# THE Dignity Report

A publication of the Death with Dignity National Center

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On the cover: Kathy O'Malley. See "Sustaining the Movement", p. 9.

## **GIVE DIGNITY**

Death with dignity laws provide peace of mind to qualified terminally ill residents in California, Colorado, District of Columbia, Hawai'i, Maine, New Jersey, Oregon, Vermont, and Washington. Help us expand the option to all Americans with a generous contribution:

- · a one-time or recurring gift;
- a gift in honor or in memory of a loved one;
- a gift of stock or mutual funds;
- a legacy gift.

#### Please visit **DeathwithDignity.org/Support** to learn more and contribute.

THANK YOU!

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## A Flourishing Movement



When I joined Death with Dignity National Center in 2005, Oregon was the only state with an assisted dying law. At that time, the state of Oregon's statute—and of the death with dignity movement overall was precarious.

Today, Oregon's law is not just secure, it has paved the way for adoption of similar laws in eight other states and the District of Columbia. In 2005, just 3.5 million people had access to a death with dignity law; now 70 million do.

In this issue of *The Dignity Report*, we honor the pioneering Oregonians who wrote and led the campaign for the first assisted dying law of its kind in the world and celebrate the 25<sup>th</sup> anniversary of the law's passage.

We also take a look at the flourishing of our movement nationwide, the breadth and depth of which have increased dramatically in recent years. The enthusiasm among longtime and first-time advocates in every region of the U.S. is palpable, and awareness and support of our issue is at an all-time high.

Our organization is growing as well. Valerie Lovelace, our longtime grassroots partner in Maine, is the newest member of our team. Val will be working to ensure implementation of Maine's law goes smoothly. She'll also help us to strengthen our partnerships with grassroots groups in Massachusetts, New Hampshire, and other states across the country.

In 2013, we set an ambitious goal: 10 states with assisted dying statutes in 10 years. Six years later, we're up to nine. Thank you for powering our progress.



Peg Sandeen Executive Director

## Looking Back, Moving Forward: Commemorating the 25<sup>th</sup> Anniversary of the Oregon Death with Dignity Act

Geoff Sugerman had been awake for 55 hours straight.

It was July 8, 1994. Sugerman and his staff at the political action committee, Oregon Right to Die, had been racing against the clock to count, organize, and sort signatures gathered to place a death with dignity measure on the Oregon state ballot for the November 1994 election.

Ten weeks prior, Sugerman had gathered the first signature on the steps of the Oregon State Capitol. Today, the committee would submit 95,777 signatures to the Secretary of State's office—30 percent more than needed to quality for the November ballot.

## "AN EXCITING DAY"

"What an exciting day that was for all of us across America, who have been working on



right-to-die issues for so long," wrote the late Peter Goodwin, MD, a co-founder of Oregon Right to Die and one of the first physicians to speak out publicly in support of assisted dying.

Years before the PAC was formed, the ballot measure was drafted, and the campaign for the passage of the Oregon Death with Dignity Act was launched, a small group of individuals began gathering. At first in a public library, then in a church, and later in their own office space, they met to discuss how to improve end-of-life choices for dying patients, many of whom endured unbearable suffering at the end of life.

## "A NEW IDEA"

Eli Stutsman, the lead author of the Oregon Death with Dignity Act and a member of Death with Dignity's Board of Directors, was a founding member of this group. By early 1993, Stutsman recalled, "We would soon go public with a new idea. We believed that a competent, terminally ill adult, with a prognosis of six months or less to live, should be allowed to hasten a difficult death within narrow and well-defined circumstances, if he or she so desired."

## FROM BILL TO BALLOT

The Oregon Legislature's refusal to move multiple death with dignity bills introduced by the late Senator Frank Roberts convinced advocates that their best chance of success was at the ballot box.

## THE UNDERDOGS TRIUMPH

Oregon Right to Die was outspent \$5 million to \$1 million in what was at that time the most expensive battle over a ballot initiative in state history. But in the end, Oregonians approved Measure 16, making their state the first place in the world with an assisted dying statute.

"With its passage," the Associated Press reported on November 11, 1994, "Oregon moves into the forefront of the movement to give the dying the freedom to choose when, and how, their lives end."

## 25 YEARS ON

A quarter century after Oregonians approved the first-of-its kind law, the Oregon Death with Dignity Act has withstood all attempts to nullify it. It has become a part of the medical standard of care in Oregon and the model for laws in eight additional jurisdictions across the country.

We applaud those who built the strong foundation for this cause and whose work we build on today.

Death with Dignity will spend the month of November commemorating the 25th anniversary of the passage of the Oregon Death with Dignity Act. We are launching an oral history project, *Voices of a Movement*, hosting a celebration reception, and featuring archival materials from the 1994 campaign on social media.

This article is an excerpt from the first installment of our online series, Looking Back, Moving Forward. Visit **DeathwithDignity.org/Oregon-25** to explore highlights from our oral history project.



Geoff Sugerman (left) with Eli Stutsman, JD, leader of the Oregon Right to Die PAC and lead author of the Oregon Death with Dignity Act, in 1994.

# Making Strides in Massachusetts

In September, Death with Dignity staff met with Massachusetts legislators and grassroots advocates to push for passage of the End of Life Options Act. Prior to our meetings at the State House, we testified before lawmakers at a June hearing on the bill.

## SUPPORTING ADVOCATES

We are working closely with a state-based organization, Western Massachusetts Death with Dignity, to support their grassroots organizing and advocacy efforts.

## THE HISTORY

Death with Dignity led a ballot-initiative campaign in Massachusetts in 2012. Despite polls showing 58 percent of state residents supported medical aid in dying, the ballot measure lost narrowly 51 to 49 percent.

"This was a fight its opponents felt they couldn't afford to lose," the *New York Times* reported after the vote. "If the proponents could pass this in 40-percentCatholic Massachusetts, they'd be running through all the states within five years."

Our opponents' efforts in Massachusetts, powered by an infusion of out-of-state money, were successful in the short term. But they did not halt the momentum of the death with dignity movement nationwide.

## THE TIME IS RIGHT

Since then, six states and D.C. have enacted assisted dying statutes. The Massachusetts Medical Society in 2017 dropped its opposition to death with dignity. Sixty-seven lawmakers in both chambers of the Massachusetts legislature are co-sponsoring the End of Life Options Act.

The time is right for policy reform in the Bay State.

To learn more about our work in Massachusetts, visit DeathwithDignity.org/States/ Massachusetts. &

## "Live Free, Die Free" in New Hampshire

New Hampshire's official motto, "Live Free or Die," embodies the state's reputation as a home for fiercely independent individuals. Bob McCown, the founder of New Hampshire Death with Dignity, coined a modified motto for his organization: "Live Free, Die Free."

Like so many supporters of death with dignity, Bob's advocacy is inspired by personal experience.

He lost a friend and family member to a prolonged, painful death. Additionally, he told us, "having worked in nursing homes for 10 years, I have dozens of stories of patients who were competent and terminally ill and were forced to suffer unimaginable pain for months."

We were proud to take part in the official launch event for New Hampshire Death with Dignity on September 27 in Concord. Attendees included physicians, nurses, and religious leaders. Seven current and former legislators discussed past efforts to pass an aid-in-dying bill and strategies to introduce legislation next session.

"I was surprised and gratified to see the diverse yet unified cross-section of the public wanting a death with dignity bill," Bob said.

Death with Dignity supports organizations like Bob's through our State Leadership Incubator, which provides grassroots supporters with tools and training that help them become effective advocates for policy reform.

#### To learn more, visit DeathwithDignity.org/ Dignity50-Incubator +++



Bob McCown (center) with, from left, New Hampshire Death with Dignity's Cheri Bach and Death with Dignity National Center's Peg Sandeen, Valerie Lovelace, and Peter Korchnak.

# Valerie Lovelace Joins Death with Dignity

In June, we celebrated when Governor Janet Mills signed the Maine Death with Dignity Act into law. It was the culmination of a nearly five-year-long effort in which grassroots advocates played a crucial role in achieving victory.

Maine resident Valerie Lovelace led the way. Now, she's joining the Death with Dignity team as our State Leadership Incubator Manager.

## TRAINING STATE-BASED ADVOCATES

We launched the State Leadership Incubator in 2017 to support grassroots organizations across the country. By providing advocates with tools and training developed by veterans and consultants into her work, successfully leading a ballotinitiative campaign and working with legislators to advance a bill. Moving forward, Val will lead our efforts to recruit and train leaders of state-based groups.

## IMPLEMENTATION ACROSS THE NATION

Val leads our on-the-ground implementation work in Maine, serving as a liaison between health care providers, patients, and state institutions. Her work serves as a model for the implementation process after a state passes an assisted dying law.

of political campaigns, we empower them to lead policyreform efforts in their respective states.

Val incorporated lessons learned from our staff



Valerie Lovelace.

"I am so excited about the potential of this program, and

being able to help folks like me figure out how to navigate the weird world of politics to pass legislation," Val said.

We are pleased to welcome Val on board and look forward to growing our advocacy efforts nationwide under her leadership. #

## Sustaining the Movement Donor Spotlight: Kathy O'Malley

Death with Dignity sustaining donor Kathy O'Malley spent years co-hosting a radio show in her home state of Illinois. While she and her co-host covered a wide variety of topics, they occasionally devoted airtime to exploring end-of-life options, including assisted dying. "There was always an outpouring of support whenever the topic came up," she says.

## "ALIGNED WITH MY BELIEFS"

Kathy became a Death with Dignity supporter after viewing the film "How to Die in Oregon," which chronicles the story of a patient who elects to use the Oregon Death with Dignity Act. "The philosophy behind death with dignity was totally aligned with my beliefs," Kathy said. It is an option she wished her mother had at the end of her life.

## HAVING CONTROL

She recalls her mother saying, "I just want to be done." But there was nothing Kathy could do to help ease her suffering. Kathy would like the option for herself should she become terminally ill. "I believe in having the control to choose how I want to die," she said.

## GIVING MONTHLY

Kathy hopes Illinois lawmakers consider death with dignity legislation soon. In the meantime, she continues to support Death with Dignity with a monthly donation. "I can talk about [supporting social issues], but I also have to

put my money where my mouth is," she said.

We are grateful to sustaining donors like Kathy for enabling us to expand our work across the country. #



Kathy O'Malley at her home in Illinois.

## What My Mother Wanted By Adrienne Dare, New Mexico

Last month, I celebrated the 17<sup>th</sup> anniversary of my mother, Louise Hall, using Oregon's Death with Dignity Act to end her suffering with terminal cancer. It was a profound and positive experience. I am grateful she had the opportunity to die on her own terms.

## UNCONTROLLABLE PAIN

My mother was diagnosed with cancer at age 90. She underwent radiation to try to reduce the tumor but had to stop because it was too painful. But even after she was on hospice her



Adrienne Dare with her mother, Louise, in 2001.

pain couldn't be controlled with medication. She was ready to die. That's when she decided that death with dignity was the path for her.

## A PEACEFUL DEATH

I was able to be with her for her last two months, as well as on the day she died. In the end, surrounded by family, she told us, "I love you all," drank the water with the dissolved medicine, and died peacefully within a few minutes. She even had a little smile on her face. She was no longer in pain.

## WORKING TO PASS A LAW

I'm passionate about this issue. Since 2012 I've worked on passing the Elizabeth Whitefield End of Life Options Act in New Mexico. where I live. I believe death with dignity should be available for any terminally ill, competent adult in every state. It not only relieves the dying person of more suffering but also gives great comfort to their family and friends. 🖶

## Save the Date: National Clinicians Conference on Medical Aid in Dying, February 14–15, 2020

As the number of Americans with access to aid in dying continues to grow, so too does the need for a forum for clinicians who provide care to patients with a terminal illness.

We are pleased to announce that Death with Dignity National Center and Bay Area End of Life Options will convene the inaugural National Clinicians Conference on Medical Aid in Dying. The conference, scheduled for February 14–15, 2020, will bring together end-of-life care professionals from across the country for in-depth conversations about the role of medically assisted death in the continuum of care for dying individuals.

We are proud to be a founding partner of this first-of-its-kind conference and invite all end-of-life care providers to attend. Learn more and register at https://nccmaid.org/.

## Voices of a Movement

For a quarter century, Death with Dignity National Center has been at the forefront of the assisted dying movement. From drafting, passing, and defending the Oregon Death with Dignity Act to leading successful campaigns in other states, our staff and advocates have led the way.

Our new oral history project, *Voices of a Movement,* features interviews with a number of individuals who played a vital role in the campaign for the Oregon law as well as those who have advanced the cause beyond Oregon.

Visit **DeathwithDignity.org/Oregon-25** to view highlights of the project, including written and video interviews with advocates, elected officials, physicians, and others who have dedicated their lives to making death with dignity an end-oflife option for dying individuals.



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# Ħ **Dignity Report**

I believe in having the control to choose how I want to die.







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