Death with Dignity
NATIONAL CENTER

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Testimony in Support of LD 1313

Before the Health and Human Services Committee of the Maine State Legislature
April 10, 2019

My name is Peg Sandeen, and I am pleased to provide my testimony to the Health and Human Services Committee of the Maine State Legislature today. I am testifying in support of LD 1313. I sincerely appreciate the invitation to provide testimony and commend Chair Hymanson in her decision to host this hearing.

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 Maine tonight will have a difficult conversation about dying and last wishes and advance directives because they heard about this hearing today.

I have been invited to testify today because I am a social worker with a PhD in Social Work and Social Research, and I have more than 20 years of experience working with people who are dying. I am an Oregonian, and I am the Executive Director of the Death with Dignity National Center. In addition, I am an academic, and I am an adjunct professor of Social Work at Columbia University School of Social Work in New York. I am here in my capacity as the Executive Director of Death with Dignity National Center, a role I have held for the past 14 years.

Most importantly, I am here to share with you our experiences in Oregon, having successfully implemented a death with dignity law for over 20 years.

The proposed law you are considering today 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 his/her death. National research published in the *New England Journal of Medicine* indicates that physicians in every state, including Maine [1], help patients die using prescription medication. By enacting this law, the Maine State Legislature will send a strong message that a compassionate response to suffering is available in the state through medical aid in dying, but physicians must follow the carefully regulated safeguards you are considering today. The state of Maine will shine a bright light on the process to ensure the protection of vulnerable individuals.

Beyond providing physicians with best practices guidelines, LD 1313 puts decisions about easing 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 1 in 5 Americans, a practice that is validated, researched, effective, and full of safeguards to protect vulnerable populations.

Today, you are going to hear a lot of accusations about what 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 or who are living with disabilities or the elderly; statements suggesting that those without medical care or access to healthcare resources will be forced to end their lives using medical aid in dying because it is cheaper than treating cancer. These slippery slope arguments are just not true. Independent researchers have concluded that the results are quite the opposite:

In 2007, Battin et al [2] explored data out of Oregon to determine if there was a disproportionate impact of 10 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 legalisation of assisted dying—concerns that death in this way would be practised more frequently on persons in vulnerable groups."

You have already heard statements suggesting that death with dignity will undermine hospice and palliative care services, and the researchers are clear on this point, also. In a comprehensive study published in the *Journal of Palliative Medicine* conducted with family members of 86 Oregonians who were participating in death with dignity [3], researchers 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."

I've heard of opponents spilling 100 pills on a table, claiming that individuals using death with dignity must ingest all of them and asserting that the practice in Oregon was undignified. While visually startling, it is an outright untruth. No patient in any jurisdiction has been forced to ingest 100 pill capsules. It doesn't and cannot work that way.

You will likely hear testimony from someone claiming that a health insurance company denied treatment, but offered medication to hasten death. It is true that insurance companies both deny treatment and cover the provisions under death with dignity laws, but linking them together to suggest that an insurance company would deny care and instead offer death with dignity, is a falsehood. Not one of these claims has ever come to pass or been independently verified. Not in

Oregon. Not in Washington State. Not in Vermont. California, Colorado, the District of Columbia, Hawaii. Nowhere.

What we do know is that opposition to medical aid in dying comes largely from religious groups that say only God can decide when to end one's life. That is why this law contains clear opt-out provisions for medical professionals and states that only qualified patients who meet the strict criteria and safeguards in this law will be able to receive this prescription.

Throughout this law you will see a series of safeguards designed to protect the patient, the health care professional, and the family; all these provisions have been designed to ensure that the patient is in control. No one else but the patient may administer the medication. The multiple safeguards in LD 1313 include:

- A diagnosis of a terminal illness with a prognosis of six months or less to live, verified by a second opinion.
- A mandatory counseling referral if either the attending or consulting physician believes the patient may not have capacity to make this health care decision.
- Oral and written request. 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.
- 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.

I want to reiterate that last point. 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.

It is no coincidence that the very first state to pass death with dignity—Oregon—was recently 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. Oregon does better than the rest of the country in such benchmarks as the number of people who die at home (as opposed to the hospital), the number of people using hospice, and the number 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 that they control. We've responded to a crisis in how people are dying in Oregon. And other states are following our lead.

A lot of people want to talk about the Oregon experience with death with dignity. But, in almost every legislative hearing I've attended, these people are not from Oregon. I've worked with this law and the people who use it for 20 years. Oregon's law has worked exactly as intended, to give dying and suffering patients more options at the end of life.

We very much appreciate Representative Hymanson, Senator Gratwick, and all the sponsors and co-sponsors for bringing forward this important law. Our organization, the Death with Dignity National Center, stands ready to help Maine enact and implement this critical piece of end of life care legislation.

Thank you.

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References

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