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Why some couldn't die on their own terms

By Carol M. Ostrom
Seattle Times health reporter

Bill Morris wasn't counted.

His case is nowhere to be found in the numbers released Thursday, tallying those who used Washington's year-old "Death with Dignity" law.

Morris, a 66-year-old remodeling designer and builder who was dying of multiple myeloma, wanted to be among those 63 terminally ill patients whose doctors helped them obtain lethal medication.

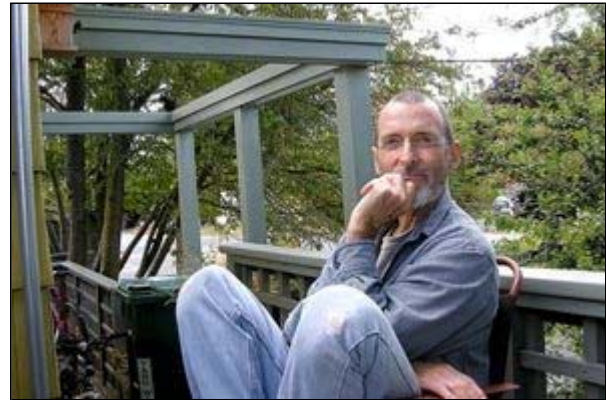
He was afraid. Not of death, but of ending up like he did: dying in an emergency room, surrounded by fluorescent lights and strangers, instead of at home in Wallingford, near the birdhouses he built and the trees he loved.

"He didn't want to die in a hospital," said his wife, Wendy John. "He was a free spirit. It made him feel like a cornered animal."

Morris had suffered for three years. "He didn't have a future, and he knew it," she said. "He told me, 'I'm not afraid of it ... Just let me go sooner than later.' "

But sooner was not to be. Like other terminally ill people wanting a say in their own death, he found a path filled with obstacles — from unrealistic estimates about how much time the patients have left to vague answers from the doctors they turn to for help, as well as their own unfamiliarity with the law's steps and conditions.

Compassion & Choices of Washington, which has provided assistance to the majority of those who successfully obtained lethal medication through the law, says as many as half of the qualified patients the group tried to help came to the organization too late.



COURTESY OF WENDY JOHN

Bill Morris, who had multiple myeloma, found a path filled with obstacles as he tried to use the law.



COURTESY OF LIZ SULLIVAN

Patrick Sullivan of Sequim (pictured third from left, with his son Kevin, wife Liz and son Brian) was diagnosed last Aug. 28 with a rare inoperable brainstem cancer.

"They don't realize it's a process," said Gretchen DeRoche, the group's volunteer coordinator. "The sad thing is, if people wait too long, they don't have any options."

THE ROADBLOCKS

Interviews with advocates and survivors of patients who tried unsuccessfully to use the law point to a number of common difficulties.

A straight-talk shortage

Under the law, a dying patient needs to find two doctors, one to write the prescription and the other to consult.

For many doctors, any conversation about death is difficult — even more so when it's "Death with Dignity."

So those who oppose the law may skirt the topic if a patient brings it up. And patients may not be eager to put a fine point on it, either.

Conversations related by survivors and advocates often go like this:

Patient: Will you help me when the time comes? Or: Will you help me if the pain gets too bad?

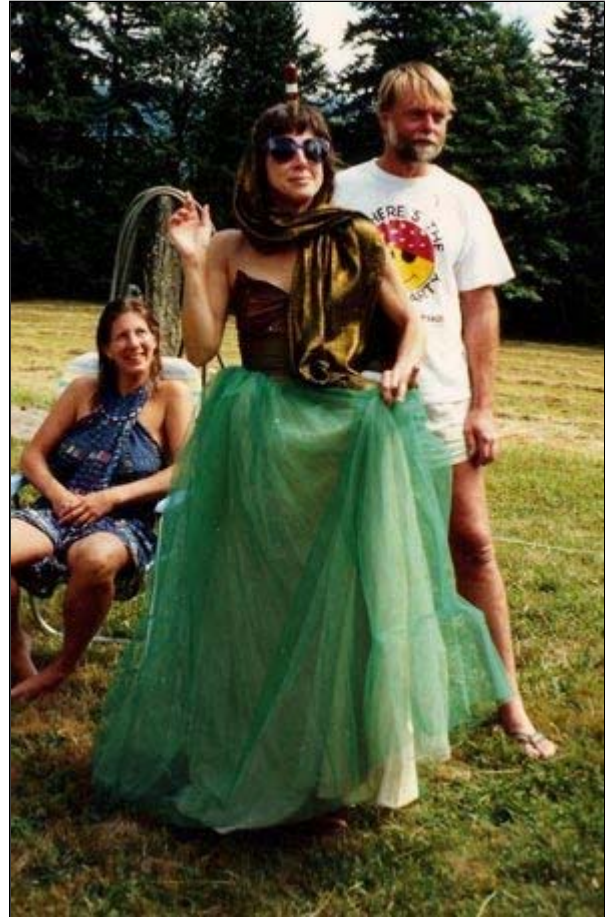
Doctor: I'll be there for you. Or: I'll make sure you're not in pain.

Such words can be easily misunderstood — and often are.

Patrick Sullivan of Sequim was diagnosed last Aug. 28 with a rare inoperable brainstem cancer.

His oncologist called his condition "potentially terminal," and said he had "a chance." But radiation and chemotherapy didn't help, and by November, Patrick began talking bluntly about using the law.

Liz and Patrick had moved from Florida to Washington in 2005. They considered Oregon instead because of its Death with Dignity law, but chose Sequim to be closer to relatives. In 2008, both voted for Washington's law even though neither was ill. "This is something we both felt very strongly about — that people should have the right to die with dignity," Liz said.



Leslie Creed, of Vashon Island (pictured in green dress in 1980s), was a free spirit who seemed to be in good health.

But after Patrick's diagnosis, when he asked his oncologist to help him use the law, "I don't believe she really gave him an answer," Liz said. "He thought she would; it was not a flat-out no."

It apparently wasn't a yes, either, so they enlisted their family doctor in Port Angeles, who agreed, then changed his mind. The search for another doctor burned up more time. On Dec. 9, Liz found one, and made an appointment for Dec. 15. By then, Patrick was suffering what Liz called "indignities."

"He was a very proud person, a very intelligent man. I think it was just devastating to him that he didn't have control over his body."

On his last day, he was rushed from nursing home to emergency room and back. Patrick Sullivan, 72, died Dec. 11.

Dr. Tom Preston, a retired cardiologist and volunteer medical director for Compassion & Choices, says patients should skip the euphemisms, and "ask their doctor a yes-or-no question now: 'If I become terminally ill, will you prescribe life-ending medication for me under the Death with Dignity Act?'"

Any answer other than "yes" means "no," says Robb Miller, the group's executive director. "You must know, so you don't waste time. I'm not saying change physicians; I'm just saying: Know where your physician stands."

The treat-until-death bias

When surveyed, most cancer doctors admit they don't talk to patients facing death within four to six months about the most standard end-of-life issues, such as hospice care, said Dr. Nancy Keating, a Harvard Medical School researcher. "To me, this suggests that they think they don't need to."

When doctors do discuss a patient's prognosis, it's to talk about treatments, not death, she said. "Doctors are typically trained to cure people, to make people better. I don't think most doctors think helping people with death falls under that."

Leslie Creed, of Vashon Island, was a free spirit who seemed to be in good health.



COURTESY OF RHODA BENSON

Roberta Turcott of Yakima had long ago selected a doctor in Yakima with ties to hospice, believing he would help her die peacefully when the time came.



WENDY JOHN

Survivors of patients who tried to use the law and failed are left with mixed emotions, including guilt. "If anything, I blame myself for not knowing the law," says Wendy John (pictured with husband Bill).

'Death with Dignity' Act: the first year's report

63 patients received lethal medications in 2009.
47 of the patients who got medications later died.

Persistent leg pain sent her to a doctor, who diagnosed lymphoma, a cancer. Despite aggressive treatment, it advanced quickly.

"Very early on, she'd said she didn't want to be hooked up to a 'drug machine' — she wanted to gather people together and say goodbye and take what she called the 'croak cocktail,' " said her son, Daniel Tobin.

But once in the care of specialists in Seattle, it seemed that every time she brought up using the law, she got stalled. It was always: *Let's wait until after we see your next scan*, her son related. "Nobody wanted to take any steps in that direction until it was known she was terminal."

Meanwhile, "We're waiting on a CT scan," he said, "and she's getting really worse" — so quickly that it was too late for her to get help under the law.

Many surviving families said their own unrealistic hopes and denial played a part in delays, too.

For one thing, it's often unclear how fast a disease will progress. Even doctors routinely misjudge that, typically erring on the optimistic side; many don't refer patients to hospice until very late.

"I was thinking that the (cancer) drugs would work," said Wendy John, whose husband, Bill Morris, died Aug. 11. "I wasn't thinking he would be terminal so quickly."

Policies and politics

Many doctors in Eastern Washington refuse to use the law, and in some communities, no pharmacies stock the drugs. Hospital policies against participation may extend to their clinics and doctors.

Some hospice organizations, particularly those with Catholic ties, won't let care providers work with patients in any way to use the law. Some leave it up to individual hospice workers.

Roberta Turcott of Yakima had long ago selected a doctor in Yakima with ties to hospice, believing he would help her die peacefully when the time came.

Turcott, a regular churchgoer, voted for the law. After she was diagnosed with ovarian cancer last May, she told her doctor she wanted the drugs in her "toolbox." But his hospice program was through a hospital that didn't support the law.

"I think hospice is a wonderful program — I could not have survived without them," said Rhoda Benson, her daughter. But for her mother, the hospice tie became a barrier. "It didn't help her," she said. "It hurt her."

Unable to find a local doctor, her family began making plans to fly one in from Seattle. Finally, they found one in Yakima, but Turcott was too sick to make her appointment on June 30. Roberta Jean Turcott, 80, who attended four world's fairs, died later that day, her Bible by her side.

36 patients took the lethal dose.

7 patients died without taking the medication.

* Four others also died, but it is unclear whether they had taken the medication.

Source: Washington state Department of Health

Requirements of state's 'Death with Dignity' law

A patient must be at least 18, competent, living in Washington and able to administer the drug.

Have six months or less to live, as determined by two doctors.

Make an oral and written request, signed and dated by the patient and witnessed by two people who are not relatives, heirs, the attending physician or tied to the patient's health facility.

Make a second oral request to the attending physician at least 15 days after the first one.

Wait two days after signing the written request before the prescription is written.

Source: The Associated Press

Unfamiliarity with the law

Many patients and doctors aren't well-versed in the new law's requirements.

Patients can underestimate the time it will take, including waiting periods such as the 15-day period between patient requests.

Compassion & Choices' advocates say the process typically takes four to six weeks, even when a patient has willing doctors, no mental-health issues, a pharmacy to dispense and means to pay for the expensive drugs.

There can be hitches at any point, particularly if a patient gets misleading information.

Leslie Creed, on Vashon, with no local pharmacy that stocked the medication, had been told 'mistakenly' that she had to personally pick up the drugs. By that time, she was too ill.

Many patients and families don't realize that disease can render a patient unable to comply with the law, which requires a patient to be mentally competent and at key times able to speak or write and swallow.

Creed had a doctor who was willing, but when time came for the second request, she was taking medications for "excruciating pain," her son said. "The doctor had to go away because she wasn't lucid." Leslie Creed, sans "croak cocktail," died at home on Dec. 13 at age 68.

Running out of time

Survivors of patients who tried to use the law and failed are left with mixed emotions, including guilt. "If anything, I blame myself for not knowing the law," says Wendy John.

She's also angry at her husband's doctors, saying both refused to help and wouldn't even talk about it.

"It makes me feel very disappointed in them," she said. "I feel abandoned and sort of betrayed. Like, 'My God, don't you know what's going on here?' They knew Bill ... Everybody liked Bill. Why would they not do this for him? It's what he wanted."

Although she gave her permission, the doctors declined to comment.

These and other survivors spoke out because they want to help others avoid pitfalls. Several said their loved one likely wouldn't have 'or couldn't have' taken a lethal dose, but would have found comfort in having it 'just in case.'

"If you've got a diagnosis like this, you don't have the luxury of waiting," said Liz Sullivan, Patrick Sullivan's widow. "It's not an easy process, and you've just got to sit down and do it, fill out the paperwork, get ahold of Compassion & Choices. They'll help you every step of the way ... "

Rhoda Benson recalls the painful scramble to find participating doctors for her mother in Yakima. "The message is: People need to start sooner if they want this as an option," she said. "The reality is, you've got to get off your behind, make some contacts," and maybe even change doctors.

"In hindsight, I do get that the law is new," and doctors have fears about it, she said. "I don't think it's where we'll be in 10 years. But it's the reality of where we are now."

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