

Waiting too long to use Hospice Care can make suffering at end-of-life worse

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Many people who are near the end of life wait too long to enter hospice care, according to a recent study published in the Journal of the American Geriatrics Society. In hospice care, attempts to cure a disease are usually replaced with treatments solely for pain and suffering, delivered by a specialized team. It usually includes medical and nursing care, counseling and social services, and it can be given at home, in a nursing home or in a hospital facility.

People who put off hospice care might spend months in and out of hospitals, with their families struggling to attend to them. "At some point, patients and their families and doctors realize that hospice is appropriate, but that happens perhaps later than it should," says study author Thomas Michael Gill, a professor of medicine, epidemiology and investigative medicine, and the Humana Foundation professor of geriatric medicine at Yale University. "When folks are referred to hospice only in the last days of their life, it's difficult to have a meaningful benefit."

For nearly 16 years, Gill and a team of researchers followed 754 people, all age 70 and older when the study began. More than 40 percent of the 562 people who died during the study entered hospice care during the last year of their lives, but the median time spent in hospice was less than two weeks.

Many of their most debilitating symptoms — including pain, nausea, depression and shortness of breath — decreased substantially only after hospice began. So, many might have been suffering needlessly for months, says Diane Meier, director of the Center to Advance Palliative Care and a professor of geriatrics and palliative medicine at Mount Sinai Hospital in New York.

Health crises, emergency-room visits and hospitalizations can become routine toward the end of life, "a very distressing and stressful experience for patients and family members," Meier says. "Remaining in your own home, a familiar place with familiar people, is safer and offers better quality of life."

What to know about hospice

Hospice has been covered by Medicare since 1982. Health-care providers have to certify that a patient is terminally ill (with six months or less to live) — which can be difficult to predict, Meier and Gill say. People can leave hospice at any time — because their condition stabilizes, for example, or they want to pursue curative treatments again. Hospice care can also be extended beyond six months.

"Many people are fearful that if they choose hospice, they won't be able to return to mainstream medicine should they improve or new treatments become available — that's not true," Meier says. "Hospice is not a one-way street."

And some evidence suggests that hospice patients live just as long as or even longer than similarly ill patients who are not in hospice.

When is it the right time?

People with terminal illnesses and their doctors should be having ongoing discussions about goals and priorities, Gill says — ideally long before hospice is broached.

"Often, patients will say, 'I'm more interested in the quality rather than the quantity of my remaining life,'" he says, and that can help inform future discussions about end-of-life care.

If you have not discussed hospice with a doctor, for yourself or a loved one, two signs suggest when it might be time to raise the topic, Meier says.

The first is when someone is having increasing difficulty with self-care, struggling with tasks such as walking, getting out of a chair, bathing, dressing and using the toilet. Hospice care is designed to help with all of those activities. The second is the presence of symptoms such as severe pain, shortness of breath, hopelessness, depression and profound fatigue. In hospice, "most of them can be improved or eliminated," Meier says. "It's challenging to have honest discussions with patients and families about death and the dying process," Gill says. "But leaving the conversation until the very end makes it more difficult."