The New York Times

A Chance to Pick Hospice, and Still Hope to Live

By REED ABELSON

Charles Tirone of Manhattan rested last month after radiation treatment while enrolled in a hospice program. CreditRuth Fremson/The New York Times

The American health care system has long given patients a terrible choice: people told that they have a terminal illness must forgo advanced medical treatment to qualify for hospice care. Cancer patients have to pass upchemotherapy, for example, or patients with kidney failure must abandon dialysis.

Forcing patients into this either-or decision has prompted many who might benefit from a hospice program to instead opt for expensive hospital care that may end up costing Medicare and other insurers far more.

But now, some hospice programs and private health insurers are taking a new approach that may persuade more patients to get hospice care for the last months of life. These programs give patients the medical comfort and social support traditionally available through hospice care, while at the same time letting them receive sophisticated medical treatments that may slow or even halt their disease.

Hospice care is intended to help patients and their families better cope with the end of life by providing social services and special care.

Experts say that if the new approach catches on more broadly, more patients who would benefit from hospice care will actually enter hospice programs — and enter them earlier. And more patients, they say, could avoid the costly, crisis-ridden final weeks in a hospital that often still represent the American way of death.

In 2005, only about a third of the 2.4 million people who died in this country were in hospice care. Perhaps twice that many patients should have been in hospice programs, according to specialists in the field. And even many of those who entered hospice care did so only at the very end of their illnesses, spending a week or less in a program that ideally would have helped them cope with the final six months or year of life.

For too many of those patients, "that's not hospice; it's last rites," said Dr. John W. Rowe, the former chairman and chief executive of Aetna, one of the big insurers that is rethinking hospice care.

UnitedHealth is another insurer that now lets hospice patients also receive advanced medical treatments. Meanwhile, some of the nation's 4,200 hospice programs are offering advanced medical treatment even when they are not paid more to do so.

The new approach, which proponents call "open access" hospice, is an example of the efforts by some insurers and health care providers to try to fix specific problems in the nation's medical system even as politicians and businesses weigh sweeping health care overhaul proposals in Washington. Being able to have potentially life-prolonging medical treatment makes all the difference to hospice patients like Gary Marko, 42, who has advanced gastric cancer and is recovering from recent surgery for his condition.

"I probably would not have elected to go to hospice, if curative care wasn't an option," Mr. Marko said. He is considering taking chemotherapy even as he receives the kind of additional care available through a hospice program, like visits from a nurse and a massage therapist at his home in Covington, Wash. Both types of care will be paid for by the Aetna coverage he receives through his employer.

Dr. Rowe, whose medical specialty is caring for the elderly and is now a health policy professor at Columbia University, pushed Aetna to begin an experiment two years ago to pay for traditional medical care even while covering hospice services, usually at home, like nursing care or a home health aide.

Many doctors say the either-or approach, if it ever made sense, is less valid now that continued advances in medicine can allow even patients with very

advanced disease to benefit from new treatments. “The whole dichotomy is entirely false,” said Dr. Ira R. Byock, the director of palliative medicine at the Dartmouth-Hitchcock Medical Center in Lebanon, N.H.

There are many reasons people are slow to consider hospice care — not the least of which is acknowledging that they are dying.

But Dr. Byock rejects the notion that the only point of hospice is to help people die. He says that by offering nursing care and palliative medicine to relieve pain and improve the quality of life, hospice care can benefit some people so much that they become well enough to leave the programs. The Aetna experiment, for which nearly 400,000 of its roughly 15 million insured members are eligible, provides some evidence that people will take advantage of hospice care if they do not have to give up other treatment intended to prolong life.

Mr. Marko said that once he learned that Aetna would not ask him to forgo chemotherapy, there was no reason not to sign up for the hospice services that allowed him to be more comfortable at home with his wife, Amy, and their three young children. His massage therapy makes him feel better, for example, and he plans to try the acupuncture available through the program.

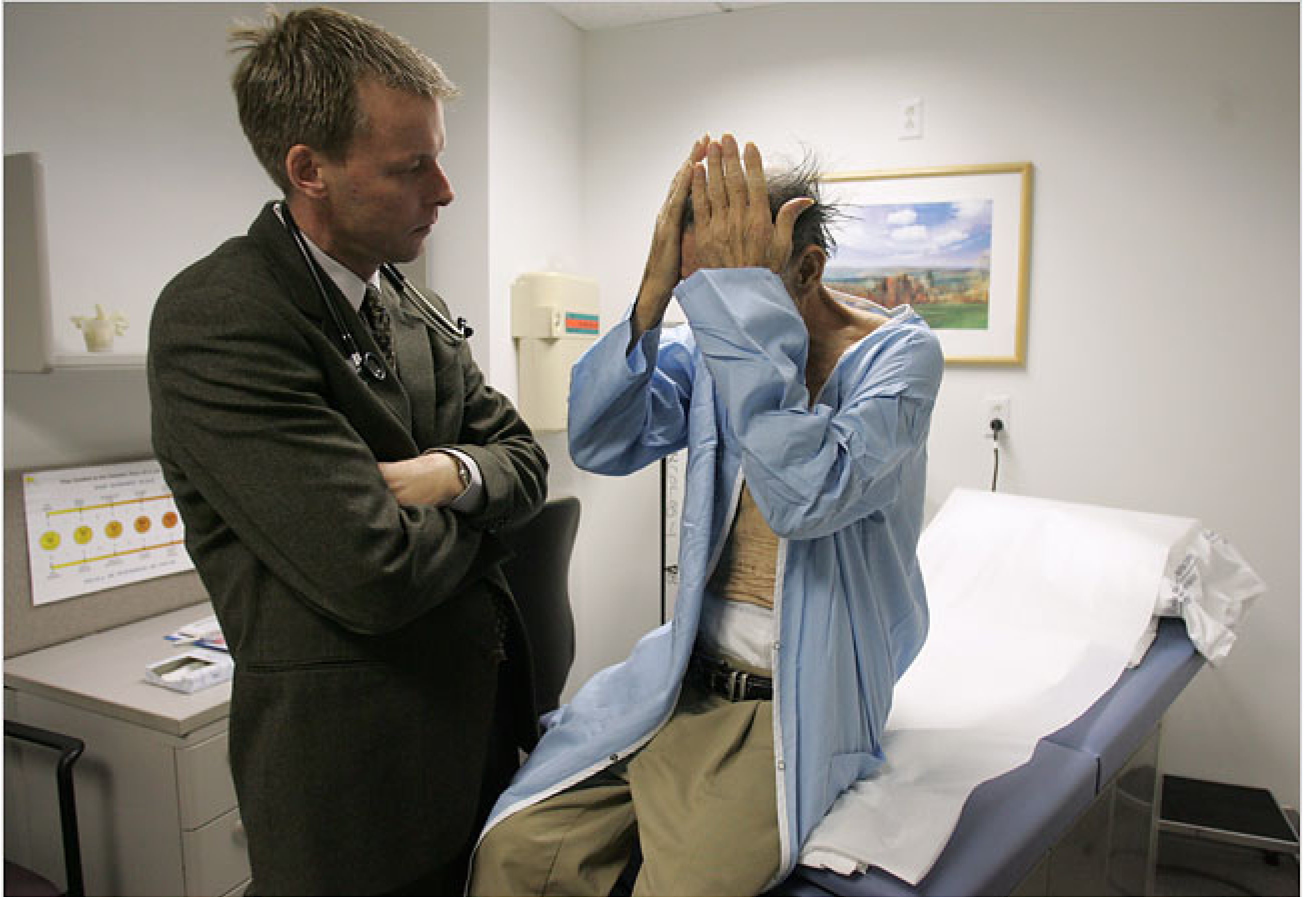
“What’s to lose?” Mr. Marko said.

What can be gained is more time to take advantage of hospice’s benefits. One woman in the Aetna experiment who had breast cancer was able to continue chemotherapy even as she enrolled in a hospice program that offered the nursing care she needed before she died.

“She just wasn’t ready to give up,” said Sharon Brodeur, a nurse and Aetna administrator who helped develop the experimental program. The patient probably entered the program two or three months earlier than she would have if she had had to give up chemotherapy, Ms. Brodeur said.

The Aetna initiative and other open-access programs are still the exceptions, though.

For example, Medicare which spent about $9 billion on hospice benefits last year out of its total spending of $406 billion, requires patients to give up regular medical coverage if they enter a hospice program.



Dr. Andrew Evans, left, with Charles Tirone in January at Roosevelt Hospital in Manhattan.CreditRuth Fremson/The New York Times

But many hospice programs do not offer advanced medical treatments because they say they cannot afford to. Medicare pays a provider about $130 a day for routine hospice care in the home, regardless of the patient's individual condition. The agency, which introduced the benefit in the mid-1980's, based its rules on the assumption that it would be too costly to pay for both hospice care and for treatments aimed at prolonging life.

Many experts, though, say that thinking is misguided because it causes patients to spend their last days in a hospital receiving expensive care they may not even want, or to frequently return to the hospital because managing their disease is too much for a family to handle.

"What they're doing instead is paying for unnecessary emergency room visits," said Dr. Diane E. Meier, a professor at Mount Sinai School of Medicine in New York and an expert in palliative care.

Medicare officials, though, cite the growing popularity of hospice programs as an indication that the benefit is valuable in its current form.

Hospice care has been allowed to "thrive and prosper," said Laurence Wilson, the director of chronic care policy for the Center for Medicare Management. But he also emphasized that patients who still wanted aggressive medical treatment had the option of sticking with traditional Medicare coverage.

Hospice is "not all things to all people," Mr. Wilson said.

Many people in the field say that Medicare's fixed-payment system discourages some hospice programs from accepting patients who need expensive treatment.

"The perverse incentive is to take the cheapest patient," said Carolyn Cassin, the chief executive of Continuum Hospice Care, who said such a patient would be someone who had already given up hope and required very little medical care. Continuum Hospice Care is part of the hospital system of the same name in New York and is among the small number of hospice programs that makes a point of taking even those patients who want sophisticated treatment.

Because Continuum Hospice cared for 2,700 patients last year, on a budget of about $42 million, the program is large enough to absorb the cost of some very expensive patients, Ms. Cassin said.

"You're never going to have to choose between treatment for the disease and care from us," she said, noting that about 40 percent of Continuum Hospice patients received advanced medical therapies.

When 76-year-old Charles Tirone, who had late-stage lung cancer, was discharged from the hospital late last year, for example, he was able to continue his radiation treatments and still enroll in Continuum's hospice program. Social workers and nurses managed his care at his West 57th Street apartment in Manhattan, until his death on Tuesday evening.

The social worker assigned to Mr. Tirone "tried her best to make Charlie comfortable," said Michael Abbassi, a longtime friend who helped care for him.

Many other hospice programs are exploring the Continuum-style of open access, accepting patients with insurance at the end of life who may want and need aggressive medical treatments.

"This has been a big movement and a big discussion over the last five years," said Malene Davis, the chief executive of Capital Hospice in Falls Church, Va., which cared for about 5,100 patients last year.

Many hospice programs, though, are too small to spread their costs, which would allow them to take patients needing expensive treatments. And if they meet basic state and Medicare requirements that include offering access to a

nurse and a doctor 24 hours a day, hospices can essentially pick and choose which treatments to offer as long as they are meeting a patient's needs.

"There is a huge variation in what programs provide," said Dr. Mark Leenay, the medical director of palliative initiatives at UnitedHealth, the big insurer.

Because Medicare does not collect detailed data about the medical treatments a hospice patient receives, there is very little information about what services are actually being provided. Some argue that Medicare should simply drop the requirement that patients forgo other coverage if they want hospice care.

As part of a much broader effort toward revamping health care, Senator Ron Wyden, Democrat of Oregon, has introduced legislation that would end that requirement. He says that the change would not significantly raise Medicare's spending, but that it would give people more control over the way they die.

"People don't want government making their choices," he said.

One insurer, Blue Cross and Blue Shield of Rhode Island, which typically pays for treatments like chemotherapy as a way to relieve pain even while covering hospice care, says it has not seen a significant increase in the use of medical services because of this broader coverage.

At Dow Chemical, an employer in the Aetna experiment, the company's executives agreed to pay for the broader coverage because "it's the right thing to do," said Steve Morgenstern, who manages Dow's health plans.

Aetna plans to continue its experiment, which in its first year increased the average length of a hospice stay to 34 days, up from 27. The insurer's chief medical officer, Dr. Troyen Brennan, predicts that the company will probably end up extending its coverage to more of its insured members.

"Looking at the preliminary data, everything suggests we should move forward," he said.

Dr. Rowe, the former Aetna chairman, said insurers should not be in the business of forcing people to give up hope. "When I was in practice," he said, "I wouldn't do that to a patient."

A version of this article appears in print on , on page A1 of the New York edition with the headline: A Chance to Pick Hospice, and Still Hope to Live.