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In Oregon, Choosing Death Over Suffering

By JOHN SCHWARTZ and JAMES ESTRIN
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Arthur W. Wilson sits in his study, breathing oxygen through a nose clip and pausing frequently for the coughs that rack his body.

"I'm not suicidal," he said. "I'm sane."

Mr. Wilson, 86, has been living with the profound pain of chronic obstructive pulmonary disease for years. Now he wants to end his life -- not today, not tomorrow, but when he chooses -- under the provisions of Oregon's Death With Dignity law.

"When the time comes," he said, "I'm going to swallow that bottle of Lethe and say goodbye."

He is no stranger to death, having fought in World War II and in Korea. And he craves being in control. His house is snaked through with a clear plastic tubing system that he devised to carry his oxygen from room to room without having to drag a tank around behind him.

He does not seem, in other words, to be the depressed, languishing patient many might expect to see applying for the Oregon program.

The state's law allows adults with terminal diseases who are likely to die within six months to obtain lethal doses of drugs from their doctors. In the six years since it went into effect, surprises have been common, including the small number of people who have sought lethal drugs under the law and the even smaller number of people who have actually used them. In surveys and conversations with counselors, many patients say that what they want most is a choice about how their lives will end, a finger on the remote control, as it were.

Last week, the United States Court of Appeals for the Ninth Circuit upheld Oregon's law, ruling that Attorney General John Ashcroft had overstepped his authority in trying to punish doctors who prescribed suicide drugs under the law.

And while there is still strong opposition around the country to laws like Oregon's, support within the state has grown over the years. Oregon voters passed the law in two separate referendums. Even some former opponents say the widespread abuses predicted by some have not emerged. And studies are helping researchers and policymakers understand how it really works in practice.

Perhaps the most surprising thing to emerge from Oregon is how rarely the law has actually been used.

"We estimate that one out of a hundred individuals who begin the process of asking about assisted suicide will carry it out," said Ann Jackson, executive director of the Oregon Hospice Association.

Since 1997, 171 patients with terminal illnesses have legally taken their own lives using lethal medication, compared with 53,544 Oregonians with the same diseases who died from other causes during that time, according to figures released by the Oregon Department of Health Services in March.

More than 100 people begin the process of requesting the drugs in a typical year. Doctors wrote 67 prescriptions for the drugs in 2003, up from 24 in 1998. Forty-two patients died under the law in 2003 compared with 16 in 1998.

Many patients say they want to have the option to end their lives if the pain becomes unbearable or if they are sliding into incompetence while still thinking clearly.

"I'd say it's less than 50-50 that I'd ever do this thing," said Don James, a retired school administrator with advanced prostate cancer who has not yet received his pills.

A Desire to Be in Control

A second surprise has been the kind of people who use the law. They are not so much depressed as determined, said Linda Ganzini, a professor of psychiatry at Oregon Health Sciences University. She led a recent survey of 35 doctors who had received requests for suicide drugs. The doctors described the patients as "feisty" and "unwavering."

A third lesson is that for most of those who seek assisted suicide, the greatest concern appears not to be fear of pain but fear of losing autonomy, which is cited by 87 percent of the people who have taken their lives with the drugs. Only 22 percent of the patients listed fear of inadequate pain control as an end-of-life concern, perhaps a sign that pain management has improved over the years.

And though opponents of the law argued that patients would feel pressured by families and even insurers to end their lives early out of financial concerns, so far concerns of being a burden to family have been cited by 36 percent of patients, and financial concerns by just 2 percent. The surveys show that the standard version of health care for terminally ill patients might not be what these patients are looking for, Dr. Ganzini said. The standard version of care says, in effect, "we're going to take care of you," she said. But "for them, the real problem is other people taking care of you."

Ms. Jackson said the surveys were changing the hospice association's practices.

In 1994, the group opposed the Death With Dignity law. Now the hospices work directly with programs like Compassion in Dying, a group that is involved in 75 percent of Oregon's assisted suicides. Thanks to the surveys of patients seeking assisted suicide, Ms. Jackson said, her organization learned that half the people who rejected hospice care did so because "they thought that hospice was condescending or arrogant."

Now the hospices fit their treatments to patients who seek assisted suicide and emphasize that their wishes will be respected, she said.

Opponents of the Oregon law like Dr. Kenneth Stevens, chairman of the department of radiation oncology at the Oregon Health and Science University in Portland, say it violates the fundamental tenet of medicine. Dr. Stevens argues that doctors should not assist in suicides because to do so is incompatible with the doctor's role as healer.

"I went into medicine to help people," he said. "I didn't go into medicine to give people a prescription for them to die."

Dr. Stevens heads an organization, Physicians for Compassionate Care, that opposes assisted suicide and the Oregon law. Members of his group, he said, tend to be "people of faith," who believe that assisted suicide violates their religious principles. But they base their opposition to the law on moral and ethical grounds, arguing that it leads down a slippery slope toward euthanasia and patient abuses.

He recalled the struggle of his wife, who died of cancer in 1982. In the weeks before she died, he said, her doctor offered her an "extra-large prescription" for painkillers.

"As I helped her into the car, she said, 'He wants me to kill myself,'" Dr. Stevens recalled. "It just devastated her that her doctor, her trusted doctor, subtly suggested that."

Others who initially opposed the law, like the hospice group, say they have learned to live with it. Michael Bailey, for example, took out a loan in 1994 to fight the Death With Dignity act. His daughter has Down syndrome, and he said that at the time he could see a straight line between voluntary assisted suicide and forced euthanasia for the handicapped.

Now Mr. Bailey says he has not seen any abuses. "I don't see that there's ever been a scandal," he said, "and the numbers are not huge." Still, he does not support the law. "If it was up to me, I'd say no, but I don't think there's any great human rights crisis here," he said.

Support for the law crosses ideological lines, said Nicholas van Aelstyn, a lawyer in San Francisco who works withCompassion in Dying. Some commentators have characterized the movement as a liberal cause, but "to most of the people exercising it, it's a libertarian issue," he said. "Many of our clients are die-hard Republicans who don't want government interfering in their lives."

That certainly describes Mr. Wilson, who calls himself a "staunch conservative" and says Mr. Ashcroft is "dead wrong" about the Oregon law.

The support for the law in Oregon, Mr. James said, reflects the pioneer spirit that flows from the wagon trains that brought the early settlers. "They were pretty well-educated, family-oriented people willing to hack a new life out of this wilderness," he said. "Pretty independent folks."

Those who drafted the Death With Dignity Act say they did not try to come up with a political document that would warm the heart of Jack Kevorkian, or that would permit euthanasia, which is repugnant to a significant portion of the population. Instead, they say, they carefully drew up a law that they believed would gain support of everyone except the most determined opponents, and that was loaded with safeguards against abuse.

Doctors have long made lethal doses of drugs available to patients inclined to end their struggle against disease, said Eli Stutsman, president of the board of the Death With Dignity National Center.

"We took something that was already happening, and we wrote a law around it," he said.

Opponents had argued that Oregon would become a magnet for people seeking suicide, so the law's provisions were restricted to the state's residents.

The law also sets a high barrier to getting the life-ending medications, giving patients the chance to change their mind up to the last moment. A patient must make two oral requests for the drugs and one written request after a 15-day waiting period. Two doctors must determine that the patient has less than six months to live, a doctor must decide that the patient is capable of making independent decisions about health care and the doctor has to describe to the patient alternatives like hospice care.

The law also requires that the drugs be self-administered by the patient, rather than given by a doctor or family member, to avoid involuntary euthanasia. The death certificate, under the law, must state the cause of death as the underlying disease, not suicide.

That provision pleases Mr. James.

"I don't like the word 'suicide,'" he said, because "if I'm really on a path, the natural path" toward death, and "just hastening it a little bit, I don't call that suicide."

Mr. Wilson's family supports him in his wishes, although his wife, Viola, says she is against the general idea.

"This is his thing, not mine," she said. "It's not the way I'd go."

Her views flow from her religious beliefs, she said.

"I'm inclined to think that I have a purpose in life until I go," she said. "God has a plan for me, and I'm here until he says it's time to go."

She said she liked her husband's idea of having family members gather in a kind of living wake, however.

"That would be fine," she said. "You should celebrate the life instead of worry about the death."

A Last Goodbye

Although the idea of an end-of-life celebration strikes some people as unseemly or exhibitionist for a most private act, many patients say it is natural to want to bring family together for a last goodbye. Most patients call for such a gathering, although relatively few take the poison in the presence of their families.

Barbara Coombs Lee, the president of Compassion in Dying Federation, said she saw the suicides not as "an impulse to self destruction," but as "an impulse to self preservation -- preservation of the self I cherish."

That point of view clearly grates on Dr. Stevens. Although he said he did not want to "put people down or label people," he added, "the 'P' word is not 'pain.' The 'P' word is 'pride.'" He explained, "Rather than being death with dignity, it's death with vanity."

But Dr. Marcia Angell, a former executive editor of The New England Journal of Medicine and a supporter of doctor-assisted suicide, said: "He can call it vanity. Somebody else might call it admirable independence."

If anything, Dr. Angell said, the Oregon law may be too restrictive and may not reach everyone who could benefit from it.

"I am concerned that so few people are requesting it," she said. "It seems to me that more would do it. The purpose of a law is to be used, not to sit there on the books."

Mr. Stutsman, one of the law's authors, said it helped people who never end up holding a cup of barbiturate solution in their hands.

"They get the comfort of knowing that the Oregon Death With Dignity Act is there if they need it," he said. Although no state has passed its own version of the act, "Oregon is leading the national debate," he said.

Compassion in Dying claims that the Oregon law prevents violent suicides and the pain such deaths cause families. The patients say, however, that to some extent, the 10-year furor over the law is academic; it is not so hard to die, and people do it around the world without the benefit of laws like that passed by the Oregon Legislature.

Mr. James, for example, said, "If it gets too bad, I might just stop eating," and refers jokingly to his "Ashcroft kit," a sturdy plastic bag and a roll of duct tape that he could use to asphyxiate himself. But, he added, that would be illegal, and "I just think that's bad karma to do it that way."

Other patients say they know a good death from a bad death, and know which kind they prefer. Lovelle Svart, a retired newspaper librarian, said she recently witnessed a horrifying auto accident on the highway.

"Not that way." she recalled saying to herself. "Not the way I want to go."