

With Time Running Out, Some Gain a Reprieve

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THURSDAY, Aug. 3 (HealthDay News) -- During the five months he spent at a Washington hospice after voluntarily ending kidney dialysis, humorist Art Buchwald said he was asked one question a lot.

"What is it like to die?"

His answer: "I don't know, because I haven't died. I thought I was going to, but then something changed."

"Instead of going straight upstairs, I am going to Martha's Vineyard," Buchwald wrote in his syndicated column last month.

And that's where Buchwald has been since his discharge from the hospice on July 1, despite the near-defunct kidneys that doctors say should have killed him long before now. Buchwald, 80, had refused further dialysis after doctors amputated his right leg below the knee in February.

Buchwald's case is not unique, however.

Hospice is generally defined as a place for palliative care for patients whose expected lifespan is less than 6 months. But, according to experts, about 8 percent of people admitted to end-of-life hospice care actually live beyond one year.

None of this surprises Jeanne Dennis, executive director of the Visiting Nurse Service of New York, which provides patients with hospice-like, end-of-life care in their own homes.

"One of the things that we know is that physicians are good at many things, but they're terrible at prognostication," she said. "There's been study after study that demonstrates their inability to project life expectancy."

Harvard medical oncologist Dr. Elizabeth Lamont has focused on the issue for years. A study she co-authored found that in 80 percent of cases, doctors' estimates of how long a patient would live were off by a third -- meaning that for a patient who died in 30 days, 4 out of 5 doctors would have estimated survival at less than 20 days or more than 40 days.

But Lamont said that if anything, doctors tend to *overestimate* the time a patient has left. That's because most patients seem to want the truth -- with a little padding.

"The research shows that patients want their doctors to be frank with them about their illness, but they also want them to be optimistic," Lamont said. "Obviously, if the patient has a terrible prognosis, it's hard to do both well."

So, while cases like Buchwald's do happen, more often patients die sooner than their physician predicted.

"Most people actually die within about three weeks of hospice enrollment," said Lamont, who is an assistant professor of medicine and health care policy at Harvard Medical School and an assistant physician at Massachusetts General Hospital.

Dennis agreed, saying the median length of care for VNS hospice patients is about 23 days.

Still, predicting how long any one patient might last is tough.

"One of the things that's happened over the past 5 to 10 years is that there's many more non-cancer patients

being cared for in hospice programs," Dennis said. While cancer can have a fairly definite trajectory, illnesses such as kidney disease, chronic lung disease, Alzheimer's or ALS often progress much more slowly. "So, hospice programs are finding themselves caring for people way beyond six months," she said.

In fact, the attention patients receive in hospice could be key to their extended survival.

"The truth is, patients often come to us looking like a train wreck, with all sorts of problems," said psychologist Stephen Connor, vice president of research and professional development at the National Hospice and Palliative Care Organization in Alexandria, Va. "We work with them, we get them better managed -- making sure they take their meds, talking to them, bathing them. And then they start to slowly get better, sometimes to a point where they get so much better, we end up discharging them. We'll even throw 'discharge parties' for them," he said.

Scott Stewart, a nurse-manager working on Dennis' team in New York City, said he has witnessed the restorative power of caring many times.

"I just met this elderly woman up in Harlem. She started crying one day while I was sitting with her, because she said that never in her whole life had she had so much attention focused on her," he said. "And that's what it's all about. We go in there, there's a social worker, a nurse, a chaplain, a doctor. We hold their hand. They might have a home health aide helping out, too. It brings a lot of joy, and that can truly extend someone's life."

Still, an unexpected few extra months or years of lifespan *can* have its downside, especially when a patient requires a lot of care.

"For families, it can become very wearing -- they think 'OK, we can do this for three or four months, we've got a plan, we can pull it together, either in terms of money or human resources,'" Dennis explained. "But then the person keeps living on."

Stressed caregivers are then torn between their love for the sick parent, partner or sibling, and the emotional and financial toll that caring for the very ill can bring over the long-term. "The patient may also be thinking, 'I'm a real burden here,'" Dennis said. "It's an issue."

Statistics from the U.S. Centers for Disease Control and Prevention show that about one-third of those patients who do get discharged from hospice will die within six months of their release. Many others end up in nursing homes because of ongoing chronic illness. Only a small number -- somewhere between 5,000 and 20,000 per year -- live on through the longer-term in relative independence and comfort.

Buchwald, whose kidneys began to fail after a stroke he suffered six years ago, seems to have landed in the latter group.

Doctors say they can't really explain how he beat the odds, but out on the Vineyard, the columnist remains his frank, wisecracking self.

He told *The New York Times* last week that he plans to have his ashes sprinkled over every New York City building owned by developer Donald Trump.

More information

Learn more about hospice care at the [National Hospice and Palliative Care Organization](#) .