

**April 11, 2013**

**The Honorable Ann Pugh**

**Vermont House Human Services Committee**

**Re: Opposition to Legislation Legalizing Assisted Suicide**

**John B. Kelly**

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**On behalf of Not Dead Yet and Massachusetts Second Thoughts**

[www.notdeadyet.org](http://www.notdeadyet.org)      [www.second-thoughts.org](http://www.second-thoughts.org)

Chairwoman Pugh and Members of the Committee:

**Thank you** for the opportunity to testify before the committee by telephone, I really appreciate it! My name is John Kelly, I am the director of Massachusetts Second Thoughts: People with Disabilities Opposing the Legalization of Assisted Suicide. I also represent Not Dead Yet, the national disability rights group that has long opposed euthanasia and assisted suicide. We were the progressive voice in Massachusetts that last November defeated the assisted suicide ballot question. Our opposition was based in universal principles of social justice that apply to everyone, whether disabled or not. Drawing on those same principles, we supported the ballot question for medical marijuana. I do have a disability, a spinal cord injury that resulted in my being paralyzed below my shoulders. I use a power wheelchair that I drive by myself. I just have to make sure these things work with a sip and puff tube.

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 Massachusetts voters supported the ballot question. But upon closer look at the real-world threats the legislation posed, voters had serious "second thoughts."

These laws draw on shoddy science to create bad public health policy. They enact 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 make mistakes. Under this bill, a misdiagnosis becomes deadly. In a letter to the Boston Globe, Oregonian Jeanette Hall wrote that she voted for "death with dignity" 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 12 years later, she wrote that she is "so happy to be alive."

Underlying the effort to pass this bill is an unwarranted faith in the accuracy of terminal diagnoses. Proponents use the word “dying” to emphasize the imminent certainty of death, but many people with a terminal diagnosis are not yet dying, and doctors admit that they cannot reliably predict when an individual will die. The disability community is full of people who have outlived their terminal diagnoses by years.

And then there is the example of longtime proponent of universal healthcare Senator Ted Kennedy, who was diagnosed with aggressive brain cancer in 2008. His widow Victoria described his story in a powerful opinion piece that sealed 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 Vermont receiving a similar diagnosis could be dead within 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 stories of the medical expenses of people's last year of life. Efforts have been intensifying to reduce these costs, and many people see assisted suicide as a cost saver. As social scientist Thomas Edsall wrote a few weeks ago in the New York Times in an article about poverty, “Throughout the country, often with the active support of state governments, adults of all ages, but especially the elderly, are under mounting pressure to sign cost-saving advanced directives, allowing hospitals and doctors to end intensive procedures at various end-of-life stages.” He then mentions assisted suicide in the same context. It is not a coincidence that Compassion & Choices’ Barbara Coombs Lee was previously employed as an HMO executive.

In 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.

Vulnerable 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 who are being abused. Every year in Vermont, it is estimated that there are over 13,000 reported and unreported cases of elder abuse. No independent, disinterested witness is required when the lethal dosage is taken, which means that the stipulation that someone “must” self-administer the drug is merely a recommendation. These bills take no notice of how self-interest can motivate family members and caregivers. Because of the typical provision in these laws that death certificates list the cause of death as the underlying illness, investigations are foreclosed.

In Oregon, the Associated Press reported in January, "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.

Hospitals complain that patients sometimes undergo unnecessary treatment to satisfy the wishes of family members who want them to keep “fighting.” But we should also be concerned that innocent people will feel pushed towards assisted suicide to benefit their family, which may be sending the message that they are a burden. Last year in Oregon, 57% of assisted suicide users were reported as feeling like a burden on their family and caregivers. As proponents themselves admit, and as Oregon's physician reporting form says, it is social reasons like these that drive the movement for legalized assisted suicide. Doctors report people choosing suicide because of loss of dignity, loss of autonomy, and loss of control of bodily functions. It is not about pain.

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 squandered 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. Over the last two weeks, disabled Vermonter Amanda Baggs has had to defend repeatedly over and over again her decision to get a feeding tube to save her life. 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. 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 to end your life.

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 support to live comfortably at home – no nursing homes, before offering hastened death. In your deliberations, please think about Vermont residents, vulnerable and without the sort of 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. Thank you very much.

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