YOUR HEALTH

Should Your Loved One Really Be in Hospice?

Hospice care provides much-needed comfort to the terminally ill. But recent scrutiny by government investigators and industry whistleblowers casts an unflattering light on some major hospice providers and raises thorny questions for patients and their families.

With its focus on pain relief and managing symptoms rather than on prolonging life, hospice care is designed to ease the final months or days of dying patients and provide support for families losing a loved one. Medicare covers the service for terminally ill patients expected to live six months or less.

As for-profit providers take a larger role in the fast-growing hospice industry, however, concerns are rising about whether hospice is serving the right patients at the right time. Seeking to maximize their Medicare dollars, some providers have allegedly enrolled patients who are not really terminally ill, according to lawsuits brought against hospice companies by former employees and the U.S. government.

With for-profit hospice providers looking to boost business, "people have to be on guard," says Ron Panzer, president of patient advocacy group Hospice Patients Alliance. "The incentives are there," he says, to sign up ineligible patients.

Premature enrollment in end-of-life care can be particularly troubling for patients because entering hospice generally means waiving coverage for treatments intended to cure a terminal illness. While good hospices will seek to ensure that patients are comfortable, they may not provide some costly medications, rehabilitation or chemotherapy. "You don't know what you're really giving up until you pin down the hospice provider and say, 'What does your hospice make off limits by defining it as curative?'" says Dr. Joanne Lynn, director of the Center for Elder Care and Advanced Illness at Altarum Institute, a nonprofit research and consulting organization.

Patients as Profit Centers

By enrolling patients requiring longer-term, less-complex care, hospice providers can receive more Medicare dollars per patient, according to a report last year by the U.S. Department of Health and Human Services' Office of Inspector General. Medicare reimburses hospice providers at an all-inclusive daily rate, regardless of the amount of services provided on a given day. Patients staying long periods in hospice also may be more profitable for providers because hospice visits tend to be more frequent at the beginning and end of the patient's time in hospice, according to reports by the Medicare Payment Advisory Commission (MedPAC), an independent Congressional agency.

In a complaint filed late last year against AseraCare Hospice, a unit of Plano, Tex.–based Golden Living, the U.S. Department of Justice alleged that the for-profit hospice pressured employees to enroll patients for whom it could bill Medicare, even if those patients didn't meet the eligibility requirements. The company set aggressive enrollment targets and submitted documentation falsely presenting patients as terminally ill, the government alleged. The allegations "are without merit, and AseraCare operates in full compliance with the law," AseraCare general counsel David Beck said in a statement responding to Justice's complaint.

For many patients, of course, hospice provides great relief from pain and anxiety. Considering that there are thousands of hospice providers in the U.S., very few are under scrutiny, says Jonathan Keyserling, a senior vice-president at the National Hospice and Palliative Care Organization, which represents hospice programs and professionals. "The vast majority of hospice programs provide the highest quality care," he says.

Although hospice care has its roots in volunteer organizations, for-profit providers have played a major role in the industry's recent growth. Medicare payments for hospice care amounted to $12.1 billion in 2009, up 53% from 2005, according to the Department of Health and Human Services. And 56% of

hospices serving Medicare beneficiaries were for-profit in 2009, up from 45% in 2005 and just 13% in 1992.

Here's how the hospice Medicare benefit works: A doctor and the hospice medical director must certify that the patient has six months or less to live. Care is often provided in the home, and the hospice team may include doctors, nurses, social workers, spiritual counselors and volunteers.

While patients don't get treatments focused on curing their terminal illness, they can get treatment for unrelated conditions. The hospice benefit is available for two initial 90-day periods and then an unlimited number of 60-day periods, as long as a doctor or medical director recertifies the patient's terminal condition. Patients can choose at any time to withdraw from hospice and return to regular Medicare coverage.

Although the Medicare hospice benefit is intended for patients with less than six months to live, such a prognosis often lacks precision, leaving gray areas for patients, families and health care providers. And hospice providers' marketing tactics may sway patients who would otherwise choose conventional treatment.

In a whistleblower complaint filed last year against Birmingham, Ala.–based hospice provider SouthernCare, former SouthernCare clinical director Karina Christensen claimed that the company aggressively marketed its services to non-terminal patients, promising free medications, wheelchairs and home health aides. With little or no documentation of a terminal illness, SouthernCare enrolled some patients on the basis of "failure to thrive," Christensen claimed. SouthernCare, without admitting wrongdoing, agreed in 2009 to pay the government $24.7 million to settle similar allegations. The company, which did not respond to requests for comment, denied Christensen's allegations in a court filing.

Asking the Right Questions

When facing a decision to forgo conventional treatment and enter hospice care, get an opinion from a trusted physician such as a longtime family doctor, patient advocates suggest. Ask whether the patient's physician can follow her into hospice care. And demand details on the hospice's willingness to provide current medications, its handling of certain scenarios such as shortness of breath and its ability to respond to emergencies around the clock.

A hospice provider's response to an emergency situation came as a shock to Nate Carpenter, 61, a former firefighter in Las Vegas. Carpenter is the caregiver and legal agent of 86-year-old Alma Natalie, who entered at-home hospice care after suffering a fall and a small stroke last year. After a few days in hospice care, Carpenter says, he had to call an ambulance because Natalie suffered a pulmonary embolism. Natalie was taken to the hospital and survived.

But, says Carpenter, "the hospice service was furious with me" for calling the ambulance. He says that the hospice wanted him to agree not to dial 911 in the future. Uncomfortable with such a commitment, and unsure whether Natalie belonged in hospice to begin with, he withdrew her from hospice and returned her to conventional care. Nearly a year later, Natalie is still living fairly comfortably at home, Carpenter says.

It's common for hospice providers to ask patients and families not to dial 911, industry experts say. "Hospice programs will say, 'Call us first, let us assess the situation with you, and then we'll make an informed decision about what the patient actually needs,'" Keyserling says.

Patients and loved ones should ask about the hospice's emergency response process in advance, says Naomi Naierman, president and chief executive officer of the American Hospice Foundation. "They're supposed to respond lickety-split, but it's not a 911 system," she says.

When choosing among hospice providers, patients and families should also determine whether the hospice is Medicare certified and what facilities are available if the patient ultimately cannot be cared for at home. The search tool at **www.caringinfo.org** allows users to find hospice providers by location and services offered.

Even after selecting a hospice, many families find they must remain vigilant to ensure their loved ones get the best care. Lisa Brenner's husband, David, entered hospice when he was dying from rectal cancer in late 2010. Lisa, a 51-year-old former information technology worker in Los Alamos, N.M., quickly withdrew her husband from his first hospice provider, whose staff seemed unable to help as David suffered from seizures. When a second hospice provider seemed reluctant to treat a urinary tract infection that David developed, Lisa became uncomfortable and ultimately had her husband treated in a hospital. "It was an awful situation," says Lisa.

Yet Lisa also recalls when hospice care brought her husband great relief in his final days. "I can't stress how much difference it made when the nursing aide came and gave him a bath and shaved him," she says. "That was just heaven on earth." K —ELEANOR LAISE