



TESTIMONY OF
DIANE COLEMAN, JD
PRESIDENT/CEO OF NOT DEAD YET
OPPOSING CONNECTICUT ASSISTED SUICIDE BILL HB 5898

March 15, 2019

I am submitting testimony as a person with an advanced neuromuscular condition. I'm also the founder and President of Not Dead Yet, a national disability rights group that opposes legalization of assisted suicide with members in Connecticut. I have personal experience with the uncertainty of terminal predictions by doctors, as well as the risks of assisted suicide laws for people who use breathing support or otherwise depend on ongoing treatments for serious chronic or conditions.

My Personal Story of Mistaken Prognosis

At the age of six I was diagnosed as having muscular dystrophy and my parents were told that I would die by the age of 12. A few years later I was re-diagnosed with spinal muscular atrophy (SMA), a progressive neuromuscular condition which has a longer lifespan. A few years ago, new DNA tests resulted in another revised diagnosis, a rarer neuromuscular condition. Regardless, since age eleven, I have used a motorized wheelchair.

I am now age 65. Beginning 17 years ago I have used breathing support at night. Over the years, the pressures required to sustain my breathing have increased. About three years ago, I went into respiratory failure. Since then I have used breathing support most of the day as well as at night. If I did not use this support, I would go into respiratory failure and die in a fairly short timeframe.

Throughout my adult life, I have worked full time, first as an attorney and then directing nonprofit disability related organizations. Over the last three years, I have continued to run Not Dead Yet, which has four staff and numerous volunteers across the country. I have spoken at conferences, published articles, submitted testimony in legislatures, and provided the day-to-day management an organization requires. I'm not saying this to be "inspirational", but to make it clear that people like me can and do work, and/or do lots of other worthwhile and fun things, and should not be written off.

How Assisted Suicide Laws Endanger People Like Me

As a severely disabled person who depends on life-sustaining treatment, I would be able to qualify for assisted suicide at any time if I lived where assisted suicide is legal. As an Oregon official recently clarified in writing, any person who becomes terminal because they do not receive treatment, for any reason, would qualify for assisted suicide under an Oregon type law.¹ If the reason that I could not get treatment were an inability to afford insurance co-pays, I would be eligible for assisted suicide in Oregon. For over a year, my breathing support had a \$500 per month co-pay which I had to pay out of pocket till my employer changed health plans.

If I became despondent, for example if I lost my husband or my job, and decided that I wanted to die, I would not be given the same suicide prevention as a nondisabled and healthy person who despaired over divorce or job loss. Where assisted suicide is legal, I would be treated completely differently due to my condition. By denying equal suicide prevention and other supports to people deemed “terminal”, assisted suicide laws are inherently discriminatory against old, ill and disabled people.

In these days of private managed care companies taking over Medicare and Medicaid, where providing expensive care has a tendency to reduce profits, we should at least question whether there is an inherent conflict of interest in having healthcare providers act as the gatekeepers, determining who is eligible under assisted suicide laws.

What I've Learned From the Oregon Assisted Suicide Data

Oregon is held up as the model for other states. I've examined the Oregon state assisted suicide reports from a disability rights perspective, and want to share with you what I've learned.

One of the most frequently repeated claims by proponents of assisted suicide laws is that there is “no evidence or data” to support any claim that these laws are subject to abuse, and that there has not been “a single documented case of abuse or misuse” in the 21 reported years. These claims are demonstrably false.

Regarding documented cases, please refer to a compilation of individual cases and source materials pulled together by the Disability Rights Education and Defense Fund entitled [Oregon and Washington State Abuses and Complications](#).² For an in-depth analysis of several cases by Drs. Herbert Hendin and Kathleen Foley, please read [Physician-Assisted Suicide in Oregon: A Medical Perspective](#).³

The focus of the discussion below is the [Oregon Public Health Division data](#).⁴ These reports are based on forms filed with the state by the physicians who prescribe lethal doses and the pharmacies that dispense the drugs. As the early state reports admitted:

“As best we could determine, all participating physicians complied with the provisions of the Act. . . . Under reporting and noncompliance is thus difficult to assess because of possible repercussions for noncompliant physicians reporting to the division.”

Further emphasizing the serious limits on state oversight under the assisted suicide law, Oregon authorities also issued a release in 2005 clarifying that they have [No authority to investigate Death with Dignity case](#).⁵

Nevertheless, contrary to popular belief and despite these extreme limitations, the Oregon state reports substantiate some of the problems and concerns raised by opponents of assisted suicide bills.

Non-Terminal Disabled Individuals Are Receiving Lethal Prescriptions In Oregon

The Oregon Public Health Division assisted suicide reports show that non-terminal people received lethal prescriptions every year except the first.

The prescribing physicians' reports to the state include the time between the request for assisted suicide and death for each person. However, the online state reports do not reveal how *many* people outlived the 6-month or 180-day prediction. Instead, the reports give that year's median and range of the number of days between the request for a lethal prescription and death. This is on page 13 of the [2018 annual report](#).⁶ In 2018, at least one person lived 807 days; across all years, the longest reported duration between the request for assisted suicide and death was 1009 days. In every year except the first year, the reported upper range is significantly longer than 180 days.

The definition of “terminal” in the statute only requires that the doctor predict that the person will die within six months. There is no requirement that the doctor consider the likely impact of medical treatment in terms of survival. Unfortunately, while terminal predictions of some conditions, such as some cancers, are fairly well established, this is far less true six months out, as the bill provides, rather than one or two months before death, and is even less true for other diseases.

In addition, it should be noted that the attending physician who determines terminal status and prescribes lethal drugs is not required to be an expert in the disease condition involved, nor is there any information about physician specialties in the state reports.

Furthermore, as noted above, many conditions will or may become terminal if certain medications or routine treatments are discontinued – e.g. insulin, blood thinners, pacemaker, CPAP, etc. Any person who becomes terminal because they do not receive treatment for any reason, including lack of insurance

coverage, including those caused by government budget cuts in Medicare and Medicaid, would qualify for assisted suicide under an Oregon type law.

Oregon reports that non-cancer conditions found eligible for assisted suicide has grown over the years, to include: neurological disease, respiratory disease, heart/circulatory disease, infectious disease, gastrointestinal disease, “endocrine/metabolic disease (e.g. diabetes)” and, in the category labeled “other”, arthritis, arteritis, sclerosis, stenosis, kidney failure, and musculoskeletal systems disorders (pages 11 & 13).

The Only Certifiers of Non-Coercion And Capability Need Not Know the Person

Four people are required to certify that the person is not being coerced to sign the assisted suicide request form, and appears capable: the prescribing doctor, second-opinion doctor, and two witnesses.

In most cases over the years, the prescribing doctor is a doctor referred by assisted suicide proponent organizations. (See, M. Golden, [Why Assisted Suicide Must Not Be Legalized](#),⁷ section on “Doctor Shopping” and related citations). The Oregon state reports say that the median duration of the physician patient relationship was 10 weeks in 2018, and 12 weeks over all years (page 13). Thus, lack of coercion is not usually determined by a physician with a longstanding relationship with the patient. This is significant in light of well-documented elder abuse-identification and reporting problems among professionals in a society where an estimated one in ten elders is abused, mostly by family and caregivers. (Lachs, et al., *New England Journal of Medicine*, [Elder Abuse](#).⁸)

The witnesses on the Oregon [request form](#)⁹ need not know the person either. One of them may be an heir (which would not be acceptable for witnessing a property will), but neither of them need actually know the person (the form says that if the person is not known to the witness, then the witness can confirm identity by checking the person’s ID).

So neither doctors nor witnesses need know the person well enough to certify that they are not being coerced.

In addition, as with the Oregon law, the definition of “competent” in the Connecticut bill allows third parties to communicate orally for the person to the doctors and witnesses, providing for the patient to be “communicating through a person familiar with a patient’s manner of communicating.” This is especially dangerous for people with speech impairments, such as from a stroke or neurological disability.

No Evidence of Consent or Self-Administration At Time of Death

In about half the reported cases, the Oregon Public Health Division reports also state that no health care provider was present at the time of ingestion of the lethal drugs or at the time of death. Without an independent witness, there is no way to confirm whether the lethal dose was self-administered and consensual. The request for assisted suicide does not prove that the person wanted to go through with it, as shown by the reported decision by many not to do so.

Therefore, although “self administration” is touted as one of the key “safeguards”, in about half the cases, there is no evidence of consent or self-administration at the time of ingestion of the lethal drugs. If the drugs were, in some cases, administered by others without consent, no one would know. The request form constitutes a virtual blanket of legal immunity covering all participants in the process.

Essentially, proponents of legalizing assisted suicide have taken what is fundamentally a third party legal immunity statute and marketed it deceptively as a personal rights statute.

Pain Is Not the Issue, Unaddressed Disability Concerns Are

The top five reasons doctors give for their patients’ assisted suicide requests are not pain or fear of future pain, but psychological issues that are well understood by the disability community: “loss of autonomy” (95%), “less able to engage in activities” (95%), “loss of dignity” (87%), “losing control of bodily functions” (56%), and “burden on others” (52%) (page 12).

These reasons for requesting assisted suicide pertain to disability and indicate that over 90% of the reported individuals, possibly as many as 100%, are disabled.

Three of these reasons (loss of autonomy, loss of dignity, feelings of being a burden) could be addressed by consumer-directed in-home long-term care services, but no disclosures about or provision of such services is required. Some of the reported reasons are clearly psycho-social and could be addressed by disability-competent professional and peer counselors, but this is not required either. Moreover, only 4.5% of patients who request assisted suicide were referred for a psychiatric or psychological evaluation, despite studies showing the prevalence of depression in such patients.

Basically, the law operates as though the reasons don’t matter, and nothing need be done to address them.

Conclusion

The Oregon assisted suicide data demonstrates that people who were not actually terminal received lethal prescriptions in all 21 reported years except the first, and that there is little or no substantive protection against coercion and abuse. Moreover, reasons for requesting assisted suicide that sound like a “cry for help” with disability-related concerns are apparently ignored. Thus, the data substantiates serious problems with the implementation of assisted suicide laws.

For all these reasons, I urge you to vote no on the Connecticut assisted suicide bill. The dangers of mistakes, coercion and abuse are simply too high, not only for people like me, but for everyone.

¹ [https://www.washingtontimes.com/news/2018/jan/11/diabetics-eligible-physician-assisted-suicide-oreg/;](https://www.washingtontimes.com/news/2018/jan/11/diabetics-eligible-physician-assisted-suicide-oreg/)
<https://drive.google.com/file/d/1xOZfLFrvuQcazZfFudEncp2b18NrUo/view>

² <https://dredf.org/wp-content/uploads/2015/04/Revised-OR-WA-Abuses.pdf>

³ <https://dredf.org/wp-content/uploads/2012/08/Hendin-Foley-Michigan-Law-Review.pdf>

⁴ <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf>

⁵ <https://dredf.org/wp-content/uploads/2012/08/Oregon-DHS.pdf>

⁶ <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf>

⁷ <https://dredf.org/public-policy/assisted-suicide/why-assisted-suicide-must-not-be-legalized/>

⁸ <http://www.nejm.org/doi/full/10.1056/NEJMra1404688>

⁹ <http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/pt-req.pdf>