

ABOUT HOSPICE CARE

What is hospice?

Hospice care focuses on improving the quality of life for persons and their families faced with a life-limiting illness. The primary goals of hospice care are to provide comfort, relieve physical, emotional, and spiritual suffering, and promote the dignity of terminally ill persons. Hospice care neither prolongs nor hastens the dying process. As such, it is palliative not curative.

Is it a place?

Hospice care is a philosophy or approach to care rather than a place. Care may be provided in a person's home, nursing home, hospital, or independent facility devoted to end-of-life care.

What kind of treatment is provided through hospice care?

Hospice care is holistic: Hospice treats the whole person, not just the disease. It focuses on the needs of both the patient and the family. The health care team attends to practical needs such as insurance coverage, transportation, and assistance with bathing in addition to emotional and spiritual needs such as caregiver stress, grief, and fear of dying. Care is provided by an interdisciplinary team including the physician, psychologist, nurse, social worker, chaplain, pharmacist, nursing assistant, volunteers, nutritionist, and physical therapist.

Is there a distinction between hospice and palliative care?

Hospice care is a specialized form of palliative care customarily provided during the last few months of a person's life. Persons with a life-limiting disease may receive palliative care early on in the course of their illness to relieve pain and other physical symptoms and to assist them in coping with how the illness impacts their daily living and family. The goals of both palliative care and hospice care are the relief of suffering and improving quality of life.

Is hospice the same as home health nursing?

Two primary differences exist between hospice care and home health nursing. First, any patient with a skilled medical care need is qualified to receive home health nursing care. The patient may be recuperating from heart surgery or require intravenous medication for an infection from which they are expected to recover. Hospice care, on the other hand, is limited to persons with a terminal illness, usually with a life expectancy of six months or less, and with a focus on palliation not cure.

Second, whereas persons in home health care receive visits primarily from a nurse (additional services such as physical or occupational therapy are sometimes ordered), persons in hospice care receive the services of an entire interdisciplinary team whose area of expertise is end-of-life care.

When is hospice referral appropriate?

A referral to hospice is appropriate when the patient and family have opted for palliative treatment for life-limiting or “terminal” illness. Medicare guidelines further require that the physician has determined that life expectancy is six months or less (if the disease follows its normal course).

Does referral to hospice mean that I am “giving up” on a patient?

Many physicians struggle with feelings of having failed a patient when no curative treatment remains. Reframing the goals of care from cure to palliation often helps physicians accept a life-limiting prognosis. Remember, there is much you can do even when curative medical treatment is no longer appropriate. By referring a patient to hospice care you are helping to relieve their physical, emotional, and spiritual suffering.

Primary physicians often remain actively involved in the care of patients after admission to hospice. For many patients, the involvement of the primary physician in hospice care provides reassurance that their doctors are NOT “giving up” on them.

How can I talk to a patient about hospice referral and not destroy their optimism or hope? (See Module 2: Communicating Bad News)

If you believe “there is much we can do” even if you are no longer offering curative medical options, patients and families will feel some sense of hope. Help them to identify their own “goals” for hospice care. This will shift the focus of their hope: To not be in pain, to die peacefully, to know my family will be ok, to be a role model and teacher for my children, to make peace with my god/gods, etc. (See Module 7: Goals of Care)

Patients and families may experience some feelings of hopelessness when hospice care is offered as the appropriate course of treatment. This is to be expected and part of the normal process of grieving and acceptance. They may also express anger. This, too, is normal.

It is important to understand the culture of your patient and family. Do they prefer to talk about “bad news” directly and openly or do they use euphemisms? Who is the decision maker in the family? Should you communicate this news to the patient or only the family or both? (See Module 13: Cultural Issues).

It is also important to know something about the religious framework of the patient and

family. What have they told you about the role of their faith in their illness and healing? Do they look to their religious leaders or practices for direction in making medical decisions? Do they look to their spirituality for strength and hope? (See Module 14: Spirituality Assessment).

Can a patient receive medical treatment after referral to hospice?

Hospice care is medical treatment. Patients will receive medications to relieve pain and other physical symptoms. The primary physician in consultation with the medical director of the hospice program will determine which forms of medical treatment advance the palliative goals of care identified by the patient and family. For example, radiation therapy may be indicated as the appropriate means for the palliation of pain, or antibiotics may be prescribed to help keep a patient comfortable rather than to prolong life.

If a patient's condition improves unexpectedly, can he or she be discharged from hospice?

The primary physician and hospice team evaluate the patient's appropriateness for hospice care on a regular basis. If a patient no longer meets criteria for hospice care, they may be discharged and readmitted at a later date.

Will my patient's health plan pay for hospice care? How are finances handled in hospice care?

A member of the hospice team will consult with a representative of your patient's health plan/insurance to determine coverage. Most, but not all health plans cover hospice care. Customarily, only treatments and medications related to the "terminal diagnosis" and that are palliative in nature will be covered: for example, if a person has end-stage ovarian cancer but also suffers from a chronic heart condition, medications for the latter illness may not be covered under the hospice benefit.

Some plans offer a "per diem" rate for hospice care; others pay on a "fee for service" basis. There may be a "cap" on how much the insurance will cover. Services that are customarily covered include doctor's fees, medications, visits by the nurse and other core disciplines, durable medical equipment including oxygen, and bereavement care. If hospice care is being provided in a nursing home, the insurance rarely covers the residential (non-medical) fee. Likewise, home health aides, nursing assistants, and private duty nurses may be covered (if at all) only in limited amounts. Billing is done directly by the hospice program to the insurance company or Medicare.

Who are the members of the hospice team?

The hospice team functions as an interdisciplinary team with a coordinated plan of care. The

patient and family are integral members of the interdisciplinary team. Regular team meetings and frequent communications among clinical staff and with the patient's primary physician ensure that patient and family needs and goals are met and constantly reassessed.

Members of the hospice team involved directly in interdisciplinary care to the patient and family include the primary physician, hospice physician, nurse, social worker, chaplain, home health aide, and volunteers. Additional team members may include occupational or physical therapist, psychologist, art and music therapist, pharmacist, and nutritionist.

Primary physician

- Provides the hospice team with medical history
- Oversees medical care through regular communication with the hospice team
- Provides orders for medications and tests, signs death certificate, etc.
- Determines his or her level of involvement on a case-by-case basis with the hospice medical director

Hospice physician

- Provides expertise in pain and symptom control at the end of life
- Works closely with the hospice team and primary physician to determine appropriate medical interventions
- Makes home visits on as needed basis
- May oversee the plan of care, write orders, and consult with patient and family regarding disease progression and appropriate medical interventions on a case-by-case basis

Nurse

- Visits patient and family in the home or nursing home on regular basis (biweekly to 3-4x per week, depending on needs of patient)
- May provide on-call services (24 hours a day, 7 days a week for emergencies)
- Assesses pain, symptoms, nutritional status, bowel functions, safety, and psychosocial-spiritual concerns
- Educates patient and family about disease progression, use of medications, daily care needs, and other aspects of the overall plan of care
- Educates and supervises nursing assistants
- Provides emotional and spiritual support to patient and family to cope with functional limitations, caregiver stress, and grief.

Home Health Aide

- Assists patient with activities of daily living such as bathing and dressing
- Provides a variety of other services depending on assessment of need

Social Worker

- Attends to both practical needs and counseling needs of patient and family based on initial and ongoing assessment
- Arranges for durable medical equipment, discharge planning (from hospital to

- home), funeral/burial arrangements
- Serves as liaison with community agencies (such as Department of Human Services, Department of Aging, Public Aid office)
- Assist family in finding services to address financial needs and legal matters (Power of Attorney, Wills)
- Provides counseling related to family communication
- Assesses patient and family anxiety, depression, role changes, caregiver stress
- Provides general grief counseling

Chaplain

- Provides patient and family with spiritual counseling to address questions of hope, meaning, despair, fear of death, relationship with divine, need for forgiveness, loss of life purpose
- Assists patient and family in sustaining their religious practice and in drawing upon religious/spiritual beliefs to cope with illness, dying, and grief
- Ensures that patient and family religious or spiritual beliefs and practices are respected by the hospice team (e.g. dietary restrictions, rituals to be observed at the time of death, disposition of the body)
- Serves as a liaison with the patient/family faith community and clergy
- May conduct funeral and memorial services for patients and families as requested
- Provides hospice staff with spiritual care and counseling.

Volunteers

- Provides respite care to family members
- May assist with light housekeeping or grocery shopping
- Helps patients stay connected with community groups and activities
- Facilitates special projects such as memoirs/legacy work, letters to family, and massage therapy
- May provide community education and outreach
- May assist with office work

Who should I interact with when making a referral?

Most hospice organizations have a referrals or admissions department/coordinator. You may also contact the hospice medical director to consult about whether or not a patient is appropriate for hospice care.

What services does hospice offer?

For the patient...

Hospice works with the family or nursing home staff to provide care to the patient. Goals of care are established with the patient and family and a care plan developed to help meet these goals (when they are realistic and achievable).

The hospice team provides the patient with medical care to relieve pain and other symptoms arising from a life-limiting illness. Medications are ordered by the primary physician or hospice doctor but are usually picked up by family members at the designated pharmacy. Coverage of these medications depends on each patient's insurance plan. Laboratory services related to symptom control, deemed essential to treatment or for recertification are provided by the hospice program. Ambulance services are also provided when medically necessary, related to the terminal diagnosis, consistent with the overall interdisciplinary plan of care.

Basic needs of daily living such as dressing, eating, cooking, getting to the bathroom are usually met by family, friends, privately hired caregivers and/or nursing home staff with hospice staff playing only a supervisory and educational role. Most hospices provide a limited number of hours of care by a home health aide for identified needs such as bath service with visits of 1-2 hour duration. Durable medical equipment such as oxygen, hospital bed, walker, commode, etc. is provided by hospice when medically necessary.

Counseling is available to patients to help them cope with their illness, address depression, grief, and anxiety as well as spiritual issues such as loss of meaning and fear of death.

Hospice staff may assist the patient with unfinished legal or financial business and in making funeral arrangements.

Religious care is available either directly by the hospice chaplain or through community resources.

For caregivers/family members...

Counseling services to help with caregiver stress, role changes, depression, anxiety, family conflict, grief, and spiritual concerns.

Respite care can be provided to family either by volunteers or, in the case of an emergency and on a short-term basis, by paid staff either at home or in the hospital.

Education to help family provide hands on care to patients, for proper usage of medications, for knowledge about disease progression, signs and symptoms of dying, normal grief response, coping with stress, etc.

Practical assistance with legal matters, completing Powers of Attorney, and accessing community services.

Assistance with cremation/burial arrangements and with funeral/memorial services.

Bereavement care is available minimally for 13 months following the death of a loved one. This may include memorial services, educational sessions, short-term counseling, grief support groups, and referrals to community resources.

If I refer my patient to hospice, can I still remain involved in his or her care?

The attending physician may continue in a primary role (writing orders for medications, consulting with patient, family, and interdisciplinary team on treatment decisions and goals, visiting patient directly at the hospital or home). He or she may also request that the hospice medical director and hospice physicians manage symptoms related to the terminal diagnosis or assume complete responsibility for the medical care of the patient.

What medical information do patients and families need to have about hospice when the referral is made?

It is important for the physician to be as clear as possible with the patient and family about the disease progression, treatment options, prognosis, and goals of medical care that have led to a hospice referral at this time. Patients and families often ask the following questions about hospice care:

How much care will family members be expected to provide?

If a patient lives at home and is unable to care for himself or herself, usually a “primary caregiver” is required since hospice team members cannot be in the home for extended periods of time. The hospice program can assist the family in hiring private nursing assistance to meet this need or in “piecing together” care among family members, friends, and community resources.

After a patient dies, what services or counseling is offered to family or loved ones?

Every hospice program offers bereavement services to family and loved ones for a minimum of 13 months following the death of a patient. This may take the form of phone contact, short-term counseling, assessment of need and referrals to community resources, support groups, educational forums, written information on the grief process, and/or memorial services.

Is it possible for a family member to receive bereavement counseling through a hospice even if the patient did not receive hospice services?

Yes. Most hospice programs serve as a resource to the larger community for grief education and counseling. Bereaved persons may contact their local hospice to inquire about the services available. If that program is unable to meet the need directly, they will provide the person with referral information.

What are the first steps that happen when a patient is referred to hospice?

A representative of the hospice will meet with the patient and family to explain the hospice philosophy and services. They will confirm medical eligibility, insurance coverage, and patient and family choice for palliative/hospice care. If hospice is determined to be the appropriate kind

of medical care, paperwork will be completed and services begin usually within 24-48 hours of referral.

What on-line resources on hospice referrals are available?

www.hospicefoundation.org Hospice Foundation of America

www.nhpco.org National Hospice and Palliative Care Organization

www.aahpm.org American Academy of Hospice and Palliative Medicine

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