

Public Health Committee
Testimony for HB 5417, An Act Concerning End-Of-Life Care

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I'm writing to advocate for aid in dying, referred to as end-of-life care in HB 5417. This legislation also goes under other names such as death with dignity and end-of-life options.

I'm going to give a true life example of someone – a neighbor and friend – who didn't have this option available to him and who therefore died a very unpleasant death about a year ago. To protect his privacy, I'll call him Tom.

About three years before Tom died at age 80, he was diagnosed with throat cancer, for which he underwent chemo and radiation treatments. The doctors declared the cancer gone, but the radiation destroyed his salivary glands. So from then on, he had to always carry a water bottle, and he was limited to eating foods like apple sauce. He got nourishment through a feeding tube to his stomach. But he stayed active and was remarkably accepting of this.

Who thinks about saliva? I never did before Tom's misfortune. You need it to swallow to keep your mouth and lips from drying out. But Tom carried on despite his compromised existence.

About a year later, he was diagnosed with lung cancer. More chemo. But the cancer was particularly malignant, and it could barely be slowed down, much less cured. The symptom that most needed relief was the difficulty in breathing due to the buildup of fluid around his lungs, which of course reduced their ability to expand. Twice, he spent several days in the hospital, hooked up to an apparatus that drew the fluid out, after which he felt much better. But the cancer was still spreading and attacking his body and numbering his days.

Tom had pride. Whenever I visited, he was dressed and sitting in an upholstered chair. Of course he needed help with most things, which he got from his devoted wife and a hospice nurse. His palliative care included morphine, of which he could have as much as he wished. He used it more sparingly than necessary because he did not want to be in a stupor, and he knew that it would not prevent what was coming. And knowing this, he decided not to undergo another round of fluid draining, which would have staved off the inevitable by a couple weeks or so.

He approached the end of his life in a stoic and courageous manner. He told me that he had joined the Hemlock Society, which in 2003 split into Compassion & Choices and Final Exit Network. This was a man who would have gratefully used aid in dying, had such an option been available. Eventually, he died, literally gasping for his last breath.

Tom's scenario was real. And there have been and are many other terminally ill patients in comparable situations. Some of them have been lucky enough to live in a state (or Canada) where aid in dying is a legal option. Connecticut, a majority of whose citizens favor this law, should most certainly have this option available to those who meet all the conditions spelled out in bill HB 5417. They may or may not choose to use it. Or they may opt for it and then decide not to take the medication. It's their choice; the wording of the bill makes that clear.

Having focused on the real-life value of aid in dying legislation, I'll next focus more on some of the flawed arguments made by its opponents.

- (1) People who want this legislation stick to the facts, i.e., real scenarios, actual experience in states that already have this law, and the stipulations in the bill. By contrast, those opposed to this option deal in hypotheticals and alarming outcomes. For instance:
 - Opponents claim there are preferable options to aid in dying. However, the end-of-life situations in which terminally ill patients would use – or have actually used -- aid in dying don't/didn't have other acceptable options.
 - Some opponents talk about this law hurting vulnerable people, but they never give actual credible scenarios. That's because they can't. Their arguments may sound persuasive, but they don't stand up to scrutiny.
- (2) Some hospice personnel oppose this legislation and say that there is no need for it because patients can be kept comfortable until the end. Tom could only have been more comfortable by being unconscious, which he considered to be a distasteful option. And what about people who become so weak that others must attend to their body hygiene? Or they need a breathing tube (intubated) to stay alive and therefore they can't speak. That wouldn't be acceptable to Tom. Nor to me.
- (3) Some doctors cite the precept to do no harm. But what's less harmful? Letting someone spend his/her final months dreading the manner of their inevitable death and then dying badly as described in (2)? Or giving them a means to have a peaceful and dignified death on their own terms? I know what I would choose. And that's the conclusion reached by Governor Jerry Brown of California when he signed their End of Life Options bill into law.
- (4) Sanctity of life is sometimes given as a reason to reject aid in dying. What if a dying patient chooses to peacefully die several days – or even a couple weeks – sooner than he/she would otherwise expire in misery? Is it better to prolong the suffering and distress? How can anyone deny the right to die to such a person? To do so is the opposite of compassionate, and it dishonors life.
- (5) Lastly, this legislation will be a godsend for the relatively few people who are eligible for it and who also choose to use it. For everyone else, it will be as though it doesn't exist.
 - If anything, it may have a positive impact. In Oregon, even the supporters of death with dignity didn't expect an increase in patients opting for hospice, but that's what happened.
 - In retrospect it makes sense that, thanks to the availability of death with dignity, terminally ill people more often thought about the best way to live out their remaining months, and they were more disposed to doing something about their well-being.

Thank you for your consideration.

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