

## **MANY PATIENTS WHO CHECK INTO HOSPICES TO DIE, DON'T**

By Frank Greve

McClatchy Newspapers

(MCT)

WASHINGTON - Thousands of patients who check into hospices expecting to die are winning reprieves instead.

Sometimes attention from loved ones and quality care from hospice staff turn things around. Or doctors guess wrong when they predict that death is near. And sometimes long-odds medical miracles happen.

Whatever the reason, roughly 100,000 U.S. hospice patients will win new leases on life this year. That number, which is based on Centers for Disease Control and Prevention figures, is expected to increase as baby boomers age. It's a trend that poses exotic challenges - some wrenching, some magnificent - for hospices and for hospice patients and their families.

"We're trained to help patients close out things," explained Betty Waters, a social worker at Alive Hospice in Nashville, Tenn. "So when they say, 'I'm going to fight this,' I'm used to thinking that that means they're in denial. It's a very awkward situation."

What happens to hospice survivors is largely a matter of conjecture. About a third die within six months of their release, according to one study. Large numbers of the rest go to nursing homes because, while not at death's door, they continue to suffer from chronic diseases, often Alzheimer's or other forms of dementia. But somewhere between 5,000 and 20,000 hospice survivors a year, by most estimates, live on with evident satisfaction.

Consider:

\_ Brian Dickinson, an editorial writer for the Providence Journal in Rhode Island, quit hospice and, when totally paralyzed by Lou Gehrig's disease except for his eyes, kept writing commentaries by blinking into a TV camera linked to his computer keyboard. "Brian knew his disease was fatal, but he always believed it'd be fatal later," said his widow, Barbara. He died at 64, five years longer than he'd been expected to live.

\_ Judy Murray, 59, of Bethlehem, Pa., a retired occupational therapist, is, to her doctors' awe, surviving stage four ovarian cancer diagnosed in 2004. "If it ever comes back, I know where you are," Murray told Ruth Fillebrown, clinical director of Lehigh Valley Hospice, when they met recently at a concert.

\_ Gloria Thomas, 57, Franklin, Tenn., a pulmonary fibrosis sufferer, had given away her beloved cat, Clyde, conferred with her minister, and checked into hospice. But when her visiting husband told her that her time was running out, Thomas ejected him from her

room and later divorced him. "Whenever you have anything negative around you, you have to get rid of it," she explained six years later.

\_ Art Buchwald, 81, the humor columnist, is enjoying another summer on Martha's Vineyard, the resort island offshore of Cape Cod, after his kidneys proved too robust to fail. Buchwald ditched plans to have singer Carly Simon, a Vineyard crony, perform at his funeral. Instead she's to serenade him with the sweet old ditty that begins, "I'll be seeing you in all the old familiar places."

Hospice survival at its best is hardly easy living, however. Chronic diseases persist, even if they're not life-threatening for the moment. Surviving costs more, since Medicare covers hospice care without co-pays. Illusions of immortality are shattered. The clock ticks.

Buchwald likens surviving hospice to booking a seat on a plane, having the flight cancelled, and ending up on standby indefinitely.

It was Buchwald's internist's inaccurate prediction that he had just weeks to live that got him into hospice.

Such errors are very common, according to Dr. Nicholas Christakis, a sociologist and internist at Harvard Medical School who's studied doctors' prognoses for hundreds of terminally ill patients. In 4 out of 5 cases, Christakis and co-researcher Elizabeth Lamont found, doctors' estimates of how long a patient would live were wide of the mark by at least a third. That is, for a patient who actually died in 30 days, 80 percent of doctors predicted 20 days or less or 40 days or more.

Specialists and non-specialists proved almost equally inaccurate, the researchers found, and the better doctors knew the patient, the bigger their errors, mostly in the optimistic direction.

"Doctors in general are optimistic," said Christakis.

Their inaccuracy was less of a problem in the '70s and '80s, the early days of hospices in the United States, when three-quarters or more of the clients were cancer patients. Their deaths followed a relatively predictable line downward from the date when treatment failed.

Today, however, nearly half of hospice patients are in for heart, lung, kidney or liver failure, or forms of dementia. For all of these, "the line toward death is like a roller coaster," said Mark Cohen, vice president of communications for VITAS Innovative Hospice Care, a Miami-based for-profit system. "The valleys are deeper and deeper over time, the peaks are lesser, but predicting which valley will end in death is very difficult."

VITAS runs hospices in Kansas City, Philadelphia, Fort Worth, Sacramento and Fort Lauderdale, among other cities.

Accurate prognoses matter because to gain in-home hospice services or admission to a hospice under Medicare and Medicaid rules, both the patient's and the hospice's doctor must agree that the patient won't survive six months. In actuality, about two-thirds of the

roughly 1.2 million patients who enter hospices annually die within 30 days, according to the National Center for Health Statistics.

Those who survive for more than six months - non-cancer patients in disproportionate numbers - are kept on if doctors agree that they probably won't live for another six. Those whose conditions improve and stabilize to the point that they're deemed likely to survive for at least six months are normally discharged.

Why there are so many of them remains something of a mystery.

One theory is that many patients only appear to be dying. Actually, they're "suffering from the dwindles," as True Ryndes, head of a coalition called the National Hospice Work Group, put it. "The patient isn't in decline; their caregiving is in decline."

Given the focused attention of hospice doctors, nurses, social workers and spiritual counselors, the patients get their minimum meds adjusted and take them regularly. They get painkillers adequate to assure a night's sleep. They eat regularly, and their loved ones get some help and relief.

"Often, just taking away the pain and enabling them to sleep through the night gives people a second wind," said Fillebrown, clinical director of the Lehigh Valley Hospice in Allentown, Pa.

This hospice-surviving population, which includes large numbers of homeless and destitute people, is also the one likeliest to go downhill fast upon release, hospice officials say.

Another theory of unexpected survivals is that pending death brings out the curative power of loving family and friends. Hospice personnel are convinced that it works, and so is Sheldon Cohen, a sociologist at Carnegie Mellon University in Pittsburgh who's studied the relationship between emotions and health.

"There's no question that people who are suffering adversity do better with social support," said Cohen, citing a 1989 study by health psychologists James Kulik and Joni Mayer. They found that male coronary bypass patients who had frequent visitors used less pain medication and recovered more quickly. Married patients also did better.

Some people who recovered while under hospice care, including Murray, the ovarian cancer sufferer, found that they had to resist hospice personnel to do it.

"When I told them that I planned to fight it, they were very professional," Murray recalled. "They'd ask me if I'd considered all the possibilities and all my options. They'd praise my positive attitude, but remind me that my numbers were very bad."

Thomas, who had great praise for her treatment - twice - from Nashville's Alive Hospice, credited her parents' optimism and her own religious faith. "Everybody else said I was going to die and I felt really rotten," Thomas said. "But I just felt so up and good about everything. I felt like if I died I was going to a better place."

Dealing with recovering patients who'd come to die, and their exhausted families, can be difficult for staff, said Chris Turner, a veteran hospice nurse who supervises the Washington Hospice Center unit.

"I've had them get angry," she said. "'What do you mean Mom's not going to die? You told me she was dying!'"

The best approach, said David Rehm, her boss, is to custom-tailor hospice counseling to each patient and adapt it as conditions change. "It's like teaching someone to dance but allowing them to lead," said Rehm, president and CEO of The Washington Home and Community Hospices.

And when patients survive hospice care, Turner was asked, on what do they most often spend their gift of time?

"On forgiveness," she said.

Giving it or getting it?

"Both," she said.

---

To learn more about hospices and hospice care, go to the National Hospice and Palliative Care Organization at: [www.nhpco.org](http://www.nhpco.org)

---

© 2006, McClatchy-Tribune Information Services.