

Hospice Aide On-the-Go™ In-service



Introduction to Hospice

BEACON
HEALTH



The idea of hospice grew out of the work of Dame Cicely Saunders, a British physician who worked with dying patients in the late 1940s. She was determined to provide care that was better than the traditional institutional end-of-life care provided to the terminally ill. She opened St. Christopher's Hospice in 1967; this was quickly followed by a homecare unit in 1969. Hospice eventually moved to the United States, arriving in the early 1970s as a result of a community-based grassroots movement.

The growth of hospice has been rapid. In 1978 there were 59 hospice agencies in the United States. By 1997 this number had grown to approximately 3,000. In 2006, 1.3 million patients received care from more than 4,500 hospice programs.

The philosophy of hospice is to provide family-centered, compassionate care for people in the final stage of life so that they may live as fully and as comfortably as possible. Hospice care is palliative in nature, not curative. That means it treats the person, not the illness. It focuses on quality of life, not on prolonging life, and it enables the patient to remain alert and pain free until the end.

Hospice care addresses the physical, emotional, and spiritual concerns of the patient and the patient's family. Care is individualized to meet each patient's needs and to respond to differences in family lifestyle.

The goals of hospice are to manage pain and other symptoms and enable terminally ill patients to live their final days in comfort in the least restrictive environment possible. Care focuses on the dignity and the wishes of the patient surrounded by loved ones.

Sometimes hospice care is not started soon enough. The doctor, the patient, or a family member will resist hospice because he or she feels that it sends the wrong message, a message of lost hope. In reality, most patients who elect hospice find that they have choices and a better quality of life.

Hospice care services

Hospice care is individualized for each patient and written into a plan of care. The plan specifies palliative care, meaning that every attempt will be made to make the patient comfortable and pain free for the remainder of his

Key Terms

Anticipatory grief

Grieving that begins even before the patient dies.

Bereavement

The time of mourning after a loss.

Curative care

Active and aggressive medical services that cure a disease.

Family

People who live together and support one another either emotionally or financially. Hospice recognizes that these individuals have special needs for support.

Hospice

A services that provides for the physical, psychosocial, spiritual, and emotional needs of a terminally ill patient and the patient's family, as outlined in a plan of care.

Interdisciplinary Group (IDG)

Many disciplines working together to plan, coordinate, and provide end-of-life care.

Palliative care

Compassionate comfort care for people in the last phases of life; treatment to relieve symptoms, but not to cure the disease.

Primary caregiver

The person who provides most of the care to a hospice patient. This person may be a family member, friend, or hired care provider.

Respite care

Care provided by the hospice to allow a patient's family and caregivers to have time away.



Hospice Care Settings

Hospice is a philosophy of care, not a place. Most hospice patients receive care at home, in a private residence. Home may be a nursing facility, an assisted living facility, or a free-standing hospice. Patients may also receive hospice care in a hospital. When a patient's condition changes and he or she needs a higher level of care, hospice services follow the patient.

or her life. It does not call for curative care, meaning that no aggressive medical treatments will be performed to prolong life. Prior to admission, a member of the hospice team will review this philosophy with a patient and the patient's family.

Care begins when a registered nurse admits a patient to the hospice program. Ongoing care is family centered, and it involves the patient and the patient's family in decision making. A hospice provides care 24 hours a day, seven days a week as needed. To handle around-the-clock patient needs or crises, a hospice has an on-call nurse who answers phone calls day and night, makes home visits, or sends the appropriate team member needed between regularly scheduled visits.

Hospice services include the following:

ANTICIPATORY GRIEF AND BEREAVEMENT SUPPORT: The hospice care team works with the family to help them through the grieving process, which may begin even before the patient dies. A trained volunteer, clergy member, or professional counselor provides support by means of personal visits, phone calls, and letters and through recommendations to support groups and other medical or professional care. These services are provided prior to and up to one year after the death of a patient; they generally include the anniversary date of the death.

FAMILY CONFERENCES: Regularly scheduled family conferences, often led by the hospice nurse or social worker, keep family members informed about the patient's condition and what to expect next. These conferences are an opportunity for family to share feelings, talk about expectations, and learn about death and the process of dying. Hospice aides may be invited to attend.

PAIN AND SYMPTOM CONTROL: The goal of pain and symptom control is to keep patients comfortable so they can remain in control of their lives and maintain a sense of dignity.

RESPIRE CARE: Most primary caregivers eventually need time away from caring for a dying family member. A

Plan of Care

In hospice, the patient is the driver of the plan of care. Each patient has the ability to choose the type of treatment and the quality of life he or she wishes to maintain.

hospice provides respite care that can range from a few hours of a volunteer's time one afternoon to breaks lasting as long as five days. This allows families to attend special events, attend to other family business, or simply get much-needed rest.

SPIRITUAL CARE: The hospice recognizes that patients and families are often in need of spiritual care during this difficult time.

Patients may wish to discuss what death means to them, they may need help with saying goodbye to friends and family, or they may wish to be put in touch with a clergy person who will perform religious ceremonies or rituals with them.



The Interdisciplinary Group (IDG)

In an interdisciplinary approach to care, a hospice forms an IDG to assess and communicate findings to team members. The core team, including physician services, nursing services, medical social services, and counselors, assesses the patient and develops the plan of care. This plan reflects patient and family goals. Services will include visits from the hospice team; the provision of medications, biologicals, medical supplies, and durable medical equipment; and both inpatient acute and respite care stays.

- **PHYSICIAN SERVICES:** This function includes a medical director who is committed to the philosophy and goals of hospice care for the terminally ill. He or she attends team meetings and provides consultation to the staff. The medical director also helps educate other physicians about hospice care, encourages them to make appropriate referrals, and may consult with the patient's primary physician to assist with pain management. A nurse practitioner may provide the services of an attending physician, but cannot certify a patient as terminally ill or serve as the hospice medical director.
- **NURSING SERVICES:** Registered nurses coordinate and provide hands-on care for hospice patients. They work with the attending physician and other core team members to focus on symptom management. They also supervise the hospice aide. In addition to the registered nurse who is part of the core team, other nurses provide services based on the plan of care. They are skilled in effective pain management and symptom control and other hands-on care.
- **MEDICAL SOCIAL SERVICES:** Medical social workers are trained to understand the emotional and social needs of patients and families and how best to help them in the end-of-life stage. They facilitate communication between family members, provide advocacy, and teach problem-solving skills. Social workers are aware of cultural differences and belief systems that affect how people respond to end-of-life issues. Social workers also link clients to community services.
- **COUNSELING SERVICES:** Each hospice team has at least one counselor. Counselors may come from one of several disciplines including chaplain, nutritionist, and psychologist.
 - o *Chaplain:* One of the goals of hospice care is to acknowledge and tend to a person's spiritual needs, and the hospice chaplain fills this important function. Spirituality is more than religious affiliation. It also centers on values and beliefs, especially those regarding what awaits a person after death. Even those not affiliated with a specific denomination may wish to address spiritual issues. If the team does not have a chaplain, other team members can refer the patient to a suitable community resource.
 - o *Nutritionist:* Medications affect appetite and many dying patients lose interest in food. A patient's eating habits and weight loss may alarm the family. A nutritionist will have suggestions to improve appetite and may suggest dietary supplements. If the team has no nutritionist, a trained registered nurse can provide this care.
 - o *Psychologist:* Depression and pre-existing psychological problems affect how people cope with death and dying. A psychologist will consult on difficult cases, making recommendations to improve the management of care.

Each hospice has a policy that identifies additional members of the hospice team. In addition to core services,



the team includes others who work together to provide direct care to the terminally ill and their family or primary caregivers.

- **HOSPICE AIDES:** Hospice aides are essential members of the team. They provide hands-on care and perform intimate tasks such as bathing and grooming. Patients and families often feel more at ease with hospice aides than with other staff.
- **VOLUNTEERS:** Trained and supervised volunteers are the backbone of many hospice programs. They may be health professionals or lay people who provide services that include personal care for patients and respite care for families. In some programs, volunteers assist with transportation or stay with patients in the hospital or nursing home, helping to reduce feelings of loneliness and abandonment. Some volunteers specialize in supporting the bereaved. They make follow-up telephone calls and arrange for a team member to assess the situation if they detect any problems. Other volunteers do fund-raising or work in the hospice office.
- **PHARMACISTS:** Pharmacists contribute their knowledge of drug potencies and the possible interaction among drugs in order to maximize pain control and symptom relief while minimizing undesirable side effects.
- **PHYSICAL THERAPISTS:** Physical therapists help hospice patients to maximize their ability to get into and out of bed, chairs, and transportation. They teach the family, volunteers, and hospice aides techniques that will prevent injury. They also may develop a range-of-motion exercise program the aide can use to provide comfort for the patient.
- **OCCUPATIONAL THERAPISTS:** The occupational therapist helps to improve the patient's activities of daily living by teaching the patient, caregivers, aides, and volunteers how to conserve energy and how to adapt the living environment for comfort, convenience, and safety.
- **SPEECH-LANGUAGE PATHOLOGY SERVICES:** Speech therapists consult with team members to develop alternative communication systems in cases where a patient's ability to speak has been compromised. They also provide instructions on special swallowing programs for those patients who have impairments. Included in this service are instructions to the caregivers, hospice aides, and volunteers who feed a special-needs patient.

THE AIDE'S ROLE

Each state has laws that govern the qualifications of a hospice aide. As a hospice aide, you must be trained to perform specific tasks. Once trained, you must demonstrate competency and then you can be added to your state's Aide Registry. A hospice checks this registry during the employment process to be sure it hires only qualified aides. Hospice aides are required to be competent in the following services:

- Creating a successful interpersonal relationship with the patient and family
- Providing hands-on personal care
- Performing simple procedures as assigned by therapy or nursing services



- Assisting in ambulation or exercise
- Assisting in the administration of medications that are ordinarily self administered
- Complying with infection control guidelines

Care Delivery

As an aide, you may be assigned to perform a variety of duties:

- Adequate nutrition and fluid intake
- Bed bath
- Companionship
- Hair shampoo
- Personal care
- Laundry
- Light housekeeping
- Nail and skin care
- Oral hygiene
- Range of motion exercises
- Respite
- Sponge, tub, or shower bath
- Toileting and elimination
- Safe transfer techniques and ambulation

Assignment: The hospice registered nurse assesses each patient and then reviews the patient's needs with the IDG. The IDG plans the type, amount, and frequency of aide services on the patient's plan of care. From this, the registered nurse develops the aide assignment.

Occasionally a therapist will add to the aide's assignment sheet. These assignments focus on exercises that provide comfort, promote feeding, or maintain ambulation.

You may be asked to attend an IDG meeting to review a patient. This usually occurs when a patient is having uncontrollable pain or other symptoms and there is a need to collect additional patient or family data.

Supervision: As an aide, you provide care under the supervision of the hospice registered nurse. At least every two weeks, the nurse visits the patient and assesses the quality of care provided by you and other aides. It is not necessary that you be in the home at the time.

The nurse may also visit when you are in the home if someone has reported concerns about your performance. Depending on what the nurse finds, you may have to go through more training and testing.

Observation, Reporting, and Documentation

One of the most important things you do as an aide is to report changes in the patient's condition to the registered nurse. The changes you report should include anything to

Reportable Symptoms

- Pain
- Dyspnea
- Nausea
- Vomiting
- Incontinence
- Change in spiritual needs
- Inability of the patient to follow a physical therapy plan
- Inability of the primary caregiver to care for the patient
- Problems with a swallowing program designed by the speech-language pathologist



do with medical, nursing, rehabilitative, social, and spiritual needs. The registered nurse will provide additional instructions regarding how to care for specific symptoms you report.

Each hospice has its own policies and procedures for documentation and you must know the requirements. Document the specific care you provide following your hospice's procedures. Describe the signs and symptoms, treatments, assistance with medications, patient's reaction or response, and any change in physical, emotional, psychosocial, or spiritual condition during a given period.

OUTCOMES AND THE HOSPICE HEALTH AIDE

The focus of care provided by the hospice aide is on improving the outcomes of the terminally ill. Hospice outcomes focus on the relief of pain and other symptoms. By providing this care and relief of symptoms, the hospice aide provides comfort to the patient. By reporting symptoms to the registered nurse as they appear, the hospice aide seeks assistance for the patient and the patient's family in a timely manner. The result is a dignified and comfortable death.

CMS' Expectations

A hospice must maintain a quality assessment and performance improvement (QAPI) program that involves all services, including hospice aides. This program, among other things, will take actions to demonstrate improvement in hospice care and palliative outcomes.



CASE STUDY

Alice Hinds, an 80-year-old woman, lives alone. Over the past year, her health declined to the point where she can barely walk 20 feet. Last weekend, her daughter Donna visited. Donna knew her mother had diabetes and problems with her heart, but was surprised to see how weak and short of breath she was. When Donna took her mother to her physician, Donna learned that her mother also had end-stage cardiac disease and severe arthritis. The physician told them both that Alice's prognosis was less than six months and that she qualified for hospice services. Donna also learned, to her amazement, that her mother had known this for two months. Thus, the journey into hospice care began.

That night Donna and her mother discussed Alice's wishes. Alice decided she wanted help from the local hospice program, so Donna called Beacon Hospice the next day on her behalf. The hospice registered nurse conferred with Alice's attending physician, the hospice medical director, and the IDG. They decided hospice admission was appropriate and it was scheduled.

When the day of admission arrived, Alice had a house full of people. She formally elected hospice care. During the initial assessment, the nurse determined that Alice needed a hospice aide four mornings a week to prepare breakfast and assist her with her personal cares. Alice told them that she wanted the same aide as often as possible. Rebecca, a new hospice aide, was assigned.

Prior to the first visit, the hospice nurse called Rebecca and instructed her to pick up Alice's new medications on her way over to Alice's home. Rebecca did so. Upon arrival, she gave the medications to Alice. Alice had questions about the medications, so Rebecca called the hospice registered nurse. While Alice and the nurse were on the phone reviewing the medications, Rebecca washed the dishes and checked the refrigerator. To her dismay, the only edible food she found in the refrigerator was a block of cheddar cheese.

After the call, Alice limped slowly back to her chair. Concerned, Rebecca asked Alice if she had any pain medication. "Do you want to take some right now, before we get started with your bath?" Alice thought this was a good idea and immediately took one of her pain pills. Then Rebecca asked Alice, "What would you like me to do while we wait for your pain medication to kick in?" Alice, who was lonely living by herself, had always enjoyed playing cards. She and Rebecca played a couple of hands of Gin Rummy while they waited. Then Rebecca helped Alice to the bathroom and assisted with her bath.

THINK ABOUT IT

1. Why didn't Rebecca answer Alice's questions about the medication she delivered?
2. What should Rebecca do about the lack of food?
3. Why do you think Rebecca did not take Alice to the bedroom right away to start a bath?
4. Should Rebecca have played cards with Alice?
5. Would you have done anything differently?

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~ VOLUME I • INTRODUCTION • CASE STUDY ~

