

THE

Death with
Dignity
NATIONAL CENTER

Dignity Report

A publication of the Death with Dignity National Center

SPRING 2016



INSIDE THIS ISSUE:

What's Next for California
A New Formulary

Option for a Peaceful Death
Advocacy in Ohio

Table of Contents

A Message from the Desk of Peg Sandeen, Executive Director	3
What's Next for California	4–5
Option of a Peaceful Death	6–7
Local Advocate Spotlight: Ohio End of Life Options	8–9
Finding a New Formulary	10
Join Us Online	11

Cover photo: Washington, DC, advocate Mary Klein (left) with her wife Stella

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You can support our work in many ways: an outright gift, a gift honoring a loved one, becoming a Sustaining Partner, or including us in your estate planning. Please check the enclosed envelope for these options. In addition, you can help spread the word about our advocacy and this important issue by liking us on Facebook and following us on Twitter.

THANK YOU!

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A Message from the Desk of Dr. Peg Sandeen, Executive Director



This spring has featured a great deal of activity and advocacy in the Death with Dignity movement.

The newest Death with Dignity law, the California End of Life Option Act, goes into effect on June 9. On that date patients can officially begin the process of requesting medication to hasten death from their physician. At the same time, nearly 40 million Americans, all along the West Coast and in Vermont, will have the opportunity to access the Death with Dignity option should they become terminally ill and qualify under stringent requirements.

We are proud to bring forth a bill in the California legislature to provide state residents with a neutral source of information about physician-hastened death. Senate Bill 1002 will establish a staffed toll-free number to answer questions about the new End of Life Option Act. Read the story on page 4.

We continue to support efforts at organizing Death with Dignity advocacy around the country so that other states will join California, Vermont, Washington, and Vermont

in bringing expanded options at end of life. We are committing resources to grassroots efforts in promising states like Maine, Hawai'i, and New York, as well as "early states" like Ohio, Texas, and Virginia.

We also welcome two new members to our Board of Directors. Lisa Vigil Schattinger, whose stepfather used the Oregon law, leads a nascent local group in Cleveland, Ohio (read the story on page 8). Stephen Dunn has retired from his tech business in California; he and his wife Judy have been long-time supporters of the arts and Death with Dignity advocates in New York City, where they've lived for 15 years.

This session, in a presidential election year to boot, 20 states have considered Death with Dignity legislation. We will not rest until every state has a Death with Dignity statute providing comfort and relief to the terminally ill.

Thank you for your continued support and inspiration,

A handwritten signature in black ink, appearing to be 'Peg Sandeen'. The signature is fluid and cursive, with a long horizontal line extending to the right.

What's Next for California

The path to the passage of the California End of Life Options Act last October was as long and difficult as the ones we had faced in Oregon, Washington, and Vermont. The stakes in California were higher because of the state's size and power.

George Eighmey, President of the Death with Dignity National Center and a former Oregon lawmaker, led our organization's efforts to support and pass the law.

"This proves the power of individual people to affect change," said Eighmey. "From Brittany Maynard's mother and the courageous legislators who sponsored ABX2-15 to the thousands of people who joined us in advocating for the law, we showed that courage and commitment can convince even the most skeptical that this right must be afforded to each person who qualifies."

In signing the legislation, Governor Brown summed it up best: "I do not know what I would do if were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn't deny that right to others."

The End of Life Option Act will go into effect on June 9.

Fighting for the New Law

Even after ABX2-15 passed, opponents who failed to stop us at the Capitol tried—and failed—to put a repeal measure on the November ballot. They are now pledging to take their desperate fight to the courts and are investing "substantial funds" to the legal effort. In other words, our opponents aim to stop Californians from being able to use the Death with Dignity option. These lawsuits are a real threat, and we will fight them vigorously, the same way we fought—and defeated—the legal challenges to the Oregon Death with Dignity Act that reached all the way to the US Supreme Court.

Our main priority for the coming days will be to beat back these court challenges and allow the California End of Life Act to stand. The people who fought so hard for this law and who may seek this end-of-life option should not be denied their right to a peaceful death of their choosing.

Our Proposal for an Information Line

Passing Death with Dignity laws, such as the new California End of Life Option Act, is just the first step in providing the end-of-life option to the terminally ill. We know from experience in states like Oregon and

Washington that providing factual, bias-free information allows people seeking to use the law a great measure of clarity and relief.

To that end, George Eighmey proposed to Senators Bill Monning and Lois Wolk and helped to author a bill that would establish a toll-free information telephone line for Californians seeking information about the California End of Life Option Act.

Senate Bill 1002 provides an avenue for Californians to get answers to questions about how the End of Life Option Act works and how to use it. The phone line would be staffed by employees of the California Department of Public Health.

“SB 1002 is in response to inquiries Californians have about the End of Life Option Act,” Senator Monning, one of the sponsors of the original Death with Dignity law said.

“Because California’s aid-in-dying law is completely voluntary, doctors and hospitals are not required to answer patients’ questions, and it is important terminally ill individuals have somewhere to direct their questions, as well as receive factual responses about the law.”

The intent of SB 1002 is to provide clear information on the rights and responsibilities of patients under the End of Life Option Act, George said. “Knowing what their rights and responsibilities are is a step forward in providing comfort for dying and suffering patients.”

SB 1002 Clears the First Hurdle

Senate Bill 1002 passed out of the Senate Committee on Health on March 30. As we expected, powerful, deep-pocketed opponents campaigned to sway legislators by repeating the same unfounded fears they used to oppose the original law. Calling this bill an expansion of the law, they said the state employees would coerce people into using the law or that people with mental health issues would seek this option.

“This law is about providing information and helping terminally ill Californians navigate through the legal and medical requirements of the law,” said Eighmey. “As people find answers to their questions about the End of Life Option Act, we can ensure that only those Californians who meet the requirements of the law and are acting of their own free will, will be able to proceed with their journey. Those who do not meet the requirements of the law will simply not be allowed to participate. But we may be able to help guide them to other options where they can get the help they or their loved ones need.”

SB 1002 is about helping terminally ill Californians navigate through the legal and medical requirements of the End of Life Option Act. California residents are now this much closer to having a toll-free line that provides information about their new End of Life Option Act. ■



Option of a Peaceful Death by Mary Klein

A fundamental human right is control over our own bodies. That control is a critical aspect of freedom.

All of us should be able to make our own path in life, including how we decide to end our journey.

That end is in sight for me. I do not know how much longer I have to live.

I have advanced ovarian cancer that has spread throughout my abdomen despite aggressive surgery and the most aggressive chemotherapy possible. I cannot be cured.

Continuing Treatment

I do know that I will die either from the effects of additional treatments or from treatment side

If I had the option of a peaceful death, a death with dignity, I might not use it, but it would bring me great comfort to know it is there.

effects combined with the cancer. I will suffer, probably a lot, and I'm unlikely to have a peaceful death.

I will lose control of my body as I did during my first five months of chemotherapy. During that time my life consisted of anemia and blood transfusions, IV feeding and hydration, large blood clots in my left leg that took away my ability to walk, nausea, painful nerve damage to my legs and hands, which I still have, a constant infectious disease because my immune system was compromised, an inability to eat or drink much, and other fun side effects.

After a seven month remission, half of which I spent recovering from chemotherapy, I will soon start treatment again.

Whatever treatment I choose—more chemo or experimental targeted drugs offered by National Institutes of Health—the treatment will be

continuous for the rest of my life. Because of the drugs' side effects, I will never feel completely well again.

Great Comfort

If I had the option of a peaceful death, a death with dignity, I might not use it, but it would bring me great comfort to know it is there.

By having that option, I would have control over my own body—the control to decide to use the option or the control to decide not to use it.

With this in mind, I urge the Washington, DC, Council to approve a Death with Dignity bill that was introduced [last] year to give terminally ill persons the choice of a peaceful death. ■

Mary Klein is a retired journalist and artist in Washington, DC. With her in the photo is her dog Adina.

Local Advocate Spotlight: Ohio End of Life Options

In line with our brand of advocacy, we provide technical assistance to a number of grassroots groups in states with no legislative activity around Death with Dignity. This work helps lay the groundwork for the eventual passage of Oregon-style legislation.

One such state is Ohio, where Lisa Vigil Schattinger, MSN, RN, has led Ohio End of Life Options.

Grandpa Jack and Death with Dignity

Lisa's journey to Ohio End of Life Options began in November 2014.

She was at her stepfather Dr. Melvin John "Grandpa Jack" Rowe's bedside in Oregon when he ended his life using the medication made available under the Oregon Death with Dignity Act. Dr. Rowe's death was peaceful and dignified—he died exactly as he had planned.

"Grandpa Jack / Dr. Rowe was adamant that, in the face of a life-ending medical diagnosis, it was his right to choose his own fate," Lisa said. "He believed, as do I, that every terminally ill person should have that option. The opportunity to die at his own time of choice, with



Lisa Vigil Schattinger (second from right) with Grandpa Jack and her family.

medication prescribed under the Oregon Death with Dignity Act gave him great peace of mind. For those who value control and choice in the face of a terminal illness, the peace that Death with Dignity brings is invaluable.”

Educating about Death with Dignity Legislation

A month after Dr. Rowe’s death, Lisa published op-eds in Ohio and Oregon newspapers with an account of her experience.

By sharing the family’s experience, she hopes to bring education to Ohio about the value of laws based on Oregon’s Death with Dignity Act.

With increasing frequency and reach, Lisa and her allies have been publishing articles, giving media interviews, offering presentations (both in Ohio and around the country), and meeting with state legislators.

Informal meetings during these activities led to the creation of a dedicated group. The ten advocates later formed a steering committee for Ohio End of Life Options (OELO).

Ohio End of Life Options

The group’s purpose is to engage in educational and advocacy activities regarding end-of-life choices to people legally achieve their wishes for a peaceful and dignified death.

OELO is now raising awareness about end-of-life options and continuing



the discussion about laws based on the Oregon Death with Dignity Act. This education continues through meetings with the medical and political communities as well as the general Ohio public.

The organization has just obtained an official 501(c)(3) nonprofit organization status. We at Death with Dignity National Center are assisting OELO with their online efforts and strategic guidance.

Lisa is also joining our Board of Directors (see “Message from the Desk of Dr. Peg Sandeen, Executive Director”).

Learn more about the group at www.OhioOptions.org. ■

For those who value control and choice in the face of a terminal illness, the peace that Death with Dignity brings is invaluable.

Finding a New Formulary for Death with Dignity

Since Oregonians approved the Death with Dignity Act, the medical profession has used drug formularies that work effectively in allowing patients using the law to self-administer the medication.

Rising Drug Costs

Original versions of the formulary relied heavily on Seconal, a secobarbital. But, as with other drugs, the cost of Seconal has increased while its usage has declined on the market for sleep relief.

In addition, after the End of Life Option Act passed in California last year, the pharmaceutical company owning the rights to Seconal announced a significant price increase—even for patients using Death with Dignity laws.

Drug companies also refuse to distribute certain drugs to states that continue to exercise the death penalty. This has created situations where people legally using the Death with Dignity law have had to scramble to find suitable prescription drugs.

A New Formulary

A team of physicians in Washington state has developed a new

compounding formulary. The mix of three drugs was used in Washington and Oregon for the first time in 2015.

Peg Sandeen, Death with Dignity National Center Executive Director, said, "As the cost of drugs used in the old formulary has increased, sometimes more than tenfold, we are committed to finding formulary options using drugs that are available widely and that provide patients with the most comfort and the least pain.

"This is sometimes challenging in a world where drug prices are tied to the commercial markets that drive the industry.

"We have always advocated for a qualified terminally ill patient's right to end their life with dignity. We will continue to work with physicians and other colleagues to ensure that right."

Ensuring Access

Our Board President, George Eighmey, concurred: "No matter who you are, whether you're rich or poor, you should have access to a lethal dose of medicine that does what you want: to end your life in a peaceful and dignified manner." ■

“
The cancer is treatable but incurable. I am watchfully waiting. Everything is fine now. But when my time does come, I want to have the choice to die with dignity.

It simply means having the choice on how I wish to end my journey. It's about having a good death, a peaceful and serene one where I can say goodbye to those I love, it's about grace.

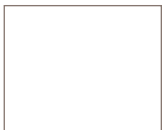
—ANN LOWER, HOLLYWOOD, CALIFORNIA

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