# THE Dignity Report

A publication of the Death with Dignity National Center

**FALL 2015** 



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Victory in California! What's Next In Memoriam Dick Walters Deborah Dempesy's Story Donor Spotlight Texas Death with Dignity

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Cover Photo: Deborah Dempesy with daughter Becca

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

#### **THANK YOU!**

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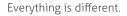
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#### A Message from the Desk of Dr. Peg Sandeen, Executive Director



I have had the pleasure of leading the Death with Dignity movement for 11 years, and have been watching it since its inception more than 20 years ago. Today, everything is different.

When Governor Brown signed the California End of Life Option Act on October 5th, everything about the Death with Dignity movement changed. The state we've always wanted to win is no longer a far-off goal—it is a reality. Once the California law takes effect, one in six Americans will live in states where Death with Dignity is an option.

The success in California rested on the legacy of our hard work. The Death with Dignity National Center was founded in California in 1993. We authored the Oregon law, worked to get it passed here (twice), and successfully defended it in the US Supreme Court; we spearheaded campaigns in Hawaii, Maine, Washington, Massachusetts, and Vermont. We returned to California this year in a political strategy role, the position in which we excel. It paid off.

Looking forward as the movement surges ahead, we will be working in New York. We will continue efforts



in Washington, DC, and in Maryland. Massachusetts and Connecticut look promising. We continue to build in Hawaii, Maine, and Nevada. We're supporting local efforts in Illinois, Michigan, Minnesota, New Hampshire, Ohio, Texas, and Virginia. Indeed, with everything different, there are opportunities all across the country, as the articles in this Dignity Report attest (we're also entering our movement's third decade with a new look).

As we envision and shape a new landscape for Death with Dignity, I am grateful. You've helped us get here: you donated; you called legislators; you wrote letters to the editor. With such an active base of donors and advocates, I couldn't be more proud of what we have accomplished together.

As we enter the holiday season, I want to thank you for having a seat at our table. Next year is going to be the most promising year for the Death with Dignity movement. I am so glad you are here.

My best,

## Local Advocate Spotlight: Texas Death with Dignity

While Texas may seem an unlikely candidate for Death with Dignity reform, one of our most active and dedicated grassroots partner groups is working hard to change that. Texas Death with Dignity, founded by Cindy Merrill and Penny Shelfer in Houston, has been educating Texans about the end-of-life option since 2013.

Aside from their active Facebook page, the tireless duo gives talks and presentations, writes letters to the editor, and meets with state lawmakers interested in the issue.

#### Meet Cindy Merrill...

A retired chief prosecutor, Cindy joined the Death with Dignity movement after

watching her father's decline. Since his death, Cindy said, "I have been seriously thinking about our responsibility, as human beings, to those in the throes of intractable pain and suffering at the end of life. I now advocate for people to have the freedom in their healthcare and end-of-life decisions."

#### ...and Penny Shelfer

Penny's dedication to the movement stems from a series of personal experiences. She was diagnosed with an aggressive form of breast cancer in 2008. She then worked for a mastectomy boutique, where she was involved with many women and their families dealing with breast cancer. When she watched both her parents





slowly succumb to disease, she faced death again. Not only did she learn to have no fear of dying but she also decided she didn't want to put her family through the hell of watching her die in unbearable pain.

#### On the Ground

With increasing frequency, Cindy and Penny have offered presentations at the AARP, churches, civic groups like Houston Freethinkers, universities, and other venues, facilitating lively discussions on the topic. Cindy's letters to the editor and an editorial piece have appeared in the Houston Chronicle and her local paper. And they're getting a Meetup group off the ground as well, with some 40 people signed up so far.

"Wherever I go I ask for a show of hands to see how many people want the legislation," Cindy said. "Most of the time, almost everyone raises their hand."

Though both Cindy and Penny anticipate it will take many years for

Photos: (Opposite, from left) Cindy Merrill, Penny Shelfer, and Cathy Cramer of the Wildflower Unitarian Universalist Church in Austin. (Top) Cindy and Penny presenting at Wildflower earlier this year. I'm going to either see Death with Dignity become law in Texas, or die trying."

#### Penny Shelfer

Texas to have a Death with Dignity statute, they are optimistic about the prospects.

What motivates them are their experiences and the knowledge there are thousands of people experiencing deaths they should not be experiencing. Penny said, "I'm going to either see Death With Dignity become law in Texas, or die trying."

#### The Future in Texas

The Texas Death with Dignity group is growing steadily. There are state lawmakers who support the option but are reluctant to express it in the current political climate in the state.

"National polls show two out of three conservatives are in favor of the option," Cindy said, quoting a recent Harris poll. "After talks, self-identified conservatives approach me to say they are in favor. People want this. The momentum is on our side. Texas will have a death with dignity law one day because sensible minds will prevail."

Find Texas Death with Dignity on Facebook at www.facebook.com/ TexasDeathWithDignityGroup.



## Death with Dignity in California: A Look Back at Our Victory

On October 5, California became the fourth state to have a Death with Dignity statute (the fifth where physician-assisted dying is legal). With the stroke of Governor Brown's pen, 39 million Californians joined Oregonians, Washingtonians, and Vermonters in having this end-of-life option. Now one in six Americans enjoy the freedom to decide how they die should they be terminally ill with a six month prognosis.

Thanks to you we've achieved monumental progress for all Americans who want the freedom to make their own end-of-life decisions.

The passage of the End of Life Option Act culminated many months of our work in the Golden State. Since December of last year, we invested our expertise and experience as a political advocacy organization in supporting the California state legislators who sponsored the bill.

We were there every step of the way. Senators Bill Monning and Lois Wolk introduced SB 128 at a press conference in the State Capitol on January 21. Things moved quickly afterward. The bill received its first hearing, in the Senate Health Committee, on March 25, where it passed 6 to 2, with one abstention; on April 7th the Judiciary Committee passed the bill 5 to 2; on May 28 the Appropriations Committee passed the bill 5 to 2; and on June 4 the full Senate approved the bill 23 to 15. We were there every step along the way: our Board member George Eighmey reviewed every piece of language in the bill for the sponsors; supplied facts and figures to refute objections; helped shape the strategy to shepherd the bill through the legislature; and provided expert testimony and answered Committee members' questions at the hearings. Our input in shaping the bill to address concerns from the medical community directly contributed to the California Medical Association's to shift from to a neutral stance on Death with Dignity. The change was instrumental in the passage of the bill in the Senate.

After the bill moved to the Assembly, we continued our assistance. Soon it became clear the Catholic Church pressured some of the legislators to oppose the bill, forcing the good Senators to withdraw SB 128 from consideration. But an opening presented itself over the summer with an extraordinary legislative session on healthcare. Assemblymember Susan Talamantes Eggman and co-sponsors introduced a revised bill. ABX2-15. on August 18th. The bill was quickly approved by the special-session Health and Finance committees, on 10 to 1 vote and 5 to 3 votes, respectively. On September 9th, the full Assembly passed the bill by 43 to 34.

Only three days later the Senate repeated its June vote, approving the bill and sending it to the Governor's desk. George was proud to sit on the Senate floor during this final vote between Brittany Maynard's parents, as all three had worked tirelessly to get this bill passed.

As the bill moved through the special session, not only did we continue

supporting the legislators in getting the bill passed, but we also rallied our constituents—you—to send letters and thank-you notes to Senators and Assemblymembers, attend hearings, and spread the word amongst friends.

We were on pins and needles while we waited for the Governor's decision. The Governor had every reason to sign this bill into law: with 76 percent public support and years of experience in Oregon demonstrating this law works, there was absolutely no reasonable argument for him to oppose the law. All along we kept in mind what our friend Steve Mione, a terminally ill San Diego resident, told us: when his end was imminent, he wanted to "be alert, say goodbye to my loved ones, and fall asleep and die peacefully, without pain and suffering."

In the end, the Governor listened to both advocates and opponents and went with his personal view. In his signing message, he wrote that, even though he didn't know what he would do if he were dying from a terminal illness, he wouldn't deny the right to people considering options afforded by the bill.

A lot remains to be done before qualified terminally ill Californians can access the Death with Dignity end-of-life option. For now, we celebrate our success and turn our political attention to other states so that, one day, all terminally ill Americans have the freedom to decide how they die.

Photo: George Eighmey with (from left) Debbie Ziegler and Christy O'Donnell at Senator Monning's office following the Senate vote on September 11, 2015.

## A Meaningful Journey By Deborah Dempesy

I have Stage IV pancreatic cancer. I will survive and struggle with this disease as long as I can. But I am trying to be very realistic about the future. As I make preparations for my life's end, I know that I will likely not live to see a Death with Dignity law passed here in Massachusetts. But I will die trying.

There are thousands like me in my state and around our country. Perhaps you are in the same situation or you knew someone who didn't have the freedom to decide how they died.

My cancer is the same disease that killed my little sister Kimberly nine years ago. For four difficult months I was Kimberly's primary caretaker at night, staying up to help her get the morphine she needed to relieve her agony.

When she was alert, we had the most wonderful conversations; the rest of the

time, she begged me to relieve her from the pain. I watched her suffer and knew I didn't ever want to suffer like that. Kimberly was only 46 when she died —she had no say in how she died. There wasn't even a semblance of dignity in the horrific way she had to go.

It is unfortunate I cannot give myself or my family the relief of dying in a more humane, gentler way than Kimberly did.

I am an educated, professional woman, and I wish to die in a way that exemplifies how I have lived my life. When it's time, I want to be with my loved ones. I believe death is a transition, a journey one takes. On my deathbed, I want the freedom to take that journey in a way that's meaningful and sensible to me.

The words "Death with Dignity" say it so clearly.

I wish to die in a way that exemplifies how I have lived my life."



There's much we can do: Tell the stories of our loved ones who die with more suffering than they should; listen to the voices of others who eloquently spoke of their suffering and desire to die with dignity; search our hearts, putting our compassion ahead of our ideology, to share in a debate about how we can give people the choice not to be forced into suffering while also protecting them from abuse and exploitation; and convince our lawmakers that we as individuals (not they) are best able to judge our quality of life, and that we deserve as much dignity in dying as we do in living."

> Jason Barber Death with Dignity Advocate

For your spouse, your parents, your grandparents, your children, your neighbors, and yourself, take a stand."



## In Memoriam: Dick Walters, 1925–2015

Our dear friend, Richard "Dick" Walters, used the Vermont Patient Choice and Control at End of Life Act to die peacefully on October 16th. Dick's tireless advocacy and dedication to personal freedom were instrumental in getting the law passed in 2013. Dick was 90 years old and died of cancer.

As president of Vermont Patient Choices, our local partner in the campaign, Dick believed Death with Dignity was a basic human right. "Thoughtful, principled people understand the profound importance of securing this human right," he wrote on our blog. "People who've watched a loved one suffer needlessly and pointlessly as I have. People brave enough to look toward their own future, and the dignity with which they hope to end a life well-lived."

Dick's journey toward the law's passage started in his living room, with his wife Ginny and their daughters, Nancy and Betsy, after watching his father suffer a difficult death. "Death with Dignity is a cause I feel in my heart, soul and conscience," Dick wrote. "It is worthy of every one of us who values life, treasures dignity, and wants never to be told by a stranger or a bureaucrat that our life is not our own, or that suffering is the property of their law or morality."

Ten years later, Vermont had enacted a Death with Dignity law. Presaging the developments in California, Dick saw the fact that Vermont was the first state to pass such a law in the legislature as very important. And he saw personal involvement as crucial as well: "For your spouse, your parents, your grandparents, your children, your neighbors and yourself, take a stand. Recognize that even a right this personal must be fought for and won."

We'll miss you, Dick; the movement will miss you, and Vermont will miss you. May you rest in peace.

## DONOR SPOTLIGHT: MICHAEL R. YOUNG

This month's donor spotlight is on Michael R. Young from Wichita, Kansas. Michael recently visited us in Portland, where we sat down with him and chat about the reasons why the Death with Dignity movement is important to him.

Like many others, Michael became engaged with the issue after he'd witnessed his parents' long, agonizing deaths. "The process made me think there had to be a more peaceful way," Michael said. "It reinforced my strong belief that people need to have Death with Dignity as an option for themselves. Every person should be entitled to make that decision."

#### A Philosophy of Dignity

Before retiring 10 years ago as CEO of York International, then a Fortune 500 company, Michael's business philosophy reflected his personal views. "I've long felt people should be treated with respect, dignity, and utmost courtesy. People should always be able to make their own choices."

The philosophy led Michael to conclude that the best way he could support our work is through financial support. "I am in good health but I am 71 years old," he said. "I know I won't get to 171, so if I have an untreatable terminal illness, Death with Dignity



would give me a choice to take a better exit."

The proposed Kansas Death with Dignity Act saw no movement in the state legislature this year. Indeed, Michael believes the state isn't politically inclined to enact the end-of-life option. "I hope this will progress as rapidly as other social issues, but it probably won't be done in the near future," he said. For it to happen, "we as a group need to start acting more responsibly, be more understanding and kind, and open up our minds to this issue."

Michael believes travel, for both work and pleasure, helped open up his mind. "Traveling allowed me to see things from many perspectives."

"If Death with Dignity isn't right for you, that's okay, you don't have to agree with me. I won't tell you to do it my way but I need to have the right to choose."



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