

Second Thoughts Connecticut

Advocates against the legalization of assisted suicide

Testimony regarding HB 6709 An Act Concerning the Right to Try Experimental Drugs

Senator Gerratana, Rep. Ritter, and members of the Public Health Committee:

Second Thoughts Connecticut is composed of citizens with disabilities and advocates primarily concerned about “end-of-life” issues. Our primary focus is opposing the legalization of assisted suicide. We support a more balanced approach to advance care planning that avoids disability-phobia and does not steer people to reject beneficial treatment. Consistent with our principles that people have a right to fight to live, we are here to offer our support to HB 6709, An Act Concerning the Right to Try Experimental Drugs.

One might ask what disability has to do with legislation dealing with the right of people diagnosed with a terminal illness to access experimental drugs and devices. As we have said in the assisted suicide debate, while not every disability is terminal, nearly everyone with a terminal illness has a disability. Furthermore, people with disabilities frequently face life-or-death medical situations.

We are aware of the complex public health policy issues “right to try” legislation entails. There have been some legitimate concerns raised by critics, such as the possible effect on clinical trials, the extent of the grant of immunity to physicians, and equity in assisting patients of limited means to obtain these drugs or devices. Certainly a careful approach is warranted. The robust definition of informed consent in Section 1 (c) is important. But we also need to remember that those who are seeking to try experimental drugs and devices do not have time on their side. They cannot wait for the cumbersome FDA approval process to work itself out. If it is a matter of try or die, when not trying may mean near certain death in a short time, the risk-benefit ratio is much different than for those of us who presumably still have a life ahead of us.

One objection to right to try legislation needs to be thoroughly challenged—namely the claim that these laws offer false hope to people with terminal illnesses. Some of you may remember the case of Barbara Wagner from the assisted suicide debate. Barbara Wagner had lung cancer and was prescribed Tarceva, which was an experimental drug at the time. She was on the Oregon Health Plan, that state’s Medicaid program, which rations treatment by a formula based on quality adjusted life years. Oregon sent her a letter stating that the Oregon Health Plan would not cover Tarceva to extend her life, but would cover suicide drugs to kill her. This deadly mix between healthcare rationing and assisted suicide caused an uproar well beyond Oregon.

What is most notable is the reaction of Compassion & Choices president and former HMO executive Barbara Coombs Lee to this controversy. Coombs Lee wrote an op-ed in *The Oregonian* chillingly defending Oregon’s denial of Tarceva while offering suicide drugs instead.

In that op-ed, she opined that public policy should aggressively steer people away from curative care and toward comfort care or doctor-prescribed suicide:

http://www.oregonlive.com/opinion/index.ssf/2008/11/sensationalizing_a_sad_case_ch.html

The burning health policy question is whether we inadvertently encourage patients to act against their own self interest, chase an unattainable dream of cure, and foreclose the path of acceptance that curative care has been exhausted and the time for comfort care is at hand.

We could not disagree more. As we have repeatedly noted regarding assisted suicide, medical diagnosis and prognosis are often very wrong. The late Senator Ted Kennedy, actress Valerie Harper, Jeanette Hall, John Norton, and Rahamim Melamed-Cohen are often cited as examples of people who outlived expectations. If medical diagnosis and prognosis can be so unreliable, how much more so predictions about the efficacy of new drugs and medical devices. Who is Barbara Coombs Lee to tell people facing terminal illness to abandon all hope to live and accept the inevitability of their deaths?

Barbara Coombs Lee and other leaders of Compassion & Choices demand their right to die but will not defend our right to live, and push the hopelessness of inevitable death while falsely claiming to promote “end of life choice.” To them, we have a six word retort: **Better false hope than no hope.** What people facing stage 4 cancer, ALS, HIV/AIDS, or any other life-limiting condition need most is hope. Even if the majority of these experimental drugs and devices prove not to be efficacious, HB 6709 offers people who desperately need hope a means to go on and fight to live.

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