

# Americans are treated, and overtreated, to death

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(AP) -- The doctors finally let Rosaria Vandenberg go home. For the first time in months, she was able to touch her 2-year-old daughter who had been afraid of the tubes and machines in the hospital. The little girl climbed up onto her mother's bed, surrounded by family photos, toys and the comfort of home. They shared one last tender moment together before Vandenberg slipped back into unconsciousness.

Vandenberg, 32, died the next day.

That precious time at home could have come sooner if the family had known how to talk about alternatives to [aggressive treatment](#), said Vandenberg's sister-in-law, Alexandra Drane.

Instead, Vandenberg, a pharmacist in Franklin, Mass., had endured two surgeries, chemotherapy and radiation for an incurable brain tumor before she died in July 2004.

"We would have had a very different discussion about that second surgery and chemotherapy. We might have just taken her home and stuck her in a beautiful chair outside under the sun and let her gorgeous little daughter play around her - not just torture her" in the hospital, Drane said.

Americans increasingly are treated to death, spending more time in hospitals in their final days, trying last-ditch treatments that often buy only weeks of time, and racking up bills that have made medical care a

leading cause of bankruptcies.

More than 80 percent of people who die in the United States have a long, progressive illness such as cancer, [heart failure](#) or Alzheimer's disease.

More than 80 percent of such patients say they want to avoid hospitalization and intensive care when they are dying, according to the Dartmouth Atlas Project, which tracks health care trends.

Yet the numbers show that's not what is happening:

- The average time spent in [hospice](#) and palliative care, which stresses comfort and quality of life once an illness is incurable, is falling because people are starting it too late. In 2008, one-third of people who received [hospice care](#) had it for a week or less, says the National Hospice and Palliative Care Organization.

- Hospitalizations during the last six months of life are rising: from 1,302 per 1,000 Medicare recipients in 1996 to 1,441 in 2005, Dartmouth reports. Treating chronic illness in the last two years of life gobbles up nearly one-third of all Medicare dollars.

"People are actually now sicker as they die," and some find that treatments become a greater burden than the illness was, said Dr. Ira Byock, director of [palliative care](#) at Dartmouth-Hitchcock Medical Center. Families may push for treatment, but "there are worse things than having someone you love die," he said.

Gail Sheehy, author of the "Passages" books, learned that as her husband, New York magazine founder Clay Felker, spent 17 years fighting various cancers. On New Year's Day 2007, they waited eight hours in an emergency room for yet another CT scan until Felker looked at her and said, "No more hospitals."

"I just put a cover over him and wheeled him out of there with needles still in his arms," Sheehy said.

Then she called Dr. R. Sean Morrison, president of the American Academy of Hospice and Palliative Medicine and a doctor at Mount Sinai School of Medicine in New York.

"Nobody had really sat down with them about what his choices are and what the options were," said Morrison, who became his doctor.

About a year later, Felker withdrew his own feeding tube, and "it enabled us to go out and have a wonderful evening at a jazz club two nights before he died" in July 2008, Sheehy said.

Doctors can't predict how soon a patient will die, but they usually know when an illness has become incurable. Even then, many of them practice "exhaustion medicine" - treating until there are no more options left to try, said Dr. Martha Twaddle, chief medical officer of Midwest Palliative & Hospice Care Center in suburban Chicago.

A stunning number of cancer patients get aggressive care in the last days of their lives, she noted. One large study of Medicare records found that nearly 12 percent of cancer patients who died in 1999 received chemo in the last two weeks of life, up from nearly 10 percent in 1993.

Guidelines from an alliance of leading cancer centers say patients whose cancer has spread should stop getting anti-cancer medicine if sequential attempts with three different drugs fail to shrink their tumors. Yet according to IntrinsiQ, a cancer data analysis company, almost 20 percent of patients with colorectal cancer that has spread are on at least their fourth chemotherapy drug. The same goes for roughly 12 percent of patients with metastatic breast cancer, and for 12 percent of those with lung cancer. The analysis is based on more than 60,000 cancer

patients.

Often, overtreating fatal illnesses happens because patients don't want to give up.

Saideh Browne said her mother, Khadija Akmal-Lamb, wanted to fight her advanced ovarian cancer even after learning it had spread to her liver. The 55-year-old Kansas City, Mo., woman had chemo until two weeks before she died last August.

"She kept throwing up, she couldn't go to the bathroom," and her body ached, Browne said. The doctors urged hospice care and said, "your mom was stubborn," Browne recalled. "She wanted her chemo and she wanted to live."

Browne, who lives in New York, formed a women's cancer foundation in her mother's honor. She said she would encourage dying cancer patients to choose comfort care over needless medicine that prolongs suffering.

It's easier said than done.

The American way is "never giving up, hoping for a miracle," said Dr. Porter Storey, a former hospice medical director who is executive vice president of the hospice group that Morrison heads.

"We use sports metaphors and war metaphors all the time. We talk about never giving up and it's not over till the fat lady sings .... glorifying people who fought to their very last breath," when instead we should be helping them accept death as an inevitable part of life, he said.

This is especially true when deciding whether to try one of the newer, extremely expensive cancer drugs such as Avastin, Erbitux and Tarceva. Some are touted as "improving survival by 30 or 50 percent" when that

actually might mean living three weeks or months longer instead of two.

"It's amazing how little benefit those studies show," Storey said, referring to research on the new drugs.

Dan Waeger tried just about all of them. A nonsmoker, he was diagnosed with lung cancer at age 22, and pursued treatment after treatment before dying nearly four years later, in March 2009.

"He decided if there were odds to be beat, he was going to beat the odds," said his boss, Ellen Stovall, then-president of the National Coalition for Cancer Survivorship, where Waeger worked as a fundraiser and development manager.

"He received just about every experimental new drug for lung cancer that I'm aware of in his last two years of life. He would get a treatment on a Friday afternoon, be sick all weekend and come to work on Monday," she recalled.

"He had these horrific rashes. He would get these horrible coughs that were not just the lung cancer. The treatments were making him cough up blood, just horrific side effects - vertigo, numbness, tingling in his hands and feet. He suffered."

Waeger's fiancée, Meg Rodgers, said they worried about exceeding the lifetime limits on his insurance, since the care was so expensive.

"I think every time he got a treatment, it was \$10,000," though he paid only a \$10 copay, she said.

Yet it was clearly worth any price to him - he died a week before they were to be married, after receiving home hospice care for only two weeks.

"I honestly believe he would have done anything he could to live one more day," Rodgers said.

Some health policy groups say cancer patients, as well as people with failing hearts or terminal dementia, should get better end-of-life counseling. Last year, a plan that would have let Medicare pay for doctors to talk about things like living wills was labeled "death panels" and was dropped.

Ultimately, how patients and their families make the journey is a matter of personal choice - and there are resources to help them, Stovall said.

"I've heard a lot of people over the years say what they would do if they had cancer until it is them. And then they will cling to even the smallest glimmer that something will help," she said.

"[Cancer](#) that can't be cured is often called daunting but not hopeless. So that's what patients hear. Hope is the last thing to go. People don't give that up easily."

**More information:** State advance directives:  
[www.caringinfo.org/PlanningAhead.htm](http://www.caringinfo.org/PlanningAhead.htm)  
Physician's orders: [www.ohsu.edu/polst/](http://www.ohsu.edu/polst/)  
Respecting Choices: [respectingchoices.org](http://respectingchoices.org)

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