

# END-OF-LIFE

# Care



## Chapter 6

Hospice: A Team Approach to Care

---

---

---

## Chapter 6: Hospice: A Team Approach to Care

### Comfort, Respect and Dignity in Dying



**H**ospice care provides patients and family members with hope, comfort, respect, and dignity with a focus on living as fully as possible while dying. With hospice, patients and family members have assurance they will have caring professionals on their side as guides on their final journey. And, they can be sure they will not have to face the unknown alone.

Hospice is a model of care specially tailored to the needs of terminally ill people and their families. It is comprehensive care, addressing the physical, emotional, social and spiritual needs of the patient, family and friends. Hospice personnel bring with them important and unique skills and resources. Using the home (whatever setting the patient considers as home) as the center for care, and family members as hands-on caregivers, hospice personnel provide both direct care and help with obtaining needed goods and services.

Trained volunteers add listening ears and provide practical help. Social workers provide compassionate assistance in coping with physical and emotional changes taking place and in finding needed special equipment, supplies and services. Physicians, nurses, allied health care professionals and support personnel provide in-home medical and nursing care. Spiritual caregivers are available to support everyone involved. Finally, hospice services include support for grieving family members for more than one year after the death of a loved one.

Besides being more humane and comforting to all those involved, dying at home, in hospice residences, or in hospice/palliative care units of hospitals and nursing homes is less costly than dying in acute care hospitals. Accordingly, Medicare, Medicaid, most insurance plans and HMOs cover hospice care. Many hospices receive support from their communities so they are able to provide services at no charge to people without insurance.

#### The Physician's Role in Hospice Care

All medical care, including hospice care, must be provided by or under the supervision of a physician. All hospices have medical directors and also work with physicians from all specialties. With the agreement of the patient and family, the hospice team will keep the referring physician involved in the care plan for the terminal illness. The hospice medical director may be consulted for assistance in challenging cases.

#### When to Call on Hospice

Hospice ideally becomes involved with patients and families during the final months of life. That is when the need for more specialized palliative care is usually greater, the amount of care needed increases, the demands on caregivers and families are heavier, and there is likely to be a need for additional equipment and services. Unfortunately, very late referrals to hospice are common, leaving only days or weeks for a hospice to adequately address the comprehensive needs of the patient and family.

The decision to call on hospice is an individual one for each patient and family. Because the financial, physical and

emotional burdens of caring for chronically ill and dying patients often become progressively more difficult, it is most practical to contact hospice sooner rather than later.

For terminally ill patients, the time to call hospice is when a decision has been made to focus on pain control, palliative care and comfort rather than continuing curative medical treatments. Though it is an individual choice—made ultimately by competent patients or their advocates—it is best when the decision is made collectively by the patient, family and physician.

Patients and families need their physicians' help. They usually need to hear an estimate of the length of life remaining. They also may want to know how death is likely to occur. And they may want to discuss the reasonable

effectiveness and potential benefits of curative treatment choices. The burdens of treatment options also should be discussed in terms of pain, inconvenience to the patient, disruption of life, effects on others, and the quality of remaining life, all of which depend on the success of the treatments. See Chapter 1 on communication and Chapter 5 on palliative care.

An individual's personal values and feelings about life, death and suffering are crucial elements in the timing of a decision to call on hospice.

## Choosing Hospice

Hospice care is appropriate once the decision is made to forego further curative treatment. Hospice can focus on palliative care and help the patient live to the fullest.

Though a hospice certification must have a physician's signature, the initial contact with a hospice may be made by a patient, a family member, a nurse or social worker. Most hospices provide an initial consultation visit without obligation for a patient not yet certain about the decision.

The hospice admission process involves obtaining relevant health care information about the patient. That

## Introducing Hospice Care to Your Patients

Talking to a patient about hospice care can be a delicate undertaking. Listed below are a few suggestions for delivering difficult news and initiating a discussion of hospice care:

- ♦ Choose a private area where there will be no interruptions. An unhurried presence will show more care and concern.
- ♦ Sit down with the patient and family members. Try to avoid discussing difficult news with the patient alone.
- ♦ Use simple language to offer an overview of the situation, the diagnosis and its implications. Make no assumptions about what the patient understands.
- ♦ Be prepared to repeat information when necessary. Allow time to recognize the emotional reactions of the patient and family members.
- ♦ Ask for and address specific concerns of the patient and family.
- ♦ Schedule a return visit in a day or two to allow the patient and family members to absorb information and ask any additional questions.
- ♦ Review "Six Steps to Communicating Bad News" in Chapter 1.

## The Process to Initiate Hospice Care

Initiating hospice care begins after a discussion about hospice has taken place and the patient and family have agreed to hospice care. Regardless of the location of the patient at the time of referral, a hospice program will need:

- ♦ Admitting diagnosis
- ♦ Prognosis—must be six months or less to be eligible for hospice
- ♦ Attending physician's order for hospice care
- ♦ Patient and family understanding of the disease and prognosis
- ♦ Orders for medications and treatments
- ♦ Current medical findings
- ♦ History and physical

---

includes diagnosis and prognosis, medications and other treatments, laboratory and other diagnostic study reports, medical history and physical examinations, and relevant information about the patient, family and significant others.

Once a patient has been accepted for hospice care, the hospice team develops a treatment plan in concert with the patient, family and physician. Regular team and family meetings are held and the plan is revised as needed.

Neither physicians nor family members need to be overly concerned about hospice regulations if a patient is admitted to a hospice too soon. A patient may be admitted to a hospice program when his or her condition meets Medicare guidelines. The patient then may be discharged if there is improvement or if hospice services are no longer needed, and re-admitted in the future if hospice care is needed again.

## Conditions for Hospice Care

The criterion that must be met to qualify for hospice care is straightforward. A patient must, in the physician's best judgment, have six months or less to live if the disease runs its normal and expected course.

The Health Care Financing Administration (HCFA) requires that the physician re-certify that the patient meets this criterion after 90 days and then again after another 90 days. After that, re-certification is required every 60 days.

Hospice treatment goals are comfort and symptom management, along with helping the patient and family to live fully, rather than to focus on cure. That does not, however, prevent the palliative use of treatments traditionally viewed as curative, such as radiation or chemotherapy when needed to relieve symptoms.

The decision about whether or not to stay in hospice care remains with the patient, referring physician and the hospice medical director.

## Hospice Care Remains Underutilized

Hospices are available and accessible to those who need their services. Medicare, Medicaid and most third-party health insurance benefits cover hospice care. Often where community support is strong, hospice is available at reduced rates or free to those without insurance.

Unfortunately, hospice remains an underutilized resource of care and comfort. In Michigan, the average length of stay for patients in hospice is well under two months and the median length of stay is under a month. Many patients use hospice services for less than one week. Generally, it takes at least a month for a patient, family and hospice team members to become comfortable working together. More importantly, it takes time for the patient to decide how to handle life closure issues. Such short stays prevent patients and families from receiving the full benefits of hospice care.

The most obvious reason for under-utilizing hospice care is a delay in making the decision to focus on comfort, rather than cure. Physicians, patients and families often find it difficult to face end-stage illness and death. It is not easy to abandon hope for a cure and begin to focus on comfort and completing the tasks of ending life and preparing for death. What patients and families need most at the end of life are comfort, support and assistance in completing the tasks of dying.

Patients, and everyone close to them, may know that death is approaching, but sometimes no one is willing to talk about it. Paradoxically, a source of immediate comfort for patients and families is the sense of relief experienced once they make the decision to call on hospice and focus on living while dying.

## Levels of Hospice Care

When a patient chooses hospice care, an interdisciplinary team of physicians, nurses, social workers, spiritual care counselors, home health aides and volunteers deliver care. This team provides pain management and comfort care for the patient, and emotional and spiritual support for the patient and family.

Hospice care falls into four main levels:

Level I—Routine Home Care—all care delivered in the patient's home, including patients who reside in nursing facilities.

Level II—Respite Care—brief care in a facility setting to give the family respite from caregiving.

Level III—Continuous Care—intensive medical and nursing care in the home when pain and other symptoms are in need of control.

Level IV—Inpatient Care—care provided in a facility setting when pain and other symptoms cannot be controlled in the home.

---

## Hospice Resources

### Web Sites

- ♦ [www.hospicefoundation.org](http://www.hospicefoundation.org)—Hospice Foundation of America’s website includes newsletters, information and other support.
- ♦ [www.mihospice.org](http://www.mihospice.org)—Michigan Hospice and Palliative Care Organization’s website includes list of and links to all hospice organizations in Michigan.
- ♦ [www.nhpco.org](http://www.nhpco.org)—National Hospice and Palliative Care Organization is a resource for professionals and volunteers committed to and providing service to patients and their families during end of life.

### Articles

- ♦ David J. Casarett and Timothy E. Quill. *“I’m Not Ready for Hospice”: Strategies for Timely and Effective Hospice Discussions.* *Ann Intern Med* 2007 146:443-449.
- ♦ Gazelle, G. Understanding Hospice — *An Underutilized Option for Life’s Final Chapter.* *N Engl J Med* 357:321, 2007.
- ♦ Wright, AA.; Katz, IT. *Letting Go of the Rope — Aggressive Treatment, Hospice Care, and Open Access.* *N Engl J Med* 357:324, 2007.

### Booklets

- ♦ *Hospice Care: A Physician’s Guide.* Michigan Hospice & Palliative Care Organization. An 86- page booklet on hospice care including Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases. Call 1-800-536-6300.
- ♦ *Hospice Services Guidelines and Definitions.* National Hospice and Palliative Care Organization. Call 1-800-658-8898.

## FOR MY PATIENTS

### End-of-Life Care: Hospice: A Team Approach

#### Making a Decision to Use Hospice Services

One of the biggest decisions for you to make when considering hospice care is to focus on comfort rather than cure. This decision requires you to openly discuss your goals, plans, loves, hopes and fears with your family and physician so plans can be made to help you live to the fullest for the rest of your life. Usually, you or your family can arrange a visit with a hospice social worker, nurse or physician to discuss your condition, prognosis and options for treatment, and to learn what hospice has to offer.

#### Hospice Care in Michigan

There are more than 90 hospice programs in Michigan operating from about 100 locations with at least one hospice serving every county. To locate a hospice resource, call the Michigan Hospice and Palliative Care Organization at 517-668-6396, or visit their web site at [www.mihospice.org](http://www.mihospice.org).

#### Paying for Hospice Care

Hospice services are covered by most insurers, including Medicare, Medicaid, Blue Cross Blue Shield of Michigan, many private insurers and HMOs. Most costs, with the exception of some co-pays for prescriptions, are covered by most policies.

It is important to note that many hospices accept patients who have no insurance or no other way to pay for their care. Hospice organizations use volunteers, sponsor fundraisers and get funding in many other ways, including community groups and grants, to help cover their costs.

#### Services Covered by the Hospice Medicare Benefit

The majority of hospice patients are eligible for the Medicare Hospice Benefit, which pays for:

- ♦ Hospice medical director
- ♦ Nursing care
- ♦ Home health aide services
- ♦ Social worker services
- ♦ Medical equipment
- ♦ Medical supplies
- ♦ Medications for symptom control and pain relief
- ♦ Short-term care in the hospital, including respite care
- ♦ Grief counseling
- ♦ Services for patient and family by trained volunteers
- ♦ Physical and occupational therapy
- ♦ Speech therapy
- ♦ Dietary counseling

If you or your family members have any questions about hospice, please feel free to ask your physician or his or her staff. You need all of the information possible to make the decision that is right for you.

