

CONTENTS

Web Exclusive: Understanding Hospice

BY THE AMERICAN HOSPICE FOUNDATION

Hospice care or palliative care: What's the right care for me?

Each year, about a million families facing life-threatening illness struggle to make the critical decisions that affect the quantity and quality of life: What's the best treatment for me? Where do I find it? What is too much or too little? How do I keep myself and my family whole— physically, emotionally, spiritually?

Many Americans find the answers through hospice care and palliative care, two terms that have redefined choices for a generation of critically ill individuals and their loved ones. Before the American hospice movement began to bloom in the late 1970s, patients and families were usually told what was best for them to do and they did it; there was no other choice. They accepted that the only place to be very sick was a hospital, the only people wise enough to make decisions and provide care were doctors and nurses, and that pain and isolation were often an expected part of the journey.

Hospice changed all that. The wise people who pioneered a healthcare revolution taught us that each unique human being can instead shape his or her final months according to personal wishes, goals and beliefs. This part of life called dying can be rich and comfortable when loved ones are helped to participate in making decisions and giving care. State-of-the-art medicine can be more than just curative treatment; its focus can also be on alleviating pain and other troubling symptoms. What makes hospice a reality is a team of profoundly skilled and committed clinicians with a vision of great, rewarding end-of-life care.

Since its introduction in 1974, hospice care has been embraced by millions of families coping with terminal illness and by insurers who recognize that hospice is cost-effective. The Medicare Hospice Benefit—the best deal in Medicare—covers virtually all expenses. Most private insurance plans and managed care organizations also offer some type of hospice coverage, usually when physicians certify a six-months-or-less life expectancy.

Over the years, many people have discovered that the hospice experience is exactly what they need in the last stage of life. Could this model be expanded to

serve others? The same principles that improve end-of-life care could also make a difference earlier in the disease process, before the determination of life expectancy can be made. Even as active treatment continues, needs for symptom management, family support, and education must be met.

In response to these needs, hospital-based palliative care programs emerged in the early 1990s. Palliation is relieving or alleviating symptoms without affecting the disease process, and while there have been elements of palliative care in most good treatment plans, today's well-defined programs are new to our healthcare system. No longer just an abstract concept, palliative care is now a carefully structured system for healthcare delivery.

The goal of modern palliative care, for persons at any stage of a serious illness, is to achieve the best quality of life for patients and their families, consistent with their values. This care, which may be given even while curative treatment is underway, includes expert symptom management, support for caregivers, and access to therapies that can improve comfort and peace of mind.

A good palliative care program coordinates patient care across multiple locations and providers. Since critically ill people often have a primary physician, at least one specialist, home care personnel and perhaps other therapists, they may, within a short period of time, be at home, the physician's office, a hospital, a nursing home, an ICU and a rehabilitation facility. It is no surprise that family caregivers often become overwhelmed and feel alone in trying to hold it all together. Palliative care programs work to ensure continuity consistent with patient and family goals. Although Medicare or insurance plans may cover some individual palliative care services, to date there is no specific, broad coverage like the Medicare Hospice Benefit for palliative care programs.

The impact of hospice and palliative care is shaping the career field for physicians, nurses and other healthcare professionals. Highly qualified registered nurses can become Certified Hospice and Palliative Care Nurses, and the American Board of Medical Specialties is preparing to offer physician certification in hospice and palliative medicine as a subspecialty. Healthcare consumers will soon be able to look for certifications as signs of clinical excellence in this unique field.

So what's the difference? When do we choose palliative care, or when do we choose hospice care? Indeed, palliative and hospice care programs share the same goals and values: physical, emotional and spiritual comfort; choices based on individual needs; respect and care for both patient and family; information to make the right decisions; continuity of care. Upon a diagnosis of a persistent, debilitating and life-limiting illness, we can ask to include palliative care in the treatment plan at any time. Early introduction to palliative care will help clarify goals and ensure that they will be followed, no matter who is providing the care and where it is delivered. In the later stages of the illness, patient and caregiver needs will increase. The time for hospice is now, taking advantage of Medicare and insurance coverage for a concentrated level of experienced, compassionate care.

When treatment-for-cure no longer offers hope for a good life and death is expected, hospice professionals provide palliative care... and more. They are the specialists in end-of-life care, uniquely able to help patients and families

maximize living even as they grieve the coming loss, ensure freedom from pain while preserving awareness and a sense of control, and recognize gifts and blessings even as the final days approach. Hospice enables families to say confidently, “We couldn’t have hoped for more.”

The Common Myths of Hospice

Myth #1: *Hospice is a place.*

Hospice care takes place wherever the need exists—usually the patient's home. About 70 percent of hospice care takes place where the patient lives.

Myth # 2: *Hospice is only for people with cancer.*

More than one-half of hospice patients nation-wide have diagnoses other than cancer. In urban areas, hospices serve a large number of HIV/AIDS patients. Increasingly, hospices are also serving families coping with the end-stages of chronic diseases, like emphysema, Alzheimer's, cardiovascular, and neuromuscular diseases.

Myth #3: *Hospice is only for old people.*

Although the majority of hospice patients are older, hospices serve patients of all ages. Many hospices offer clinical staff with expertise in pediatric hospice care. Almost 20 percent of hospice patients are under 65 years of age.

Myth #4: *Hospice is only for dying people.*

As a family-centered concept of care, hospice focuses as much on the grieving family as on the dying patient. Most hospices make their grief services available to the community at large, serving schools, churches and the workplace.

Myth #5: *Hospice can only help when family members are available to provide care.*

Recognizing that terminally ill people may live alone, or with family members unable to provide care, many hospices coordinate community resources to make home care possible. Or they help to find an alternative location where the patient can safely receive care.

Myth #6: *Hospice is for people who don't need a high level of care.*

Hospice is serious medicine. Most hospices are Medicare-certified, requiring that they employ experienced medical and nursing personnel with skills in symptom control. Hospices offer state-of-the-art palliative care, using advanced technologies to prevent or alleviate distressing symptoms.

Myth #7: *Hospice is only for people who can accept death.*

While those affected by terminal illness struggle to come to terms with death, hospices gently help them find their way at their own speed. Many hospices welcome inquiries from families who are unsure about their needs and preferences. Hospice staff are readily available to discuss all options and to facilitate family decisions.

Myth # 8: *Hospice care is expensive.*

Most people who use hospice are over 65 and are entitled to the Medicare Hospice Benefit. This benefit covers virtually all hospice services and requires

little, if any, out-of-pocket costs. This means that there are no financial burdens incurred by the family, in sharp contrast to the huge financial expenses at the end of life which may be incurred when hospice is not used.

Myth # 9: *Hospice is not covered by managed care.*

While managed care organizations (MCOs) are not required to include hospice coverage, Medicare beneficiaries can use their Medicare hospice benefit anytime, anywhere they choose. They are not locked into the end-of-life services offered or not offered by the MCOs. On the other hand, those under 65 are confined to the MCOs services, but most provide at least some coverage for hospice.

Myth # 10: *Hospice is for when there is no hope.*

When death is in sight, there are two options: submit without hope or live life as fully as ever until the end. The gift of hospice is its capacity to help families see how much can be shared at the end of life through personal and spiritual connections often left behind. It is no wonder that many family members can look back upon their hospice experience with gratitude, and with the knowledge that everything possible was done toward a peaceful death.

Hospice Care or Palliative Care: What's the Right Care for Me? is reprinted with permission from the American Hospice Foundation. © 2009 American Hospice Foundation. "The Common Myths of Hospice," excerpted from *Debunking the Myths of Hospice*, is reprinted with permission from the American Hospice Foundation. © 1999 American Hospice Foundation. All Rights Reserved. Additional information is available at American Hospice Foundation's website at www.americanhospice.org.