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PUBLIC HEALTH COMMITTEE
Testimony regarding HB 5898
An Act Concerning Aid in Dying for Terminally Ill Patients
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Senator Abrams, Rep. Steinberg, and members of the Public Health Committee:

My name is Cathy Ludlum, and I am one of the leaders of Second Thoughts Connecticut, a group of people with disabilities and allies who are working to prevent the legalization of assisted suicide. I am here to oppose HB 5898.

Let me start by explaining why the disability community is working so hard across the country to stop legislation of this type.

Nobody wants people to be in pain, desperate, and feeling that they have no control over what is happening in their lives. Believe me, those of us with disabilities know what it is to feel like you have no control.

But the harsh reality is that we will be the collateral damage in any formalized death-by-choice system. Many of us with severe and obvious disabilities are already too frequently thought of by medical practitioners as having reached a final stage, where death might be expected in the near future.

If we go to the hospital, we bring friends. We have to.

This will be even more true now that the Connecticut State Medical Society has dropped its opposition to assisted suicide. The last thing we need is for practitioners to have in the back of their minds, "Maybe it's time for 'Aid in Dying.'" If the CSMS will not advocate for good medical practice, who will?

It is reasonable to ask why a disabled person would choose a doctor who does not seem willing to fight for his or her life and health. Unfortunately, people are not always in a position to choose their own doctor. Private insurance often requires that the patient see a doctor in their network, or pay for the privilege of going out-of-network. Not every physician accepts Medicare or Medicaid, so again, choices can be limited.

Further, if a person lands in the hospital, he or she will be treated by doctors unfamiliar with the individual's situation. This is what happened to my colleague, William Peace. He was hospitalized with a deep and grossly infected pressure sore. As a paraplegic, both his life and his quality of life were in serious jeopardy. A doctor spoke to him about devastation he would face as a result of this pressure sore: loss of job, bankruptcy, at least six months

and probably more than a year in bed, and complete dependence on others, most likely in a nursing home. The doctor offered Bill the choice of refusing antibiotics, promising to make him “comfortable.” Bill refused. Many of those terrible things did happen, but eventually Bill recovered and resumed his life as a college professor. Assisted suicide was not an option in that state at that time, but the story demonstrates that the doctor believed Bill would be better off dead. ¹

Any physician will tell you that medical science is inexact, at best. Sometimes predictions are slightly off, but sometimes they are off by decades. Look at the case of John Norton, a member of Second Thoughts Massachusetts. He was diagnosed with ALS when he was 18 years old. The diagnosis was verified by the prestigious Mayo Clinic. For some reason the progression of his disability stopped, and he was 74 when he submitted testimony to a Canadian court in opposition to assisted suicide. By then, he had a wife and children, and was retired from a successful career. Yet he testified that if assisted suicide was available in the 1950s, he would have taken advantage of it. Think of all he would have missed based on what was a reasonable prognosis for his condition. ²

We can spend time talking about problems with the proposed legislation.

- Believe it or not, I would qualify as terminal under the definition given in Section 1, 19:

"Terminal illness" means the final stage of an incurable and irreversible medical condition that an attending physician anticipates, within reasonable medical judgment, will produce a patient's death within six months.

Nowhere does it say “with or without treatment.” Most people assume this legislation is for people who have exhausted all their treatment options, but that is not what it says. I eat with a feeding tube and use respiratory support when I am sleeping. Without these treatments, I would not last six months. I would probably not last six days. What is to prevent someone like me from showing up at a doctor’s office and saying, “I have had enough. I will be stopping all my treatment”? While the typical population would receive suicide prevention services at that point, this person would be more likely to get compassionate nods of approval. ³

- “Competent” is defined as allowing a third party to speak for a patient with a communication disability if that person claims to be “familiar with a patient's manner of communicating.” What is to protect a patient with very difficult communication from having an exhausted caregiver misrepresent his or her wishes?
- The proposed legislation says the prescription “may” be self-administered, not that it “shall be.” There is no language preventing another person from administering the prescription.

Unfortunately, adjusting the legislative language does not help. Proponents say that with adequate safeguards, no one is at risk. **But in reality, no package of safeguards has ever or CAN ever be developed that will provide 100% protection from misdiagnosis, incorrect prognosis, coercion, or the devaluation of the lives of disabled people.**

Finally, proponents' repeated statements that there have been no problems with the Oregon and Washington State assisted suicide systems are false. There may be times when everything goes the way it is supposed to, but with over 1500 people dying under the law, it is hard for me to believe that no one died under questionable circumstances.

Even Dr. Katrina Hedberg of the Oregon Department of Human Services (who is a supporter of the state's Death with Dignity law) said, "We are not given the resources to investigate [assisted-suicide cases] and not only do we not have the resources to do it, but we do not have any legal authority to insert ourselves." Those words may be comforting to people whose want total privacy, but they send chills up my spine. We as a society cannot just set this in motion without any mechanism to protect people who will inevitably be taken advantage of. Privacy is certainly important, but so is balance, and there is no balance in this legislation.

The Disability Rights Education and Defense Fund has written a report showing that the safeguards in the Oregon and Washington State laws have not always been effective, and that assisted suicide does not always result in a peaceful death.⁴

Is it acceptable for some lives to be shortened because people are acting on a wrong prognosis, or because they are pressured into making this final move, so that others can exercise what they see as a personal right? The last thing my colleagues and I want is to interfere with anyone's choice. But when this choice becomes legislation that poses a direct threat to us and to others in our network, we must emphatically say NO.

Even if you support this legislation in concept, there is just no way to avoid having some people die for the wrong reasons.

HB 5898 is bad medicine, bad for people, and bad public policy. Please stop it from moving forward.

Thank you for your consideration.

Sources:

- ¹ William J. Peace, "Comfort Care as Denial of Personhood"
http://infiniteability.yolasite.com/resources/Hastings%20report_Peace.pdf
- ² John Norton, "Affidavit in Opposition to Assisted Suicide and Euthanasia"
<http://www.massagainstassistedsuicide.org/2012/09/john-norton-cautionary-tale.html>
- ³ Carol J. Gill, PhD, "Suicide Intervention for People with Disabilities: A Lesson in Inequality"
<https://pdfs.semanticscholar.org/196b/2ab9f5a29e2e41e7958d35c055a26d5f4386.pdf>
- ⁴ The Disability Rights Education and Defense Fund, "Some Oregon and Washington State Assisted Suicide Abuses and Complications"
<https://dredf.org/public-policy/assisted-suicide/some-oregon-assisted-suicide-abuses-and-complications/>