TESTIMONY OF

DIANE COLEMAN, JD, PRESIDENT/CEO OF NOT DEAD YET

OPPOSING CONNECTICUT HB 5417

PUBLIC HEALTH COMMITTEE

March 19, 2018

I am a severely disabled woman, and head up the national disability group, Not Dead Yet, which has members in Connecticut. I've spent a lifetime advocating for the rights of disabled people, young and old, to control our own lives and not have our choices dictated by doctors and other professionals. So you might wonder why I oppose a bill that is widely portrayed as giving people choice and control over their own death.

But who actually has choice and control under assisted suicide laws? Anyone could ask their doctor for assisted suicide, but the law gives the authority to doctors to determine who is eligible. More importantly, the purported "safeguards" to prevent mistake, coercion and abuse are empty window dressing, with little substance or effect.

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 Oregon during the 20 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.[1] For an in-depth analysis of several cases by Dr. Herbert Hendin and Dr. Kathleen Foley, please read Physician-Assisted Suicide in Oregon: A Medical Perspective.[2] More recent cases of insurers denying coverage of prescribed healthcare while offering coverage for assisted suicide are described by Stephanie Packer[3] and Dr. Brian Callister.[4]

The focus of the discussion below is the Oregon Health Division data.[5] 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.[6]

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 Health Division assisted suicide reports show that non-terminal people receive 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 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 11 of the 2017 annual report.[7] In 2017, at least one person lived 603 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, and the Connecticut bill uses the same definition. 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. Add the fact that many chronic conditions will or may become terminal if certain medications or routine treatments are discontinued – e.g. insulin, blood thinners, pacemaker, CPAP – and "terminal" becomes a very murky concept.

The state 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 and, in the category labeled "other", arthritis, arteritis, sclerosis, stenosis, kidney failure, and musculoskeletal systems disorders (pages 10-11).

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.

Recent published emails from the Oregon Public Health Department have confirmed that a person who becomes terminal because they do not receive treatment, regardless of the reason for non-treatment, including lack of or inadequate insurance coverage, would qualify for assisted suicide under the Oregon law.[8]

The Only Certifiers of Non-Coercion And Competence 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 competent: 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,[9] 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 2017, and 13 weeks over all years (page 11). 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.[10])

The witnesses on the request form[11] need not know the person either. 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. In addition, 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.

So neither doctors nor witnesses need know the person well enough to certify that they are not being coerced and, in some cases, someone else can speak for the person.

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

In about half the reported cases, the Oregon 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. Footnote six clarifies:

"A procedure revision was made mid-year in 2010 to standardize reporting on the follow-up questionnaire. The new procedure accepts information about time of death and circumstances surrounding death only when the physician or another health care provider is present at the time of death. This resulted in a larger number of unknowns beginning in 2010."

While the only specific example mentioned is the "time of death," other "circumstances surrounding death" include whether the lethal dose was self-administered and consensual

at the time of death. 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.

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 all-too-familiar to the disability community: "loss of autonomy" (91%), "less able to engage in activities" (90%), "loss of dignity" (76%), "losing control of bodily functions" (46%), and "burden on others" (44%) (page 10).

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 4.9% 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 20 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 problems with the implementation of assisted suicide laws and validates the concern that the risks of mistake, coercion and abuse are too great. Well-informed legislators on both sides of the aisle should vote against this assisted suicide bill.

Please vote NO on HB 5417.

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[1] https://dredf.org/wp-content/uploads/2015/04/Revised-OR-WA-Abuses.pdf

[2] https://dredf.org/wp-content/uploads/2012/08/Hendin-Foley-Michigan-Law-Review.pdf

[3] https://www.youtube.com/watch?v=hwLs3D062Vk&feature=youtu.be

[4] https://www.youtube.com/watch?time_continue=6&v=CWrpr_5e4RY

[5]http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf

[6] https://dredf.org/wp-content/uploads/2012/08/Oregon-DHS.pdf

[7]http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf

[8] https://www.washingtontimes.com/news/2018/jan/11/diabetics-eligible-physician-assisted-suicide-oreg/

[9] https://dredf.org/public-policy/assisted-suicide/why-assisted-suicide-must-not-be-legalized/

[10] http://www.nejm.org/doi/full/10.1056/NEJMra1404688

[11]http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/pt-req.pdf