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Hospice care helps patients and loved ones

More patients use the service for end-of-life care. But what is it?

By Christie Aschwanden

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Over the last 25 years, the number of Americans turning to hospice for end-of-life care has climbed dramatically -- from 25,000 in 1982 to 1.45 million in 2008, as more and more people choose to spend their final days in the comfort of home or a patient facility with a home-like environment rather than in a hospital pursuing aggressive treatments.

During the last decade, Medicare reimbursements for hospice have also risen, allowing more hospices to open without relying on fundraising for survival, says Christy Whitney, chief executive of Hospice and Palliative Care of Western Colorado in Grand Junction.

The decision to stop curative treatment and enter hospice is never easy, and it comes at a stressful time. Even once the decision is made, arranging for hospice care requires the acknowledgment of unpleasant realities, which doctors themselves may hesitate to discuss. This reluctance can put the onus on patients and families to initiate difficult conversations about end-of-life care.

Here's a guide to navigating the hospice system so that you and your loved ones can get the information you need to make informed decisions.

What is hospice? Hospice provides support for people entering the final stages of their lives, and their families; the word is a medieval term that describes a brief resting place on a long and difficult journey.

According to the official philosophy statement of the National Hospice and Palliative Care Organization, "Hospice affirms life and neither hastens nor postpones death." Instead, it strives to enhance the quality of a person's remaining life by providing medical care, pain management, and emotional and spiritual support.

When hospice first came to the U.S. from England in the 1970s, it was used mainly as a home care program for cancer patients. It soon broadened its scope to include anyone facing a terminal diagnosis. Today, cancer accounts for fewer than 40% of all hospice patients, says Donald Schumacher, president and chief executive of the National Hospice and Palliative Care Organization.

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Hospice service is most commonly delivered in the home, but it can also be provided at a nursing home or in-patient hospice care facility.

Who is eligible? Anyone with a terminal illness who has decided to stop seeking curative treatment. The initiation of hospice care requires a referral from a doctor certifying that the person has been diagnosed with a disease or illness that, if it ran its normal course, would result in a prognosis of six months or less to live. That doesn't limit patients to six months of care, though. "You can continue receiving hospice as long as you're still terminally ill," Schumacher says. In 2008, the median number of days that patients received hospice care was 21.4 days, and the average was 69.5.

What does it cost? About 84% of hospice care is paid for by Medicare, and most insurance companies cover it. But hospice services are provided without regard to the ability to pay, and most have programs to help families pay if they lack coverage or means. "No one is turned away," says Mary Ellen Blakley, administrator for the Hospice Partners of Southern California.

Make plans long before you are sick: Whether you're perfectly healthy or you've just been diagnosed with a serious condition but are still feeling fine, now is a good time to put your last wishes in writing. "It's hard to make good decisions when you're in the midst of a tragedy or drama," Schumacher says.

An advanced directive, a legal document that identifies your wishes regarding medical treatment at the end of life, gives doctors formal instructions on the care you want if faced with a terminal illness or injury, and can give peace of mind to loved ones who can know for certain they're following your wishes, Whitney says.

Often family members have different ideas about "what Mother really wanted," and that can put families in conflict. "Don't assume that anybody knows what you want. Get it down in writing," Schumacher says.

Each state's advanced directive forms are different; you can download them free at Caringinfo.org. Leave copies with family members and your doctor, not in a safe-deposit box where no one can get to it.

Perhaps the most effective thing you can do in advance is to designate a medical power of attorney, a person you assign the authority to make medical decisions for you if you become incapacitated, Whitney says. Ideally, this is someone who understands your values and wishes and can explain these to family members who might feel torn about what to do.

When and how to have the discussion: Family members and terminally ill patients often struggle to initiate discussions about death, and this can result in a conspiracy of silence that can delay hospice care, Whitney says. "Very often the patient says to me, 'I know I'm dying, but please don't tell my wife.' And then I'll talk to the wife and she'll say, 'I know my husband is dying, but please don't tell him.' "

Because doctors too may be reluctant to suggest hospice, it's often up to the patient or family to ask. If needed, hospice staff can call the doctor to help initiate the discussion.

Some loved ones fear that raising the idea of hospice care could make the patient think that they're withdrawing support, but Schumacher, a clinical psychologist, says that's rarely the case. Discussing what is happening in frank terms can often come as a tremendous relief to the person who's dying.

"They can be living under this pressure to stay alive for the wife and kids. I'm surprised at how often they feel guilty, like they've let people down by getting ill, and giving them permission to be sick can lift this burden," Schumacher says.

One way to begin the discussion is by taking an "expect the best but prepare for the worst" approach. "You don't want to push people into talking about it if they're not ready," Schumacher says. "But you can say, 'Listen -- we're going to fight with you, but let's just talk about what we should do if you aren't getting better, just in case.' "

What to expect from hospice: Hospice care begins with a visit from a nurse, who meets with the patient and the family to put together a care plan that fits with the patient's values and needs. But it's not just for the patient. "Our basic philosophy is that the patient and the family are the unit of care," Schumacher says. "The family receives a lot of psychosocial and spiritual support throughout the process."

Hospice provides visits from doctors, nurses, home health aides and volunteers, but these do not take the place of the primary caregiver, Blakley says. Instead, hospice workers go in as an extra set of hands, helping to bathe the patient and assisting with bed changes and similar tasks. A hospice volunteer might also visit to read to the patient or offer a listening ear for family members. Workers help caregivers ensure that their loved ones are comfortable and deliver pain medications, nursing care and palliative measures as needed.

Most hospice care is delivered in the patient's residence, where routine visits from hospice doctors, nurses and home health aides are designed to make the dying process as comfortable as possible for the patient and family.

Hospice doesn't take hope away, Whitney says. "There's no rule that you have to die because you go into hospice. We discharge 15% of our patients every year, because they get better." In fact, many people make improvements after they begin hospice, because they stop treatments that were making them feel lousy, she says.

Preliminary evidence suggests that hospice may actually extend life. A study published in the Journal of Pain and Symptom Management in 2007 examined the outcomes of 4,493 patients with six different terminal illnesses -- five cancers and congestive heart failure -- and found that those who received hospice care had an average survival of 29 days longer than those who did not.

After a loved one has died: Support for the family continues for a year or more. Men often remarry quickly to avoid grieving, but hospice helps surviving spouses and other loved ones manage better than that by offering individual grief counseling, information about coping strategies and support groups.

The hospice period gives people an opportunity to finish up their life business and let go of loved ones in a way they can feel good about, Schumacher says. "When people have those final conversations, they can become very close. It's a very intimate process, and it's unique to each person."

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