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PUBLIC HEALTH COMMITTEE
Testimony Opposing SB 88
An Act Concerning Aid in Dying for Terminally Ill Patients
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Co-chairs and members of the Public Health Committee:

My name is Cathy Ludlum, and I am one of the leaders of Second Thoughts Connecticut, a group of disabled people and allies who are working to prevent the legalization of medical assisted suicide. I am opposed to SB 88.

The question at hand is not whether people can take their own lives. Suicide is not illegal. The question is how many other struggling people will follow their lead, pressured by society and assisted by the healthcare system to die?

Every year when this bill comes up, I testify against it. I stand before you as a competent, creative, and successful professional who has a good life while experiencing a high level of disability.

Not this year.

The shortage of direct care workers (whether you call them personal assistants, PCAs, or home health aides) has reached a point where lives hang in the balance, including mine.

Yes, I am talking about the fact that people are not consistently getting out of bed in the morning, or must go to bed at 5 in the afternoon. Sometimes meals are skipped or other bodily needs go unmet because there is no one to assist with these critical activities.

These workers are significantly undercompensated and are leaving the field by the hundreds because they cannot make ends meet. They do not feel respected or appreciated, and the value of the support they provide has been largely unrecognized.

But in the context of today's legislation, I am talking about the psychological impact of being severely disabled and not having enough support ... for years.

Every so often, someone asks what medical assisted suicide has to do with disability. For two decades, the disability community has been pointing to the End-of-Life Concerns listed in the Oregon and Washington State data summaries. The top four concerns never change:

From the Oregon Death with Dignity Act 2020 Data Summary ¹

- Less able to engage in activities making life enjoyable (94.3%)
- Losing autonomy (93.1%)
- Loss of dignity (71.8%)
- Burden on family, friends/caregivers (53.1%)

From the Washington State 2020 Death with Dignity Act Report ²

- Less able to engage in activities making life enjoyable (90.6%)
- Losing autonomy (89.6%)
- Loss of dignity (74.8%)
- Burden on family, friends/caregivers (58.6%)

Let me show how this is relevant to me and my colleagues.

Less able to engage in activities making life enjoyable – With the dedicated support of my personal assistants, I have lived in my own home for 30 years, worked, traveled, done things with friends, and basically had a great life. That seems to be over as I struggle to get enough supports. Advertising no longer produces new hires. Without enough workers, my focus every day has to be on shifting people around so I can get my most basic needs met.

Losing autonomy – My independence depends on interdependence. Technology allows me to do a few things for myself, mainly on the computer. But without human assistance, I cannot clean my house, take a shower, or get to a doctor’s appointment; much less work toward my personal and business goals.

Loss of dignity – I believe that dignity is inherent in everyone, but not everyone is treated that way. I have had to hire a number of people who were literally repulsed by normal bodily functions. Some hurt me with their words. I have adjusted so many things in my life, my home, my relationships, and my personal care that I don’t even know where I can trim anymore.

Burden on family, friends/caregivers – Everyone is going to burn out eventually. Not having enough workers, I overrely on the ones I have left. In times past, I had backup assistants, but you can’t find those now. When I cannot find anyone else, I have to rely on friends, some in their 70s, to provide care. I know like I’ve never known before what it means to feel like a burden.

I am telling my story because I want you to understand that death has begun to look preferable to living like this.

You can keep saying that medical assisted suicide is not intended for the likes of me, but it takes a lot of effort every single day to keep my body working and my lungs breathing... and increasingly I think about giving up.

Don’t believe I would qualify under SB 88? Look at the bill. It clearly points to people like me as appropriate users of medical assisted suicide.

Sec. 1 (21) "Terminal illness" means the final stage of an incurable and irreversible medical condition that an attending physician anticipates, within reasonable medical judgment, will produce a patient's death within six months if the progression of such condition follows its typical course.

The progression of spinal muscular atrophy is death if it follows its typical course. I am almost 60 years old because I have been vigorously interfering with the typical course of SMA. When I was 35 I became unable to eat enough to sustain my life and started using a feeding tube. At 38 I was choking in my sleep so I started using respiratory support.

SB 88 says nothing about the impact of treatment on life expectancy. The public likely assumes that the lethal prescription is only available to people who have exhausted all treatment options. But this is not so. An individual may stop life-sustaining medications or technologies at any point, rendering them terminal within six months. In my case, we are talking days, not months.

In their discussion on whether people with anorexia qualify for assisted suicide, the American Clinician's Academy on Medical Aid in Dying's (ACAMAID) Ethics Consultation Service notes:

Mandating that the patient exhaust all possible treatments before requesting aid in dying is not in keeping with other "terminal" illnesses. For example, we allow patients with end stage cancer to forgo chemotherapy or other potentially life - extending treatments and request medical aid in dying.³

As an Oregon official has clarified in writing, any person who becomes terminal because they do not receive treatment, for any reason (including not only refusal of treatment, but inability to pay for treatment), would qualify for assisted suicide under an Oregon-type law.^{4 5}

The law is best seen as a permissive law, and states only that patients must have a terminal illness with six months or less to live. It does not compel patients to have exhausted all treatment options first, or to continue current treatment. It is up to the patient and doctor to discuss disease and treatment options. But if the patient decides they don't want treatment, that is their choice.

I am not suggesting that people be forced to accept treatment they do not want. But we must understand that populations other than those traditionally considered to be terminal (end stages of cancer, COPD, kidney failure, for example) will be affected by this legislation.

Refusal of treatments that have previously allowed people not only to live, but to thrive, should point in the direction of suicide prevention. Instead, there is too often an assumption that death is imminent and even preferable. Connecticut's State Suicide Prevention Plan 2025 describes the challenges faced by disabled people in getting equal access to suicide prevention services. It also acknowledges that physician assisted suicide puts people with disabilities at particular risk. Please see pp. 56-58.⁶

Suicide is contagious, and this is suicide, no matter how often and fervently you deny it.

I am not alone. Many people are hanging on by a thread. Maybe because of unmet disability needs. Maybe because of economic distress. Maybe from isolation and sadness.

Do we as a society want to strengthen that thread so it does not break? Do we want to make sure people who need supports (whether home care or other supports) get them?

Or do we want to create a policy that says, in effect, “ending your life is reasonable if your problems are big enough”? Given that wink of approval, some (I suggest many) will cut that thread. Perhaps not right away, but more and more as the years go by.

I am aware that there is intense pressure to get this bill passed in this legislative session. If it does, there will be plenty of time to go back later and gut the hollow safeguards it contains. This is already happening in other states.

Again, I say, the question at hand is not whether people can take their own lives. The question is how many other struggling people, pressured by society and assisted by the healthcare system, will follow their lead?

SB 88 is bad medicine, bad for people, and bad public policy. Please vote NO.

Thank you.

Sources:

- ¹ Oregon Death with Dignity Act 2020 Data Summary
<https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/Pages/index.aspx>
- ² Washington State 2020 Death with Dignity Act Report
<https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/Pages/index.aspx>
- ³ Summary of Consultation concerning a Patient with Anorexia Nervosa, American Clinicians Academy on Medical Aid in Dying (ACAMAID), Aid in Dying Ethics Consultation Service
<https://www.acamaid.org/wp-content/uploads/2021/09/Ethics-Consultation-Anorexia-Nervosa-9-3-21.pdf>
- ⁴ Fabian Stahle, “Oregon Health Authority Reveals Hidden Problems with the Oregon Assisted Suicide Model”
<https://drive.google.com/file/d/1xOZfLFrvuQcaZfFudEncp2b18NrUo/view>

- ⁵ “Diabetics Eligible for Physician Assisted Suicide Oregon, ” The Washington Times
<https://www.washingtontimes.com/news/2018/jan/11/diabetics-eligible-physician-assisted-suicide-oreg/>;
- ⁶ Connecticut’s State Suicide Prevention Plan 2025, pp. 56-58
<https://www.preventsuicidect.org/wp-content/uploads/2021/05/Suicide-Prevention-Plan-2020-2025.pdf>