

Testimony Against H.B. No. 5417 (Raised)

An Act Concerning End-Of-Life Care

Public Health Committee

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Once again, I speak in opposition to the legalization of euthanasia. Previously named “medical aid in dying” and “physician assisted suicide,” these bills have been introduced on a regular basis and fortunately defeated each time in committee. This year’s iteration, brought forth by the Public Health Committee, has been given a particularly Orwellian title, “End of Life Care.”

The concept of empowering health care providers to terminate the lives of their patients is the antithesis of “public health,” the opposite of “care.”

Because of my personal experience with the broken medical system, I have testified against these bills each time they have been raised since 2013, the year after my mother’s death. In these dark days of alt-right power, with a federal administration dedicated to the destruction of all the social safety nets that protect the most vulnerable among us, it is more crucial than ever to defeat this legislation.

In the fall of 2011, I lay sleepless in the middle of the night on a cot in the Medical Intensive Care Unit at Yale New Haven Hospital near my 89-year-old mother, Catherine. I had recently signed a “Do Not Intubate” directive for her, accompanying her “Do Not Resuscitate” order.

My mother had never provided a living will, and for several years had progressed (or regressed) along a path of vascular dementia. And yet she continued to tell me, clearly, that she was not ready to die.

I knew my Mom, and I knew what she said was true of her. It wasn’t a function of her dementia. She knew she was close to her end, but she was not yet quite ready for that final step. She was very, very ill. She could not easily swallow, and at any time could have choked on her own saliva. With this DNI directive in place, the remediation of her suffering would be massive doses of Morphine, which would quickly end her life. And this course of action was what was many of the medical professionals at Yale New Haven Hospital demanded- demand- that I accept.

I watched her all that night, and I realized that if she was in distress and I called for help for her, with this order in place, this is exactly what would happen: I would have to sit by, passively, as she was effectively euthanized.

The next day, I rescinded the DNI order, not an easy thing to accomplish, I discovered, as I stood up against the accepted program. And for the next several months, I was continually harassed by hospital personnel of all ranks and professions, some well-meaning if misguided (some of her younger doctors and nurses) and some more consciously driven by the profit (or lack thereof) motive. In addition to being vulnerable because she was quite old and had dementia, my mother was also a Medicaid patient. Her care was costing them too much.

I want to say that again. Please understand it in all its terrifying implications.

Her care was costing them too much.

Consider this: the same system that paid Marna Borgstrom, the CEO of Yale New Haven Hospital, close to \$3.8 million in salary and benefits in FY 2016, making her the highest paid employee in our state for two years running, decided that my mother's continued health care as a Medicaid patient was too pricey.

I learned quickly that our experience is not unique. In fact, it is the norm. Attitudes and prejudices against the vulnerable are being carefully cultivated in medical schools, by hospital administrators and by the insurance companies to enforce the cost-cutting agenda. Patients, their families, advocates, and friends are being steered toward one decision. This is not a choice. This is coercion. At the most vulnerable times of their lives, people are being offered the "right" to die, versus the "right" to live with inadequate health care that will cause much suffering and trauma for themselves and their families. Death is cost effective.

Being caught between a rock and a hard place is not a choice.

In the first testimony I offered before the legislature on March 20, 2013, I said:

"Given the health care system in this country and the fact that some lives are clearly deemed expendable, it is neither compassionate or wise to support any measure that would, intended or not, legalize further pressure and abuse. When I think of the constant harassment to which I was subjected to make a decision that I did not feel I could or should make, it doesn't take much more to imagine the subtle or not so subtle coercion to which a terminally ill person and their family could be subjected—and, as my experience shows, likely would be subjected— if assisted suicide is in fact made legal. The system is already geared in that direction and is becoming more so as 'cutting medical costs' becomes the mantra of the day."

What I was talking about five years ago is much more frighteningly true today.

The well-financed advocates of this bill try to tar those who oppose it with one brush, to render invisible the deep and committed opposition to assisted suicide that comes from the disability rights community and from those of us left or liberal activists who clearly see these bills for what they are: another piece of the medical cost-cutting agenda that seeks to ration health care for the most vulnerable among us, the poor, the elderly and the disabled. To continue to advocate for this legislation in the era of alt-right power, where the highest officials in our nation are slashing the most basic of our hard won, already inadequate, safety nets, is short-sighted and irresponsible.

I realize that there are those who support this legislation from a place of true compassion, hoping to alleviate suffering and offer real choice to dying patients. I don't want to try to render them invisible as some of their allies have tried to do to us. As a pro-choice, human rights advocate theirs are values that I share. Everyone must have the right to choose for themselves to refuse treatment or to opt for palliative care only, and to receive the medication they need to manage pain or alleviate suffering. Everyone must have the right to refuse aggressive intervention, and to refuse sustenance if they choose. There is a complex balance between allowing people those rights of choice and denying the right to choose of those who may want to go in a different direction. There is no "correct" choice, no "one size fits all." But the imposition of this legislation would in fact codify what already exists de-facto: couched in euphemisms like "death with dignity" and "my life, my choice," the "right to die" has, for the most vulnerable among us, already become the "duty to die."

Please do not vote this legislation out of committee. Thank you for the opportunity to testify.