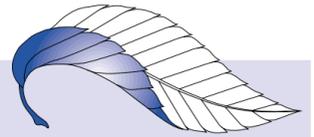


STEVEN ROSENBERG/KRT

Hospice volunteers Jim and Toni Hodapp have established such close relationships with the dying patients they have cared for that they've attended each of their funerals. "I have had so many family members tell us they couldn't have kept their husband or wife at home if it hadn't been for hospice," says Toni, who has volunteered for 15 years.



FINDING YOUR WAY

WEB SITES

National Hospice and Palliative Care Organization, (703) 837-1500: Offers a hospice database and provides statistical and educational material about hospice care. Or call the toll-free HelpLine at (800) 658-8898 to find a hospice near you. www.nhpco.org

National Hospice Foundation, (800) 338-8619: Consumer-oriented site, with tips for communicating end-of-life wishes and guidelines for choosing a hospice program. www.hospiceinfo.org

HospiceWeb: Offers a message board, a list of frequently asked questions about hospice and links to numerous hospice-related sites throughout the world. www.hospiceweb.com

American Academy of Hospice and Palliative Medicine, (847) 375-4712: Includes a selection of links to general hospice informational sites. www.aahpm.org

The Hospice and Palliative Nurses Association: Check on background and credentials for hospice nurses. www.hpna.org

Hospice Foundation of America, (800) 854-3402: The site does not have a searchable database but does provide guidelines for choosing hospice, tips for dealing with grief and other consumer resources, such as a collection of hospice readings and Web links. Call the foundation to find a hospice near you. www.hospicefoundation.org

American Hospice Foundation, (202) 223-0204: Includes a collection of articles with practical information for the dying or the grieving. Offers "Grief at School Training Guide & Video" to help teachers respond to grieving children and choose on-site training workshops. www.americanhospice.org

Project on Death in America: Supports programs that illuminate the social and medical contexts of dying and grieving. www.soros.org/death.html

Children's Hospice International: A nonprofit organization that provides a network of support and care for children with life-threatening conditions and their families. www.chionline.org

BOOKS

"The Hospice Handbook: A Complete Guide," by Larry Beresford (Little and Brown, 1993; \$14.95).

"Hospice: Practice, Pitfalls, and Promise," by Stephen Connor (Taylor & Francis, 1998; \$28.95).

"All Kinds of Love: Experiencing Hospice," by Carolyn Jaffe and Carol Ehrlich (Baywood, 1997; \$29.95).

"The Hospice Choice: In Pursuit of a Peaceful Death," by Marcia Latanzi-Licht, John J. Mahoney and Galen Miller (Simon & Schuster, 1998; \$12).

"Handbook for Mortals: Guidance for People Facing Serious Illness" by Dr. Joanne Lynn (Oxford University Press, 2001; \$15.95).

For more resources, go online to www.findingourway.net

ABOUT THE AUTHOR

Dr. Stephen R. Connor is vice president for research and professional development at the National Hospice and Palliative Care Organization in Alexandria, Va. He has published journal articles, reviews, and book chapters on issues related to the hospice movement and the care of dying patients and their families. He is the author of "Hospice: Practice, Pitfalls, and Promise."



The core of caring

Hospice offers end-of-life guidance for patients and their loved ones

BY STEPHEN R. CONNOR

When a hospice nurse walks into the home of a person facing life's most intimate passage, one of the more crucial questions he or she will ask is: What are your hopes and fears?

That question is at the core of what hospice care is all about.

Hospice nurses are the doorway to an end-of-life care system that includes doctors, social workers, chaplains, home health care aides and trained volunteers. They work together to answer any and all of their dying patients' needs, be they physical, psychological or spiritual. The goal is to help keep patients as pain-free — and lucid — as possible, with loved ones nearby, until death arrives.

There is no typical patient at the end of life. "Each person is unique, therefore their care needs to be uniquely tailored," said Mary Raymer, chair of the social work section for the National Hospice and Palliative Care Organization in Alexandria, Va.

But patients do share many concerns, said Raymer. "The most common concerns people express are fear of becoming a burden to others, loss of control, loss of dignity and choice, finding meaning in their lives, spiritual concerns — in short, not necessarily the physical component of dying but the psychosocial component."

That's why hospice care serves both patients and families. Workers concentrate on providing pain medication and relief for nausea and other symptoms, all the while working to help the patient deal with the effect their dying will have on their loved ones. Team members provide spiritual counseling, help work out arrangements for dependents, answer caregivers' questions and make themselves available 24 hours a day, seven days a week.

Sandi Sunter, a hospice counselor for 20 years at The Hospice of the Florida Sun-coast, discovered the comfort her profession can provide when her mother, 81-year-old Eleanor Goldstein, became a hospice patient there, later succumbing to bladder cancer.

"In a society where the end of my mother's life could have been met with cold tubes, heartless machines and strangers, her choice of hospice allowed her to be the author of her own end-of-life story. ... I experienced the value of hospice in transforming the end-of-life journey for my mother and for our family. As patients and families come together, sharing this bittersweet chapter of life, hospice offers hope."

One couple who found this hope last year was Christie Cohagen and her husband, Pat Towell, of Falls Church, Va. Christie, 49, a government analyst, was suffering from incurable cancer when she entered Hospice of Northern Virginia last August.

For the next month, which was to be the last of Christie's life, Pat learned how to care for his wife of 15 years in their home, with

Starting the search

Most Americans don't know what hospice is, according to research conducted by the National Hospice Foundation. Nearly 75 percent don't know that hospice care can be provided at home and less than 10 percent know it provides pain relief for the terminally ill. Nearly 80 percent don't think of it as a choice for end-of-life care and 90 percent don't know that Medicare pays for it.

Here are questions to ask when you're looking for a good hospice program:

- What services does hospice provide?
- What kind of support is available to the family/caregiver?
- What roles do the attending physician and the hospice physician play?
- What does the hospice volunteer do?
- How will hospice meet spiritual and emotional needs?
- How does hospice work to keep the patient comfortable?
- How are hospice services provided after hours?
- How and where does hospice provide short-term inpatient care?
- Can hospice be brought into a nursing home or long-term care facility?

For patients with no insurance coverage whose family or loved ones can't provide primary care, will the hospice work with the family to care for the patient at home or move him to another setting?

Medicare and private insurance, including new long-term care policies, cover many, if not most, hospice services for anyone with a terminal illness, including cancer and non-cancer diseases. While you should check with your insurance provider for specifics on your coverage, here is a list of what Medicare covers. New long-term insurance policies also may cover these caregiving expenses when Medicare doesn't.

- Physician services for the medical direction of the patient.
- Regular home visits by registered and licensed practical nurses.
- Home health-aide and homemaker services, such as dressing and bathing.
- Social work and counseling services.
- Chaplain services for the patient and loved ones, if desired.
- Medical equipment, such as hospital beds.
- Medical supplies, such as bandages and catheters.
- Drugs for symptom control and pain relief.
- Volunteer support to assist patients and loved ones.
- Physical therapy, speech therapy, occupational therapy, and dietary counseling.

— Stephen Connor

the help of the hospice team. Christie's wishes were respected: She was cared for by Pat and a close circle of longtime friends, surrounded by her books and mementos of world travel.

A week before Christie died, some of her work friends came to the townhouse with a T-shirt they all had signed.

"This really perked her up," Pat says. "Her last lucid time was seeing how much those around her cared about her."

After Christie's death, Pat became eligible for bereavement counseling, a service provided by hospices for each family member for at least a year after a patient's death. "I know they are there for me," says Pat.

Considered a radical alternative in the 1970s when the first American hospices were established, hospice has become the most recognizable care offered specifically at the end of life. It became part of the Amer-

ican medical mainstream when the hospice Medicare benefit was enacted in 1982. Last year, 700,000 Americans moved through hospice, most cared for at home, though also in nursing facilities and hospitals. More than 3,000 programs are available throughout the United States.

Yet hospice remains widely misunderstood and under-used. Some doctors — reluctant to admit defeat against illness — may put off referrals to hospice care until their patient is very close to death.

The typical hospice patient is served less than one month — usually not long enough to put affairs in order, say goodbyes to family and friends, create memory tapes or books for loved ones, or simply enjoy a favorite view out the back window while free from pain, tubes, aggressive drugs and tests.

Although Medicare fully covers hospice care, doctors need to establish a prognosis of

less than six months to live for their patient. If a hospice patient lives longer than six months, Medicare will allow the hospice benefit to be renewed.

Dr. William Lamers, a psychiatrist who started one of the country's first hospices in California in the early 1970s, said, "People should not be afraid to ask their doctors for hospice care sooner."

"Pre-hospice" programs are being developed throughout the United States in which patients with chronic, severe conditions — but who do not yet have a six-month prognosis — are treated as if they were in hospice care, with visits by a team looking at all their needs.

Another factor is a basic misapprehension about what hospice is. A National Hospice Foundation survey shows that 75 percent of Americans don't know that hospice care can be provided at home and 90 percent don't realize that Medicare pays for it. Yet, the same national research results show that Americans want the kind of end-of-life care hospice provides.

Because round-the-clock, hands-on care is such a vital part of the hospice experience, hospice can provide trained volunteers, who relieve primary caregivers, do household chores and help bathe patients. Perhaps most important, says Jim Hodapp, a 76-year-old volunteer in Rockford, Ill., "is to be a good listener," whether it is to the dying person or their worried family.

Hodapp, a retired electrical engineer, began volunteering five years ago, joining his wife, retired nurse Toni Hodapp, 73, a hospice veteran of 15 years.

"Most hospice patients are very interested in talking about themselves," says Jim. "I've found out most are quite frightened of dying."

Because of the relationships Jim and Toni build with their patients, they attend each patient's funeral. They've found their attendance is just one of many hospice services greatly appreciated by the family.

"I have had so many family members tell us they couldn't have kept their husband or wife at home if it hadn't been for hospice," says Toni.

Jim has had one patient die in his presence. The man was alone, in a nursing home. As Jim held the man's hand, he noticed him breathing very rapidly. Gradually, Jim says, the man's gaze shifted to the distance, his eyes opened wide, and then his breathing stopped.

Had Jim not been there, the man — whose daughter had not yet arrived — would have died alone.

Again, this compassion lies at the core of hospice. Jim says that while his friends say they don't think they could do this type of work, he believes it "is one of the best things I have ever done. It is very rewarding."

For more resources and contacts on end-of-life issues, go to www.findingourway.net.