

Testimony of Peg Sandeen, PhD, MSW

Bill: [SB 845](#), End-of-Life Option Act (The Honorable Elijah E. Cummings and the Honorable Shane E. Pendergrass Act)

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Position: SUPPORT

My name is Dr. Peg Sandeen. I am the CEO of Death with Dignity and a social worker with a PhD in Social Work and Social Research.

I am testifying in support of the End-of-Life Option Act (The Honorable Elijah E. Cummings and the Honorable Shane E. Pendergrass Act) | [SB 845](#).

I am from Oregon, the place where the first Death with Dignity law was passed in 1994 and affirmed in 1997. I have more than 20 years of experience working directly with people who are terminally ill, including individuals who have opted to hasten their death using medication prescribed under Death with Dignity legislation.

I come to you today to tell you that in Oregon, and in the nine other jurisdictions where medical aid in dying is codified, the procedures and processes we put in place have worked precisely as designed. And I will, with clear research and data, dispel the myths and fears our opponents have tried to spread for years as simply not grounded in reality or fact.

In every state, the very first people who come forward to support this law are those who are facing a terminal diagnosis and simply want to make their own decisions about their end-of-life care.

Like Marcy Rubin from Montgomery County, who was diagnosed with stage IV metastatic breast cancer just five months after her husband, Jon, experienced a painful death from lung cancer. Marcy spent precious time advocating for Death with Dignity in Maryland – fighting for the freedom to choose aid in dying once her suffering became unbearable. Marcy wanted control over her death. She wanted to peacefully die at home surrounded by loved ones. But, instead, she died in a manner that was against her wishes because Maryland did not pass this law in time for her.

The second group of people who come forward are family members of those who died difficult, painful deaths and vowed that they would never watch others suffer as they were forced to watch their loved ones.

Passage of this law will work to increase access to health care for all citizens of Maryland, something I know this Committee cares about deeply.

In my career working with people who are terminally ill and dying, I have come to believe that one of the most difficult things for a terminally ill individual is the silence arising out of society's unwillingness to face death directly. Public conversations, of which testimony to a legislative body is a perfect example, provide an avenue for private conversations about dying to occur among family members. At least one family in the state of Maryland tonight will have a difficult conversation about dying, last wishes, and advance directives because they heard about this hearing today. This bill will help end the taboo on discussions over dying.

SB 845 is, at its core, a medical standard of care designed to provide physicians and pharmacists with best practice guidelines for situations in which a terminally ill and competent patient requests the right to control the timing and manner of their death. SB 845 is modeled on legislation that has been enacted in ten jurisdictions.

Beyond providing physicians with best practice guidelines, the End-of-Life Option Act puts decisions about easing their own suffering in the hands of terminally ill patients, allowing them to engage their family members, their physicians, clergy members and anyone else they choose, if they so choose. It sets aside outdated and archaic government bans on a medical practice that is currently legal for 70 million Americans, a practice that is validated, researched, effective, and full of safeguards to protect vulnerable populations.

The multiple safeguards in Senate Bill 845 include:

- A diagnosis of a terminal illness with a prognosis of six months or less to live, verified by a second physician's opinion.
- A mandatory counseling referral if either the attending or consulting physician believes the patient may not have capacity to make their own health care decisions.
- The individual must be a resident of Maryland.
- Oral and written requests are required. The written request must be witnessed by at least two people, one of whom must be someone who is not a relative or an heir set to receive an inheritance from the individual. The physicians involved cannot be witnesses. The two required oral requests must be at least 15 days apart.
- Information must be provided to the patient on all forms of palliative care, hospice care, and other end-of-life options.
- The patient may opt out at any time and for any reason.
- The patient must self-administer the medication.
- Any health care professional or healthcare institution may choose not to participate.
- Coercion, fraud, euthanasia, lethal injection, and mercy killing are all specifically prohibited in this legislation, as it is in every state where the law is in effect.

To reiterate: No physician, pharmacist, nurse, or any type of care facility may be forced to participate. Whether by conscience, religious belief or moral objection, every person potentially involved in this process may refuse to participate.

And no person may receive the prescription unless they are deemed to be within six months of death, acting voluntarily, capable of making their own health care decisions and able to self-administer the medication.

The policy you are considering has been subject to independent research protocols by individuals from a myriad of academic disciplines. These researchers have examined the safeguards and demonstrated there have not been any instances of abuse or coercion of patients in the more than 25 years since all of these laws took effect. These findings continue to refute the claims of our opponents who have never once produced a single shred of verifiable evidence of their claims.

As I said, I am an Oregonian, and I'm very proud of the fact that Oregon has successfully implemented a Death with Dignity law for over 25 years. I want to share with you some facts about the Oregon experience offering Death with Dignity under the very same safeguards you are considering.

The law is rarely used. Statistics collected by the Oregon Health Authority [1] demonstrate that since the law was implemented in Oregon, only 2,159 individuals have ended their lives using the Death with Dignity law in 25 years.

Every year, about one third of the individuals who go through the process to become qualified patients do not ingest the medication, but rather, go on to die from their underlying condition.

Death with Dignity for them is all about peace of mind.

- The median age of participants is 74;
- Over 90 percent are enrolled in hospice;
- Over 87 percent of them die at home;
- Over 99 percent of them have insurance, either private or government sponsored.
- Overwhelmingly, these patients have cancer.

Oregon's law has worked exactly as intended: to give dying and suffering patients more options at the end of life.

Opponents of this legislation allege a lot of things this bill does and does not do. For more than two decades now, we have heard these same slippery slope arguments: statements that this law will target individuals who are poor, who are living with disabilities, or the elderly; statements suggesting that those without medical care or access to health care resources will be forced to end their lives using medical aid in dying because it is cheaper than treating cancer.

The data from independent researchers proves that these arguments are based entirely on myths and falsehoods.

In 2007, Battin et al. [2] explored data out of Oregon to determine if there was a disproportionate impact of ten groups of potentially vulnerable patients. The data led the researchers to conclude

“...people who died with a physician’s assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges...there is no current factual support for so-called slippery-slope concerns about the risks of legalization of assisted dying—concerns that death in this way would be practiced more frequently on persons in vulnerable groups.”

To reiterate, there is no factual support for the slippery slope argument that vulnerable individuals are at risk for being coerced into using the law. It has simply never happened because of the safeguards in place.

Death with Dignity does not replace, but complements hospice and palliative care services.

In a comprehensive study conducted with family members of 86 Oregonians who were participating in Death with Dignity, researchers [3] concluded:

“...another concern regarding the legalization of PAD [physician aid in dying] is that PAD would become a substitute for quality end of life care...Insofar as family rating of the quality of a loved one’s death is an indicator of end of life care, this study adds to the evidence that the choice to pursue PAD does not appear to be due to, or a reflection of, poorer end of life care.”

It is no coincidence that the very first state to pass Death with Dignity—Oregon—was identified in an article published in the *New England Journal of Medicine* [4] as a state with significant and positive differences in how people die, as compared with other states in the country.

We in Oregon do better than the rest of the country in such benchmarks as:

- the percentage of people who die at home (as opposed to the hospital),
- the percentage of people using hospice, and
- the percentage of people who received intensive care services at the end of life.

The passage of our law and subsequent end-of-life policy changes sent a signal nationwide, and in Oregon, that dying patients must be accorded more and better care. Death with Dignity is part of that equation.

National research published in the *New England Journal of Medicine* indicates that physicians in every state, including Maryland [5], help patients die using prescription medication. By enacting this law, the Maryland Senate will send a strong message that a compassionate response to suffering is available in the state through medical aid in dying, but patients, families and physicians must follow the carefully regulated safeguards you are considering today.

As legislators in this great state, if you want to improve the quality of life for dying individuals in your jurisdiction, there is nothing better that you can do than enact a Death with Dignity statute. That's what the data tell us.

It will be rarely used, but a great source of comfort. Its safeguards will protect vulnerable individuals from coercion. Medical aid in dying will likely improve the quality of end-of-life care for the whole population, not just for people who contemplate it or use it.

Many individuals with a terminal illness who have shared their stories, like Marcy Rubin and others you will hear from, have no control over the trajectory of their disease. But they should have control over the time and manner of their death: the right to die on their own terms, with autonomy and peace of mind.

Thank you.

Peg Sandeen, PhD, MSW
Chief Executive Officer
Death with Dignity

References

- [1] Oregon Public Health Division. Death with Dignity Act Annual Report, Year 21. Available at <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRE>.
- [2] Battin, M.P., van der Heide, A., Ganzini, L, van der Wal, G., & Onwuteaka-Philipsen, B. D. (2007). "Legal physician-assisted dying in Oregon and the Netherlands: Evidence concerning the impact on patients in 'vulnerable' groups." *Journal of Medical Ethics*, 33, 591-597.
- [3] Smith, K.A., Goy, E. R., Harvath, T. A., & Ganzine L. (2011). "Quality of death and dying in patients who request physician-assisted death." *Journal of Palliative Medicine*, 14(4), 1-6.
- [4] Tolle, S.W., & Teno, J. M. (2017). "Lessons from Oregon in embracing complexity in end-of-life care." *New England Journal of Medicine*, 376(11), 1078-1082.
- [5] Meier, D.E., Emmons, C. A., Wallenstein, S., Quill, T. Morrison, R. S., & Cassel, C. K. (1998). "A national survey of physician-assisted suicide and euthanasia in the United States." *New England Journal of Medicine*, 338(17), 1193-1201.

About Dr. Peg Sandeen and Death with Dignity

Dr. Peg Sandeen (she/they) is a longtime social worker, patient care advocate, and professor who currently serves as the CEO of Death with Dignity. Death with Dignity was at the forefront of the passage of the first Death with Dignity law in the country: Oregon's in 1994. Since then, Death with Dignity has continued highlighting the importance of ensuring everyone has the right to options in the face of terminal, painful death sentences, including cancer. Currently, Death with Dignity is legal in 10 states, including California, New Jersey, and the District of Columbia.