



Talking About Hospice Tips for Nurses

A PUBLICATION OF THE AMERICAN HOSPICE FOUNDATION

Talking About Hospice challenges nurses to discuss hospice with patients well before the brink of death and to make it a comfortable part of patient education. Patients can benefit from information about hospice even if they do not face a life-threatening illness. Before the stress of a medical crisis, early discussions about hospice can facilitate open communication, avoid late referrals, and provide patients a choice and a sense of control. For many people, acceptance of death is a step toward emotional and spiritual growth. Nurses can help patients make that step by discussing all options for care early in the progression of a terminal illness.

While hospice care is most effective over a period of months, half of all hospice patients in the U.S. die within one month after enrollment. During the last weeks or days, there may be time to control a patient's pain and stabilize symptoms, but there is little time or strength to address spiritual and emotional needs. On the other hand, an early referral to hospice gives patients time to say goodbye and reduces the chance that the family's grief will be prolonged and complicated.

Why Are Hospice Referrals So Late?

Patients may be referred to hospice late—or not at all—because discussions about end-of-life care are difficult. Barriers to hospice referrals may include:

- ◆ Discomfort with death and grief
- ◆ Sense of failure about inability to “cure”
- ◆ Hesitation about prognosis
- ◆ Perception that hospice is only a “last resort”
- ◆ Concerns that patients will feel abandoned
- ◆ Uncertainty about hospice clinical services
- ◆ Financial concerns
- ◆ Doubts that hospice offers hope to patients and families
- ◆ Case management approval delays

Talking About Hospice

Tips for Nurses

Hospice Is Comprehensive And Affordable Care

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 can serve as the attending physician. The patient's own physician may also serve in this role, working 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 experts in state-of-the-art pain treatments, helping patients feel comfortable with pain management options. If caregiving requires new skills, family members can count on the hospice staff for training and guidance.

Most medical care for patient comfort 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 hospice facilities are often available.

Emotional and Spiritual Support

The fear of death can be due to a fear of pain or abandonment. The hospice professional 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 goodbyes, healing broken family relationships, distributing precious belongings, and completing a spiritual journey.

“Unfinished business” can make dying harder and grieving more difficult for those left behind. Hospices recognize that a person who comes to terms with dying has a more peaceful 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 their family will receive ongoing bereavement support.

Practical Considerations

The day-to-day chores of life can become overwhelming for family caregivers. The 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 with household activities.

Financial Relief

Financial worry 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, medical equipment and supplies, 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. Virtually all other medical plans include some level of hospice coverage. For patients without hospice insurance, financial accommodations are made based on ability to pay.

Hospice Care Is Not Just For Cancer Patients

Although most hospice care is provided to cancer patients, hospice is also for patients with HIV/AIDS; advanced respiratory, cardiac, liver and kidney diseases; Alzheimer's Disease; Parkinson's Disease; Multiple Sclerosis; or Amyotrophic Lateral Sclerosis (ALS). Many hospices serve children as well as adults, and most communities have hospices that specialize in pediatric care.

Through my years as a hospice doctor, I have learned that dying does not have to be agonizing. When people are relatively comfortable and know that they are not going to be abandoned, they frequently find ways to strengthen bonds with people they love and to create moments of profound meaning in their final passage.

Ira Byock, M.D.

Hospice care is designed for terminally ill persons in a variety of living situations. The vast majority of hospice care is provided in the home, where a patient is surrounded by family, friends and familiar objects. Patients benefit from having a primary caregiver living at home, and many hospices have innovative programs for persons who live alone, or with a frail spouse or partner. Hospice care is increasingly available to adult care residents, as cooperative relationships grow among hospices, nursing homes, and assisted living facilities.

Hospice Care Is For Grieving People

A key component of comprehensive hospice services, grief counseling is offered to all family members during the illness and for about a year after the death. Most hospices offer bereavement support groups which are open to the community, and the hospice bereavement team welcomes opportunities to work with schools, employers and religious organizations.

Nurses can help patients recognize problems that may be related to unresolved grief. Common symptoms include apathy, fatigue, confusion or depression, withdrawal from family or friends, diminished job performance and loss of appetite. Grief can also be an underlying cause of alcohol or drug abuse. For children, grief may be a factor in poor school performance, behavioral problems and even serious depression. Local hospices can help with grief counseling services or referrals to community-based therapists with expertise in complicated grieving.

When To Introduce Hospice

Nurses know their patients best and can identify opportunities to introduce hospice as an option within the care continuum. The less urgent the occasion, the greater the opportunity for dialogue. Indeed, when its full benefits are highlighted, hospice can be discussed in a hopeful and constructive manner.

Nurses interested in fully supporting patients in end-of life decisions can initiate discussions about hospice when:

- ◆ Describing the general philosophy of care
- ◆ Presenting a continuum of care after a patient's life-threatening diagnosis
- ◆ Discussing a life-threatening illness a family member is facing
- ◆ Distributing patient education materials
- ◆ Responding to grief-related problems in the family

On each of these occasions, the discussion can take many directions. Below are suggestions for getting started:

- ◆ Describing the general philosophy of care:

We believe that patient comfort and quality of life are as important as curing a disease or prolonging life. When curative treatments no longer have the desired effect, we have found that hospice care is a good option because it offers patients an opportunity to stay at home and to make personal decisions about how to spend the time that remains. We work with local hospices that offer services, not only to people with a terminal illness, but also to families that need grief counseling. Most hospices extend their bereavement services to the whole community, so if there is a loss in your family elsewhere in the country, bereavement support is available to you right here at a local hospice.



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◆ Presenting a continuum of care after a patient's life-threatening diagnosis:

We have a number of options to choose from. Chemotherapy may eradicate the cancer, so you might want to start there. Next we could try You should also know about hospice, which cares for people at home if treatments don't help.

◆ Discussing a life-threatening illness a family member is facing:

Have you considered hospice services? We think it's a good idea to explore all possibilities, so that when you are faced with a crisis, you aren't looking around frantically for vital information.

◆ Distributing patient education materials:

Among the materials that you will receive are hospice brochures that describe available services and helpful concepts about advance planning. These materials may help you make decisions about end-of-life care which you could share with your family. It is important that you inform at least one person about your wishes, in the event you cannot speak on your own behalf.

◆ Responding to grief-related problems in the family:

Since there has been a recent death in the family, there are bound to be grieving adults and children who could use support and information. We suggest calling the local hospice for resources available to all community members. The hospice bereavement staff may even be willing to come to the school (or the workplace) to consult with the teachers (or supervisors). Hospice has grief experts who can provide advice, support and helpful reading materials.

In the End, It Comes Down To This...

A sensitive presentation about hospice care offers patients maximum choice at important life stages. Deferring discussions about hospice may deprive patients and families of comprehensive care at home, emotional support, spiritual resolution and financial protection.

Resources

Representatives from your local hospice are willing to meet and discuss their particular services. Additional information about hospice is available from the following sources:

◆ The National Association for Home Care (NAHC) and the National Hospice and Palliative Care Organization (NHPCO) both maintain locators on their Web sites, www.nahc.org, and www.nhpco.org, respectively. The NHPCO also offers the hospice helpline at 800-658-8898.

◆ The American Hospice Foundation, 2120 L Street, NW, Suite 200, Washington, DC 20037. Tel: 202-223-0204, fax: 202-223-0208. E-mail: ahf@americanhospice.org Website: www.americanhospice.org.

The Foundation has also published *Talking About Hospice: Tips for Physicians; The Power of Grief: Responding to the Bereaved; Grief at School: A Guide for Teachers and Counselors; Grief at Work: A Guide for Employees and Managers; Grief and Faith: Spiritual Paths through Loss; Alzheimer's Disease and Hospice.*



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