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Hospice Care: What Is It, Anyway?

Seeking Shelter

The word hospice originated from the Latin *hospitium*, which means “to host or offer a place of shelter.” In 2009, an estimated 1.56 million patients, more than 40 percent of deaths, received hospice services in the United States. But many others who might have benefited from hospice care did not seek services, perhaps due to misconceptions, fears and the lack of information of patients, caregivers and even physicians.

“Hospice is a collection of services that are designed to support the patient and family through the course of a serious or terminal illness,” said Donald Schumacher, Psy.D, president and CEO of the National Hospice and Palliative Care Organization (NHPCO). The aim of hospice is to provide physical and emotional care and comfort in the months, weeks and days before death.

It’s often hard for patients and their loved ones to acknowledge that the time to consider hospice care has come. People come to that realization differently and there are some that might never seem to face that the end of life is near. But through the ups and downs of emotions and physical status, hospice team members are prepared to help patients and their families with sensitivity and flexibility.

Renata Rafferty, a consultant and author, used hospice services at home initially to assist her in caring for her husband, Jerome, diagnosed with Lewy Body dementia. “Once hospice got involved and came to us at home, it was anything we needed,” she recalls. She says that one of the major benefits of hospice was the education provided about what to expect before Jerome’s death.

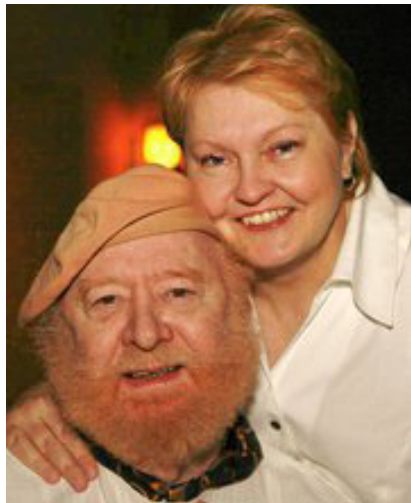
Locate a Hospice Agency

- U.S. Administration on Aging (<http://www.eldercare.gov/>)
- National Hospice and Palliative Care Organization (<http://www.nhpco.org/>)
- Hospice Foundation of America (<http://www.hospicedirectory.org/>)
- National Association for Home Care and Hospice (<http://www.nahcagencylocator.com/>)
- Visiting Nurse Associations of America (http://vnaa.org/vnaa/g/?H=HTML/Find_a_VNA.html)

When they signed on to hospice, a nurse brought them a booklet about what to expect, including common physical actions and behaviors, when someone is dying, Rafferty said. “When those things started happening, I was very comfortable rather than afraid,” Rafferty said.

Hospice services typically involve care from a hospice team that includes a physician, nurse, medical social worker, and nutritional, pastoral and other counselors. Hospice patients also may receive home health care services, medical supply deliveries and physical, occupational and speech-language therapy.

For caregivers and families, hospice services don’t end with the patient’s death. Alan Guinn, a management consultant from Bristol, Tenn., lost his mother to breast



Jerome and Renata Rafferty

cancer. Guinn notes that the counseling provided to him after his mother's death helped him address many of his concerns.

"Very few people ever go through the loss of a loved one without asking, 'What could I have done differently?' Hospice workers help to alleviate the concern that you

didn't do the right thing, or you didn't do enough, or you did too much. They help you understand that what you do, or did, or wanted to do — but didn't — was probably the right thing to do for you and for your loved one," Guinn says.

Hospice and Palliative Care Options

Although the terms hospice and palliative care are often used together, their meanings differ. *Hospice care* generally refers to care received during the period of time when a patient has stopped seeking treatment for a life-threatening illness or when more treatment is extremely unlikely to prolong life.

Palliative care provides therapies and medications that are designed to make patients more comfortable and ease the symptoms of serious illnesses or conditions—care designed to improve the quality of daily life. Palliative care relieves pain, addresses breathing difficulties, severe nausea, fatigue and emotional symptoms such as depression and anxiety at any stage of a life-threatening disease or illness.

Though palliative care is always a part of hospice care, palliative care can happen at any point during the course of an illness.

In the 1960s, hospice care was most frequently provided to people who were dying of cancer — where the prognosis was clear and few if any treatments were left to offer. At that time, "palliative care" was given in those late stages of illness. But the focus of palliative care has since evolved: it is often now given earlier in the course of a disease, and is sometimes appropriate while patients are still receiving treatment for that disease.

"It can happen at the beginning of a diagnosis or early on in the disease process. Palliative care is about symptom and pain management, but also about psychosocial and emotional and spiritual support that goes along with having a serious illness," says Judith Redwing Keyssar, R.N., an end-of-life care expert and director of the palliative care program of the San Francisco-based Seniors At

Hospice and Palliative Care Info

- American Society of Clinical Oncology: Advanced Cancer Care Planning (<http://www.cancer.net>)
- Hospice and Palliative Nurses Association (<http://www.hpna.org/>)
- National Institute of Nursing Research: Palliative Care (<http://bit.ly/igYnjw>)
- Palliative Care Policy Center (<http://www.medicaring.org/>)
- Last Acts of Kindness (<http://www.lastactsofkindness.com/>)

Home, a division of Jewish Family and Children's Services.

Most hospice patients receive relatively short periods of care. The average length of a hospice stay was only 69 days in 2009, according to the latest statistics from the NHPCO.

Patients may delay enrolling in hospice care because they want to continue what they hope will be life-sustaining treatments, because they don't know what hospice is or because they're concerned about the cost of hospice care, reports the American Geriatrics Society.

Generally, for insurance companies or Medicare to pay for hospice benefits, a person must have a predicted life expectancy of less than six months. But signing onto hospice is neither a permanent contract nor a death sentence; it doesn't mean you're going to die tomorrow. "It simply means you meet the criteria to receive this benefit" says Kathryn Gurland, a licensed clinical social worker and cancer navigation consultant with PEG'S Group in New York City.

"A lot of times people think hospice is provided at a specific place, but we can provide care at home, assisted living facilities, nursing homes and in acute care settings," says Nancy Kraft, R.N., director of clinical services for Covenant Home Care in Reading and Pottsville, Pa. More than two-thirds of hospice patients receive care at home, according to the NHPCO.

In a hospital-based hospice program, a special unit is reserved for hospice patients and their caregivers and families, who have access to support services and social workers, chaplains and other professionals to help them deal with the emotions and stress of a terminal illness. Nursing homes and long-term care facilities may also offer hospice services. Stand-alone hospice centers are another option in some communities. Those facilities provide hospice care only for patients with life-threatening illnesses, in a home-like environment.

“Families are often managing distressing psychological and emotional symptoms on their own, with some support from a primary care doctor, but with not a lot of support with issues related to terminal illness. What they generally get [with hospice] is a whole menu of people — doctors, nurses, social workers, speech and dietary, pastoral care — designed to meet all of the patient’s needs,” Schumacher says.

Who pays for hospice? For patients who qualify for Medicare, the hospice benefit pays for home and inpatient care and services not normally covered by Medicare. At little or no financial cost, patients receive care from nurses, doctors, and other members of the hospice team, as well as supplies like walkers and medical beds. Medicare is the primary payer for more than three-quarters of hospice patients.

Most employer or private health insurance plans also include a hospice-care benefit, although they may pay primarily for home care and services and offer limited coverage for inpatient care.

For some people, especially those in rural areas, hospice options may be limited. A lack of qualified hospice staff and family caregivers, limited hospice programs and greater expenses for travel may restrict hospice choices in some communities. Talk to your doctor about nearby hospice resources. Also, because your state health department handles certification of hospice services, they might help you find local agencies to provide assistance.

Making Decisions

Making the decision to use hospice care typically occurs after a physician informs the patient that more aggressive treatments are unlikely to prolong life and may even make remaining days more difficult. A doctor may suggest to families that the extra care offered by hospice may alleviate pain and provide much-needed support with daily challenges.

“Generally, more than 50 percent of referrals come from primary care physicians. During a course of treatment, the primary care doctor might say, ‘In all likelihood there is no cure, we’re going to recommend hospice care for you,’” Schumacher says.

Patients often wonder whether entering hospice means they can still receive care from their primary care doctor, says Elizabeth Metz, R.N., director of community outreach and program development for Covenant Home Care.

“When you accept the hospice benefit, it doesn’t mean you automatically have a different doctor. Most people have a doctor whom they have known, but some hospices have the option to allow the hospice medical director to be the doctor of record. That doctor has specific expertise in pain and symptom management, whereas often a person’s primary care M.D. or oncologist does not necessarily have this expertise,” Keyssar says. A patient can also receive care from their primary physician in collaboration with the hospice team.

The first few days of hospice can be intense, with visits from new care team members such as admissions nurses, doctors, home health aides, medical supply deliveries, chaplains and even volunteers. But the sooner a patient signs up for hospice, the greater the improvement the hospice team can make in his or her quality of life, Gurland says. And greater support will be more readily available to the family/caregivers.

Though patients enrolled in home hospice care receive weekly or more frequent visits from a nurse and other members of the hospice team, caregivers still provide most of the care. “Patients assume they’re going to have round-the-clock care at their bedside, which is not true in most states,” Keyssar says.

After Rafferty’s early-morning call to the hospice and a talk with the hospital chaplain, she realized that having access to the medical equipment and round-the-clock care of a hospice facility would help Jerome be more comfortable — and relieve some of her emotional and physical burden, too. Once she made the choice to transfer Jerome to the hospice facility, she could finally relax in the home-like atmosphere there.

“It gave me some relief. From a caregiver’s standpoint, it meant that I could leave the room to go to the bathroom or leave to make a phone call to a family member and know that he was cared for,” Rafferty says. Jerome died in the hospice facility five days after admission.

What Hospice Nurses Do at a Home Visit

What can you expect when a hospice nurse knocks on your door? Here are some of the activities he or she might do during typical home-based care:

- Greet patient and caregiver(s); the nurse may offer support to the patient and caregivers privately during the course of the visit.
- Ask about appetite, energy levels and whether patient is experiencing pain or symptoms.
- Take patient’s blood pressure level, heart rate, weight, and other vital signs.
- Ask if medications seem to be helping or if they are causing problems.
- Assist patient and caregiver in obtaining medical supplies or equipment needed at home.
- Offer advice to caregiver and patient about what to expect next in disease process and when/how to request for special assistance.
- Listen to patient’s and caregiver’s emotional concerns and suggest/arrange assistance from a social worker or pastoral care.

I Wish I'd Known

Regardless of the type of hospice people choose, talking openly about the process and the patient's wishes and expectations is critical. "You know the saying about death and taxes? We review our taxes every year, but often we don't even discuss death or dying and what that might look like in any regular way. It's important to determine what we want," and talking about hospice options and end-of-life planning helps people do that, Keyssar says.

Determining what you want extends to the hospice organization you choose, too. To get started with the hospice process, talk to your doctor about his or her hospice recommendations and experiences. Rafferty recommends asking members in your faith community for local hospice recommendations. Or you can use a hospice locator to find organizations in your area. (See Sidebar: Locate a Hospice Agency)

If you and your family are considering hospice care, above all, remember that your choices, needs and wishes are paramount, experts say. "If families are not satisfied with their hospice team, they have the option to choose another hospice," Gurland says.

"What sets hospice apart is that it's a patient-driven model. If you only want a little assistance, that's what we'll do. If you need a lot of assistance, then we'll do that as well," Gurland says.

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