

Testimony for the Public Health Committee against Passage of “An Act Concerning Compassionate Aid in Dying for Terminally Ill Patients” (HB 6645)

Offered in memory of my mother, Catherine: February 22, 1922—May 23, 2012

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Wednesday, March 20, 2013

## **SUMMARY**

This bill is a wolf in sheep’s clothing. I can recognize its terrifying implications because of my own, personal experience with the health care system. Couched in terms of “compassion” and “choice,” its outcomes will be anything but compassionate; and, for most of us, they will not be about choice. The bill cannot be tweaked or improved to be made safe or unthreatening to those who of us are physically, mentally and/or emotionally vulnerable.

As you consider HB 6645, I ask each and every one of you to remember that, if not today, someday, *all of us* will be physically, mentally and/or emotionally vulnerable.

## **REMARKS**

I am an archivist and historian by profession. By avocation, I am a life-long peace and justice activist, a member of the War Resisters League and the Connecticut Network to Abolish the Death Penalty. I support reproductive freedom, gay rights, labor unions, disability rights and civil liberties in all forms. And I am convinced that this bill is an assault on every value and every right that I believe in and have tried to work for throughout my life.

This is a painful, painful discussion. There are unquestionably some progressive people who are promoting this bill for reasons that they believe to be compassionate. What those advocates fail to recognize—possibly because they come from places of relative physical and social advantage with all the health care privileges that implies—is that there is a malevolent agenda behind it. Just as the hospice movement has been increasingly subverted to a darker purpose of medical cost cutting, this bill, if it passes, will be another notch on the belts of those who seek to restrict health care, to decide whose life is worth saving and whose is expendable; indeed, whose life can be “acceptably” terminated.

This is an agenda that has snaked its way through human history with disastrous results. Think of the Social Darwinists who so inspired the racists and eugenicists of our own country and Nazi Germany as recently as the 20<sup>th</sup> century. Think of how some health care practitioners accommodated themselves so easily to these philosophies even where they weren’t codified.

As an historian, I would have to be against this bill because of the lessons that history teaches us if only we would heed them. As a social justice advocate, I would oppose it absolutely on principle. But I am also passionately against it for personal reasons, based on my own recent experience of trying to safeguard the rights of a physically, mentally and emotionally vulnerable parent trapped in the machinations of the cost-cutting health care system during the last years of her life.

I went through hell trying to get my Mom the treatment that she needed to keep her alive (her desire) when most of the health "care" system had decided that it was time for her to die because she was old, suffering from dementia and (although they didn't say this) poor. I have talked with other family member caretakers who have had the same experience of continual harassment by medical professionals arguing against the expressed wishes of the family and patient. Under this despicable system, there is no way that a Physician Assisted Suicide Bill would not continue (and codify) the abuse and pressure that is already occurring and has been escalating over the past several years.

Before my Mom was, thankfully, transferred to the New Britain Hospital for Special Care where she lived in relative peace for the last four months of her life, I stayed with her at Yale New Haven Hospital from the end of September 2011 until the middle of January 2012. Prior to that, I had been her primary caregiver for 16 years while she lived at home, and, for the four years that she was in a nursing home, her medical executor. For all those years, I was continually and increasingly pushed to limit her treatment, change her code status to DNR/ DNI [Do Not Resuscitate/ Do Not Intubate], and/or put her under hospice care, even though that was not her desire or mine. During her five months at Yale New Haven Hospital, the pressure to end her treatment occurred on a daily, almost moment by moment, basis and I literally lived in a constant state of anxiety and fear. It came from all directions--doctors, nurses, administrators. I was treated as someone who wasn't going along with the program, an impediment to the agenda.

If it hadn't been for her wonderful cardiologist and a few thoughtful doctors at YNH, my conscience and Mom's desires might very well have been overruled. I was repeatedly warned that an ethics committee could be convened at the request of any of her health care providers. During her last stay in the Intensive Care Unit, such a hearing was indeed convened, where Mom's fate was debated. I refused to attend it because I considered it a travesty. Yes, they really could have ruled against my wishes to continue her treatment. Fortunately, the attending physician in the Intensive Care Unit at the time advocated in our favor at the hearing, and my mother received the surgical procedure that she needed to remain alive.

Even after that, the very day before my mother was transferred to New Britain, the head of ICU called her cardiologist to inform him that under no circumstances would he allow her to be readmitted to intensive care for treatment should she need it.

Many of these people no doubt were convinced of their own moral rightness, although they were perhaps unaware that they may have been conditioned to accept the terms of a debate that were imposed upon them for less altruistic reasons. They may have even been

trained to believe that they were doing something positive by pressuring people to put their loved ones under hospice care and end “aggressive” treatment. In my Mom’s case (and in how many others?) what they were really advocating was euthanasia. What it boiled down to was the fact that she was old, suffering from dementia and that her long hospitalization was costing them too much. And all of this occurred without the sanction of a law such as the one being proposed here.

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.

The assisted suicide bill currently before you is particularly weak in providing safeguards against abuse, and I believe others’ testimony will address those particulars. For me, however, it isn't just the text of this legislation that is so disturbing, it's the fact of the legislation itself. It cannot be fixed.

Although there might be a way to frame a bill that would be somewhat better on paper, with all kinds of assurances of "monitoring" and "oversight", checks and balances, the "monitors" and "overseers" will nevertheless be the same people who run the institutions that are putting it into practice. Years ago I complained in writing to Yale New Haven Hospital about the treatment my Mom and I were receiving, which at that time mainly took the form of repeated pressure from hospital staff to change her code status. I got a nice letter back assuring me that health care professionals at the hospital were undergoing "sensitivity training" etc. and that my "experiences" would be taken in to consideration. Absolutely nothing changed. And, several times in 2011 when I went to the hospital "patient care representative" to ask for intervention so that my Mom would not be transferred out of the hospital back to a nursing home because of her ongoing need for nasotracheal suctioning, that "representative" referred me back to the "Nurse Manager" on the Acute Care for the Elderly floor, who was one of the people most invested in getting her out of the hospital in the first place. *(As an FYI: the term “nurse manager” should be re-named for truth and accuracy. There is no nursing care involved in this job.)*

If we lived in a society with a health care system geared to human needs, not profit; where universal, equitable health care was understood to be a fundamental human right, not a privilege; where the fundamental rights of all human beings were understood to be non-negotiable; and where a new generation of health care professionals were trained, above all, to think in those terms, then possibly this idea of physician assisted suicide for terminally ill patients who are suffering and request help to end that suffering, without coercion or guilt tripping, might be acceptable.

However, if all that were true and in place, I think the very idea would be largely unnecessary. There are many available ways to ameliorate if not entirely eliminate suffering at the end of life. Health care providers should be about doing that to the best of their ability, not about **ending** life. We all die soon enough. My Mom did, when there was no further treatment possible. It wasn't an easy road, but she died knowing that her life had not been thrown away; that she had been helped to live as long as possible; that she was loved and valued and cared for. I believe that awareness allowed her, finally, to let go with some degree of equanimity and peace.

Passage of HB 6645 would do nothing to improve quality of health care; it would do nothing to offer equal access to quality health care for the most vulnerable among us; it would do nothing to provide physical or emotional support to any of us as we face our inevitable mortality. It would merely take us further down a path that compromises our humanity and makes us all justifiably fearful of our health care providers. Its only true beneficiaries would be those who profit from the inequitable health care system in the first place.

I implore you: stop HB 6645 right here. End it here. And turn your attention to these other, fundamental issues whose resolution could *truly* relieve much suffering.

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