

10 Facts You Need to Know About Hospice

Is hospice care the right option for you or a loved one?

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Here's what you need to know.

1 Hospice is a philosophy of care, not a brick-and-mortar location. Most people say they want to die at home, but only about 1 in 4 end up doing so. One big reason: It's often just too hard. "Trying to care for someone with a serious illness, especially at home, without hospice is like trying to have surgery without anesthesia," says Ira Byock, the executive director of the Providence Institute for Human Caring.

Hospices bring everything you might need to the home — hospital bed, bedside commode, medications, bandages, expert consults — tailored to your needs.

But if you're daunted by home care, or simply don't want a loved one to die in your home, hospice care also is available in facilities and hospitals.

2 Signing up does not mean giving up all medical care. Transitioning to hospice means shifting from one set of goals (how to get longer life through a cure) to another (how to get the best quality of life out of whatever time is left).

"When people say, 'I don't want to give up,' the key is to understand what they think they're giving up," Gross says. Even when a cure is no longer viable, therapies that improve symptoms and raise comfort can continue. "I deliver very aggressive care in hospice," she adds.

If, however, you feel that you have not exhausted all of your treatment options in search of a cure, hospice may not be for you. Medicare hospice rules require forgoing curative treatments.

That may soon change, though. In July, Medicare announced the expansion of a five-year pilot program to 141 hospices in 40 states to allow patients to continue pursuing curative treatments while under hospice care.

3 You have to qualify for hospice, but you can opt out at any time. To qualify for hospice benefits, either through Medicare or private insurance, two physicians must certify that you have a life-altering condition with an expected prognosis of six months or less. This time frame is arbitrary, however; there's no biological or scientific basis for knowing how long you have left, Gross says.

4 If you start hospice and realize it's not for you, you can quit. How can you know when to try hospice? This should be part of ongoing discussions with your health care team, Byock says — "ongoing" because goals and needs evolve.

5 You may live longer during the time you have left. Hospice recipients live longer, on average, than those receiving standard care, research shows. A 2010 study of lung cancer patients found they lived nearly three months longer; another study, looking at the most common terminal diagnoses, found the same, ranging from an average of 20 more days (gallbladder cancer) to 69 days (breast cancer).

6 You can still see your regular doctor. Multidisciplinary by intention, a basic hospice team consists of a physician and nurse (both on call 24 hours a day); a social worker, counselor or chaplain; and a volunteer. Many hospices offer added services: psychologists, psychiatrists, home health aides, art or pet therapists, nutritionists, and occupational, speech, massage or physical therapists. You may also continue to see your regular doctor. And you remain in charge of your medical decisions.

7 The goal of pain management in hospice is to enable you to live well — not sedate you. "People often mistakenly think pain medicine will make the person sleepy to the point where they can't interact," says Karen Whitley Bell, a hospice nurse for 20 years and author of *Living at the End of Life*. "To the contrary, if you live with pain unnecessarily, it makes you more tired and irritable, and robs you of quality of life." When drugs like morphine are used, it's to treat anxiety and to lessen pain, which has been shown to be undertreated at the end of life — not hasten death, as many people mistakenly believe.

8 Hospice can enrich, and sometimes salvage, the last stage of life. Almost a third of those with a terminal illness die in the hospital, hooked up to machines that do little to halt the process of dying. Hospice is designed to support the more personal aspects of this life stage: reflecting on one's legacy and life meaning, focusing on relationships in a deeper and more intentional way, achieving a sense of closure, and realizing any end-of-life goals, such as attending a grandchild's graduation or getting financial affairs in order.

9 Hospice is for the entire family. It's not always easy to witness the hallucinations of delirium or understand the body language of someone who can no longer speak, for example. A hospice nurse can help interpret what's happening, or explain the signs of imminent death. And when families need a break, the sick person can spend up to five days at a time in inpatient respite care, such as in a nursing home or hospice facility.

10 Hospice continues after death. Many people don't realize that optional follow-up grief support for 12 months is included under Medicare rules. "For many of our families, their journey with hospice is only beginning once their loved one dies," says bereavement counselor Anne Alesch. Adds Ira Byock: "We make a mistake in assuming that serious illness and dying are mostly medical. They're fundamentally personal."

Paula Spencer Scott is the author of *Surviving Alzheimer's: Practical Tips and Soul-Saving Wisdom for Caregivers*.