DEATH WITH DIGNITY

Testimony of Geoff Sugerman

Bill: SB 239
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Organization: National Legislative Director, Death with Dignity
Position: SUPPORT

Chair Donate and members of the Senate Health and Human Services Committee:

My name is Geoff Sugerman and I am pleased to be here today in support of SB 239.

I am from Oregon, the place where the first Death with Dignity law was passed in 1994 and affirmed in 1997. I was the campaign director for that original Oregon citizens' initiative. I was there when the first words of the proposed ballot measure were written and since then, we have worked to amplify the voices of people who are terminally ill, including individuals who have opted to hasten their death using medication prescribed under medical aid in dying 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.

People including Deb Black, a Carson City resident who testified before this legislature and visited many of your offices. Deb died last year of breast cancer that metastasized to her brain. She fought her disease for years, but knew that, at the end of her life, she faced excruciating suffering she did not want to endure. The bills she advocated so hard for never passed and she died in a manner she did not want.

In an op-ed in the Nevada Appeal, Deb had this to say:

"I want to have the right to control my future. So as I continue to fight, I also am planning for the eventual end of my life…I do not want my family's last image of me as a shadow of someone they knew: unable to meaningfully interact with my children and grandchildren, doped up on medication just to be able to tolerate the pain, incontinent or bed-ridden with no quality of life…Or I can continue to ask the Nevada legislature to give me control over the end of my life, and allow me to die with dignity."

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 Nevada, something I know this Committee cares about deeply.

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 Nevada 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 239 is, at its core, a medical standard of care designed to provide health care providers 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 239 is modeled on legislation that has been enacted in ten jurisdictions.

Beyond providing health care providers with best practice guidelines, SB 239 puts decisions about easing their own suffering in the hands of terminally-ill patients, allowing them to engage their family members, their health care providers, 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 239 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.

- Oral and written requests are required. The written request must be witnessed by someone who is not a relative or an heir set to receive an inheritance. 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 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 medical aid in dying 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.

Medical aid in dying, for qualified patients, 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.

Medical aid in dying 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 medical aid in dying, 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. Medical aid in dying is part of that equation

National research published in the *New England Journal of Medicine* indicates that health care providers in every state, including Nevada [5], help patients die using prescription medication. By enacting this law, the Nevada 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 health care providers 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 Deb Black 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.

References

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[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.

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[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 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 laws exist in 10 jurisdictions, including California, New Jersey, New Mexico, Colorado, and Washington, D.C.