there must be a grain of sand in the oyster," she explains. "To make a truly beautiful world, there must be people like me: the irritants that keep everything growing."

Advocating for Death with Dignity

Marsha's activism extends to assisted dying, stemming from a simple belief: "People who live their life with dignity must be allowed to choose to die with dignity."

Marsha speaks in support of Death with Dignity on our behalf as well as President of the Chamber of Commerce for Persons with Disabilities.

As the host of *Navigating the Journey*, a streaming show dedicated to end-of-life issues,

Marsha has interviewed a broad range of personalities from legal experts to hospice personnel to clergy of various denominations. On the show she has also showcased a broad range of Death with Dignity supporters, from Scott Foster, founder of the Hawai'i Death with Dignity Society, to Mary Steiner of Compassion & Choices, to Hawai'i State Senator Lorraine Inouye, co-sponsor of the pending bill (see screenshot).

In addition, Marsha believes that "Death with Dignity is not only a legal issue, but a cultural and spiritual issue as well." Armed with Catholic-school education, she also likes to call the institution out for its hypocrisy on life and death issues: "The Church's story is more often written in blood than with ink. And the Church has the audacity to reject Death with Dignity as a morally bankrupt practice." ■



Marsha Joyner interviewing State Senator Lorraine Inouye on *Navigating the Journey*

New in Our Library

In recent months we have added several books to our library. To purchase them and support us, go to [Smile.Amazon.com](https://www.amazon.com) and select Death with Dignity National Center as your beneficiary.



Good Life, Good Death (2017)

by Derek Humphry

A memoir from the giant of the Death with Dignity movement, shedding light on the journey to fulfilling his life's purpose.

Who Lives, Who Dies, Who Decides?: Abortion, Neonatal Care, Assisted Dying, and Capital Punishment, 2nd edition (2015)

by Sheldon Ekland-Olson

Explores assisted dying and other contentious issues from legal, sociological, and philosophical perspectives.

Modern Death: How Medicine Changed the End of Life (2017)

by Haider Warraich, MD

A physician's perspective taking a broader look at death and dying, from biology to economics to history to morality.

How to Get the Death You Want: A Practical and Moral Guide (2017)

by John Abraham Rev.

A manual of death education for those approaching end of life and the people around them.

The Good Death: An Exploration of Dying in America (2016)

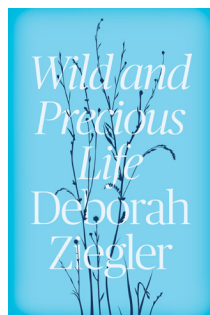
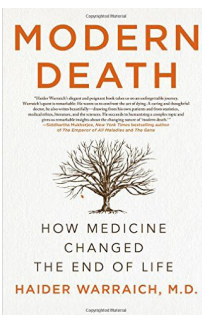
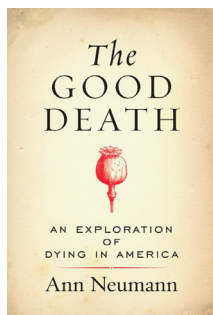
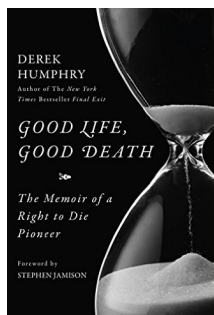
by Ann Neumann

A journalistic exploration of what it means to die in today's U.S.

Wild and Precious Life (2016)

by Deborah Ziegler

A memoir from our organization's friend about her experience living through her only daughter Brittany Maynard's final days.



Dignity50: A State Leadership Incubator

In the early days of our movement, we ran one state campaign at a time. Since then a momentum has built to sustain multiple parallel campaigns. The energy for these campaigns must come from the individual states. To spur the development of independent advocacy groups working toward Death with Dignity policy reform, we have launched a new state leadership incubator program, Dignity50.

Information Exchange for State Legislators

Dignity50 supports the exchange of information between state legislators aiming to enact policy reform. The program kicked off on December 5, 2016, with a legislative roundtable conference call with California State Senate Majority Leader Bill Monning, a sponsor of the successful End of Life Option Act, and legislative sponsors from several states.

Technical Assistance to Advocacy Leaders

The new program also provides strategic guidance to activists on our issue. A pilot group of advocates from 8 states has

completed a series of webinars on grassroots advocacy basics, communications, field organizing, and deployment of online tools. An online toolkit consisting of articles, recordings, slideshows, videos, and other training resources will complement the webinars. Finally, participants can apply for mini grants to help their group build capacity for their advocacy work.

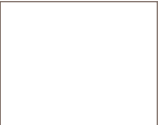
"This has been a phenomenal opportunity for our young organization to learn from the experts," said Lisa Vigil Schattinger, Executive Director of Ohio End of Life Options. "We've also appreciated 'meeting' people from other organizations."

Ed Tiryakian, E.D. of Dying Right North Carolina, concurred: "The program has been invaluable by giving me access to successful role models who have shared their wisdom."

As we complete the program's pilot phase, we will be expanding the program to additional communities. If you are committed to starting an organized effort in your state or would like to financially support the program, please email us at info@deathwithdignity.org. ■



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