

Dignity Report

FALL 2021



The Power of Storytelling

DEATH WITH DIGNITY

In This Issue

On the Cover Dr. Plumer after returning from New Zealand and re-entering the American medical system in 2017.

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, New Mexico, Oregon, Vermont, and Washington.

You can help 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.

To learn more and contribute, visit **DeathwithDignity.org/Support**.

Thank you!

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Stories Make Our Movement

Storytelling has—without a doubt—inspired masses of advocates to join in grassroots efforts, given voices to patients with terminal illness, and led to the passage of new death with dignity laws.



When I think about stories within our movement, the first that comes to mind is that of Brittany Maynard, a California resident diagnosed with terminal brain cancer at only 29 years old. An assisted-dying law had not yet passed in California, so her family uprooted their lives to move to Oregon, where she was able to access the Oregon Death with Dignity Act. Brittany spent the final days of her life sharing her story across hundreds of news outlets, advocating for the right to die with dignity. Seven years later, her story continues to inspire, and we are honored to have her mother, Deborah Ziegler, serve on our board.

Sometimes we hear powerful stories from unexpected sources. During this year's legislative session, Assemblyman Edgar Flores, bill sponsor for the proposed aid-in-dying law in Nevada, AB351, opened a hearing with a powerful story about a loved one who suffered terribly at the end of his life. This transformed Flores' view on death and led him to become an advocate for this movement, despite his Catholic upbringing. His story not only inspired folks within the movement but also energizes his continued fight to get a law passed in Nevada.

Our work cannot be done without stories. Our movement depends on them. This issue of the Dignity Report highlights stories of patients and advocates within the death with dignity movement today.

In action,



Do you have a story you want to share? Please visit **DeathwithDignity.org/take-action/share-your-story** and share your story with us today.

Peg Sandeen Executive Director

Honoring My Patients' Last Wishes

BY DR. ROBIN SUSAN PLUMER

Dr. Plumer with a lamb in New Zealand while pursuing a postgraduate diploma at University of Auckland in hospice and palliative medicine in 2013.



People sometimes ask me if I have chosen to provide end-of-life care to patients with terminal illness because I like to see people die. Of course, the answer is "No!" Throughout my career in medicine, I witnessed many patient deaths that were anything but peaceful and dignified. Since medical aid in dying (MAID) has become an option, I attend a very different kind of death: a patient in control, choosing a dignified and painless death on their own terms.

Dr. Plumer has been practicing medicine for over 30 years. She lived in New Zealand for nine years, where she practiced emergency medicine and trained in hospice and palliative care. In 2020, Dr. Plumer and her business partner, Elizabeth Stanton, established Compassionate Endings NJ, a specialized medical practice focused on caring for patients desiring medical aid in dying.

IMAGES OF A PEACEFUL DEATH

Sitting in their living room, amid a warm atmosphere with snacks and a curated playlist, **Howard** and his family raised glasses of fine wine, toasting to his life. I was extremely careful to give Howard the correct glass; his contained the MAID medications prescribed through the New Jersey Medical Aid in Dying for the Terminally Ill Act. He fell asleep in his favorite recliner, surrounded by those he loved. He died peacefully the way he wanted to.

Sarah knew she wanted to be surrounded by her children when she took her MAID medications. She died in her bed, cuddled up with her daughters, her son nearby on FaceTime. She got the death she hoped for.

Surviving one last Christmas was all **Peter** wanted. Shortly after New Year's, he drank his MAID medications surrounded by family. His last words before closing his eyes were "It's been fun!" His last wishes were fulfilled.

Mark, an accomplished actor, drank his MAID medications with his adoring partner and a close friend beside him. As he fell asleep, we admired photos illustrating Mark's career and spoke of all the joy he brought others throughout his lifetime of performance. He died in the manner he had chosen.

RESOLUTE UNTIL THE LAST MOMENT

Just as my patients are resolute in their decision to pursue MAID, I am committed to supporting their final wishes. Not all physicians who participate in MAID attend their patients' deaths; in fact, most do not. All 17 of my patients so far this year who used New Jersey's law expressed intense relief at having us there at the time of ingestion. I believe patients and their loved ones should have medical support on hand so they can focus on the emotions of the day.

When discussing "good" deaths, my patients express similar feelings: wanting to be at home, surrounded by loved ones, peacefully going to sleep, and maintaining dignity to the last moment without painful or invasive procedures. Without MAID, few people are lucky enough to die in such a peaceful and gentle manner. I look forward to the day when all Americans have this option.

We Asked, You Answered

The last few years have been tough. The COVID-19 pandemic continues to disrupt our lives. So many of us have lost loved ones. This uncertainty is difficult. More people in the United States have been talking about end-of-life matters than ever before. At Death with Dignity, we have witnessed and taken part in countless candid discussions around dying and death.

We recently asked our supporters for input on what we should prioritize as an organization and how we can offer more support. We received many thoughtful responses.

We asked about our organizational priorities, and you answered.

YOUR TOP PRIORITIES FOR US:

- ★ Utilizing death with dignity laws
- ★ Supporting grassroots organizing
- ★ Expanding the right to die with dignity
- ★ Protecting existing death with dignity laws
- ★ Elevating expert voices
- ★ Fighting misinformation



Thank you for sharing these priorities with us. Your feedback informed our decisions about organizational focus and resource allocations.

Here are some of the stories and sentiments shared by supporters across the country:

"This work matters. My husband's ability to choose death with dignity gave him twenty-two months of anxiety-free, joy-filled living after receiving his terminal diagnosis. The freedom to end prolonged and debilitating suffering gave him peace of mind. I will be forever grateful."

-VERMONT

"Every human being has a right to choose their own end-of-life plan. Everyone dies. It is a fact for everyone, and the sooner we can remove the stigma around death, the better we will all be."

-TENNESSEE

"It is our personal right to be able to die with comfort and dignity when it's time to go."

-TEXAS

a year ago after suffering horribly with ALS. I cared for him, and while I appreciate every precious moment we had, he was miserable. He made the best of it, but he didn't deserve that extended suffering. People deserve the right to choose."

"My brother died just over

-INDIANA

"My mom said a few days before she passed, 'The worst part is waiting to die.' I wish we had the option to take away 'the worst part' for her. She had already suffered through cancer for so long. It hurts to say this but when you love someone it's hard to run out of options to help them."

-OHIO

"It is inhumane to let anyone suffer. What purpose does it serve? I hope this state, and everywhere else in this country, does the right thing, and allows someone the right to die with dignity."

- WISCONSIN

Now Is the Time for Georgia

5 Questions for Phyllis Talley, Georgians for End of Life Options (GAELO)

In addition to working as volunteer organizer for GAELO, Phyllis Talley runs her own estate planning and probate law firm in Atlanta, GA, Talley Life Planning Law, LLC.

Why did you get involved in the death with dignity movement?

I believe everyone has the right to autonomy, which involves the legal option of pursuing medical aid in dying (MAID). MAID allows an individual with terminal illness to write the ending to their own life story and respects the sacredness of life by creating dignity—not just for the dying patient, but for everyone.

Why does Georgia need a death with dignity law?

It is time to examine what endof-life choices Georgians want for themselves. Passing a death with dignity law in Georgia will bring personal peace of mind to those in the state who choose this end-of-life option.

What actions are you taking?

I'm working to organize a statewide advocacy organization, GAELO, which seeks to improve autonomy in advance-care planning and making end-of-life decisions, while honoring the wishes of patients with terminal illness. We are about to convene



Phyllis Talley, GAELO Volunteer Organizer, at Georgia State University College of Law in 2018.

GAELO's Steering Committee Kick-off Meeting, for recruiting potential advisers and committee members. I am hoping to secure some volunteers for the long haul!

How can Georgians get involved?

We are advocating for the Georgia Assembly to establish a study committee to determine whether Georgians with terminal illness have a right to determine the time and circumstances of their death. All Georgians can help by contacting their state assembly members to let them know that now is the time for Georgia to pass a death with dignity law.

What does death with dignity mean to you?

It not only provides a rational option of self-determination to the patient, but it's also an act of compassion. The right to die on one's own terms gives everyone the chance to say goodbye while grieving in an intimate, loving, and meaningful manner. Self-determination in matters related to end of life and death should be a basic human right.

The Right to Choose My Own Death

BY NIKI WIDMAYER



Niki (left) celebrating her sister, Susan's, birthday in 2014.

My mother, Joan, was wonderful and unique. After raising four children, she became a school librarian, joining my dad in the field of academia. She loved the outdoors and exploring. We spent the bulk of our summers camping in national parks.

Shortly after I had my second child, she was diagnosed with small cell lung cancer. I will never forget receiving the call with this tragic news, on Mother's Day of all days, or how quickly she died. I sat vigil at her bedside, watching the daily horrific scene of nurses draining her lungs. She was fed up and demanded they stop. I was with my dad when she died, and we both missed saying goodbye. I never questioned those protocols, but I know she deserved a better death.

THE SAME EXPERIENCE DECADES LATER

My sister, Susan, was a painter and schoolteacher. Unable to have children, she formed strong bonds with her students. She married a successful medical executive and had a fulfilling life, skiing, hiking, and taking great care of herself. It was a shock to hear of her adenocarcinoma diagnosis. With a prognosis of a few years, she underwent every treatment, including new drug trials. These efforts failed and hospice was called, and she made the difficult decision to stop eating and drinking. Her death earlier this year is still raw, and I believe her death should have been more peaceful.

I WANT SOMETHING DIFFERENT

Reflecting on both of their deaths, I know I want death with dignity when my time comes, but I live in Texas. Although Texans are proud of individual rights and independence, this right has not been granted to us, and it needs to be. Nobody has a choice in how they come into this world, but they should have the right to choose their own death. \clubsuit

My Way of Enacting Change

BY BETTY BREUHAUS, MASSACHUSETTS



Betty in 2017.

"It is as natural to die as to be born." – FRANCIS BACON

Of course we all can agree on the wisdom of these words. Whether sitting in a church, in a philosophy class, or on a rocky seacoast, this thought seems rational and soothing at the same time. Then comes reality. The crushing reality. Not only will our loved one be gone forever, but they must pass through a physical transition that can be horrific. Needlessly horrific.

A PERSONAL CHOICE

The fact that death with dignity provides an alternative to suffering at the end of life is a modern-day blessing and a personal choice. Certainly, one can choose not to use this option, but for their opinion to intrude on another person's beliefs and actions seems borderline immoral. This choice should be left up to the person who matters most: the patient.

USING MY POWER

While I strongly believe in death with dignity, I am not politically connected in a way that gives me power to pass assisted-dying laws across the country. Nor am I a public speaker who can sway the masses with my persuasive opinions. However, I do have one power in this arena: money. My donations help enact change and stand behind those with effective voices for this movement. I am comforted knowing my monthly contributions lead to advancements for this vital cause.

Learn more about making a monthly gift by contacting Ben Flax at **BFlax@deathwithdignity.org** or simply sign up online at **DeathwithDignity.org**.

Staff Recommendations:

What We're Reading and Listening to



ELIA LAWATSCH, DIGITAL COMMUNICATIONS MANAGER/WRITER/SOCIAL WORKER

"Death Doulas" Provide Aid at the End of Life, Abby Ellin, New York Times essay

This essay highlights the rise of a profession in end-of-life care as depicted through the story of a grieving mother who trained as a death doula after her daughter's death. For an introduction to this world and available services for patients with terminal illness, this is an excellent read.



VAL LOVELACE, STATEWIDE CAMPAIGNS DIRECTOR

Tear Soup: A Recipe for Healing After Loss, Pat Schwiebert, Chuck Deklyen, and Taylor Bills, children's book

Life-affirming and grief-affirming, *Tear Soup* is the beautifully illustrated story of Grandy, who has suffered the loss of someone she holds very dear. Combining her grief and memories into a "recipe," she is able to digest what happened.



BEN FLAX, LEADERSHIP GIVING MANAGER

Planet Money, episode 521: "The Town That Loves Death," NPR podcast

Using the town of La Crosse, WI, as an example, the *Planet Money* team shows how normalizing conversations around death and dying has changed a community and hospital system for the better by alleviating emotional distress, uncertainty, and economic burdens.



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Dignity Report THE

"Medical aid in dying allows an individual who is terminally ill to write the ending to their own life story and respects the sacredness of life by creating dignity."

VOLUNTEER ORGANIZER, GEORGIA







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