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Terminal Uncertainty

Washington's new "Death With Dignity" law allows doctors to help people commit suicide—once they've determined that the patient has only six months to live. But what if they're wrong?

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Maryanne Clayton with her son, Eric, in the Fred Hutch waiting room: "I just kept going."

Details:

- Study: [Why Now?](#) Timing and Circumstances of Hastened Deaths
- [Dilemmas by caretakers](#) and other Oregon studies
- [Stats on people](#) who have used Oregon's Death with Dignity law.
- [Harvard professor Nicholas Christakis](#) looking at the accuracy of prognosis.
- [JAMA study](#) examining the accuracy of prognosis.

UPDATE: ["It Felt Like the Big One"](#)

She noticed the back pain first. Driving to the grocery store, Maryanne Clayton would have to pull over to the side of the road in tears. Then 62, a retired computer technician, she went to see a doctor in the Tri-Cities, where she lived. The diagnosis was grim. She already had Stage IV lung cancer, the most advanced form there is. Her tumor had metastasized up her spine. The doctor gave Clayton two to four months to live.

That was almost four years ago.

Prodded by a son who lives in Seattle, Clayton sought treatment from Dr. Renato Martins, a lung cancer specialist at Fred Hutchinson Cancer Research Center. Too weak to endure the toxicity of chemotherapy, she started with radiation, which at first made her even weaker but eventually built her strength. Given dodgy prospects with the standard treatments, Clayton then decided to participate in the clinical trial of a new drug called pemetrexate.

Her response was remarkable. The tumors shrunk, and although they eventually grew back, they shrunk again when she enrolled in a second clinical trial. (Pemetrexate has since been approved by the FDA for initial treatment in lung cancer cases.) She now comes to the Hutch every three weeks to see Martins, get CT scans, and undergo her drug regimen. The prognosis she was given has proved to be "quite wrong."

"I just kept going and going," says Clayton. "You kind of don't notice how long it's been." She is a plain-spoken woman with a raspy voice, a pink face, and grayish-brown hair that fell out during treatment but grew back newly lustrous. "I had to have cancer to have nice hair," she deadpans, putting a hand to her short tresses as she sits, one day last month, in a Fred Hutchinson waiting room. Since the day she was given two to four months to live, Clayton has gone with her children on a series of vacations, including a cruise to the Caribbean, a trip to

Hawaii, and a tour of the Southwest that culminated in a visit to the Grand Canyon. There she rode a hot-air balloon that hit a snag as it descended and tipped over, sending everybody crawling out.

"We almost lost her because she was having too much fun, not from cancer," Martins chuckles.

Her experience underscores the difficulty doctors have in forecasting how long patients have to live—a difficulty that is about to become even more pertinent as the Washington Death With Dignity Act takes effect March 4. The law, passed by initiative last November and modeled closely on a 14-year-old law in Oregon, makes Washington the only other state in the country to allow terminally ill patients to obtain lethal medication. As in Oregon, the law is tightly linked to a prognosis: Two doctors must say a patient has six months or less to live before such medication can be prescribed.

The law has deeply divided doctors, with some loath to help patients end their lives and others asserting it's the most humane thing to do. But there's one thing many on both sides can agree on. Dr. Stuart Farber, head of palliative care at the University of Washington Medical Center, puts it this way: "Our ability to predict what will happen to you in the next six months sucks."

In one sense, six months is an arbitrary figure. "Why not four months? Why not eight months?" asks Arthur Caplan, director of the Center for Bioethics at the University of Pennsylvania, adding that medical literature does not define the term "terminally ill." The federal Medicare program, however, has determined that it will pay for hospice care for patients with a prognosis of six months or less. "That's why we chose six months," explains George Eighmey, executive director of Compassion & Choices of Oregon, the group that led the advocacy for the nation's first physician-assisted suicide law. He points out that doctors are already used to making that determination.

To do so, doctors fill out a detailed checklist derived from Medicare guidelines that are intended to ensure that patients truly are at death's door, and that the federal government won't be shelling out for hospice care indefinitely. The checklist covers a patient's ability to speak, walk, and smile, in addition to technical criteria specific to a person's medical condition, such as distant metastases in the case of cancer or a "CD4 count" of less than 25 cells in the case of AIDS.

No such detailed checklist is likely to be required for patients looking to end their lives in Washington, however. The state Department of Health, currently drafting regulations to comply with the new law, has released a preliminary version of the form that will go to doctors. Virtually identical to the one used in Oregon, it simply asks doctors to check a box indicating they have determined that "the patient has six months or less to live" without any additional questions about how that determination was made.

Even when applying the rigid criteria for hospice eligibility, doctors often get it wrong, according to Nicholas Christakis, a professor of medicine and sociology at Harvard University and a pioneer in research on this subject. As a child, his mother was diagnosed with Hodgkin's disease. "When I was six, she was given a 10 percent chance of living beyond three weeks," he writes in his 2000 book, *Death Foretold: Prophecy and Prognosis in Medical Care*. "She lived for nineteen remarkable years...I spent my boyhood always fearing that her lifelong chemotherapy would stop working, constantly wondering whether my mother would live or die, and both craving and detesting prognostic precision."

Sadly, Christakis' research has shown that his mother was an exception. In 2000, Christakis published a study in the *British Medical Journal* that followed 500 patients admitted to hospice programs in Chicago. He found that only 20 percent of the patients died approximately when their doctors had predicted. Unfortunately, most died *sooner*. "By and large, the physicians were overly optimistic," says Christakis.

In the world of hospice care, this finding is disturbing because it indicates that many patients aren't being referred early enough to take full advantage of services that might ease their final months. "That's what has frustrated hospices for decades," says Wayne McCormick, medical director of Providence Hospice of Seattle, explaining that hospice staff frequently don't get enough time with patients to do their best work.

Death With Dignity advocates, however, point to this finding to allay concerns that people might be killing themselves too soon based on an erroneous six-month prognosis. "Of course, there is the occasional person who outlives his or her prognosis," says Robb Miller, executive director of Compassion & Choices of Washington. Actually, 17 percent of patients did so in the Christakis study. This roughly coincides with data collected by the National Hospice and Palliative Care Organization, which in 2007 showed that 13 percent of hospice patients around the country outlived their six-month prognoses.

It's not that prognostication is completely lacking in a scientific basis. There is a reason that you can pick up a textbook and find a life expectancy associated with most medical conditions: Studies have followed *populations* of people with these conditions. It's a statistical average. To be precise, it's a median, explains Martins. "That means 50 percent will do worse and 50 percent will do better."

Doctors also shade their prognoses according to their own biases and desires. Christakis' study found that the longer a doctor knew a patient, the more likely their prognosis was inaccurate, suggesting that doctors who get attached to their patients are reluctant to talk of their imminent demise. What's more, Christakis says, doctors see death "as a mark of failure."

Oncologists in particular tend to adopt a cheerleading attitude "right up to the end," says Brian Wicks, an orthopedic surgeon and past president of the Washington State Medical Association. Rather than talk about death, he says, their attitude is "Hey, one more round of chemo!"

But it is also true that one more round of chemo, or new drugs like the one that helped Clayton, or sometimes even just leaving patients alone, can help them in ways that are impossible to predict. J. Randall Curtis, a pulmonary disease specialist and director of an end-of-life research program at Harborview Medical Center, recalls treating an older man with severe emphysema a couple of years ago. "I didn't think I could get him off life support," Curtis says. The man was on a ventilator. Every day Randall tested whether the patient could breathe on his own, and every day the patient failed the test. He had previously made it clear that he did not want to be kept alive by machines, according to Curtis, and so the doctor and the man's family made the wrenching decision to pull the plug.

But instead of dying as expected, the man slowly began to get better. Curtis doesn't know exactly why, but guesses that for that patient, "being off the ventilator was probably better than being on it. He was more comfortable, less stressed." Curtis says the man lived for at least a year afterwards.

Curtis also once kept a patient on life support against his better judgment because her family insisted. "I thought she would live days to weeks," he says of the woman, who was suffering from septic shock and multiple organ failure. Instead she improved enough to eventually leave the hospital and come back for a visit some six or eight months later.

"It was humbling," he says. "It was not amazing. That's the kind of thing in medicine that happens frequently."

Every morning when Heidi Mayer wakes up, at 5 a.m. as is her habit, she says "Howdy" to her husband Bud—very loudly. "If he says 'Howdy' back, I know he's OK," she explains.