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## **Debunking the Myths of Hospice**

Hospice is a set of services that we all may need someday — if not for ourselves, for our parents. While 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 the best option in the last months of life because it offers a whole 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 to this country. That hospice remains a mystery is due in part to our society's resistance to discuss matters related to death. Also accountable is the Federal Government's poor performance in educating the public about the Medicare hospice program instituted in 1983. It is also 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 policymakers' reluctance to use the word "hospice," and instead rely on words like palliation or palliative care. So, 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 on whole, 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, so referring patients

may mean financial losses. In contrast, using the MCOs own home health services may be financially more attractive. This represents a biased incentive that may not be favorable to the 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 on a timely basis. 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 hospice benefits, we become prey to the vagaries of the health care system.

If we inform ourselves of the hospice concept, its comprehensive services and its financial aspects, we can more fully participate in the decisions that doctors and policymakers 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.

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

## **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% 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 towards 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 requires a new skill, family members can count on the hospice staff for training and guidance.

Most medical treatments needed to make a terminally ill patient physically comfortable can be provided at home. Recent technological 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 is often due to the fear of pain and abandonment. Hospice staff includes bereavement and spiritual counselors who help patients and families come to terms with dying. They assist patients in finishing important tasks, saying their final goodbyes, 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 recognizes 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 — administer medications, operate equipment and coordinate services. Volunteers are integral members of the hospice staff, providing 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 eliminates 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 ability to pay.

Hospice: The Challenge to American Health Care Consumers

Hospice is easily confused with less attractive alternatives, and, as a concept, it suffers from a powerful denial syndrome in our society. Hospice must be better understood if it is to reach all those who need it. When all Americans know what hospice is, they will not only make it an explicit part of their long-term plans, but their fear of death will be abated. Increased visibility of hospice, locally and nationally, will result in more people becoming pro-active advocates for themselves and their families.

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