

Testimony in **Opposition** to Raised Bill No. 5417, An Act Concerning End-of-Life Care

Presented to the Public Health Committee

March 20, 2018

by: James D. McGaughey

This Bill would make two major changes in current law: 1) it would exempt physicians who prescribe a lethal dose of drugs to a patient who is determined to be terminally ill from prosecution under the provisions of the criminal code that prohibit one person from assisting another to commit suicide; and 2), it would prohibit reporting the act of taking those drugs to end one's life as "suicide". At first blush, it may seem reasonable and humane to adopt these changes. After all, what's wrong with extending a choice to people who meet the Bill's criteria – a clean, quiet, medically provided, legally authorized way for them to end their lives by their own hands. A deeper look, however, reveals some major problems.

Proposals such as that reflected in this Bill are often presented alongside images of individuals with terminal diagnoses who fear a painful end, and stories of others who did experience suffering as they died. Proponents also cite the experience in states such as Oregon, where a "Death with Dignity Act" has been on the books since 1997, and where certain statistics on its utilization have been compiled for several decades. Yet, according to those Oregon statistics, concerns about facing uncontrolled pain rank relatively low on the list of reasons people seek lethal prescriptions. Other reasons, such as concern over loss of autonomy, being less able to engage in activities that make life enjoyable, concern over loss of dignity, loss of control over bodily functions, and being a burden to families and caregivers all ranked significantly higher on the list of reasons given for seeking lethal prescriptions than did worries over uncontrollable pain.

The practitioner-provided reports upon which Oregon's statistical compilation is based are considered confidential, and they are destroyed approximately one year after the data they report has been summarized in an annual report. So, there is little opportunity for independent research or detailed analysis of policy questions. What Oregon's annual statistical summaries do show, however, is a steady increase in numbers – both the numbers of those who seek lethal prescriptions, and the number of people who actually take them to end their lives. In the first years after the statute was adopted, fewer than 50 people per year sought lethal prescriptions. Last year, the number was 218. According to the most recent summary report: "Since the law was passed in 1997, a total of 1,967 people have had prescriptions written under the DWDA, and 1,275 patients have died from ingesting the medications." A line graph in the latest annual summary report illustrates that the trend has been steadily upward.

The exact circumstances surrounding most of those deaths – who, if anyone, was present, how long it took for the person to die after ingesting the drugs, whether there were any difficulties, complications (or worse, whether there might have been some form of coercion or prohibited third-party administration) – remain largely unknown. Oregon only requires reports of such matters if a doctor, nurse or other healthcare worker is present at the time the patient takes the drugs, which in a majority of cases, they are not. In fact, the statistics suggest that, in most instances, the physicians who write the lethal prescriptions – the "attending physicians" - have not been treating those patients for very long –

an average of just 10 weeks. So, it appears that, at least in Oregon, most of the lethal prescriptions are not written in the context of longstanding doctor-patient relationships.

I dwell on the Oregon statistical reports because proponents of this type of legislation often refer to Oregon's experience as evidence that legalizing this practice produces few problems. But, how can we really know that? While the data compiled by the Oregon Health Authority may be sufficient to debunk the notion that people seek lethal prescriptions primarily to escape the prospect of intractable pain, and, further, to suggest that the doctors who write those prescriptions may not know their patients very well, those data leave many other questions unanswered. Limitations in the primary reporting requirements, coupled with the destruction of those primary reports after the information they contain has been compiled, effectively preclude the possibility of independent, in-depth studies and policy analysis. And, given the absence of safeguards surrounding the actual ingestion of the lethal drugs (such as a requirement that independent witnesses be present to ensure that the person is truly acting on his or her own volition and to ensure that any untoward complications are reported), there may well be problems that just are not being reported. At the very least, we should think twice before we glibly assume that that everything is working well in Oregon.

One thing we do know is that Oregon is feeling increasing pressure to expand the criteria for obtaining lethal prescriptions, and that other states with similar laws are experiencing similar pressures. This past week, the *Washington Post* published an article describing efforts to extend "eligibility" for physician-prescribed lethal drugs to patients with Alzheimer's Disease, and other disabling-but-not-terminal conditions, such as Parkinson's. (See article and link below.) This is a similar pattern to what has occurred over a period of decades in the Netherlands and Belgium, where lethal prescriptions can now be administered to terminally ill children, to people "suffering" from mental illness, and, sometimes, to elders as an alternative to entering a nursing home. Once the genie is out of the bottle, it is hard to contain it with mere statutory language.

My interest in this issue developed as a result of my experience over the past 30 years as an advocate for the rights of people with disabilities, particularly as those rights play out in the health care arena. One of the many things I have learned from this experience is how difficult it is for physicians to accurately predict how long someone has to live, particularly if that person has a progressively disabling condition. I know a number of people with such conditions who have far outlived the prognostications of medical specialists. On the public stage, the example of Stephen Hawking comes to mind. Professor Hawking was diagnosed with Amyotrophic Lateral Sclerosis (called motor neurone disease in the U.K.) in 1963, and, at the age of 21, was told he had two years to live. It is distressing, therefore, to note that, according to the most recent Death with Dignity Act summary report from Oregon, since 1997, exactly 100 people with ALS have died in that State from lethal doses of drugs prescribed by physicians. To me, this is doubly distressing because I am aware that depression is often the initial companion of disability. A number of people have told me that, before they worked through what was sometimes a difficult and lengthy period of adjustment, when they first became disabled, or, sometimes when they experienced a notable increase in the level of their disability, they went through a period when they just wanted to end it all.

Given the ambiguities inherent in making medical prognoses, and the widely differing perspectives from which medical practitioners view the "quality" of the lives of people living with significant disabilities, I have no doubt that, if this Bill is passed, some people with disabilities who are not, in fact, near the ends

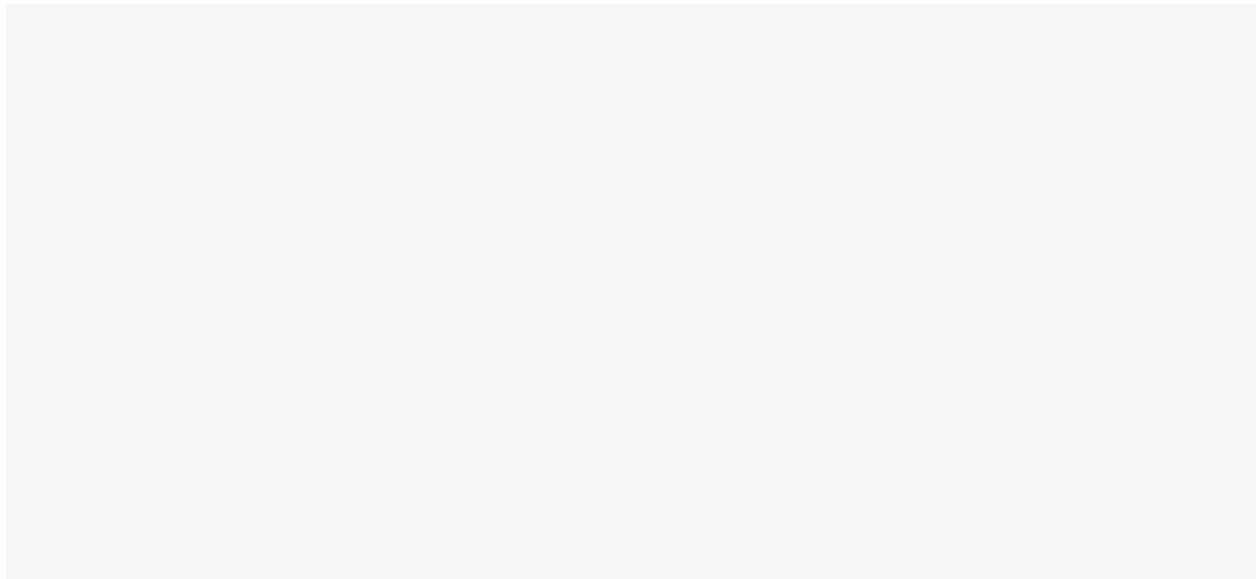
of their lives, will find the way to doctors who will write lethal prescriptions for them. Indeed, if the reasons people seek lethal prescriptions are as reported in Oregon summaries - concerns over loss of bodily control, becoming dependent on (or even a burden to) others – one of the effects of the legislation would be to confer legitimacy to the view that death is preferable to living with a significant disability. If this Bill becomes law, I believe we will lose people who would otherwise have years of contributions to make.

There is no question that, despite the miraculous progress being made by medical science in the fight against disease, too often we fail people who are nearing the end of their lives. Most practitioners are not well trained in, nor even oriented to recognize the importance of palliative medicine, and the circumstances under which many people must face their end are, by any measure, unsatisfactory. We need to do much better – to ensure that hospice referrals are not seen as “giving up”; that they are made many months in advance of imminent death, rather than just a few weeks before, as is too often the case. Medical practitioners need to be willing to discuss end of life issues with their patients, sometimes multiple times. They also need to be as well trained in palliative care as they are in fighting disease. And, the institutions and structures and finance mechanisms that increasingly define our healthcare system need to be constantly reminded to focus on people, and on values that genuinely confer respect and sensitivity up to the end. We should be working on those things, not creating early exit ramps that, in the long run, are likely to grow ever wider.

The article from the *Washington Post* is pated below. Here is a link to the story:

https://www.washingtonpost.com/national/in-oregon-pushing-to-give-patients-with-degenerative-diseases-the-right-to-die/2018/03/11/3b6a2362-230e-11e8-94da-ebf9d112159c_story.html?utm_term=.a6fa1c36a310

Thank you for your attention. If there are any questions, I will try to answer them.



Washington Post March 11, 2018

In Oregon, pushing to give patients with degenerative diseases the right to die



People demonstrate in support of allowing doctors to prescribe life-ending medication to terminally ill patients in Sacramento in March 2015. The law passed, but it excludes people with degenerative diseases such as Parkinson's and Alzheimer's. Efforts are under way in Oregon to open up more avenues for people with these diseases to hasten death. (Rich Pedroncelli/AP)

by Rob Kuznia by Rob Kuznia

[National](#)

March 11 at 11:48 AM

LOS ANGELES — Shortly after she was diagnosed with Alzheimer's disease at age 56, Nora Harris moved to Oregon from California with her husband, thinking it would be a place where she could die on her own terms.

Shortly after he was diagnosed with Parkinson's disease at age 58, Bruce Yelle migrated to Oregon from the Golden State for the same reason. This was the state, after all, that pioneered medically assisted suicide in the United States when its [Death With Dignity Act](#) took effect in 1997.

As it turned out, both Harris and Yelle were ineligible: People with Alzheimer's, Parkinson's, Huntington's, multiple sclerosis and a host of other degenerative diseases are generally excluded from the Oregon law.

This is because some degenerative diseases aren't fatal. People die with Parkinson's, for example, not because of it. Other diseases, such as advanced Alzheimer's, rob people of the cognition they need to legally request the suicide medications.

Harris — a onetime Virginia Woolf scholar who worked as a library branch manager — died in October at 64, unable to speak coherently, feed herself or recognize loved ones. Though she had filled out an advance health-care directive instructing caregivers not to feed her if she lost the ability to feed herself, she was spoon-fed until two days before her passing.

“Nora did not have a peaceful death,” said her husband, Bill Harris, who lobbied on behalf of a newly approved bill to update Oregon's advance-directive law.



Bill Harris of Ashland, Ore., visits his wife, Nora Harris, who had Alzheimer's disease, on Sept. 8, 2016. Nora died in October after caregivers spoon-fed her to keep her alive, a move Bill said was against her will. "Nora did not have a peaceful death," Bill said. (Denise Baratta/Medford Mail Tribune/AP)

[Legalizing assisted suicide has stalled at every level]

Yelle, also 64, is alive and active, trying to change laws in Oregon that would essentially open up more assisted suicide avenues for people with these diseases. He said that unless he can obtain a doctor's prescription for a lethal medication, "I'm going to have an ugly death."

Their efforts are among several throughout North America that highlight a quiet but concerted push to bring the right-to-die debates to a new frontier: people with dementia, Alzheimer's and other degenerative diseases.

Relatively modest drives are afoot in Washington state and California, where organizations have launched education campaigns on how people can fill out instructions for future caregivers to withhold food and drink, thereby carrying out an option that is legal to anybody: death by starvation and dehydration. (It is often referred to as the "voluntarily stopping eating and drinking" method.)

The boldest bid is taking place in Quebec. Prompted by a 2017 murder case involving the apparent "mercy killing" of a 60-year-old woman with Alzheimer's by her husband — who smothered her with a pillow — the provincial government is studying the possibility of legalizing euthanasia for Alzheimer's patients. Unlike medically assisted suicide, a medical doctor would administer the fatal dose via injection. A survey in September found that 91 percent of the Canadian province's medical caregivers support the idea.

"The process that could lead to [legislative] changes has already begun," said Marie-Claude Lacasse, a spokeswoman for the Quebec Ministry of Health and Social Services.

Somewhere between these points is Oregon, where several lawmakers are trying to push the right-to-die envelope.

Under the current law, eligible patients can obtain prescriptions for lethal barbiturates. Qualified patients must be diagnosed with a terminal illness, have a prognosis of six or fewer months to live, and self-ingest the drug. The

vast majority — more than 70 percent, according to the Oregon Health Authority — have cancer; most others have either heart disease or amyotrophic lateral sclerosis, also known as Lou Gehrig's disease.

Washington state, Vermont, California, Colorado and the District of Columbia have passed laws modeled on Oregon's.

Rep. Mitch Greenlick (D), chair of Oregon's House Committee on Health Care, began looking into expanding the state's Death With Dignity Act a few years ago, when a well-known 78-year-old lobbyist in the capital, Salem, fatally shot himself in the head after learning that he had Alzheimer's.

"That really shook me up," said Greenlick, a retired director of the Kaiser Permanente Center for Health Research. "I started thinking, people with Alzheimer's should be able to have some control over how they die, rather than having to shoot themselves."

His 2015 attempt to expand the terminally ill window from six months to a year failed. Next year he plans to float another bill that would open up the state's Death With Dignity law to dementia patients by doing away with all stipulations about terminal time limits.

Some of the efforts have faced opposition from an unlikely adversary: the national right-to-die movement. In particular, groups such as Compassion & Choices, the nation's largest right-to-die organization, and the Death With Dignity National Center, a main author of the original law, have little appetite for widening access to lethal drugs in the states where medically assisted suicide already is legal.

Such meddling, they fear, could give ammunition to critics and frustrate their efforts to bring the narrowly defined statute to as many states as possible.

But it's not all about tactics for them.

“It’s really important that the person is the decider of how they die,” said Kim Callinan, chief program officer for Compassion & Choices. “And for that reason we would not expand the eligibility criteria for medical aid in dying for somebody, for example, who has advanced dementia. Because when a person has advanced dementia, they’re no longer able to speak for themselves.”

The national movement is at a critical juncture: Public support for medical aid-in-dying laws has surged, with a [2017 Gallup poll](#) showing that 67 percent of Americans support doctor-assisted suicide, up from just more than half in 2013. But 2017 wasn’t a great year for right-to-die advocates legislatively. Though about 30 states saw efforts to legalize medical aid in dying, not a single bill became law.

Bill Harris sued his wife’s care facility for spoon-feeding Nora, but he lost. The judge wrote in the ruling that the possibility couldn’t be ruled out that she had changed her mind about feeding because she opened her mouth when a spoon of food was put to it. Since then, elderly patients across the state have been adding written statements to their advance directives explicitly demanding not to be spoon-fed if they lose the capacity to feed themselves, said Harris’s attorney, Jason Broesder.

He said that at least 50 of his clients have recently made or requested the change in their advance directives. “Clients are saying, ‘I want you to make sure the state is not going to make me eat from a spoon when I don’t want to,’ ” he said.

In late February, Oregon lawmakers passed legislation — in a party-line vote, with Democrats prevailing — that would study how to improve the process of creating and carrying out advance directives. Gov. Kate Brown (D) is expected to sign it.

Supporters such as Harris and Yelle hope it will lead to a new advance-directive form enabling people to check a box instructing future caregivers to

withhold spoon-feeding — also known as “assisted feeding” — so as to hasten death, should they become incapacitated by dementia. This would probably put Oregon on the national forefront of advance directives, said Thaddeus Mason Pope, director of the Health Law Institute at Hamline University School of Law in St. Paul, Minn.

“Advance directives are normally used to opt out of . . . feeding tubes, mechanical ventilation, cardiopulmonary resuscitation, antibiotics and surgery,” he said. “To be very explicit and tackle [spoon-feeding] head on, that, I think, would be a novel move.”

The bill has stoked the fury of Oregon Right to Life, whose leaders fear the legislation would, if signed into law, “endanger Oregonians with dementia and Alzheimer’s, allowing their health-care representatives to remove their access to food and water.”

Lois Anderson, executive director of Oregon Right to Life, says Alzheimer’s patients often have more capacity than meets the eye.

“They might not be able to get in a car and drive to Seattle, but they maybe have agency to decide what movie they want to watch, or if they want to go to the sunroom, or do they want to eat,” Anderson said. “We believe that that agency, that ability to make those decisions, should be respected. That’s part of human dignity.”

Yelle is working with state Sen. Arnie Roblan (D) to advocate an expansion of the state’s Death With Dignity law to include sufferers of not only Parkinson’s, but also Alzheimer’s, dementia, multiple sclerosis, and any “incurable condition that will result in unbearable physical or mental pain.”

The phrase “unbearable suffering” is a term also used as the eligibility threshold in Belgium and the Netherlands, which have the world’s most liberal euthanasia laws. Lethal injection by a physician is available to terminally ill

children and clinically depressed adults, as well as people with dementia, in those countries.

Roblan says he plans to introduce a bill in 2019, during the next full legislative session. In Oregon, the sessions during even-numbered years are brief.

“It’s a conversation I think we need to have, and I think Oregon is a place where that can happen,” Roblan said.

Rob Kuznia is a freelance reporter and frequent contributor to The Washington Post.

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