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PUBLIC HEALTH COMMITTEE
Testimony regarding HB 5417
An Act Concerning End-Of-Life Care
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Sen. Gerratana, Sen. Somers, Rep. Steinberg, Rep. Srinivasan, and members of the Public Health Committee:

My name is Cathy Ludlum, and I am here for the fourth time to express my opposition to an assisted suicide bill, in this case HB 5417. I am one of the leaders of Second Thoughts Connecticut, a disability rights organization opposed to the legalization of this practice.

It is well and good to say we need a dialogue about this issue... except that we have already had a dialogue about this specific bill. It was HB 7015, and we spent 12 hours at a hearing to discuss it in 2015. All the concerns raised in that testimony are still valid and apply to HB 5417.

It distresses me that with people's lives and well-being at stake, the exact same bill is being brought up again. Section 18 of HB 5417 makes reference to the Office of Protection and Advocacy for Persons with Disabilities, a state agency that has not existed for over a year. It does not seem like much thought was put into this.

Year after year members of the disability community come to speak against assisted suicide legislation. We are not lacking in compassion. Believe me, we fully grasp the complexities involved. Nobody wants people to be dying in pain, desperate, and feeling that they have no control anymore over what is happening in their lives.

But the harsh reality is that those of us with disabilities will be the collateral damage in any formalized death-by-choice system that is created. For that reason, we have been fighting this hard all over the country. Some have called us "disability hardliners," which we don't understand since we are simply fighting for our lives.

Do you think I'm overstating it? Not at all.

Many of us with severe and obvious disabilities tend to be thought of by medical practitioners as having reached a final stage, where death might be expected in the near future. This may or may not be the case at that particular time; but many of us have experienced the willingness of healthcare workers to give up on us because they do not see any point in continuing to treat us. If we go to the hospital, we bring friends. We have to.

These problems already exist, and are well documented. The last thing we need is for practitioners to have in the back of their minds, “Maybe it’s time for ‘Aid in Dying.’”

Any doctor 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 is alive at the age of 80, with a wife and children, and retired from a successful career. Yet he testifies that if assisted suicide were available 60 years ago, he would have taken advantage of it. Think of all he would have missed based on what was a reasonable prognosis for his condition.

We can spend time picking apart problems with the proposed legislation and trying to design the perfect set of safeguards. Here is a partial list of ways HB 5417, like HB 7015, fails to protect people with disabilities and elders from abuse:

- Although heirs and family members are prohibited from witnessing the written request for the prescription, what is to stop their friends from acting as witnesses?
- The request does not need to be made in the presence of a physician but can simply be mailed in. How can we ever know what is going on in that home? Is the ill person being threatened with abandonment? Being told he or she is too much work? If the patient is physically unable to write, who is actually making the mailed request?
- “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? Dawn Parkot of New Jersey has spoken eloquently about her concerns as a user of augmentative communication.
- “Self-administer” merely means to ingest. Nothing in the proposed legislation prevents another person from administering the prescription.
- Likewise, nothing in HB 5417 says that the prescription must be taken orally. Even if the patient consented initially, a liquid form of the drug could be administered to a sleeping patient through a feeding tube without his or her knowledge or consent at that moment.
- No independent witness is required at the death. Was the prescription taken willingly? If the person struggled (or was asleep), who would know?
- There is no investigational authority, so once the prescription is in the home, there is absolutely no protection for the patient, and no ability to look at suspicious cases.
- Doctors will be obligated to falsify death certificates by listing the underlying illness as the cause of death instead of assisted suicide or an overdose of barbiturates. The

State of Connecticut Division of Criminal Justice submitted testimony on HB 7015, not taking a position on assisted suicide itself, but objecting to the falsification of death records. The same objection applies to HB 5417.

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 people with disabilities.**

Assisted suicide will always be the cheapest treatment, and for that reason, it will always distort choice. Stephanie Packer was denied chemotherapy but offered assisted suicide for a \$1.20 co-pay soon after California legalized the practice. Withholding treatment shifts from the end of the spectrum to the middle, in between potential lifesaving options and suicide, and therefore becomes the norm.

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? My colleagues and I do not want to interfere with anyone's personal 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.

There is one more thing. Proponents' repeated statements that there have been no problems with assisted suicide programs in other states are false. Marilyn Golden, from the Disability Rights Education and Defense Fund (DREDF) has compiled a report showing that the existing safeguards are ineffective. It also describes how a supposedly "peaceful death" goes awry an estimated 15 - 25% of the time from side effects such as vomiting or waking up after a long period of unconsciousness. She has submitted this report as her testimony, so please read it.

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

HB 5417 is bad medicine, bad for people, and bad public policy. Please stop it from moving forward.

Thank you for your consideration.