

Debunking the Myths of Hospice

Naomi Naierman
President and CEO, American Hospice Foundation



What Hospice Means

Having access to hospice and the Medicare hospice benefit means that comprehensive care at the end-of-life does not have to be expensive or burdensome. Hospice means that we can die in comfort and dignity in our own home, with the support of and under the supervision of a coordinated team of professional staff and volunteers. Family members, too, will be supported in their care giving roles and in their grief.

Hospice is a set of services that we all may need someday-if not for ourselves, for our parents. Although death is not an option for any of us, we do have choices about the services we use at the end of life. Hospice is undoubtedly one of the best options in the last months of life because it offers a variety of benefits, not only to those of us who are dying, but also to those we leave behind.

Yet, despite its many advantages, hospice is still a mystery to most Americans 25 years after its introduction in this country. That hospice remains a mystery is due in part to our society's resistance to discussing matters related to death. Also responsible is the federal government's poor performance in educating the public about the Medicare hospice program instituted in 1983. In addition, it is fair to say that, as a whole, hospices have not been effective in raising the public awareness about hospice.

Now, more than ever, there is a sense of urgency to dispel the myths and to learn as much as possible about hospice. Otherwise, we will participate, albeit inadvertently, in the erosion of hospice and its benefits. The threats to hospice are undeniable, and they come from many directions. Among those

threats is the reluctance of policy-makers to use the word hospice, relying instead on words such as palliation or palliative care. As a result, even before hospice becomes a commonly understood concept, it could well disappear from our language.

Hospice programs throughout the country are facing a decrease in use of services due to government constraints. The federal government arbitrarily restricts hospice care to those whose death is six months away or sooner. Although the timing of death is difficult to predict, hospices are being held accountable for accepting patients who outlive their six-month prognosis. Physicians, who in general refer patients to hospice only reluctantly, are increasingly more wary of government oversight of their prognostic decisions and their pain management practices. As a result, people who qualify for hospice care are referred too late, or not at all.

Managed care organizations (MCOs) may also create barriers to hospice. Most MCOs do not have financially rewarding arrangements with hospices; consequently, referring patients may mean financial losses, whereas using the MCO's own home health services

may be financially more attractive. This situation constitutes a biased incentive that may not be favorable to dying patients.

Another threat to hospice is physician-assisted suicide, which could be all too readily substituted for hospice care, especially if dying people are not offered the hospice alternative in a timely way. Without the pain relief, emotional support, and spiritual guidance that hospice offers, physician-assisted suicide may look like a reasonable alternative to dying people in distress.

Ultimately, however, a public that is clueless about hospice is the most serious threat to the long-term survival of hospice in America. If we are not fully aware of the many beliefs of hospice, we become prey to the vagaries of the healthcare system. On the other hand, if we are informed about the hospice concept, its comprehensive services, and its financial aspects, we can more fully participate in the decisions that doctors and policy-makers are making on our behalf. If we learn about hospice, we can work to preserve it for the time that we, or someone we love, may need it.

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Common Myths of Hospice 1

To learn about hospice, it is useful to start by debunking the common myths that in themselves create barriers to hospice.

Myth #1. Hospice is a place.

Hospice care takes place wherever the need exists--usually the patient's home. About 80 percent of hospice care takes place in the home.

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

More than one-fifth 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, such as 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.

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 patients. Most hospices make their grief services available to the community at large, serving schools, churches, and the workplace.

Myth #5. Hospice can help only when a 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 few, if any, out-of-pocket expenditures. This coverage reduces the family's financial burdens, and hospice care can be far less expensive than other end-of-life care.

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

Although 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 end-of-life ser-

vices offered or not offered by the MCOs. On the other hand, those under 65 are confined to the MCO's services, but are likely to gain access to hospice care upon inquiry.

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 that often are not made. 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.

What is Hospice?

Hospice includes medical care with an emphasis on pain management and symptom relief. Hospice teams of professionals and volunteers also address the emotional, social and spiritual needs of the patient and the whole family. Overseeing all patient care is the hospice medical director who may also serve as the attending physician. Alternatively, the patient's own physician may continue in this role, in coordination with the hospice team and its plan of care.

Medical Care

Pain management is of particular concern for a patient with a life-threatening illness. Hospice staff are the experts in state-of-the-art pain treatments, helping patients feel comfortable with pain management alternatives. If administering pain medication at home requires a new skill, family members can count on the hospice staff for training and guidance.

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Most medical treatment needed to make a terminally ill patient physically comfortable can be provided at home. Recent technology advances allow for a wide variety of equipment to be installed in the home, thus reducing the need for hospitalization, except in the most complicated cases. In rare cases when symptoms cannot be controlled at home, inpatient facilities are available.

Emotional and Spiritual Support

The fear of death can be due to the fear of pain and abandonment. Hospice staff include bereavement and spiritual counselors who help patients and families come to terms with dying. They assist patients in finishing important tasks, saying their final good-byes, healing broken family relationships, distributing precious objects, and completing a spiritual journey.

Unfinished business can make dying harder and grieving more difficult for those left behind. Hospice staff recognize that a person who comes to terms with dying has a less stressful death, and that the family benefits from a less complicated grieving process. A source of relief and comfort for many hospice patients is the knowledge that the family will receive ongoing bereavement support.

Practical Considerations

The day-to-day chores of life can become overwhelming for family caregivers. Hospice staff can teach them to care for the dying person at home; family members learn how to administer medications, operate equipment, and coordinate service. Volunteers are integral members of the hospice staff, pro-

viding companionship and assistance in household chores.

Financial Concerns

Financial worries can be a major burden for a patient facing a terminal illness. Most hospice patients are Medicare participants with ready access to a hospice benefit that minimizes out-of-pocket expenses in the last months of life. The Medicare hospice benefit covers prescribed medications, visits by medical and nursing professionals, home health aides, short-term inpatient care, and bereavement support for the family after the patient has died. The Medicare hospice benefit also eliminated the burden of paperwork, as families are not required to submit claims or pay bills. For patients without hospice insurance, financial accommodations are made based on the ability to pay.

Hospice: The Challenge to American Healthcare Consumers

Hospice as a concept suffers from a powerful denial syndrome in our society. Hospice must be better understood if it is to reach all who need it. When all Americans know what hospice is, they are more likely to make it an explicit part of their long-term plans, and their fear of death will be abated. Increased visibility of hospice locally and nationally will result in more people becoming active advocates for themselves and for their families.

What Lack of Hospice Knowledge Can Mean

if you don't know all about hospice, you may...

...die in pain, especially if you are

in the hospital or in a nursing home. Studies show that a majority of people who die in these institutions die in pain. People die in pain because hospital and nursing home staff often lack adequate skills in pain management. Hospice staff are the experts in pain management and can virtually guarantee a comfortable death.

...be sent home from the hospital with home health services that are not comprehensive and are not provided by staff trained in end-of-lifecare. For example, prescription drugs, which are not covered by Medicare under home health care are especially costly.

...have difficulty getting hospice care if you live in a nursing home. You have a right to hospice care, regardless of where you live. And, if you are over 65, you are entitled to a comprehensive hospice benefit.

...leave behind family, friends, and relatives without support through their mourning period. Only hospice programs offer this support free of charge for at least a year after the death.

¹Adapted from Naiermman, Naomi and Turner, Jo. A. "Demystifying Hospice," AAPA News, July 15, 1009, p.7.

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Partnership for Caring: America's Voices for the Dying is a national non profit organization devoted to raising consumer expectations for excellent end-of life care and increasing demand for such care. It is the only end-of-life organization that partners individuals and organizations, consumers and professionals in a powerful collaboration – joining their voices to demand that we improve how dying people and their loved ones are cared for within our society. Partnership for Caring has a dual focus: we provide service for individuals and we work for societal change. Services include:

- A unique national hotline to answer questions and/or respond to patients and loved-ones in end-of-life crises;
- Printed and video education resources to help members of the public and professionals think about end-of-life planning and decisions;
- Advance Directives (living wills and medical powers of attorney) for every state;
- Quarterly newsletter, Voices, which highlights important developments affecting end-of-life care and provides education and tools for improving care;
- Legal tracking of law and policy affecting end-of-life care;
- Web Site resources that address various end-of-life issues.

For more information contact:

Partnership for Caring

800.989.9455 (24-hour hotline)

202.296.8071

pfc@partnershipforcaring.org

www.partnershipforcaring.org