

THE

Death with Dignity  
NATIONAL CENTER

# Dignity Report

A publication of the Death with Dignity National Center

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*Cover photo: Maine Death with Dignity volunteers collecting signatures for a ballot measure petition*

## GIVE DIGNITY

Death with dignity laws provide peace of mind to qualified terminally ill residents in **California, Colorado, District of Columbia, Hawai'i, 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](https://DeathwithDignity.org/Support)** to learn more and contribute.

THANK YOU!

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## Enthusiasm and Opportunity



Five years ago, our *10 States with Death with Dignity Statutes in 10 Years* goal seemed lofty. Now, it's within reach.

The list of states ripe for policy reform continues to grow. The recent midterm election opened new opportunities across the country. Two bright spots are Nevada, where we have been working to build support among legislators and the public since 2015, and New Mexico, where local advocates are building enthusiasm at the grassroots.

Perhaps no state better embodies enthusiasm and opportunity than Maine, where we have both legislative support for policy reform and a grassroots ballot initiative campaign.

Last November, Death with Dignity staff traveled to Maine to support 124 volunteers across the state as they worked tirelessly to collect nearly 24,000 signatures in one day to place an assisted-dying measure on the ballot.

Watching this work unfold in real time via a group text thread was as heartening as it was impressive. When one team needed an extra table, staff drove an hour to deliver it. When a volunteer reported she'd filled a petition sheet in just 30 minutes, the thread became a chorus of 'Congratulations!'

The sheer excitement brought me back to our successful 2008 ballot initiative campaign in Washington state. Then, as now, we matched our national expertise with locals' on-the-ground knowledge, combining our resources and building on each other's unique strengths.

Your support has paved the way for these successes. Thank you for helping us move ever closer to our goal of 10 in 10.

A handwritten signature in black ink, appearing to read 'Peg Sandeen'.

*Peg Sandeen*  
Executive Director


# Momentum in Maine: Scenes from a Campaign

Since 2017, Death with Dignity has been supporting the ballot initiative effort led by grassroots political action committee, Maine Death with Dignity.

In November, Death with Dignity staff joined volunteers who braved the elements on Election Day to gather nearly 24,000 signatures. To date, more than 58,000 Mainers have signed the petition—a testament to the overwhelming support for death with dignity.

It was an honor to work alongside the dedicated Mainers who advocate tirelessly for improved end-of-life options.

We are in awe of their commitment, and look forward to supporting Maine Death with Dignity in 2019 and beyond.

*See p. 8 to read one volunteer petition circulator's story.* 



*Volunteers assemble packets for signature gatherers in preparation for Election Day.*





To learn more about the campaign and get involved, visit [MaineDeathwithDignity.org](https://MaineDeathwithDignity.org)

# On the Ground in Maine: “Why I Volunteer”

By Karen Hinson, Maine

I learned at an early age that death is part of life. The doctors, nurses, and dentists in my family talked about blood and guts at the dinner table.

As a hospice volunteer I later learned of the terrible toll on those with terminal illnesses and their families. I have never met anyone who says, “I’d prefer a long, slow, degrading, painful death,” but I have met many who want to die at home.

I do, too.

This is why I volunteer gathering signatures for Maine Death with Dignity’s citizen initiative.

When I gather signatures for the petition in rural Maine, I see three kinds of people: those who look quickly and walk on by; those who ask for information and want to ponder it and discuss it with family; and those who bound right up, thank me for my work, and ask where to sign the petition.

The work is challenging but the reward is well worth it.

I am proud to work alongside more than 100 Maine Death with Dignity volunteers, who share my commitment to end-of-life choice.

Together, we are working toward the day when Mainers are free to decide how they die. ☺



*Karen Hinson (right) collecting signatures for the petition*

# Resources, Suggestions, Support: Social Work at Death with Dignity

Every day we receive phone calls from people across the country seeking information about death with dignity—or just someone to listen. Enter Elia Lawatsch, Death with Dignity’s social worker, who provides both technical and emotional support to callers.

## DEMYSTIFYING DEATH WITH DIGNITY

Elia explains how assisted-dying laws work; connects people with resources in their region; and offers suggestions for those who are seeking information about other end-of-life options or pain management for a non-terminal illness.


Above all, she listens, providing comfort and encouragement

when callers are at their most vulnerable.

## CONTINUING A LEGACY

Our social work builds on the pioneering efforts of our Board President, George Eighmey. For 12 years after the Oregon Death with Dignity Act was enacted, he led the organization which provided information and counseling to over 1,600 terminally ill individuals accessing the law.

“Every single one of those people had a powerful impact on my life,” George recalls.

We remain committed to offering personalized support to patients, their loved ones, and anyone who needs us. 

*“I applaud people for their bravery and make sure they are getting the support they need.”*

—ELIA LAWATSCH, SOCIAL WORKER, DEATH WITH DIGNITY

# Major Victory in California

In late November, the California Fourth District Court of Appeal overturned the lower court's May 2018 decision nullifying the End of Life Option Act. The Act continues to provide Californians with peace of mind and control over their final days.

## FIGHT NOT OVER

The Court of Appeal's decision is not the last word on death with dignity in California. The appellate court sent the issue back to the lower court, giving opponents an opportunity to mount a new challenge.

*The court's ruling came as a major victory for supporters of assisted dying and validated Death with Dignity's work to defend the California law.*

—SIMONA STRAUSS, DEATH WITH DIGNITY'S ATTORNEY,  
SIMPSON THACHER & BARTLETT LLP

## NO STANDING

The Court of Appeal's decision is consistent with past court rulings on the issue. The plaintiffs argued the law is invalid because it violates equal protections and puts doctors in harm's way. The appellate court ruled the physician plaintiffs who brought the suit forward had no grounds to do so.

The battle to protect the California law from attempts to undermine it may take years. But we have defeated similar challenges in the past and we know what it takes to prevail.

We will not stop until the right of all terminally ill Californians to decide how they die is protected. 🏠



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# The Case for Death with Dignity in California

When a California district court judge in May 2018 overturned the End of Life Option Act, we leapt into action, filing an *amicus curiae* brief to provide the court with essential information about death with dignity and its crucial role in improving end-of-life care.

The following is a summary of the key arguments in the brief, which we expounded on in a white paper publication.

## **DEATH WITH DIGNITY IMPROVES END-OF-LIFE CARE**

The impact of assisted-dying laws, starting with the Oregon Death with Dignity Act in 1994, extends far beyond providing end-of-life options.


These laws bring conversations about death and dying into mainstream discourse across the nation and improve end-of-life care overall.

## **CALIFORNIA'S END OF LIFE OPTION ACT IS PART OF HEALTHCARE**

The End of Life Option Act clearly relates to healthcare and the directive in Governor Jerry Brown's 2015 proclamation to "consider and act upon legislation necessary to (...) improve the health of all Californians."

The Act provides eligible persons with access to another end-of-life care option which runs tandem with palliative care, hospice care, and other options of last resort.

Healthcare professionals report engaging in more comprehensive conversations with their patients about end-of-life care.

This has led to better use of end-of-life care options that existed prior to the Act. 

Learn more about the brief and download the white paper at  
**[DeathwithDignity.org/healthcare](https://DeathwithDignity.org/healthcare)**



*Kappy Wells outside (left) and in her studio drawing her father in his final days (right)*

# The Art of Dying Well

## Donor Spotlight: Kappy Wells

Kappy Wells tells stories in bronze and charcoal. With sculptures in collections in New York, Paris, and Santa Fe, where she lives part-time, Kappy is an accomplished and well-traveled artist.


Some of her most powerful work is her most personal. As her father, Malcolm, was dying, Kappy documented his prolonged decline in large-scale charcoal drawings.

A respected figure in the conservation architecture movement, Malcolm Wells was vibrant and engaging. But his final years were filled with suffering.

“Had he been able to end his life legally [through an assisted-dying

law], he happily would have done it,” Kappy said. But because he lived in Massachusetts, a state without a death with dignity statute, he couldn’t.

Her father’s experience sparked Kappy’s support for the assisted-dying movement, and of Death with Dignity National Center.

Kappy generously contributes to Death with Dignity so we can work toward policy reform in states across the country, including New Mexico, one of our priority states for 2019. Her support stems from her desire to honor her father’s memory and her commitment to ensuring others have an option for a dignified and peaceful death. 

# Dignity, Autonomy, and Choice

By Sara Deskar, North Carolina

Earlier this year, I watched my dad die of lung disease. He remained independent and dignified in spirit throughout his seven-year illness, but his final deterioration robbed him of who he had been his whole life—and left my family with lasting trauma and grief.

## DYING IN AGONY

At the very end, it took an agonizing amount of time for him to pass. He had suffered for seven long years. Why did he have to struggle those last few days, too?

Watching my dad leave this world slowly and painfully broke my heart—but also inspired me to ensure others don't have to die that way.

Neither Ohio, where my dad died, nor North Carolina, where I live now, has an assisted-dying statute. I believe this is a right everyone should have.

## WHAT DEATH WITH DIGNITY MEANS

Death with dignity is about compassion, autonomy, and the right to choose. By allowing an individual the right to die with dignity, we ensure someone's transition to death can be as peaceful and painless as possible.

I am proud to share my father's story in the hope it will strengthen the death with dignity movement and contribute to policy reform in North Carolina, Ohio, and nationwide. 🇺🇸



*Sara Deskar with her father*



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# THE Dignity Report

*“Together, we are working toward  
the day when Mainers are free to  
decide how they die.”*

—KAREN HINSON, VOLUNTEER PETITION CIRCULATOR,  
MAINE DEATH WITH DIGNITY

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