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Connecticut Public Health Committee

In Opposition to HB 5326

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On behalf of Not Dead Yet and Massachusetts Second Thoughts

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Chairs Gerratana and Johnson, Members:

Thank you for the opportunity to testify. My name is John Kelly, and I am the New England Regional Director for Not Dead Yet, the national disability rights group that has long opposed euthanasia and assisted suicide. I am also the director of Massachusetts Second Thoughts: People with Disabilities Opposing the Legalization of Assisted Suicide. We were the progressive voice in Massachusetts that defeated the assisted suicide ballot question in 2012. Our opposition is based in universal principles of social justice that apply to everyone, whether disabled or not. Drawing on those same principles, we support medical marijuana.

We chose our name Second Thoughts because we find that many people, once they delve below the surface appeal of assisted suicide, have “second thoughts” and oppose it. In Massachusetts a month before the election, 68% of voters supported the ballot question. But just as closer looks in Massachusetts – and more recently in the New Hampshire Statehouse – led to a considered rejection of assisted suicide, we urge you to reject HB 5326 because of the real-world threats it poses.

HB 5326, like all assisted suicide laws, draws on shoddy science to create dangerous public health policy. The bill would establish a government recommendation that doctor-prescribed suicide is sometimes the best treatment. Innocent people who are not terminal and are not making a voluntary and informed choice will lose their lives as a result.

Because as we all know, doctors are not good at predicting when people will die. In Massachusetts we had the example of longtime proponent of universal healthcare, Senator Ted Kennedy, diagnosed with aggressive brain cancer in 2008. His widow Victoria described his story in a powerful opinion piece that helped seal defeat for the Massachusetts referendum.

“When my husband was first diagnosed with cancer,” she wrote, “he was told that he had only two to four months to live, that he’d never go back to the U.S. Senate, that he should get his affairs in order, kiss his wife, love his family and get ready to die. But that prognosis was wrong. Teddy lived 15 more productive months.”

Under this bill, someone in Connecticut receiving a similar diagnosis could be dead in 15 days, based on the tragically mistaken belief that death was imminent. Legalized assisted suicide, Vicki Kennedy wrote,

“turns Kennedy’s vision of health care for all on its head by asking us to endorse patient suicide -- not patient care -- as our public policy for dealing with pain and the financial burdens of care at the end of life.”

In this age of induced austerity, the media is full of calls for healthcare cost containment. So in the state of Oregon, Barbara Wagner and Randy Stroup received letters from Oregon Medicaid denying coverage for prescribed chemotherapy. The letters noted, however, that the state would cover the \$100 cost of suicide. Because assisted suicide will always be the cheapest treatment, its availability will inevitably affect medical decision-making. This will actually end up constraining choice.

Depressed people will be harmed by this bill. Oregonian Michael Freeland easily obtained a lethal prescription for his terminal diagnosis, despite a 43-year history of severe depression, suicide attempts, and paranoia. Fortunately, other doctors and counselors intervened to address his real needs and he died a natural death about two years later. When this story came to light, the prescribing doctor said he didn't think a psychological consult was "necessary." Oregon’s statistics for the last four years show that only 2% of patients were referred for a psychological evaluation. Experts agree that most doctors are not capable of identifying such psychological problems.

And if one doctor declines to approve of a prescription, families can simply go “doctor shopping.” So when a consulting psychologist found that Oregonian Kate Cheney lacked the "level of capacity" necessary to weigh her options, and that Kate's daughter was pushing harder for suicide than she was, the angry daughter got the insurance company to fund a second opinion. The second psychologist had the same concerns, but ruled that Kate was competent anyway. On the day that she got back from a nursing home stay as respite for her family, Kate suggested that she take the lethal overdose. Her family facilitated her death that same day. Choosing between a nursing home and a family who sees you as a burden is not a true choice.

There is nothing in this or any other assisted suicide bill that can protect people like Kate Cheney. Every year in Connecticut, it is estimated that out of 660,000 people over age 60, there are 73,000 reported and unreported cases of abuse. Connecticut has a poor record in this area – 32nd out of 35 states surveyed in funding protective services, and fifth worst in number of “substantiated” complaints. Only in the fantasy world of the proponents are all families, including the thousands of abusive and dysfunctional ones, happily gathered around the peaceful and willing suicide.

The Committee on Public Health should not be recommending the sending of poisonous drugs into abusive situations and then not even require an independent, disinterested witness be present at the dying. The bill shouts out the phrase “self-administer” 12 times, yet defines “self-administer” more prosaically as the simple act of – willful or not – “ingesting” (Section 18). This bill takes no notice of how self-interest can motivate family members and caregivers. Because of the provision in these laws that death certificates list the cause of death as the underlying illness, investigations are foreclosed. This explains the absurd claim by proponents that there has been not one case of abuse in Oregon.

In Oregon, the Associated Press reported last year, "Tami Sawyer also faces charges of criminal mistreatment and theft as a result of a state charge that she stole more than \$50,000 after a man who suffered from Lou Gehrig's disease moved into her home, named her his estate trustee, deeded his home to a trust, and then died by physician-assisted suicide." Two days after Thomas Middleton died, Sawyer listed the property for sale and deposited the sale money into one of her own accounts. This story came to light, not through any assisted suicide program safeguards, but through suspicious real estate transactions.

Americans place tremendous value on individual, autonomous choice, whereas policy makers must recognize the social realities that affect people's health and healthcare decision-making. When people become ill and dependent, their desire to live or die is affected by the level of support they receive. Of course this is true!

Oregonian Kathryn Judson wrote of bringing her seriously ill husband to the doctor. "I collapsed in a half-exhausted heap in a chair once I got him into the doctor's office, relieved that we were going to get badly needed help (or so I thought)," she wrote. "To my surprise and horror, during the exam I overheard the doctor giving my husband a sales pitch for assisted suicide. 'Think of what it will spare your wife, we need to think of her' he said, as a clincher." We are social creatures.

We already see innocent people feeling pressured and pushed towards assisted suicide for the sake of their family. Last year in Oregon, 49% of assisted suicide users were reported as feeling like a burden on family and caregivers.

As proponents themselves admit, and as Oregon's physician reporting form demonstrates, it is social factors that make up the suffering this bill talks about. Doctors report people choosing suicide because of loss of dignity, loss of autonomy, and loss of control of bodily functions.

These reasons suggest a meaning of dignity that is fragile and easily lost through disability and dependence on others. The people acting on these views, proponents admit, tend to be wealthier, better educated, and people with a strong preference for control. This is presented as a good thing.

Assisted suicide proponents are also overwhelmingly white. 97.6% of program suicides in Oregon have been white, in a state 22% nonwhite. The Pew Research Center found earlier this year that, while whites support assisted suicide 53%-44%, black and Latino voters register 65% opposition. The election map for Question 2 in Massachusetts revealed the same trends. We have a public health problem, but it isn't certain people's lack of dignity, it's the turn to suicide as a social solution by a powerful social class. High rates of white suicide are already a social problem.

What ever else assisted suicide is, it is not about pain.

Pain is a medical problem that palliative care can solve. As renowned palliative care expert Dr. Ira Byock has testified,

If I thought lethal prescriptions were necessary to alleviate suffering, I would support them. In 34 years of practice, I have never abandoned a patient to die in uncontrolled pain and have never needed to hasten a patient's death. Alleviating suffering is different from eliminating the sufferer. Allowing a person to die gently is importantly different from actively ending the person's life.

In recognition of this fact, when the New England Journal of Medicine held an online poll last year, its invented case was a man with metastatic pancreatic cancer, with pain well-controlled. Two thirds of respondents, by the way, opposed legalization.

We disabled people have lives that frequently look like the lives of people requesting assisted suicide, but we reject as bizarre the notion that personal dignity is somehow lost through physical dependence on others, or because we are not continent every hour of every day. We already encounter massive

prejudice in the medical care system, which is all too ready to have us die without treatment. I know many people with disabilities living vibrant, active lives contributing to the community who have been encouraged to sign Do Not Resuscitate orders or decline life-saving treatment.

HB 5326 uses a definition of “terminal condition” that directly threatens the lives of many disabled and chronically ill people. Section 19 reads:

"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.

Like the Massachusetts bill, the definition omits the crucial phrase “with or without treatment.” So while my quadriplegia or someone’s diabetes or multiple sclerosis constitute “an incurable and irreversible medical condition,” we are not typically understood as “terminal.” Otherwise, the day this bill takes effect, thousands of us can become terminal by simply declining life-sustaining medication or treatment. People will be discouraged from trying treatment.

In a 2011 letter to the Boston Globe, Oregonian Jeanette Hall wrote that she voted for “death with dignity” in her state, and when she received a terminal diagnosis, asked for a lethal prescription. "I didn't want to suffer," she wrote. Fortunately, she had a doctor who persuaded her to try more treatment. Now, more than 13 years later, she wrote that she is “so happy to be alive.”

In its last two yearly reports, Oregon listed individuals whose cause of death was diabetes and multiple sclerosis. If I was like the thousands of Connecticut residents who were abused or neglected, I might easily find a doctor to validate temporary feelings of being a burden as being worse than death. Legalizing assisted suicide sends the wrong message to anyone who depends on caregivers, the message that feeling like a burden is not only an acceptable reason for suicide, but a justification for our health care system to provide the lethal means. We are not better off dead. We are not better off dead.

What we disabled people see in legalizing assisted suicide is that some people get suicide prevention, while others get suicide assistance, based on value judgments and prejudice. As Vicki Kennedy wrote, “We’re better than that. We should expand palliative care, pain management, nursing care and hospice, not trade the dignity and life of a human being for the bottom line.”

Let’s make sure that people have the choice and support to live comfortably at home – not in nursing homes, before offering hastened death. In your deliberations, please think about Connecticut residents, elders and disabled people who may be vulnerable and without the sort of support and control assisted suicide proponents take for granted, innocent people who will be impacted by this piece of bad social policy. Invidious quality-of-life judgments have no place in social policy.

Reject this bill and the discrimination it promotes.

Thank you very much.

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