

A Surprise Reflection of Who Picks Assisted Suicide

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SEATTLE — Dr. Richard Wesley has amyotrophic lateral sclerosis, the incurable disease that lays waste to muscles while leaving the mind intact. He lives with the knowledge that an untimely death is chasing him down, but takes solace in knowing that he can decide exactly when, where and how he will die.

Under Washington State's Death With Dignity Act, his physician has given him a prescription for a lethal dose of barbiturates. He would prefer to die naturally, but if dying becomes protracted and difficult, he plans to take the drugs and die peacefully within minutes.

"It's like the definition of pornography," Dr. Wesley, 67, said at his home here in Seattle, with Mount Rainier in the distance. "I'll know it's time to go when I see it."

Washington followed Oregon in allowing terminally ill patients to get a prescription for drugs that will hasten death. Critics of such laws feared that poor people would be pressured to kill themselves because they or their families could not afford end-of-life care. But the demographics of patients who have gotten the prescriptions are surprisingly different than expected, according to data collected by Oregon and Washington through 2011.

Dr. Wesley is emblematic of those who have taken advantage of the law. They are overwhelmingly white, well educated and financially comfortable. And they are making the choice not because they are in pain but because they want to have the same control over their deaths that they have had over their lives.

While preparing advance medical directives and choosing hospice and palliative care over aggressive treatment have become mainstream options, physician-assisted dying remains taboo for many people. Voters in Massachusetts will consider a ballot initiative in November on a law nearly identical to those in the Pacific Northwest, but high-profile legalization efforts have failed in California, Hawaii and Maine.

Oregon put its Death With Dignity Act in place in 1997, and Washington's law went into effect in 2009. Some officials worried that thousands of people would migrate to both states for the drugs.

"There was a lot of fear that the elderly would be lined up in their R.V.'s at the Oregon border," said Barbara Glidewell, an assistant professor at Oregon Health and Science University.

That has not happened, although the number of people who have taken advantage of the law has risen over time. In the first years, Oregon residents who died using drugs they received under the law accounted for one in 1,000 deaths. The number is now roughly one in 500 deaths. At least 596 Oregonians have died that way since 1997. In Washington, 157 such deaths have been reported, roughly one in 1,000.

In Oregon, the number of men and women who have died that way is roughly equal, and their median age is 71. Eighty-one percent have had cancer, and 7 percent A.L.S., which is also known as Lou Gehrig's disease. The rest have had a variety of illnesses, including lung and heart disease. The statistics are similar in Washington.

There were fears of a "slippery slope" — that the law would gradually expand to include those with nonterminal illnesses or that it would permit physicians to take a more active role in the dying process itself. But those worries have not been borne out, experts say.

Dr. Wesley, a pulmonologist and critical care physician, voted for the initiative when it was on the ballot in 2008, two years after he retired. "All my career, I believed that whatever makes people comfortable at the end of their lives is their own choice to make," he said.

But Dr. Wesley had no idea that his vote would soon become intensely personal.

In the months before the vote, he started having trouble lifting weights in the gym. He also noticed a hollow between his left thumb and index finger where muscle should be. A month after casting his vote, he received a diagnosis of A.L.S. Patients with the disease typically live no more than four years after the onset of symptoms, but the amount of time left to them can vary widely.

In the summer of 2010, after a bout of pneumonia and with doctors agreeing that he most likely had only six months to live, Dr. Wesley got his prescription for barbiturates. But he has not used them, and the progression of his disease has slowed, although he now sits in a wheelchair that he cannot operate. He has lost the use of his limbs and, as the muscles around his lungs weaken, he relies increasingly on a respirator. His speech is clear, but finding the air with which to talk is a struggle. Yet he has seized life. He takes classes in international politics at the University of Washington and savors time with his wife and four grown children.

In both Oregon and Washington, the law is rigorous in determining who is eligible to receive the drugs. Two physicians must confirm that a patient has six months or less to live. And the request for the drugs must be made twice, 15 days apart, before they are handed out. They must be self-administered, which creates a special challenge for people with A.L.S.

Dr. Wesley said he would find a way to meet that requirement, perhaps by tipping a cup into his feeding tube.

The reasons people have given for requesting physician-assisted dying have also defied expectations.

Dr. Linda Ganzini, a professor of psychiatry at Oregon Health and Science University, published a study in 2009 of 56 Oregonians who were in the process of requesting physician-aided dying.

"Everybody thought this was going to be about pain," Dr. Ganzini said. "It turns out pain is kind of irrelevant."

At the time of each of the 56 patients' requests, almost none of them rated pain as a primary motivation. By far the most common reasons, Dr. Ganzini's study found, were the desire to be in control, to remain autonomous and to die at home. "It turns out that for this group of people, dying is less about physical symptoms than personal values," she said.

The proposed law in Massachusetts mirrors those in Oregon and Washington. According to a telephone survey conducted in May by the Polling Institute at Western New England University, 60 percent of the surveyed voters supported "allowing people who are dying to legally obtain medication that they could use to end their lives."

"Support isn't just from progressive Democrats, but conservatives, too," said Stephen Crawford, a spokesman for the Dignity 2012 campaign in Massachusetts, which supports the initiative. "It's even a libertarian issue. The thinking is the government or my doctor won't control my final days."

Such laws have influential opponents, including the Roman Catholic Church, which considers suicide a sin but was an early leader in encouraging terminal patients to consider hospice care. Dr. Christine K. Cassel, a bioethicist who is president of the American Board of Internal Medicine, credits the church with that effort. "But you can see why they can go right up to that line and not cross over it," she said.

The American Medical Association also opposes physician-assisted dying. Writing prescriptions for the drugs is antithetical to doctors' role as healers, the group says. Many individual physicians share that concern.

"I didn't go into medicine to kill people," said Dr. Kenneth R. Stevens, an emeritus professor of radiation oncology at Oregon Health and Science University and vice president of the Physicians for Compassionate Care Education Foundation.

Dr. Steven Kirtland, who has been Dr. Wesley's pulmonologist for three years, said he had little hesitation about agreeing to Dr. Wesley's request, the only prescription for the drugs that Dr. Kirtland has written.

"I've seen a lot of bad deaths," Dr. Kirtland said. "Part of our job as physicians is to help people have a good death, and, frankly, we need to do more of that."

Dr. Wesley's wife, Virginia Sly, has come to accept her husband's decision. Yet she does not want the pills in the house, and he agrees. "It just feels so negative," she said. So the prescription remains at the pharmacy, with the drugs available within 48 hours.

There are no studies of the psychological effect of having a prescription on hand, but experts say many patients who have received one find comfort in knowing they have or can get the drugs. About a third of those who fill the prescription die without using it. "I don't know if I'll use the medication to end my life," Dr. Wesley said. "But I do know that it is my life, it is my death, and it should be my choice."